

# **Adult Family Members' Perspectives on the Play of a Young Disabled Child within the Family**

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## DECLARATION

I, Belinda Davies, hereby declare that, except where acknowledgments indicate, the work on which this thesis is based is my original work. Neither the whole work, nor any part thereof is being or is to be submitted for any other degree at this or any other university. I empower the University of Cape Town to reproduce either the whole or a portion of the contents of this work for research purposes.

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Date: 15 February 2007

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# CONTENTS

<b>ABSTRACT .....</b>	<b>1</b>
<b>DEFINITION OF TERMS .....</b>	<b>2</b>
<b>INTRODUCTION .....</b>	<b>5</b>
Research Question.....	7
<b>LITERATURE REVIEW .....</b>	<b>8</b>
Introduction .....	8
Play and Disabled Children .....	9
Defining Play and the Play of Disabled Children .....	10
The Evolving Perspective of Play in Occupational Therapy .....	16
Playfulness .....	20
Occupational Science as a Platform for Studying Play.....	22
Play and Family.....	24
Conclusion .....	26
<b>METHODOLOGY .....</b>	<b>28</b>
The Researcher.....	28
<i>Personal Background and Experience of Play</i> .....	28
<i>Background to the Study</i> .....	32
<i>An Acknowledgement of Preconceived Ideas and Beliefs About Play</i> ....	34
Aim of Study.....	35
Objectives of Study .....	36
Research Purpose.....	36
Study Design .....	36
<i>Qualitative Research</i> .....	36
<i>Case Study Design</i> .....	37
Study Population and Sampling .....	38
<i>Sampling Method</i> .....	38
<i>Inclusion Criteria</i> .....	39
<i>Exclusion Criteria of Participants</i> .....	39
<i>Recruitment of Participants</i> .....	40
<i>Sample</i> .....	44
<i>Thick Description</i> .....	44
Data Collection .....	45
<i>Parent Questionnaire</i> .....	45
<i>Semi-Structured Interviews</i> .....	46
<i>Daily Play-Chart</i> .....	47
<i>Photographs</i> .....	47
<i>Reflective Interviews</i> .....	48
Trustworthiness and Rigour .....	49
<i>Credibility</i> .....	49
<i>Transferability</i> .....	51
<i>Dependability</i> .....	51
<i>Confirmability</i> .....	51
Ethical Considerations.....	52
<i>Access</i> .....	52

<i>Full Disclosure</i> .....	52
<i>Voluntary Participation</i> .....	52
<i>Confidentiality</i> .....	53
<i>Risks</i> .....	53
Data Management and Analysis .....	54
<b>FINDINGS</b> .....	<b>57</b>
Theme: Playing Together – You, Me and Us .....	57
Category: Jasper’s play is a lot about the adult .....	58
<i>Sub-Categories: Who I Am, My Beliefs, What I Enjoy and What I See As Play</i> .....	58
Category: A Picture of Jasper’s Play .....	68
<i>Sub-Category: Jasper, the Person and Agentic Player</i> .....	69
<i>Sub-Category: Facilitated Play</i> .....	70
Category: Play within the Family Context .....	72
<i>Sub-Category: The Marital Relationship</i> .....	72
<i>Sub-Category: The Impact of the Nurses’ Presence</i> .....	73
<i>Sub-Category: The Sibling Relationship</i> .....	76
<i>Sub-Category: Everyone’s Needs Are Important: Finding The Balance</i> .....	77
Category: The Environment and Play .....	78
<i>Sub-Category: Resources and Opportunities</i> .....	78
<i>Sub-Category: Environmental Stressors, Personal State and Play and Playfulness</i> .....	80
Category: Play as a part of daily life .....	81
<i>Sub-Category: It Happens When it Happens</i> .....	81
<i>Sub-Category: Evolution Over Time</i> .....	83
<i>Sub-Category: Routines and Rituals</i> .....	85
<i>Sub-Category: Play as a Tool for Getting Daily Tasks Done</i> .....	87
<b>DISCUSSION</b> .....	<b>90</b>
Play as an Interaction Between Two or More Individuals .....	90
The Rationale for Playing with a Young Disabled Child .....	91
Factors that Inhibit Play with a Young Disabled Child .....	94
Factors that Support Play with a Young Disabled Child .....	97
Transactional Experience Leading to Co-Constructed Play .....	98
The Disabled Child’s Contribution .....	101
Conclusion .....	102
<b>CONCLUSION</b> .....	<b>103</b>
Limitations of Study .....	105
Recommendations .....	105
<i>Research</i> .....	105
<i>For Occupational Therapy Practice</i> .....	106

<b>REFERENCES .....</b>	<b>107</b>
<b>APPENDIX 1: CHILD INFORMATION LETTER .....</b>	<b>119</b>
<b>APPENDIX 2: INTRODUCTORY LETTER.....</b>	<b>120</b>
<b>APPENDIX 3: ASSENT FORM .....</b>	<b>123</b>
<b>APPENDIX 4: CONSENT FORM .....</b>	<b>124</b>
<b>APPENDIX 5: ADULT FAMILY MEMBER'S QUESTIONNAIRE .....</b>	<b>125</b>
<b>APPENDIX 6: DAILY PLAY CHART .....</b>	<b>126</b>
<b>APPENDIX 7: SEMI-STRUCTURED INTERVIEW GUIDE.....</b>	<b>127</b>

## **ABSTRACT**

Play is a universal phenomenon which, from an occupational perspective, is seen as the primary occupation of childhood. Play is regarded as being of vital importance to all children and is recognised as a personal experience which holds unique meaning for each individual. Despite this, relatively little research has been conducted into the nature of the play of disabled children. Play is intrinsically tied to the context in which it occurs and therefore this study was conducted within the family of a disabled child. A qualitative case study of a single unit explored the adult family members' perspectives on the play of a young disabled child in order to gain insights into the way in which disabled children play, as well as the unique ways in which families incorporate this play into their daily lives. Data triangulation was used as a means of promoting the credibility of the study. This involved collecting data from the adult family members in a variety of ways. Analysed data revealed one theme: Playing together – you, me and us. The theme consists of 5 categories which describe how the disabled child's play is a lot about the adult, a picture of the disabled child's play, play as a part of the family context, play and the environment and play as a part of daily life. The theme describes how the experience of play with a disabled child within a family is about more than just the disabled child's play. Instead, the adult family member's experience of the play with the disabled child is discovered to be significant and the interactional nature of play is highlighted. Numerous factors inhibited and promoted this play but despite challenges, the adult family members engaged in parallel and enfolded play. Co-constructed play also occurred and this allowed the disabled child to become an active agent in the play process. The findings contain insights which are relevant to researchers of play and disability, health professionals as well as parents and family members of disabled children.

## DEFINITION OF TERMS

**Co-constructed Play:** Play that occurs between two or more individuals due to the transaction between a variety of affirming factors. This play is meaningful to those involved because it is co-created.

**Disabled Child:** The term '**impairment**' *"refers to the functional limitation(s) which affect a person's body"* (Morris, 1993, p. 10). Whereas, the term '**disability**' *"refers to the loss or limitation of opportunities owing to social, physical and attitudinal barriers... by prejudicial attitudes and discriminatory action... people are disabled by society's reaction to impairments"* (Morris, 1993, p. 10). '**A Person with a Disability**' *"refers to people with impairments"* (Morris, 1993, p. 10). Consequently, *"the disability movement prefers to use the politically more powerful term, **disabled people**, in order to place emphasis on how society oppresses people with a whole range of impairments"* (Morris, 1993, p. 10). In keeping with this, this study uses the term '**disabled children**' to refer to all children who have an impairment and who experience disability as a result of the impact of society. '**The Disabled Child**' in this study refers to the disabled child of the participating family. He is a physically disabled boy who is unable to move around independently due to Spinal Muscular Atrophy with Respiratory Distress Type 1 (SMARD 1). He has no cognitive impairment.

**Enfolded Play:** Enfolded occupations refer to the simultaneous engagement in a variety of occupations (Bateson, 1996). In this study, enfolded play, refers to the play of a child which is facilitated by an adult who is simultaneously engaged in other occupations.

**Family:** Families are dynamic groupings of individuals which change over time due to births, deaths, marriages, divorce and migration. Families may be small or large, consist of individuals from several generations or individuals who are not blood relatives nor linked to the family via marriage (Fitzgerald, 2004). In this study the term '**adult family members**' refers to the three main

adults of the family. These adults included a mother (Elizabeth), a father (Steven) and the main day nurse involved with the disabled child (Pamela) .

**Leisure/Recreation:** While *“the practices and activities commonly referred to as play in childhood and youth are typically referred to as leisure or recreation in adulthood”* (Rigby and Rodger, 2006, p. 178), within this study all these activities are referred to as play unless discussing another author’s work who has in his/her work specifically referred to the activity in this way.

**Nurse:** The disabled child of the family in this study has 24 hour nursing care, therefore when the term, **‘the nurse’** is used, it refers to the main day nurse (Pamela). When the term **‘a nurse’** is used, it refers to a nurse other than Pamela. The term **‘nurses’** refers to all the nurses involved in the 24 hour care of the disabled child.

**Occupations:** *“personally, socially, and culturally meaningful activities in which people actively participate”* (Primeau, 1998, p. 188)

**Occupational Science:** *“the study of humans as occupational beings”* (Clark, Parham, Carlson, Frank, Jackson, Pierce, Wolfe and Zemke, 1991, p. 300).

**Parallel Play:** In this study, parallel play, refers to two or more people engaged in individual play alongside each other

**Parents:** The parents in this study consist of the biological mother and father of the two children in the family, viz the disabled child and his brother.

**Play:** There have been so many attempts at a definition of play, none of which have fully captured its essence (Sutton-Smith, 1997). Part of the reason for this difficulty in defining play is the unique meaning it holds for every individual. Therefore, although definitions of play are discussed in this study, no attempt has been made to define play or to ask the research

participants to define play in order to prevent limitations being imposed on the data collected.

**Transactional View of Occupation:** *“Occupation can be viewed as a transaction joining person and situation. It becomes a way to functionally co-ordinate the intimate person-situation relationship. The goals of that functional co-ordination depend on the particular person and the situation. This means that individuality and context are important, but they must be seen as transactionally a part of the other”* (Dickie, Cutchin and Humphry, 2006).

**Well-Being:** *“A subjective assessment of health which is less concerned with biological function than with feelings such as self-esteem and a sense of belonging through social integration”* (Wilcock, 1998, p. 98).

**Young Disabled Child/Young Child:** The addition of the word ‘young’ to the words ‘disabled child’ or ‘child’ indicate that the child is at an early stage of childhood. Case-Smith and Shortridge (1996) clarify *“early childhood”* (p. 57) as being between the ages of 2½ and 6 years old. The child is no longer an infant but is not yet of middle childhood age (7 – 11 years of age) (Case-Smith et al, 1996).

# CHAPTER 1

## INTRODUCTION

Play has long been a phenomenon of interest to a variety of disciplines such as biology, psychology, anthropology, philosophy and occupational therapy (Reilly, 1974). Consequently, a vast amount of literature exists on the topic of play.

Play has been of interest to occupational therapists since the beginnings of the profession, although at one point in the past it was relegated to the background of occupational therapy research because of its seemingly frivolous and non-serious nature (Parham and Primeau, 1997). Currently, play is recognised in occupational therapy as a serious and important part of the lives of all individuals and particularly children (Bundy, 1993). Furthermore, with the introduction of the discipline of occupational science, it is no longer only viewed as significant because of its contribution to development or as an occupation of rest in preparation for work, but also as an important occupation in its own right (Parham et al, 1997).

From an occupational science perspective, play is recognised as a life-long occupation and the primary occupation of childhood (Parham et al, 1997). This makes play extremely important in the lives of all children, particularly as engagement in occupations that are meaningful to the individual are considered to promote life-satisfaction, a sense of well-being and health. On the other hand, being deprived of opportunities to engage in meaningful occupations (occupational deprivation) is considered to impact negatively on individuals' health and well-being (Christiansen and Townsend, 2004). Consequently, some believe, "*when a child cannot play, we should be as troubled as when he refuses to eat or sleep*" (Hartley and Goldenson, in Florey, 1971, p280).

Research into the play of disabled children\*, indicates that these children experience barriers in regard to play because of their disabilities (Gralewicz,

1973; Rubin, Fein and Vandenberg, 1983; Williams and Matesi, 1988; Missiuna and Pollock, 1991; Hinojosa and Kramer; 1997). However, despite the awareness of the importance of play for all children, research into the nature of disabled children's play and how to best support them in their play endeavours is limited. Furthermore, although play is recognised as a personal experience which holds unique meaning for each individual (Bundy, 1993), there is limited research available that investigates the play of disabled children from their own perspective.

Studies which have investigated the perspectives of disabled children do not always cite the barriers that are assumed to impede these children's play (Pollock, Stewart, Law, Sahagian-Whalen, Harvey, and Toal, 1997). The children's impairments have been found to be less significant than the physical and social environment with regard to creating barriers to play (Pollock et al, 1997). This notion reinforces the opinion of scholars of disability studies who criticise traditional beliefs about disability, as these are often show negative attitudes and misunderstandings (Kielhofner, 2005). Consequently, it is essential to conduct research about the occupational experiences of disability from the perspective of the disabled people themselves. In order to gain insight into and understanding of a disabled child's play, it is necessary to understand the child's perspectives, feelings, opinions and thoughts about his/her play. However, this is difficult to achieve with a young child who cannot yet express him/herself at the level required for a study of his/her play. The perspectives of the adult family members may therefore offer as close an understanding of the play of a young disabled child as possible.

Another concern within the study of play is that it should not be viewed in isolation of the environment in which it occurs. Play, as with other occupations, is influenced by the environment (Canadian Association of Occupational Therapists (CAOT), 1996; Stagnitti, 2004). The environment of young children is usually within the family (Kramer and Hinojosa, 1999). Consequently, the family usually has a significant impact on the play of a young child. Furthermore, as Fitzgerald states, families are a, "*cultural*

*universal and ... central features of all societies and thus, all people's lives, occupational therapists must interact with families and take them and their influences into consideration" (p. 489). As a result of this, it seems essential to study the play of a young disabled child within the family.*

Thus play, families and disabled children are found in all cultures and levels of society and it is therefore necessary for occupational therapists and occupational scientists to begin to find ways in which to understand and support the play of disabled children and their families.

With these factors in mind, the following research question was developed.

### **Research Question**

What are adult family members' perspectives on the play of a young disabled child within the family?

\* The term disabled child/children/person/people/individual/s is used throughout this document, instead of a child/person/individual with a disability or children/people/individuals with disabilities. This is in keeping with the preferred term used in disability studies (Morris, 1993; Kielhofner, 2005).

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **Introduction**

Play has been a topic of interest to many disciplines for many years (Rubin et al, 1983). It is recognised by most cultures as being an extremely important part of the lives of all children (Rigby et al, 2006) however disabled children are generally viewed as having limited access to play (Missiuna et al, 1991). These play limitations are not always recognised as such by the children themselves (Pollock et al, 1997) and so it is necessary to consider the perspectives of disabled children when attempting to understand their play. Unfortunately, it is not possible for a young child who is just beginning to talk and to communicate with language to express these perspectives at the level required for a study of his/her play. As a result of this, the perspectives of the adult family members may offer as close an understanding of the play of a young disabled child as possible. Consequently, this study examines adult family members' perspectives on the play of a disabled child within the family.

This exploration of literature begins by explaining the importance of play in the lives of all children and focuses on the right of disabled children to enjoy play opportunities. The difficulty in defining play and the characteristics of play that have been widely accepted will then be discussed in relation to the literature on the play of disabled children. Following this discussion, the need to view play from the perspective of the player is highlighted. The importance of the perspectives of adult family members on the play of a young disabled child will subsequently be explained. The evolving nature of how play has been viewed in relation to occupational therapy will then highlight the reasons for the limited literature available on the play of disabled children from an occupational perspective. The current view that play is an occupation in its own right is then explained with reference to studies on playfulness and the discipline of occupational science. Finally, the impact of the environment on

play is discussed in relation to the family which is often the environment of a young disabled child.

## **Play and Disabled Children**

In the past, play has at times been considered trivial and inconsequential (Rigby et al, 2006). Certain authors have even indicated that some cultures still regard play as being unimportant (Goldbart and Mukherjee, 2000). However, in many western cultures of today play is viewed as a valuable aspect of all children's lives (Rigby et al, 2006).

Play is considered to contribute to children's learning and development (CAOT, 1996). Play is thought to encourage children to explore and subsequently master their environment. It is seen as a means of developing a child's cognitive, social, emotional and sensory-motor skills as well as communication, self-awareness and problem solving. It is also considered to promote a children's flexibility in their thinking and their ability to adapt to their environment (CAOT, 1996; Stagnitti, 2004).

The importance of play in the lives of all children is reflected in the United Nations convention on the Rights of Children (Save the Children Canada, 2000) where it is recognised as the right of every child. However, under Article 31 of the UN Convention on the Rights of the Child (2005), it is recognised that *"disabled children are routinely excluded from opportunities for play, sport and recreation - either through rejection by other children, or physical barriers impeding access. Arts institutions also widely fail to provide access to enable disabled children to enjoy theatre, film, art or dance."* In South Africa disabled children are viewed as a particularly vulnerable population who are open to marginalisation (Office of the Deputy President (OSDP), 1997). The National Plan of Action for Children of South Africa (NPA) is concerned with protecting the rights of all children and offers specific programmes which provide inclusive opportunities for disabled children (OSDP, 1997). However, despite the awareness nationally and internationally

of the difficulties that disabled children have in accessing their right to play, there is limited research involving the play of disabled children. The main reason for this seems related to the difficulty in defining what is thought to be typical play. This impacts on the ease with which play can be studied and particularly play that may occur under special circumstances, such as the play of disabled children (Clifford and Bundy, 1989). From an occupational viewpoint, the limited research into the play of disabled children seems related to the evolving nature of play in occupational therapy and occupational science.

### **Defining Play and the Play of Disabled Children**

Play is easily recognised although it is not easily defined (Bundy, 1991; Bracegirdle, 1992). Many attempts have been made at defining play, however, *“even when people agree that what they are observing is play, they may struggle to articulate what play is. Scholars over the years have attempted to define it, explain it, suggest criteria for it, and relate it to other types of behaviours, but the fuzzy boundaries of play remain”* (Parham et al, 1997, p. 3).

As a result of play being so problematic to define, it has been a difficult concept and behaviour to study (Parham et al, 1997). Consequently, due to this difficulty as well as the uniqueness of each disabled child's abilities, attempting to study the play of disabled children may have seemed too daunting a task for many. It not surprising, therefore, that the Canadian Association of Occupational Therapists (CAOT), in the Practice Paper on Occupational Therapy and Children's Play (1996), states that, *“our knowledge of the relationship between disability and play is limited...and... the nature of the interaction between disability and play behaviour is just beginning to be explored”* (p. 3).

Rubin et al (1983), three psychology experts on play, attempted to consolidate play definitions by grouping them into three categories. These categories

include: play as a disposition, play as an observable behaviour and play as a part of context. While these categories are widely accepted (Morrison, Metzger and Pratt, 1996), when they are compared to literature available on the play of disabled children, questions arise as to whether it is possible for disabled children to experience play according to these categorical definitions. However, since so little is known about the play of disabled children, it seems reasonable to question whether it is possible that these definitions simply do not accommodate the individual differences and special circumstances of disabled children in play. In consideration of this, the categories of play presented by Rubin et al (1983) are compared to the literature that is available on the play of disabled children.

The first category, play as a disposition, includes six characteristics that provide guidelines for distinguishing play from other behaviours (Morrison et al, 1996). These dispositional characteristics include the following:

- Play is intrinsically motivated. This means that play occurs purely for the sake of it. It is not performed in order to meet expectations or to gain external rewards.

Tamm and Skär (2000) investigated how ten children between the ages of 6 and 12 years old with limited mobility played by interviewing them directly and observing them in play. They found that these children played primarily by themselves or with adults. Consequently, their play was often facilitated by adults who impacted on the children's play by bringing their own ideas and expectations into the play (Tamm et al, 2000). Missiuna et al (1991) suggested that disabled children spend much time engaged in therapeutic programmes which aim at achieving therapeutic outcomes from play. These factors will impact on the intrinsic motivation of disabled children. If intrinsic motivation and playing for its own sake is essential for play, what does this mean for the play of disabled children?

- The means is the focus of play and not the ends. The "doing" of play is more important than the outcome.

Pollock et al's (1997) findings show that disabled children associated being with others as play. The sharing of play with others was more important than the play itself. This suggests that disabled children may not always experience play the way it is theorised to be experienced. Sutton-Smith (1997) explains that there, "*often is very little relationship between the player's own play definitions and those of the theorists*" (p. 16).

- The focus is on the player rather than the objects involved in the play. Play is driven by the question of what can be done with an object and not by the question of what the object can do. Consequently, play is distinguished from exploratory behaviour.
- Play may involve imitation of reality but is not a true version of life activities, for example, a child may pretend to make a meal but not actually make one.
- Play is not subject to rules which are externally imposed. This factor suggests the flexibility which is inherent in play. It also separates play from games and this has been a contentious issue as this separation is not always possible.

Technology such as computer games and virtual reality games have been found to provide pleasurable play opportunities for disabled children (Miller and Reid, 2003). These games, however, have rules which frame the play. This calls into question the need for play to be free of externally imposed rules.

- The player is actively engaged in the play. This point excludes passive behaviours such as daydreaming from play (Rubin et al, 1983; Parham et al, 1997).

Tamm et al (2000) found that disabled children often perceived themselves to be involved in play when they were watching the play of others. Humphry, (2005), states that "*observation of and vicarious sharing in, another's occupations is a form of occupational engagement...children experience emotions in response to the affective reactions of other people, so that while they watch, children*

*associate subjective experiences with doing something even before engaging in the activity themselves” (p. 40).*

The second category, play as an observable behaviour, includes various groupings of play types. For example, Piaget in 1962 theorised that the practice play of an infant was followed by symbolic play and later by games with rules as the child developed (Parham et al, 1997). Parten in 1932 described different forms of social play, such as unoccupied, solitary, onlooker, parallel, associative and co-operative play (Morrison et al, 1996). These observable play behaviours are based on childhood developmental norms but little is known about how the presence of a disability in childhood would impact on the engagement in these forms of play.

More recently, *“free play, guided play, directed play and work disguised as play”* (Rodger and Ziviani, 1999, p. 349) have been described. These play forms could be considered an observable play grouping. Free play is highlighted by various researchers as the only form of play which is intrinsically motivated and controlled by the player. It is therefore considered to be the only type of play that truly offers the player all the benefits that play can afford (Bundy, 1993; O’Brien and Smith, 2002). This has implications for disabled children who have been found to spend much of their play time with adults (Tamm et al, 2000).

The third category, play as a part of context, highlights the impact of culture and the environment in which play occurs. In this category, a child’s play may be affected by factors such as:

- access to a variety of toys, play materials and other players,
- the possibility for the child to choose his/her play,
- a sense of safety and comfort
- fatigue, illness and hunger (Rubin et al, 1983).

The interaction between the environment and the player is considered to have a significant impact on play. However, *“the relationship between a child and the environment during play, and the potential impact of a disability on play*

*experiences, while relevant to current occupational therapy practice, has not yet, been fully explored” (Pollock et al, 1997, p. 26).*

The gaps in knowledge regarding the play of disabled children become evident when the limited available literature on the play of disabled children is compared to Rubin et al’s work. However, Rubin et al’s work on play has been influential on a number of occupational therapists’ definitions of play and on how play is viewed from an occupational perspective (Bundy, 1991; Sturges, 2003; Rigby et al, 2006). Factors such as being intrinsically motivated and actively involved, player controlled and playing for the sake of it are seen to be essential for play to occur (Bundy, 1991; Sturges, 2003). It is therefore not surprising to find that the literature on play and disabled children highlights the difficulties these children have in accessing play (Gralewicz, 1973; Rubin et al, 1983; Williams et al, 1988; Bracegirdle, 1992; Hinojosa et al; 1997).

Missiuna et al (1991) describe primary and secondary forms of play deprivation in physically disabled children. Primary play deprivation occurs directly as a result of the child’s physical disability which prevents him/her from being able to participate in various play experiences. Secondary play deprivation occurs as a result of limited play experiences and include social, emotional and psychological difficulties. Particular barriers were highlighted as obstructing a physically disabled child’s ability to engage in free play. Firstly, caregivers may restrict the child’s opportunity to play due to over-protectiveness or a lack of awareness of the importance of play. Secondly, the child’s play may be limited by his/her physical inability to explore or negotiate challenges or by personal issues, such as *“withdrawal due to lack of skill or frustration”* (Missiuna et al, 1991, p. 884). Thirdly, environmental restrictions in the home and community may prevent the child from accessing play opportunities. Finally, *“social barriers”* (Missiuna et al, 1991, p. 884) may result in reduced play interactions with peers and subsequently impact on the child’s social skills. Reduced playfulness of the child’s parents during interactions with the child may also impact on the child’s social play (Missiuna et al, 1991).

In 1997 Pollock et al performed a qualitative study exploring the meaning of play for young people with and without physical disabilities. When taking into account the perceptions of the disabled children themselves, *“previous assumptions about the negative influences of having a disability were not supported by the study findings. Throughout the participants’ descriptions of play experiences and their perceptions of play, disability was only one of several influential elements, including gender, cultural background, personality, family values and other attitudes”* (Pollock et al, 1997, p.30). Environmental barriers were found to be more limiting than personal and physical limitations. Psychosocial aspects of play were found to be more influential on their play experiences in both a positive and negative way than physical aspects of play. Being with friends and a sense of belonging were strongly associated with interactions being associated with play. Finally, it seemed that the distinction between work and play was not always clear but that activities could occur somewhere along a continuum (Pollock, et al, 1997).

Taking into account the perspectives of the individuals experiencing play is essential when it is considered that, *“individuals will differ in their favoured contexts and styles of play as a result of their personality, environment and life experiences”* (Sturgess, 2003, p. 106). Consequently, what one person may call play may not be considered play to another person (Parham et al, 1997). The manner in which play holds a personal meaning for the person engaged in it is possibly one of the reasons why deriving an accurate, all-encompassing definition of play has remained a difficult and elusive challenge to play theorists for so many years. Essentially this means that in order to understand the play experiences of disabled children it is necessary to consider their perspectives rather than to make judgements based on observations framed by theories of play which have not been developed with disabled children in mind.

The field of disability studies has criticised traditional rehabilitation approaches, including occupational therapy, for viewing disability as being a

problem and attempting to normalise disabled people rather than focusing on how they feel and how the environment needs to change to accommodate them as they are (Kielhofner, 2005). By giving disabled individuals and their families the opportunities to voice their experiences of life, occupations and disability, disabled individuals may be supported *“in achieving the lives they choose for themselves”* (Kielhofner, 2005, p. 494). It is essential that disabled children have the right and opportunity to express their own views about their experiences of life, disability and play.

### **The Evolving Perspective of Play in Occupational Therapy**

From an occupational perspective, studies investigating the play of disabled children are limited. The reasons for this may stem from the dynamic, evolving nature of perceptions of play over time.

In the early years of occupational therapy, Adolf Meyer, one of the founders of the profession, theorised that the performing of daily occupations had an organising effect on behaviour which could assist in the promotion and maintenance of health. He therefore highlighted the importance of man's lifestyle and the need for health to be viewed in the context of daily life with its balance of work, play, rest and sleep (Kielhofner and Burke, 1977). In the first edition of Occupational Therapy's first formal journal, "Archives of Occupational Therapy," Meyer (1922) states, *“the whole of human organisation has its shape in a kind of rhythm. It is not enough that our hearts should beat in a useful rhythm...There are many rhythms which must be attuned to: the larger rhythms of night and day, of sleep and waking hours, of hunger and its gratification, and finally the big four – work and play and rest and sleep, which our organism must be able to balance even under difficulty”* (Meyer, 1922, in Shannon, 1977, p230). The founders of occupational therapy were influenced by Meyer's ideas and literature of the time, which highlight play as a means of promoting health by developing the *“mind-body connection”* (Morrison et al, 1996, p. 504). Thomas Kidner and Eleanor Clarke Slagle both wrote about play as a way in which to facilitate remedial or

curative gains (Kielhofner et al, 1977). One of the early leaders in occupational therapy, a nurse named Susan Tracy, wrote a book in which she describes how to make toys from common objects with the involvement of sick children. The aim of this intervention was to divert children's thoughts away from their illness by engaging them in a creative occupation (Morrison et al, 1996). Despite Meyer's philosophy on the importance of play as a part of a balanced lifestyle, the literature on play of the time indicates that play was primarily used as a means of treatment rather than that play itself should be the outcome of intervention. Consequently, discovering if disabled children are able to play, and if so, what, how and in what context they played would not have been a focus during this time.

In the late 1940's and 1950's medical professionals began to criticise occupational therapy for lacking a scientific basis to its practice (Kielhofner et al, 1977; Shannon, 1977; Kielhofner, 1992). The criticisms focused on the belief that occupational therapy's core knowledge was merely common sense (Kielhofner, 1992). These criticisms had serious implications as physicians played a dominant role in the health care system and had the ability to exert economic and philosophical pressure on occupational therapy. This resulted in a gradual shift towards an alignment with the medical model with its reductionistic base (Kielhofner, 1992). As a consequence of this shift in focus, occupational therapy for children became centred around aspects of performance such as visual perception, motor skills, sensory integrative skills, self-care activities and technical concerns such as neuro-muscular techniques and adaptive equipment (Parham et al, 1997). During this time very little is documented about play in occupational therapy literature (Parham et al, 1997).

In the 1960's and 1970's, under the leadership of Mary Reilly, a frame of reference called occupational behaviour was introduced to occupational therapy. Occupational behaviour was explained by Reilly (1969) to be the entire developmental continuum of play and work. Through play in childhood and recreational activities in adulthood the development of the skills necessary for successful adaptation to work are achieved. Play is viewed as

literature is based on the use of play as a means of intervention. Examples of this include an investigation by Singdahlsen, Sparling and Walker (1984) of play techniques with neurologically impaired pre-schoolers and a discussion by Anderson, Hinojosa and Strauch (1987) of the integration of play in neurodevelopmental treatment.

In the 1980's tradition of synthesis, Clifford et al (1989) investigated the play preference and play performance of boys with and without Sensory Integrative (SI) dysfunction. This study, together with Bundy's comparison of the play skills of boys with and without SI dysfunction, provided important findings and implications for future research (Bundy, 1989). Clifford et al (1989) identified the fact that, with so many difficulties in defining normal play, little work had been done on defining abnormal play or play deficits. Clifford et al (1989) explained how assessment of children's play was usually measured in relation to their chronological age and their level of development of play skills. They acknowledged that assessment of a typically developing child's play along developmental lines may provide some information on a child's play but defining deficits in play as the result of a developmental delay was not sufficient. This is because *"although a child's play may not be typical, it may or may not be abnormal"* (Clifford et al, 1989, p. 203). Consequently, two types of play deficits were defined. The first type of play deficit results when a child is unable to successfully engage in the play of their choice. The second type results when a child has poor skills in an area of play and consequently adapts his/her play preference to match his/her strengths. This finding has important implications for disabled children as it accepts that even if play does not occur typically within developmental norms it does not mean that the play is abnormal.

Bundy (1989) also noted that therapists using a SI approach tended to view a child's play as a *function of the SI capacity of the child*" (p. 85). The results of her study which compared the play skills of boys with and without SI dysfunction indicated that therapists assessing children's SI dysfunction cannot, on the basis of Sensory Integration assessment results, conclude

anything about a child's level of play. Finally, many of the boys with SI dysfunction appeared less playful than those boys without SI dysfunction although, on the pre-school play scale, they scored within normal limits. This indicated once again that it is inadequate to assess children's play according to play skills based on developmental norms as it did not provide adequate information on a child's play. In view of this, it was concluded that an investigation of playfulness might prove helpful in occupational therapy (Bundy, Fisher and Morrison, 1991), as might the development of a tool to assess the qualitative aspects of play, such as playfulness (Bundy, 1989).

Occupational therapy literature of the 1990's showed the emergence of a deeper and wider knowledge and understanding of play, the elements of which it is composed, and its purpose and importance in the lives of all children. Instead of valuing play as a means of learning, developing skills, and promoting health, it has become recognised as being important in its own right (Bundy, 1997, Parham et al, 1997, Stagnitti, 2004). This seemed to occur in correspondence with the development of Bundy's model of Playfulness and the emergence of the discipline of Occupational Science.

## **Playfulness**

Bundy (1993) observes that play in occupational therapy is acknowledged as a lifelong occupation and therefore occupational therapists need to take play seriously. In order to do this, play needs to be assessed, implemented and promoted. Bundy (1989) established the need for an assessment of playfulness. Based on the work of Neumann, an educator, Bundy (1993) developed a model of Playfulness. She defines playfulness as the "*disposition to play*" (Bundy, 1998, p. 1) and identifies three pervasive traits of play: internal control, intrinsic motivation and freedom to suspend reality. Bundy proposed that these elements can be traits of individuals who are playful. Furthermore, she described these three elements as being part of a continuum and claimed that it is the combined effect of all three elements that reflects the extent to which a transaction is play or non-play; playful or non-playful. In addition to these three elements the concept of framing, which

involves providing and reading cues, forms a fourth element essential to a definition of playfulness. Bundy explains that playfulness is found in the presence of a combination of intrinsic motivation, internal control, freedom to suspend reality and framing.

As a result of her belief that it is necessary to be able to evaluate play in order to acknowledge its full value. Bundy developed the Test of Playfulness (ToP), based on her model of playfulness. This test is the first evaluation of play in occupational therapy which attempts to assess play directly instead of merely evaluating the developmental skills of a child. The ToP has undergone much rigorous testing and consequent revisions in order to ensure its validity and reliability (Bundy, 1997; 1998).

A number of studies have explored the differences in the play and playfulness of children with and without disabilities using the ToP. The results of these studies are inconsistent (Hamm, 2006). Harkness and Bundy (2001) did not find significant differences in the playfulness of children with and without physical disabilities who had no known cognitive disability. These findings seemed to result as a consequence of various unexpected scores. For example, the disabled children scored highly for the extent to which they clowned or joked. This was explained by the suggestion that physically disabled children may learn to joke and clown as a means of compensating for their disability and as a way of gaining "*positive attention*" (Harkness et al, 2001). Okimoto, Bundy and Hanzlik (2000) investigated the playfulness of children with cerebral palsy and developmental disabilities and found that the disabled children were less playful than their peers without disabilities. Similarly, Hamm (2006) found that children with developmental disabilities were less playful than their typically developing peers. In Okimoto et al's study (1999) it was found that disabled children's playfulness increased once the parents of these children had received intervention to enhance their parent-child play interactions. Developing parent-child play interactions was found to be more effective in improving playfulness than working with the children directly to improve their developmental skills. Hamm (2006) found a strong link between environmental supportiveness and the playfulness of

children with developmental disabilities. From these results it is clear that factors other than the disability of a child have a significant impact on playfulness and play. These seem to include mainly personal characteristics of the child, such as a tendency to joke and clown, as well as physical and social environmental factors.

### **Occupational Science as a Platform for Studying Play**

During the 1990's the emergence of a new academic discipline promised to enrich the knowledge base and practice of occupational therapy (Yerxa, 1994). This is the discipline of occupational science which is defined as, "*the study of humans as occupational beings*" (Clark et al, 1991, p. 300). Occupational scientists attempt to discover the nature of occupations and how they are incorporated into the daily lives of individuals and their families (Primeau, 1998). Within this science occupations, which are defined as "*personally, socially, and culturally meaningful activities in which people actively participate*" (Primeau, 1998, p. 188), form the main construct of study. This means that occupations are no longer studied by investigating their component parts, such as motor or social skills, but instead they are studied directly (Parham et al, 1997).

Within the occupational science tradition of observing occupations directly, the realisation has occurred that play is of value for its own sake. Until recently, play had been viewed in a functionalistic way as a means of achieving skills, such as sensory integration, social and motor skills. However, the sense of pleasure experienced in play and the absorption in the moment is health-promoting in itself (Parham, 1996). Furthermore, "*because we freely choose them, our play and leisure activities may be some of the purest expressions of who we are as persons*" (Bundy, 1993, p. 217). In this way, play allows an individual to experience those elements of his/her life which are important and satisfying to him/her and thus play enhances quality of life (Parham, 1996; Parham et al, 1997).

When viewed as an important occupation in its own right, play needed to be studied directly. This meant that play could no longer be studied, *“from the actions or skill development of the child alone,”* instead, *“the transaction between the child and the environment,”* needed to be considered (Pollock et al, 1997, p. 6). Consequently, in occupational science, *“play is studied by observing it as it occurs in natural environments and by gathering information from people regarding their experiences and perceptions of play, so as to provide a description of naturally occurring patterns of play. This, in turn, is expected to lead to new insights that have the potential to restructure clinical practice”* (p. 16).

The framework of occupational science therefore provides an appropriate platform from which to explore the questions and considerations about the play of disabled children raised earlier, in relation to the definitional aspects of play. This is because within the occupational science tradition of observing occupations directly it becomes essential when studying the play of disabled children to take into consideration the perspective of the child and to study their play within their natural contexts. This links with Sturgess' (2003) suggestion that the experience of play is unique and personal to each individual and that in order to understand the player's experience of play their perspective is necessary. It also links with the suggestion highlighted under definitional aspects of play that more research is needed.

Occupational science is also concerned about occupational justice for all individuals. Occupational justice occurs when individuals are enabled to engage in a variety of occupations which they feel are meaningful to themselves, their families and their communities. Occupational injustice occurs as the result of occupational deprivation, occupational marginalisation, occupational alienation and occupational imbalance. Literature on the play of disabled children indicates that these children experience occupational injustice in all of these ways. This is seen in the following examples.

- Occupational deprivation may result when individuals are deprived of opportunities to engage in occupations of meaning. Children who are

unable to play due to disability may experience occupational deprivation (Missiuna et al, 1991; Christiansen and Townsend, 2004).

- Occupational marginalisation occurs when individuals are excluded from occupations because of society's tendency to create environments based on, "*Normative standardizations of expectations about how when and where people 'should' participate*" (Townsend and Wilcock, 2004, p. 81). Environmental barriers have been found to make accessing play situations and play with others difficult for disabled children (Pollock et al, 1997; Ziviani and Rodger, 2006), resulting in occupational marginalisation.
- Occupational alienation occurs when individuals engage in occupations that have no meaning for them. It has been found that disabled children play less with other children and more with adults who may impose their own ideas of what play should be on the play (Tamm et al, 2000). It is also suggested that these children spend much time involved in therapeutic programmes, catching up school work and self care activities and that they therefore have less time to play in ways that are meaningful to them (Gralewicz, 1973; Missiuna et al, 1991). This suggests that they experience occupational alienation.
- Occupational imbalance occurs when individuals are over or under occupied. Missiunal et al (1991) suggest that over-protective caregivers may limit disabled children's involvement in play experiences due to fears for their safety and well-being. These limits placed on disabled children's play opportunities may lead to under-occupied children and occupational imbalance.

## **Play and Family**

The importance of the environment in which occupations occur is well documented in occupational therapy and occupational science literature (Rebeiro, 2001). Various models describe the interaction between the person, the occupation and the environment (Law, Cooper, Strong, Stewart, Rigby, and Letts, 1996; Baum and Christiansen, 1997). These models

suggest that the environment may either support or promote occupational engagement. Kielhofner (1995) states, *"If we want to understand any person's occupational behaviour, we must also understand the environments in which that behaviour takes place"* (p. 91). Play is a complex, multidimensional occupation (Reilly, 1974) that cannot be studied in isolation (Rubin et al, 1983). Knox (1996) reports, *"many studies have examined the effects of quality care and types of interactions between care givers and children in play behaviour. They found, among other things, that socio-economic status, variations in home environment, and variations in the quality of day-care programmes have substantial effects on children's activities in terms of social interaction and levels of play, imaginary play, and creativity"* (p. 82). This further clarifies the impact of the environment on children's play. As Cameron, Leslie, Teplicky, Pollock, Stewart, Toal and Gaik (2001) state, *"a child's play is determined by his or her transactions with the environment"* (p. 104).

For a young child with a disability the family environment is often where the child spends most of his/her time (Kramer et al, 1999). Families are found in all societies and cultures and are a universal phenomenon. However, defining what a family is can be problematic (Fitzgerald, 2004). Families are dynamic groupings of individuals which change over time due to births, deaths, marriages, divorce and migration. Families may be small or large, consist of individuals from several generations or individuals who are not blood relatives nor linked to the family via marriage (Fitzgerald, 2004). For children Hinojosa et al (1997) describe the family as, *"A group of two or more individuals who provide the environment within which the child physically develops, matures and learns"* (p. 159). The family environment will therefore impact significantly on the child's experience of occupational engagement, health, well-being and play.

Kramer et al (1999) state, *"The world of a child is framed within the context of family and culture"* (p. 47). As a consequence of the importance of the environment on play and the family being the main environment for many young children, it seems essential to investigate the play of a young disabled

child within the family environment. Despite this, the literature available in the fields of occupational therapy, occupational science, disability studies and leisure studies reveal, "*minimal, if any, attention to*" (Mactavish and Scleien, 2004, p. 123) the play of families which include a disabled child. Furthermore, no studies were found which investigated the play of a young disabled child within the family environment.

## **Conclusion**

The importance of play for all children is acknowledged by many societies and cultures throughout the world. It is viewed as a vehicle for development and learning, as a means of promoting health and as influential on quality of life. It is also seen as an occupation of worth for its own sake. Play, however, is a notoriously difficult phenomenon to define. Despite this, a number of categories including various characteristics of play have been widely accepted for determining whether an individual is playing or not. When disabled children's play is viewed in relation to these characteristics questions arise as to whether it is possible for these children to play. It is thus not surprising that disabled children are viewed as having difficulty accessing play as result of their disability. Studies that have investigated disabled children's play from their perspectives reveal that the children feel as if they are playing although possibly not in a conventionally accepted form. This highlights the need to understand play from the perspective of the disabled child. In order to gain insight into and understanding of a disabled child's play it is essential to understand the child's perspectives, feelings, opinions and thoughts about his/her play. However, it is not possible for a young child who is just beginning to talk and to communicate with language to express these at the level required for a study of his/her play. Consequently, the perspectives of the adult family members may offer as close an understanding of the play of a young disabled child as possible.

The environment has a significant impact on an individual's engagement in all occupations, including play. For the young disabled child the family is often the main environment. The family of a young disabled child will therefore

have a significant impact on the child's play. Despite these factors no studies were found which explored the play of young disabled children within the family environment from the perspective of the adult family members.

By exploring how a physically disabled child plays within the family environment from the perspective of his adult family members a better understanding of the way in which disabled children play, as well as the unique ways in which families incorporate play with their disabled family member into their daily lives, may be gained. Instead of focusing on the difficulties that disabled children have in accessing play, this study hopes to provide new insights into the positive and unique ways in which children with disabilities play. This may lead to further ways of encouraging play in families who have difficulty incorporating play with their disabled child into their daily lives. It may also provide ways of supporting families with disabled children in ways that are meaningful to the family.

## CHAPTER 3

### METHODOLOGY

The methodology that follows describes the researcher's experience in relation to play, how the research topic evolved and the researcher's assumptions about play. This section provides the reader with information about the researcher in order to enhance the trustworthiness of the study. It also makes the researcher's beliefs and pre-conceived ideas explicit and contributes to reflexivity. The aim, objectives and purpose of the study as well as a justification for the use of qualitative research and a case study design is presented. The details of the study design with respect to sampling and data collection are described. Methods ensuring trustworthiness and rigour are also discussed and ethical considerations taken into account. The chapter concludes with a break down of the data analysis procedure.

#### **The Researcher**

Bracketing, or epoche, is a process used in qualitative research where the researcher explains his/her own experience of and perceptions about the phenomenon under investigation so that these may be set aside and the phenomenon may be understood from the participants perspective (Holloway and Wheeler, 1996; Creswell, 1998, Finlay, 2000).

#### ***Personal Background and Experience of Play***

I am a white South African woman and I grew up in Durban as part of a large blended family. My childhood experience of play strongly reflects the social and physical environments of my childhood as well as my age and stage of development. This reflection on my childhood play serves to demonstrate my personal stance on and interest in childhood play.

My earliest memories of play centre around my immediate family and the nursery school I attended. Week day mornings were full of ring time songs,

painting, sand and water play, outdoor bike and jungle gym play and imaginary play with friends. In the evenings, my father would sing and dance with me on his shoulders after returning home from work. I also remember my brother and I playing alongside him while he gardened and him teaching me to ride my bike. I do not remember playing with my mother but photographs of my young childhood show how she set up painting activities and water play activities, organized my birthday parties with other children and read stories to my brother and I. This is possibly a reflection of her training as a teacher.

My memories of play change at around the age of five and are connected to the environmental and social changes of my life at the time. I commenced primary school and my brother and I spent week days with my mother and weekends with my father following their divorce. The weeks were spent at school during the day and in the afternoons we played with the large number of similarly aged children in the housing complex where we lived. This play consisted mostly of outdoor games such as hide-and-seek and chase games, swimming in the pool, playing in the park or exploring the neighbourhood. In the weekends, my father treated my brother and I with very enjoyable play activities such as going to the beach. He also taught us to play games such as cards, chess and board games and we enjoyed singing with him while he played the guitar. We often played alongside my father while he worked in the garden or fixed things around the house or attended my father's social leisure activities.

Social and environmental changes once again created changes in my play at eight years of age when my brother and I moved to England with my mother and step-father. The first year was spent in a place where we had school friends but no neighbourhood friends. This meant that we often visited friends to play at their houses. It was at this age that I also started organised play activities such as Brownies, swimming training and gymnastics. My mother facilitated play for me by setting up a child-sized table and chair in my bedroom with creative materials and I enjoyed drawing and writing letters from here. At the beginning of the second year in England we moved to another

part of the country. Here there were many children of similar ages in the neighbourhood and we spent much time together in the afternoons after school riding bikes, engaging in pretend play and putting on dance routine performances, particularly in the long summer afternoons/evenings. I also enjoyed watching the variety of children's TV programmes available in the UK at the time. This was something we had not had access to in South Africa. I also spent much time playing with my baby brother who was born the previous year. Occasionally, during our time in England, we would take family trips to visit different places. While efforts were made to accommodate my brother's and my interests, such as visiting the Beatrix Potter museum in the Lake District, at this age I tended to prefer to be at home playing with my friends.

When I was ten years old, we returned to South Africa during the summer and enjoyed going to the beach, swimming in pools and making the most of the warm weather. Play at this time changed depending on whether it was the week or the weekend. This was mainly due to school demands and the differing social environments of my mother or father's houses. At my father's house, over the weekends, my brother and I enjoyed playing with my step-mother's three children, who were of similar ages to ourselves. At my mother's house, during the week, play was limited by homework but I enjoyed after school sports and other school activities. I also enjoyed swimming, reading, watching TV and playing with my younger brother and sister.

During my pre-teens and early teens, when homework didn't intrude, the weekends were spent playing constantly. My brother, my three step-siblings and I were constant peer company for each other and we enjoyed swimming, playing outdoors, and creating games wherever we went. The environments we were in facilitated different types of play but wherever we were, we played. At one point, my father lived in a house near a tennis court so then we played tennis. Similarly, if there was a swimming pool available, we swam. We also played games which we developed as a family of children, which held special meaning for us and which we thoroughly enjoyed. I also attended gymnastics during this time, played hockey at school and attended club tennis. Family

outings and holidays were also enjoyed as opportunities for playing together and with others.

The influence of age and stage of development was evident in my later teens when social play/activities started to shift away from the family, as my brother, step-siblings and I all started to enjoy socialising outside of the family. I enjoyed spending time with my school friends, going to movies, sleeping over at their houses, being involved in school cultural events and going out to social gatherings.

My childhood held many turbulent times, challenging transitions and difficult experiences, however, in many ways play is what carried me through those times. I feel incredibly privileged to have had a childhood so full of play. It seems to have permeated every aspect of my life. It happened when I was working such as drawing pictures as part of homework. It happened during self care tasks such as bubble play in the bath. It happened when I was alone such as losing myself in some individual creative activity. It happened while enjoying the competition of sporting events, and it happened with my parents and grandparents, with my siblings and cousins, with my friends or with strangers who became friends through play.

Childhood play for me lasted for a long time due to being the eldest in a family of many children. For me, memories of play define what my childhood was essentially all about and the feeling of joy experienced during playful moments is still vivid for me today. Furthermore, sharing memories of play with my family still makes us laugh and gives us a sense of family and a shared past. This makes the play that I shared with others close to me even more meaningful.

As a result of my past experience of play, it is a phenomenon which I feel passionately about. This has fuelled my interest in studying play and discovering more about disabled children's play, especially since they are believed to so often be denied their right to play.

## ***Background to the Study***

I began my MSc studies at the University of East London, England in September 1999 and completed the required course work in April 2001. During my course work I discovered the developing field of occupational science and the renewed interest of occupational therapists in the occupation of play. This, together with my own childhood experience of play, sparked a keen interest in this area of research. In March 1999 I attended a 3 day course on Play and Assistive Technology for Young Children run by Shelley Lane, a well recognised Occupational Therapist from the USA. This course highlighted for me the world of possibilities that assistive technology can offer to disabled individuals who have access to it. Technology is often viewed negatively in relation to the play of children but for disabled children it can provide opportunities for independent and social play that they may not otherwise have been able to experience. Consequently, I feel that technology should be viewed with an open mind, particularly when considering the play of disabled children. In June 2000 I attended a 5 day course on the Test of Playfulness run by Anita Bundy, an Occupational Therapist from the USA, who developed the test and who is the leading expert in occupational therapy on the concept of playfulness. This course afforded me the opportunity to study play from a closer perspective in that it was broken down into component parts and viewed within the context of the environment. It also gave me a sense of confidence in my feeling that play is valuable not only as a way of promoting learning but as an occupation in its own right. It was then that I began to feel that further study of play would be a worthwhile venture.

At the time that I began my MSc studies I was working in community paediatric occupational therapy in Brighton, England. Here I worked with children of all ages and with a variety of difficulties, impairments, conditions and disabilities. Being a community based service, much of my work occurred within children's homes and with their families. It was working with these families that lead me to believe that, while children are undeniably individuals in their own right, they cannot be worked with or seen in isolation

of their families. It seemed clear to me that children's health, development, well-being and occupational engagement were largely reliant on their families.

It was from this perspective, together with an awareness that very little occupational therapy literature has explored the play of disabled children within their family, that I developed my research proposal. An example of my thoughts at this time are seen in the following quote from my reflective diary.

*"Although play may seem like a frivolous and unimportant occupation to study, it is worth considering the effect it would have on children if all their play was removed from their lives. It is then that we are able to understand the seriousness of play. In young children, play is considered to be the primary occupation of childhood, and children who do not play or cannot play will experience serious repercussions on their development and health. Disabled children have been found to have difficulty in accessing play. This should therefore be of concern to all individuals who are interested in the development, health and well-being of disabled children"* (February 2002).

My proposal was submitted to the University of East London and South Downs Health Care Ethics Committees in November 2001 and I gained ethical approval in June 2002. I subsequently began my search for a family who was interested in participating in the study but, in December 2002, I returned to South Africa.

In 2003 I began to work in a paediatric private practice in Tokai, Cape Town. Being based in a private school, the work was primarily focused on the performance components of school related needs. In 2004 I resumed my MSc studies at the University of Cape Town (UCT). I gained credit for the work I had already done but completed the Rehabilitation Module through the UCT Occupational Therapy Department to add to this. Through this module I was able to gain a perspective on rehabilitation in South Africa, the international, national and local policies that influenced rehabilitation and the diverse needs of the South African population. This had a significant influence on my thoughts concerning the relevance of my research proposal.

What had seemed particularly relevant to my practice in the UK suddenly seemed inconsequential in the face of performance component driven private practice and the poverty of much of the South African population. This concern was added to by the fact that the family who chose to become involved in the study was representative of a small minority in the country because they were a white family of higher socio-economic circumstances. However, on consideration of The Integrated National Disability Strategy, I realised the vulnerability of all disabled children regardless of their socio-economic status. This vulnerability occurs because society conventionally accommodates what is perceived to be the norm and does not allow for individual differences such as the special circumstances of disabled children. I also reflected on the fact that families, disabled children and play are all universal constants and are present in any society and culture. Consequently, I realised that this exploratory study could provide a useful starting point for gaining further insights into disabled children and their play within their families.

In March 2005 the proposed research gained ethical approval from the University of Cape Town Research Ethics Committee.

### ***An Acknowledgement of Preconceived Ideas and Beliefs About Play***

It is hoped that by making clear my personal underlying hopes and assumptions, the reader would be able to recognise the impositions and influences of these on the data.

The general implications of much literature on play and disabled children suggest that their play is limited due to reduced access. However, during my work with disabled children I was often involved in their play and observed interactions and occasions which clearly and yet inexplicably qualified as play. This play occurred within the children's homes, at school and wherever the child was interacting with others. Consequently, I felt that, when studied in context, a disabled child may have more opportunities for play than is

generally assumed. These opportunities for play may not be conventional forms of play or what we imagine them to be.

I was determined to be open to the adult family members' beliefs, opinions, feelings and perceptions and not to judge these but to always come from a point of understanding. This decision was based on my belief that play is an experience which is personal and unique for every individual. I consequently expected the adult family members' to have differing experiences of play to my own and did not want this to impact on my ability to understand the adult family members' perspectives.

I grew very fond of all the members of the family I worked with and admired them for the way they played the roles that they had adopted in the family. Also, in my clinical experience, I have found that most parents, care-givers and adult family members of children are doing their very best for their children within the constraints of their environments, resources and opportunities. I therefore hoped to discover findings that were positive and encouraging rather than negative.

Despite my own experience of play which involved primarily other children and much outdoor, physical play I did not believe this to be the only form of play.

I enjoy watching television and can see how others may classify this as a form of play. I do not enjoy computer games but have seen how much enjoyment others can gain from such games and therefore am convinced that, if an individual enjoys these games, they may be considered play. For disabled children I believe that technology, which includes television and computers, offers many opportunities for occupational engagement including play.

### **Aim of Study**

The aim of the study was to explore adult family members' perspectives on the play of a disabled child within the family.

## **Objectives of Study**

The objectives were:

- to gain insight into care-givers' perspectives on the nature of the play of a disabled child within the family
- to gain insight into care-givers' perspectives on the manner in which the play of a disabled child occurs within the family
- to gain insight into care-givers' perspectives on the context of the play of a disabled child within the family
- to identify factors which impact on a disabled child's play

## **Research Purpose**

By exploring how a physically disabled child plays within the family environment from the perspective of his adult family members, a better understanding may be gained of the way in which disabled children play and the unique ways in which families incorporate play with their disabled family member into their daily lives. Instead of focusing on the difficulties that disabled children have in accessing play, this study aims to provide new insights into the constructive and unique ways in which disabled children play. This may lead to ways of encouraging play in families who have difficulty incorporating play with their disabled child into their daily lives. It may also highlight opportunities for supporting families with disabled children in ways that are meaningful to the family.

## **Study Design**

The study design used for this qualitative research was a case study of a single unit.

## ***Qualitative Research***

Qualitative research is a form of inquiry which seeks to explore and understand phenomena from the individual's perspective within their natural

environment (Krefting, 1991; Cook, 2001). *“Qualitative techniques are essential for exploring new topics and obtaining insightful and rich data on complex issues”* (Bowling, 1997, p. 114). Since little is known about the play of a disabled child within his family environment, qualitative research was used to investigate this phenomenon in depth. Qualitative research is *“based on distinct methodological traditions”* (Creswell, 1998, p. 5), including case studies.

### ***Case Study Design***

Case studies may be qualitative or quantitative in their approach (Stake, 1995; Denzin and Lincoln, 1998). The purpose of this study is exploratory in nature and involves the investigation of a phenomenon as it occurs in its natural setting. It was therefore appropriate to follow a qualitative line of enquiry.

The research question of this study is, ‘what are adult family members’ observations of the play of a disabled child within the home environment and daily life of his/her family?’ As case study designs are *“ideal for describing persons in depth and over time in their contemporary context without sacrificing or reducing the complexity of human experience”* (DePoy and Gitlin, 1998, p144), it was felt that a case study would provide the most truthful answers to this question.

A case study of a single unit was used instead of investigating multiple cases (collective case study) (Creswell, 1998). This provided the opportunity to investigate and capture one family’s experience of play in all its complexity without compromising the depth of this experience by attempting to study too large a sample. Furthermore, it was not the aim of this study to compare or generalise the findings of this investigation to other situations, although it was hoped that it might lead to questions for further research. Since the focus of this study is the play of a disabled child, this case study is classified as an instrumental case study. This is because the case study is instrumental in

developing the understanding of one disabled child's play within the family (Denzin et al, 1998).

Case studies are described as "bounded systems" because they are confined within a certain time and context (Stake, 1995; Creswell, 1998). The data of this case study was collected over a three week period which was chosen by the adult family members as a convenient time for them. Prior to the data analysis of this study, the context of the study was perceived to be the family's "home" or residence. The data revealed, however, that the context of play during this period could not be constricted to the family's residence because much of the family's play discussed in the interviews and documented in the weekly play charts occurred outside their residence. The reason for this was, firstly, that much of the family's play involves outings to various locations. Secondly, some mention of the disabled child's play at play group was made. Since he attends play group with his nurse and she is involved in most of his play while there, it seems that this may still qualify as play within the family. Finally, the family went away on holiday for 5 days during the data collection period. It therefore seems to indicate that the context of this study is bound within the context of the family rather than by a specific place. What is clear is that every case is unique and that *"the nature of cases are situational and influenced by happenings of many kinds"* (Denzin et al, 1998, p. 91).

Consequently, a case study design provides the most meaningful method of exploring play within one family as it occurs in its natural setting within the family.

## **Study Population and Sampling**

### ***Sampling Method***

A purposeful sampling method was used for this study. Instrumental case studies require the case or sample to be chosen specifically for optimal understanding of the phenomenon under investigation. This type of purposeful sampling is known as criterion sampling (Creswell, 1998). The

sample selection may also have been classified as an opportunistic form of purposeful sampling as in order to find a family to participate in this study every opportunity that presented itself and all possible leads to a family who met the inclusion criteria were followed (Creswell, 1998).

Due to the in-depth nature of this investigation, it was necessary for the family involved to be available and willing to participate. Using a purposeful sampling method meant that the participant family chose to become involved. This increased the likelihood of finding individuals who were willing and enthusiastic to participate.

### ***Inclusion Criteria***

The following inclusion criteria were used:

One family was required for this case study investigation of a single unit. It was proposed that this family would include at least one adult family member and a disabled child of pre-school age with a physical impairment which caused the child to be unable to move around independently. A maximum of one other child who did not have a disability was considered to be an acceptable variation of the participant family. This was based on my assumption that this study would place too great a demand on a family that consisted of more than two children.

### ***Exclusion Criteria of Participants***

Families who met the inclusion criteria described above but in whom the disabled child also had a communication disorder, such as autism or another form of Pervasive Developmental Disorder, was not considered for the study. This is because these disorders add another dimension to the concept of play. The play of children with these types of disorders is complicated by poor communication and other difficulties (Gordon, Schanzenbacher, Case-Smith and Carrasco, 1996). This would have complicated the data analysis stages of the study as another factor impacting on play would have to have been included, investigated and analysed.

Families who did not speak English as their first language were excluded from this study due to the in-depth nature of the investigation and the reliance on the researcher's thorough understanding of the adult family members' personal reflections and feelings about their experience of play. The depth of understanding gained might have suffered due to ignorance, on the researcher's part, of the subtleties implied in another language.

Families who had been involved in child protection issues or concerns were also excluded from this study. This is because, firstly, these issues could have placed the researcher in the position of needing to involve other agencies and as a result the family's confidentiality could not have been guaranteed. Secondly, these issues may have impacted on the data collected.

### ***Recruitment of Participants***

The initial plan for the recruitment of a family was as follows:

Potential families were to be recruited directly from service providers who work with physically disabled children. The researcher planned to contact a number of service providers and discuss the proposed research and its purpose with them. The service providers would then have been able to identify and contact appropriate families without the researcher's involvement. The service providers were to have been informed of the inclusion and exclusion criteria so that they would have been able to contact families appropriate for the study. The service provider was to explain the proposed research and its purpose to potential families without the family feeling any pressure to participate. If a family refused to participate the researcher would have no knowledge of the family or that they were ever approached as potential participants. Families who were interested were to give the service provider permission to share their details with the researcher so that the researcher could contact them with further information regarding the study.

The family who participated in this study was recruited by the method discussed above. The researcher discussed the study with the occupational therapist who works with the family's disabled child. She felt that she worked with a few families who met the inclusion criteria and agreed to discuss the study with them. The family who participated in the study was, however, the only family she contacted about the study. The reason for this was that on reflection the occupational therapist reconsidered the in-depth requirements of the study and the needs of the families and decided that only the one family would cope with the research demands.

Prior to the recruitment of the family who participated in this study, the researcher was put in contact with three other families. Initially the researcher approached service providers and this led to a discussion about the study with the mother of the first family. Following this discussion the mother of the family agreed that her family would be prepared to participate. However, this family withdrew once she had discussed the study with the father of the family. They both concluded that there were too many demands on the family at that time for them to participate in the study. One of these demands was that their disabled child was expected to need surgery within a few months of the time the study was to commence.

The second and third families were discovered via friends, acquaintances and colleagues with whom the researcher had discussed the study. The second family did not meet the inclusion criteria because the disabled child had a communication disorder. The third family initially agreed to participate following the researcher's discussion with the mother of the family. This family later withdrew following their receipt of the letter of introduction to the study. Their reason for withdrawing was that they felt they would have difficulty coping with the demands of the study as well as everything else they were coping with at the time.

Many other leads were pursued but few families met the inclusion criteria and a variety of difficulties prevented service providers from contacting three other potential families about the study.

Reflections on this process in the researcher's personal diary were as follows:

*"It seems that when discussing the study with me over the phone the mothers of these families are interested and willing to engage in this exploration of the play in their family. However, when left to think about it and discuss the study with their husbands, the study becomes an unnecessary addition of stress, another demand into their already overwhelmingly busy lives."*

The mothers of both the first and the third families initially agreed to participate in the study following conversations with the researcher. They later chose to withdraw from the study following conversations with their husbands. It seemed that perhaps the fathers needed to be consulted by the researcher as well as the mothers.

*"Furthermore, although the letter of introduction is supposed to be friendly and informative it is in reality long and full of what may seem like many demands. It is also possible that the mention of child protection procedures in the letter may seem threatening. I imagine that these families must feel that they are having to give much for very little in return."*

The letter of introduction was carefully written to include everything that needed to be done by the family in the study. It was necessary to ensure that the family would be clear about their involvement and what they were committing themselves to. This meant that the letter consisted of two detailed pages. Including mention of child protection procedures was necessary as, should issues related to this have occurred, other agencies would have needed to become involved which would have impacted on the confidentiality of the family. It is possible that this might have seemed threatening.

*"Perhaps it is also my anxiety at asking a family to do this for me with not enough belief in the personal returns the family will gain from participating in this study that is subconsciously putting these families off. I will need to find a way to introduce the study and the introductory letter to the family in a way*

*that truly reflects the exciting findings that this study may reveal. I myself must stop feeling so anxious about finding a family and asking them to do this and start focusing on all the positive and exciting aspects of this study. I do believe that if I could just chat with a family who was interested face to face and they could get a sense of who I am together with a verbal explanation of the study, they would feel more comfortable about inviting me into their home to share their experiences with me."*

I was concerned about asking a family with a disabled child to participate in this study. This was because I was aware of how busy the lives of families with children are. Furthermore, the presence of a disabled child would probably add responsibilities and time demands. Being involved in this study would add to these demands.

In the context of these thoughts, when the family who participated in this study expressed an interest in being a part of the research, the researcher and the research supervisor agreed that the introduction of information about the study should be approached differently. Consequently, instead of discussing the study with a parent over the telephone and then sending the information letter to the family via the post, the researcher made an appointment to meet with both parents of the family to discuss the details of the study with them personally. Once the study had been discussed in depth with both parents the letter of introduction was read by both of them. Following this they both agreed to participate and the researcher had the opportunity to discuss the study with the nurse who was present during the same meeting.

The following quote summarises why the researcher feels that meeting with the adult family members to introduce the study, instead of sending an impersonal letter, ultimately lead to a family feeling comfortable enough to embrace such an in-depth study of their play and their lives. *"To engage in qualitative research, one engages in close interpersonal relationships with informants/participants. While friendship is not an essential condition for conducting research ... being accepted and trusted is"* (Cook, 2001, p. 8).

### **Sample**

The family involved in this study consisted of a 2½ year old disabled boy, his parents, his 4 year old brother and his main day nurse. The nurse spends a large amount of time with the disabled child and consequently knows him very well and is involved in much of his play. For this reason the parents felt that the nurse should be included in the study as a third adult family member. They felt that to exclude this nurse would mean that the data of the study would be lacking. Therefore, following discussion with the supervisor of this study and the nurse herself, it was decided to include her in the study by engaging her in a semi-structured interview, involving her in filling in the weekly play chart and encouraging her to take photographs.

Humphry and Case-Smith (1996) explain that family boundaries may be “porous” (p. 68) and individuals who are not related to other family members may be included as part of a family.

### **Thick Description**

The family live in an affluent area of Cape Town in a large house with a garden, swimming pool, outdoor trampoline, a swing and a slide. The house was designed and built with Jasper in mind and is therefore wheelchair accessible throughout.

Steven is the father of the family. He is 30 years old and works as a director of a computer company. Elizabeth is married to Steven. She is 27 years old and describes herself as a housewife and mother. Charles is their eldest child and is 4 years old. He had slightly delayed speech development but has otherwise attained all his developmental milestones age-appropriately.

Jasper is their youngest child and is 2½ years old. He was born via an elective caesarean at 38 weeks with no complications. At 2½ months of age he presented with respiratory difficulties and was diagnosed with Spinal Muscular Atrophy with Respiratory Distress Type 1 (SMARD 1). This condition is the result of a recessive gene and requires him to be fully

ventilated due to diaphragmatic paralysis. Neurological degeneration has caused incomplete paralysis of his body although this has remained static since he was 6 months old. Loss of movement since this time has been due to his weight gain. A number of day and night shift Intensive Care Unit (ICU) nursing sisters provide him with 24 hour care. He also receives intensive physiotherapy, occupational therapy and speech therapy.

Pamela is 46 years old and is Jasper's main day ICU nursing sister. She has worked with Jasper since he was 6 months old and spends fifteen 12 hour shifts with him a month. She has also been away on holiday with the family as Jasper's day nursing care during this time. As his main nurse, Pamela is the team leader to the other nurses and specifies when and how daily schedules of therapy and care need to be carried out.

## **Data Collection**

An important element of case study research is its dependence on the use of multiple methods of data collection. This promotes the rigour of the investigation and allows for a more accurate reflection of the complexity of the case (Bowling, 1997). Consequently, data collection in this study included the following research instruments:

### ***Parent Questionnaire***

A parent questionnaire (see Appendix 5) was used to gain basic demographic details of the family, some background to the disability of their disabled child and a brief developmental description of their non-disabled child. The information gained from the parent questionnaire was useful in providing a thick description of the family who participated in this study. This has led to the possibility of transferability for future research and has consequently enhanced the trustworthiness of the study.

## ***Semi-Structured Interviews***

The semi-structured interview is one of the methodological means of gaining qualitative data. The semi-structured interview is based on an interview guide (see Appendix 7) consisting of open-ended questions (Flick, 1998).

The semi-structured interview (Flick, 1998) was chosen for this study as a means of guiding the participants' thoughts around the topic of play but without the restrictions imposed by a standardised questionnaire with regard to the fullness of these thoughts and perceptions. The researcher allowed each of the participants the opportunity to explore their thoughts in response to each of the questions and used encouraging gestures, such as nodding, and words such as "that's interesting" or "can you tell me more about that." The next question was only moved onto when it was felt that all thoughts raised by the present question had been expressed. At times questions in the schedule had already been answered but even so the question was repeated by saying, "it seems that this may have already been answered but, in relation to this question, is there anything more you would like to add?" This often prompted further ideas and perspectives which allowed for greater richness of the data.

Each participant engaged in one semi-structured interview. These took approximately 1–1½ hours to complete. No time limit was set for the interviews and the length of the interviews was dependent on how much the participant had to say in relation to the schedule of questions and related prompt questions. The semi-structured interviews were set up for the participants at a time convenient for them so that they could spend as much time as they wished expressing their thoughts. The parents spoke separately to the interviewer on a Saturday morning so that they could take turns in looking after their children. The parents encouraged the nurse to use her work time to engage in the interview so that she did not have to use her "personal time" to discuss an issue related to their child and family. This interview occurred during the disabled child's sleep time so that she could focus on the interview without interruption. Each of the interviews was

conducted in a room away from the rest of the family so that the interviews were private and there were few interruptions

The semi-structured interviews were recorded using audio recording equipment. Semi-structured interviews were used by the researcher during various previous investigations which were performed in part fulfilment of the researcher's MSc. Consequently, the researcher had previous experience in using this technique.

### ***Daily Play-Chart***

The care-givers were asked to fill in a daily play chart over the three week data collection period (see Appendix 6). This chart recorded the play that occurred on an hourly basis during each day of the three weeks. The aim of the chart was to discover what was played, when and where it was played and who the players were. Diary methods have been found to be valuable for gaining detailed information when used with a small number of individuals and over a short period of time. Diary methods are, however, prone to non-completion (Bowling, 1997). The mother and nurse attempted to fill in the daily play charts but explained that this was difficult due to the spontaneous, fleeting nature of play and the sense that they were often not consciously aware that they were playing at the time. This meant that the chart tended to be filled in later when play was being reflected on with the result that details were often missed. The daily play chart was, however, useful in prompting discussion about the play that had happened in the family over the three weeks of data collection in a follow up reflective interview. Mason (2002) explains that documents often provide a means of verifying data collected in other ways, such as, interviewing.

### ***Photographs***

Two disposable cameras were given to the care-givers so that they could take photographs of play in their family with their disabled child during the three weeks of data collection. Flick, (1998), describes the use of photographs

taken by participants as a form of *“photographic diary, in which people capture aspects and events of their daily lives as these unfold. The decision about which of these aspects or events is selected to be photographed is taken not by the researcher but by the subject. What he or she selects and takes as a picture allows the researcher to deduce statements about the views of the subjects towards their own everyday lives ”* (p. 153). This method of data collection is therefore consistent with ensuring that the adult family members expressed what was significant to them and reduced the possibility of the researcher imposing her ideas of what was important and what was considered play on the data collected.

These photographs were later used in a follow up reflective interview where the adult family members were able to reflect on the photographs and tell the stories behind them. The photographs taken were found to primarily be examples of play that typically occurred with Jasper in the family, which the adult family members wanted to share with the researcher.

When discussing the use of photography as a record with the adult family members, the father of the family felt that he would be better at taking photographs than filling in the weekly play chart and he would use his own digital camera to take the photographs. As such, this would be his document of play over the three week period. Unfortunately, the digital camera broke prior to the data collection period and the father of the family did not take any of the photographs. These were mainly taken by the mother and a few by the nurse. This in itself, however, may be considered representative of the roles played in the family.

### ***Reflective Interviews***

A reflective viewing of the photographs and daily play chart was held with the parents of the family following the three week data collection period. These interviews focussed on discussion concerning the photographs and the daily play chart, giving the parents the opportunity to express any insights, thoughts, opinions and perspectives on their disabled child’s play that had

developed during the data collection period. It also gave the parents the opportunity to discuss how the use of the daily play chart and photographs had worked and to reflect on the photographs taken and what was written in the daily play chart. The purpose of this interview was to achieve a saturation of information. Saturation occurs when no additional information is gained from the participants of a study (Flick, 1998). This was achieved in these interviews as much of what had already been expressed was reiterated and the interviews were much shorter than the semi-structured interviews because the parents felt that they had no more to add.

## **Trustworthiness and Rigour**

*“It is generally agreed that research needs to be ‘trustworthy’ (a term often used in place of ‘validity’ in the qualitative researcher’s lexicon), in the sense of being able to demonstrate both rigour (process) and relevance (end product)”* (Finlay, 2006, p. 320). Credibility, Transferability, Dependability and Confirmability are four criteria used to establish the trustworthiness and quality of qualitative research. Various strategies are used in qualitative research to contribute to these criteria and to enhance the accuracy, *“value and integrity”* (Finlay, 2006, p. 319) of qualitative findings. The four criteria for trustworthiness were adhered to in this study and the strategies that contributed to these are as follows:

### ***Credibility***

Data triangulation (Huysamen, 1994; DePoy et al, 1998) involved collecting data from a number of different sources, all of which reflected the adult family members’ perspectives and observations of the play of their disabled child within his family. These data collection methods included semi-structured interviews, photographs taken by the adult family members, a daily play chart and reflective discussions on these.

The semi-structured interviews provided the researcher with the participants’ in-depth reflection on their perspectives on the play of their disabled child.

This was complimented by the photographs which provided a visual observation of the play that occurred with the disabled child within the family. The daily play chart provided evidence of the play that happened over the three week data collection period. The reflective discussion with the parents following the data collection period allowed for added observations about the play of their disabled child within the family. Using these varying methods of data collection provided the researcher with different lenses on the same phenomenon.

Data triangulation assisted the researcher in discovering consistencies, conflicting views and ambiguities in the opinions, perspectives and observations of the adult family members. This contributed towards gaining a fuller and more truthful reflection of the adult family members' experiences and added to the credibility of the study (Yin, 1984; DePoy et al, 1998).

Member checking is a technique where the researcher's assumptions are checked by a number of the participants in the study. It is a technique used routinely throughout the data collection and data interpretation phases of the study as it decreases the risk of having the researcher's biases imposed on the outcomes of the study. In this study, the adult family members were involved in checking the researcher's assumptions and interpretations of the data collected (DePoy et al, 1998).

This was a delicate process and sensitivity was required in presenting the findings to the adult family members. As Denzin et al (1998) state, *"the value of the best research is not likely to outweigh injury to a person exposed. Qualitative researchers are guests in the private spaces of the world. Their manners should be good and their code of ethics strict"* (p. 103).

In this study peer debriefing occurred when the data was collected and the interpretations of this data were discussed with and reviewed by the researcher's supervisor and co-supervisor, both of whom are experienced in qualitative research. This occurred at regular intervals during the data collection, data analysis and during the planning and writing up of the findings

and discussion phases of the study. It allowed for the development of the depth of the findings, the acknowledgement of other possible interpretations of the data and the overall honesty of the work (Krefting, 1991). This process has aided in establishing the credibility of the final interpretations of this work.

### ***Transferability***

A **thick description** has been provided about the family who participated in the study. This allows for the transferability of this work to other research projects of a similar nature (Seale 1999; Finlay, 2006).

### ***Dependability***

The use of an **audit trail** provides dependability (Finlay, 2006). This technique included keeping a record of the thinking, methods and action processes involved in deriving the outcomes of the study. It allows others to follow in a logical manner how these outcomes were reached. Consequently, others may decide whether they agree or disagree with what was found (DePoy et al, 1998). An audit trail was used during the data collection and interpretation phases of this study.

### ***Confirmability***

As researcher bias is always present it is important to be aware of this bias in order to establish its effect on the data collected. **Reflexivity** is a process where the researcher examines and reflects on his/her thinking processes and perspectives and the influence these factors have on his/her understanding and learning. Throughout the duration of this study the researcher kept a personal diary. This allowed the researcher to reflect on personal feelings, thoughts, perspectives, attitudes and reactions throughout the research process. This assisted in clarifying how and why the meanings and assumptions gained from the data were reached. Consequently, the trustworthiness of these assumptions was enhanced (DePoy et al, 1998; Finlay, 1998; Ballinger, 2004).

## **Ethical Considerations**

### ***Access***

Ethical approval to commence this study was gained through the University of Cape Town Faculty of Health Sciences Research Ethics Committee.

### ***Full Disclosure***

Prior to the family's decision to volunteer to participate in the study, the adult family members discussed the aim and rationale of the study as well as the methods of data collection with the researcher. This was further clarified in the introductory letter (see Appendix 2) which the adult family members read prior to each of them individually signing a consent form (see Appendix 4).

### ***Voluntary Participation***

Families approached by their service providers as potential participants in this study were not known to the researcher. The researcher only contacted potential participants when a family had expressed an interest in taking part in the study and had given their service provider permission to provide their details to the researcher. This was to ensure that the family experienced no feelings of obligation to participate. It was explained to the family that they were under no obligation to participate in the study. The fact that they were able to withdraw from the investigation at any time was highlighted. Prior to the commencement of the study, written informed consent was obtained from all three adult family members. Furthermore, a letter of information regarding the study and written specifically for the children was read to them by their mother (see Appendix 1). Following this, an assent form (see Appendix 3) was signed by the mother of both children allowing them to participate in the study.

the emerging categories and subcategories were constantly checked against the data and so greater accuracy was ensured. Also at this stage some deductive reasoning was used when the categories were tested against the data. From here themes were developed from groupings of categories. This provided the opportunity to begin writing up the findings of the case study.

During the writing up of the findings the process of selective coding was finally employed. This meant that the main story of the case was made clear (Flick, 1998) when it emerged that all the themes were in fact categories and the categories were subcategories under one theme. DePoy et al (1998) describe how writing up the findings of a qualitative study helps to refine the interpretation of data, develop a deeper level of understanding and finally develop a theory on the phenomenon of interest.

## CHAPTER 4

### FINDINGS

The data analysis of this study revealed 1 theme, 5 categories and 16 sub-categories. These are presented below.

#### Theme: **Playing Together – You, Me and Us**

Categories	Sub-Categories
<b>Jasper's Play is a Lot about the Adult</b>	Who I am
	My Beliefs
	What I enjoy
	What I See as Play
<b>A Picture of Jasper's Play</b>	Who Jasper Is
	Facilitated Play
<b>Play within the Family Context</b>	The Marital Relationship
	The Impact of the Nurses' Presence
	The Sibling Relationship
	Everyone's Needs are Important: Finding the Balance
<b>The Environment and Play</b>	Resources and Opportunities
	Environmental Stressors, Personal State and, Play and Playfulness
<b>Play as Part of Daily Life</b>	It Happens When it Happens
	Evolution Over Time
	Routines and Rituals
	Play as a Tool for Getting Daily Tasks Done

## **Category: Jasper's play is a lot about the adult**

### ***Sub-Categories: Who I Am, My Beliefs, What I Enjoy and What I See As Play***

Although the interviews explored the adult family members' perspectives of Jasper's play each adult family member reflected on themselves and their play, and how this impacted on Jasper's play. The adult family members tended to explain how they play and how they play with Jasper as a reflection of "**who I am.**" This included characteristics such as their personality, role in the family, confidence regarding play and their childhood experiences of play. Their personal **beliefs** impacted on how, what and why they played with Jasper and his brother, Charles. Play with Jasper was also influenced by **what the adult family members enjoyed doing.** Furthermore, in keeping with their individual characteristics, **play was seen** differently by each of the adult family members.

The four sub-categories of this category have been presented within the three adult family members' stories of their play and their play with Jasper. The sub-categories are presented in this way because they are intricately linked and are inherent to all three stories.

### ***Elizabeth (The Mother)***

Elizabeth describes herself as a relaxed person with low energy levels and as not very physically active. She prefers to watch others play and mainly engages in "*quiet*" play with Jasper as this suits her nature. This preference is evident in the photographs where Elizabeth is seen relaxing in a chair while cuddling Jasper in her lap and singing to him. Although she frequently played outside as a child she did not enjoy sports or outdoor play as an adolescent. Consequently she does not engage in sports or physical play with her children. She finds the play with Jasper tiring as he often requires physical facilitation during activities. For instance, even when playing with a puzzle, his arm has to be assisted in order to place the puzzle pieces.

The influence of Elizabeth's personal preferences on her play with Jasper can be seen when she says, *"we generally go out every day to something, whatever it is, and as I say I am better with that. It is more my personality. Even if it is going for a drive around the neighbourhood. I am not very good at sitting down and playing. I find it very frustrating so I don't do it."*

As the mother of the family Elizabeth's role requires a variety of other occupations besides playing with her children. Having two little boys with differing needs and interests makes it challenging to meet both their play needs simultaneously. She subsequently has multiple demands on her time. As a result she incorporates play with her sons into the numerous other occupations involved in managing a household. Play, such as watching TV, is used as a means of keeping the children occupied when she has other tasks to complete. At other times, when Jasper is engaged in a play session with a nurse, she joins in for brief periods and participates by showing support for the play and interacting for a while before returning to her other demands. She may also incorporate the children's play into occupations she is involved in. For example when making Charles his dinner she may let him and sometimes Jasper help her. All of this is done in a playful manner. In attempting to meet both her children's needs Elizabeth describes having to make some compromises. In doing so, she describes feeling guilty about the quality of her play with each of her children. *"With Jasper I feel that I don't play enough with him because I rely a lot on the nurses to play with him because I am needing to be available to Charles for that play that happens with us. Where if I am focussed on Jasper I can't play with Charles and he has to...I am like 'Charles I can't play with you now. I am busy with Jasper'. As I say it happens when it happens but when it is in the process of happening, whatever the play might be, it is dedicated. I can't be doing other things and that is probably why I don't have structured play with him either because I don't have the time. It would be like 5 minutes here or 5 minutes there but the nurses...I don't feel I have enough play time with Jasper but my play time with Jasper is more focused than my play time with Charles. So when I am playing with Jasper - focused like that, I would feel bad that I am not playing with Charles in the same manner basically."*

Elizabeth also commented on the family's play together, as a whole. She expressed satisfaction with play activities which the family could do together, where Jasper was included. She found great pleasure in observing her sons playing together. In the future she hoped that her children would play together as then she felt she could engage with them simultaneously instead of having to divide her time.

In her play with the children she tended to let them initiate play or choose what they wanted to play. This was based on her belief that, *"kids need to be able to develop themselves within their environment instead of just being dictated to on how something should work. So I guess we kind of encourage independence a little bit more rather than telling them what they should be doing and what time, letting them kind of initiate and also because we never initiate ourselves. That is something that I do feel very strongly about."*

Elizabeth believes that play is important for children and this belief stems from her own childhood experiences of play. She explains this when she says, *"when I was growing up, I had a mother who played constantly with us and I see how important it is and I know how important it is to forming all sorts of a child's personality. It is important that they have dedicated time, that they know they are very important and they are deserving of that time...it makes you feel very worthy because they are dedicating that time to play with you...I think my mom is one of my best friends now because of that."*

Elizabeth feels, however, that she is unlike her mother in that she is *"not very good at actual play"* and doesn't enjoy it. She expresses how she wishes she could *"let go"* enough to engage in pretend play because she knows the children enjoy it and that it is important for them but that it is very difficult for her.

Elizabeth states that *"what I believe and what I manage to do are two different things."* One of the main reasons for this for this incongruence is her lack of enjoyment of the play that she feels is important. For example she feels

physical and outdoor play is very important but she doesn't encourage it because she doesn't enjoy it. She feels that her children don't engage in enough of this type of play because they tend to choose activities that they know their parents will do with them. Elizabeth explains the impact of her dislike of physical play when she says, *"I am not a physical person so even though I see it as being important and I want him to do it, I am not, so for me to say come let's go play cricket I am just like 'whatever' you know. And so he does not get enough of that, except when he has friends around and he will never initiate to go and ride his bike because we never take him to go and do it, so he would rather do something that he knows we are going to become involved in than go off and do something that we are not necessarily going to become involved in."*

Apart from physical and outdoor play Elizabeth also values reading as an important play activity. This is a past-time that she enjoys and she often reads to Jasper. Charles does not enjoy reading as much and so, in keeping with her beliefs about allowing children to choose their own forms of play, she doesn't force him to engage. Baking is another of Elizabeth's favourite occupations and she and Charles bake together regularly.

Elizabeth believes that *"anything can be play"* but at the same time she worries that this belief is just an excuse for her lack of play. She explains this by saying, *"I think anything can be a game, and anything is playing other than being sent to your room for being naughty. It's a game. And I find it really hard because I see so many things as being playing and not everybody does. I think maybe it is a good excuse for me because I can say well he has been played with the whole day, without having to do anything. But like sitting on the couch with him on my lap or whatever and tickling each other or pretending to eat or whatever. That to me is playing and we really just sitting on the couch."*

Elizabeth believes that *"structured play"* is the *"actual play"* that is important for children. This type of play refers to pre-organised activities where she has dedicated time set aside for playing. This belief conflicts with her definition of

play as virtually any activity. Elizabeth explains that other parents she knows play with their children in a structured manner. She does not, however, engage in this manner as she attempts to have her children play in a natural way where they select and initiate their own play. Despite this valid justification Elizabeth's low confidence in her play skills, her lack of time and enjoyment of what she perceives to be "actual play" seem to have lead to concerns and guilt about her play with her children.

### **Steven (The Father)**

In the following story about Steven, his identity and personal beliefs, his interests and personal interpretations of play are shown to influence, what, where, when and how he plays with Jasper. His thoughts, feelings, concerns and hopes about Jasper's play within the family are also presented.

Steven describes himself as a solitary person. This is reflected in his enjoyment of individualistic play occupations such as golf, fishing and computer games. Steven finds that because of this character trait it is difficult to cope with playing together with both boys. He finds Charles quite demanding and this becomes stressful when trying to play Jasper's games as his attention is divided. He also relates that his ability to relax and enjoy himself is impacted on when Jasper joins family excursions since a nurse is usually required to accompany them. *"It is circumstances but with Jasper comes a nurse and usually the whole family. Now the way I like to enjoy myself and this goes from shopping or any form of entertainment, anything, is I like to be completely unplanned. We might be walking towards the game arcade and I will say to Charles 'come let's look in there quickly and then let's go to McDonalds or let's go and play a little and then go to McDonalds and then back and play a little bit' and that kind of behaviour which is so typical of me and he is like that as well, it does not suit a big group of people...I mentioned it to Elizabeth and she feels it is a better way to go, is to actually separate things"*

Steven found that separating into family sub-groups made playing with the boys easier. For example on one occasion he and Charles went out alone together because Jasper was sleeping and he explains, *“we had a less stressful time and he (Charles) went off to a party in the afternoon and then Jasper and I had time together and we sat on the trampoline literally for about 3 hours and we jumped a bit and we chatted a bit and we laughed a bit and we tickled a bit and that was much more fun than it would have been if Charles had been around.”*

In his role as the father and main income generator of the household Steven's time is limited. Play with his children is thus restricted to the evenings and often only one day of a weekend because he works long hours. As result of the limited time slots available for play, there is an expectation from the children and Steven himself to play as much as possible when he is available. Steven has found that when there has been little time available for the boys it has impacted the quality of their play. *“I find that what happens is that if I am playing with them regularly, like I have seen Jasper regularly and I am playing with Charles regularly and he is getting a good deal of my attention, then our play together will be very good. It will be fine. It will be demand free. Whereas if I don't see that much of him or I haven't been playing with him that much, then the play can be quite stressful because he becomes incredibly demanding. Jasper is like that as well. I think children are just like that. Because they feel that this might be a limited time offer only, we need to maximize it, and as a result it can get out of hand.”*

Elizabeth and Steven share the belief that leaving the children to make their own play choices will facilitate independence, confidence and individuality. Furthermore Steven believes that disallowing a child to play in a certain way often has an adverse effect in that the child will become even more anxious to play in that way. This is one of the reasons why he will not stop Charles from watching a DVD even if it is a sunny day and he could be playing outside. He feels that Charles will eventually tire of watching TV and make his own decision to play outside.

Like Elizabeth, Steven also expresses appreciation for opportunities for the family to play together particularly when it is just the four of them. Unlike Elizabeth, however, Steven seems less concerned with Jasper's inclusion in family play and feels that as long as he is spending quality play time with each of his sons it is not essential for them to be together.

Steven believes that, *“Children have play and then whatever goes in between is just waiting for the next time to play. That is what children's lives are like, you know. They have no use for seriousness whatsoever. When they are having dinner they would rather be playing and when they are sleeping they would rather not be sleeping because they could play. So it is their entire universe, so the only way to engage a child is really through play as far as I am concerned. Trying to sit down and have a conversation with Charles that is going to lead to any results is totally pointless. You can discuss things while you play and you can use play in order to show certain lessons and things like that – don't hit, don't scratch, don't do whatever. Those things are only ever remembered by children if it is under those kind of circumstances... It is your only channel to them, if you don't engage in it then you will lose them. They will just continue to play by themselves until they don't really acknowledge you anymore. And I think that is why children do become more kind of introspective and introverted. I mean, Charles is potentially a very introverted child and I was a very introverted child but I became very introverted because a lot of the games I chose to play, a lot of more indoor stuff and that kind of thing, nobody was interested in doing that with me.”*

Steven's own childhood experience of being unable to share his interest in computers with his father due to his lack of interest and the distancing effect this had on their relationship has influenced Steven in his play with his children. He explores ways to play with them and wants them to make their own play choices but at the same time he hopes they will choose the things he enjoys so they can enjoy them together. This can be seen when he says, *“I want to be able to enjoy the activity with them, so the kind of one that made me cringe, was Charles wanted to skateboard and I sort of tinkered on a skateboard a little bit, but I don't enjoy it. I don't enjoy it at all, so I kind of just*

*sat there praying that he wouldn't get into it, because it wouldn't be something that I would enjoy with him so I kind of had to suffer it. Which is fine. There is always going to be those things and I am not saying that he is only going to do what I want to do, but I really hope he does, because then we will have more fun together."*

Steven enjoys playing golf, cricket and computer games with Charles and knows that he would enjoy fishing with him too. With Jasper he enjoys jumping on the trampoline and is keen for him to be able to play computer games competitively as this would be something that he, Charles and Jasper could all enjoy together. Based on the belief that play is important in establishing and maintaining relationships with children Steven describes how he does make an effort to play with Jasper even though, due his stage of development and his disability, their shared interests are limited.

*"The thing is Jasper's play is so much scaled down... I mean we try and think of things or I try and think of things that I can do with him... The thing is for me as a person, I find it very difficult to play their games. Sometimes I will get sucked into it but I have always waited or longed for the time when they can do things with me that we both enjoy together, like fishing and golf. So when Charles and I play cricket it is fun and the trampoline is always fun and little games like traditionally young kids games and that kind of thing, I find it very hard to get into the game and enjoy it and follow it through. But with Jasper that has changed quite a bit. I do manage to do more of that and try and enjoy it because it pretty much all that I have got with him. I mean the fishing side of it and the golf, he is never going to have that, so I am trying to form games with him. So wherever I see an opportunity to play with him then I will try and take that opportunity so there is nothing that I can think of to say that this is how I will try and organise it, it is whatever it is."*

Even though Steven attempts to find games to play with Jasper he is realistic in his acceptance of how much he and the family can manage with regards to giving Jasper play opportunities. He explains this when he says, *"we are not strong enough or courageous enough or have enough energy to put ourselves*

*through unlimited stress just to ensure that he gets a good constant playing environment. So we are trying to make those things easier because as a result it will happen more often."*

### ***Pamela (The Nurse)***

Pamela is Jasper's main nurse and has worked with him since he was six months old. Elizabeth describes the nurses, including Pamela, as part of the family although there are conflicting feelings about this. This is discussed further in Category 3, Sub-Category 8, on page 73.

Pamela describes her role in the family as that of Jasper's home therapist and nurse. She sees herself as being *"his fun nurse but also his discipline nurse and his get-things-working nurse."* The *"therapist"* and *"getting things working"* role is seen in Pamela's tendency to be directive or *"controlling"* in her play with Jasper and encouraging play activities which have an educational or therapeutic benefit. Playing with Jasper, she feels, is part of her job and most of her day with him involves play. As part of her role as his nurse she wants Jasper to have the best of everything, including the best play. This attitude is evident when she discusses one of her reasons for not liking TV: *"... reason why I don't like TV play is because it is a way for one of his nurses to get out of doing work – just put on a video. It is a way of putting him in a corner and forgetting about him. Whereas if you take him out of his buggy, put him on your leg and swing him and roll him around and rough and tumble, it is very tiring. It is very tiring playing with a two year old but it is the better thing in my opinion."*

Pamela differs from Elizabeth and Steven in that she does not feel that watching TV and playing computer games qualifies as play. For this reason she tries to *"steer him away from square box visuals,"* when she is with him. She will only put on a DVD when she is feeling unwell or needs some time to feel ready to play again. She explains this by saying that it is neutral ground and is not demanding for either of them.

Pamela is confident in her play skills with children and apparently has been told that she is good with children. She says that she enjoys playing with them and they enjoy playing with her. She feels that Jasper associates her with a good day of playing. This confidence is evident in her ability to take charge of a play situation, even with Jasper's brother Charles, and initiate play. Her confidence is also obvious from her posture and the centrality of her body positioning in the photographs, where she appears to be the protagonist or leader of the play.

Pamela believes that children learn to play from adults and so her play with Jasper tends to be quite directive. She also believes that play should be fun and that play is learning. As such her play with Jasper seems to be mainly boisterous, exuberant play or play as an opportunity for learning. She describes herself as having a *"playful nature."* She says, *"I am just a playful, energetic person and that comes out in my work."* This is seen in the lively, physical nature of much of her play with Jasper and sometimes with Charles too. She does rough and tumble play with Jasper at least once or twice a day and is the only nurse who plays with Jasper in this way. This play is animated, physical and exuberant. She acts out stories to him, runs around with him in shopping centres, plays catch with Jasper and the other children at school, has races in the driveway with Jasper in his buggy and Charles on his bike and rolls around on the floor with Charles. She says, *"It is so childish sometimes. I think I am a grown woman and I am rolling around the floor."*

Pamela also likes to give Jasper, and at times Charles, opportunities to learn life lessons that she feels are valuable and that they need to learn. This can be seen in games such as 'shop-shop' which aims to teach the value of money and the skill of purchasing goods. She also likes to sometimes play with home-made toys as opposed to always playing with bought things. This reflects her own childhood experience of play.

With regard to Jasper's play Pamela also feels it is important for him to experience all kinds of play. Even if he cannot actually perform the play activity alone she likes to somehow find a way for him to be involved or to try.

She will manipulate his body on a jungle gym and down a slide so that he can have the experience or she will somehow assist him to play tennis using the suspension frame.

Pamela's belief and attitude towards Jasper's play is expressed when she says, *"sometimes you push the boundaries. Like sometimes I make him play tennis but I know that he can't do that but just try otherwise you are always going to think I can't do that. I want him to get over that. Yes, I can do anything I want. I can play with anything that I want to. If it breaks it breaks. As long as it can't hurt me. We are still growing."*

Pamela speaks less about what she enjoys than the parents do. She says that Jasper and her have *"a lot of fun"* during the day and that she enjoys playing with children. She also says that she likes playing with Jasper because he has so much fun and that she must do it because it is part of her job. The difference between Pamela and Jasper's parents is that playing with Jasper is part of her job and therefore what she specifically enjoys is possibly not seen as relevant in relation to playing with Jasper.

### **Category: A Picture of Jasper's Play**

Jasper seems to have many opportunities for play. Pamela says, *"He always has time for play in a day except if we are travelling and then we still play because we will sing along in the car and do blocks and puzzles and stuff."*

The adult family members all express the importance of play in Jasper's life. Elizabeth tends to see play as a means of promoting his inclusion in the family and as a part of his future inclusion in society. Steven tends to focus on play for Jasper as a way for him to find enjoyment in his life and in the utilization of his time. Pamela's focus tends to be on the power of play for Jasper as a means for learning and developing positive personality characteristics. Based on these play benefits of inclusion, enjoyment and development of positive personality characteristics it seems that ultimately play for Jasper is seen as a

powerful tool for promoting his present and future happiness, life satisfaction and well-being.

Elizabeth says, *“play for Jasper is in his mind extremely important. I think it makes him feel more normal and I think as he gets older it will be a huge part of him feeling accepted and integrated into the family and school and environment and friends and everything. So it is extremely important for him. It is what makes him happy and what makes him a confident, likeable child. I think if he didn't have any play in his life he would be extremely miserable and unhappy and probably a very sick child. Where I believe very strongly that a lot of his health is just the fact that he is as normalised as we possibly can with him at the moment.”*

#### ***Sub-Category: Jasper, the Person and Agentic Player***

Pamela describes Jasper as a playful, play orientated and play aware little boy and a pleasant person. Steven feels that Jasper is not a serious child as interactions with him are usually humorous and playful. Elizabeth feels that whenever she is with Jasper she is playing with him on some level. The adult family members all emphasise Jasper's flexibility in play in that he is extremely open to play and invites play with other family members whenever he can. Steven explains this when he says, *“Jasper is usually up for anything.”* It seems that his playful nature allows for great flexibility and spontaneity of play. This is observed by Pamela when she says, *“he associates everything in his play world as fun, so it is easy to use any of those things but it might not be what he specifically wanted to play with.”* From this observation it is also possible to deduce that for Jasper the play itself is of secondary importance to the interaction with others.

On the other hand Elizabeth says, *“he is very bright so we have been very careful about allowing him to lead us, rather than us leading him, especially when it comes to puzzles or stories or sticking or drawing or just anything - matching whatever. Those type of games because we obviously want him to*

*develop that side of his brain. So we are very careful to facilitate rather than instruct I guess.”*

Steven describes Jasper's play as being a reflection of who he is rather than as merely a result of his disability. This is clear when he says, *“he likes just about anything but obviously again with his condition, but I think it is more than that; I think that he is this kind of kid as well, in that his games are more kind of cerebral and more intellect based. The condition obviously kind of promotes that but I think that is part of who he is as well. So you give him two sticks to knock together and it won't last very long. Whereas if you gave him a puzzle of some sort, that will last a bit longer. And different kids enjoy different things like that. But his games are mostly thought orientated.”*

The person that Jasper is contributes to how much others play with him, how willing they are to play with him, what they play with him and how they feel when playing with him. Consequently Jasper is an active and powerful agent in creating and developing play experiences with others.

#### ***Sub-Category: Facilitated Play***

One of the greatest impacts that Jasper's impairment seems to have on his play is that he plays predominantly with adults. Elizabeth describes how the family socialises with people who have children the same age as Jasper and Charles. These children come to play regularly but, although they greet Jasper lovingly and interact with him for a short time, soon they progress to playing with Charles. Elizabeth feels that the reason for this is that at Jasper's age children tend to play physically rather than sitting and doing fine motor or intellectual games. Physical play is difficult for Jasper to be a part of despite the nurses facilitating his involvement in other children's games by following them around. Pamela seems quite successful at drawing Jasper into physical games with other children at playschool. For example she initiates a game of catch where the children chase her and the teacher pushes Jasper so he is part of the chase. Alternatively she will use Jasper's wheelchair to hide behind in order to draw him into the game. In this way Pamela uses herself to

engage Jasper in play with the other children. Elizabeth describes how when Pamela facilitates play with Charles and Jasper it involves each of the boys playing with Pamela rather than with each other. Elizabeth does however appreciate that at least Charles and Jasper are sharing the same game.

In other games that Pamela describes where she plays “shop-shop” with Charles and Jasper she will crawl around with Charles under chairs and Jasper will watch. She describes Jasper’s involvement as follows: *“we play house-house. We put two chairs together and throw a sheet over... They want to play house-house, so he sits and looks because he can’t climb under the stuff but he is participating in that it is evoking in him emotion. He gets excited and says ‘house more, more’. So he gets involved that way because he can’t get out the chair and crawl around.”*

While Pamela is clearly artful in her ability to engage children in play, tension exists in the need for discernment as to who is actually playing. However, when Jasper is present in play of this type he is Pamela’s main priority and as such she usually engages in it for his sake. Her awareness of his sense of enjoyment and inclusion in the play is part of what guides the play. Consequently he is a dominant part of the play. Steven explains that when Jasper is involved in watching play in this way he is mentally, emotionally and socially involved in the play. Steven therefore feels that Jasper is actively involved in playing the game even though he is not physically active in the play.

Steven describes common play for Jasper as having a “puppet-master theme” when he says, *“considering his situation, something that he gets the biggest kick out of is people doing things for him because he can’t do them himself. So a lot of his games revolve around him giving you orders and instructions and he likes you to do things on command like with the flowers – you have to sniff it and then you have to sneeze and ... that is the game. So he is like that with most of his games. So when we are on the trampoline he will say whether he wants to be up or down or whatever. So most of his games have that theme of where he is puppet-master arranging everything around him*

*because he can't kind of change the game at all and he relies on you to do that. So that is kind of a common theme to his games."*

Despite the limited play Jasper shares with other children he spends most of his daily life engage in play. This play is primarily facilitated by his adult family members.

### **Category: Play within the Family Context**

The family context consisting of each individual family member, their impact on each other and the relationships between them create an environment in which Jasper and his family's play occurs. Within Elizabeth and Steven's marital relationship they are seen to adjust to each others beliefs and opinions about play. This flexibility allows for accommodation and acceptance of slightly differing views about play and ways of engaging in play. The constant presence of a nurse in the family and the relationship between the nurses and the rest of the family, has both positive and negative influences on Jasper's play and his play with the family. Within the sibling relationship the existence of Jasper and Charles' differing needs impacts on the opportunities available for them to play together.

### **Sub-Category: The Marital Relationship**

Steven and Elizabeth both enjoy watching TV and playing computer games but with regard to this type of play for their children Elizabeth and Steven have differing views. Steven is happy for his children to play computer games and watch TV whereas Elizabeth expresses reservations when she says, *"what I believe and what I manage to do are two different things, but what I believe is physical play is extremely important and outside play and neither of my children have nearly enough of that. You will hear that Steven's ideas are completely different to mine and that is one of the reasons. I don't like ... I am strongly against or was strongly against, but have kind of changed because of Steven's beliefs about computer games, and TV games and time in front of the TV, though it is the best cop out for me. I mean it really is and I use it all*

*the time so I have changed the way I see those things as well with Jasper because it is a lot of the things that he can do. There is not much that he can do so for him to sit and have a dedicated hour and a half of enjoyment - he can sit and watch a movie and Charles and him can do it together whereas when Charles was little I had a lot more routine as far as how much and when and that type of thing but now it is kind of definitely part of their day."*

Elizabeth tries to feel comfortable with allowing her children to watch TV because of the benefits she feels it provides. These benefits include:

- When the children are engaged in watching TV Elizabeth is free to complete other tasks.
- Jasper's play opportunities are limited and TV provides him with a way of enjoying his time.
- It is something Jasper and Charles can do together.

She also finds ways of making TV watching and playing computer games personally acceptable by encouraging the children to watch educational TV or movies with morals as opposed to Cartoon Network. She also does not allow them to play fighting computer games when she is with them. Watching Cartoon Network and fighting games are, however, acceptable to Steven and he will engage in these activities with the children when he is with them.

Within the marital relationship there appears to be a synchronising of views. This is done by finding ways to justify play choices and by finding compromises within the play to make it seem more acceptable to the person who was not initially comfortable with the form of play in question.

### ***Sub-Category: The Impact of the Nurses' Presence***

The nurses are present in the family environment nearly all the time. This creates a dynamic which can be difficult because in one sense they are part of the family and yet they are not. This conflict is expressed by Elizabeth when she says, *"It is very difficult to get like a family thing going when you have an outsider who...I mean they are really part of our family but it is not the same."*

The presence of the nurses in the family environment impacts on the space in which the family has to play. Elizabeth explains that when she has a quiet time with Jasper, such as sitting with him on her lap and singing to him and cuddling him, the nurses will leave them alone. She says how she enjoys this as it is not easy always having someone else in your space. Steven describes the family's relationship with the nurses and how it impacts on their play when he says, *"most of them (the nurses) are divine and we like them very much but at the same time that dynamic, that energy, is very different when there is a third wheel involved so it is not that there is any clash or anything like that but sometimes Elizabeth will dare to come and jump with us and that time when we are just alone – the four of us, then Jasper absolutely adores that, so I think he needs that kind of break from them as well. As far as play is concerned, that person being involved, it does make it a bit different than it would otherwise be – not quite so free."*

To play in an uninhibited, relaxed and unselfconscious manner is difficult if someone with whom you are not entirely comfortable is in your environment. Steven describes this when he says, *"some of the games that children of his age have, you have to make a fool of yourself, and sometimes you are only prepared to do that up until a point having somebody there, especially if it's someone that you don't really like, then you are not willing to make a fool of yourself. So that will differ from nurse to nurse. If it is someone that I am totally comfortable with and like a lot, then I am happy to go that way."*

While not directly expressed many differences in background, beliefs about play and play preferences were expressed by the parents and Pamela. These factors lead to differing approaches between the nurses and the parents in their family play. This unacknowledged conflict became obvious in two of Elizabeth's quotes. Firstly she expresses that, *"some of the nurses are very good at almost forcing Charles to become involved in whatever they are playing with, whether it is 'won't you go and fetch Jasper's ball and bring it.' So trying to make him participate so that they are at least doing something together because Charles has really struggled to accept Jasper and start*

*interacting with him.” In a second quote, however, she says, “... It is very difficult because you can't force a child to do something they don't want to do, so with Charles we have let it come from him when he has been ready for it rather than forcing him to interact.”*

For Jasper the impact of these diverging views is often positive because he experiences variety in his play due to playing with individuals with differing play beliefs and preferences. He experiences a large amount of play in his life and much of this is with the nurses who care for him. As Elizabeth says, *“he loves playing and all the nurses that we have are awesome”*. The nurses seem to focus on play with a purpose, including therapeutic, educational and personality forming purposes. Pamela explains that she prefers toys with educational value so will favour these with Jasper. When she plays the piano and sings for him she explains that it is to evoke different emotions in him and to help him identify these emotions. Rough and tumble play is part of his physiotherapy home programme. Pretend play like *“shop-shop”* is to teach him about the value of money and that purchases cannot be made for free. She will also purposefully leave him alone for short periods to play by himself because she feels he has so much input from others and that it is important for him to learn how to play alone as it develops confidence.

As his main nurse and someone who puts a large amount of effort into Jasper's play, Pamela facilitates a variety of play experiences and fun. Elizabeth and Steven, by employing Pamela, have also indirectly provided this for Jasper. He is, however, also able to experience play with his parents in which he is encouraged to make his own play choices and is then supported in these choices by his parents. For example, Steven states that, *“whatever takes his fancy would be brilliant and we would try and encourage that as much as possible. Whatever it is that he can find that will make him enjoy his time is perfect and then we will find a way to make that possible. So he has whatever he can choose, he can choose and we will try and encourage him to do things like get different kinds of puzzles or this and that, and see what he tries to enjoy or whatever. If he shows any indication of doing a particular type of thing, whether it is stickers or block puzzles or whatever then we will*

*just throw those at him because whatever it is, whether it is a sticker or a puzzle or turning the pages of a books, or whatever, every single activity is great, and it is something that he can do from a fun point of view... So whatever he enjoys he can go for it."* As a result of these two approaches to play Jasper experiences a balance between facilitated play, which tends to be used as a means to an end, and self-initiated play, which is engaged in for its own sake.

There are some negative impacts of the nurses' continual presence on Jasper's play. These include difficulty with his inclusion in some family excursions as well as limited time to himself for playing alone. Furthermore, the constant presence of adults around Jasper seems to inhibit his brother, Charles, from playing with him.

***Sub-Category: The Sibling Relationship***

The adult family members discuss how Charles has never shown an interest in Jasper or in playing with Jasper. He tends to ignore Jasper. In contrast, Jasper loves having any contact with or attention from his brother and is always open to playing with him. Elizabeth explains that Charles has had difficulty coping with having nurses in his space and that their differing needs have meant that common interests in play are limited. This is clear when she says, *"Charles has just never wanted to interact at all. From his point of view until recently Jasper has just been nothing to him because he hasn't been able to do anything with him. A normal child would probably have been able to interact with him from about a year old because he would have been walking and following him around and playing cars and doing that type of thing where Jasper can't do that."*

Recent developmental changes mean that Jasper has started talking more, is showing an interest in watching similar movies and is starting to play on the computer. These factors seem to have made a difference and the adult family members have all noticed an increase in interaction between the two boys.

They have also become aware that Charles would approach Jasper and play with him if no one was around or watching.

***Sub-Category: Everyone's Needs Are Important: Finding The Balance***

Jasper's play is recognised by the adult family members as being an extremely important part of his life for various reasons. Playing with a young disabled child, however, is not always easy or fulfilling for the adult family members. Consequently, the adult family members find ways to participate in play occupations and occupations that hold meaning for them while balancing these with Jasper's requirements for play. For example, instead of "actual play" which Elizabeth does not enjoy, she goes out with the boys nearly every day. Visiting different venues, such as the farm village which has a playground or the petting zoo, she can watch them while they play or share enjoyable experiences together. Watching others play is something Elizabeth enjoys doing. Also, when Jasper is engaged in play with a nurse at home, she will enter the play at intervals, interacting for short periods while still being able to engage in occupations that she chooses or needs to be involved in.

Steven works during the week and sometimes over weekends too. He balances this with playing in the evenings with boys and looks forward to times when they can do things together that they all enjoy. The trampoline and computer games are play activities that he enjoys and therefore playing these games with the boys is enjoyable for him too. At times he takes Charles out individually to do play activities that they can both enjoy but that would be difficult for Jasper to engage in but he balances this by returning home and playing with Jasper individually, doing things that Jasper chooses to do. This is discussed further in Category 1, page 62. In this way, Steven is able to achieve a balance between his work commitments, meeting the play needs of his children and being able to engage in play that he enjoys. One of the ways he manages this is by finding ways in which he can also enjoy the time spent playing with them.

Pamela expresses how it is her job to play with Jasper and that she enjoys it, but that she is able to go home at the end of the day and forget about the responsibility of caring for, teaching and playing with him. She also ensures that Jasper has a rest or a sleep in the middle of each day so that she can complete other tasks and have a break.

Regarding Charles' needs Steven describes how care has been taken not to push Charles to interact with Jasper as he is very sensitive about this and with pressure tends to become less interested. Elizabeth explains that she has to balance being a mother to both Jasper and Charles separately as they do not play together. Furthermore, because the nurses are available to play with Jasper she feels she plays less with him so she can be available to play with Charles. Steven also attends to both Charles and Jaspers' separate play needs by occasionally separating their play activities.

The various ways in which the adult family members accommodate their own play needs with those of the children is influenced by daily time demands and the changes of needs that occur over time. This is discussed further in the Category 5, page 81.

## **Category: The Environment and Play**

### ***Sub-Category: Resources and Opportunities***

The impact of the environment on Jasper's play is significant and can be seen from the following perspectives: the financial environment, the immediate physical environment, societal influences and individual attitudes. These influences can be both positive and negative.

Due to the fact that the family has access to sufficient resources they live in a house which was recently purpose built and provides easy access for Jasper in his wheelchair. Furthermore Jasper is able to live and play at home with his family because he is home ventilated. The family's play and engagement in daily occupations of their choice is further supported by the presence of 24

hour home nursing care for Jasper. Jasper's parents employ the nurses directly so they are able to choose who they are happy to have spending time with and playing with Jasper and ensuring a good standard of care. He has his own bedroom with many toys. He has access to technology such as TV and computer games. The family home has two TV's in separate adjoining lounges. This enables Jasper and Charles to watch different movies if they choose to. This aspect of the home has both positive and negative attributes. It gives the children the opportunity to make their own choices but it may also prevent them from spending time together. Having the financial resources to employ a nurse for Jasper's care and having a large house also means, for instance, that when Jasper is bathed in one bathroom by a nurse, Charles is bathed in a separate bathroom by his mother. Elizabeth and Pamela both describe Jasper's bath-time as a 45 minute play session which happens consistently everyday. This is a potential play opportunity which the boys could engage in together but, because of the physical and social environment, this opportunity is missed.

The immediate physical environment provides Jasper with opportunities to play indoors or outdoors, depending on the weather. He is able to swim in the pool when he is assisted. The trampoline, swing and slide in the garden provide play opportunities for Jasper and the family. He is learning to use an adapted mouse for the computer which then provides him with opportunities for play with his family. The driveway is used at times as an area for races, where Pamela pushes Jasper in his buggy and Charles rides his bicycle. The garden is a place to "*greet the day*" and pick flowers.

The family went away for 5 days during the data collection period. They spent this time together with Steven's sister and her family. During this time Elizabeth reported that because there were more people around it was not necessarily an inclusive environment. Elizabeth found that, while trying to balance the needs of everyone there and trying to relax herself, it was more difficult to dedicate time to Jasper. Steven was also busy with his family and so had less time for play. Consequently, Jasper was often left to play with his nurse. Steven explains that on holiday more happens "*in spite of him*",

whereas at home they don't do many things without including Jasper. This event highlights how the physical and social environment at home is set up to be supportive of Jasper's play and family involvement.

Elizabeth provides an observation on the impact of the immediate physical environment and societal influences on the safety of children's play and the subsequent restrictions on this play.

*"It was instilled in me when I was an au pair that you need to know where the kids are at all times. You don't let a kid go out and do whatever because there is the possibility that something is going to happen, whether I don't know... I guess someone could jump over the fence and grab them or he (Charles) could fall in the swimming pool and hit his head and we don't keep the net on the pool because he can swim. But something could happen so if he is playing outside on his own, it is for like 2 or 3 minutes max and then I will go and check on him, if I am not actually outside with him."*

Personal attitudes were also seen to enable Jasper's play. For instance, Jasper's teacher at the playgroup which he attends 3 mornings per week is described as being fantastic with Jasper and ensuring that he is included in all play activities.

***Sub-Category: Environmental Stressors, Personal State and Play and Playfulness***

The relationship between environmental stressors, personal state and play and playfulness was described from two different angles by the adult family members.

The first angle was the impact that environmental stressors and personal state have on play. This was related to playing with young children in a child-centred manner. The adult family members stressed how they have to be relaxed to play with young children because it is quite tiring and not something that they would necessarily choose to do. Feeling stressed, irritated, tired,

unwell, distracted or hungry were all felt to impact negatively on their play with the children. Elizabeth, who generally felt that she was not very good at *“actually playing”* with young children, felt that her low energy levels attributed to this. Consequently, in order to play with the children in a child-centred manner, the environment and personal state of the adult family members needs to be just right.

The second angle was that play has the power to turn your mood around when feeling stressed or *“grumpy.”* This was seen in relation to both the adult family members and the children. Regarding Jasper, Elizabeth explains that she knows when Jasper loves a certain play activity because it can make him happy when he is feeling miserable. Similar responses are evident in the adult family members when performing activities that they enjoy and would choose to do.

Steven clarifies these two angles when he says, *“at this age, mood is a big contributing factor because often the games you are playing are not things you would do. I mean I could be in a really bad mood and still go and enjoy a game of golf. I would probably play badly and I probably wouldn’t enjoy it that much, but I would still want to go because I would be hoping it would turn my mood around. Whereas if I look at a child’s game, I know it’s not going to turn my mood around, because of the effort of trying to get into the game...As they get a bit older then even if I’m grumpy, then going to play a game of golf or playing a computer game or something I would enjoy would be cool. Those are things that might actually change my mood. So I would be more inclined to do them.”*

**Category: Play as a part of daily life**

**Sub-Category: It Happens When it Happens**

Jasper spends much of his daily life engaged in play and a large amount of this play is spontaneous in nature. Pamela says, *“we play a lot and you never think about it because you are doing it all the time.”* All three adult family

members explain how play is seldom planned and tends to happen in a spontaneous manner as the moment arises and wherever and whenever it fits in. It is not set or structured and it is not something they usually think about. It is more of a subconscious act. Each adult family member perceives this aspect of play in a slightly different manner.

The parents feel that the majority of their play *“happens when it happens.”* They both mention the idea that play may involve small moments which are difficult to remember and describe, that you are not always conscious of the fact that you are playing when you are and it may therefore pass by unnoticed. This made documenting all play interactions on the daily play chart difficult. Furthermore, this spontaneous manner of playing is how they play with both Jasper and Charles. Elizabeth, however, clarifies that there is still a difference in their play when she says with regard to Jasper, *“as I say, it happens when it happens, but when it is happening, whatever the play might be, it is dedicated. I can’t be doing other things.”*

When playing with Charles, however, she can often engage in other daily tasks at the same time. Elizabeth feels that her play with the boys is relatively unstructured in nature because she lacks the time and because it is part of her personality to be this way. She does not feel it is necessarily a good thing but at the same time she says that play should be natural and unforced so that children can develop their independence.

Steven frames this aspect of play in relation to the family as a whole saying that as a family they seldom plan to do anything because their lifestyle is very unstructured. He feels that the spontaneity and the element of surprise that an adult can bring to a child’s play is part of what makes children want to play with adults. He describes this when he says, *“The thing a parent can do to a child that makes play so brilliant, is that they can surprise them. You see a child very seldom surprising themselves and their friends, at this age, don’t often manage to do that either. Like Charles will jump up and I will bend down and grab him by his ankles and lift him up so he does this back-flip and you*

*can do things like that. Things like that is what makes them want to play with you, because you surprise them.”*

Steven also suggests that if play cannot occur spontaneously it will happen less often.

*“If the swimming thing is just a matter of like plonking him down there, whipping the Velcro thing and off he goes, he will swim all the time. Whereas at the moment it is like a three man job. Someone is holding this, someone is holding that and so we think about it and we say, ‘Oh God not today,’ and then it never happens.”*

Jasper has more time for play with his nurses and this type of play happens in a variety of ways. The nurses have structured play time as there are times during each day dedicated to play. Pamela feels, however, that play just happens and evolves in a day and that it is seldom planned. This spontaneity is seen when she says, *“If we are going somewhere and he is a bit bored, I will just put him on my lap and I will throw him backwards or roll him around or put him upside down...it’s just ‘come and play with me, let’s play rough and tumble’..”* Despite having a daily schedule of caring and therapy tasks which she has to perform with Jasper every day, the play which is often used to achieve and complete these tasks still tends to be spontaneous.

### ***Sub-Category: Evolution Over Time***

A number of factors were found to be related to the evolving, dynamic nature of play, including: Jasper’s age and stage of development, weather and seasons, discovering play and building on it, and “streamlining”. The adult family members showed an awareness of the changing nature of play and often expressed this in their hopes and concerns for and imaginings of Jasper’s play of the future.

Elizabeth pointed out how quickly play changes when she says, *“Literally two days go by and all of a sudden the whole dynamic has changed completely.”*

At Jasper's age of 2½ years old, Elizabeth mentions that the "terrible two's" are having some impact on Jasper's play as he wants what "he wants and he wants it now." Also at this age Jasper's speech and language skills are developing rapidly. This has a significant impact on his ability to communicate his needs and his preferences in play. Pamela explains that at this age she is still able to be in control of his play because if he indicates that he wants to play with a puzzle she can choose which puzzle she feels is most appropriate for him because he can't tell her exactly which one he wants. As he learns to talk more she feels he will become more in control. His understanding of situations has changed as he has grown older, for instance, Elizabeth explains that he used to hate going to physiotherapy but now he loves it. This is because he now understands that they help him to do things he couldn't do otherwise and because he gets to play when he is there. With age his interests are developing and changing. The adult family members describe how the boys seem to go through stages of favourite interests or "obsessions." For instance, Jasper went through stages of being very interested in puzzles, then matching items and then stickers. A recent interest in computers and computer games facilitated some interaction between Jasper and his brother. As Elizabeth explains, "they will choose to watch the same movie or they will go to the movies together and Charles is just starting to see that Jasper has something to offer now that he is speaking and enjoys the same things he does."

A change of seasons from summer to winter impacted on the play of the family because of the cooling weather and it becoming darker earlier in the evenings. This impacted mainly on Steven's play with the children because it is in the evenings when he gets home from work that he has his main opportunity for play. The major change that occurred was that, instead of their usual routine of Steven and the boys jumping outside on the trampoline together, they started playing indoors on the computer together. Also, in the summer they had enjoyed spending time in and around the pool on sunny days and this was not possible in winter.

It was evident from all three adult family members that games and play routines often occurred by accident and then evolved over time. *“Rough play”* which is described as one of Jasper’s favourite play activities evolved from the time when he was younger and enjoyed being held on his little motor bike. A number of factors were involved in the evolution of this play. Firstly, the adult family members were encouraged by Jasper’s enjoyment of these games. Secondly, the adult family members’ confidence and trust grew in Jasper’s ability to tolerate the increasingly physical aspects of the play. Thirdly, the adult family members’ confidence in their ability to handle him as well as Jasper’s trust and confidence in their handling of him meant that *“rough play”* became more and more frequent and boisterous.

Framed by these changes, many hopes, imaginings and concerns were expressed about the future. The parents hoped for the development of a friendship between the two boys and that they would then play together. It was generally agreed, however, that this was not something that could be forced, as Steven states, *“they will make their own friendship as time goes by.”*

Steven expressed hopes for Jasper to be able to ultimately use a computer mouse and play computer games competitively as it would be something they could all do and enjoy together. There were also hopes expressed about how an electric wheelchair would allow him to have a greater independence of movement and influence his ability to play. Elizabeth and Steven voiced concerns about how he might feel in the future if he showed an interest in play activities that, due to his disability, he could only enjoy limited participation. They hoped, however, that they would be able to assist him in finding ways to overcome or cope with these difficulties.

***Sub-Category: Routines and Rituals***

Play is a daily occurrence which apart from the occasional structured play session seems to occur in and around other daily occupations. The versatility

and spontaneity of play means that, as Elizabeth says, *"It just fits in where we are, at whatever time."*

The form that play takes may depend on the time of day and who is involved in the play. Play may be used as a means of keeping the children entertained while the adult family members are performing other occupations. Elizabeth, for instance, describes the TV as a babysitter in the morning while she is getting showered and dressed.

Certain daily routines of play seem to occur as a result of the demands and routines of other daily occupations, such as quiet play and story-time before bedtime. During his daily rest time, Pamela explains that, *"if he wasn't sleeping, I would let him listen to the story and read the book by himself. There would be no interaction. It is self entertaining time and if he lies and stares into space and if that is what he chooses to do, then that is what happens for that hour."*

Pamela describes routine play times which occur every day during other daily occupations such as dressing him in the mornings or during bath-time in the evenings. *"Starting in the morning when I come on duty, I will put a particular CD on – one that he has requested. It will either be a story or it will be a sing song. So if it is a sing song then I must sing along and he sings along and I must do actions. If it is a story thing then I must act out the story in between doing his therapy and changing him for school and washing and whatever. So it is not just a set play for 20 minutes; it is play, do a bit of this and play again"*

The different days of the week seem to have different impacts on play. On weekdays Steven is at work all day and so play with him happens in the evening when he gets home. This play, however, is dedicated play time and does not involve getting other occupations done. Elizabeth says, *"Steven comes home and he jumps on the trampoline with the kids and that is their set play time, so he does have a set play time because he is not here."* The boys look forward to playing with him and there are certain play activities that are

seen as belonging to him and the boys. This includes jumping on the trampoline together and playing on the computer together. Furthermore, there seems to be an expectation of play in relation to these routines. For example, when Steven gets home from work, Jasper will say “bounce, bounce” or “puter, puter.”

Within these routine daily play activities, rituals of play also seem to develop. These involve the specific way in which the games and play activities take place. Steven describes one of these rituals when he says, *“okay I will take him out of his chair and then I will hold him at first just against my hip and that... It is a game that we play where Charles ... I try and double bounce Charles to get him down and then Jasper and I team up against him and then he runs up to the side of the garden and then he runs all the way back and like bounces across the trampoline and we try and trip him and stuff like that. That is Jasper... and after a while Jasper will want to lie down because it is the other game we play and then he lies down and then sometimes I get them both lying down next to each other and then I bounce them both, which Jasper loves because he loves having physical contact with Charles and that is very rare because Charles hates being too close to anybody. So he quite enjoy and then usually I will lie down next to him and then Charles will try and jump over both of us and jump backwards and forwards. Then sometimes Jasper will be on the ground and then I will pick Charles up and spin him over Jasper and then drop him on the other side, and backwards and forwards and backwards and forwards.”*

#### ***Sub-Category: Play as a Tool for Getting Daily Tasks Done***

Pamela and Elizabeth, who are the adult family members involved in Jasper's daily self-care tasks, express how play is a useful tool for completing these tasks. Changing his nappy, bathing, brushing his teeth and dressing all involve play.

The nurses also carry out occupational therapy and physiotherapy home programmes with Jasper as part of the daily schedule during the week. Play

is involved in these programmes but is used as means of achieving therapy related goals, so it is usually less intrinsically motivated. There is some uncertainty by the adult family members as to whether these home programmes are actually play. Elizabeth and Pamela both talk about them involving play but also say that there are times when he is doing things he doesn't want to do or that he has to focus on achieving something so it is not play. Steven feels that these home programmes are more like work for Jasper and because he never does it in the weekends as he would never ask for it. Elizabeth explains the need for play of this nature when she says, *"the majority of the time we let him lead us as to what he wants to play, but there is obviously times when he needs to do certain things because we have to fit them into his daily routine."*

Pamela describes how aspects and moments of the home programmes may be play for Jasper when she says, *"some of his day is structured therapy like he has to have OT in a structured environment and he has to have physical therapy in a structured environment and he has to have school in a structured environment. But during the structure I break it up into short periods of structure and play and sometimes I overlap the two and sometimes they are just completely mixed."* The skill in which play is incorporated into the chore of performing daily tasks could be considered a form of artistry. This is evident when Pamela explains carrying out a physiotherapy programme with Jasper. *"The moment he does not like something, if I am playing physiotherapy, then I stop doing it and I swing to something else and he won't have picked up on that but suddenly I can see his expression has changed and he is happier. He gets a certain look on his face and then I will switch to something else...It could be that the play is hurting him. I have got him into a certain position that is uncomfortable and it is not fun to be sore. So then you do something else and then he is happy again."*

Pamela's sensitivity to Jasper's affect and enjoyment within the play activities she engages in with him shows not only her skill in carrying out these home programmes but also the level to which she knows and understands Jasper as a person. Pamela explains that her ability to play with Jasper in ways that

are at times challenging for him results from the level of trust and comfort with one another that they have in their relationship. This was also evident in the way she facilitates physical play seen in Category 5, Subcategory 14, pages 84 – 85.

## CHAPTER 5

### DISCUSSION

The findings of this study described the perspectives of the adult family members' of a disabled child on his play within the family. These perspectives revealed a vivid picture of the disabled child's play and the adults family members' experience of his play. Although the latter finding was unexpected, it is not surprising considering the often social nature of play. The picture of the disabled child's play revealed that he spent much of his daily life engaged in playful occupations. However, he played mainly with adults as his disability limited independent play or opportunities for play with other children.

This discussion highlights how play is often an interaction between two or more individuals and yet modern play literature tends to be individualistic in its stance (Sutton-Smith, 1997). The adult family members' rationale for playing with their young disabled child is then discussed in relation to the rhetorics that society holds about play. The factors which inhibit and support the adult family members' play with their young disabled child are highlighted and ways in which the adult family members' balance their own occupational and play choices with the play needs of the children in the family are then presented. The occurrence of shared or co-constructed play between family members is then explored in relation to the transaction between a number of affirming factors. Finally, the impact of the disabled child's play and presence on the play of the family is discussed.

#### **Play as an Interaction Between Two or More Individuals**

Although, "*occupation rarely, if ever, is individual*" (Dickie et al, 2006, p. 83), modern play literature tends to be individualistic in focus (Sutton-Smith, 1997). The focus on play as a personal experience is evident in modern play literature which regards the individual player as the only one who can decide

whether an activity qualifies as play or not (Bundy, 1993; Sturges, Rodger and Ozanne, 2002). Added to this, it is widely accepted that play should be player controlled (Rubin et al, 1983). From this perspective, when two or more individuals play the same activity together, it cannot be expected that they will all experience the same level of enjoyment and satisfaction with engagement in the play. Parten (1932) describes different forms of social play as part of a child's development but an understanding of what the play interactions mean to the different players is not considered (Morrison et al, 1996). From the individualistic viewpoint, other players are usually considered to be part of the social environment (Parham et al, 1997). Florey (1971) even describes other players as human play objects. Consequently, understanding of the nature of the interaction between two or more players during play is limited. The findings of this study illustrated adult family members' experiences of playing with a disabled child. The fact that the findings reflect the involvement and experience of more than just the disabled child highlights the importance of the interactional nature of play.

### **The Rationale for Playing with a Young Disabled Child**

The adult family members' perceptions of the play of the disabled child were based on who they were as people; their beliefs; what they enjoyed and what they recognised as play. These factors often influenced the type of play they engaged in with the disabled child and the meaning they gave to these experiences.

Despite individual differences in the adult family members' perceptions of the disabled child's play, they all believed that play is important for all children. This belief was based on each adult family member's own childhood experiences of play, what these experiences meant to them and how they had impacted on them. Every individual's personal experiences and values, social background and individual circumstances have been found to influence their occupational choices and beliefs (Parham et al, 1997; Darlington and Rodger, 2006). The belief in the importance of play was also grounded in the tacit

influence of family, culture and current day society. Sutton-Smith (1997) describes these influences as “*popular rhetorics of play which are large scale cultural ‘ways of thought’ in which most of us participate in one way or another.*” He explains that “*the larger play rhetorics are part of the multiple broad symbolic systems – political, religious, social, and educational – through which we construct the meaning of the cultures in which we live*” (p. 8-9). The impact of the pervasive rhetorics that influence how the adult family members act in relation to their roles is discussed in the following paragraphs.

The adults family members’ general perceptions of the disabled child’s play were that he had little opportunity for playing independently or with other children. Consequently, as a result of their belief in the importance of play for children and as part of their role of parent or nurse, the adults took responsibility for finding ways to play with the disabled child and for facilitating and enabling his play. While the adult family members had similar reasons for believing play to be important, their roles as parent or nurse seemed to influence their focus on these reasons. The nurse of the disabled child, while being aware of and enjoying the bond that play created between the child and herself, focused on play as a means of developing skills, learning life’s lessons, experiencing fun and other emotions and ensuring his future as a well-adjusted individual. The view of play as a means of developing other skills is well documented (Parham, 1996) and accepted in western societies (Sutton-Smith, 1997). This is considered to be a “*rhetoric of play as progress*” (Sutton-Smith, 1997, p. 9) and is often viewed as more important than play as a form of enjoyment (Sutton-Smith, 1997). The parents of the disabled child acknowledged the importance of play as a vehicle for development and learning, of laying the foundation for his future identity and play interests. However, despite the pervasive rhetoric of play as a form of development, the parents’ focus on the importance of play in the disabled child’s life was as a means for developing and maintaining relationships within the family and promoting family inclusion. The difference between the parents and the nurse in their focus on the importance of play related to their roles. While it was the nurse’s job to play with the disabled child, the parents felt play to be an important part of creating relationships and bonds between individual family

members, or family sub-groups, and the family as a whole. Mactavish et al (2004) found similarly that parents of children with developmental disabilities valued family recreation for the opportunities it provided for children's learning and skill development and the "*enhancement of family relationships*" (p. 123). Hinojosa et al (1997) describe how engaging in enjoyable family occupations allows for the development of family togetherness. Sutton-Smith (1997) suggests that this understanding of play as a means of creating togetherness is a "*rhetoric of play as identity*" (p. 10) in that it is seen as a means of "*confirming, maintaining or advancing the identity of the community of players*" (p. 10). Interestingly, the rhetorics focused on by the adult family members in their reasons for playing with the disabled child were related not only to their roles in relation to the disabled child but their roles in relation to the family as a whole.

The adult family members' motivation for playing with the disabled child, even though this was often challenging for them, was in order to provide him with play opportunities that he would not have been able to access independently and to provide him with what he was perceived to need from play, such as learning, social interaction, skill development, therapy and enjoyment of his time. Shaw and Dawson (2001), in their study on parents' experience of family leisure, found that parents' involvement in family leisure was linked to their roles and responsibilities to the members of their family rather than due to intrinsic motivation. The motivation for engaging in family leisure activities was consequently found to be different to the motivation for engaging in individual play. This is because family leisure tends to be engaged in for underlying reasons and is therefore extrinsically motivated. This lead to Shaw et al's (2001) description of this type of leisure as "*purposive leisure*" (p. 217).

Bundy (1993) suggests that "*play is a transaction or activity in which we engage only because we want to, not because we feel we must*" (p. 217). If this is considered to be true then for the adult family members, who play with the young, disabled child because they feel it is important for the child and not because it is always personally satisfying for themselves, it is not surprising that this play is not always easy.

## Factors that Inhibit Play with a Young Disabled Child

Rodger et al (2006) suggest that personal and environmental factors may offer either a supportive or inhibitory effect on play. Rigby et al (2006) explain that the player's motivation to engage in a play experience is essential in order for play to occur. The findings of this study show that the adult family members' motivation to play with the disabled child was inhibited and supported by a number of factors which involved child and adult-related factors, environmental factors, factors related to the play activities themselves and the interaction between these factors. These factors are elaborated on in the following paragraphs. Rigby et al (2006) explain that "*the goodness of player-environment-play activity fit is crucial to a successful play exchange*" (p. 190). The interaction of these factors becomes more complicated when the needs of two or more players is taken into consideration.

One of the **player-related** factors which caused difficulty in the "*goodness of fit,*" between the **play activity** and the individual players' needs was the different ages and stages of development of the adult family members and the young, disabled child. The play that a young child finds inherently interesting and intrinsically motivating would generally not appeal to an adult in the same way (Vandenberg et al, 1982). Types of play and play skills are often shown to be a reflection of age and intellectual, social, emotional and physical development (Sheridan, 1975; Morrison et al, 1996; Smith, Cowie and Blades, 1998). Furthermore, Rigby et al (2006) explain that the player's "*level of developmental maturity, skills, abilities and emotional self-regulation are important components of the fit equation*" (p. 190). Consequently, during play interactions between the adult and child, there is a mismatch between the play needs of the child and those of the adult. In fact, the findings of this study show that when an adult family member plays with a young child in a child-chosen play activity, the adult family member's role often becomes one of facilitation and support rather than that of a fellow player. Rodger et al (2006) explain that an individual who "*plays with a child or group of children with the goal of facilitating play and social interaction,*" may be described as a

*“play partner”* (p. 194). The focus of this type of play is child-centred in that it is not something the adult family members would choose to engage in for themselves. When this is considered in relation to the dispositional characteristics of play discussed in Chapter 2, pages 10 – 13 (Rubin et al, 1983; Parham et al, 1997), it is evident that child-centred play for the adults is not intrinsically motivated, focused on the adult as a player nor is it controlled by the adult. Therefore, when taking these dispositional characteristics into consideration, engaging in child-centred play as a play partner does not qualify as play for the adult. Consequently, it is not surprising that the findings of this study indicate that child-centred play is not always easy or enjoyable for the adult family members. Similarly, Parham et al (1997) explain that, due to the personal nature of play, what is considered play for one person may be work for another. Furthermore, Shaw et al (2001) found that, while engagement in family leisure occupations *“involved pleasure and satisfaction, it also involved work, effort, and sometimes frustration and lack of enjoyment on the part of the parents”* (p. 228).

In order to accommodate the differences in this player and play activity mismatch due to age and stage of development, the adult family members found ways to make playing with the children easier and more satisfying for themselves. Esdaile (1994) reports that the demands on mothers to care for children, maintain households and often to engage in paid employment provides little time for personal leisure. Instead, leisure for mothers is often limited to family leisure time. Consequently, it is not surprising that it was often preferable for the adult family members, particularly the parents, to find opportunities for the children to play while they, the adult family members, were engaged in occupations of meaning to themselves. This is done in two ways which consist of playing in *“parallel”* and *“enfolded play.”*

Playing in **parallel** provides an opportunity for both the adult family member and child to play alongside each other although not playing together. In this way, the differing **play activity** needs of the individual players can be met. However, with a young, disabled child, playing in this manner is made difficult by the presence of the child's impairment. Consequently, the young disabled

child's impairment is another **player**-related factor which impacts on the ease and level of personal satisfaction with which the adult family members are able play with the child. A physical disability impacts on a child's ability to engage physically in play. This means that the child requires physical facilitation in order to play with most toys and to engage in any play outside of his/her wheelchair, buggy or bed. Facilitating the child's play makes playing with him physically challenging and tiring for the adult family member. Depending on the physical ability of the adult, a mismatch between the ability of the adult and the play needs of the child may exist. The findings show that when the adults, particularly the parents, find a play activity difficult, effortful or stressful to engage in, it is less likely to occur regularly. This links with the concept of flow which suggests that any activity which is too challenging will cause stress in the individual while too little challenge will result in boredom (Csikszentmihalyi, 1993; Emerson, 1998). Stress as a result of this physical challenge would prevent the adult family member from enjoying the play activity and may make it feel more like hard work.

Another way in which the adults were able to engage in occupations of meaning to themselves, while still accommodating the play needs of the disabled child, was through "**enfolded play**." Bateson (1996) and Primeau (1998) describe how adults often engage in "**enfolded play**" with their children as a means of being able to engage in occupations of their choice, such as chores, while simultaneously meeting the play needs of their children. The parents in this study found that they often played in this manner with their non-disabled child but that it was more difficult to do this with their disabled child. The child's physical disability means that when playing with him close supportive contact is necessary and so the adults have to set aside time to focus their attention on his play. This prevents the adults from engaging in other occupations whilst simultaneously engaging in play with the child.

The **player**-related factor of the disabled child's difficulty in engaging in the **play activity** of physical play also impacts on the ease with which adult family members and other children can play with him. Physical play or play which involves moving around independently provides greater allowances for

differences in age and ability during play. Rough-and-tumble play, for instance, is regularly engaged in by young children and their parents, often fathers, and enjoyment is experienced by both adult and child (Smith et al, 1988). Children of differing ages may share in the enjoyment of chasing each other or playing "hide-and-seek." Smith et al (1988) refer to these as "*low yield activities*" (p. 196), because they do not involve complex cognitive skills. However, in non-physical play, or "*high yield activities*" (Smith et al, 1988), such as building or doing puzzles, differing cognitive and language abilities tend to prevent similar interests and shared play.

The impact of the family **environment** also contributed to the challenge of playing with the young disabled child. This is because the adult family members, particularly the parents, have to accommodate for individual differences in activity needs and interests. Consequently, it is difficult for the adult family member to play when they feel distracted and divided by the demands of others' needs. This mismatch of player activity needs and an environment of distraction means that there is a poor "fit" (Rodger et al, 2006, p. 41) of player and environmental factors for the parents. This may impact negatively on the play of the entire family.

### **Factors that Support Play with a Young Disabled Child**

Despite these player, play activity and environmental challenges, play often occurred within the family and between family members. The adult family members found time and ways to engage in play occupations of their own while balancing these with the play needs of other family members and the disabled child. This was facilitated by supportive player and environmental factors.

**Environmental** human resources provided opportunities for the parents to engage in parallel and enfolded play with the disabled child and for the disabled child to access play with other children. These types of play were possible for the parents and other children with the disabled child due to the presence of the nurse who directly facilitated his play. Enfolded play was

made possible by the nurse facilitating the disabled child's play alongside the parents, while the parents performed meaningful occupations of their own. Parallel play involved play occupations chosen by the parents with the children's play needs in mind. These activities gave the parents opportunities to enjoy a play activity while accommodating the play needs of the children. The disabled child's play was often facilitated in these situations by the nurse. This led to time spent together although not always actively playing together. For instance, the mother of the family enjoyed taking the children out so they could play and she could watch them. Physical play with other children was also possible at times through the nurse's facilitation.

The desire of both the adult family members and the disabled child to enjoy play together was a **player-related** factor which served to promote play. The adult family members emphasised how they wanted to do things together that they could all enjoy. Lawlor (2003) states, "*Our character and human experience only exist through our interrelatedness with one another*" (p. 426). It is the need for connection with others that drives humans as social beings to seek to engage in occupations with others (Lawlor, 2003). The disabled child within this study was found to be a playful child who was open to play and invited play with others. As a result of the combination of his playful nature and the adult family members motivation to spend time with him and do enjoyable things together, family members regularly enjoyed playing together and sharing play experiences.

### **Transactional Experience Leading to Co-Constructed Play**

According to the widely accepted definitions of play discussed in Chapter 2, pages 10 – 13, the shared play experiences regularly enjoyed by family members would not be viewed as play because the play activities were extrinsically motivated, controlled by more than one player and the focus was on the interaction between the players rather than on the process of play itself. Despite this, the players perceived these interactions as play. These

shared play experiences took place regularly and were often enjoyable for those involved.

An explanation for the occurrence of play of this nature may be partly offered by Rebeiro (2001) who emphasises *“the importance of an affirming environment”* (p. 80) for satisfactory engagement in occupations. However, the environment alone was not enough for these shared play experiences to evolve. It also seemed that when time, player-related factors and play activity factors were accommodating for play, family play often evolved from playful moments. During these moments, play was discovered almost by accident due to the blending of affirming time, player, environmental and play activity factors.

This blending of affirming factors was often more likely to occur when shared play took place in subgroups of family members. This was for two main reasons. Firstly, playing in subgroups made accommodating everyone’s play needs more manageable. Mactavish et al (2004), in their study of recreation in families that included children with developmental disability, similarly found that *“recreation involving small groups of family members was essential for making activities more manageable and inclusive”* (p. 131). Secondly, for the parents in this study, playing in subgroups generally allowed for play with the children without the involvement of a nurse. This helped to create an environment in which it was more comfortable to play, because the nurse’s presence was at times found to impact negatively on the players’ sense of ease in the play environment. This increase in player comfort levels, as well as the way in which the subgroup unit made it easier to accommodate the players’ particular needs, helped to create an environment in which it was more encouraging to play.

Interestingly, the influence of time factors was evident when playful moments which evolved due to the blending of affirming factors were repeated with the same family members at regular times. This play often became part of the daily routine. Segal (2004) explains how family routines provide the foundation for the development of family rituals. Rituals of play were formed

when specific actions and behaviours were required from specific family members within the process of a specific play interaction. *“Family rituals are the mechanism for the construction and affirmation of family identity because of their symbolic and affective components. This identity is constructed by the family’s participation in and performance of rituals, by the inclusion and exclusion of family members in rituals, and by the socialization of children ... Routines give life order whereas rituals give it meaning”* (Segal, 2004, p. 500). Humphry (2005) describes the development of meaning between individuals while engaged in shared occupations when she states that *“the dynamic, interactive process of creating and sustaining the activity is thought of as a co-construction of the occupation where doing and experiencing meaning go beyond the individual and take place in an interpersonal space”* (p. 40). It is with this in mind that the limitations of the individualistic outlook on play become clear.

The findings show that under the right circumstances the adult family members could find themselves enjoying play with their disabled child that initially they were not intrinsically motivated to perform. Rodger et al (2006) clarify why it is possible for this to happen when they explain that within one activity the *“complex interaction between individual and environmental factors at any stage of engagement can modify an individual’s perceptions and motivations about activity participation”* (p. 285). Dickie et al (2006) similarly discuss how viewing the engagement in occupations from an **individualistic** or even an **interactional** stance is limiting in gaining a full and holistic picture of the experience. Instead it should be seen as a **transaction between the individuals involved, the environment, time and space**. In this way the relationship between the factors involved is emphasised rather than the factors themselves. During the co-construction of play family members are allowed to develop a family identity as well as a sense of inclusion and belonging. Furthermore, co-constructed play becomes meaningful to each player in its own right and due to relationship of all the factors involved. In this way the play, which may initially have seemed like a chore to the adult, becomes a meaningful experience and a pleasurable opportunity for spending time and being with the family. As Humphry (2005) states *“co-constructing an*

*occupation alters performance and changes an occupation's meaning. Intersubjective experiences may lead to a redefinition of an occupation"* (p. 42).

Wilcock (1998) explains that an individual's social well-being is developed *"when the range of each individual's occupations and roles enables maintenance and development of satisfying and stimulating social relationships between family members, with associates and within the community in which they live"* (p. 104) and through a balance of shared or social occupations and individual quiet time. Furthermore, DeGrace, (2003) states that *"research has suggested that the identity of the family unit has a direct relationship to health. A family's identity forms through negotiating and engaging in daily living experiences"* (p. 348). It is the essential contribution that each of the family members makes to playing together that allows for the development of the meaningfulness of these co-constructed play experiences, their family's identity and consequently to the well-being of the individual family members and the family as a whole.

### **The Disabled Child's Contribution**

*"An understanding of individual experience is a necessary but insufficient condition for understanding occupation that occurs through complex contexts"* (Dickie et al, 2006, p. 83). For disabled children, the individualistic outlook on play as discussed in Chapter 5, page 89 raises many questions about these children's ability to engage in play. However, when considered from a transactional viewpoint within co-constructed play the findings of this study demonstrate the agency which a disabled child has access to within play.

The powerful nature of co-constructing shared family play is clear when viewed in relation to the benefits for individual and family health and well-being. Despite the challenges involved in playing with a young disabled child within the family, this child is one of the essential factors for creating transactional opportunities for co-constructed play between family members.

This is not only because he has a playful nature and tends to invite play with others but because he is a part of the family and as such is an essential part of the play of the family. His involvement in co-constructed family play is part of what provides meaningful play experiences for the family and this, in turn, enhances the family's identity and well-being. It is therefore within the realms of co-constructed play that the disabled child's agency within play in the family is discovered.

## **Conclusion**

From this discussion, it is evident that the adults of a family play with a young disabled child because they believe in its importance as a means of developing skills, learning life's lessons, experiencing fun and other emotions as well as its role in ensuring his future as a well-adjusted individual. The parents also believe play to be a means of developing and maintaining their relationship with the disabled child, with other family members and for the togetherness of the family as a whole. Consequently, based on their roles as parents or nurse, the adults take responsibility for ensuring these play needs are met. However, when play is viewed from an individualistic stance, the fact that play with the disabled child is not always intrinsically motivated or controlled by the adult family member means that for these family members playing with him is not always easy. A number of player, environmental and play activity related factors were both inhibiting and supportive of play between the adult family members and the disabled child. Furthermore, the adult family members found ways to engage in play and occupations of their choice while simultaneously accommodating the play needs of the other family members. This involved playing in parallel or enfolded play. When player, environmental, time and play activity factors blended together in an affirming manner, co-constructed play occurred between family members. It was in this sharing and creating of play experiences that the family members were able to create meaningful family experiences and within this co-constructed play that the disabled child was seen to become agentic.

## CHAPTER 6

### CONCLUSION

The aim of this study was to explore adult family members' perspectives on the play of a young disabled child within the family. Previous research has shown that disabled children are viewed as generally having limited access to play (Gralewicz, 1973; Michelman, 1974; Williams et al, 1988; Missiuna et al, 1991; Hinojosa et al, 1997; Miller et al, 2003). These play limitations are not, however, always recognised as such by the children themselves (Pollock et al, 1997). In order to gain insight into the play of a young disabled child within the family, the adult family members' perspectives were explored.

Taking an individualistic view of play (Sutton-Smith, 1997), the findings of this study confirmed those of other studies in that the disabled child's play was perceived to rely on adult facilitation. Furthermore, as in many other studies, the child was seen to have limited opportunities for independent play or play with other children (Missiuna et al, 1991; Tamm et al, 2000). The findings of this study, however, serve to highlight the interactional nature of play as the adult family members' experiences of playing with the disabled child were uncovered.

The findings of this study showed that the adult family members believed that play was extremely important for the disabled child. Consequently, as a result of their roles as parents and nurse, they took personal responsibility for playing with him. According to their roles and position in the family, the nurse focused on play as a means of promoting the development of skills, while the parents focused on play as a means of developing and maintaining family relationships.

Numerous factors inhibited and supported the adult family members' play with the disabled child. These factors consisted of player, environmental and play activity factors. When considered from an individualistic viewpoint, it is not

surprising that the adult family members found play with the disabled child challenging at times, as it was often extrinsically motivated and not controlled by the adult. Despite this, much play occurred between the adult family members and the disabled child. The adult family members found ways to balance the play needs of the children in the family with their own play and occupational choices. This was seen in parallel and enfolded play. Shared or co-constructed play also occurred at times when there was a transaction between affirming environmental, player, play activity and time factors. Co-constructed play was significant for the family members in that it was meaningful just to be a part of it. Furthermore, co-constructed play contributed to each family member's sense of belonging to each other and to the family as a whole. In this way co-constructed play helped to create a family identity. This phenomenon has been found to have links with family health and well-being (Wilcock, 1998; DeGrace, 2003). Consequently, it was from this transactional viewpoint of play and within co-constructed play that the disabled child, as a playful individual who invited play and as a member of the family, was able to access agency in play through creating, promoting and maintaining meaningful play experiences within the family.

These findings are significant for modern day researchers of play who are concerned with individualistic forms of play. While the importance of play as a phenomenon which holds unique and personal meaning for each individual is clear there is a wealth of information to be discovered regarding play as a transactional and co-constructed experience. For parents and caregivers of disabled children, as well as health professionals who work with disabled children and their families, this study highlights how the play needs and occupational choices of each member of a family are important and how it is necessary for a balance to be created to meet these needs. Furthermore, there are numerous possibilities for disabled children to play and to access their agency in play within a family depending on how play is viewed and constructed.

## **Limitations of Study**

Prolonged engagement with the participants of this study was limited to three weeks. This time constraint was determined by two factors. Firstly, due to the intense involvement of the adult family members in the data collection process, three weeks was considered a reasonable amount of time for them to accommodate. Secondly, the study period was limited by the time frame allocated to the Masters dissertation. This limitation may have compromised the depth of the findings, particularly in relation to the dynamic nature of play and the way in which the play of a disabled child within the family changes over time.

The use of direct observation would have promoted the researcher's insights into the adult family members' perspectives on the play of their disabled child. However, the researcher chose not to use direct observations in order to keep personal perspectives on the play of the disabled child within the family to a minimum.

The disabled child and his brother were too young to offer their perspectives on their play experiences within the family but, if this had been possible, it would have added to the depth of the findings.

## **Recommendations**

### ***Research***

Further research should be conducted on the play of disabled children from both their own perspectives and those of the individuals who play with them, within the contexts in which they play over time, and taking into consideration the transactional nature of play.

Definitions of play and research into play in general need to begin to take into account a transactional view of play. This involves defining and studying from the perspective of all players involved as well as considering the relationship

between all the factors which may impact on the play transaction. Continuing to view play from the perspective of the individual player alone is limiting, especially when the social nature of play is considered.

### ***For Occupational Therapy Practice***

The challenges in finding the time, energy and motivation to play with young children should be taken into consideration when working with families of disabled children. Furthermore, it is essential to consider the needs of the other family members and the environment in which they live before issuing home programmes related to play or any other occupational need.

Families of disabled children should feel encouraged to play together in ways that suit them. Spending time together in family sub-groups may provide opportunities for less stressful and demanding moments and situations and the occurrence of meaningful co-constructed play.

## REFERENCES

- Anderson, J., Hinojosa, J. and Strauch, C. (1987) Integrative Play in Neurodevelopmental Treatment. *The American Journal of Occupational Therapy*, 16 (no. 41), 421 – 426.
- Ballinger, C. (2004) Writing Up Rigour: Representing and Evaluating Good Scholarship in Qualitative Research. *The British Journal of Occupational Therapy*, 67 (no. 12), 540 – 546.
- Bateson, M.C. (1996) *Enfolded Activity and the Concept of Occupation*. In: Zemke, R. and Clark, F. (Eds.), *Occupational Science The Evolving Discipline*. F. A. Davis Company, U.S.A.
- Baum, C. and Christiansen, C. (1997) *The Occupational Therapy Context: Philosophy, Principles, Practice*. In: Christiansen, C. and Baum, C. (eds.), *Occupational Therapy Enabling Function and Well-Being*, 2<sup>nd</sup> ed. Slack Incorporated.
- Bracegirdle, H. (1992) *The Use of Play in Occupational Therapy for Children: How the Therapist Can Help*. *British Journal of Occupational Therapy*, 55 (no. 5), 201 – 202.
- Bowling, A. (1997) *Research Methods in Health: Investigating Health and Health Services*. Open University Press, Buckingham, UK.
- Bundy, A.C. (1989) A Comparison of the Play Skills of Normal Boys and Boys With Sensory Integrative Dysfunction. *The Occupational Therapy Journal of Research*, 9 (no. 2), 84 – 101.
- Bundy, A.C. (1991) *Play Theory and Sensory Integration*. In: Bundy, A., Fisher, A. and Murray, E. (eds.), *Sensory Integration Theory and Practice*. F. A. Davis, Philadelphia.

Bundy, A.C. (1993) Assessment of Play and Leisure: Delineation of the Problem. *The American Journal of Occupational Therapy*, 47 (no. 3), 217 – 222.

Bundy, A. (1997) *Play and Playfulness: What to Look For*. In: Parham, L. D. and Fazio, L. S. (eds.), *Play in Occupational Therapy for Children*. Mosby, St. Louis.

Bundy, A.C. (1998) *Test of Playfulness*. Unpublished manual, available from the Colorado State University, Collins.

Bundy, A.C., Fisher, A. G. and Morrison, C.D. (1991) The Contribution of Motor Skills and Playfulness to the Play Performance of Preschoolers. *The American Journal of Occupational Therapy*, 45, 687 – 694.

Canadian Association of Occupational Therapists (1996) Practice Paper: Occupational Therapy and Children's Play. *Canadian Journal of Occupational Therapy*, 63 (no. 2), 1 – 9.

Cameron, D., Leslie, M., Teplicky, R., Pollock, N., Stewart, D., Toal, C. and Gaik, S. (2001) The clinical utility of the Test of Playfulness. *Canadian Journal of Occupational Therapy*, 68 (no. 2), 04 – 11.

Case-Smith, J. and Shortridge, S.D. (1996) *The Developmental Process Prenatal to Adolescence*. In: Case-Smith, J., Allen, A.S. and Pratt, P.N. (eds.), *Occupational Therapy for Children*, (3<sup>rd</sup> ed.). Mosby, Missouri.

Chritiansen, C.H. and Townsend, E.A. (2004) *Introduction to Occupation: The Art and Science of Living*. Prentice Hall, New Jersey.

Clark, F.A., Parham, D. , Carlson, M.E., Frank, G., Jackson, J., Pierce, D., Wolfe, R.J. and Zemke, R. (1991) Occupational Science: Academic Innovation in the Service of Occupational Therapy's Future. *The American Journal of Occupational Therapy*, 45, 300 – 310.

Clifford, J.M. and Bundy, A.C. (1989) Play Preference and Play Performance in Normal Boys and Boys With Sensory Integrative Dysfunction. *The Occupational Therapy Journal of Research*, 9 (no. 4), 202 – 217.

Cook, J.V. (2001) *Qualitative Research in Occupational Therapy*. In: Cook, J.V. (ed). *Occupational Research in Occupational therapy*. Delmar Thomson Learning, Canada.

Creswell, J.W. (1998) *Qualitative Inquiry and Research Design*. Sage Publications, California.

Csikszentmihalyi, M. (1993) Activity and Happiness: Towards a Science of Occupation. *Journal of Occupational Science*, 1 (no. 1), 38 – 42.

Darlington, Y. and Rodger, S. (2006) *Families and Children's Occupational Performance*. In: Rodger, S. and Ziviani, J. (eds) *Occupational Therapy with Children*. Blackwell Publishing Ltd, Oxford.

DeGrace, B.W. (2003) Occupation-Based and Family-Centred Care: A Challenge for Current Practice. *The American Journal of Occupational Therapy*, 57 (no. 3), 347 – 350.

Denzin, N.K. and Lincoln, Y.S. (1998) *Strategies of Qualitative Inquiry*. Sage Publications, California.

DePoy, E. and Gitlin, L.N. (1998) *Introduction to Research: Understanding and Applying Multiple Strategies*. (2<sup>nd</sup> ed.). Mosby, USA.

Dickie, V., Cutchin, M.P. and Humphry, R. (2006) Occupation as Transactional Experience: A Critique of Individualism in Occupational Science. *Journal of Occupational Science*, 13 (no. 1), 83 – 93.

Emerson, H. (1998) Flow and Occupation: A review of the literature. *Canadian Journal of Occupational Therapy*, 65, 37 – 44.

Esdaille, S.A. (1994) A Focus on Mothers, Their Children With Special Needs and Other Caregivers. *Australian Occupational Therapy Journal*, 41, 3 – 8.

Finlay, L. (1998) Reflexivity: an Essential Component for All Research? *The British Journal of Occupational Therapy*, 61 (no. 10), 453 – 456.

Finlay, L. (2000) Multiple Voices, Multiple Paths: Choosing between Qualitative Traditions. *The British Journal of Occupational Therapy*, 63 (no. 12), 580 – 582.

Finlay, L. (2006) 'Rigour', 'Ethical Integrity' or 'Artistry'? Reflexively Reviewing Criteria for Evaluating Qualitative Research. *The British Journal of Occupational Therapy*, 69 (no. 7), 319 – 326.

Fitzgerald, M.H. (2004) A Dialogue on Occupational Therapy, Culture, and Families. *The American Journal of Occupational Therapy*, 58 (no. 5), 489 – 498.

Flick, U. (1998) *An Introduction to Qualitative Research*. Sage Publications, London.

Florey, L.L. (1971) An Approach to Play and Play Development. *The American Journal of Occupational Therapy*, 15 (no. 6), 275 – 280.

Goldbart, J. and Mukherjee, S. (2000) Play and Toys in West Bengal: self-reports of parents of children with cerebral palsy. *International Journal of Disability, Development and Education*, 47 (no. 4), 337 – 353.

Gordon, C.Y., Schanzenbacher, K.E., Case-Smith, J. and Carrasco, R.C. (1996) *Diagnostic Problems in Paediatrics*. In: Case-Smith, J., Allen, A.S. and Pratt, P.N. (eds.), *Occupational Therapy for Children*, (3<sup>rd</sup> ed.). Mosby, Missouri.

Gralewicz, A. (1973) Play Deprivation in Multihandicapped Children. *The American Journal of Occupational Therapy*, 27 (no. 2), 70 – 72.

Gunn, S.L. (1975) Play as Occupation: Implications for the Handicapped. *The American Journal of Occupational Therapy*, 29 (no. 4), 222 – 225.

Hamm, E.M. (2006) Playfulness and the Environmental Support of Play in Children With and Without Developmental Disabilities. *OTJR: Occupation, Participation and Health*, 26 (no.3), 88 – 96.

Harkness, L. and Bundy, A. C. (2001) The Test of Playfulness and Children With Physical Disabilities. *The Occupational Journal of Research*, 73 – 89.

Hartley, R. and Goldenson, R. (1963) *The Complete Book of Children's Play*. Thomas Y Crowell Company, New York.

Hinojosa, J. and Kramer, P. (1997) *Integrating Children with Disabilities into Family Play*. In: Fazio, L.S. and Parham, L.D. (eds.), *Play in Occupational Therapy for Children*. Mosby, U.S.A.

Holloway, I. and Wheeler, S. (1996) *Qualitative Research For Nurses*. Blackwell Science Ltd, London.

Huysamen, G.K. (1994) *Methodology for the Social and Behavioural Sciences*. Southern Book Publishers Ltd, Pretoria.

Humphry, R. (2005) Model of Processes Transforming Occupations: Exploring Societal and Social Influences. *Journal of Occupational Science*, 12 (no. 1), 36 – 44.

Humphry, R. and Case-Smith, J. (1996) *Working with Families*. In: Case-Smith, J., Allen, A.S. and Pratt, P.N. (eds.), *Occupational Therapy for Children*, (3<sup>rd</sup> ed.). Mosby, Missouri.

Kielhofner, G. (1992) *Conceptual Foundations of Occupational Therapy*. F. A. Davis Company, U.S.A.

Kielhofner, G. (1995). *A model of human occupation: Theory and application*. Second Edition. Gary Port City Press, USA.

Kielhofner, G. (2005) Rethinking Disability and What To Do About It: Disability Studies and Its Implications for Occupational Therapy. *The American Journal of Occupational Therapy*, 59 (no. 5), 487 – 496.

Kielhofner, G. and Burke, J. (1977) Occupational Therapy After 60 Years: An Account of Changing Identity and Knowledge. *The American Journal of Occupational Therapy*, 31 (no. 10), 675 – 689.

Knox, S. (1996) *Play and Playfulness in Pre-school Children*. In: Zemke, R. and Clark, F. (Eds.), *Occupational Science The Evolving Discipline*. F. A. Davis Company, U.S.A.

Kramer, P. and Hinojosa, J. (1999) *Frames of Reference for Pediatric Occupational Therapy* (2<sup>nd</sup> ed.). Lippincott, Williams & Wilkins, U.S.A.

Krefting, L. (1991) Rigor in Qualitative Research: The Assessment of Trustworthiness. *The American Journal of Occupational Therapy*, 45, 243 – 247.

Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P. and Letts, L. (1996). The person-environment-occupation model: a transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63 (no. 1), 9 – 23.

Lawlor, M.C. (2003) The Significance of Being Occupied: The Social Construction of Childhood Occupations. *The American Journal of Occupational Therapy*, 57 (no. 4), 424 – 434.

Mactavish, J. B. and Schleien, S. J. (2004) Re-Injecting Spontaneity and Balance in Family Life: Parents' Perspectives on Recreation in Families that Include Children with Developmental Disability. *Journal of Intellectual Disability Research*, 48 (no. 2), 123 – 141.

Mason, J. (2002) *Qualitative Researching* (2<sup>nd</sup> ed.). SAGE Publications, London.

Meyer, A. (1922) The Philosophy of Occupational Therapy. *Archives of Occupational Therapy*, 1, 1 – 10.

Michelman, S. (1971) The Importance of Creative Play. *The American Journal of Occupational Therapy*, 25 (no. 6), 285 – 290.

Michelman, S. (1974) *Play and the Deficit Child*. In: Reilly, M (ed.) An Explanation of Play. In: Reilly, M. (ed.) *Play as Exploratory Learning: Studies of Curiosity Behaviour*. Sage Publications, London.

Miller, S. and Reid, D. (2003) Doing Play: Competency, Control, and Expression. *CyberPsychology & Behaviour*, 6 (no. 6), 623 – 632.

Missiuna, C. and Pollock, N. (1991) Play Deprivation in Children with Physical Disabilities: The Role of the Occupational Therapist in Preventing Secondary Disability. *The American Journal of Occupational Therapy*, 45, 882 - 888.

Morozini, M. (1998) *Exploring the perspectives and engagement in play of parents with their 2-year old child*. Unpublished thesis, available from the University of East London, UK.

Morris, J. (1993) *Independent Lives Community Care and Disabled People*. The MacMillan Press Ltd, London.

Morrison, C.D., Metzger, P. and Pratt, P.N. (1996) *Play*. In: Case-Smith, J., Allen, A.S. and Pratt, P.N. (eds.), *Occupational Therapy for Children*, (3<sup>rd</sup> ed.). Mosby, Missouri.

Okimoto, A.M., Bundy, A. and Hanzlik, J. (2000) Playfulness in Children With and Without Disability: Measurement and Intervention. *The American Journal of Occupational Therapy*, 54, 73 - 82.

O'Brien, J. and Smith, J. (2002) Childhood Transformed? Risk Perceptions and the Decline of Free Play. *British Journal of Occupational Therapy*, 65 (no. 3), 123 – 128.

OSDP (1997) *An Integrated National Disability Strategy*. Office of the Deputy President, Pretoria.

Parham, L.D. (1996) *Perspectives on Play*. In: Clark, F. and Zemke, R. (eds.) *Occupational Science: The Evolving Discipline*. F. A. Davis Company, U.S.A.

Parham, L.D. and Primeau, L.A. (1997) *Play and Occupational Therapy*. In: Fazio, L. S. and Parham, L. D. (eds.), *Play in Occupational Therapy for Children*. Mosby, U.S.A.

Pollock, N., Stewart, D., Law, M., Sahagian-Whalen, S., Harvey, S. and Toal, C. (1997) The Meaning of Play for Young People with Physical Disabilities. *Canadian Journal of Occupational Therapy*, 64 (no. 1), 25 – 31.

Primeau, L. A. (1998) Orchestration of Work and Play Within Families. *The American Journal of Occupational Therapy*, 52 (no. 3), 188 – 195.

Rebeiro, K.L. (2001) Enabling occupation: The importance of an affirming environment. *Canadian Journal of Occupational Therapy*, 68 (no. 2), 80 – 89.

Reilly, M. (1962) The Eleanor Clarke Slagle. *The American Journal of Occupational Therapy*, 16 (no. 1), 1 – 9.

Reilly, M. (1966) A psychiatric Occupational therapy program as a teaching model. *The American Journal of Occupational Therapy*, 20 (no. 2), 61 – 67.

Reilly, M. (1969) The Educational Process. *The American Journal of Occupational Therapy*, 23 (no. 4), 299 – 307.

Reilly, M. (1974) *An Explanation of Play*. In: Reilly, M. (ed.) *Play as Exploratory Learning: Studies of Curiosity Behaviour*. Sage Publications, London.

Rigby, P. and Rodger, S. (2006) *Developing As A Player*. In: Rodger, S. and Ziviani, J. (eds) *Occupational Therapy with Children*. Blackwell Publishing Ltd, Oxford.

Robinson, A.L. (1977) The Arena for Acquisition of Rules for Competent Behaviour. *The American Journal of Occupational Therapy*, 31 (no. 4), 248 – 253.

Rodger, S. and Ziviani, J. (1999) Play-based occupational therapy. *International Journal of Disability, Development and Education*, 46 (no. 3), 337 – 363.

Rodger, S. and Ziviani, J. (2006) *Children, Their Environments, Roles and Occupations in Contemporary Society*. In: Rodger, S. and Ziviani, J. (eds) *Occupational Therapy with Children*. Blackwell Publishing Ltd, Oxford.

Rubin, K.H., Fein, H. and Vandenberg, B. (1983) *Play*. In: Mussen, P.H. (Series Ed.), *Handbook of Child Psychology* (Vol. 4). Hetherington, E.M. (Vol. Ed.), *Socialisation, Personality and Social Development* (4<sup>th</sup> edn.) John Wiley, New York.

Save the Children Canada (2000) *United Nations convention on the rights of children, articles 2, 3, 12, 23, 31*. Retrieved 15 January 2007 from:  
<http://ssmu.mcgill.ca/savethechildren/UN%20conventions.htm>

Schaaf, R.C. and Mulrooney, L.L. (1989) Occupational Therapy in Early Intervention: Family Centred Approach. *The American Journal of Occupational Therapy*, 43 (no. 11), 745 – 754.

Seale, C. (1999) *The Quality of Qualitative Research*. Sage Publications, London.

Segal, R. (2004) Family Routines and Rituals: A Context for Occupational Therapy Interventions. *The American Journal of Occupational Therapy*, 58 (no. 5), 499 – 509.

Shannon, P. D. (1977) The Derailment of Occupational Therapy. *The American Journal of Occupational Therapy*, 31 (no. 4), 229 – 234.

Shaw, S.M. and Dawson, D. (2001) Purposive Leisure: Examining Parental Discourses on Family Activities. *Leisure Sciences*, 23, 217 – 231.

Sheridan, M.D. (1975) *From Birth to Five Years Children's Developmental Progress*. Wellprint Production Services, Hong Kong.

Singdahlsen, J., Sparling, J.W. and Walker, D.F. (1984) Play Techniques With Neurologically Impaired Preschoolers. *The American Journal of Occupational Therapy*, 38 (no. 9), 603 – 612.

Smith, P.K., Cowie, H. and Blades, M. (1998) *Understanding Children's Development* (3<sup>rd</sup> ed.). Blackwell Publishers, Oxford.

Stagnitti, K. (2004) Understanding play: The implications for play assessment. *Australian Occupational Therapy Journal*, 51, 3 - 12.

Stake, R.E. (1995) *The Art of Case Study Research*. Sage Publications, Thousand Oaks.

Sturgess, J. (2003) A model describing play as a child-chosen activity – is this still valid in contemporary Australia? *Australian Occupational Therapy Journal*, 50, 104 - 108.

Sturgess, J., Rodger, S. and Ozanne, A. (2002) A Review of the Use of Self-Report Assessment with Young Children. *British Journal of Occupational Therapy*, 65 (no. 3), 108 – 116.

Sutton-Smith, B. (1997) *The Ambiguity Of Play*. Harvard University Press, Cambridge, Massachusetts.

Takata, N. (1971) The Play Milieu – A Preliminary Appraisal. *The American Journal of Occupational Therapy*, 25 (no. 6), 281 – 284.

Tamm, M. and Skär, L. (2000) How I Play: Roles and Relations in the Play Situations of Children with Restricted Mobility. *Scandinavian Journal of Occupational Therapy*, 7, 174 – 182.

Townsend, E. and Wilcock, A.A. (2004) Occupational Justice and Client-Centred Practice: A Dialogue in Progress. *Canadian Journal of Occupational Therapy*, 71 (no. 2), 75 – 87.

United Nations Convention on the Rights of the Child (2005). *Rights Violations Experienced by Children with Disabilities*. Retrieved 11 February 2007 from: <http://www.un.org/esa/socdev/enable/rights/documents/ahc6side3aug3.doc>

Vandenberg, B. and Kielhofner, G. (1982) Play in Evolution, Culture, and Individual Adaptation: Implications for Therapy. *The American Journal of Occupational Therapy*, 36 (no. 1), 20 – 28.

Wilcock, A.A. (1998) *An Occupational Perspective of Health*. SLACK Incorporated, USA.

Williams, S.E. and Matesi D.V. (1988) Therapeutic Intervention With an Adapted Toy. *The American Journal of Occupational Therapy*, 42 (no. 10), 673 – 676.

Yin, R.K. (1984) *Case Study Research Design and Methods*. Sage Publications, Beverly Hills.

Yerxa, E.J. (1994) Dreams, Dilemmas, and Decisions for Occupational Therapy Practice in a New Millennium: An American Perspective. *The American Journal of Occupational Therapy*, 48 (no. 7), 586 – 589.

Ziviani, J. and Rodger, S. (2006) *Environmental Influences on Children's Participation*. In: Rodger, S. and Ziviani, J. (eds) *Occupational Therapy with Children*. Blackwell Publishing Ltd, Oxford.

## APPENDIX 1: CHILD INFORMATION LETTER



Dear Jasper and Charles,

Hello, my name is Belinda and I am hoping to find out all about the play that happens in your family. This is because play is very important for everyone. If you and your mom and dad are happy to help me with this, then I will visit your house a few times to chat with your mom and dad about how you all play. I will also lend your mom and dad a camera so that they can take photographs of some of the playing that happens in your home. I hope this will be fun for you. If you are worried about anything, please tell your mom and dad.

I hope to see you soon,

from,  
Belinda



## **APPENDIX 2: INTRODUCTORY LETTER**

Dear Elizabeth and Steven

Thank you very much for volunteering to participate in my study on adult family members' perspectives on the play of a disabled child within the family. My name is Belinda Davies and I am an Occupational Therapist. At the moment I am studying part-time at the University of Cape Town for my MSc in Occupational Therapy. This study on play is the final part of my studies.

Before you decide if you would like take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please do not hesitate to ask if there is anything that is not clear or if you would like any more information.

The reason that play has been chosen as a topic for my study is because play is important in occupational therapy as a means of helping children learn and develop skills. It is also an enjoyable, health promoting experience to be encouraged in the lives of all children. This study aims to investigate adult family members' perspectives on the play of a disabled child within the family. This is an in-depth study about one family's experience of play and therefore if you agree to participate, your family will be the only family involved in this research. It is hoped that through the in-depth information gained from this study, a better understanding of the way in which your disabled child plays with within your family may be gained.

The benefits for your family in being involved in this research are:

- An increased awareness of your family's play may be gained.
- You will have the opportunity to explore how, when, why and what you play with your child and what play means for you as a family.
- It may allow you to reflect on all the unique ways in which you as a family incorporate play into your daily life.
- Your feelings, opinions and thoughts about your family's play will be of great importance to the outcomes of the research and therefore you will be involved in contributing to this previously unexplored area of research together with the researcher.
- You will also be offered a copy of the completed research.

The benefits for other families from this research are:

- Further research opportunities related to discovering more about the play of disabled children. This may ultimately lead to new ways of encouraging play in families of disabled children, particularly if they find difficulty incorporating play into their daily lives.
- Research which follows this initial study may also provide greater understanding and insight into the lives and needs of families of disabled children.

As part of this study, you will be asked to observe the play that occurs in your family over a three week period. During this three week period, you will be requested to:

1. complete a daily play chart
2. each adult family member will individually undergo an interview about the play experienced in your family
3. use a disposable camera to photograph the play between your family members

Prior to this, I will need to visit your home in order to observe its layout and gain an understanding of where play might occur. You will also be requested to complete a questionnaire regarding some of your family's details.

After the three week period is over and the adult family members' interviews have been transcribed, I will send these to you so you can comment on them and add or change anything that you wish to. Also, at a time convenient for you we will look at the photographs and have the opportunity to talk about them. Finally, when I have completed interpreting and writing up all the information gathered, you will have the opportunity to read this and we will be able to discuss your opinions and feelings about what has been written. If there is anything in your opinion which then needs to be changed or to be added into my write-up, this will be discussed and decided upon. This research is about the play in your family and as a result your input will be extremely valuable and important.

All information which is collected about your family during the course of this research will be kept strictly confidential. Any information about you which is given to anyone other than the researcher will have your name and address removed so that you cannot be recognised from it. The results of the research will be written up as a dissertation which will be marked at the University of Cape Town. Copies of this dissertation will be given to the University of Cape Town. If you would also like to have a copy, you will be most welcome to one. The only time that confidentiality may not be able to be maintained is if a child protection issue arises. If this happened, the study would have to stop, the matter would be discussed with yourselves and then with my supervisor at the University of Cape Town. Any further action would have to follow local Child Protection Procedures.

It is important for you to know that it is up to you to decide whether or not to take part in this study. If you do not wish to take part or subsequently wish to withdraw from the study, you will be able to do so without having to give a reason.

When you have read this letter, if you have any questions or would like to clarify any aspect of the study, please don't hesitate to contact me and we can discuss these. There are two consent forms which are attached to this letter. Each adult family member needs to sign one of these consent forms. A letter

has also been sent herewith, to your children to explain the study to them. Please could one of you read this to them and then sign the enclosed assent form. Please could you return the two consent forms and the assent form to me once you have read and agreed to the above-mentioned procedures.

If you have any questions or concerns, please do not hesitate to contact me. I look forward to hearing from you and thank you once again for volunteering to participate in this study.

Yours sincerely,

Belinda Davies

### APPENDIX 3: ASSENT FORM

*Adult Family Members' Perspectives on the Play of a Young Disabled Child within the Family.*

A study to be conducted by: Belinda Davies

I have read the children's letter of introduction to them and they fully understand what is expected of them.

My children are aware that they are under no obligation to participate in this study.

My children are aware that they may withdraw from the study at any time without giving a reason

My children agree that they will participate in this study.

Adult family member's signature: \_\_\_\_\_

Name (print): \_\_\_\_\_

Date: \_\_\_\_\_

Researcher's signature: \_\_\_\_\_

Name (print): \_\_\_\_\_

Date: \_\_\_\_\_

## APPENDIX 4: CONSENT FORM

*Adult Family Members' Perspectives on the Play of a Young Disabled Child within the Family.*

A study to be conducted by: Belinda Davies

I have read the letter of introduction and fully understand what is expected of me

The purpose of this study is clear to me

I understand that my family's personal details will be kept strictly confidential

I am aware that the outcomes of this study will be made available to others for further research, knowledge advancement and learning

I understand that there are no risks to my family in participating in this study

I understand that I can withdraw my family from the research at any time without giving a reason.

I hereby agree that I will participate in this study.

I hereby give consent on behalf of my two children for them to participate in this study.

Adult family member's  
signature: \_\_\_\_\_

Name (print): \_\_\_\_\_

Date: \_\_\_\_\_

Researcher's signature: \_\_\_\_\_

Name (print): \_\_\_\_\_

Date: \_\_\_\_\_

## APPENDIX 5: ADULT FAMILY MEMBER'S QUESTIONNAIRE

DATE: \_\_\_\_\_

Adult Family Member 1 Details:

Adult Family Member 2 Details:

NAME:..... NAME: .....

DATE OF BIRTH: ..... DATE OF BIRTH: .....

EDUCATION: ..... EDUCATION:.....

OCCUPATION: ..... OCCUPATION:.....

Details of disabled child:

Details of non-disabled child:

NAME

\_\_\_\_\_

*Date of birth*

\_\_\_\_\_

Pre-natal history:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Birth:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Post-natal history:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Nature of disability:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Describe development of child:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Other:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## APPENDIX 6: DAILY PLAY CHART

DAY: ..... DATE: .....

	TIME	WHO	WHERE	WHAT
	5-6am			
	6-7am			
	7-8am			
	8-9am			
	9-10am			
	10-11am			
	11am-12pm			
	12-1pm			
	1-2pm			
	2-3pm			
	3-4pm			
	4-5pm			
	5-6pm			
	6-7pm			
	7-8pm			
	8-9pm			
	9 – 10pm			
	10 – 11pm			

## **APPENDIX 7: SEMI-STRUCTURED INTERVIEW GUIDE**

### **1. Play interaction between adult family members and child/children**

- a. Typical play interactions that occur between the adult family member and child/children
- b. When the play interactions occur
- c. How the play interactions fit into the daily lives
- d. The differences between the play of the adult family member with the child with a disability and with the non-disabled child
- e. The play of the disabled child: the type of play the disabled child engages in; what the disabled child finds enjoyable and the playfulness of the disabled child
- f. The type of play that occurs between the adult family member and the two children together
- g. Any difficulties in play experienced
- h. The feelings of the adult family member around these play interactions

### **2. Adult family member's effect on play**

- a. The adult family members' beliefs and preferences about the type of play the child/children should be engaging in
- b. How they influence play as a result of these beliefs and preferences
- c. The type of play that is encouraged in the child/children
- d. The type of play that is encouraged when the children play together
- e. The types of toys with which the child/children are encouraged to play

### **3. Views about play in general**

- a. The adult family member's views on the meaning of play for children and for families
- b. The importance of play in the life of a disabled
- c. The importance of play in the life of a non-disabled child
- d. The effect that the adult family members have on the child/children's play

Reference: Morozini (1998)