The experience of play for children with high levels of physical disability

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Abstract

Play is children's primary occupation, and all children have the right to play. Despite this, children with physical disabilities are often described as playing less than their typically developing peers. Play is a complex concept to define and remains insufficiently researched for children with high levels of physical disability due to Cerebral Palsy.

This thesis used Interpretative Phenomenological Analysis to explore the experience of play for six children age 6-11 with high levels of physical disability due to Cerebral Palsy. Each child participated in three in-depth interviews about their play experience. Most of these interviews initially involved the child choosing to show the researcher a play activity which was videoed for 5-10 minutes. The videos, together with drawings created with the researcher, were used within the interviews to gain greater depth of discussion. Interviews were then transcribed and analysed in line with the methodology.

The findings suggested that making choices and controlling play was important for the participants; this occurred through a facilitated sense of independence, and a sense of self as strong and successful. Sometimes the children chose to make compromises when playing, at other times they were forced to compromise in an activity, which prevented play being experienced. Children participated in play differently to their typically developing peers through seeing their disability as part of themselves; participating through watching play; experiencing extreme emotions; and seeing themselves without a physical disability in their imaginary play. Finally, children connected with others in play through the use of their communication skills and humour.

Discussion of the findings suggested a new concept of 'vista play' in which children embodied their helper and perceived independence in play, despite physical support. Recommendations follow to further explore 'vista play' as a concept, and the extended view of embodiment which includes people as well as objects. Further research is also recommended to explore children's sense of 'being' and identity negotiation which occurred in play between themselves with a disability and an imagined self without a disability. Participating in 'doing' play was part of children 'becoming' themselves and negotiating this identity. Children sensed 'belonging' as part of a social group in play through using communication skills and humour; these skills appeared to be drawn upon more than the participant's typically developing peers.

It is recommended that parents and professionals recognise the experience of play for children with high levels of physical disability as captured in this research.

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Definitions of key terms

Agency is the sense an individual has of being the author of their own actions and having the capacity to act.

Being is the true essence of oneself that makes one distinctive from others.

Becoming is closely linked to the development of identity and a sense of self; it is a process which occurs through *doing* and *being* which enables individuals to grasp more of their potential.

Belonging is about the connectedness of others which provides context to the experience of occupation.

Choice within play is demonstrated by a child’s motivation to choose an activity.

Control within play suggests that the process and objective of the play is controlled by the player.

Dasein means ‘*being there’* or ‘*being in the world’.* Human being’s nature is always located ‘*there*’ within a meaningful context.

Doing is described as the way that individuals engage in purposeful action throughout their everyday life.

Embodiment is the experience of the world through the body we perceive it in. Encounters with an experience can be affective, moral, embodied and interpersonal. Individuals seen as embodied agents in the world influenced by objects, relationships and language.

Freedom in play is also described as internal reality, it is the concept that the players reality is suspended, and play is directed by their own rules and wishes.

Intentionality is an experience of conscious expression which is always of something. Intentionality refers to the relationship between conscious process and object of thought.

Lifeworld is the social world in which an individual’s life is based from which they base their context and meaning.

Person-in-context suggests that knowledge is generated and meaning understood through interaction between a person and object within their social context.

Phenomenology is the lived experience of a particular phenomenon.

Play is an activity which is characterised by its freedom, choice and control within a frame of play cues.

Resilience is an individual's ability to successfully adapt to life tasks in the face of social disadvantage or highly adverse conditions.

Self-efficacy reflects confidence in the ability to exert control over one's own motivation, behaviour, and social environment.

Spatiality is defined as an individual’s lived space; the environment around someone which changes their perception of their experience.

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Declaration of Authorship

I declare that the research contained in this document, unless otherwise formally indicated within the text, is the original work of the author. This has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Naomi Graham

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1. Introduction

This thesis is presented in partial fulfilment of the requirements of the University of Brighton for the degree of Doctor of Philosophy. This chapter provides an overview of the research study, the topic of play, and definitions of key terms used throughout this thesis. A reflexive account of my experience as an occupational therapist and the influence of this on my research project is included. A summary and overview of the chapters contributing to this thesis is outlined.

1.1. Overview

All children have the right to play (UNICEF 1989) and play is widely recognised as a primary occupation for all children (Chiarello et al. 2006). Despite this, children with physical disabilities are often described as playing less than their typically developing peers (Okimoto et al. 2000, Whittingham et al. 2010). Little research to date has asked children with significant physical disabilities about their experience of play. This study aimed to explore the experience of play of 6-12 year olds with significant physical disability, due to Cerebral Palsy. The research has contributed to a greater understanding of the meaning of play for these children. Interpretative Phenomenological Analysis was the methodology used.

Children age 6-12 were invited to participate through posters, and newsletters at The London Bobath Centre; The Bobath Centre Wales; The London Centre for Cerebral Palsy; and 1Voice: which are all charities working with children who have Cerebral Palsy. Therapists and staff were permitted to sign post families to the study information; snowball sampling through families and professionals who had heard about the study took place. The researcher met and carried out three interviews with each child. In most sessions the child chose to participate in a play activity for up to 10 minutes which was videoed by the researcher. Following this, the child participated in an interview to prompt a deeper discussion of the play experience; this included playing back and discussing the video recorded at the start. The children could also choose to show the researcher toys or photos of themselves playing and had the opportunity to draw a picture with the researcher to help them talk about their experience. Most children in the study had limited or dysarthric speech and therefore some used Augmentative and Alternative Communication devices to help communication. Video recording of each child’s interview allowed their words, and any additional signs and gestures they used, to be fully captured, transcribed, and understood for analysis.

The findings of this research have outlined the experience of play for the six participating children. This has led to an understanding of the way in which they make choices and control their play; the way they play differently to their peers; and the way they connect with others in play. Children were seen to participate in play through ‘vista play’ a term developed within this thesis which describes a facilitated independence in which children perceive their play as independent despite having physical support. This provided a new view of embodiment which occurred to the extent that children not only embodied equipment, such as their wheelchairs, but also embodied their helpers as a part of their play. Furthermore, children were found to experience a contention within their lifeworld between themselves with their disability as integral to their being, and themselves without a disability in their imaginary play. This raised interesting debate as to the extent of normalisation and adaptation to disability which occurs for children within play. Children were observed to participate in play through watching others, an experience which challenged the concept of active participation for children with disabilities.

This thesis highlights several new insights into the experience of play for children with high levels of physical disability. Several areas for further research have been raised, together with practical implementations and means by which the research informs occupational therapy practice.

1.2. Key terms

1.2.1. Children and childhood

A Child is defined as an individual who is under the age of 18 (UNICEF 1989). The United Nations rights for the child suggest that every child has the freedom to express their thoughts, and their point of view should be respected (UNICEF 1989). Following the ‘Convention of the Rights of the Child’ in which the UNICEF (1989) guidelines were developed, there has been an increased awareness of the importance of child perspectives in research (Woodhead 2006). Kehily (2009) suggests that childhood studies, which focus on childhood experience and perspective, are a growing and important area of research. It is considered that: culture, society, representation of family, and experience, will all influence an individual's childhood (Kehily 2009). The child's voice is suggested to be key to conducting research, with the recognition that children are social actors within their own right (Kellet 2005). Researchers such as Harcourt (2011) are actively recognising this through exploring children's lived experiences of their social world and contrasting this to adult perspectives. Although research involving children has existed for several years, it is in more recent years that the young child's perspective of their own experience is argued to be *'the most crucial starting point for policy and practice.'* (Woodhead 2006, p34).

1.2.2. Disability

Disability is defined as '*a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on the ability to do normal daily activities'* (Equality Act 2010, c. 15, part 2, 6(1)). Children with disabilities are often under researched and underrepresented within research (Connors & Stalker 2007). Goodley & Runswick-Cole (2010) have argued for an increased inclusion of children with disabilities in research projects. The disabled children's childhood studies approach is presented by Curran and Runswick-Cole (2014) and represents a distinct area of study within a global context which focuses on representing the voice of the child or young person with a disability. The approach draws upon, but is distinctly different from, both disability studies and childhood studies in three ways: the child is viewed as an able participant; the child's voice and experience is central; the focus is away from the 'norm' (Curran & Runswick-Cole 2014). This thesis follows a disabled children's childhood studies approach that seeks to gain the experience of children with Cerebral Palsy with regards to their play. A social model of disability is recognised in which an individual's experience is influenced by the social, attitudinal and physical environments around them (Lawlor et al. 2006); for children with Cerebral Palsy, environment is thought to have a significant impact on participation (Lawlor et al. 2006). The social environment and context of each child's life were therefore essential considerations for this research.

1.2.3. Cerebral Palsy

Cerebral Palsy is defined as a group of disorders of movement or posture and motor function which is due to a non-progressive lesion or abnormality in the developing brain (Surveillance of CP in Europe (SCPE 2000). Cerebral Palsy is a permanent condition thought to occur in 2-3 children per 1000 live births (SCPE 2000). Individuals with Cerebral Palsy are likely to need medical intervention and therapy input throughout their lives (National Institute for Health and Care Excellence, 2014). Although research for children with Cerebral Palsy exists it is significantly limited for children who particularly have very high levels of physical disability; researchers argue that further research should take place with this population of children (Powrie et al. 2015, Imms et al. 2017).

The Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS) and Communication Function Classification System (CFCS) are used to describe levels of functioning for children with Cerebral Palsy (Cooley Hidecker et al. 2012). The levels range from one to five: levels IV and V on the GMFCS and MACS indicate that children may use powered mobility and be able to manipulate a limited number of objects in adapted environments (Eliasson et al. 2006, Palisano et al. 2007). The CFCS also ranges from one to five: levels I and II in the CFCS suggest that children can send and receive information with familiar and unfamiliar partners but occasionally needed extra time (Cooley Hidecker et al. 2012).

1.2.4. Play

Play is often referred to as a multidimensional and complex concept which is difficult to define, and varies according to the perspective of the individual (Neumann 1971, Reilly 1974, McInnes et al. 2009). Neumann (1971) discusses *'the problem of play'* and describes how child development; education; the function of play; and the benefits of play; have all driven varying play definitions. Play can be seen as an activity defined by its freedom, choice and control (Sheridan et al. 2011). Freedom within play, also described as internal reality, is the concept that the players' external reality is suspended, and play is directed by their own rules and wishes (Schiller 1795). Choice within play is closely linked to the child's motivation (Bundy 2012). Sheridan et al. (2011) focused on spontaneous play and suggested that children have a natural drive towards play. Internal control suggests that the process and objective of the play is controlled by the player (Nuemann 1971). Parten (1932) argued that internal control can also be experienced through cooperative control which is when an individual chooses to share their play with others.

The characteristics of freedom, choice and control are used by several play researchers, within educational and health fields, as a basis for their definition of play (Bundy 2012, Howard 2002, Neumann 1971, Sheridan et al. 2011). Bundy (2012) argues that definitions of play will slightly vary according to the aspect of play, five play aspects are given: the players approach to play (playfulness), the environment of play, the play activities, the play skills, and the motivation to play. Bundy (2012) suggests that play is defined by a combination of freedom, choice and control, all within a 'frame' of play. This frame gives others cues that an activity is play, for example, a child crawling and barking is giving cues that they are playing being a dog (Bundy 2012). Within this thesis play is recognised as a complex concept which is understood according to the perspective of the player (Neumann 1971) and is broadly defined by an activity where a child has freedom, choice and control.

1.3. Chapter summary and thesis overview

1.3.1. Chapter 2: Literature review

The discussion provided within chapter two outlines the research literature and justification of the research project. A critical appraisal of play theory and research studies contributing to the current understanding of play for children with physical disabilities is presented. The research question and aims of the study are presented at the end of this chapter.

1.3.2. Chapter 3: Methodology

This chapter presents the methodology for the research project. The theoretical and philosophical perspectives are presented including a discussion of the ontology and epistemology underpinning the research. Interpretative Phenomenological Analysis is the overall methodology for this project and an outline of this is presented within this chapter.

1.3.3. Chapter 4: Methods

The methods chapter presents a detailed account of the data collection process as informed by the methodology. It includes discussion of the use of advocates to inform the research, and a reflection on the pilot interview process and how this informed the method for future participants.

1.3.4. Chapter 5: Findings

The findings chapter provides a detailed overview of the participant data and the analysis process. The researcher's interpretations of the participant data are explored through the themes and subthemes which are outlined. The findings suggest that children experience making choices and controlling their play through: a facilitated independence involving embodiment of a helper; a sense of self as strong and successful; and in choosing or having to compromise. Children were seen to participate differently to their peers: their disability became a part of their self; they engaged in play through watching; extreme emotions were played out; and they experienced a new spatiality in their play through an imagined self without disability. Children were seen to connect with others in play: they used humour to enable connection; and use their voice to be heard.

1.3.5. Chapter 6: Discussion

The discussion chapter provides detailed consideration of the findings in relation to research theory and literature. The discussion outlines the occupation of play for children with high levels of physical disability in relation to their *doing, being, becoming and belonging* (Wilcock 2007). Children were seen to participate in *doing* through a new kind of play termed *vista play* in which they embodied their helper and perceived physical support as independence. Discussion around children's negotiation of their identity and the fluctuation they experience in their lifeworld between their 'disabled self' and 'imagined self without a physical disability' is presented. The process of *becoming* an occupational being in relation to play is discussed; this involves a synthesis of literature understanding means by which individuals can participate in activity. Finally, literature discussing the concept of *belonging* in relation to children with high levels of physical disability will be commented on in relation to the study's findings.

1.3.6. Chapter 7: Conclusions

The conclusions highlight the contributions to knowledge and the implications that this has for both practice and further research. Children were seen to experience a fluctuating lifeworld and it is recommended that parents and professionals enable children the opportunity to express their imagined self and to negotiate their identity as their disabled self. A discussion of how improving component skills and recognising children's ability to play by watching occurs in relation to children's *becoming* in play. The importance of the embodied unit and recognition of the experience of *vista play* is discussed in relation to children's *doing.* Finally, conclusions are drawn in relation to children's sense of *belonging* within their play and the importance of parents and professionals providing strategies for connection and focusing on opportunities for belonging. These implications for practice are then summarised in terms of further research. Limitations of the study are discussed and final conclusions are drawn.

1.4. Reflexive account

At the start of this research I was aware of the influence I would have on the shape it would take. My understanding of the world and my being within it has an impact upon my decision making. I am a Christian and therefore my worldview is that I believe God's love extends to everyone and he sees value in everyone. This has a strong influence in my life and the way that I respond to others; my perspective is to always see potential rather than limitations. I feel that my Christian worldview complements the understanding I have gained as a children's occupational therapist; my role is to see potential in the children that I am working with and enable the children and their parents to see this potential too, then support them to work towards it. This perspective has influenced my exploration of children's experiences within the study. I was also influenced by my Masters research (Graham et al. 2014, Graham et al. 2015) in which I explored parents' understandings of play for their children with Cerebral Palsy. The Masters study highlighted some interesting points which led me to want to explore play further from the child's perspective. One such point being the view that parents had of their children's play suggesting that they participated in play more than appears to be represented within the research literature. I was most challenged by the finding which suggested that children could participate in play vicariously by watching their peers; this is something that I wanted to explore with children from their own perspective. Within my everyday practice I saw that motivation to play enabled children to more easily engage and participate in activity; within my Master's research parents suggested that children's therapy was at times seen as play. As part of the current research I was therefore interested to see whether children mentioned their therapy as a part of their play or whether this was outside of their play experience.

I was further led to the current study because of the mismatch that I saw between occupational therapy philosophy which places importance on client-centred intervention, and occupational therapy practice with regards to the occupation of play. I knew that children experience play as a primary occupation and that this is something of great importance to them; yet within practice play appeared to seldom be an occupation of focus. Play as an activity within practice appeared to be used as a means to an end, rather than as an activity which has therapeutic value in and of itself. In some instances the focus of my occupational therapy colleagues appeared to be on ‘work’ and achieving functional activities and goals in a highly structured manner with very little opportunity for play. Considering the value of play as an occupation I felt disconcerted as to the lack of awareness of the importance of play among some of my occupational therapy colleagues.

Whilst disseminating my Master’s research around play I found that practitioners often commented that play was missed within assessment or goal setting, and this commonly focused upon washing, dressing, eating, positioning, and writing. Discussion with children’s therapists would suggest that service constraints, and sometimes parents, demand a *functional* goal that involves the child achieving something concrete. This ignores an understanding that engagement in play has developmental benefits for all children, and stands in contrast to the philosophy underpinning practice. Occupational therapists would always view their practice as client-centred and would aim to involve children within the therapy process. Yet, if play is recognised as a primary occupation, it appears problematic that conversation with other therapists suggests children are not commonly asked about their play. Although occupational therapists are aware of the benefits of primary and meaningful occupations such as play, play appears to often be overlooked within practice. It is for this reason that I aimed to gain an understanding of play from the child’s perspective in order that occupational therapists can deepen their understanding of the meaning of play to each child, and then successfully use this within the occupational therapy process.

Although sometimes appearing to miss the value of play for play’s sake, it was within practice that I experienced colleagues interacting and playing with children who had high levels of physical disability. On several occasions I observed children appearing to be fully participating in a play activity alongside a therapist. I think I have encountered some of the most playful, engaged and fun-loving children in my occupational therapy work. For me this strongly challenged the perspective of the literature which appears to suggest that children with significant physical disabilities cannot participate in play as much as their typically developing peers. I could recognise that some therapists had a natural ability to engage with a child in play and that this level of skill could create a picture which perhaps looked more playful than it was experienced. However, it was the child's motivation and ability to play which stood out for me when observing these interactions. The observation of the sheer joy and fun experienced by children when they participated in play was sometimes not recognised by parents and other therapists. The lack of recognition of children's ability to play and participate in activity both within the literature and in practice led to a frustration I felt which motived me to want to explore children's perspectives further.

I was motivated to engage in this research both as an individual, and as an occupational therapist, because of the value I place on every individual child and their perspective. I found that I wanted to resist the literature's summary that children with disabilities cannot play well and need to be taught. I was encouraged by the presence of Disabled Children's Childhood Studies (Curran & Runswick-Cole 2014) as an approach which places the child and their experience at the forefront of research. I care about the perspective of children with high levels of physical disability and therefore aimed to capture and represent each child's own experience of play. I wanted to be able to share this experience with therapists, parents, teachers, peers, and those who interact with each child in their everyday lives.

2. Literature review

2.1. Introduction

This chapter provides a background to the research project through a critical review of the literature. Definitions and perspectives influencing the understanding of play are discussed. The rationale for researching the experience of play for children with high levels of physical disability due to Cerebral Palsy is argued below.

The following literature review is divided into sections. The search strategy is discussed initially, followed by a discussion of play as a multifaceted concept; this includes different theoretical perspectives of play, discussion of play definitions, and the distinction between play and leisure. Play is a recognised primary occupation for children and this is discussed within the fourth section. The experience of play for typically developing children and play for children with disabilities are outlined within the following two sections. The use of play within therapy and the importance of play to occupational therapy are discussed within the penultimate section. The final section draws together the gaps of knowledge evident within the literature review and provides the research question and aims of the research, concluding with a reflexive account of the literature review process.

2.2. Search strategy

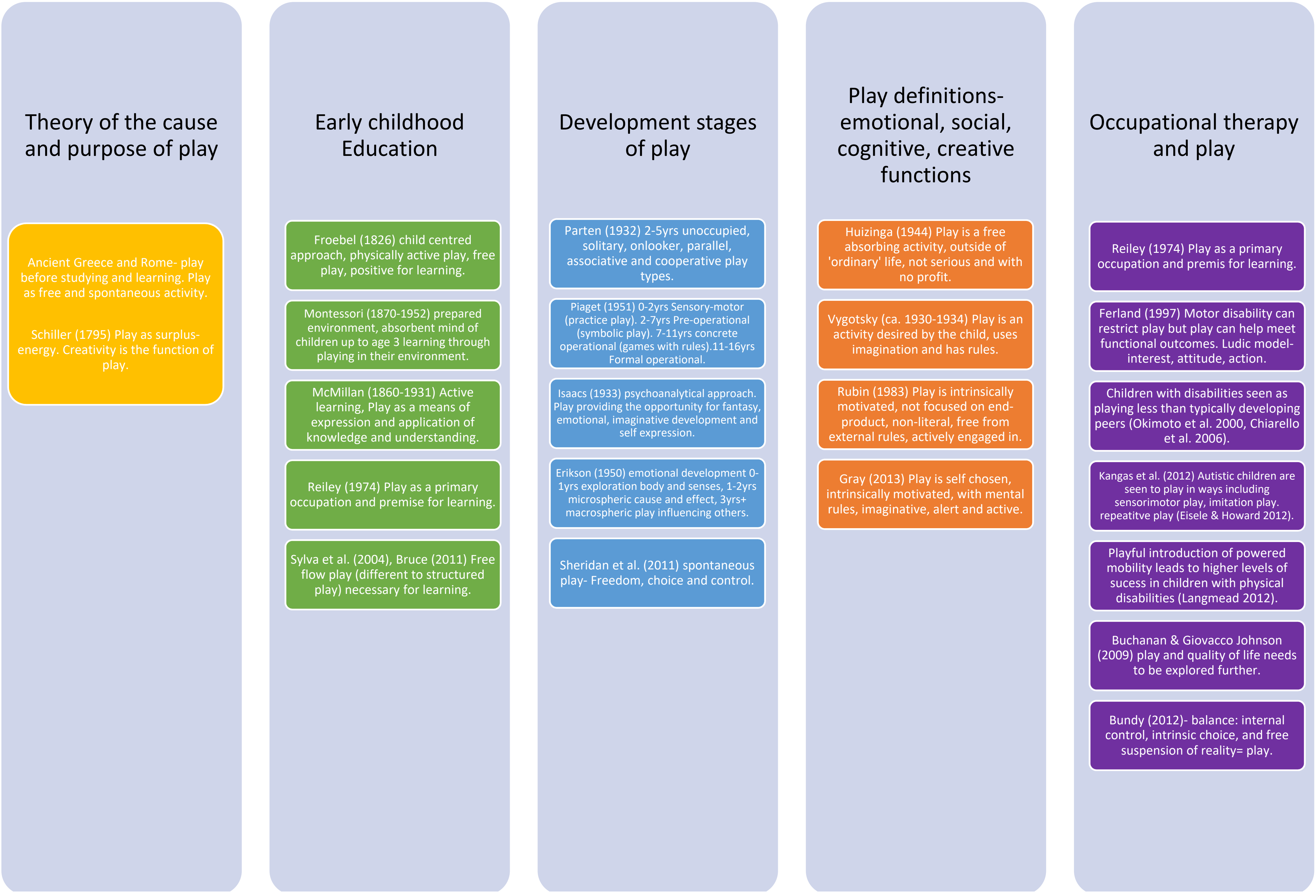
The databases MEDLINE, PsychINFO, CINAHL, EMBASE, and OVID were searched in order to find relevant literature in relation to this review. Manual searching of the works of key authors, text books, and journals was also used in order to gain all relevant information for this review. Play is a complex concept which is difficult to define (Reilly 1974), in order to capture all the studies related to play the search terms ‘play’ or ‘playthings’ or ‘leisure’ or ‘recreation’ were used. In order to capture the experience of children with Cerebral Palsy ‘physical disabilities’, ‘Cerebral Palsy’, and ‘disability’ were used. The terms ‘experience’ and ‘perception’ were used to search for articles related to children’s experiences of play.

Literature was screened according to its title and abstract in order to ascertain its relevance to the review; this was then synthesised with other relevant sources in order to understand each topic relating to play for children with Cerebral Palsy.

The quality of the literature used within this review was assessed using Pluye et al. (2011) Mixed Methods Appraisal tool which allows for the critical appraisal of both qualitative, quantitative and mixed methods studies. Only English sources were used due to lack of translation services being available.

2.3. Play – a multifaceted concept

As discussed previously (Chapter 1) play is found to be a multidimensional concept which can vary according to the perspective of the individual (McInnes et al. 2009). Play is broadly defined as an activity encompassing: freedom, choice and control; also referred to as internal reality, intrinsic motivation and internal locus of control (Bundy 2012, Howard 2002, Neumann 1971, Sheridan et al. 2011). In 1971 Neumann carried out a systematic review of theory and literature contributing to definitions of play. Neumann (1971, p.5) discussed '*the problem of play*' in reference to the difficulty of forming a consensus of what play is and how it is defined. Few researchers provide an explanation for the difficulties in reaching a consensus; although publishing a long time ago, Neumann (1971) provides a useful explanation which can be used as a framework to explore the research literature. Neumann (1971) suggests that four perspectives of play lead to different nuances and emphases within play theory: theories of the cause and purpose of play; early childhood education; play alongside child development; and play as an emotional, social, cognitive and creative function (Neumann 1971). The following section will critically examine the variation in play definitions and theory through discussing key sources as summarised in figure 1. The definitions and theory are discussed based on Neumann's (1971) perspectives with an additional perspective of occupational therapy and play. This is essential to consider as this research is being undertaken from an occupational therapy perspective. Following this a review of play-based assessments, the concept of playfulness, and the differences between play and leisure, will also be discussed within this section before summarising the working definition of play used for the purposes of this thesis.



Theory of the cause and purpose of play

Ancient Greece and Rome- play before studying and learning. Play as free and spontaneous activity.

Schiller (1795) Play as surplus-energy. Creativity is the function of play.

Early childhood Education

- Froebel (1826) child centred approach, physically active play, free play, positive for learning.
- Montessori (1870-1952) prepared environment, absorbent mind of children up to age 3 learning through playing in their environment.
- McMillan (1860-1931) Active learning, Play as a means of expression and application of knowledge and understanding.
- Reiley (1974) Play as a primary occupation and premise for learning.
- Sylva et al. (2004), Bruce (2011) Free flow play (different to structured play) necessary for learning.

Development stages of play

- Parten (1932) 2-5yrs unoccupied, solitary, onlooker, parallel, associative and cooperative play types.
- Piaget (1951) 0-2yrs Sensory-motor (practice play). 2-7yrs Pre-operational (symbolic play). 7-11yrs concrete operational (games with rules).11-16yrs Formal operational.
- Isaacs (1933) psychoanalytical approach. Play providing the opportunity for fantasy, emotional, imaginative development and self expression.
- Erikson (1950) emotional development 0-1yrs exploration body and senses, 1-2yrs microspheric cause and effect, 3yrs+ macrospheric play influencing others.
- Sheridan et al. (2011) spontaneous play- Freedom, choice and control.

Play definitions- emotional, social, cognitive, creative functions

- Huizinga (1944) Play is a free absorbing activity, outside of 'ordinary' life, not serious and with no profit.
- Vygotsky (ca. 1930-1934) Play is an activity desired by the child, uses imagination and has rules.
- Rubin (1983) Play is intrinsically motivated, not focused on end-product, non-literal, free from external rules, actively engaged in.
- Gray (2013) Play is self chosen, intrinsically motivated, with mental rules, imaginative, alert and active.

Occupational therapy and play

- Reiley (1974) Play as a primary occupation and premis for learning.
- Ferland (1997) Motor disability can restrict play but play can help meet functional outcomes. Ludic model- interest, attitude, action.
- Children with disabilities seen as playing less than typically developing peers (Okimoto et al. 2000, Chiarello et al. 2006).
- Kangas et al. (2012) Autistic children are seen to play in ways including sensorimotor play, imitation play. repeatitve play (Eisele & Howard 2012).
- Playful introduction of powered mobility leads to higher levels of sucess in children with physical disabilities (Langmead 2012).
- Buchanan & Giovacco Johnson (2009) play and quality of life needs to be explored further.
- Bundy (2012)- balance: internal control, intrinsic choice, and free suspension of reality= play.

Figure 1 Theories and perspectives of play

ORIGINAL IN COLOUR

2.3.1. Theory of the cause and purpose of play

Play is a concept which has existed throughout history. This has been highlighted by theorists such as Cohen (2006) and Frost (2010) who have explored play in the ancient world. Play artefacts such as dolls, rattles, images of children engaging in physical play and ball games have been found in countries such as Greece, Rome, China, Peru and Egypt (Cohen 2006, Frost 2010). Early philosophers such as Plato and Aristotle discussed play as a part of child development; both argued that children needed the opportunity to play and experience life before focusing on study and learning (Frost 2010). Initially recorded as discussed in the 5th and 4th Century BC (Frost 2010), the early presence of play within history would suggest that there is an innate existence of play which continues to be observed across time, culture and species.

The idea of children having a natural instinct to play was introduced by Schiller (1795), a philosopher who wrote letters about ethics and aesthetics. Schiller's 27th letter (1795) discusses the idea of play as an innate expression of freedom which occurs both in animals and humans. Schiller's argument, combined with the thinking of Spencer (1873), a sociologist, and Groos (1895), a biologist, have been summarised in the theory that the cause of play is surplus energy which leads to creativity (cited in Henricks 2015). Other theorists such as Lazarus stand in contrast to the idea of play being surplus energy, and have suggested that play is a way in which individuals can conserve energy (Wood 2012). This highlights one of many tensions that exist within the debate about play; theorists have argued play to be on opposing ends of a spectrum, both as a surplus energy and as a way of conserving and regaining energy.

There appears to be a general consensus, of both early philosophers and occupational therapy and education researchers, that children in particular have an inner drive to engage within play (Schiller 1795, Bundy 2012, Howard 2002, Neumann 1971, Sheridan et al. 2011). The purpose or cause of this drive to play continues to be debated and discussed within a range of spheres including education, psychology and therapy. The importance of recognising and allowing individuals to act on their inner drive to play is reflected within the United Nations rights for the child, that states: *every child has a right to play* (UNICEF 1989).

2.3.2. Early childhood education

Educational perspectives of play have developed through history as children have been observed to engage more readily in education and learning through play (Wood 2012). Froebel, an educationalist, suggested that the child-centred educational approach, where children had the opportunity for physically active and directed play, had a positive impact on children's participation in learning and their ability to achieve educational goals (Froebel 1826). Following Froebel's educational work, the Montessori school of thought began to develop in 1889 when Dr Montessori ran her first school (Wood 2012). The Montessori approach started with the combination of everyday activities such as self-care; cleaning and tidying; the development of gross motor skills; and the opportunity to play (Wood 2012). The current approach of the Montessori method focuses on the inner drive of the child to participate in activities which allow them to develop and learn; the presence of the teacher is as a silent observer and guide rather than active director; the environment is set up in order that the child has the opportunity to learn (Montessori 2008). This is considered an approach which allows children to learn more effectively through the use of play and child-led activity (Montessori 2008). Despite the continued presence of schools and pre-schools using this approach, there appears to be limited current research providing evidence for its success.

Several other early years teachers and researchers have promoted the benefits of play within the classroom. The McMillan sisters founded outdoor nurseries in 1911 for early childhood education in the United Kingdom, and theorised that outdoor free play was a means of expression and allowed application of knowledge and understanding (Knight 2013). This was argued to be a successful approach (Knight 2013). The crossover between play and education by early educational theorists suggested that play was a fundamental and unavoidable aspect of educational settings (Knight 2013, Montessori 2008).

Following the development of both Montessori and nursery schools, Reilly (1974), an occupational therapist, argued that play is a primary occupation and therefore the premise of learning for all children. Reilly (1974) suggested that children were driven to play by a curiosity which enabled learning through a process of exploratory, competency, and achievement behaviours within play. The achievement behaviour of play and learning was focused around external competition and structure (Reilly 1974). More recently, this understanding of play for learning has developed to focus upon play without structure for children's learning (Sylva et al. 2004, Bruce 2011). Despite this, the use of educational toys and items such as toy letters are recommended within early childhood education policy to encourage children in play which develops their learning (Sylva et al. 2004).

The research and theory presented above emphasises the focus on play within education practice and policy for children across the last few centuries. Although play was previously seen as a structured activity to promote educational achievement (Froebel 1826, Montessori 2008); more recent schools of thought suggest that exploratory learning and free play are more beneficial to children's cognitive development (Bruce 2011). Researchers such as Janet Moyles, a play and early years consultant, continue to contribute to play theory and literature within the field of education. 'The excellence of play' edited by Moyles (2010) promotes the '*central role of playful learning and teaching worldwide'* (Scott 2010, xvii). Play therefore appears to continue to have a central role within educational theory and literature in terms of its influence of children's learning, particularly in early years settings.

2.3.3. Developmental stages of play

The links between children's play and general development have been referred to by developmental theorists (Parten 1932, Piaget 1951, Isaacs 1933, Erikson 1950). It is clear that much of the literature surrounding the concept of play is based within development theory. Early theorists such as Parten (1932) discussed different types of social participation in play: Parten discussed solitary, onlooker, parallel, associative, and co-operative play types. This suggests a child participates in play on their own, through watching, through playing alongside others, and then through playing with others (Parten 1932). Children are thought to be able to participate in play not just through internal control but through co-operative control (Parten 1932). Parten's theory particularly around co-operative control may suggest that children with physical disabilities who cannot physically control play may be able to control their play through the co-operation of a playmate.

Several developmental theorists provide varying stages of play that children are thought to progress through. Piaget (1951), following a series of experiments and observation of children, suggested that children engage in sensory-motor practice play; pre-operational symbolic play; concrete operational play of games with rules; and then formal operational play as they progress into adolescence. Piaget (1951) based many of his observations of play stages upon his three children; the use of such a small sample which is limited in variation, together with potential bias as a parent, brings to question the reliability of Piaget's play stages. Despite this, the research, which focused primarily on the development of cognition, provides a helpful insight into progression through play stages as a part of children's learning (Piaget 1951). Isaacs (1933), in contrast, suggested a psychoanalytical approach to play in which play is argued to provide the opportunity for fantasy and the development of emotion, imagination and self-expression. This continues to highlight the complexity of play and the variation that occurs from the perspective of different individuals and theorists.

Within the 1960s and 70s development theories challenged the set progression through stages argued by psychologists such as Piaget and moved towards a more broad approach. Erikson (1950) focussed upon emotional development suggesting that children participate in exploration of the body and senses, cause and effect and then play which influences others. Mary Sheridan, a developmental paediatrician, suggested in 1977 that the development of play is less rigid than suggested by previous theorists and summarised play as an activity in which children have freedom, choice and control (Sheridan et al. 2011). Sheridan particularly emphasised children's spontaneous play and drive to engage in play activities. Observations of children's spontaneous play led to a record of play activities children appear to participate in at different ages (Sheridan et al. 2011). Sheridan was interested in the development of children with disabilities and therefore observed play in order to note differences between children who were typically developing and those who had disabilities. Sheridan's focus on observing play is limiting in terms of defining and understanding play as it is based upon her own perspective as a theorist and researcher rather than the perspective of the children. Although observation can enable some understanding of play as a concept for each child it is also essential to consider the child's perspective in defining play (Kellet 2005). The research exploring children's own perspectives of play is discussed later within this chapter (2.5.2, 2.6.5).

In 1950 Erikson published 'Childhood and society' writing from the fields of psychoanalysis and human development. Erikson was both a clinician and an academic; his theory portrays the multiple influences through thoughts, bodies, and social interactions which enable the development of identity (Erikson 1950). Erikson discusses this in the context of play. Within Erikson's (1959) book *'Identity and the lifecycle',* the development of the ego, sense of self, is discussed in more detail. Erikson (1959) suggests that the development of ego identity is about creating an awareness of ones 'selfsameness' (p22). This selfsameness is understood as a consistency and recognition across time of one's individual characteristics which make up oneself and mean that one is always seen as the same person (Erikson 1959). This can occur through practicing role play and learning to understand play in relation to others (Erikson, 1950).

The theorists discussed within this section: Parten, Piaget, Isaacs, Erikson and Sheridan all made significant contributions to child development literature and the understanding of play that is current within practice (Parham & Fazio 2008). It is clear, however, that each definition and understanding is shaped and influenced by the setting or perspective of the theorists. The need for an understandable definition of play and various attempts to do this are discussed below.

2.3.4. Play definitions

Several authors have made attempts to define the concept of play in order that this can be more easily understood (Reilly 1974). Huizinga (1944) suggested that play is a free activity which absorbs the player, it occurs outside of ‘ordinary’ life, it is not serious and there is no profit. Vygotsky (ca. 1930-1934) defines play as an activity which is desired by the child, has rules and makes use of imagination. Rubin et al. (1983) places a similar emphasis on the child’s desire to play, suggesting that children are intrinsically motivated to participate in a play activity, the focus is not on an end product and it is free from external rules. Similar definitions are offered by more recent researchers such as Gray (2013) who suggests that play is self-chosen, intrinsically motivated and that the child is an alert and active participant who makes use of mental rules and imagination within the activity.

2.3.5. Occupational therapy and play theory

Occupational therapists using play in their practice have contributed to the development of play theory. Mary Reilly wrote ‘Play as exploratory learning’ in 1974 as discussed above; this is a valuable contribution to the field as it addresses many aspects of the development of play and the difficulties in definition. Reilly’s (1974) approach is however, based upon learning and therefore the focus is that a child with a disability needs to have their play facilitated in order to learn and develop. In order to broaden the approach to play within occupational therapy, away from an emphasis purely on development and learning, Ferland (1997) developed the Ludic Model. This model takes a biopsychosocial approach to play and has a focus upon the concept of pleasure during play activity suggesting that: an interaction between interest, attitude and action shapes a play activity, leading to pleasure in action, and capacity to act, which in turn enhances autonomy and wellbeing (Ferland 1997). This model suggests that an attitude of pleasure and interest in an activity, in which a child leads or directs its acting out, constitutes play (Ferland 1997). For example, within practice, a child choosing to play with their favourite toy, laughing and demonstrating pleasure when the therapists manipulates it as directed by their gaze, could be defined as play.

Since the development of Reilly’s theory and the Ludic model of play occupational therapists have conducted research to assess and understand participation in play for children with disabilities (Chiarello et al. 2006). The literature appears to overwhelmingly suggest that children with disabilities cannot participate in play as much as their typically developing peers and need intervention to improve play skills (Okimoto et al. 2000, Chiarello et al. 2006, Imms 2008, Imms et al. 2017). The emphasis within the literature is that the higher the level of physical disability the less children experience participation (Imms 2008, Imms et al. 2017). Chiarello et al. (2006) used the Test of Playfulness, an observation based play assessment, to observe the extent of play occurring in video recorded parent-child interactions and suggested that levels of playfulness for the children with physical disabilities were below the average norms for the scale. Despite seemingly conclusive results it is important to note that a small study population was used and the research is based upon an observational tool.

As seen within the discussion above, play experience depends upon the perspective of the player, it is therefore difficult to adequately capture this experience without asking the players perspective. Similar studies have hypothesised that limited playfulness for children with disabilities may be due to poor parent-child interactions (Okimoto et al. 2000). Again, children with disabilities were seen to have lower playfulness scores than their typically developing peers; following intervention, either with neurodevelopmental treatment or mother-child interaction education; the mother-child dyads who had disabilities were found to have improved test of playfulness scores (Okimoto et al. 2000). Okimoto et al. (2000) concluded that the goal of enabling children to express their inherent playfulness may be best met through parent-child interaction intervention. The findings would suggest that the Test of Playfulness captures a particular type of play experience that is improved by parent-child interaction intervention. There is no sound evidence that suggests this is causally linked to each child’s experience of play. It is therefore important to ensure that play from the perspective of the child is adequately explored before it is defined and used as a measurement.

Some occupational therapy researchers seem to have expanded upon the traditional perspective of play and what it means for children with disabilities. Researchers such as Kangas et al. (2012) and Eisele & Howard (2012) have suggested that children with autism can play through sensorimotor and repetitive play. Several researchers have explored the introduction of powered mobility to enable children with physical disabilities to access exploratory play (Langmead 2012, Sonday & Gretschel 2016). The opportunity to participate in play has been highlighted as an essential everyday activity for children with disabilities; it is recognised that further research is needed to understand the experience of play for these children (Buchanan & Giovacco Johnson 2009). As discussed by Dunford and Bannigan (2011) it is recognised that participation of children with disabilities is difficult to measure and needs to be further explored. In additional to this, Canadian occupational therapy guidelines based on literature, clinical practice and theory, discuss occupational engagement, suggesting that an individual can be fully engaged and participating within an activity despite limited performance (Polatakjo et al. 2007). It is therefore possible that children with high levels of physical disability can participate and engage within an activity such as play despite limited physical performance. This would suggest that the experience of play for such children is likely to be difficult to observe as an outsider and therefore hard to capture and measure within observational studies.

More recently, Anita Bundy, an occupational therapist and researcher, has developed a model which she suggests captures the essence of play (Bundy 2012). Play is described as a balance of internal control, intrinsic choice and free suspension of reality, all within the ‘frame’ of play (Bundy 2012). Bundy’s model of play is presented within a scale (figure 2): the extent to which an activity has internal control, choice and freedom and the frame of the activity determines whether the balance tips and it can be defined as play. Within the occupational therapy field, Bundy’s definition of play, which informs the Test of Playfulness, is often discussed and used within practice. Occupational therapists understand play to be an important everyday occupation; various play based assessments and interventions are used within the field with the aim to improve children's play skills (Stagnitti & Unsworth 2000).

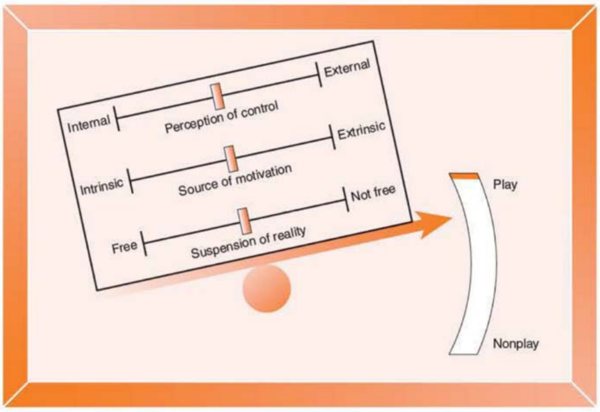


Figure 2 Elements of play. Taken from: Bundy, A. (2012). Children at play: can I play, too? In: Lane, S.J. & Bundy, A.C. (eds.) Kids Can Be Kids: A Childhood Occupations Approach. Philadelphia: F.A. Davis Company, pp. 28-43.

2.3.6. Play assessments

Play assessments such as: the test of playfulness (TOPs) (Skard & Bundy 2008), the Revised Knox Preschool Play Scale (RKPPS) (Knox 2008), and the Child Initiated Pretend Play Assessment (ChIPPA) (Stagnitti 2007) have all been developed by occupational therapists. These assessments aim to capture and assess a child's ability to play. The focus of each assessment is slightly different. The TOPs assessment aims to observe the characteristics of a child's play based on Bundy's model of playfulness and the extent, intensity and skill with which these are carried out (Skard & Bundy 2008). The ChIPPA aims to assess children's ability to engage in both pretend and symbolic play (Stagnitti 2007). The RKPPS is helpful in enabling therapists to observe and assess development levels through free play; it has been validated for children with disabilities (Knox 2008).

Although each assessment has been standardised and validity and reliability assessed, it is possible that they are not measuring what was originally intended. Children with physical disabilities often score low in play assessments such as the TOPs (Okimoto et al. 2000) and the ChIPPA (Pfeifer et al. 2011). An early study by Harkness & Bundy (2001) found that children with physical disabilities and typical cognition had similar scores to their typically developing peers in the TOPs; the fit between the scores however was not statistically significant and the children with disabilities were often observed in a more supportive environment. They suggested that some differences were found between children with Cerebral Palsy and their typically developing peers in terms of lower scores on remaining engaged, and higher scores in clowning and joking (Harkness & Bundy 2001).

Harkness and Bundy (2001) provide a useful insight into the ability of the TOPs to capture playfulness for children with physical disabilities without gaining a low score. This concurs with observation in practice which would suggest that children with disabilities do have the ability to participate in play. It would appear that the physical nature of each assessment with the need for children to manipulate and interact with objects or direct others and demonstrate their play can provide a false picture of the child's ability to play. Indeed, within Harkness and Bundy's (2001) study some children with physical disabilities scored lower than their typically developing peers. Poor scores within such assessments are intended to prompt therapists to provide intervention to support the development of play skills (Bundy 2012). However, it may be that if the assessments are not actually measuring a direct experience of play children are being taught skills, or being told they need to improve their play skills unnecessarily. The challenge for children with physical disabilities is that their play is not always as observable as it may be for their typically developing peers, this was an area which needed to be addressed within research.

2.3.7. Playfulness

Both Howard (2002), an academic in the field of psychology and education, and Pollock et al. (1997), an academic and occupational therapist, define playfulness as an attitude or approach which makes an activity feel like play. Bundy (2012) an occupational therapist, and lead researcher within the field of play and occupational therapy, concurs that playfulness is about the approach to play and therefore playfulness is dependent upon the child's internal control, intrinsic motivation, suspension of reality and ability to frame the activity as play.

There are five aspects of play which are discussed within the literature: approach, skills, environment, activities, motivation (Bundy 2012). Play is a combination of all of the five aspects whereas playfulness purely focuses upon how a child approaches play.

2.3.8. Play and leisure as separate concepts

The International Classification of Functioning, Disability and Health: Children and Youth version (ICF-CY) (World Health Organisation, 2007) identifies play as an important part of a child's leisure activities. Play, leisure and recreation are all concepts which have a degree of overlap, however, it is important to understand and define each of these. Clear definition of concepts enables clarity within the research process particularly when exploring a specific phenomenon. Play is typically marked out as an internally motivated behaviour which can occur during both work and leisure often observed by having a lack of structure (Mclean & Hurd 2011). Leisure is defined as time separate from work and self-care and can involve a variety of activities such as reflection, relaxation or spiritual experiences as well as organised activity (Mclean & Hurd 2011). A recent systematic literature review by Powrie et al. (2015) has explored the experience of leisure for children with physical disabilities. The focus on leisure participation, rather than directly play participation, creates limited transferability to the current research. Despite this, Powrie et al. (2015, p.993) suggest that *'fun', 'freedom', 'fulfilment'* and *'friendship'* were important components of the meaning of leisure and it is anticipated that there may be some similarities to the meaning of play. Recreation is typically seen as a voluntary activity which occurs during leisure time, such as playing football with a team (Mclean & Hurd 2011). This research project is focused upon children's experiences of play; within the search strategy the terms 'leisure' and 'recreation' have been used to ensure all potential articles are included, however these have then been screened in order to assess their relevance to play.

2.3.9. Defining play

In summary, following a literature review and exploration of the variety of play definitions, the concept of play used within the rest of this research is defined as: an activity in which an individual has freedom, choice and control which is framed by play cues.

2.4. Play as an occupation

2.4.1. Occupation

People are occupational beings; occupation is defined as the activities that people both choose to do and have to do out of necessity (Wilcock 2007); it is intrinsically linked to an individual’s health and well-being (Wilock 2007, Hinojosa & Blount 2014). Wilcock (2007), both an occupational therapist and occupational science researcher, has suggested that the concepts of *doing, being, belonging and becoming* are all part of the experience of occupation which enables health. Occupational therapists aim to use a client-centred approach to understand, utilise and enable clients to participate in meaningful occupation that will enable development in health and well-being (College of Occupational Therapists (COT) 2010). Participation in meaningful activities often occurs within play and leisure based occupations for children (Dunford et al. 2016).

2.4.2. Play as a primary occupation

Play is thought to be a primary occupation for children (Stagnitti 2004, Chiarello et al. 2006, Brooks & Dunford 2014) and is therefore considered by children’s occupational therapists as an indicator of health and wellness (Chandler 1997). Lester & Russel (2008) support this in suggesting that play as part of a child’s everyday life promotes a sense of mastery and motivation. The importance of play as a primary occupation is highlighted by its inclusion in the ICF (WHO 2007). Furthermore, the United Nations convention of the rights for the child, article 31 states that every child has the right to play (UNICEF 1989). In addition, the United Nations published General Comment on article 31 in 2013; this emphasised the importance of the right to play as a core aspect of all children’s participation. Play is therefore an essential consideration for children’s occupational therapists who are concerned with meaningful occupations for their clients.

2.5. Play for typically developing children

Play is widely known to have developmental benefits for all children (Ginsburg 2007, McInnes et al. 2009, Brooks & Dunford 2014). The developmental benefits of play will be discussed in the next section before exploring the experience of play for typically developing children. Several studies, predominantly in the education field, have researched play from the perspective of typically developing children (King 1979, Wing 1995, Howard 2002, Howard et al. 2006, Rogers & Evans 2006, Gmitrova et al. 2009, Berkhout et al. 2013, King & Howard 2014) these are summarised in figure 3 (p.44).

2.5.1. Developmental benefits

Throughout history theorists and researchers as early as Plato have suggested that play is an essential component of healthy child development (Frost 2010). The developmental benefits of play are often cited within the research literature (Childress 2011, Fisher 2008, Ginsburg 2007, McInnes et al. 2009).

Experimental studies such as those by McInnes et al. (2009) found that children were able to complete a jigsaw puzzle significantly faster in playful conditions compared to restricted conditions alongside an adult. The conditions were based upon research by Howard (2002) where children reported an activity felt more like work if it was at a table and an adult was present. McInnes et al. (2009) therefore created the playful condition as completing the puzzle on the floor and without an adult present. This study is helpful in providing some evidence as to the benefit of play in enabling problem solving skills in completing the puzzle. Despite this, there are some limitations within the research, such as the possible influence of the presence of the adult researcher in measuring the puzzle completion. There is a need for further experimental studies that aim to capture the benefits of participation in activities which the children report as playful.

A further research-based study used surveys with mothers and child development professionals to explore types of play and its developmental benefits (Fisher 2008). Child development professionals tended to deem unstructured activities as playful and structured activities as much less playful; mothers, on the other hand, were more likely to deem both structured and unstructured activities as playful (Fisher 2008). Children are often reported to see an activity as less playful when an adult is present (Howard 2002); within free play children are also recognised to have more control over their own actions (Ginsburg & Runswick-Cole). When considered in relation to the definition of play as an activity of freedom, choice and control (Sheridan et al. 2011, Bundy 2012) it would appear that the research discussed above suggests less structured play is more beneficial to development. As health professionals have a need to be aware of the evidence base (Bennett & Bennett 2000) it is possible that they have a broader perception of the research above and therefore an alternative view to parents. Where parents perhaps do not have the knowledge presented within the literature they may tend to prefer or equally value structured play activities as these are easier to define and implement with their children.

Although some research studies exist (Fisher 2008, McInnes et al. 2009), much research discussing the developmental benefits of play is based upon opinion (Ginsburg 2007, Whitebread 2012). Although opinion based information does not have ensured validity (Bennett & Bennett 2000), the combination of expert and parent opinion should not be taken lightly. This is reflected within guidelines for evidence based practice which have suggested that a combination of experimental research, clinical reasoning and expert opinion lead to best practice (Bennett & Bennett 2000).

Researchers and policy makers within the field of play have reviewed the literature and developmental benefits of play (Ginsburg 2007, Goldstein 2012, Whitebread 2012). Ginsburg's (2007) article, written in collaboration with several psychologists, and based upon a review of the literature, suggests that play enables creativity, mastery, healthy brain development, social skills, problem solving, and learning. This is supported by Goldstein

'Every child has a right to play' (UNICEF 1989)

'Identifying play as one of the fundamental forms of human relating keeps alive the prospect of understanding the importance of transformative, consuming activities in the human quest for self-realization. Play is not trivial endeavour. It is necessary for comprehending what we can be and what we can do.'
(Henricks 2015, p15)

Box 1 Summaries of the necessity of play

(2012) who discusses benefits of play in terms of neurological development; reduction of stress and promotion of joy; increased empathy and sharing; and increased co-ordination and motor skills. Furthermore, Whitebread (2012) discusses the correlations between development and playfulness in mammals, the benefits of play in developing language and the purpose of play for self-regulation. In addition to this, theorists such as Henricks (2015) suggest that play is distinctive in children's development of their sense of self. These researchers argue that when children have the space and opportunity to play they are able to engage in problem solving, negotiate conflict, practice adult roles, and express themselves in a way that is not possible within other activities (Ginsburg 2007, Henricks 2015).

There is overwhelming evidence that play is beneficial to children's social, emotional, cognitive and physical development (Brooks & Dunford 2014, Fisher et al. 2008, Ginsburg et al. 2007, Goldstein 2012, Henricks 2015, Whitebread 2012, box 1). Play is recognised as beneficial for children both with and without disabilities (UNICEF 1989). All young children participating in play often need individualised scaffolding support to play (Jung & Recchia 2013); this can enable the children a greater sense of participation. There appears to be few research studies which translate the benefits of participation in play directly to children with disabilities, which do not have a focus on specific play intervention. However, reviews such as that by Childress (2011) suggest that collaborative play is beneficial for all disabled children. This together with the United Nations right for every child to play (UNICEF 1989), leads to the assumption that the benefits of play will be applicable to all children.

2.5.2. Children's experience

The studies listed in figure 3 (p.44) all explore the experience of play for typically developing children. Children emphasised the importance of play being an activity chosen by themselves (King 1979, Wing 1995). One aspect of choosing the activity was that children often reported participation without an adult present as more playful (King 1979, Howard 2002, Howard et al. 2006). This is supported by findings of Rogers and Evans (2006) who observed that children became frustrated when an adult tried to end the play or move them from the play situation. This appears to reflect children's need for control over their play activity; another possible example of this is that children find an activity more playful when it occurs not sitting at a table (Wing 1995, Howard 2002). This is supported by the combination of both observational and interview methods used in the above studies which enabled the children to express their experience and understanding of play. Each child's desire to gain a sense of choice and control over play concurs with play theory which suggests that internal motivation to participate and internal control strongly influence a child's understanding of an activity as play (Sheridan et al. 2011, Bundy 2012).

Rogers and Evan's (2006) found that children had a clear idea of what was real and what was pretend when participating in role play; children are often observed to participate in pretend play of everyday tasks such as household play (Gmitrova et al. 2009). Although based within different cultures and using different methods both studies provide support for each other in the presence of pretend play. This is further supported by the idea of play as a suspension of reality, which is widely discussed within play theory, and freedom for children to express themselves outside of this reality (Skard & Bundy 2010).

Within studies exploring children's experience of play, children reported that they play a lot (Ceglowski & Bacigalupa 2007); this supports the widely accepted view that play is a primary occupation for children (Goldstein 2012). Several kinds of play were mentioned across the studies looking at children's experience: art and games play (Berkhout et al. 2013); pretend play (Rogers & Evans 2006); reading and storytelling (Ceglowski & Bacigalupa 2007); object play (King & Howard 2014); and physically active play (Barnett 2013). The emphasis on active play for some children (Barnett 2013) is likely to differ for children with physical disabilities and will therefore be important to explore. All of the above studies have different approaches to understanding children's experience of play; although some used conversation with children to gain their understanding (Rogers & Evans 2006, Ceglowski & Bacigalupa 2007), they have some limitations. Ceglowski & Bacigalupa (2007) were focusing on experiences of day care rather than experiences of play and therefore it is unclear as to the extent to which children's discussion captured their play experience. Rogers & Evans (2006) ethnographic study was based within the school environment; this was a limiting factor as being at school, where the focus is often on 'work', may have influenced how children talked about play. Further to this, interviews with children were based on informal conversation, therefore, children may not have had the focus or time that a formal interview set up may provide to fully discuss their experience of play. Despite this, the combination of studies, across different settings and cultures, reflects the diversity of play experience and possibility of the experience of different kinds of play for all children.

Play was often associated with positive effect; in several of the studies children reported play as fun and enjoyable (Wing 1995, Barnett 2013). Participating in activities alongside or with another child were considered by the children to be part of play, this reflected parallel and cooperative play types (Howard et al. 2006). Turnbull & Jenvey (2006) found that 9-12 year olds experienced pretend play when it occurred with props and at least one other player. Although this is based on observation and not discussion with children about their experience, it would appear that the presence of friends or peers is important to children's participation in play. This is currently not widely explored within the literature and further research to ascertain the influence and necessity of others within play experience would be beneficial. This research should use a combination of research methods, such as both observation and interviews, in order that children's experience can be accurately captured.

A variety of methods have been used for these studies; some are based upon observation (Berkhot et al. 2013, Turnbull & Jenvey 2006, Gmitrova et al. 2009); some interview (Barnett 2013, Howard 2002, Howard et al. 2006); some play diaries (King & Howard 2014); and some a combination of the above (King 1979, Wing 1995, Rogers & Evans 2006). Methodologies such as play diaries and questionnaires have been used to collate children's self-reports of play (King & Howard 2014, Turnbull & Jenvey 2006). However, the use of tick boxes and small open response spaces provided surface level data without the opportunity for further questioning which may have allowed for a greater depth of understanding of the child's perspective of play. The most rigorous studies in gaining an understanding of children's experience of play appear to use a combination of observation and interview in order to collect data (King 1979, Wing 1995, Rogers & Evans 2006). Within these studies the opportunity to reflect on and discuss with the children play activities, which were also observed, enabled a greater understanding of children's play. The understanding of play as an activity allowing freedom, choice, and control (Sheridan et al. 2011) is closely reflected in children's descriptions of their experience of play within research.

2.5.3. A work-play dichotomy

A small number of studies have looked at typically developing children's experience and understanding of play, predominantly from an educational perspective (King 1979, Wing 1995, Howard 2002, Howard et al. 2006, Rogers & Evans 2006, Gmitrova et al. 2009, Barnett 2013, King & Howard 2014). Although it is important to consider the presence and use of play within an educational setting it appears that most studies became focused on a discussion of whether an activity was considered play or work.

Howard (2002) and Howard et al. (2006) used the activity apperception story procedure in order to give children the opportunity to sort photographs into categories of play and work, and learning or not-learning. Although this is helpful in determining children's contrasting view of play and work; it provides limited understanding of children's experience of free play. Through creating a work-play dichotomy the definition of play becomes the opposite of work; play, however, can be considered a more complex concept. Wing (1995), when interviewing children, found some described the concepts of work and play as merged; in addition, some activities that the teachers described as play, the children discussed as work. It is possible that this is because of the presence of an adult (Howard et al. 2006); or the influence of the school environment on each child's experience (Roger & Evans 2006). Furthermore, as described by Sheridan et al. (2011), children's play activities, such as building lego, could be seen by an onlooker as serious or work-based, even when they are described by the child as play. This illustrates that the concepts of play and work can overlap. Therefore, in order to consider an in-depth understanding of experience of play, a work-play dichotomy is not helpful.

2.6. Play for children with disabilities

Several researchers and theorists have suggested that any given play experience varies according to the perspective of the player (Bundy 2012, McInnes et al. 2009, Chandler 1997). It is therefore important to consider that play for children with disabilities may look different to the play of their typically developing peers. Some researchers support this in suggesting that children with disabilities may experience play differently (Goodley & Runswick-Cole 2010, Graham et al. 2015). A systematic literature review by the current researcher considering the perspective of children and young people with physical disabilities and their experience of play has been published in the Child: Health, Care and Development Journal (Graham et al. 2017f appendix 1 [enclosed with permission]). This provides a summary and critique of current research exploring the experience of play for children with disabilities. The following section will discuss studies focusing on this experience both from the child's perspective and from the perspective of parents, health care providers and researchers. These are summarised in figure 4, page 45.

2.6.1. Retrospective studies

It is recognised that it may not always be possible to ask children about their experience due to age or level of disability. Researchers such as Sandberg et al. (2004) attempted to use a retrospective method to explore the experience of play through interviewing adults with disabilities. Sandberg et al. (2004) found two themes across their 15 participants; that play was seen as both participation and exclusion. The participants discussed barriers to play which led to their exclusion from activities, but also peer adjustment and self-adjustment to play which enabled their participation (Sandberg et al. 2004). The experience of the adults participating in this study appears to have both positive and negative connotations for play which would be helpful for health care professionals and carers to consider for children with disabilities. All adults participating in the study appeared to value their play experiences and were able to discuss play across a variety of environments and situations (Sandberg et al. 2004). It is important to note that as social interaction and culture changes over time, the retrospective experience of play may be far from the experience of a disabled child living in today's society and culture. It is possible that the increased emphasis on the International Classification of Functioning (WHO 2007) and the focus on participation has shifted the experience of children with disabilities as they participate in play today. Although Sandberg et al.'s study (2004) provides some helpful insight into the multidimensional concept of play, it is difficult to capture the true nature of play through a memory of it. Leisure studies literature indicates that adults have difficulty in accurately remembering childhood events and experiences when participating in retrospective studies (Snelgrove & Havitz 2010). It therefore appears that retrospective studies can only provide a limited understanding of disabled children's experience of play.

King (1979)

- Kindergarten children in 4 classrooms
- Observation of classroom activities and then interviews about activities
- Children appeared to distinguish between work and play.
- Work involved the teacher
- Play was chosen by the child and undirected by the teacher.
- Further research needs to further explore children's definition of play in relation to participation in school.

Wing (1995)

- 28 Kindergarten and first and second grade children
- Observation and in-depth interviews
- Children distinguished between work and play
- Play activities were considered fun, something you 'can' do, chosen by the child and often not sitting down.
- Work activities were considered as something you 'have to', often with the teacher present, and requiring effort. Reading and writing were often seen as work.
- Further research would look at what happens if the teachers become co-players and co-investigators within the classroom.

Howard (2002)

- 111 children aged 3-6yrs across 6 sites
- Activity Apperception Story Procedure (AASP)
- Children sorted 26 photos into play/work and learning/not learning.
- Children then were asked to re-categorise and explain their choice for a smaller number of photos.
- Presence of an adult, space and constraint (e.g. at a table or on the floor) and type of activity (e.g. blocks or maths book) influenced children's choice of work or play.
- Based on pilot study where 28 children were asked what they were doing in a classroom setting.
- Some unexpected definitions were used to explain pictures e.g. 'play is pretending', 'toys are not work' level of choice and level of difficulty.
- There was an association between being in school and needing to work.
- Further research should look at characteristics of activities which may provoke feelings of playfulness.

Howard, Jenvey, Hill (2006)

- 92 children aged 4-6yrs in Australia
- Completion of the AASP as in Howard (2002)
- Photos sorted into 'play/ not play' and as a seperate condition 'learning/ not-learning'
- Children associated teacher absence, parallel and cooperative activity with play.
- Children had no significant social cues that they used to indentify learning/ not learning
- Contrast in results to Howard (2002) is suggested to be due to culture difference in early years education approach.
- Further research needs to identify cues used by children to categorise activities which may provide more opportunity to research the developmental potential of play.

Turnbull & Jenvey (2006)

- 98 children age 9-12 and 38 adults.
- Watched 10 videos and ticked criteria categorising behaviour
- Aim was to look at pretend play vs. activity play
- Pretend play was seen to have the following criteria:non-literality, communication and intimacy, use of toys or props and the presence or more than one player
- Further research could test wether these stand for pretend play
- Suggests that 9-12 yr olds have the capacity to categorise play.

Rogers & Evans (2006)

- 144 children participated in a year long ethnographic study of children's role play in school.
- Data collection included partipant observation, focus group discussion, photos, informal conversation with children, children's drawing and role play scenarios.
- Data was transcribed and field notes underwent systematic content analysis.
- Children were between aged 4 and 5 yrs. They had a clear idea of what was 'pretend' and 'real' in terms of role play.
- Freindships with other children were important in their play
- Children were frustrated and found it difficult when adults wanted to finish the play or remove them from the situation.
- A multi-method approach allowed children's views to be captured.
- Children's active involvement in classroom environment and participation could be gained from further research as to their play.

Ceglowski & Bacigalupa (2007)

- 104 children in America aged 1-18yrs participated in interviews and the opportunity to draw about their day care experience.
- Pre-school children often commented that they 'play a lot'
- Older children aged 7/8 commented less about play and discussed caregivers having 'baby toys'
- Interviews included asking about what the child did/ did not like about day care.
- Reading and story telling were important for pre-school children.
- Discussion over the extent of television watching.

Gmitrova, Podhajecká & Gmitrov (2009)

- 123 kindergarten children aged 3-6 years participating in free-play at school in Slovakia.
- Observed as to type of play that they were participating in-pretend play/ construction play/ dramatic play.
- Children were most likely to particpate in household pretend play.
- Teacher directed play should help teach children more self-sustained creative pretend play.

Barnett (2013)

- development of a play scale for school age children 8-10yrs 47 children helped to examine a draft of the scale
- 25 items that underwent factor analysis and were seen to be valid and reliable as a measure of play
- Items which children identified as characteristics of play inlcuded 'I like to be active', ' I get involved in what i'm doing', 'I enjoy time off school', 'I enjoy being alone'

Berkhout , Bakkers , Hoekman & Goorhuis Brouwer (2013)

- 877 children aged 4-6yrs in the Netherlands.
- Free play time underwent viedo analysis.
- Different play types were categorised. Make believe play and arts and games ere observed most in this age group.
- Pretend play was observed to take time to engage in.

King and Howard (2014)

- 22 children in afterschool clubs (age 6-11yrs)
- Play detective diary (self report free play questionnaire) tick boxes and space for drawing/ writing.
- Children percieved more choice when playing alone.
- Object play was most popular
- Further research would benefit from looking at factors influencing choice.

Figure 3 What do typically developing children think about play? A summary of research

Pollock et al. (1997)	Nabors & Badawi (1997)	Buchanan & Cooney (2000)	Tamm & Skär (2000)	Sandberg et al. (2004)	Ahonen-Eerikäinen et al. (2008)	Kramer (2009)	Nind et al. (2010)	Matthews & Rix (2013)
• Interviews of 20 13-18 yr olds with and without disabilities. 10 with physical disabilities (CP, Spinal Bifida and Juvenille arthritis) • Highest level of disability was participant in powered chair. All able to communicate vocally. • Themes surrounding the nature of play, environmental barriers and supports and personal factors. • Play was seen as fun, enjoyable, relaxing and something you do not have to do. This was discussed in relation to work. • Some barriers to participation and choice: it usually was not me who chose because if I ever did get someone to play with, I usually said ‘Ok, you’re playing with me, that’s good enough, like, you choose.’ • Further research needs to look at the emerging concepts of play.	• Observation of 3-5yr olds in the playground, 45 typically developing and 19 children with special needs (3 of whom had CP) • Snap shot observations of the childrens play for 10 seconds- play was then categorised into playing alone (included parallel play), playing with a teacher, and playing cooperatively with peers • Children with special needs were found to engage in more alone and teacher play and less cooperative play than typically developing peers. • Ethnographic research would be useful to look at why children with additional needs engage in less cooperative play. • Strategies to improve social skills need to be developed.	• Toddlers 30-32 months • Home environment • Case study (3 children) • Imaginative play acted out by care giver. • Video observation of mother- child interaction. Played back and discussed with mother. • Child with Cerebral Palsy was able to participate in peer interaction and play through communication with his mother who could support a dramatic play scenario. • Play can depend upon context, children may be able to more readily play in a familiar home environment.	• Interview/ observation of 5 girls and 5 boys aged 6-12yrs with physical disabilities dependent upon walking aids. • Children's accounts indicated a model of three types of play: Play with friends, play alone, play with adults. • Child indicated they were active players when watching play. • Further research needs to look at the way children feel they are participating in play as an onlooker. Further research also needs to expand upon the population investigated. • Opportunities to initiate play and choose playmates need to be valued and encouraged.	• 15 Adults aged 25-76 with visual disabilities, motor disabilities, or Asperger syndrome. • Individuals were interviewed about their past play experiences. • Personal, social and environmental components influenced participation or exlusion in/ from play. • For individuals with physical disabilities play that involved movement was important. • Adults/ assistants could interfere with play and become a barrier not facilitator. • Play is a multidimensional concept, play described by participants contrasts to play focusing on development and learning.	• Qualitative pilot study about the use of a virtual musical instrument for children with CP. • 6 children aged 5.5-10yrs participated all had at least one voluntary movement. • Case study approach- music therapy sessions videoed and notes transcribed. • Increased visual, auditory, kinesthetic and self awareness • Improved opportunity for actice participation in play	• Observation of 2 children with CP within a free play situation in a classroom/ playground • Both children with a high level of physical disability- both unable to stand unaided, one unable to sit unaided. both able to move around floor. • 45 minute observation of non-verbal social interaction. • Interaction was mostly aimed at the teacher or an adult. Children used eye contact, gesture, verbalisations, posture and touch most. • Indicates that children with CP can engage in free play • Further research needs to address play in different environments and the benefit of interactice play opportunities such as dance/ movement therapy.	• Observation of 3 4yr old children with learning disabilities within different environments. • Observations videoed and then coded and qualitatively analysed according to factors such as touch, gaze, facial expression, body orientation. • Children's enviornment has an impact upon their social participation within activity • The child's voice and experience is important to consider within a social model of disability. This 'voice' may be seen through observation within social context and environment.	• Ethnographic study of early intervention with two children with Downs Syndrome across 5 months. • Looking at child agency, play and creativity as supported and developed by parents and professionals. • Several interviews with family and professionals. Photos taken of children playing and accounts writen in first person of each child's play. • Children were seen to have increased agency and choice of activities dependant on context. Instruction and led play decreased child agency • Reconceptualising everyday play activities could help foster creativity and develop child agency.

Figure 4 What do children with disabilities think about play? A summary of research

2.6.2. Play deprivation

Some researchers have suggested that children with disabilities face play deprivation as a secondary disability and this can have a negative impact upon their health and wellbeing (Missiuna & Pollock 1991). Two levels of deprivation are discussed. Firstly, direct deprivation and inability to participate in an activity because of a sensory motor impairment; for example, a child who is blind would be unable to participate in play with lights and visual play (Missiuna & Pollock 1991). Secondly, play deprivation and secondary disabilities in social, emotional and psychological functioning as a result of the experience of disability (Missiuna & Pollock 1991).

It is suggested that children with physical disabilities are more likely to spend time in self-care and passive activities and therefore have less time for play (Missiuna & Pollock 1991). This is supported by a review of participation of children with Cerebral Palsy which suggests that although children do participate in play they also often experience exclusion (Imms 2008). Social exclusion and bullying is reported by children with Cerebral Palsy to be experienced in the school setting (Lindsay & McPherson 2012). Children with physical disabilities are less able to independently mobilise towards a play activity, for example, they may be unable to go to the park independently or fetch a toy (Missiuna & Pollock 1991). This is emphasised by the United Nations General Comment 17 (2013) on the rights of the child, which suggests that children with disabilities are one of the populations of children at risk of not being facilitated in their right to play. Missiuna and Pollock (1991) summarised barriers to play for children with physical disabilities as: limitations imposed by caregivers, physical and personal limitations of the child, environmental barriers, and social barriers. It is suggested that occupational therapists have a role in enabling children to have greater opportunity to participate in free play and supporting parents in this (Missiuna & Pollock 1991).

Missiuna & Pollock (1991) provide a helpful overview of the potential barriers that occupational therapists can recognise for children with physical disabilities facing play deprivation. There are some limitations to the article in that it is a combination of opinion and research literature which limits its trustworthiness. The article was written over 25 years ago and few researchers have specifically addressed play deprivation for children with physical disabilities more recently. It is more than likely that some of the barriers discussed within the article will have changed with societies increasing awareness of disabilities and move towards a social model of disability (Curran 2013). It is possible that children with disabilities do not face play deprivation and an inability to play as argued by Missiuna & Pollock (1991); but rather their play experience is different to the experience of other children.

2.6.3. Observing play

An alternative method of understanding the experience of play for children with disabilities is through observation (Nabors & Badawi 1997, Buchanan & Cooney 2000, Kramer 2009, Nind et al. 2010), this provides the opportunity to explore children's play when they may not have the necessary language to communicate their experience. Nabors and Badawi (1997) and Kramer (2009) both observed children within an educational setting and found that children often sought out teacher support in their play. Research also suggests that play for children with disabilities varies according to their environment (Buchanan & Cooney 2000, Nind et al. 2010). In an education setting, two children with Cerebral Palsy were seen to use vocalisations and communication through gaze to participate in play (Kramer 2009). Buchanan & Cooney (2000) observed that a pre-school child with Cerebral Palsy could participate in dramatic play with the support of his mother. The above studies suggest a range of participation experiences for children with disabilities in play (Buchanan & Conney 2000, Kramer 2009).

A variety of observational methodologies were used within the above studies to observe and analyse children's play. Nabors and Badawi (1997) used a snapshot and checklist observation method which allowed for long observation periods but limit depth of data collection. In contrast, Kramer (2009) carried out detailed observation and analysis of the behaviours, vocalisations and social communication between two children. The use of a close, in-depth method led to a rich account of interaction between two children with Cerebral Palsy (Kramer 2009). This would suggest that in-depth observation may enable researchers to more readily capture the experience of play for the children they are observing.

Observation methods have both benefits and limitations in terms of capturing the play experience of children with disabilities. One benefit of using observation is that it provides the opportunity to develop some understanding of the play experience of children who are unable to communicate to researchers. Observation can be carried out within a child's natural setting and may give a more accurate picture of a child's participation than if they are using recall. Nind et al. (2010), in following the social model of disability, attempted to portray the voice of the children with disabilities in their study through using first person to describe observations. Although the first-person account within Nind et al.'s (2010) study was based on recorded observations this provided a limited representation of the child's perspective as it did not consider the experience of the child themselves. The primary limitation of observation in that the child's experience can only be captured through the lenses of the researcher who interprets the data. This provides some insight into children's play experience but it is important to explore other methods which may provide more scope to capture the child's opinion.

Other researchers have used a combination of qualitative methods including observation and note taking of therapy or intervention sessions (Ahonen-Eerikäinen et al. 2008, Matthews & Rix 2013). These studies suggest that both music therapy (Ahonen-Eerikäinen et al. 2008); and practice of play activities (Matthews & Rix 2013) improved the play skills and ability to participate for children with disabilities. Although the studies describe enhanced play, the focus is upon experience of intervention rather than experience of play.

2.6.4. Disabled Children's Childhood Studies

Further research is needed to explore the experience of play for children with disabilities; this is currently only addressed in a small number of studies (Buchanan and Giovacco Johnson 2009). The disabled children's childhood studies approach is a recognised field based upon a social model of disability, children are seen as active participants and capturing their experience is essential (Curran 2013). Within this approach children are recognised not by their impairments but in their participation (Curran & Runswick-cole 2014). The difficulty within the field in relation to play, is that it is challenging to find a method which will capture the experience of play from a child's perspective.

Buchanan and Giovacco Johnson (2009) use the traditional psychoeducational research paradigm and contrast this with the more recent childhood studies paradigm. Buchanan and Giovacco Johnson (2009) discuss their findings within the context of a multiple case study in which videoed play episodes of three toddlers with disabilities, and interviews with their mothers, were analysed. The psychoeducational research paradigm focuses on education and development of children and therefore would interpret the study's findings with a focus on the engagement in free play similar to typically developing peers: toddlers within the study demonstrated an ability to engage in exploratory, manipulative and functional play as well as pretend play (Buchanan & Giovacco Johnson 2009). Mothers were able to facilitate their child's play and follow their lead; one child with Cerebral Palsy was seen to engage in substitute typical pretend play by using symbolic and song play through signing to his mother (Buchanan & Giovacco Johnson (2009). The researchers argue that this paradigm neglects some perspectives of play, namely, the child's experience. The childhood studies paradigm focuses on the everyday world of the child and aims to improve their quality of life (Curran & Runswick-Cole 2014). Buchanan & Giovacco Johnson (2009) provide a contrast by presenting their findings from this perspective, suggesting that children were imaginative and competent players, they often had complexity in their play similar to typically developing peers, but would sometimes need adult facilitation to follow their lead. The contrast between the paradigms demonstrated here highlights the importance of the researcher perspective and the influence this has upon the findings. This thesis concurs with the disabled childhood studies paradigm in which the focus is on the lifeworld and experience of the child (Curran & Runswick-Cole 2014). Further discussion of the researcher perspective, theory, and philosophy of this research is discussed in chapter 3.

2.6.5. The experience of play of children with physical disabilities

Within the literature there are a limited number of studies which directly capture the experience of play of children with physical disabilities (Burke 2012, Egilson & Traustadottir 2009, Gcaza & Lorenzo 2008, Miller & Reid 2003, Mundhenke et al. 2010, Pollock et al. 1997, Ripat & Becker 2012, Schiariti et al. 2014, Skär 2002, Sonday & Gretschel 2016, Spencer-Cavaliere & Watkinson 2010, Tamm & Skär 2000, Young et al. 2007). These studies often only make brief mentions of play from the perspective of the child, often referring briefly to the experience of play as part of a wider discussion of experience of their disability, school, mobility aids or playground use. The studies therefore have limited transferability to the experience of play for children with physical disabilities but are discussed and synthesised further within the systematic review published by the researcher (Graham et al. 2017f, appendix 1). This section will therefore primarily discuss the only two research studies which entirely aimed to explore the experience of play for children with physical disabilities (Pollock et al. 1997, Tamm & Skär 2000).

> *'I think I'm a normal kid, I just happen to have a disability'.*
> (Shikako- Thomas et al. 2009, p825)

Box 2 Quote from an adolescent with Cerebral Palsy

Quotes from participants in other research studies, such as in Shikako-Thomas et al.'s (2009) study, shown in box 2 above highlight that children with Cerebral Palsy can often see their participation in activities such as play as the same as their typically developing peers. Research has emphasised that adolescents with Cerebral Palsy value spending time with friends and choosing the activities they participate in (Shikako-Thomas et al. 2013). Although in general research reports that children with disabilities like to be like their friends, close examination of the research studies discussed below enables a broader understanding of the experience of play for children with Cerebral Palsy. Pollock et al. (1997) carried out semi-structured interviews with 10 young people with physical disabilities in order to gain an understanding of their experience of play. It was suggested that play is a fun, enjoyable and relaxing activity that you do not have to participate in (Pollock et al. 1997).

This suggests that for some adolescents with disabilities play experience is closely linked to the play of typically developing children. Despite this, Pollock et al. (1997) also highlighted within their study some differences in the play experience for children with disabilities. Some barriers to play were reported by adolescents with physical disabilities: they discussed not being able to physically access the playground or play environments; they also discussed social isolation and allowing others to choose the game because they had been given the opportunity to join in (Pollock et al. 1997). This study therefore provides a helpful insight into the experience of some adolescents with physical disabilities. One limitation of Pollock et al.'s (1997) study is that it is carried out with older adolescents who often referred back to play experiences as children. It is possible that that their current experience may have influenced how they perceived their play as they reflected on it. Despite this, interviews of adolescents both with and without a disability enabled some comparison of experience to occur which still provides a helpful insight into the experience of play for children. Further to this, the methods used were rigorous and are clearly outlined within the article (Pollock et al. 1997, figure 4, page 45) – thus improving its trustworthiness.

In addition to Pollock et al.'s (1997) study, one other study has looked at the experience of play from the perspective of children with physical disabilities. Tamm & Skär (2000) used a combination of observation and interview in order to gain a greater depth of understanding of play from the perspective of children. Tamm & Skär (2000) observed and interviewed 10 children with Spina Bifida, Cerebral Palsy, or Polio, the children were age 6-12 years and used walking aids such as crutches or walking frames, some of the children used wheelchairs. Tamm & Skär (2000) chose to use children who could communicate verbally in order to allow for an in-depth discussion and interview to yield sufficient data for analysis. The themes summarised in the findings included: play with friends, solitary play, and play with an adult. Children expressed positive emotions about the opportunity to participate in play, even though it was often on the terms of others (Tamm & Skär 2000); this reflects a similar finding in Pollock et al.'s (1997) study suggesting the possibility of experiencing play with adults for children with disabilities is an important area to consider. The opportunity to play alone was both described in terms of social isolation and as voluntary solitude (Tamm & Skär 2000). Play with adults as an additiofriend was common particularly when children had an adult as a support for them (Tamm & Skär 2000). This is important to consider in light of the expression of play experience by typically developing children where the presence of an adult made an activity feel like it was not play (King 1979, Howard 2002, Howard et al. 2006). This grounded theoretical research appears to have taken a rigorous and trustworthy approach that has led to the development of a theory about the play of children with disabilities. The focus of Tamm & Skär's (2000) discussion remains upon limitations each child experienced in play due to their disability, rather than alternative ways of playing. Further research is therefore needed to explore the experience of play from the perspective of children with high levels of disability, rather than focusing on situations where they could not play, or faced limitations.

It appears clear that although there are similarities in the play experience of typically developing children and children with disabilities, there are areas in which the play of children with disabilities is different and needs to be explored further. This includes the possibility of 'onlooker play' which is described by children within Tamm & Skär's (2000) study as participation in play through observing. This is supported by the idea of 'vicarious play' suggested by Graham et al. (2014) following interviews with parents about the experience of play for children with Cerebral Palsy perceive more barriers to play and social isolation than their typically developing peers (Pollock et al. 1997, Tamm & Skär 2000). The above areas are all unique to children with physical disabilities in their experience of play and require further exploration as to their impact on play as a primary occupation.

2.7. Play in therapy

Play is often used by occupational therapists as an opportunity to achieve therapy goals and outcomes with children who have disabilities (Missiuna & Pollock 1991). Play is used both as a means for carrying out therapy or as a therapy goal and area to improve (Missiuna & Pollock 1991); participation is often a goal within therapy (Imms 2008). The links between play and therapy will be summarised and discussed in this section.

2.7.1. Intervention to improve play skills

Several researchers, in recognising play as a primary occupation, have aimed to develop play skills for children with physical disabilities (Chiarello et al. 2006, Ahonen-Eerikäinen et al. 2008, Ryalls et al. 2016, figure 4, page 45). Interventions such as: music therapy (Ahonen-Eerikäinen et al. 2008); early intervention and practice of play skills (Matthews & Rix 2013); neurodevelopmental approaches (Okimoto et al. 2000); motor intervention to improve sitting skills (Ryalls et al. 2016); and coaching in parent-child interaction (Okimoto et al. 2000); have all been found to improve the play skills of children with physical disabilities. Although the methods within each of the above studies were rigorously carried out they are all based upon the premise that children with physical disabilities cannot participate in play to the extent of their typically developing peers. It is beneficial to children to be able to improve in their skills, however, it is also essential that the experience of play is captured and understood from the child's perspective (McInnes et al. 2009). This will enable researchers and parents to understand the areas in which children may like to learn new play skills and areas in which their unique experience of play should be more readily realised.

Provision of equipment, such as computer based technologies, can be one aspect of therapy intervention used to enable play for children with disabilities. Chantry and Dunford (2010) reviewed research literature discussing computer use for children with disabilities, finding that use of technology enabled: new opportunities to engage in play, autonomous and independent free play, increased playfulness, and more opportunities for social interaction. Further research was recommended in order to ascertain the impact of such technologies on children's participation (Chantry & Dunford 2010). This research therefore also considered the impact of technology provision on the experience of play for children with high levels of physical disability due to Cerebral Palsy.

2.7.2. Therapeutic engagement

There are several benefits to using play and promoting play within therapy which are often utilised by occupational therapists (Missiuna & Pollock 1991). Play is a known primary occupation for children (Chiarello et al. 2006), and the use of everyday activities for the use of home therapy programmes is promoted for children within occupational therapy (Novak 2011, Brooks & Dunford 2014). Novak (2011) suggested that the use of everyday activities, such as play, enabled improved outcomes in home programmes for children. Within occupational therapy there is a wide recognition that everyday activities are an important part of home programmes (Dunbar 2007, Wolf et al. 2015). As an everyday activity, play can therefore be seen to promote good outcomes for home programmes.

Within therapy sessions play is often used to build rapport with children (Robinson 2011, Brooks & Dunford 2014). Play activities are seen to help children to feel motivated to participate within therapy (Csikszentmihalyi 1975, Majnemer et al. 2010). The concept of ‘flow’ as originally developed by Csikszentmihalyi (1975) is defined as an experience that individuals have during an activity which is at is optimum when there are high opportunities for action or challenge, matched with the individual’s level of skill and capacity (Csikszentmihalyi & LeFevre 1989). In 1971 Csikszentmihalyi and Bennett published an article proposing an exploratory model of play. Play was understood to be an action which generates an action appropriate to the individual’s skill level and therefore a flow from one moment to another is experienced during play (Csikszentmihalyi & Bennett 1971). The idea of flow within a play experience may help to explain its success in improving therapeutic engagement with children. Within an occupational therapy setting this is implemented through therapists grading an activity to make it harder or easier in order that it is at an appropriate level in which the child can experience flow in their play (Hutton 2008).

2.7.3. Play in therapy

With the heightened focus on children’s achievement in the 21st century, play appears to be promoted as purposed primarily for development benefits (Whitebread, 2012). Goodley and Runswick-Cole (2010) have argued for the ‘emancipation’ of play suggesting that true play is only experienced as separate from therapy or education. Clinical experience, therapist and parent opinion disagree, suggesting that children with disabilities may experience a greater level of play during therapy (Bundy 2012, Graham et al. 2014). This is further supported by a recognition that play is often an integral part of motivation and a child-led approach within therapy (Hutton 2008). It is therefore important to consider the concepts of play and therapy from the perspective of children with disabilities to understand their experience.

2.8. Gaps of knowledge

The present review highlights the complexities of understanding play and the impact that it has on the lives of children with physical disabilities. Further study of the emerging concepts of play is needed particularly for individuals with physical disabilities (Tamm & Skär 2000). Children are seen as active agents in constructing their own lives and identities and are therefore pivotal to a research process within a disabled children’s childhood studies paradigm (Curran 2013). Research exploring children’s perceptions and definitions of play is minimal particularly for children with disabilities, however, this has been highlighted as an area for development (Buchanan & Giovacco Johnson 2009).

The research discussed above has suggested that children with physical disabilities have unique play experiences which would be valuable to capture and expand upon in future research (Pollock et al. 1997, Tamm and Skär 2000). Significant gaps were found within the research literature exploring the experience of play for children with physical disabilities. Both Pollock et al. (1997) and Tamm & Skär (2000) included children and young people with a range of physical disabilities but did not include children using alternative forms of communication or with high levels of physical disability. Further research aiming to understand play from the perspective of children with high levels of physical disability due to Cerebral Palsy will allow therapists to exercise a client-centred approach with a group widely seen by occupational therapists. This group is seen to be often missing from research and needs to be included (Imms et al. 2017). The ability to consider occupation from the perspective of the client is considered vital for occupational therapy practice (College of Occupational Therapists (COT) 2010).

Children at levels IV and V on the Gross Motor Function Classification System, who use wheelchairs and need support for all of their everyday activities (Cooley Hidecker et al. 2012), have been found to be the most ‘at risk’ of play deprivation, having the least play activities described in a mail based survey of 93 children with Cerebral Palsy (Malkaw 2009). A more recent study supported this, finding that following completion of questionnaires about play participation, children functioning at GMFCS IV/V reported more activities they could not participate in but would like to than their peers with lower GMFCS levels and better physical skills (Imms et al. 2017). Malkaw (2009) argues that therapists should therefore focus their attention towards participation in play for children with this level of disability. The current research therefore aims to study a population not addressed in Tamm & Skär’s (2000) research by exploring the perspectives of play of children aged 6-12 years who are functioning at GMFCS and MACS levels IV and V and have CFCS levels I and II. Cooley Hidecker et al. (2012) suggest that participation in relation to the International Classification of Functioning should be researched in relation to children in different levels of functioning within the above scales. Play is seen as a primary occupation for children within the ICF (WHO 2007). Children with CFCS levels I and II will have the ability to communicate to the researcher who will be an unfamiliar conversation partner, this will allow the opportunity to truly reflect each child’s perspective within a qualitative study building upon Tamm & Skär’s (2000) work.

2.9. Research question and aims

There are significant gaps within the research literature surrounding the experience of play for children with high levels of physical disability due to Cerebral Palsy. This research therefore poses the following question ‘How do 6-12 year olds with high levels of physical disability due to Cerebral Palsy experience play?’. This will be addressed through the following three aims:

1) To understand how children explain their experience of play in relation to their Cerebral Palsy
2) To contribute to a deeper understanding of what play means for children with Cerebral Palsy
3) To consider possible occupational therapy practice implications following a greater understanding of play for the study population.

It was anticipated that the findings of this study would contribute to occupational therapy practice in terms of being able to understand children's experience of play. The findings will also enable further education of parents and other professionals as to how they can recognise and promote play in a way that is meaningful to children with high levels of physical disability due to Cerebral Palsy.

2.10. Summary

This chapter has provided a critical review of the literature which justifies the importance of this project. Play is defined within this thesis as an activity in which an individual experiences freedom, choice and control within a frame of play cues. Children with disabilities are regularly described as playing less than their typically developing peers (Whittingham et al. 2010). Some researchers have argued that they do not play less but rather play differently to their peers (Graham et al. 2015). There appears to be some recognition in the literature that children with Cerebral Palsy may experience play differently to their typically developing peers (Pollock et al. 1997, Tamm & Skär 2000, Graham et al. 2014, Graham et al. 2015). Children with high levels of physical disability such as those at GMFCS IV and V are considered the most 'at risk' of play deprivation (Malkaw 2009). To date, no research has been found exploring the experience of play for this population. In light of the childhood studies approach it is important to ascertain play from the perspective of the child with physical disabilities, to understand how their right to play (UNICEF, Article 31, 1989) can be realised, and they can participate in the everyday occupation of play (Chiarello et al. 2006), in a way that is meaningful to them. This project therefore aimed to understand the experience of play for 6-12 year olds with high levels of physical disability due to Cerebral Palsy. This has enabled a deeper understanding of play as an important and primary occupation which will be helpful to both parents and professionals.

2.11. Reflexive account

As an occupational therapist my primary concern is with the occupation of the client group I am working with. As I am working with children, the occupation of play is something that I utilise and aim to support children with on a regular basis. Play is a concept that at the start of my PhD I felt I had a good grasp of in terms of its definition and its application to children with disabilities. I had experience of playing with children as an occupational therapist; outside of work with family friends; and in remembering my own play as a child. I had created a personal framework of play in which I felt I could easily observe and recognise a play activity through the joy that it created in a child. However, as I started to explore the literature and read the varying research and theory related to play as part of my PhD I found that my view and understanding of play was challenged. The literature challenged my view that play can always be observed in the appearance of joy (Sheridan et al. 2011). Serious play was a concept that I was aware of in my observation of children but it was not originally something that would have been a part of my play definition. The research literature challenged my concept of play being a known and understandable entity.

I wanted to cover a wide breadth of literature as part of my literature review and I tried to combine research papers and theories from a wide range of disciplines. This led to some difficulties in synthesising research and creating a coherent argument. The more I read, the more I realised the extent to which the definition of play varies according to every individual's perspective and therefore cannot be easily captured or summarised. Several research titles help to capture the complexities and confusion that exploring the topic of play can involve: *'the ambiguity of play'* (Sutton-Smith 2006); *'the cobweb of play'* (Riley 1974); and *'The problem of play'* (Neumann 1971). These titles mirror my own experience of ambiguity in the processes of exploring the literature. It was like going through a tunnel which on stepping inside the plethora of literature confused the view of the endpoint and understanding play. On coming through the tunnel I found I had a new understanding of the wide range of literature, contributing to the body of knowledge about play. I found a new contentment in holding all the varying understandings and theories at once with the overarching view that play definition would vary according to the perspective of the player (McInnes et al. 2009). In order to capture the vast and varying perspectives of theory and literature within this review I went through several iterations of trying to map this out in a visual summary. I found that the best way was to initially capture theory and definitions of play and then to separately explore experience of play from the perspective of children and young people both with and without a disability.

I attempted creations of timelines and summarising graphics but I found that with each attempt it was difficult to adequately capture and summarise the information. I then re-looked at the work of Neumann (1971) whose first chapter is aptly titled *'the problem of play'.* It was through Neumann's (1971) suggested framework that

I found a solution to summarising the theories influencing the definitions of play. Writing as an occupational therapist and from an occupational therapy perspective I was eager to be able to capture occupational therapist’s theories and influences on the development of defining and understanding play. I therefore added a fifth section to Neumann’s framework ‘occupational therapy and play’. This enabled a summary which I felt provided a fuller picture of varying theories and perspectives of play within the literature. This graphic (figure 1) enabled a summary of my understanding of play and the combination of literature contributing to it.

I was aware that play cannot be researched without starting with a definition of it. As the literature points to every individual having their own perspective of play and as play is the primary occupation of children it therefore seemed essential that the literature review had a focus on literature exploring children’s experience of play. I summarised this literature through creating summaries of articles which explored the experience of play from the point of view of typically developing children and the point of view of children with disabilities. This enabled me to organise and process my thoughts and therefore create a clear argument within the review.

My understanding of play as a concept, and my leaning to provide and enable play opportunities for all children, impacted my reaction to the literature that I read. I found that, particularly when reading studies that focused on children with disabilities not being able to play as much as their typically developing peers, I felt a sense of injustice that the child’s perspective had not been accounted for. I think this initially led to a level of criticism where I tended to critique these articles to a greater extent than perhaps reasonable. On re-reading and editing this chapter I have reflected on my perspective and endeavoured to provide a fair analysis of such articles.

It took me several months to process and understand the motivation of the researchers who have varying perspectives of the play for children with disabilities, particularly those who focus on barriers to play rather than ability to play. There were threads within play literature in which I shared a view with the majority, if not all researchers, such as the thread that every child has a right to play. Despite this, there were other focuses within play research in which I appeared to take a different view and perspective. In some ways my research runs along a similar theme to researchers such as Goodley & Runswick-Cole (2010) who emphasised the importance of play for plays sake. However, there remains an emphasis within Goodley & Runswick-Cole's (2010) work on the barriers to play for children with disabilities. It was the focus on the barriers to play and the reasons why children cannot participate that I found a challenge in light of the perspective that every child has a right to play. Through the process of reading, coming back to this literature and conversing with researchers in the field at conferences such as the International Play Association Conference (Sept 2017), I found that I gained a deeper understanding of this view point. I could more readily realise that the focus on barriers to play and adaptations needed to play came from a motivation to enable all children to be able to experience play. As someone wanting to enable all children to be recognised in their experience to play I realised that my voice, in representing the voices of the children I interviewed, does not directly contradict other research, but adds to it in providing a deeper understanding of experience from the point of view of children themselves. I also realised that some of the studies, even when specifically focused on barriers, do provide a valid and important expression of children's views which need to be represented. I felt confident that the combination of literature which challenges societal barriers to play, and literature which discusses children's ability to participate in play, will contribute to a shift in policy and practice for children and young people with high levels of physical disability and their families. I was therefore pleased to be able to be adding to the body of literature which represents the child's voice and experience.

My completion of a systematic literature review addressing the meaning of play for children and young people with physical disabilities (Graham et al. 2017f) gave me great confidence in the need for further research addressing the experience of play for children with physical disabilities. I found the process of completing the systematic review one that was both challenging and rewarding. It was challenging in the sense of the large number of articles to screen and process, but rewarding in that the thematic synthesis of the applicable sections within each article led to a better understanding of play for children with physical disabilities. It was the first systematic literature review which I had undertaken for journal publication and therefore it felt important that that method was particularly rigorous and thorough. I attempted submission to two journals before it was successfully accepted within Child: Health, Care and Development. This process was frustrating but enabled me to develop my research skills. I learnt that I needed to be able to adequately define the concept of play, particularly to be able to define it as separate from other concepts which can be viewed as similar such as recreation and leisure. This led to the decision to clarify my terms within this literature review in order to make this separation clear. I also learnt about the need for academic rigour in the systematic review process. I spent a great deal of time following the PRISMA review process and critically appraising relevant articles. At the point of the third submission following comments from previous reviewers I decided to bring in a fourth author in order that the screening, critical appraisal and synthesis process could be carried out by two authors independently and then compared. Although it was frustrating to start again with the screened list of articles I found that the process taught me the benefit of a second independent individual in analysing and reviewing articles. The process of talking the review process through and deciding upon themes and subthemes provided a fresh insight to the article which had not been present in previous iterations. This contributed to my process of writing this chapter as it enabled me to critically appraise and synthesise literature to a greater extent and also to be able to view it from an alternative perspective. These research skills were positive to my journey as a researcher and my ability to be able to re-create a high quality review in the future.

I felt that the breadth of sources that I was able to look at and think through as part of this literature review has been helpful in the formation of a broad understanding of the concept of play. I felt that this clearly highlighted the need for play to be explored, particularly within the context of children with disabilities. Although unsurprising, it was disappointing that there was a significant lack of literature which purely focuses on play and the child's perspective of play. Whilst minimal within populations of typically developing children, there were very few and no recent studies looking at the experience of play for children with high levels of physical disability. This realisation came with both frustration and hope: frustration that the study population were so under represented within the research literature; and hope that this thesis could provide a helpful contribution to the field in terms of understanding and promoting the experience of children with high levels of physical disability due to Cerebral Palsy.

3. Methodology

3.1. Introduction

Congruency between methodology, methods and research topic is essential for designing rigorous research (Stanley & Nayar 2014). This chapter discusses the **minimal hermeneutic realist** ontology, **constructionist** epistemology and the **interpretivist** theoretical perspective and paradigm in which this thesis is positioned. The aforementioned are congruent with **Interpretive Phenomenological Analysis** as a methodology: this has informed the interview methods used to explore children's experience of play which are detailed in chapter 4. It is influenced by three philosophies of knowledge: phenomenology, hermeneutics and idiography (Smith et al. 2009). The philosophical and theoretical perspectives underpinning this research are discussed within the following chapter.

A visual demonstration of the perspectives underpinning the research can be seen in figure 5. This is based upon Crotty's (2003) suggestion of a scaffolding for developing a congruent research study design through four elements: epistemology, theoretical perspective, methodology and methods. Crotty (2003) suggests the philosophical perspective underpinning each of these elements starts with the research question or problem. In this case the problem was that in practicing as an occupational therapist I often observed children with high levels of physical disabilities appearing to be engaged in play; however, this stood in contrast to the literature suggesting that children with physical disabilities cannot play as much as their typically developing peers (Imms 2008, Whittingham et al. 2010). I wanted to be able to capture the children's experience of play so their perspective is represented within research. This problem enabled me to think and explore the philosophical and theoretical concepts underpinning my research question. Within figure 5 I have added my ontological perspective which complements my epistemology and can be considered alongside this in the scaffolding approach (Crotty 2003). Within research, the ontology, epistemology and methodology are considered essential components which underpin the design and method of a particular study (Duncan & Nicol 2004). The following chapter will discuss each aspect of philosophy and theory underpinning the research methodology. The methods will be discussed in chapter 4.

Ontology- Minimal Hermeneutic realist

- One reality in the world but this is understood and its nature is recognised within individual contexts. (Heidegger's perspective of reality as described by Larkin et al. 2006).
- The study findings represent children's experiences of the reality of play for them.

Epistemology- Social Constructionism

- Knowledge is constructed and influenced by society and our interactions with others (Crotty 2003). The focus is on the *person-in-context* (Larkin et al. 2006).
- Within this study an understanding of the meaning of play for children with Cerebral Palsy was constructed through the participants account and interaction with the researcher within their own context.

Theoretical perspective- Interpretivism

- The study is based on interpretation of the meaning of a phenomenon (Finlay & Ballinger 2006).
- This study presents interpretations of the meaning of play to each of the research participants.

Methodology-IPA

- Interpretative Phenomenological Analysis (IPA) aims to understand and interpret the meaning of a lived experience of a particular phenomena (Smith & Osborne 2015).
- This study aimed to understand the meaning of the experience of play for 6-12 year olds with high levels of disability due to Cerebral Palsy.

Methods- Interviews, visual methods

- In-depth semi structured interviews were used to explore the experience of play for children with Cerebral Palsy.
- Visual methods such as the use of video recordings of the children playing, photos and favourite toys were used to elicit greater in depth discussion.

Figure 5 An outline of the perspectives underpinning the study.

3.2. Ontology: Minimal hermeneutic realist

Ontology is the study of being, what is real, and the nature of reality (Fletcher 2016, van de Erve 2006). It is made up of the Greek word '*ontos*' meaning being, and '*logos*' meaning study (van de Erve 2006). This thesis is underpinned by a **minimal hermeneutic realist** ontology which suggests that one reality exists but there are multiple interpretations of this reality which are dependent on the individual making the interpretation (Larkin et al. 2006). This ontological perspective originated with Heidegger (1927) and has since been discussed by Larkin et al. (2006) in relation to Interpretive Phenomenological Analysis (IPA) (Box 3). This suggests that play is a real phenomenon which exists within the world but can be interpreted differently by varying individuals. Being able to understand each individual's perspective of play helps to build a greater picture of the whole reality of play for children with high levels of physical disability due to Cerebral Palsy. This ontology is appropriate for play research as the concept of play varies according to individual perspective and circumstance (McInnes et al. 2009). The following section will discuss the minimal hermeneutic realist stance within ontological philosophy and its relevance to this thesis.

> *'It must be stated that the entity as an entity is 'in itself' and independent of any apprehension of it; accordingly, the being of the entity is found only in encounter and can be explained, made understandable, only from the phenomenal exhibition and interpretation of the structure of encounter.'*
>
> (Heidegger 1925, p217)
>
> *'The minimal hermeneutic realist duly recognizes that certain 'things' exist and would have existed even if humans had not (and that these 'things' are real), but that the very question of this separate existence (and hence questions about the **nature** of their reality) can only arise because **we are here** to ask the question.'*
>
> (Larkin et al. 2006, p107- emphasis within original quote)

Box 3 The question of ontology- a minimal hermeneutic realist perspective

The ontological perspective of a researcher will influence the manner in which they conduct their research and base their claims; it therefore must be considered as part of the research process (Gray 2009). Within this research, the minimal hermeneutic realist perspective meant it was recognised that each individual would have a differing interpretation of play, and this would also be influenced by the researchers own interpretations. The recognition of this ontological perspective within IPA as a methodology led to specific considerations within the method (chapter 4). This included the use of a reflexive diary to be aware of my own varying interpretations as a researcher (Larkin et al. 2006); and the close inductive approach of analysis for each participant before analysing all the interviews as a whole (Smith et al. 2009).

The history of ontology allowed a broader understanding of its influence on the research process. Traditionally a *realist* approach to research was undertaken by early researchers; this assumes that cause and effect are absolute and there is one reality, and one interpretation of the world through which being is understood and based (Finlay & Ballinger 2006). This is more commonly linked to a positivist approach. *Realist* approaches contrast to a *relativist* approach which suggests that diverse interpretation and realities are possible, and that no one reality exists (Finlay & Ballinger 2006). This is more commonly linked to an interpretivist approach. The current research took a view that combines the two perspectives in stating that play is a real phenomenon which exists and is tangible within the world and each individuals interaction with it, yet different individuals may have differing perspectives of the reality of play. This is labelled as a '*minimal hermeneutic approach*' which originates from Heidegger's ideas of the essence of reality (Larkin et al. 2006).

The contrasting perspectives of relativism and realism originated within ancient Greece and the philosophy of *becoming* and *being* (Gray 2009). Heraclitus (*c.535–c.475BC*) introduced the idea of *becoming* focusing on chaos, formlessness and the changing and emerging nature of the world; this developed into the western philosophy of relativism (cited in Gray 2009). Parmenides (*c.515–c.445BC*) emphasised *being* and an unchanging reality in the world; this has led to the western philosophy of realism (cited in Gray 2009). Within more recent philosophy the idea of subtle or critical realism has emerged, these have subtle differences but are based upon similar principles of reality (Maxwell 2012).

Maxwell (2012) argued that core similarities between the various types of realism present an ontology for qualitative research which can stand alongside interpretivism. In 1992, Hammersley, an ethnographic researcher, introduced the idea of multiple possible viewpoints of one reality which remained a reality independent of the claims made about it and coined this *subtle realism*. The idea of one reality with multiple viewpoints of this reality is similar to the concept of **minimal hermeneutic realism** which is used as the ontology for the present research. Similarities between this approach and both subtle and critical realism are clear: all argue that one single view of reality is not possible, and therefore reality is seen according to multiple viewpoints (Maxwell, 2012). Despite this, differences between these approaches, such as the use of slightly different terms within different disciplines, and the slight variation in position on the scale between realism and relativism, meant that the minimal hermeneutic realist approach was adapted here, as this is consistent with IPA as a methodology (Larkin et al. 2006).

3.3. Epistemology: Social Constructionism

Epistemology explores the theory of knowledge and how we gain understanding (Finlay & Ballinger 2006). **Social constructionism** is the epistemological perspective informing this research study. This reflects the interaction between the researcher and the *person-in-context* which is considered a vital part of IPA (Larkin et al. 2006). Smith et al. (2009) described social constructionism as the interpretation of meaning through the interaction between the researcher and a particular participant in their particular context. IPA aims for interpretation which is grounded in, but goes beyond, the participants description of their experience (Smith et al. 2009). Thus, epistemologically, this study constructed the meaning of play through the interaction between the researcher and each participant and their data within the social context in which their play experience was based. Furthermore, this is supported by the social model of disability which recognises the impact and influence of social interaction upon meaning and experience for individuals with disabilities (Lawlor et al. 2006).

Epistemology allows researchers to define the construction of knowledge and provides criteria to justify that this is knowledge (Petty et al. 2012). Constructionism is concerned with the making of meaning which is reliant upon interaction between object and subject (Crotty 2003). Social constructionism has more of a focus on the social context of the situation. Crotty (2003) describes social constructionism as the view that all meaningful reality is socially constructed and therefore meaning is constructed through the interaction of a subject and an object in a social context. It contrasts from constructivism which focuses on a cognitive approach to the constructing meaning (Raskin 2002).

Constructionism holds together the opposing views of objectivity and subjectivity by suggesting that the world is *'always already there'* (Heidegger 1927, Merleau-Ponty 1945) and meaning is constructed through interaction with the world (Crotty 2003). Within the field of phenomenology *intentionality* refers to the relationship between conscious processes, and the object of thought; it suggests that an experience or conscious expression is always of *something* (Smith et al. 2009). The construction of meaning is always related to the '*aboutness'* of the object in question (Crotty 2003). Intentionality suggests that the subject and object are always interlinked in terms of being understood and having meaning (Crotty 2003). Within social constructionism, used within the current research, and commonly used within IPA research, the recognition that we are '*always already there*' (Heidegger 1927) means that the making of meaning always occurs in the social context of the world around us (Larkin et al. 2006).

Berger and Luckmann (1967) wrote '*The Social Construction of Reality*', which is considered a seminal work within the field of constructionism (Burr 2015). Their view of constructionism was closely linked to symbolic interactionism as founded by Mead (1863-1931) and Blumer (1969), which argues that people construct their own and others' identities through social interactions with others (cited in Burr 2015, Crotty 2003). Within the field of psychology, Gergen (1973) influenced the development of social constructionism and argued that the social world is always changing and therefore attempts to understand it are based in history and aim to capture an understanding of the view of the world at the present time (cited in Burr 2015). This was important to consider within this research which aimed to capture the experience of play for children with high levels of physical disability due to Cerebral Palsy. The researcher focused on each child within their social context at the time of the interview in order to try and understand their lifeworld and current experience of play.

The social constructionist perspective and the extent to which culture and interaction influences the generation of knowledge has been discussed by IPA researchers (Smith et al. 2009). Larkin et al. (2006) advocate an epistemology which supports Heidegger's idea of a *person-in-context* where knowledge generation occurs through interaction with context. Relatedness to the world around us or to a particular phenomenon is considered a fundamental part of our reality and therefore our development of knowledge (Larkin et al. 2006). This is captured by Heidegger's concept of *Dasein* 'Being there' in which a human being's nature is always located 'there' within a meaningful context (Heidegger 1927). This has implications for reflexivity within research and particularly within IPA studies which recognise the interaction of the researcher with the participant in which meaning is shaped and constructed in tandem (Larkin et al. 2006). Reflexivity involves a process of recording, questioning and reflecting upon pre-conceived ideas and thoughts throughout the research process (Smith et al. 2009). Smith et al. (2009) suggest that in recognising the importance of context in understanding the meaning of an experience, IPA researchers should endeavour to understand the participant's cultural context and the frame of reference for each participant. This has implications for the study method, for example, in starting the interview with the opportunity for each child to tell the researcher about their social context for play.

The discussion of theory and research above suggests that social constructionism is an appropriate epistemological perspective for IPA studies (Larkin et al. 2006, Smith et al. 2009), and the current project. The construction of meaning between the researcher and the participants within their context will enable interpretation of the experience of play for children with high levels of physical disability due to Cerebral Palsy.

3.4. Theoretical perspective: Interpretivist paradigm

The research followed an interpretivist theoretical perspective which aims to explore and understand human and social reality; this provided a basis for the research methodology (Crotty 2003). The interpretivist paradigm suggests that perceptions and experience are produced by interactions between subject and object and an individual's interpretations of these (Finlay & Ballinger 2006). It stands in contrast to a positivist paradigm which focuses on objective knowledge gained from an unbiased researcher (Finlay & Ballinger 2006). The interpretivist paradigm is often contrasted to the positivist paradigm; these are generally but not exclusively linked to qualitative and quantitative research respectively (Petty et al. 2012). The following section considers the use of the interpretivist perspective; the links between this and occupational therapy theory; and the way this has informed the study methodology.

The interpretivist paradigm aims to understand meaning that people find in the world (Petty et al. 2012). It is grounded in the thinking of Max Weber (1864-1920) who suggests that researchers are concerned with gaining understanding or *Verstehen* (cited in Crotty 2003). Weber argues that interpretive research should focus on the meaning of actions (cited in Crotty 2003). An interpretivist approach cannot fully explain a causal relationship but it can provide an exploratory understanding of a phenomenon (Bowling 2009). This view of interpretivism suggests that the social world cannot be researched in the same way as the natural world (Petty et al. 2012). As a paradigm, an interpretivist perspective allows meaning to be both interpreted and explored.

The key concepts of the interpretivist paradigm can be seen to be closely linked to occupational therapy philosophy. Occupational therapists value a client-centred approach, which focuses on the individual and provides assessment and intervention surrounding activities which are meaningful for each person (Molineux 2004). This is also reflected within the disabled children's childhood studies approach on which this thesis is also based, which emphasises the importance of the individual child's account (Curran & Runswick-Cole 2014). It is therefore necessary to explore, understand and interpret the experience of the individual within occupational therapy research. Occupational therapists recognise that health is closely linked to doing and being (Wilcock 2006). As an occupational therapist the researcher has valued an individual approach which allows children to express their preferences and considers the meaning of occupation to them as individuals.

Interpretivism is often used to inform qualitative research approaches (Finlay & Ballinger 2006). The interpretivist perspective underpins the present research in its aim to explore and understand the meaning of play of children with high levels of physical disability due to Cerebral Palsy. The interpretivist approach is concurrent with a minimal hermeneutic realist ontological perspective, and a social constructionist epistemological perspective, on which the present study was based.

3.5. Methodology: Interpretive Phenomenological Analysis

Interpretive Phenomenological Analysis (IPA) was the chosen methodology for this research project. As an approach, IPA aims to gain an insider perspective of the meaning of experience of an individual situated within their lifeworld (Smith &

Osborn 2015). IPA does not seek to find one single reality but aims to provide an account of the participant's experience of reality (Pringle et al. 2011). IPA developed from the field of phenomenology concerned with the lived experience of an individual with regards to a particular phenomenon (Dean et al. 2006). It is based upon three principles: phenomenology, hermeneutics, and idiography (Smith et al. 2009). The development of each of these principles and their application to IPA will be discussed within this section.

3.5.1. Phenomenology

Phenomenology is a combination of the Greek words *phenomenon* and *logos;* the word *phenomenon* can mean 'show' or 'appear' and the word *logos* means study (Smith et al. 2009). Phenomenology is concerned with the meaning of the reality of experience which appears when it is studied; it is a philosophy which has influenced the development of IPA as a methodology (Larkin et al. 2006). Phenomenology focuses on the 'lived experience' of a particular phenomenon and has a particular emphasis on discovering the ***essence*** at the heart of an experience (Creswell 2007). Phenomenology has two main strands: descriptive phenomenology as developed by Husserl (1927), and hermeneutic phenomenology as developed by Heidegger (Smith et al. 2009). IPA which is used as the methodology within this thesis is influenced by Heidegger's hermeneutic phenomenology. Therefore, the following section will provide a brief overview of descriptive phenomenology, before discussing hermeneutic phenomenology and its relevance to IPA and this thesis which explores the experience of play.

Descriptive phenomenology originated with the philosopher Husserl. Husserl (1927) aimed to discover the ***essence*** of a phenomena; the very substance of an experience which is a necessary and invariant part of it. Husserl suggested that the essence of a phenomena could be discovered because of ***intentionality***; the idea that consciousness is always situated around an action and is always referring to something, this means that a phenomenon can be explored through conscious reflections of it (Smith et al. 2009). Husserl suggested that phenomenological enquiry should start with exploring meaning behind experience, any preconceptions should be 'bracketed' out of the researcher's reality and interpretation in order to first look at the experience itself (Ashworth 2008). Husserl (1927) recognised the influence of culture on shaping individual's values and pre-conceptions of phenomena, yet argued for separation from this influence in order to try and understand the meaning of an experience specific to an individual aside from the meaning system assumed (Smith et al. 2009). Husserl originally developed his philosophy for phenomenology as a basis to explain concepts with regards to arts, science and humanity with a greater depth of rigour (Ashworth 2008). More recent researchers such as Giorgi and Giorgi (2008) have developed a phenomenological approach based on Husserl's phenomenology. Giorgi and Giorgi (2008) suggest an approach to phenomenology which aims to provide a general structure of a phenomenon as a result of analysis. The focus on developing broad description rather than deep interpretation within descriptive phenomenology limits this approach in understanding the experience of play for children with high levels of physical disability. The descriptive phenomenology approach is strongly based within a realist ontology in which it aims to identify one reality of a phenomenon (Finlay 2009); this contrasts to the minimal hermeneutic realist perspective underpinning this research. IPA's focus on interpretation and idiography (Smith 2004), made it more suitable for the small population participating in this research project. Within IPA although the researcher should be aware of pre-conceptions and ideas which are influencing their interpretation of the data, these are not bracketed, rather become part of the analysis process and gaining a greater understanding of what is being said (Smith et al. 2009).

IPA is based primarily upon a Heideggerian phenomenology, however there are some important influences from Husserl's philosophy which have been considered within IPA as a methodology (Smith et al. 2009). The idea of moving back to the things themselves is central to understanding the way a particular phenomenon is related to and experienced as part of an individual's lifeworld (their everyday world and experience) (Smith et al. 2009). Husserl's aim was always to get to the very ***essence*** of an experience; IPA aims to capture a particular experience for particular people (Smith et al. 2009). IPA also draws upon the work of Sartre (1943) who suggested that ***existence*** precedes ***essence*** and that ***becoming*** is an important part of forming meaning. Sartre's work emphasises the importance of an embodied, interpersonal, affective and moral nature of encounter with a phenomenon (Smith et al. 2009). Within IPA, being able to reflect and be attentive to our own pre-conceptions as researchers can help further our understanding of the experience for the participant; this explains the emphasis placed on reflexivity throughout the analysis process (Smith et al. 2009).

Heidegger and Merleau-Ponty developed Husserl's phenomenological work and provide alternative lenses which have, in turn, influenced IPA (Smith et al. 2009). Existential phenomenologists suggest that it is not possible to bracket out conscious reflections of experience but rather these experiences need to be explored within the context of the world (Smith et al. 2009). Heidegger, a key interpretative phenomenologist, introduced the concept of ***Dasein*** which is often referred to as the concept of '*being-in-the-world*' and focuses on the experience of the person in context (Smith et al. 2009). Heidegger suggests individuals are intentional actors within the world; his argument follows an existential perspective and discusses how time is finite and how this influences our perception of objects, relationships and language in our experience of '*being-in-the-world'* (Smith et al. 2009, p18). Within phenomenology the meaning of an experience is closely interlinked with an individual's everyday practice of it (Van Manen 2007). Merleau-Ponty (1945), a phenomenological philosopher influenced by both Husserl and Heidegger, focuses on *embodiment* and the experience of the world through the body that we perceive it in.

Embodiment is a concept discussed in depth by Merleau-Ponty (1945). His book: *'The phenomenology of perception'* describes embodiment as a way of attributing meaning to an experience perceived through a sense of self of *'my body-in-the-world'* (Merleau-Ponty 1945, p164). The view of an embodied self as *being-in-the-world* is common in phenomenology and creates an ontological and epistemological understanding beyond a subject- object divide (Leonard 1994). Individuals are viewed as embodied beings interacting and intentionally living in social and physical contexts

(Papadimitriou 2008); the body is seen as both subject and object in the context of every individual’s experience (Blanchard & Øberg 2015). This Heideggerian perspective contrasts from a Cartesian view of self in which the self is seen as *subject* but in possession of a body as a functional *object* which is external to self (Leonard 1994). This view of embodiment fits well within a current biopsychosocial model of health in which psychological and social context influences health (Leonard 1994).

IPA is influenced by Merleau-Ponty’s (1945) philosophy and recognises that the body shapes our knowing of the world and our experience in it (Smith et al. 2009). The idea of being in the world and within context is key to the phenomenological perspective influencing IPA and this project. This is congruent with the social constructionist epistemology, and recognises that a child’s discussion of their experience of play must occur within the context of their own experience, this is how meaning can be created and understood with the researcher. As the study population was children with physical disabilities, Merleau-Ponty’s philosophical ideas about embodiment and the experience of the body within the world were considered to be important. The outward experience of play is physically different for children with physical disabilities and therefore the conscious processing of their experience was interesting to explore.

Merleau-Ponty (1945) also suggests that it is possible to embody an object so that it becomes an extended part of an individual’s experience of the external boundaries of themselves. This is seen within disability research where individuals can embody a wheelchair (Giulia et al. 2015, Papadimitriou 2008, Sawadsri 2011). Giulia et al. (2015) carried out a study exploring how the wheelchair as a full-body tool can extend the peripersonal space – the space immediately around the body in which an individual experiences their interactions with the world (Giulia et al. 2015). Although Giulia et al. (2015) report some statistically significant extension of the peripersonal space and therefore embodiment of equipment this was further emphasised by subjective comments within their study. The subjective experience of embodiment is reflected by researchers such as Papadimitriou (2008) who discuss *‘becoming en-wheeled: the chair as an extension of the self’.* This is further supported by a Thai case study report of a wheelchair becoming an embodied part of life (Sawadsri 2011). The recent research discussed above practically demonstrates Merleau-Ponty's (1945) theory of embodiment of tools and objects as an extension of self.

IPA aims to interpret the experience of an individual who is an embodied agent in the world influenced by objects, relationships and language (Smith et al. 2009). Heiddegerian phenomenology provides an approach to IPA which focuses upon the meaning of a particular experience within a particular context for an individual (Smith et al. 2009). Gaining an understanding of the meaning of an experience is key to those with a phenomenological view point (Ashworth 2008). The use of IPA within this research has allowed the exploration of the *meaning* of play to children with high levels of physical disability as situated within their lifeworld. IPA considers the meaning of the human lived experience and possible embodied, cognitive-affective and existential domains of psychology which may contribute to this (Smith et al. 2009).

3.5.2. Hermeneutics

Hermeneutics is the theory of interpretation; it initially developed with regards to interpretation of biblical texts and has subsequently expanded to interpretation of a broad range of texts and documents (Crotty 2003). In 1927 Heidegger wrote '*Being in time'* which introduced the concept of hermeneutic phenomenology. Heidegger (1927) focused upon the study of ontology and being, for him being was explained by making sense of an object in and of itself; this could only occur through a hermeneutic process of interpreting the meaning which occurs when interacting with an object. Heidegger (1927) describes Dasein as *being* occurring in cycle of interpretation away from, and back towards, the original understanding of a phenomena. Hermeneutics, as described by Heidegger, is closely drawn upon within IPA (Smith et al. 2009); this will be discussed in this section.

Heidegger's work *'being in time'* (1927) presents a clear argument for hermeneutic phenomenology. Heidegger's focus on the *appearance* of a phenomenon to interpret is one which is drawn upon within IPA (Smith et al. 2009). The idea that the thing itself is interpreted and made sense of is essential to IPA (Smith et al. 2009). Heidegger (1927) recognises that the interpreter will bring their own experience to any interpretation; he refers to this as the fore-structure. In contrast to Husserlian phenomenology where experience is bracketed out; Heiddeger suggests an awareness of one's fore-structure should be used to prevent this from being an obstacle to interpretation (Smith et al. 2009). Heidegger suggests that the researcher should direct their phenomenological enquiry first to the object of interpretation and then to the fore-structure; within IPA the complexity of this process means that reflexivity on behalf of the researcher is key (Smith et al. 2009).

Philosophers such as Gadamer (1960) have argued the influence of history upon interpretation and the importance of bringing together the past and the present in order to understand a phenomenon. Gadamer (1960), building on Heiddeger's ideas, contributes to the idea of reflexivity through a process of interpretation and understanding one's own fore-structure (Smith et al. 2009). Gadamer (1960) emphasises a cycle of moving between the thing itself, its interpretation, the development of fore-structure and interpretation before moving back to the thing itself. The engagement with the participant through the process of interpretation is captured by the idea of the ***double hermeneutic*** (Smith & Osborn 2003); in this study the researcher has made sense of the participant making sense of their experience of a phenomenon as demonstrated in the researcher's reflexive accounts.

Cerbone (2008) suggests that Heidegger's hermeneutical phenomenology recognises neutrality cannot be obtained because *being-in-the world* is an essential component of Dasein (Heidegger's concept of being-there). Therefore, all interpretation must occur in light of *being-in-the-world* (Cerbone 2008, Gelven 1970). This is reflected in the concept of *appearing* where phenomena shows itself (Cerbone 2008). Heidegger (1927) suggests that interpretation occurs in making sense of a phenomenon which appears, and in understanding its possibilities. Heidegger therefore presents a case for interpretation in which the experience of a phenomenon needs to be captured, analysed and made sense of; this is drawn upon within IPA (Smith et al. 2009).

Schleiermacher (1998) suggests that interpretation of a text must always consider the experience of the author of the text in order to be able to interpret and analyse effectively; Schleiermacher takes this to the extent of suggesting that one can develop an understanding which is deeper than the understanding of the utterer (Schleiermacher, 1998). Gadamer (1960) takes an alternative perspective, suggesting the content of a text is of primary importance to interpretation. Within IPA the process of analysis combines both Schleiermacher and Gadamer’s perspectives aiming to understand both the person providing the account of their experience and the account itself (Smith et al. 2009).

Hermeneutics provide a basis for the interpretative component of IPA, and help to facilitate the researcher’s process of analysis and understanding as a phenomenon appears (Smith et al. 2009). The hermeneutic circle which involves iterative and moving interpretation of data is one that is drawn upon with IPA and therefore in this thesis (Smith et al. 2009). Wagstaff et al. (2014) suggests that the double hermeneutic comes into practice through the acknowledgement within IPA that the researcher and participant’s perspectives of a phenomenon can be different.

3.5.3. Idiography

Idiography has also influenced the development of IPA (Smith et al. 2009). IPA researchers recognise the contention between understanding the uniquely embodied experience of a phenomenon to a particular person and context but also the perspective of the phenomena as it occurs relationally within the world (Smith et al. 2009). The key component of the idiographic approach used within IPA is the focus on the particular: a phenomenon will be explored with a ‘*particular people, in a particular context*’ (Smith et al. 2009, p29). As an approach within the field of health, IPA focuses on individual experiences and allows meaning to be captured in relation to health and wellbeing (Dean et al. 2006).

The emphasis on the particular is important both in terms of a sense of detail, and in capturing the perspective of the individual (Smith et al. 2009). Layered analysis is a key component of the IPA methodology which allows the researcher to explore the meaning of a single experience in depth (Dean et al. 2006). Dean et al. (2006) likens the process of carrying out

IPA to the layers of an onion suggesting that there are several layers and stages of analysis which occur throughout the process of interpreting the data. IPA is designed so that the researcher interprets what has been said whilst considering the participants emotional states and influences on what they have and have not said; this leads to a deeper exploration and therefore understanding of the phenomenon (Dean et al. 2006). Wagstaff et al. (2014) suggests this has implications for the sample size used within research studies; a sample that is too large can make it difficult for suitably in-depth analysis to take place. Within the research project presented here, a sample of 6 children was decided upon in order to allow for sufficient data analysis in line with the idiographic approach.

The focus on the individual as part of the idiographic underpinning of IPA means that researchers will often look for small, homogenous sample populations (Smith et al. 2009). IPA does not aim for generalisations but rather emphasises meaning for a particular group of people within their context (Smith et al. 2009). Heidegger (1927) consistently suggests that Dasein is about the experience of a phenomena through being in the world. Smith et al. (2009) therefore caution that the idiographic approach of IPA does not purely mean ‘individual’ but considers the complexities of focusing on the individual within their particular lifeworld. Pringle et al. (2011) suggest that the idiographic nature of IPA is helpful for the nursing context and holistic approach to patient care. Occupational therapy, the professional background within this thesis, has a similar holistic focus which considers the individual in context (Wilcock 2006), and IPA is considered an effective methodology in this field (Clarke 2009, Cronin-Davis et al. 2009).

Within the present study, the idiographic focus means that each child’s experience of play will be interpreted in turn; this will then allow for a greater insight into the phenomenon of play for children with physical disabilities as a whole.

3.5.4. Conclusions

IPA as a methodology was originally situated within the field of psychology; it has since broadened and is used within fields such as occupational therapy (Smith et al. 2009). IPA is considered to be a useful methodological approach for occupational therapy research (Clarke 2009). The interpretivist paradigm in which IPA is based is congruent with the profession, which aims to consider occupation that is meaningful to the individual client (Clarke 2009). My professional training as an occupational therapist contributed to my interpretivist perspective and the importance I place on understanding what is meaningful to an individual. It is clear that both the experience of a phenomenon and the interpretation of this is vital to the IPA approach: *'Without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen.*' (Smith et al. 2009, p37). As an approach which considers the individual's experience, and the meaning of this experience, IPA is considered an appropriate methodology for this thesis which will allow the exploration of the experience of play for children who have high levels of physical disability due to Cerebral Palsy.

3.6. Other methodologies

Several approaches to qualitative enquiry present themselves as possibilities for exploring the concept of play, these approaches include: narrative research, phenomenology, grounded theory, ethnography and case studies (Creswell 2007). The following section will discuss these qualitative methodologies and the reasoning for using IPA in preference to these.

Narrative enquiry focuses on a story told by a participant about their experience, there are varying focuses possible such as autobiography, life history or oral history (Creswell 2007). The analysis of a narrative will often involve a descriptive and then interpretive phase (Murray 2008). This process can be referred to as 'restorying', where researchers unpack and reorganise stories into a framework (Creswell 2007). Narrative research often connects stories with the context of the participants situation; it can analyse both the content and structure of a participant's story (Murray 2008). Narrative enquiry has developed from social constructionism in a similar way to IPA (Smith et al. 2009). Some similarities to IPA can be drawn upon in terms of the construction of meaning through each participant's narrative (Smith et al. 2009). It is important to note that IPA varies from narrative enquiry in the way that it considers other aspects of experience, such as thought processes, emotions or body experiences, which are not necessarily discussed with the participant in a narrative manner. The narrative approach would focus on stories of children's play as a whole and the construction of these stories (Creswell 2007). It is therefore not an appropriate methodology for this study, which aimed to capture the experience of play for children in the present with a focus on their experience rather than the way stories were constructed and told.

Grounded theory aims to go beyond description and to develop a theory as a result of interaction with participants (Creswell 2007). Grounded theory generally uses interviews as a data collection tool to generate an explanation of a process or action. Differing grounded theory methodologies are presented by researchers such as Strauss and Corbin (a systematic approach) and Charmaz (a constructivist approach) (cited in Creswell 2007). Theoretical sampling is used in order to help the researchers to gain data that will best help theory to be formed, particularly following initial data collection and analysis (Charmaz 2008). As a process, grounded theory will often start inductively with individual cases and then move towards theoretical sampling and theory generation (Charmaz 2008). Grounded theory often requires generating a larger scale sample population than IPA in order to develop theory (Smith et al. 2009). Some similarities exist between grounded theory and IPA particularly in terms of the inductive approach to enquiry (Smith et al. 2009). However, in comparison to grounded theory, IPA tends to provide a more in-depth interpretation of experience of a small group of participants exploring convergence and divergence within findings (Smith et al. 2009). This contrasts to the depth of interpretation used in grounded theory for explanation of a phenomena and theory generation (Charmaz 2008). Grounded theory was considered inappropriate for addressing the experience of play for children with high levels of physical disability as the research question is concerned with gaining an in depth understanding of experience rather than generating a theory of play development for similar children.

The subtle realist approach suggested by Hammersley (1992), a founding ethnographer, is similar to the minimal hermeneutic realist ontology drawn upon within this thesis. However, some key differences stand between IPA and ethnography which led to the use of IPA for this research. Ethnography is an approach in which a certain culture, society or environment is the basis for the research (Creswell 2007). Realist ethnographers aim to report a situation from the objective point of view of an observer, critical ethnographers commonly aim to empower a group of people (Creswell 2007). Ethnography can be challenging due to the extended periods of time often needed for data collection in order to truly reflect the culture researched (Creswell 2007). This thesis aimed to primarily capture children's experience of play, this was situated within the context of their lifeworld, however the focus of analysis was not upon the culture and environment in which children play, as it would be within an ethnographic study.

The case study approach is also common within social science research and this involves exploring a phenomenon for a single or small number of cases, using multiple sources of evidence, within a specific bound system; the approach can be used for both descriptive and explanatory research questions (Yin 2012). The advantage of this approach is that it provides a detailed exploration, often using a combination of methods, within the context of one system (Creswell 2007). Yin (2012) successfully combines both qualitative and quantitative methods within a case study approach in order to gain a broader understanding of cases, a case study will often consider several sources of data and several influences upon a phenomenon. An IPA approach is more appropriate within this thesis as the focus is upon participants who share a common experience not within a bound system. The IPA approach provides the opportunity for in-depth analysis to understand the nuances of each participant and their situation (Smith et al. 2009).

3.7. Potential limitations in IPA research

Wagstaff et al. (2014) suggests that IPA research has many strengths in its rich interpretative account of participants' experiences of phenomena. IPA is also seen to be a methodology which is appropriate across disciplines and offers informative research findings which can shape practice (Wagstaff et al. 2014). Smith et al. (2009) suggests that IPA is a methodology which is both dynamic and holistic, it focuses on phenomenology, hermeneutics and idiography but also provides some flexibility within the approach. IPA is a relatively new methodology and there are some limitations in its application to research which will be discussed within this section.

IPA is relatively new to occupational therapists and therefore has not been widely used and applied to the occupational therapy field (Clarke 2009). The application and congruence with occupational therapy has however been argued (Clarke 2009, Cronin-Davis et al. 2009) and demonstrated above. IPA continues to be applied to a variety of fields despite its foundation in health psychology (Smith et al. 2009). As IPA continues to be used on a wider basis some concerns have been raised by Wagstaff et al. (2014) about the possibility of contrasting standpoints in terms of ontology and epistemology which can be applied by IPA researchers. Although this can be seen as a strength for the approach, Wagstaff et al. (2014) argue that this could lead to some philosophical inconsistencies in use of IPA. Despite this, as argued by Crotty (2003) if research is designed with congruity between its underlying philosophy, theoretical perspective and methodology then it can be produced with good quality and consistency. Within this research the key principles of IPA: phenomenology, hermeneutics and ideography (Smith et al. 2009) are aligned with the theoretical perspective and methodology and therefore philosophical consistency is seen throughout the study.

One often discussed limitation of IPA as a methodology is the time it takes to analyse the data; for this reason Smith et al. (2009) suggest that particularly for researchers new to IPA small sample sizes are used. Clarke (2009) states it is essential that enough time is given in order to analyse data in sufficient depth. Smith (2008) demonstrated different levels of interpretation that could be made within IPA research; within this research time and care was taken to go beyond a surface level of interpretation. A sample of 6 children was sought in order to provide enough time for in-depth analysis. In particular, recruitment was started as early as possible in order to give the time to begin the analysis process as each child was interviewed.

A further limitation to IPA as a methodology is that the emphasis on commonality between themes could be unhelpful and mean that the individual's perspective is lost within the study findings (Wagstaff et al. 2014). In reviewing the experience of carrying out IPA, Wagstaff et al. (2014) suggested that being able to represent the participants' suitably across the themes can be difficult in some cases. Despite this, the use of direct quotes from participants and close reference back to the transcripts during analysis can be used to ensure each participants voice is heard within the study findings. Within this thesis an emphasis was placed upon considering the multiple layers of analysis particularly in terms of each individual's perspective as focused on within the ideographic aspect of IPA.

The possibility of IPA being carried out with an insufficient level of interpretation can lead to IPA being thought of as a less rigorous and descriptive qualitative method; one of the essential pre-requisites to rigorous IPA research is in-depth analysis (Brocki & Wearden 2006, Larkin et al. 2006). In-depth analysis occurs through several levels of interpretation which emerge through interaction with the text rather than through pre-existing theory (Smith 2004). Brocki and Wearden (2006) suggest that as a key element of IPA the interpretation of data should be discussed in greater depth within published papers.

The small homogenous sample used within IPA studies is important to consider when evaluating research (Pringle et al. 2011). A small sample is recommended by Smith et al. (2009) but caution is given in the transferability of the study findings to a wider population. Pringle et al. (2011) suggests that researchers should recognise the limitations of a small population and not make over ambitious claims about transferability. Within this thesis a relatively small sample of children was sought. The research was aware of the use of a small and specific population within the population of children with Cerebral Palsy, this meant any application of findings to the wider population were carefully considered.

Finally, IPA has also been criticised for its concern with cognitions which can be seen as incompatible with its phenomenological approach (Brocki & Wearden 2006). Smith et al. (2009) suggests that at the core of IPA is a participant making sense of their experience, which can be considered a core human activity. Phenomenology involves both reflective and cognitive responses to a phenomenon (Smith et al. 2009). Smith et al. (2009) present a bandwidth of reflection suggesting different layers of awareness of an experience; data collected within an IPA study is thought to be within the '*attentive reflection on the pre-reflective*' where the importance of an experience is cognitively recognised and reflected on. Thus, Smith and colleagues present a clear argument for the place of cognition within the process of IPA and the suitability of this whilst still being a phenomenological approach. Within this thesis the thought processes and cognitions of the children reflecting on their experience have been considered as a part of the analysis.

3.8. Summary

The importance of congruence between the theoretical perspective, theory and methodology underpinning a research project is frequently stated within the literature (Stanley & Nayar 2014). The research presented in this thesis used a minimal hermeneutic realist ontology, social constructionist epistemology, and interpretivist theoretical perspective: this led to the use of interpretive phenomenological analysis as a methodology. The application of IPA to the study design led to the development of an interview protocol including visual methods in order to address the research question and this is discussed within Chapter 4. This study focused on the experience of play for children with Cerebral Palsy, believing that there is a reality of play, of which individuals have different perspectives, that is constructed through interaction with the world, and then interpreted through both the individual and researchers' perspective.

3.9. Reflexive account

Understanding and exploring the philosophical and theoretical perspectives which could underpin my research design was an interesting but challenging aspect of the present research. I found that I needed to read around the topic a considerable amount in order to be able to gain an understanding of the terms.

The process of understanding ontology and epistemology was particularly challenging. I found that I wanted my ontology and epistemology within my research to align with my ontology and epistemology in the rest of my life. As a Christian I have a perspective of reality in that there is one existing and present God. I found it difficult to align myself with the relativist perspective often used by qualitative researchers, in which every individual experiences their own reality, because I felt this directly contradicted my monotheistic worldview.

As I explored ontology further, I came across subtle or critical realist perspectives in which one reality is considered but with different viewpoints of this reality. During this process of exploring and beginning to understand the ontological spectrum between realism and relativism, my church was completing a talk series called *Windows on the Cross* (King's Cross Church 2015). The talks described a courtyard with the cross of Jesus in the middle of the courtyard, and several windows looking onto the courtyard; they outlined that each window provided a different perspective of the cross and of what Jesus did on the cross to enable relationship with God. This understanding of one reality, with multiple perspectives of that one reality in the imagery of a courtyard with several windows and perspectives of the object in the middle, enabled me to understand the idea of a minimal hermeneutic realist ontology. This ontological perspective as referred to by Larkin et al. (2006) describes one reality that exists but with different individuals interpreting this reality from different perspectives. For me this appeared congruent with both my worldview and understanding of reality, and perspective of the reality of play. This also concurred with the play research literature which, in its complexities, often concludes that play experience is real but is best defined from the perspective of the player (McInnes et al. 2009).

Once I had grasped the basis of ontology and epistemology, and the way they informed my methodology, I gained confidence in my research question and in the way in which I designed my research. I was pleased that the understanding of my methodology, and the theories underpinning this, led to clear answers to design questions which I was unsure of before. One example of this was in the use of the ideographic approach to data analysis. This meant that each participant’s view was analysed in depth before linking these to the whole. This approach recognised that knowledge was constructed within the context of the child constructing it; it also recognised that reality was understood by the child’s own interpretations. It was, therefore, clear that the analysis process should first start with the individual before it moved to the participants as a whole. As I understood my own ontology and epistemology and the implications this had for my research design, I was able to more easily structure and explain the philosophical perspective within this chapter.

The idea of social constructionist epistemology is one which made a great deal of sense to me, particularly in terms of the interaction of people within their context. This complemented the research question and the influence of context upon each individual’s experience of play. It took me a while to understand the differences between constructionism, social constructionism and constructivism, and at times I found interchanging use, and confusion of terms, frustrating. Once I felt like I had grasped the differences between these concepts, and the way in which the social construction of knowledge is fundamental to IPA and the making of meaning through a *person-in-context* (Larkin et al. 2006), I felt like I had a much clearer perspective of my research question.

I was pleased to be able to gain a better understanding of the philosophies and perspectives which underpin IPA as a methodology. I felt confident that IPA was the appropriate methodology for my research question and reflected both my personal and professional philosophy. I was keenly aware that in order to carry out IPA well I had to insure sufficient depth of data and analysis. This strongly impacted the way in which I designed my method. I wanted to be able to show that it is possible to use IPA with children, in particular a population of children whose communication and expression can sometimes be hard to understand. As part of exploring IPA as a methodology I posted on the IPA Yahoo discussion group in order to question the possibility of using IPA with children with Cerebral Palsy. I had a positive response from Jonathan Smith [one of the key IPA authors] in which he suggested that visual methods may provide a helpful addition to my method in order to gain a sufficient depth of response, but that in principle IPA was a helpful methodology for my research. Again, this led to an increased confidence in the writing of this chapter as I realised the contributions of the philosophy underpinning the methodology and its usefulness to this research. This was particularly clear in exploring the influence of theorists such as Merleau-Ponty (1945) and the concept of embodiment. It was clear that the idea of experiencing the *body-in-the-world* and the influence this has on understanding the meaning of an experience was going to be important for understanding the experience of play for children who had physical limitations to their bodies.

My professional experience as an occupational therapist and the knowledge of occupational therapy philosophy which has become a part of how I think and interact as part of my own *being-in-the-world* strongly influenced the philosophical and theoretical underpinnings of my research. As an occupational therapist I believe that well-being is improved through occupation and it is important to consider this occupation from the child's perspective within their own context in order that it is meaningful to them. This position reflects both my ontology and epistemology in that I recognise the reality of certain disabilities or activities but I work to understand and value each child's perspective (minimal hermeneutic realism). I also do this in combination with the child and their family in the context they are in in order to create a solution or meaning around an activity in a way that is helpful for the child (social constructionism). Within this research I was therefore aware that as a therapist my worldview, and my lean towards wanting children to be as independent as possible, would impact the way I would interact with and interpret the children's experience. I therefore felt the in-depth analysis, recognition of the double hermeneutic, and need for reflexivity, all outlined within IPA as a methodology, were important for this research considering the professional context that I brought to it.

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4. Methods

4.1. Introduction

The research design and method was fully considered and underpinned by the Interpretive Phenomenological Analysis (IPA) methodology, social constructionist epistemology, and minimal hermeneutic realist ontology, which are detailed and discussed in chapter 3. Semi-structured interviews were the primary method of data collection for this study, visual methods such as videos and photographs were used to prompt a greater depth of discussion within each interview. This chapter will summarise the involvement of advocates in the research design, the ethics and governance considerations, the participant criteria, the influence of the pilot interviews and the research protocol.

4.2. Involving advocates in research design

4.2.1. Importance of advocates

The importance of involving service users within the research process is emphasised within both literature and research grant application processes (Oliver et al. 2014) and has been seen to have a positive impact (Staley et al. 2015). As the participants in the current study were not service users the term ‘advocates’ was found to be an appropriate description of individuals who discussed and informed the research process (Graham et al. 2017e). A poster discussing the process of engaging children and young people as advocates in research design was presented at the European Academy of Childhood Disability Conference (Graham et al. 2016b, appendix 2). An overview of the involvement of advocates within this research is published within the British Journal of Occupational Therapy (Graham et al. 2017e).

A review of the research surrounding the involvement of service users to inform research would suggest that further publications and transparent evaluation of this involvement and the impact it has upon research practice is needed (Staley et al. 2015). Research highlights there are both benefits and costs to advocate involvement in research (McLauglin 2010), this was also seen within the current research project (Graham et al. 2017e).

Research involving young people or children as advocates within the research process is not widely reported. However, researchers such as Watson and Feiler (2012) were able to successfully involve a group of young people with disabilities in their study design and then two young people within observation in a study looking at how children with little or no speech can be involved in education. The focus on involving children and young people as active meaning makers (Nind et al. 2010) is becoming more apparent within research involving children and young people with disabilities. As this research focused on the experience of play for children with Cerebral Palsy it was essential to discuss the project with advocates who have Cerebral Palsy and could comment upon the study design and value of such a project.

As reported within the British Journal of Occupational Therapy (Graham et al. 2017e) the involvement of advocates was an integral and informative aspect of this project. Although standardised outcomes were not used to measure advocate involvement the practice analysis demonstrates the overall merit to the research process (Graham et al. 2017e). It is essential that advocates are involved at a collaborative rather than consultation level (Minogue et al. 2005); within this research advocate involvement directly informed study design (Graham et al. 2017e).

There were some challenges to the involvement of advocates when both pragmatics and experience highlighted an advocates idea as inappropriate: an example being the suggestions to use beanbags for communication of emotions by one of the advocates (Graham et al. 2017e). These challenges are also reflected by other researchers who suggest that sometimes researchers need to make decisions which consider but do not directly follow advocate suggestions (Oliver et al. 2014). There were however, several benefits to the involvement of advocates within the current study (Graham et al. 2017e). This included appropriate and informed design of participant information, interview questions, the format of the participant interviews, and practice and consideration of communication difficulties associated with Cerebral Palsy (Graham et al. 2017e). Similar benefits had been reflected within other literature reporting the involvement of advocates (Watson & Felier 2012). The present study therefore supports other existing literature in promoting the involvement of advocates in research design in order to enable studies which have a positive impact for the population they are designed to benefit. The article concludes that occupational therapy researchers should endeavour to involve advocates who are similar to their study population in research design, even when working with vulnerable populations (Graham et al. 2017e).

There is a recognition that there are some limitations in trying to find service users or advocates who represent the study population (McLaughlin 2010). Within this research study the population of children meeting the inclusion and exclusion criteria was very small; a pragmatic approach of involving advocates with similar needs who did not quite meet the inclusion criteria was therefore taken.

Two advocates were chosen for the present study, they were known to the researcher through family friends and through private practice. ‘Rose’ is a child the researcher had previously worked with as a private therapist. She is slightly more physically able than the children who were recruited for the study. As the potential study population was very small, using Rose as an advocate who did not meet the inclusion criteria meant that the researcher avoided reducing opportunities for potential participant recruitment. Tim is a family friend and had met the researcher on a couple of occasions previously and fell outside the age range for the study. The following section summarises each advocate and reflects upon changes to the protocol following meeting them.

4.2.2. ‘Rose’, study advocate

‘Rose’ (Pseudonym)
Rose is eight, and has a diagnosis of Cerebral Palsy. She is a part time wheelchair user and can walk short distances using sticks. She can move around independently through hopping on her knees. She can use gross grasps to manipulate small objects. Rose has no understandable speech but communicates through direct access to an iPad. Rose types words onto software which has voice output. She signs ‘yes’ and shows thumbs down for ‘no’.

Box 4 'Rose' study advocate

4.2.3. Reflection and summary following meeting with Rose

Discussion with Rose occurred dynamically. Rose moved around the room in order to show toys and illustrate what she wanted to talk about in terms of study design. Rose felt that her Disney characters were very important and she wanted to share these with me on several occasions. This enabled us to consider the best way to talk about play experience for children with Cerebral Palsy and highlighted that some children might like to show their toys and talk about them.

Rose sometimes answered questions slowly and would not always respond in the anticipated way. It therefore took time to understand Rose's full response and I sometimes did not understand her meaning. This emphasised the importance of allowing enough time for response when children are using alternative communication.

In discussing the study design with Rose she commented that she felt participants would be happy with their play being videoed and then watching the video back to talk about the experience. Rose commented that she would agree to this were she a participant. In addition to using videos, Rose discussed with me the use of photographs. Rose showed me photos of herself in order to demonstrate how she could talk about the link between these and her play experience. Rose had just been to Disneyland and enjoyed showing me a photo of her with a person in a Mickey Mouse costume but she did not think that was playing. In a second photo Rose looked like she was happy and was showing a drink she had made at school. Again, even though Rose looked like she was enjoying participation, she did not describe this experience of play. It is difficult to look at play experience without categorising activities. This enabled me to recognise that as much as possible questions during the interview needed to focus on experience of play rather than asking about categories of an activity, for example if something was considered play or work.

When talking about how to look at play experience Rose tended to comment on activities she liked to participate in and found playful. This highlighted that within the study interviews it was important to be able to go beyond a list of activities and look at feelings and thoughts during play in order to capture experience. Rose talked about playing with friends at school as an important part of her play experience- this was discussed and reflected on within participant interviews. In order to engage Rose in discussion she liked playing a yes/no game and she said that this was a good way to talk to children. This was used within the study interviews in order to both clarify participant responses and as a starting point for wider discussion.

Rose asked if I like playing with children that I work with. It was important to consider that some children may want to know what I think about play. When carrying out the interviews when children asked me about my own opinion I therefore re-directed them to ask them to share their ideas with me in order that their experience was captured.

Meeting with Rose enabled positive changes to my research protocol in the way that I used visual methods such as videos, toys and images to enable children to discuss their experience. It also provided a helpful contribution to the details of participant interviews in terms of initially using short questions but being aware of using open questions and discussion to elicit in depth rather than surface level discussion. Details of the changes made to the research as a result of advocate involvement are discussed in greater detail within the journal article published as a result of this process (Graham et al. 2017e).

4.2.4. Tim Ford, study advocate

Tim Ford
Tim is 19, he has Cerebral Palsy and is a full time wheelchair user, has very limited hand function and uses a dynavox to communicate controlled by switches within his head rest. Tim says 'yes' through raising his shoulders and arms and 'no' by looking to his right. Tim asked that his name is used in order that his contribution to the research can be recognised (consent form-appendix 4).

Box 5 Tim Ford, Study advocate

4.2.5. Reflection and summary of meetings with Tim

Discussion with Tim highlighted that understanding each child's 'yes' and 'no' is particularly important for children who have a physical disability. Tim said *'Some children are hard to understand and so some families give up and you need to find out their yes/no because I think 90% can say yes/no. I know one person who cannot [say yes/no]. But it is so few'*. Tim really emphasised that being able to understand his yes and no was key to communicating with him and would be key to communicating with children within my research project. When I started to chat to Tim his mum asked him to show me his yes and no so that I would understand what he was saying. Discussion with Tim suggested that he thought using yes and no questions was an easy way for communication that would take less effort than using a communication aid and would be helpful during interview.

Tim discussed some of his experiences in order to look at interviews and how to talk to children about their experience of play. Tim discussed that he enjoyed playing 'clown' and being funny. It was clear that this was really important to him because Tim used an exaggerated 'yes' with his body language and showed a big smile and eye contact to make sure I knew it was important. This led to me thinking about how I would be able to interpret and understand each child's experience, it appeared that expression and body language was really important to understanding what Tim was saying. It seemed that body language and facial expression gave Tim intonation and expression to the voice output of his dynavox this was important to capture when interviewing children about their experience of play.

As well as clowning and playing with traditional toys Tim talked about the importance of siblings in his experience of play- he discussed playing dens and holidays and on the computer together. This highlighted how important it would be to explore the experience of interacting with siblings in play in the study interviews.

We discussed that children would need to have the opportunity to withdraw, Tim suggested that instead of using the word stop children might find it easier to understand ‘finished’. This was therefore used as the term to talk about needing to stop within the study interviews and protocol.

I had an initial discussion with Tim about the participant information sheet. He suggested that photos or symbols would be helpful. He suggested a picture of a heart and a hand might be good for play; he was perhaps indicating that play is something that someone likes doing and therefore a heart representing ‘like’ and hands representing ‘doing’ may help to portray play. Tim also suggested symbols of things like ‘lego, doll, and bubbles’.

On meeting Tim for the second time he helped me to work through a selection of posters, which I had created following his and Rose’s suggestions, to choose the one that he felt was most appropriate for the children in my study. He chose one with simple wording and suggested that I changed the colour to yellow so it was bright, sat the girl in the picture in a wheelchair and used symbols for the main question about play. Tim also helped me to think about the question for play used within the participant information and suggested that I should use ‘What do you feel and say about play?’ to explain that I want to find out children’s experience of play. Tim suggested that the participant information sheet was good but needed ‘*more colours as white is a hospital colour’*. Tim was able to make helpful suggestions about the wording and presentation of each of the posters, participant information and assent forms I showed him. I made edits to these in consideration of Tim’s recommendations (appendix 4, 5, 6, 7, 8).

Tim was also able to discuss the interview schedule with me. He thought that most of the questions were good but there were some that he suggested I should not include because he thought that they were too similar to the previous questions. Some edits were made to the interview schedule following an interview with Daniel (the pilot and first participant) but most of the interview schedule remained as it was following Tim's recommendations (appendix 9).

Communication with Tim was easier on the second visit because I was more familiar with his mode of communication. It was difficult when participating in conversation to be patient and wait for the child to respond before second guessing when I was unsure of what is being said. I learnt to wait until Tim had used his dynavox to find the word that he wanted to use and then I could ask him yes and no questions to clarify this. I used a lot of clarification questions where I reflected back what had been said to make sure I understood. This is a technique I needed to use during interviews- using reflective statements and asking children 'is this right?' allowed them to correct me if I understood them wrong. Asking each child at the start of their interviews at what point they wanted me to guess or wait for their communication meant that the children were able to communicate more effectively.

Several changes were made to the research protocol following discussion with Tim, particularly in terms of the visual material used for recruitment, the interview schedule and the method. Tim was also helpful in contributing to discussion and my own thinking during the process of data analysis. Contact was made through one face to face meeting discussing initial findings and then further email and postal exchange. Further details of the benefits and challenges through this process are found in appendix 2 (Graham et al. 2016b) and Graham et al. (2017e).

4.2.6. Reflexive summary of using study advocates

The use of advocates who have similar experiences to the sample population was really helpful in informing my research design, allowing me to consider aspects of my project which I had not previously considered.

The opportunity to talk to the advocates really emphasised the importance of using yes and no questions as an initial means of communication which enabled more in-depth discussion to take place following yes and no responses. This was clearly something that Tim felt was really important and wanted me to take into consideration for my study design.

It was helpful to discuss length of time for each participant interaction with both advocates. My discussions with each advocate took longer than I anticipated and I was surprised that Tim said two hours as a reasonable time for each visit to my study participants. I had previously felt that by two hours children may feel fatigued and would not want to continue to engage with me. This is something individual to each child and needed to be considered with each participant. Rose found that she needed breaks from talking to me and shorter 10 minute bursts of discussion in between opportunities for her to play enabled me to best discuss my study design with her. Flexibility was essential in talking with each participant. It was recognised that the use of communication aids takes a long time and therefore participants need extra time to be able to give their response. Both advocates also commented that they would be happy with the researcher attending their home to carry out interviews on more than one occasion.

There were some aspects of communication which I found difficult to understand and interpret. I could see the effort it takes to type a sentence on an alternative communication device and therefore I really wanted to be able to understand what each advocate was saying. On reflection I am not sure whether I fully understood what Tim was trying to tell me at one point in the interview despite several attempts to clarify this during the discussion. As communication was a whole body process and included words as written on alternative communication devices together with ‘yes’ ‘no’ signs carried out with varying degrees of enthusiasm, and some vocalisation, I felt that I needed to video record the interviews in order to accurately transcribe them. Through videoing each interview I was able to capture more of each child’s experience through the extent to which they portray emotion through their body language, this is similar to capturing intonation used in speech which cannot be portrayed in a computer output device. Although this information could be written down, it would be difficult to accurately capture it all, particularly if several yes and no responses are used, therefore video recording was considered the best way to collect the data accurately.

Another situation that was encountered in discussion with the advocates is to the extent to which Cerebral Palsy is mentioned. Although I had met both advocates previously I was unaware of their knowledge surrounding Cerebral Palsy and their limitations in terms of their physical disability. I did not want to talk about this directly but I could see that in interviewing the children I might want to try and look at their experience of playing when they need to use alternative communication for their voice. I needed to be aware of each child's awareness of their physical limitations and take great care in discussing play in these terms when interviewing each child. As I was not looking at how they do *not* experience play I did not want to focus on activities that children *cannot* do, rather I want to look at how they *do* experience play.

4.3. Ethics and governance

Full ethical considerations were made in the design of this research project and ethical approval was sought and received from the Faculty Research Ethics and Governance Committee in the School of Health Sciences (appendix 10). Ethical approval from the Integrated Research Approval System (IRAS) was not sought following discussion with IRAS advisors, a certificate showing that the Research Ethics Committee (REC) approval was not needed is also shown in appendix 10. The following section will summarise considerations made in terms of risks and conflicts of interest, consent and assent, personal data, and sensitive research topics. The section will finish with a summary of the recruitment process before following onto the next section describing the research protocol.

4.3.1. Risks and conflicts of interest

As an occupational therapist it was important to consider any conflicts of interest in terms of my professional and researcher roles. It was possible within the research that children may have mentioned therapists or therapy provision known to the researcher. In most cases this did not take place and any discussion of those known to the researcher was kept confidential. As an occupational therapist, I was also aware that I had the responsibility to safeguard any children that I encountered in professional practice who may be at risk of harm (COT 2010). This was considered within the research protocol and any children disclosing information regarding situations which may have caused harm to themselves or another would have been discussed with the researcher’s primary supervisor. This follows government advice and standards for safeguarding children and young people (The Charity Commission 2014). No safeguarding issues were raised during this study. Had any issues arisen these would be raised with the local authority social services team with a summary of what was said. In an emergency the police would have been contacted. In the case of poor practice being disclosed on behalf of the therapists this would have be discussed with the researcher’s primary supervisor and passed on to the manager of the therapist’s team if deemed necessary.

The risk of psychological distress the participants may have felt was considered to be low. This risk was reduced in the first instance by making sure that the children were aware they could withdraw at any time. Each child’s parents were asked to provide their child with support should they feel distressed during the study. Both the child and the parent had the opportunity to talk about what the study would involve and think about the kind of areas that would be discussed. This meant parents could talk through any issues or comfort their child if they did experience distress. Parents were advised that should children appear to be particularly distressed on an ongoing basis they should seek psychological support for their child via their general practitioner. Children were also provided with information about the charity ‘Childline’ if they wanted this on the initial meeting, this meant children could then choose to contact Childline should they experience any distress or unease. No psychological distress was reported as having arisen as a result of the interviews.

The opportunity to finish participation or have a break during research is recommended by ethical guidelines for research with children and young people (Shaw et al. 2011). Children experiencing distress or fatigue could ask to ‘finish’ at any time. This was the most appropriate term as suggested by the study advocates (4.3). The researcher discussed the process of pausing or finishing the interview at the start of each meeting with the study participants. Participants could request a break at any point in the meeting, following this the researcher would check with each child whether they wanted to stop for the day or continue. Most children needed at least one break during their interviews for the opportunity to stop for a drink or snack, or to ask their parents a question; all the children continued the interview following this break.

One risk also considered was that children and parents may feel coerced into participation (Shaw et al. 2011). It was possible that the parents or children may have perceived their choice to participate as impacting upon their involvement in the charities used for recruitment. It was made clear within the participant information that involvement in the study would have no impact upon their current or future involvement within the charities (appendix 5, 6). It was recognised that participation in the study involved a large time commitment, therefore the researcher was as flexible as possible in terms of arranging times and locations that were beneficial to the family. The study took place in the home environment but for one child this was across two extended family homes and their own home as they had been staying there for the holidays. The researcher followed the child and parents lead as to the location of the interview within each home, where possible the researcher encouraged the child to choose.

As the charities used for recruitment are national organisations, it is possible that in a future occupational therapy role the researcher may encounter a child who participated in the study. Following the completion of the project, should one of the children from the study be allocated to the researcher’s caseload, this will be discussed with the family and the researcher’s manager at the time in order that the family can choose to work with a different therapist if they prefer.

4.3.2. Sensitive interview topics

Interviews focused upon asking children about their experience of play. When discussing their thoughts feelings and interactions around play experience there was a minimal risk that children may discuss topics which they found sensitive, embarrassing or upsetting. The Nuffield Council on Bioethics (NCB) (2015) highlighted the importance of making sure that children fully understand and are aware of the possible sensitivity of topics they discuss. Following the consent process, interviews therefore started with broad questions about experience before prompting greater depth so that children had the opportunity to build rapport with the researcher. As an occupational therapist regularly working alongside children with disabilities and their families, the researcher has a good understanding of non-verbal cues which may indicate a child is not comfortable. At any point the researcher felt the child may be uncomfortable they asked the child if they were ‘finished’ in order to give them the opportunity to have a break or finish the research meeting entirely.

4.3.3. Risks to the researcher

The researcher followed a lone-working policy, and friends of the researcher knew the general town and area that the researcher was going to and when she was expected home. The researcher made sure that the phone she was using for the purposes of contact with participants for this study was on at all times during meeting participants and could therefore be used quickly in an emergency. During the interviews, no emergencies took place and the researcher remained safe throughout.

4.3.4. Consent and assent

Informed consent was gained from a parent or guardian of each participating child. Both the child and parent had the opportunity to read and consider the participant information sheet written specifically for them before discussing this with the researcher (appendix 5, 6). Consideration was made to ensure that children fully understood the study and had thought about the potential positives and negatives of taking part (NCB 2015). Children with disabilities particularly have suggested that they do not want to be seen as more vulnerable but would like the opportunity to participate in research in the same way as their peers (NCB 2015); the participants were therefore given the full opportunities to consider participation in the study.

Research being undertaken with children needs to have careful consideration of the involvement of children throughout the research process, particularly with regards to gaining informed consent (NCB 2015). The process of explaining the study to the child was important and enabled a trusting relationship to be developed. Assent is appropriate for children who have the ability to form views and express their wishes with regards to research but do not have the capacity to make an independent decision (NCB 2015). All children participating within the study fell into this category. The National Research Ethics Service (NRES) (2009) suggest that children between the ages of 11 and 14 may become able to make an informed decision and fully understand the project, the recommendation is therefore to seek assent rather than consent from children until they are 14. Research suggests that children from around age 6 have the ability to provide informed assent (NRES 2009). Therefore, as the children within this study are between ages 6-12 they were all asked to assent. Tait et al. (2003) found that children age 7-15yrs had less competence than older children in their decision making. Other researchers such as Hurley and Underwood (2002) found that children under age 10 had limited understanding about confidentiality. This highlights the need to work in partnership with the family as highlighted by several ethics recommendations (NRES 2009, Shaw et al. 2011, NCB 2015). Parents legally must give consent for all children under the age of 16 to participate in research (Shaw et al. 2011). Throughout the consent/assent process the researcher worked in partnership with the child and their parent in order to explain the study and gain agreement for participation. Separate forms were used to make a record of this process: a consent form for parents (appendix 7), and an assent form for children (appendix 8). As consent and assent relies on close partnership with the child and their parents', discussion in this document with regards to recruitment refers to the 'family' unless it is specific to the child or their parent.

As part of the ongoing process of assent, the researcher checked with each child at the start of each meeting that they were happy to continue. It was made clear the child could stop participating at any time. The researcher made sure she would ask if the child was appearing disengaged and may like to stop (Shaw et al. 2011). Had a child chosen to finish all their involvement within the study this would have been respected and the child would have been withdrawn. The child's data to that point would have been used unless upon discussion the child requested this was not used.

The researcher who went through the process of consent and assent has 6 years of clinical experience working with children who have disabilities and therefore has the ability to communicate with and understand the children who participated in this study. Prior to discussion with the researcher and completion of the assent form, parents were asked to talk through the child's version of the participant information sheet and consent form with their child without the researcher present. This helped to reduce the possibility of children feeling too embarrassed or shy to ask the researcher certain questions or decide not to participate. It is possible that children may have felt pressure to participate from their parents, the researcher therefore spent time discussing the research process and assent form with the child in order that they could make an informed decision and choose to not participate if they wished.

Following the start of the analysis process it was recognised that the analysis would be enhanced by the use of the participants' video data. Therefore, further consent and assent was needed for the participants' video data to be used as part of discussion. This resulted in application for an extension to ethical approval. This was granted, and new forms were sent out to parents by both email and post with a stamped addressed envelope (appendix 11). These were all returned completed by parents and their children.

4.3.5. Consent and assent process with potential playmates

The children participating in this study were asked to allow the researcher to video them playing at the start of each meeting. This video was recorded on a tablet computer and played back during the interview with the child to prompt deeper discussion about their experience of play. The children had the opportunity to involve any playmates, toys or activities that they choose to play with in their home environment in order to aid discussion. This was not restricted as the study aimed to capture the child's experience of play and this may involve other people. Limiting playmates to just those in the child's family may have prevented a child from discussing a large proportion of their play experience which could be with friends. An information sheet and consent/assent form (appendix 12) would have been provided for children who were asked to be playmates and their parents. No participants requested a child playmate who was not a sibling. Had they requested this, the forms would have been given to the parent of the child participating in the interviews prior to data collection meetings in order that any potential playmates could discuss this with their parents. Parents of participant children would have been asked to give the information and forms to the playmate's parents at least 5 days before the data collection meeting in which they would attend. The opportunity to contact the researcher to discuss the study would have been provided. The parent/ adult consent form was also provided for any adult playmates such as carers (appendix 7).

Only siblings, parents and carers participated as playmates within the child's videoed play sessions. Before the videoing commenced the researcher made it clear that the purpose of the video was to inform discussion with the participant and would not be used for data analysis. If a consent or assent form was not provided, or children withdrew their assent, then the play activity would not have been videoed at that time and the participant would have had the opportunity to play independently or rearrange the session for another time.

4.3.6. Personal data

Following the Caldicott principles, the researcher only sought out necessary information from each participant (Crook 2003). A basic demographic information sheet was used to collate: parent's name, child's name, gender, age, number of siblings, address, schooling type and support level, and type of Cerebral Palsy and level of functioning were captured according to the GMFCS, MFCS and CFCS. These details helped with the interpretation of each child's experience. The researcher used pseudonyms to represent each child who chose to participate in the research. Only the researcher had access to confidential details such as each participant's address, phone and email details. The researcher used a separate mobile phone for the purposes of the study. Any personal information e.g. names and addresses were kept in paper format in a locked cabinet, personal video data was kept on a password protected external hard drive. One coding sheet linking participants to pseudonyms was also kept in the locked cabinet. Other information sharing, including details such as age, number of siblings and type of Cerebral Palsy, was referred to using the child's pseudonym in order to protect their anonymity. All data collection and personal information remained anonymous, transcripts were shared with the researcher's supervisors and key sections were discussed with one of the research advocates, Tim (4.3). It was made clear to the participants that this sharing of information would take place. Following the successful completion of the PhD all video data will be deleted and all personal information in hardcopies shredded. Anonymised transcripts, using pseudonyms, of participant interviews will be kept securely.

4.3.7. Participants

Six participants who were age 6-12 and had high levels of physical disabilities due to Cerebral Palsy were sought for this study. Tamm & Skar (2000) used 6-12 year olds for their study as they suggested that children younger than six would be unable to participate in interview, and children older than twelve would spend less time playing. The use of this age group was further justified through the developmental stages: children aged six to twelve are thought to be at a stage where they are developing concrete operations and games stage of play, they will be competent in manipulating objects physically and cognitively, as well as using symbols (Piaget 1951, Michelman 1974), this may enhance recall of play experiences. Although children with physical disabilities may not be able to physically manipulate objects as their typically developing peers it was assumed by the researcher that the rest of their play ability had the potential to be at this level. Children older than age twelve transition to the formal operations stage of play where they are developing mastery of thought in preparation for adulthood and adult occupation (Michelman 1974), these children therefore may not have been able to represent the view of children whose primary occupation is play.

Smith and Osborn (2015) discuss the difficulty in deciding a sample size for research studies using IPA, but suggest that 5-6 participants or less would be a recommended number for researchers new to IPA in order that sufficient depth of interpretation can be reached. Six participants were therefore sought for this study in order that the researcher had the possibility to gain enough in-depth data. A homogenous sample- one with similar participant characteristics, is commonly sought for interpretive phenomenology (Smith et al. 2009) and therefore narrow inclusion criteria of 6-12 year olds with specific levels of functioning indicating high levels of physical disability was used. It is recognised that this is a very small percentage of the population of children with Cerebral Palsy (Cooley Hidecker et al. 2012). Participants for this study were recruited from national and regional charities working with children who have Cerebral Palsy in order that a sufficient number of participants could be recruited.

4.3.8. Inclusion criteria

The following inclusion criteria helped to include children with high levels of physical disabilities who are currently under represented in discussing their experiences within research (Powrie et al. 2015).

- **Diagnosis of Cerebral Palsy.** The children who participated needed to have a Cerebral Palsy diagnosis.

- **CFCS level I-II**. The children included within this study were at Communication Function Classification System (CFCS) levels one and two and were therefore able to send and receive information with familiar and unfamiliar partners but occasionally needed extra time (Cooley Hidecker et al. 2012). These children had the capacity to provide assent to participate within the study.

- **GMFCS IV-V.** Children were functioning at Gross Motor Classification System (GMFCS) level IV or V. This meant that children could have some self-mobility with limitations, and would use powered mobility or be transported in a manual wheelchair (Palisano et al. 2007).

- **MACS II-V**. Children had hand function at Manual Ability Classification System (MACS) levels III-V meaning they needed help to prepare or modify activities involving their hands and may have been able to handle a limited selection of easily managed objects in adapted situations (Eliasson et al. 2006).

- **Children who could participate in a one hour discussion, in at least 20 minute bursts.** Children may have used a communication aid, they needed to be able to engage in a length of discussion which allowed them to sufficiently share their experience of play.

4.3.9. Exclusion criteria

- **Limited understanding of English.** Research participants who had difficulties in adequately understanding English were excluded from this study as conversations already take a long time and can be frustrating for children who use communication aids (which was likely in the study participants). Additional time taken to translate was likely to make communication more frustrating and confusing for the participants. In addition, the cost of an interpreter was not within the budget allocated for this research project.

- **Living outside of mainland UK.** Participants living outside mainland UK were excluded due to money and time limitations which restricted travelling further afield within the remit of the study.

- **Previous occupational therapy provision by the researcher.** Although the researcher does not work for any of the charities through which recruitment is took place, in the unlikely event that a child who had received therapy from the researcher in her role as an occupational therapist offered to participate they would have been excluded. This would have been to avoid coercion or influence on the way that the child talked about their experience. This, however, did not occur.

4.4. Data collection

4.4.1. Introduction

Commonly interpretive phenomenological approaches would primarily use interviews in order to gain an understanding of the participants' experience (Smith & Osborn 2015). However, other researchers within the field of nursing have also suggested that observation can be a part of an interpretive phenomenological methodology (Crist & Tanner 2003). Within this project video recording of play experiences allowed each child to observe and reflect back on their play during interviews. Interviews needed to be slightly more guiding in nature than an IPA project with adults in order to capture enough depth from children as participants (Smith 2004).

This study used interviews in order to explore the experience of play for children with high levels of physical disability. Visual methods such as videoed play experiences, photographs, and each child's favourite toys, were used during meetings with each participant. This enabled the researcher to gain more in-depth information during interviews through helping the children to reflect more deeply. A detailed explanation of the recruitment process and methods are as follows.

4.4.2. Recruitment

Potential participants received the study advertisement in charity newsletters or through posters or flyers inviting participants to the study within the charity centres (appendix 4). Charity staff who were aware of the study could signpost potential participants to the posters, flyers, or newsletters for their information. The following charities agreed to place posters and notices within newsletters for the purposes of recruitment within their centres: the London Bobath Centre, The Bobath Centre Wales, The London Centre for Cerebral Palsy, and 1Voice. Participants were able to opt in if they wanted to participate within the research. The participants either made email or phone contact with the researcher, or completed a response slip, which was passed onto the researcher by charity staff. Snowball sampling was used to identify additional participants once some participants had been found, parents and therapists who had heard about the study were able to pass on the study poster/ flyer/ newsletter advert to friends they had who may have be interested in study participation. It was made very clear that choice to participate or not would not affect each family's involvement in the charities.

Once contact had been made the researcher sent the participant information sheets (both the child and parent version) (appendix 5, 6) via email to the child's parents and did not request any further personal data. The researcher asked the parents and children to carefully read the participant information and then let the researcher know if they were happy to proceed with the study. The researcher then requested permission to contact the families via their preferred communication method (phone or email) a week after sending the participant information in order to check whether they would like to participate. If families no longer wished to proceed, their email, name and telephone number, were deleted. This occurred for one potential participant and parent who felt her daughter was too old (age 12) to reflect on her experience of play. If participants wished to proceed, the initial visit was arranged via phone or email, in order to discuss the study, gain consent, and set up further meetings with the participants in order to collect data. The researcher collected all the research data with each participant and their family.

4.4.3. Pilot data

The researcher made contact with a parent known to her as part of a wider professional network whose child did not know the researcher and participated as the pilot participant. Three pilot interviews were carried out. The pilot interviews informed the researchers approach to data collection and resulted in slight changes to the interview schedule. For example, the need for further discussion of how each child saw themselves and what was important to them, prior to discussion of play, was seen within the pilot interviews. This led to the adaptation of the interview schedule to include initial questions around who and what is important to each child before we talked about their play. The interview schedule which was used as a guide during interviews is found in appendix 9.

Another key realisation that took place during the pilot interviews was that the depth of data and discussion appeared to increase across the three interviews. It appeared that by the third interview the child had covered more surface level discussion of play and therefore was able to discuss and explore his own experience in more depth. Although originally the intention was to carry out two to three interviews with each participant, it appeared that three interviews were more appropriate in order to gain a sufficient depth of data.

As the research population is small, the pilot data was included within the findings of the main study in order that as much in-depth data as possible could be gathered.

4.4.4. Research location

Meetings with each participant took place in the child's home environment as this was a familiar context. One participant had been staying in the house of a friend and the house of family members and asked that two interviews took place there. The context of an occupation is important within occupational therapy practice (Hinojosa & Blount 2014), social context is also important to consider within an interpretive phenomenological approach (Crist & Tanner 2003). The use of the participant's home or an environment chosen by the participant also meant the families did not need to travel unnecessarily for the research. The familiarity of each participants' home also meant that they could more easily draw upon toys or objects around the home to discuss their play experience. Parents were asked to be present in the vicinity but not in the same room in order that the child could feel free to share their experience. If children requested the presence of their parent then this was made possible, but it was made clear that the child needed the opportunity to express their view without influence or interruption (Shaw et al. 2011).

4.4.5. Protocol

An initial meeting was arranged with participants in order to build rapport and discuss the study. There was the opportunity for this to be as a separate visit, however, each of the participants chose to do this prior to the first interview. This appeared to be easier for families in terms of time commitments to the study. On initially meeting each child, the researcher aimed to interact with the child in order to build rapport and learn how they preferred to communicate. The researcher provided the opportunity to discuss the participant information sheet and answer any questions that the participants had. At this initial stage, if the child did not seem aware of the study process, the researcher used pictures of each stage of the research to talk through what would happen; these pictures were taken from the participant information sheet, printed on A5 and laminated. This allowed the opportunity for informed discussion and the building of rapport. Consent and assent forms were then discussed with both the child and the parents and they were given the opportunity to consider and complete these. If the child agreed their assent but did not have the physical ability to sign or make a mark they could choose for their parent or carer to sign on their behalf.

The basic demographic information sheet was completed by the parent and their child in order to place the child's experience within their context. The criteria for GMFCS, MACS and CFCS was provided on laminated sheets so the parents could identify their child’s level of functioning if this was unknown. There was a low risk of distress for parents in looking at the criteria, however, this was considered a minimal risk as most parents would have recognised the classification systems through previous interaction with therapy services. Parents were reminded of their right to withdraw their child from the study should their child ask to withdraw or appear to become distressed. Children were also reminded of their right to withdraw.

During the initial meeting the researcher also discussed with the child the kind of play experiences that they would like to show the researcher during each visit. If the child wished to invite other children or adults to participate in their play the information and consent forms for this were given to the child and their parents.

On each visit the researcher provided the child with further opportunity to ask questions. The researcher then used a tablet to video a play experience of the child’s choice lasting 5-10 minutes at the majority of the interviews. This was agreed with Tim and Rose, the study advocates, as a suitable length of time to record play experience and participate in a play activity. The child was given the opportunity to choose this play experience in order that they could discuss it within the interview. The playmate was sometimes mentioned within the child’s discussion of their experience. Pseudonyms were also used for playmates in order to protect their identity. The researcher tried to remain neutral and just record the play experience at this time. If the child tried to involve the researcher within the video the researcher asked them to show the camera what they were doing and tried to redirect them to a playmate already present. Some of the participants chose not to do a video on all of their three interviews but chose to engage in other visual methods such as drawing a picture of their play.

Following the video recording of a play experience, the researcher sat down with the child. Most children tended to sit in their wheelchair or a supportive seat in order that they had the postural control to communicate effectively. The researcher made sure they were sitting on a level with the child in order that they could make eye contact and communicate with them but also read any responses the child might make on their communication aid, if present, in order that these could be clarified if necessary. The researcher set up a Go Pro on a stand in order to video capture the interviews; an iPhone audio recorder was also used as a backup in case the video recording did not work. The researcher then followed the interview schedule to start a general discussion about the child's experience of play.

Flexibility of the data collection instrument is an important feature of IPA (Smith & Osborn 2015). As the research process needs to be individualised and flexible with children who have disabilities (Shaw et al. 2011), the use of the interview schedule and visual methods were slightly different for each participant. Following each interview, the researcher transcribed the data and wrote new interview questions to prompt discussion around further play experience or to clarify what had been said. The children were therefore engaged in a conversation about their experience of play with the researcher, making use of the interview schedule to gain deeper discussion where necessary. Depending on the child, at a time deemed appropriate to the child and researcher, the discussion focused on the video recorded at the start of the session. This was played back and paused to allow the researcher to ask questions such as 'what were you thinking?', 'What were you feeling?' and therefore elicit more in-depth data. On some occasions the child chose not to use the video but used the opportunity to show their toys or draw a picture of their play experience and talk about it with the researcher. Each child also had the opportunity to show photos of themselves playing if they wanted to. As photos and toys were used to enhance discussion within the interviews they were not copied or specifically recorded as data separate to the interview transcripts. Any drawings done with the researcher and the participant were kept in order to enhance the data analysis of the interviews. Consent was gained to include these within the thesis as a point of reference.

Throughout the interview process it was appropriate to allow occasions for the child to have a comfort break, receive personal care, talk to their parent, or have a rest from talking. The option of having a break was made clear at the start of each interview. The researcher then asked the child whether they would like to continue or whether they would like to finish. At each point the child requested a break the researcher paused the recording, this was then resumed when the conversation was continued. It was hoped that interviews would be recorded in at least 20 minute intervals at a time; this occurred throughout the participant interviews. As per discussion with Tim, one of the study advocates, the researcher went to each child's house for up to two hours. Interviews lasted between 1 and 1 ½ hrs as discussion using a communication aid or with a child with dysarthric speech can take a long time to clarify. If the child did not request any breaks or ask to finish the interview was not continued after one and a half hours.

Interviews were transcribed verbatim; this included a process modelled by Wickenden (2010) who carried out interviews with teenagers using communication aids. Anything said using a voice output communication aid was recorded in italics; anything the child speaks was written in standard text, anything signed or pointed to in a communication book was written with the mode of communication in brackets. Non-verbal communication, body language and expression was also noted in brackets. Discussion with the study advocates indicated that this expression is important to capture in terms of understanding play experience. With an IPA approach to analysis transcription tends to look at the conversation and consider significant pauses, laughs, and key body language (Smith & Osborn 2008). This was captured through the video recording of each interview for this study population.

As each interview was completed the analysis process began in order that the researcher could clarify any areas which were not fully understood or go back to the play experience videos to ask further questions as necessary.

The second and third meetings were repeated as the first. More than one interview was necessary, as demonstrated by the pilot interview, in order to gain an in-depth exploration of each child's experience.

4.5. Data analysis

Interpretive Phenomenological Analysis was used as the analytical approach for exploring the data. Interview data was transcribed by the primary researcher, making note of any gestures, signs, speech and alternative communication the child used. The analysis process then involved: consideration of each transcript individually; reflexivity of the researcher; reading and rereading transcripts; making initial interpretations; creating themes; making links between transcripts; and then further interpretation for dissemination. Analysis is a flexible process which may be adapted by the researcher, however, Smith and Osborn (2015) suggest the broad outline of the process which occurred as follows:

- Consideration of each individual's transcript before looking at differences and comparisons between participants (Biggerstaff & Thompson 2008);

- Reflexivity of the researcher throughout the process by using a research diary. Reflexivity allowed the researcher to be aware of any assumptions they made during the research process and consider the dynamics between themselves and the participant (Crist & Turner 2003). A diary compiled by the researcher is commonly used for reflexivity within IPA (Biggerstaff & Thompson 2008);

- Reading and re-reading transcripts whilst noting any thoughts, feelings and assumptions that occurred within the margins (Biggerstaff & Thompson 2008). Sustained engagement and interpretation of meaning is key within IPA, it was important for the researcher not to just capture descriptions;

- Initial interpretations occurred and any links between what the participant had said throughout their interview were noted down at this stage. The researcher also noted down anything significant or interesting that the child had said;

- Initial interpretations were then developed further to look for themes. The researcher read through their thoughts in order to develop concise phrases or themes which captured what was said by each participant;

- The researcher then went through a process of connecting the themes by listing them and looking for connections. This can be done through clustering themes together to create concepts of key ideas. The clusters of themes were then checked with the original transcript in order to make sure these stood true for the participant. Phrases that participants said which directly related to and supported themes were noted at this point. The themes and sub-themes were then summarised in a table with references to where they occurred within each transcript;

- The researcher then continued the analysis with other cases, looking for similarities and differences between cases. Themes were not selected and focused on due to prevalence with the transcripts but due to meaning placed on them by the participants;

- During the write up of the initial findings further interpretation of the participants' data occurred as the researcher looked for a way to appropriately capture this. This involved explaining the themes and creating a narrative which captured the experience of play for the children who participated in the study. This needed to carefully identity what was said by participants and the interpretation as a result of this.

2.1. Rigour

Rigour of qualitative research is an important consideration within research design. One of the ways in which rigour is demonstrated is through consistency in philosophy, methodology and theoretical perspective which underpins the choices in the method (Bunniss & Kelly 2010, Stanley & Nayar 2014). This was ensured through careful consideration of the researcher's philosophy and methodology (see chapter 3).

Stanley and Nayar (2014) address rigour in qualitative research specific to occupational therapy. They suggest that within phenomenological research it is important to gather data from participants who will be able to provide a rich experience captured through methods such as in-depth interviews (Stanley & Nayar 2014). This study used multiple interviews of the study participants in order that an in-depth level of data analysis could take place. Within qualitative research which recognises the influence of the researcher upon interpretation a research diary and reflexivity is key (Stanley & Nayar 2014). Within this study a researcher diary was used to provide a reflexive account which could be referred to throughout the data collection and analysis process.

Long and Johnson (2000) discuss the debate of quality criteria within a qualitative research paradigm and the application of the terms 'reliability' and 'validity' as measures of rigorous research. It is argued that the terms reliability and validity should be continued to be used for all research in order to not cloud and confuse quality issues (Long & Johnson 2000). However, interpretive research cannot provide the same reliability or demonstrate consistency of a measure in the way that quantitative research can; therefore, new ways in which qualitative researchers can seek to demonstrate validity within research is considered necessary (Long & Johnson 2000). Member checking, where participants check the accuracy of their transcripts before data analysis, is one such way of increasing rigour (Long & Johnson 2000). Whilst member checking was not used, the researcher made use of follow up interviews to clarify and further explore topics that each child had brought up previously. This opportunity to explore and clarify areas which appeared significant to the data helped to improve rigour.

Within IPA Smith et al. (2009) discuss the quality criteria as suggested by Yardley (2015). Yardley (2015) suggests the following criteria which were used to inform the quality and validity of the present study:

- **Sensitivity to context** involves both being aware of the socio-cultural context of the participant and being sensitive to the participants' data (Yardley 2015). IPA is firmly situated as an approach looking at the person-in-context (Smith et al. 2009). The ideographic approach of the present study in line with IPA helps to enable its sensitivity to context. The use of a demographic information sheet, and general questions about what was important to each participant at the start of interviews enabled the research process to be sensitive to the context of each participant.

- **Commitment and rigor** requires the researcher to carry out the research with sufficient depth and breadth in order to be able to accurately provide an account of the participants' point of view (Yardley 2015). Yardley (2015) suggests that this involves personal commitment to the research to ensure that it is carried out well and the methods are appropriate for the study aims. Within IPA attentiveness to each participant is key at each stage of the research process; sufficient idiographic engagement and levels of interpretation will demonstrate commitment and rigor (Smith et al. 2009). Within the present study the researcher committed to a thorough and in depth interpretive analysis of each participant's data. The researcher also undertook rigorous planning of the research method, and extensive learning about IPA as a methodology, in order to explore the understanding of play for 6-12 year olds with high levels of physical disability due to CP.

- **Transparency and coherence** involves clarity of description of the research process, and the extent to which the study makes sense as a whole (Yardley 2015). This depends upon a strong fit between the theoretical approach, methodology and methods used (Yardley 2015). Smith et al. (2009) suggests that building a coherent argument within an IPA study will involve close description of recruitment, interviews and analysis. Within the present study, this is found within the current chapter (sections 4.1-4.5). Examples of the analysis process are found within the findings chapter (chapter 5).

- **Impact and importance** is essential within qualitative research; the researcher needs to show how the study has an impact upon understanding and practice (Yardley 2015). Yardley (2015) suggests this is often a result of asking the ‘so what?’ question. Smith et al. (2009) concur with this and suggests that IPA research should aim to be of impact and importance. This research aimed to bring an original contribution to knowledge in terms of understanding the experience of play from the perspective of children with high levels of physical disability.

4.6. Summary

The importance of transparency and coherence within the methods is essential to rigorous qualitative research (Yardley 2015). This chapter has provided a detailed account of the methods of this research project and the way in which it has been carried out. Three semi-structured interviews with each child, informed by the use of visual methods such as video, drawing and looking at toys, were the primary method of data collection within the research. The IPA methodology informed the research method and analysis process which has been detailed above.

4.7. Reflexive account

The process of carrying out the research was one that I thoroughly enjoyed. It was interesting and exciting to be able to take the time to discuss and try to understand the views of children with high levels of physical disabilities. There were times in which it was a challenge to know what to ask each child and times in which it felt like I may not have been able to gain enough depth of data. This particularly occurred when I was interviewing children who were using assistive communication devices or had very dysarthric speech. Some children particularly gave very short answers and did not expand on these despite me trying to ask them to. A couple of sections of my reflexive diary following interviews with Daniel summarises this:

‘I was concerned that I went on from questions too quickly and did not allow room for exploration. This was perhaps because I was relieved that I had understood. I was pleased that the conversation moved from predominantly eye gaze

[technology use] to predominantly speech in terms of providing slightly more opportunity for flow in conversation. The need for constant clarification was difficult as this often interrupted or meant the flow of what was being said was lost.' (Following interview 1 with Daniel- pilot participant)

'Despite not needing to use AAC [augmentative and alternative communication] except at the beginning I still tended to check [what Daniel was saying]. I need to try and leave more silence and gaps for Daniel to continue his story. At the start of the next interview I want to encourage Daniel to tell me stories not about what or how he plays but what he thinks and feels about play and what it means to him- I'm hoping this will gain more in-depth responses.' (After interview 2 with Daniel, pilot participant).

The challenge of a lack of depth of data felt very real and of importance because I knew that in order to carry out a good IPA study I need sufficient depth of data and analysis (Larkin et al. 2006). I found that as I analysed the data from the first two participants I was able to get more depth of analysis than it may have initially appeared. This was both a relief and an encouragement that I would be able to capture the experience of play for children with high levels of physical disability due to Cerebral Palsy. I also found that some of the later participants naturally discussed their experience in more depth. This meant that I was able to more easily analyse and understand their data.

Throughout the process of interviewing the children I felt that my skills as a researcher improved with the study population: I developed my ability to understand the communication of children with high levels of physical disability; I developed my skills in exploring participant's experience in-depth; I also developed confidence in my ability to adequately capture and explore this data with each child. This occurred in several ways. For example, as I became familiar with my own interview schedule and started to analyse previous participant's data I was more open to what each child's experience could be, and this enabled me to prompt and question further when necessary. As the interviews evolved it became clear that children's own experience of their play contrasted to what was observed on the video. This meant that in latter interviews I could draw more attention to this and explore this in greater depth than I did in initial interviews.

As I built rapport with each child and practiced understanding dysarthric speech, I was able to more easily understand communication and therefore used less clarifying repetition of what the participants said. I learnt to be able to stop myself from jumping in straight away to clarify understanding and instead wait until each child had had the opportunity to fully express what they were saying. This occurred both from the first to the sixth participant and from the first to third of each child’s interviews. By the third interviews I was often more able to leave space for the child’s communication and understand what they said. I felt that by the third interview with Daniel (pilot participant) I had become more confident in gaining a balance between clarifying communication and allowing space and time in order for him to expand his answers. This was a skill that I then used in subsequent interviews. I still however, had moments of uncertainty:

‘I am challenged when I transcribe by the number of times I still manage to misunderstand what Daniel is saying to me. At points this means I miss key pieces of meaning which could have been explored further had I understood the first time. I feel that in some ways my lack of understanding prevents Daniel from expanding his ideas as much as I’d like him to. Whilst interviewing I [experienced] an internal struggle between thinking I’ve understood and wanting to nod and encourage further expansion, and at the same time a real fear that I may have misunderstood or not understood correctly [and that] when I transcribe [I may then] completely misrepresent Daniel’s point of view… In Daniel’s case I do not feel like this has changed the meaning of his transcript, however, it highlights the difficulties of being able to accurately capture the views of the group of children that I am working with.’ (After interview 3 with Daniel, pilot participant).

I found that communication with my second participant, Abi, was easier than my first interviews with Daniel and I was able to encourage more depth within conversation as I had grown in my interview skills. As I continued to interview the participants they all had different communication challenges but I felt that I became more familiar and more able to overcome these barriers. In particular, Jess gave very detailed responses and this really helped with the findings and analysis process in terms of understanding her perspective in depth. I felt that it was most difficult to gain an appropriate depth of response from Tom who had no verbal speech and only used his eye gaze technology and eye pointing for choices. This meant that I had to be creative in the way that I explored depth with

Tom without putting my own opinion into his responses. Tom is cognitively very able and this meant that I could give him the option of ‘something else’ and he would choose this until I understood what he was trying to say.

The more I spoke with the participants the more confident I became in exploring their experience in depth. Following Daniel’s interviews as the pilot participant I introduced the use of drawing as part of visual methods. The opportunity to draw with each participant appeared to be significantly helpful in enabling more discussion with each child. Some children chose to draw themselves and at times this reduced the amount of time and discussion as they could not talk at the same time as drawing. This happened for Abi who used her mouth to hold the pen. Despite this, discussion about what the children chose to draw and the words they would use to describe each aspect of their experience were particularly helpful. This enabled me to reflect on and understand what each child prioritised in their play as well as how they wanted to represent this to others. As I interviewed each of the children, I became more familiar with questions and phrases I could use to elicit a greater depth of response. I increasingly used the phrase *‘I want you to pretend you’re like a teacher’* in order to ask children to explain to me what they meant by a certain phrase or word. I became less afraid of leaving pauses in order to enable children to expand on their thoughts and ideas and this was often helpful in generating a rich response.

I found that all of the children were able to manage the methods used well. Where children appeared fatigued, I recognised this and made sure they stopped when they wanted to. Most of the children found it difficult not to talk to their parent or carer during the interviews unless they were out of the room; once the children became familiar with me as a researcher I sometimes took the decision to ask the child and parent if they would be happy with the parent out of the room. This often appeared to enable the children to talk more freely and to start to share in more depth with me rather than focusing their communication towards their parent. There were times when children wanted to stop and clarify something they had done or to get help to find a toy they wanted to show me from their parents. Requests such as asking where their teddy was, or when they were moving to a new school, often occurred by the children initially shouting for their parent. At these points we paused the recording in order that the child could talk to their parent before resuming the interview if they wanted to proceed. There were times in which children needed to stop for a drink and snack or for personal care within the interviews, again, we would pause the recording and then continue this when the child was happy.

In terms of videoing each child playing at the start of their interviews there were a couple of occasions where children chose not to do this. This only occurred because the child had already recorded a video at the previous interview and had not had time to talk about this properly. This therefore meant there was more time to discuss what they had already shown me previously. I found that none of the children requested a child playmate to join their play. This raises an interesting question for the future in terms of how often children with high levels of physical disability have their friends around to play at a time that they have chosen. Children tended to play either on their own, or with their parent, carer or a sibling.

I found that the distance travelled to the participants' houses gave me time to think and reflect on what I was going to ask each child during each meeting. On the way home I was able to reflect on what had been said and then record this in my reflexive diary. I felt like this time enabled me to be able to process some of what I had been thinking in response to the children's accounts. One example from my reflexive diary is this:

'Abi appears to have a sense of adventure and wants to pursue independence and being first to do/ try things- she appeared to feel happy that she is the first person to have a joystick she moves with her mouth. Abi talked about her electric wheelchair and how she wants to be able to do tricks and crashes- it appeared that this was not a desire for physical sensation but just because of a sense of play?' (Following second interview with Abi).

Reflections such as this one enabled me to be aware of my view and what I was thinking about the data during the analysis process. They were also helpful in enabling me to consider the possible meaning behind what each child has said. The immediate reaction to the interviews recorded within my reflexive diary was helpful to consider and contrast to my reaction to the data upon re-reading and addressing it through the analysis process.

I found that whilst the method remained almost exactly the same as originally intended, throughout the research process I was able to develop my skills as a researcher and therefore improve the success of the method. The skills I have developed through the process of carrying out the method have not only been helpful in my development as a researcher but also as an occupational therapist. I have found that I am now more attuned to understanding the slight communications of children with high levels of physical disability, I now also place more value on stopping and letting children fully explain their view point and experience before trying to help them by guessing. I have realised that although my intension is often to help children to communicate with me effectively, second guessing can actually cause more barriers and breakdowns to communication than waiting for a child's full response. The flexibility of the IPA approach and the visual methods meant that as I carried out the research process and better understood each child's communication it was easy to adapt to each child's needs and preferences within the interviews. This also meant that I could focus on visual methods (such as creating play drawings) which were helpful as a point of discussion.

5. Findings

5.1. Introduction

This chapter outlines the findings of the research following a process of Interpretative Phenomenological Analysis (as detailed in chapter 4). Superordinate and subordinate themes representing the experience of play for the six participants will be discussed in relation to quotes from their interviews.

5.2. Participants

Pseudonym	Daniel	Abi	Lucy	Jess	Ben	Tom
Child Age	9	11	8	8	8	6
Child type of Cerebral Palsy (CP)	Dystonic quadriplegia	Dystonic, athetoid quadriplegia	Spastic Quadriplegia	Spastic Quadriplegia with dystonia	Spastic Quadriplegia	Dyskinetic quadriplegia
Child Schooling	Mainstream, 50hrs support per week	Mainstream with 1:1 support	Specialist provision for physically disabled children	Mainstream with 1:1 support	Mainstream with 1:1 support	Mainstream with 1:1 support
GMFCS	IV	V	IV	IV	IV-V	V
MACS	IV	V	III	III	IV	IV
CFCS	II	II	II	I	II	II
Number of siblings	1	4	1	1	1	1
Notes	Sibling not always at home. Communicates with eye gaze and verbally.	Bilateral hearing loss. Verbal communication. Siblings no longer at home.	Developed speech in the last 3 years, communicates verbally.	Identical twin of sister who does not have CP. Communicates verbally.	Verbal communication	Communicates through eye gaze and choice making. Sibling no longer at home.

Table 1 Summary of participant information

Six children participated in interviews as part of the study. Details of each participant can be found in table 1 alongside their pseudonyms. Pseudonyms are used throughout this thesis to refer to the participants and friends and family they mention. All 6 children have high levels of physical disability due to Cerebral Palsy (CP). Three boys and three girls took part. The youngest participant was 6 years old and the oldest 11; the majority of participants were age 8 or 9. The children varied in their chosen communication method: one participant only used eye gaze technology, one participant used a combination of eye gaze technology and speech; the other four participants used speech to communicate. Four of the participants have dystonia or dyskinetic movements as part of their CP diagnosis; this means that they experience fluctuations in tone which impact on their ability to control their movements (SCPE 2000). Five of the children attended mainstream schooling with support, one child attended a specialist provision for children with physical disabilities. All the children had siblings who influence their play participation, however, only Abi, Lucy, Jess and Ben had siblings who were always at home.

5.2.1. Pilot participant

Daniel initially participated in the study as a pilot participant in order to ascertain the effectiveness of the method. Daniel's interviews led to some slight changes to the protocol in terms of the introduction of further visual methods such as giving each child the opportunity to draw their play experience, however, the interview data collected from Daniel still provided an insight into his experience of play. As the study population is very small (Cooley Hidecker et al. 2012) it was decided to include Daniel's data within the findings of the whole study in order that helpful data was not lost; Daniel and his mum gave consent for this. Daniel is therefore referred to here alongside other participants.

5.2.2. Influence of communication on analysis

The nature of each child's physical disability is such that it had an impact upon their interview participation. All of the children, apart from Jess, function at CFCS level II, which meant that their communication was effective but at a slow conversation pace, and needed time for composing messages and repairing miscommunications (Cooley Hidecker et al. 2012). This had an impact on the way that each child was interviewed. Often the children responded with short answers, as communicating extended answers was too difficult with a communication aid or dysarthric speech. This meant that the researcher often had to ask several questions in order to reach a sufficient level of depth of response, for this reason several quotes used to illustrate themes also include the researcher's communication.

Each participant's communication was significantly enhanced by the play video that was captured before each interview and then played back and discussed within the interview. For this reason, in analysing the data it was important to consider the participant play videos alongside their responses and comments about the videos. The contrasts between what was observed within the videos and what each participant said will be reflected on within this chapter. Screen shots of aspects of the video have been presented with short descriptions of what was occurring within the video in order to supplement the discussion of the themes. Throughout the analysis process the researcher reflected back on the participant videos and these supplemented the interpretation of the findings.

5.3. Analysis process

The analysis process occurred as outlined within the previous chapter. Each participant's data was analysed ideographically; each interview was taken in turn and commented upon. Following this, themes and subthemes were created alongside a narrative summary for each participant. This can be found in appendix 13. All the participants' themes and subthemes were then considered at once and drawn together as part of the process of interpretative phenomenological analysis. Discussion of the first iteration with the supervisory team found that this did not reach sufficient depth; therefore, a process of carpeting – laying out and grouping each theme and subtheme together – enabled the researcher to begin to create a more coherent iteration of themes and subthemes. Photos of this process can be seen within appendix 14 alongside an example of the analysis process. Following this, the researcher took time away from the data focusing on reading articles and theories applicable to the data. The analysis process was then revisited and themes and subthemes were further interpreted and went through several iterations. The process of writing the findings chapter enabled the researcher to finalise the findings and ensure that sufficient interpretation, grounded in the participant's data, had been reached.

5.4. Developing themes

Following the analysis process superordinate and subordinate themes were finalised. A summary of the superordinate themes and subthemes can be found below in table 2. Further participant quotes to illustrate themes are found in appendix 15.

Superordinate themes	1. Making choices and controlling play	2. Participating differently to peers	3. Connecting with others in play
Subthemes	1.1. Facilitated independence- helpers become an embodied part of self	2.1. Disability as a part of self	3.1. Using humour to enable connection
	1.2. Seeing self as physically strong and successful	2.2. Engaging in play through watching	3.2. Using voice to be heard in play
	1.3. Choosing to compromise vs. having to compromise	2.3. Extreme emotion- frustration and excitement played out	
		2.4. Imagined self without disability- a new spatiality	

Table 2 Summary of superordinate themes and subthemes

5.5. Narrative summary of themes

For Daniel, Abi, Lucy, Jess, Ben and Tom **making choices and controlling play [1]** appeared to be an important part of their play experience. It appeared that even when an outsider sees an adult physically facilitating and enabling play to happen, the children had a sense of independence and control over their play. All of the children discussed at different points within their interviews a ***facilitated independence – where helpers become an embodied part of self [1.1].*** This occurred when the children were observed to have an adult physically supporting their participation and yet reported choosing and controlling the play independently. Within each child's mind their choice to participate meant that they perceived control over the play activity, even when they were letting the movements of their body be controlled by another. By ***seeing themselves as physically strong and successful [1.2],*** children appeared to experience a sense of being in control even when an observer may not view the experience in the same way. For example, Ben talked about being the *'beast'* at rugby, a term used to demonstrate his strength and success, yet when observed playing rugby he needed his mum's physical support to participate. This feeling of self-efficacy seems to enhance the experience of making choices and controlling play. Part of making choices and controlling play was influenced by times in which children ***chose to compromise versus times when they had to compromise [1.3].*** There were occasions when children made decisions to play something and participate in a game that would not be their first choice because they still had the opportunity to participate. At these times children's choice to compromise appeared to still give them a sense of control over their play. On the other hand, there were times when children had to compromise their choices and this led to feelings of isolation and lack of control. For example, when all of Abi's peers participated in netball in the playground she initially felt like she was not able to join in.

Each child, although often drawing similarities between their play and their peers, also talked about **participating differently to their peers [2].** Each child saw their ***disability as a part of self [2.1]***; there appeared to be a normalised, everyday acceptance of life with a significant physical disability. Two of the participants referred to themselves as *'disabled'* (Abi, Jess), other participants talked about things they *'can't'* do (Daniel, Ben). The normalised sense of disability as a part of self particularly occurred in terms of wheelchair use; the use of a wheelchair appeared to be such an integral part of each child's experience that it was often not mentioned. Children's view of their life with a disability often led to them commenting on different ways they participate from their peers. For example, ***engaging in play through watching [2.2].*** There were times in which physical participation was not possible because of the child's disability and therefore through watching, instructing or cheering, children could experience participation in play activities with their peers but in a different way. Examples of this occurred when playing with lego or playing netball in the playground. The extent of each child's physical disability also meant there were times in which children experienced a need to persist in trying to play something they would like to. As each child's disability impacted their participation, their experience often involved ***extreme emotion – frustration and excitement played out [2.3].*** The nature of Cerebral Palsy is that when children experience heightened emotion such as excitement this can often lead to an increase in tone and exaggerated movements (Yap et al. 2010). These exaggerated movements were often played out during activities when children achieved success or were frustrated because they could not participate in the way they wanted to. For example, when experiencing excitement at winning a game, or frustration at not being able to move with the intentionality needed to push a button. It is possible that the level of frustration and difference experienced in play for the participants meant that they choose to experience a different reality in their imaginations. The majority of the participants spoke of an ***imagined self without disability – a new spatiality [2.4]*** in their imaginary play. They discussed themselves as playing in their imaginations, yet with the only difference that they could walk, run, jump and climb freely. There is a distinct contrast between each child's lived experience of embodying their disability as a part of themselves, and the new spatiality and freedom they experience when playing as their imagined self without physical restrictions. This contrast highlights the possible differences in play experience to that of each child's typically developing peers.

The final theme highlights children's preference for **connecting with others in play [3].** Feeling a sense of belonging is important to every individual's health and wellbeing (Wilcock 2008). Part of belonging within play is being able to connect with others. Although similar strategies may be used by typically developing children, it appears that the children within the study particularly made use of communication strategies to enable connection with others. It is possible that because of their physical limitations and good communication skills the participants draw upon communication as a strength within their play participation more than their typically developing peers may. ***Using humour to enable connection [3.1]*** was one way in which most of the children demonstrated playfulness with their peers. Children discussed using jokes, doing silly things at playtimes and using funny words to make their peers laugh. This appeared to provide a joint sense of fun within play, which enabled a feeling of belonging. The participants also ***used their voices to be heard in play [3.2].*** This was particularly significant for children who used alternative communication rather than speech. The use of their voice and sound was used by children to highlight to others that they were playing. The connection this enabled appeared to provide validation of the play experience for the child.

5.6. Theme 1: Making choices and controlling play

Each child frequently spoke of participating in activities through the first person: for example, *'I played a little game' (Daniel, interview 1); 'I played jenga' (Abi, interview 3); 'I played babies' (Lucy, interview 1); 'I play with my cats' (Jess,* *interview 1); 'I played in the garden scoring a try with my Gilbert [rugby ball]' (Ben, interview 1);* and *'I play football' (Tom, interview 1).* These first-person responses were inevitable as each child was asked about their own experience of play. There is an assumption that the use of first person indicates the first person involved has been active themselves in what they are commenting on. However, for the participants often their use of *'I'* and expression of choice and control occurred at the same time as receiving significant levels of adult support or adaptation within their play. This level of support needed for children with disabilities is discussed within the literature (Lauruschkus et al. 2015) and appears to directly contradict the sense of agency the children appear to demonstrate through the use of *'I'.*

The feeling of making choices and being in control of a play activity appeared to be important. Jess' comment *'I just like doing what I want'* (interview 2) emphasises the importance of this. It appears that children use active choices, which could range from doing something alone, to letting someone physically take over, in order to remain in control of their play. The tension of gaining this control and making choices to play is seen as children weigh up their physical limitations alongside doing what they can.

5.6.1. Facilitated independence – helpers become an embodied part of self

There were several times within the participant interviews where children perceived themselves as making independent choices and having control of their play, even when they were being physically supported and moved by an adult. This subtheme has been termed '*facilitated independence – helpers become a part of self*' because the independence the children experience is facilitated through the physical support of an adult. In some situations this facilitation is recognised (see Tom's extracts below); in other situations children need prompting to recall the physical facilitation they required (see Abi's extract below). In both cases, and throughout participant interviews, this facilitated independence appears to lead to children experiencing their helper as a part of themselves. The children to some extent embody their helper- their helper becomes the external edge of themselves which then enables them to experience independence in an activity such as rolling a dice.

In following the research protocol Tom chose to be videoed playing with his iPad so he could then discuss this. This is captured in figure 6 where Tom is seen being supported by his mum to manipulate the iPad and play the game that he has chosen. Tom's interviews suggest he experiences a tension between an awareness that his mum is facilitating his play and a perception in which his mum has become an embodied part of himself and his play. When commenting on the play video (seen in figure 6) in the first interview Tom comments that he is choosing the play and not his mum. However, Tom then chooses *'Mummy doing it'* when asked *'when Mummy's helping you, is it still [you doing it] or is it [Mummy doing it]?'*[1] As the conversation continues, Tom recognises that it is *'Tom's hand'* but his mum helping him. It seems that Tom perceives his mum's hand over his as an embodied extension of his own hand. This perhaps occurs because it enables Tom an experience of choice and control; where Tom physically cannot get his hands to do what he would like to do he can choose to embody his mum's hands, which enable a freedom and control in completing the chosen activity.

Figure 6 Facilitated independence- helpers become a part of self. Tom is playing with his iPad and receives physical support from his mum but perceives this as himself leading and controlling the play.

When the same play clip is discussed during Tom's third interview he appears to have a much stronger view that this is play that he is doing by himself (box 6). Although within the first discussion Tom does recognise that his mum is helping, he is perceiving it as his hand and therefore himself controlling the play. Within the second quote Tom sees himself as playing by himself, choosing and controlling the play. This is further illustrated within other interviews. Abi is also seen to perceive herself as independently controlling her play despite having had physical support from the researcher to roll the dice (box 7).

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[1] (square brackets ([ ]) within quotes indicate options given by the researcher through holding up hands for Tom to choose from to communicate his thoughts).

N- You’re playing with your iPad! And how does that feel? How does it feel playing on your iPad?
T-car
N- it feels like cars
T- (looks yes)
N- does it feel [like driving a car] or [something else]?
T-[chooses ‘like driving a car’]
N- and is that because you had to [move it a bit like driving a car] or [something else]?
T- [chooses ‘move it a bit like driving a car’]
N- move it ok and were [you playing] or was [somebody else]?
T- [chooses ‘you playing’]
N- you were playing, excellent
T- (vocalises)
N- yeah, were you doing it [by yourself] or [not]?
T- [chooses ‘by yourself’]
N- by yourself cool, and was [someone helping you move it] or were you [doing it by yourself]?
T- [chooses ‘by yourself’]
Tom, Interview 3

Box 2 Tom, Interview 3- Perception of playing by himself despite having adult support.

N-ok so who helps you roll the dice?
A- I do it on my own, do you remember, shut the box. (indicating back to game where Abi rolled the dice), like that, rolling the dice.
N- Rolling the dice like that, but in shut the box I had, I was holding your hand?
A- oh yeah
N- but I was just, I was just helping?
A-Yeah
Abi, Interview 3

Box 7 Abi, Interview 3- Perceives herself as rolling the dice independently despite adult support.

For Abi she has embodied the researcher to the extent that she needs prompting to remember the researcher’s physical support which enabled her to throw the dice. Abi sees herself as doing *‘it on my own’* (box 7), as being independent. The rest of Abi’s interviews indicate that independence is an important concept for her and this is intrinsically woven into her play narrative; she frequently comments: *‘I want to be independent’* (interview 3). Abi has a high level of physical disability, which she explains impacts her ability to hold objects: *‘I don’t use my hands…[I] use my mouth’* (interview 1). Abi’s Cerebral Palsy means that she cannot use her hands to manipulate objects unless she has a high level of physical facilitation.

When Abi's helper becomes an embodied part of her and an extension of what she can do, Abi has a means by which she can physically achieve more of the activities she would like to when she is playing. Abi's desire for independence and control over her activities, including play, appears to influence her perception. This occurs to the extent that Abi perceives facilitated independence as herself being independent and in control. This directly contradicts the experience of play that may be summarised by an observer, where Abi is seen to participate through the physical facilitation of an adult. It is possible that Abi makes a conscious choice in enabling an adult to physically support her play. However, it appears that the facilitated independence that Abi experiences occurs on a subconscious level. As Abi has grown up with her disability she would be very familiar with the presence of adults supporting everyday activities- this may lead to a greater extent of experiencing independence despite adult facilitation. It is possible that the narrative of adults supporting Abi, such as parents commenting on independence or achievement, have increased Abi's perception of doing activities by herself even when she receives support.

Figure 7 Section of Ben's play drawing- Playing bulldog as 'just me'. Perception of control despite having facilitated independence.

Facilitated independence appeared to be a way in which all the participants experienced a sense of control of their play. Figure 7 shows a section of Ben's play drawing where he has asked to draw himself playing bulldog. Ben, earlier in his interviews, talks about having a teaching assistant push his chair during bulldog. Then when drawing bulldog as part of his play Ben refers to it as *'just me [playing]'* when he is asked if there's someone helping him. Ben embodies his helper to the extent that he perceives his movements in bulldog as independent. This suggests that children experience a facilitated independence not only with the familiarity of their parents but also with other adults who support them. It is possible that although when pressed Ben is aware of the presence of a helper he has become used to receiving support and therefore his definition of 'independence' and being able to participate in an activity may include the support of an adult as a normal occurrence. This facilitated independence through the embodiment of a helper is perceived as full independence by the child and is a type of play that should be captured and discussed by parents and professionals working with children who have high levels of physical disability.

5.6.2. Seeing self as physically strong and successful

Although there were times in which children spoke of the limitations caused by their Cerebral Palsy, each child appeared to have a dominant narrative in which they perceived themselves as physically strong and successful in their play. It appeared that the children have an internal tension between knowing the restrictions that the Cerebral Palsy places on their body and experiencing play as a positive activity. Often, despite facilitation, adaptation, or support to physically participate, children would perceive their participation as physically strong and successful. The experience of play and the feeling of being able to participate appeared to be a positive contributor to each child's sense of identity and self-esteem. Each child talked about success within their interviews in relation to their play. Ben comments *'I'm a brilliant goal keeper'* (interview 1) and Jess celebrates her success at horse riding- *'I didn't have space for [all my rosettes] on my t-shirt, I had to have one on my fleece!' (interview 3).* The children seemed to have an understanding of success that could be different to the understanding success of typically developing children. It is possible that they were unaware of the level of support they needed to achieve that success, or that they had experienced encouragement from peers and adults around them to the extent that they perceived success even when they needed significant adaptation in an activity.

The participation within physical activities in which they could demonstrate their strength was often a choice that children made to participate. All of the children chose to participate in physical games or sports: Daniel, Boccia; Abi, netball; Jess, horse riding; Lucy, football; Ben, rugby; and Tom, kicking a ball. Within each physical activity the children participated in, supports were in place to enable them to take part, but these were often only mentioned following prompting. Abi needed to be able to ask her peers to throw the ball in netball; Jess had two helpers either side of her horse to make sure she did not fall off; Lucy was passed the ball and could push it with her wheelchair; Ben was physically held and moved by his mum to play rugby. The physical support needed appeared to be an afterthought for each child; their reporting of their play focused on a perception of themselves as physically strong and successful. It could be argued that there is an unspoken different definition of success for the participants in the study in comparison to their typically developing peers. Adaptations such as allowance to hold the ball, the opportunity to move slowly, and redefinition of what counts as a goal were not discussed by the children but appeared to be in place. Despite the need for these adaptations and adjustment to 'success' the children continue to view themselves as physically strong and successful in their play.

The portrayal of a greater sense of excellence than may be noted by an observer is seen within Tom's interview when he is playing the keyboard with two hands to create a tune (box 8).

> *N- So are you doing [one hand at once] or [two hands]?*
> *T- [Chooses two hands]*
> *N- two hands! And is two hands, which is better [one hand] or [two hands]?*
> *T- [chooses two hands]*
> *N- two hands. And why is that because it [makes a better sound] or [something else]?*
> *T- [chooses it makes a better sound]*
> *Tom, Interview 2*

Box 8 Tom, Interview 2- Talks about creating a tune which sounds 'better' on the piano.

Although to an observer Tom may appear to just be hitting the keys in a way that does not seem to be creating an obvious melody, his perception is that he is creating something of excellence. Tom is deliberately choosing to move his hands in a way that he feels creates something *'better'.* This view of success (where a child perceives something as better than an observing adult) is seen in all children's play, but is perhaps more pronounced for the children participating in the study. It is possible that for Tom the action of being able to participate in an activity that has clear cause and effect feels very satisfying. The nature of Tom's physical disability is that he often would find it difficult to generate an intended action towards an object. Playing the piano allows direct and consistent feedback to Tom knows he can control, this is likely to enable a greater sense of success for him.

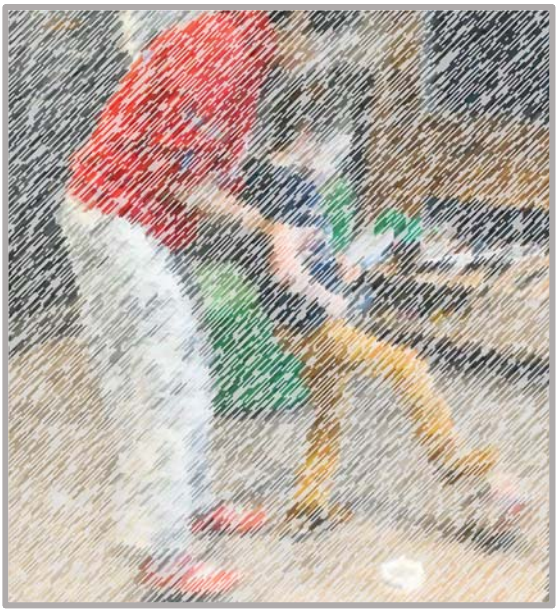

Figure 8 Ben 'I'm going to kick off' (interview 3) kicking the rugby ball with the support of his mum.

Celebration of success is common among the children and they often celebrate achievement when they participate in games. Daniel celebrates success in his iPad game, he comments *'I sometimes win'* and that winning makes him feel *'joyful'* (interview 1). Ben, when demonstrating how to use a rugby ball comments *'I am the beast at rugby'* (interview 1). This attitude of success continues throughout Ben's interviews where he discusses how he is going to *'win the world cup'* within his physical rugby play which is supported by his mum (figure 8, box 9). The identity that Ben presents when talking about his participation in play is one of being successful and being able to achieve what he would like to. This identity supersedes and appears to overlook any frustrations or difficulties where physical disability may limit the potential of success of his play. Ben realises the need for his mum to be physically supporting him in the play. He comments *'I do it too'* when asked about sliding along the floor with the rugby ball. Ben has made a choice to give his mum some physical control over his play but he sees them as making the choice and physically and successfully participating together. Ben holds this in tension with the physical instruction that he needs to follow (*'bend down, bend in the middle and then you slide', interview 3)* in order to be able to successfully participate. Within the play video Ben attempts the slide a couple of times before he achieves a flexed position with his body so that he can slide. As opposed to becoming frustrated that his body is not complying with his choice to participate in a slide as part of his play, Ben overcomes this by trying again, alongside his mum, and focuses on his thought that he is *'winning the world cup'.* Ben's comment *'you kind of break your knees though'* suggests that he

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experiences some physical pain in practicing to slide. Although Ben mentions his knees, his focus appears to be on the celebration and the idea of winning. This is interesting in considering the nature of play for Ben. It appears that his mind is predominantly focused on being in his game and the thought of winning. Although Ben has an awareness of his physical needs and is following his mum's instructions so that he can physically slide his predominant view is around being physically strong and successful in the way he is controlling his play.

N-What else did you do for your celebration?
B- slide along the floor
N- how do you do that?
B- so you bend down, bend in the middle and then you Slide (emphasis and shout) along!
N- wow
B- you kind of break your knees though
N- oh do you, and who normally does the sliding?
B- Mummy!
N- so does Mummy normally help you slide?
B- yep and I do it too
N- and what are you thinking in your head when you're sliding?
B- I'm going to win the world cup
Ben, Interview 3

Box 9 Ben, Interview 3- Talking about how he celebrates his success in playing rugby

Ben often discusses physical play as part of his interviews. He also talks about how *'[he] love[s] playing rough and tumbles it is fun'* with his sister and his dad (interview 3). Ben's identity as a player is focused on being able to physically move and participate. This ability to move and to perceive physical strength and success enables Ben a sense of control over his play. Ben needs to choose to participate and focus on helping his body to move (i.e. *'bend in the middle'* (interview 3)) even when his mum is physically supporting him. Ben is controlling the narrative of the play in his mind; as he slides he is picturing himself as a rugby player who is part of the world cup. His physical participation, even though it is supported, augments his perception of choice and control of his play activity.

The concept of success and physical strength as enhancing children's perception of making choices and controlling their play is clearly seen within Daniel's interviews. Daniel picks up a Harry Potter wand within his third interview and he engages in a play dialogue stating: *'I've got the* *power'* and *'I am the conqueror'* (interview 3). His assurance in his ability as strong and powerful appears to transfer to his identity as a player who is physically strong and successful in making choices and controlling play. Because of the participants' high levels of physical disability, it is possible that they build physically powerful play identities within their suspended reality play that then enable them increased confidence and motivation when they do participate within an activity physically.

There is also a recognition with the children that their choice and control of their play and their participation within activities can change over time. This was related to their perception of their strength and success. Daniel talks about how he has improved his physical strength and participation in a way that enables him to now play by throwing balls down some guttering: *'but it is ok because now, now I can open my hand for it'.* Daniel was aware that his physical strength had improved and this enabled him to have more control over his play activity. Improving in strength and success did not just occur naturally and Daniel commented on how he *'had to practise when [he] was little to get it now [he is] bigger'* (interview 3). Lucy had a similar experience and talked about how she had to *'[keep] trying to talk until I learned (smiles) if somebody doesn't hear you, you've got to keep talking'* (interview 3). Jess recognises that there are play activities she could participate in more easily if she gained greater physical strength: *'I would like to do the acting which would be good, and that's why I do this therapy to help me be able to do more stuff'* (interview 2). When children participate in therapy their ability to move physically and manipulate objects, and to communicate their choices, is likely to be something that they will practise. Although most children do not mention their therapists specifically they do note how an improved physicality and communication positively impacts their play experience. The narrative of needing to improve skills is part of every child's development, however, for the children within the study it seems that they needed to take a more focused approach to improving their strength and success. It would appear that during the time of practising and trying to physically improve the children also continued on a journey of redefining success in a way that enabled them to have a sense of control over their play.

5.6.3. Choosing to compromise vs. having to compromise

One aspect of making choices is that all individuals at times face decisions to compromise in their choice. The need to compromise in decision making occurred several times within the participant interviews. Making compromises would appear to be a direct contradiction to making choices as part of play. However, when children actively made the choice to compromise in their play decisions, they appeared to have a greater feeling of choice and control over the activity they were participating in and therefore they reported experiencing this as play. The tension is that there were also times in which children were forced to compromise. This was no longer an active choice, and therefore meant that an activity would stop being experienced as play.

Jess talks about how she shares play with her twin sister, Josie, and that often Josie will make the choices in play, Jess comments *'I just really want to be able to choose'* (interview 2). Despite this, Jess continues to want to play with her sister because it means that she is able to keep playing with someone. Jess actively makes the decision to compromise her preference and holds this in tension with the fact that she would like to choose because it enables her to still participate in the play. Jess continues to refer to the experience with Josie [twin sister] choosing the roles as a play experience, and it appears that Jess has made a choice to continue to participate as part of her compromise. This desire to compromise to continue playing is seen within a conversation with Tom when he chooses a pen to draw with (box 10).

T- [chooses the green]
N- the green! Ah that was nice and easy. Did you choose, was it the first one because [it was easier] or [that was what you wanted]?
T- [chooses because it was easier]
N- because it was easier, which one did you really want? Did you want to choose a different one?
T- (looks yes)
N- lets see, how we could do it really quick. If you tell me no when it is the wrong one. Or if not you can look at the colour you want. Is it one of these?
T- (looks yes and at red)
N- is it the red?
T- (looks yes)
N- is it definitely the red?
T- (looks yes) (putting hands on paper ready), Tom, Interview 2

Box 10 Tom, Interview 2- Choose the green because it is the first colour the researcher holds up. Compromises choice in order to keep playing.

Tom is making a compromise in his choice in order that he can more quickly participate within the play experience. It is possible that because, out of all the participants, Tom requires the most time to participate in communication, that he will often compromise on choice in order that he can take the time to communicate things that are most important to his play experience. In this way Tom's Cerebral Palsy could be seen to be limiting his ability to make choices and control his play. Despite this, it appears that Tom actively chose to override his preference and accept a different colour. Tom is continuing to control and make choices in his play by weighing up when he decides to compromise, and when he decides to communicate his actual choice.

Although the participants do not talk extensively about compromising in order to enable play activities to continue, there is a sense that they often compromise their choices during play. Jess' comment about horse riding: *'I'm actually just doing something that I like and I enjoy it'* (interview 1) suggests that this is a good activity which she enjoys in comparison to other activities which she may not like as much. Each child's level of physical disability means that opportunities to play are often grasped despite not being the first choice. This could be seen as a restriction to each child's ability to make choices and control their play, however, the lack of discussion about compromise would suggest that children's experience is that they are making their own choices and controlling their play. That the physical limitations their Cerebral Palsy places on what they can participate in does not restrict their experience of control. Each child spoke extensively about play that they participate in and even when adaptations were made, such as someone going to get a game or set something up for them, the participants portrayed the play as their own choice.

One possible interpretation of children's choice to compromise would be that they are being limited by the social world and environment they are in because of perceptions of them that they are less able. It could be the case that the participants' peers and carers often expect less vocal or obvious choice making from them, or that historically less choice making has been expected of the participants in settings such as school. This may have led to more times in which children choose to compromise or learn not to mind when they do not have a choice because this is what they are used to. An alternative explanation of this is that children are unaware of the limitations to their choice because they have always experienced a need for individuals to support them (for example when fetching a game or choosing a colour to draw with). This could mean either a residual feeling of having a lack of choice, or an understanding of choice in which compromises are sometimes deliberately made in order to enable a greater feeling of participation. It would appear that the latter is the case as the children talked about situations where others were in control of the play as if they had made the play choices.

Despite this, there were also times in which children were forced to make compromises in activities that then stopped these activities being experienced as play. This is clearly seen within Daniel's interview where he is kept on a theme park ride he says: *'I had to go on it again because my wheelchair was on the other side, but I didn't want to go, but I had to go because my wheelchair was right over there, and there was a middle bit that I could really quickly go over but they said no, go on, you have to go on again.'* (interview 2). Daniel's need for his wheelchair and the decision of the theme park staff meant that he was forced to compromise and had to go on a ride a second time. Daniel appeared to feel frustrated by the fact that he had to go around twice. The lack of choice that Daniel had in his play activity was a significant memory for him that he recounted; this could suggest that this does not happen very often for Daniel and that usually his choices within play match decisions made by peers and carers around him. Possibly, when in a new environment, such as the theme park, the environmental factors place greater restrictions upon a child's ability to make a choice and perceive control over their play. This could be due to an increased feeling of anxiety of a child not knowing their surroundings. Alternatively, as in Daniel's case, the control lies not with a familiar carer or peer but with a stranger; this could significantly contribute to the feeling of being forced to compromise without the opportunity for choice.

There are also times when children are forced to compromise their choices when they are alongside their peers. This can occur to the extent that they experience exclusion from play. When reported by the current participants, this occurred because peer groups activities are not physically possible for children to join in with whilst using their wheelchairs. Abi talks about this forced compromise in her play in the playground (box 11).

N- and who do you like to hang out with at school?
A- I don't, I'm on my own at the moment, I'm on my own
N- You're on your own at the moment, ok
A- Because they're playing netball
N- oh ok
A- Yeah
N- at play time?
A- Yeah, and then I can't play it, because it is not adapted.
N- yeah, it is not adapted
A- no
N- that's frustrating
A- Yeah
N- So does everybody play netball?
A- Yeah, Yeah
N- ok, and you just, where do you go?
A- I'm on my own really, I watch them, yeah
Abi, Interview 1

Box 11 Abi, interview 1- Forced compromise in choice experienced at school because netball is not adapted and this is all peers play.

The experience of being forced to compromise in the playground is also commented on by Jess. During interview 1 she commented: *'my favourite things are to play with people. But the problem with my new school is that they have the playground, the bit, the most of the playground is on this bark, this rough material that my chair won't go on'* (interview 1). Although Jess was yet to start in her new school she was already perceiving this as somewhere she would be forced to compromise in her choice. Jess had created alternative means by which she could continue to participate in play when she felt excluded by her peers. She commented that *'Sometimes I play catch with [my TA], just cos no one plays with me I just play with her instead, I know it may sound a bit boring, but I still do'* (interview 1). Within this statement Jess has a recognition that play with an adult might be perceived as boring, when she is forced to compromise her choice because of physical restrictions to accessing play with her peers Jess has to choose an alternative option. Although Jess may in the moment be happy with a catching activity it appears to clearly be framed around having no one else to play with. This perhaps highlights the desire to compromise in other play choices, such as which character to play, when Jess is able to physically participate in an activity alongside her peers.

It is clear that there are forced compromises that children have to make in their play. Sometimes these compromises may be directly because of their Cerebral Palsy, such as when their wheelchair cannot go over the playground bark, or when they play in a classroom to practice therapy activities. These compromises are sometimes expressed negatively by the study participants (i.e. *'I can't'*). However, often children demonstrate a sense of regaining choice and control over these play activities and use reasoning to help them to negotiate the feeling of having to compromise. This is seen within Abi's continued discussion of netball in subsequent interviews (box 12,13).

N- can you tell me about a time that you watched your friends playing?
A- No, I can play with them now, I've been playing with them now, they've been ok with me really. It is been ok really, it is ok
N- what have you been doing with them?
A- I was playing netball, I was playing netball and it is been ok
N- how were you doing that?
A- huh?
N- how? How were you playing netball?
A- I just asked my friend to throw the ball.
Abi, Interview 2

Box 12 Abi, interview 2- Now able to play netball as peers are choosing to play with Abi.

Abi's experience of netball summarised in boxes 11,12,13 demonstrates the tension that she feels between having to compromise her choice and control in play and the opportunity that she is given to participate. In experiencing her world through her body which has physical limitations because of her Cerebral Palsy Abi feels a vulnerability in playing netball and talks about how it means she can get *'hurt'.* Abi's high level of physical disability means she cannot move away or catch a ball as easily as her typically developing peers. This has an impact on Abi's experience of participation and the choice and control she feels over her play which is already limited as it is a game her peers have chosen. Despite this, when

Abi's peers support her and she can drive her powered chair it seems that Abi is able to participate in netball and it feels *'ok'*. Being able to drive her powered chair and move around freely gives Abi a renewed sense of choice and control which then enables her to choose to compromise her preference and to choose to play netball with her peers.

N-Could you tell me a bit about some of the things you wish you could play?
A- (voice quieter, long pause) playing netball. Netball because, um, I can't, it is not adapted, it is not adapted so that's why.
N- mm hm, and how does that feel?
A- I played it at school but I might get hurt. Have you played netball before?
N- yeah
A- it is really hard. Are you really good at netball?
N- I'm ok
A- I can't play it
N- Oh
A- (long pause) What are you doing tomorrow?
N- what am I doing tomorrow? Um, I'm working tomorrow. So when you, what do you do when people are playing netball then?
A- well I can play with them, (pause) I play with them but I've got to get hurt that's why
N- So how do you do that?
A- I drive and then, then it is ok really.
Abi, Interview 3

Box 13 Abi, interview 3- Abi continues to voice the tension she feels between netball not being adapted and her friends enabling her to play.

Abi has a range of adult-like expressions, such as *'it is not adapted',* which appear to be repetition of language that she may have heard from adults around her. In some cases, such as Abi's discussion in interview 3, the comments of netball not being adapted become a barrier to Abi thinking about times that she does play netball with her peers. It is possible that adult expressions and societal views about disability, ability, and adaptation to activities can have an impact upon the experience of children who experience daily life with a physical disability.

Abi's contrasting views between the three interviews demonstrate the way in which children's experience and recollection of experience can change over time. There may be periods of time in which a compromise is accepted by a child and they therefore experience control over their play and then other times when the same compromise feels isolating and limits the child's control and participation in play. The tension of negotiating emotion and experience around being able to physically participate appears to be closely linked to identity and the way in which each child sees themselves. For Abi as *'it is not adapted'* is a common narrative within her interviews; it seems that Abi is more likely to experience situations where she feels she has to compromise. This could possibly lead to her having fewer moments of experiencing making choices and being in control of her play because she is stopped by the sense of it not being adapted to meet her needs.

5.7. Theme 2: Participating differently to peers

There were several indications through the participant interviews that they participate in play differently to their peers. The participants were part of the study because of their high levels of physical disability. Through participating at GMFCS levels IV or V all the children were wheelchair users and dependent upon others to support their physical activity. Through the very nature of their disability the participant's play cannot be exactly the same as their typically developing peers play. The following section explores the way that the findings suggest each child's identity as an individual with a disability has developed and the impact that this has on their play.

5.7.1. Disability as part of self

For each child there appeared to be an unspoken recognition that their play is different because their disability is a part of who they are. This feeling of disability as part of 'me' seemed to be seen through the way that disability itself was not referred to within four of the participants' interviews. Abi had the strongest focus on her disability within her play narrative, frequently commenting: *'I've got Cerebral Palsy'* (interview 1). She often articulated the impact that this has on her physically- *'It means I can't walk, it affects my muscles… and I've got my spasms'* (interview 1). Yet Abi also identified that having Cerebral Palsy *'It feels, its normal, it doesn't hurt me'* (interview 1). Abi's discussion of her disability suggests she is aware of the physical restrictions that she faces and the impact this has on what she can do, this is seen in the way that she frequently refers back to her disability. In her comment *'it doesn't hurt me'* it is as though Abi has personified her Cerebral Palsy – she describes a living thing that could hurt her. She states that *'it is normal':* she is able to live with her Cerebral Palsy and has a way that it does not hurt her. Abi's personification of her Cerebral Palsy suggests that she perhaps sees it as something which is both a part of her and separate from her. This is reflected in the rest of this section and each child's creation of their identity with Cerebral Palsy.

Jess also directly comments within her interview that *'I'm not the only disabled child in the [new] school there's one other person who is blind (interview 1)'.* Jess is identifying herself as a *'disabled child'* and likening this to a boy who is blind. Jess has clearly marked out a difference between herself and her typical developing peers that she felt was important to share. Jess makes comments such as *'sometimes I pretend I'm not disabled'* (interview 2). Jess can picture a distinct reality in which she remains herself but her disability is taken away. Like Abi, it would seem that Jess feels that her Cerebral Palsy is both a separate entity but integral to who she is.

On another occasion, when talking about her imaginary play, Jess comments *'I could walk, I could do all the things I can't do',* when asked how that felt she said *'really good, but I just wish it was actually real'* (interview 3). There appears to be a sadness in Jess' sense of wishing that her imaginary play is real. This appears to be part of a negotiation of identity for Jess and a coming to terms with her disability. This will be explored further throughout this section and 5.7.4.

Most of the participants did not discuss their disability or the impact that it had on them as readily as Abi and Jess. Some participants mentioned their disability when talking about the experience of needing a helper or a carer to support them within their play. Children were aware that they needed support for everyday activities (as seen in Lucy's discussion in box 14) and it appeared that often carers became an important playmate that they could participate alongside. It is possible that having been born with a disability each child had a normalised view of needing support within activities. This normalised view meant that often children did not mention needing help (see facilitated independence section 5.6.1), and needing a helper was part of their experience of their disability being integral to their sense of self and who they are. Although an external observer may feel that children would be frustrated by the constant need for help, when children, such as Lucy (box 14), discussed their helpers this appeared not to be the case.

L- I, yes, I, a grown-up helps me to play with my friends
N- Mm, so who was helping you today?
L- Laura
N- What's that like? what's she like?
L- she's good (smiles/ laughs)
N- is she? So what does she do?
L- She, she helps me a lot
N- Can you tell me about how she helps you?
L- She, she yes, she helps me with hoist, she helps me with lots of other things, she helps me when I'm at the playground, she helps me when I'm playing with my friends and, and I'm in my manual chair and also she likes to help me a lot! (exclaims)
Lucy, Interview 1

Box 14 Interview 1- A grown-up helps Lucy to participate in play.

Although each child mentioned the experience of their disability in different ways, the way that each child talked about their experience of play provided an insight into their understanding of disability as a part of themselves. This was reflected within Jess' interviews. Jess within her second and third interview talks about the experience of playing a mermaid game in the swimming pool (box 15).

In Jess' game she was identifying as being a mermaid, a character with no legs. This is interesting considering the nature of Jess' Cerebral Palsy, which means she cannot use her legs to walk or move independently. Jess discusses participating in the mermaid game with herself as a princess and her mum and dad as the mermaid king and queen. Jess then saves her twin sister who becomes *'one of us'.* This may be an inverted picture of Jess' lifeworld and her perception of her family and her twin who does not have a physical disability. Within the play scenario both Jess and her parents are free to move around in the water; as mermaids they have no legs but they can swim without resistance. Jess' sister however needs rescuing to become *'one of us'* so that she can also move freely in the water. It is possible that in Jess' lifeworld she perceives that her parents and her sister are able to move around freely, and that because of her physical disability Jess herself in some way needs rescuing to become *'one of us'.* This desire for wanting to experience a greater freedom is reflected in Jess' discussion either side of her play experience; she discusses having the freedom to go on an imaginary girl's night and being able to *'just swim freely'* with her armbands. Perhaps reflecting on being able to swim freely with armbands leads to Jess reflecting more upon her own experience of freedom in comparison to her sister and parents.

Alternatively, it is possible that Jess is using her imaginary play with her family to experience and express freedom to move in her play. The imagery of being a mermaid is perhaps a helpful metaphor for Jess' lifeworld. A mermaid is part human, part fish and therefore has to stay in the water. Jess experiences some physical restrictions (like the mermaid

N- so what imaginary game are you and Josie playing in this picture?
J- We're playing a game where we're friends from work and we go off on a girls night and it is all really fun
N- and what do you do on your girls night?
J- so we go to a pizza hut and then we go to the swimming pool and then we play in the swimming pool for ages and then we go home
N- great, what do you like to play best in swimming pool?
J- Probably games where my Dad is the mermaid king and my mum is the mermaid queen and we are the mermaid princesses
N- ah huh
J- that's probably my favourite game
N- that sounds really fun. And then what do you do in those games?
J-um, I kind of do this thing where I have to find, we have to dive down to our grotto kind of things and it is really fun.
Jess, Interview 2

N- so if you do swimming then it is different to if you do swimming with Daddy?
J- yes because when I do swimming with Daddy I'm in a different pool and I can just swim freely. But the reason why I have armbands is because I, that means that I can have more freedom with my swimming whereas if I don't have it I have to have someone in front of me.
N- ok, so if you have armbands does it make it feel more like play
J- yeah so I can just swim around on my own
N- cool, so what do you play?
J- so we play that mermaid game, remember, and um, that's all we play really
N- ok so does he, does Daddy chase you?
J- no never
N- so what happens in that game?
J- so Mummy's the Queen, Daddy's the King and me and Josie are the princesses and Josie is just a mermaid who gets trapped and I see her and I free her and she becomes my friend and she becomes another, one of us, so it is really fun.
Jess, Interview 3

Box 15 Interview 2, 3- Participating in the mermaid game in the swimming pool. Jess is able to rescue her sister so she can become 'one of us'.

not being able to get out of the water) in her everyday reality; yet in her play she is able to participate and experience the freedom of a mermaid moving around. The human reality and the mermaid freedom could represent the two parts of Jess' world: her reality of the experience of her disability and the freedom she experiences in imaginary play (further discussed in 5.7.4).

It appeared that for all of the children the experience of having a disability and negotiating freedom within their experience and their perception of experience was an everyday part of play. Freedom to access play was often enabled through the use of a wheelchair. For some participants (such as Ben and Tom), they did not mention their disability but only referred to their limitations when talking about their wheelchair and the need for help. Ben's discussion in box 16 suggests that he sees it as *'perfect'* that he is the only person using a wheelchair. There are several possible interpretations of this statement. It could mean that Ben finds his wheelchair *'perfect'* because of the way it enables him the opportunity to move around. It could be that Ben finds it *'perfect'* that he is the only one with a disability as he is distinct from his peers and gets a greater level of attention. Alternatively, it could be that Ben finds it *'perfect'* that he has Cerebral Palsy as this is a normalised part of himself and as he has had his disability for all of his life he does not want to see himself any differently.

In contrast to this, Ben slightly hesitated before he used the word *'perfect'* it could be that Ben is experiencing an internal dilemma at this point. Ben's lifeworld and experience of play appears to be one in which he sees himself as physically strong and successful (5.6.2) and he is encouraged in this by parents, carers and peers. It is possible that Ben feels that those close to him see him as *'perfect'* and this is something that he should reflect in his own view.

N- and does anyone else use a chair?
B- No, I'm the only person who uses a wheelchair
N- and how does that feel
B- great
N- it feels
B- er, perfect
Ben, Interview 1

Box 16 Ben, Interview 1- Feels that it is perfect that he is the only person who uses a wheelchair.

If this were the case it would seem that Ben would mention more frustrating aspects of play more readily, as Ben does not do this it is possible that his wheelchair is so much a part of his identity that Ben embodies it as part of himself and therefore he sees it as *'perfect'.*

The importance of equipment such as wheelchairs and walkers in enabling mobility and some freedom of movement, together with the extent to which children spent time in their wheelchairs each day, meant that equipment often became an embodied part of self and experience of identity with a disability. Each child discussed times in which they moved or needed their equipment such as a wheelchair or walker to enable an activity to occur, yet they often did not mention this as part of the play experience because it appeared to be part of an embodied view of themselves where their own external boundary included their wheelchair. Daniel discussed how he could move fast in his walker because it gave him *'energy'* (interview 1). He appeared to embody this as a part of him and his identity as it enabled him to be fast. Daniel's view of himself as fast was not separate from needing to use a walker and the use of the walker was an integral part of his discussion of this experience.

Figure 9 Embodiment of wheelchair. Abi's ability to use her joystick in her mouth means that she can move around freely. When discussing a computer game Abi wants to be able to represent herself as using a wheelchair.

As well as using walkers, every participant discussed their use of a wheelchair; some children could move their wheelchair independently and others relied on being supported to move by an adult. Abi talked about her wheelchair enabling her to move around independently with her joystick (figure 9). Her wheelchair was closely tied to her identity and experience of being independent. Abi perceived her wheelchair as a part of herself to the extent that it was embodied: her wheelchair became the external boundary which separated herself from the world. This view of her wheelchair as integral to her is seen in her desire to *'put a wheelchair on it'* in her representation of herself on an iPad game (interview 3).

In discussing her play and different possibilities for imaginary play, Abi also expressed a desire to be able to do *‘a flip’* in her wheelchair (interview 2). She did not appear to realise this may not be a physical possibility for her. This would suggest that she embodied her chair to the extent to which she felt like anything was possible in terms of mobility as it was a part of her and enabled independence. Both Abi and Tom appear to view their wheelchair as an embodied part of themselves both in their everyday reality and within their imaginary play. Tom talks about *‘using his wheelchair’* in an imaginary game he is playing in his head when he is watching a toy train go around a track (interview 3). Tom also does explore a different freedom within his imaginary play when he does not have a physical disability (further discussed in 5.7.4). It is possible that as the only two participants functioning at GMFCS V Abi and Tom are the most heavily reliant on their wheelchairs and therefore find it difficult to separate themselves from their wheelchair even in their imaginary play. Alternatively, as the participants will have used a wheelchair for the majority of their lives it is possible that they have embodied their chairs to the extent that they are part of both their external and internal reality. This is reflected within Abi’s desire not to be able-bodied but to use a wheelchair to represent herself within her iPad game.

The majority of the children made use of iPads and referred to the opportunity to use technology as part of their play. The use of an iPad appeared to almost be a part of each child’s identity and everyday lives with Cerebral Palsy because of the independence that it enabled. This is summarised within a discussion with Abi where she comments that her iPad is important because she can *‘use it independently, [she] can use it to play’* (interview 3). A section of Abi’s drawing of her play experience is in figure 10. This shows Abi’s iPad that she drew as an important part of her play experience which she *‘likes best’* and feels is *‘amazing’.* Daniel, Ben and Tom all also drew iPads or talked about using iPads as an important part of their play experience.

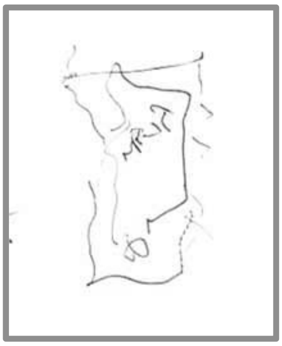

Figure 10 A section of Abi's drawing of her play experience showing her iPad as important for independent play.

It appeared that all the children had an understanding of their disability as a part of themselves. This is further seen in the way that disability is referred to in play. Jess participates in an imaginary game with her twin sister where her sister has a physical disability and sits in Jess' wheelchair. It is possible that Jess chooses to participate in this game, and enable her sister to sit in her wheelchair, in order to share with her sister her expression of herself and negotiation of identity where disability is a part of self. As Jess acts as the non-disabled friend of her twin sister within an imaginary play scene she is able to talk through and discuss with her sister a situation which may occur because of having a disability.

Jess and her twin sister Josie are playing a game where Josie has a disability following an accident. Jess is lying in the hammock and talking to Josie, who is sitting in Jess' wheelchair, about going to a school disco. During this play scenario Jess comments *'I'm trying to look after you';* she sees her role as Josie's sister to help her with the decision about going to the disco. Jess perhaps feels like she has the capability to enable Josie to negotiate this decision and play role because of her own experience of disability as a part of herself. A screen shot of the twins acting out the play is seen in figure 11. Jess' comment about her sister using her wheelchair is in box 17.

Figure 11 Jess is playing with her twin sister who is using her wheelchair and pretending to be a girl with a disability in their game. Jess is pretending to be her sister who does not have CP (and is lying in the hammock). Jess supports her sister Josie in negotiating her identity as someone with a disability.

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For Jess the presence of her Cerebral Palsy as part of herself and as impacting upon her play is highlighted because she has a twin sister who does not have a physical disability. When Jess is asked about the role reversal within the play scenario that she and her sister acts out she comments that *‘it felt like she was the disabled person, not me’* (box 17). It is possible that as Jess’ disability is a part of her sense of self it feels *‘funny’* to see part of the expression of her identity, such as the use of a wheelchair, being taken over by her sister. This response is perhaps due to the fact that her disability and wheelchair use is an integral part of herself; in seeing her wheelchair used by another it could have felt as though it was missing from herself. As Jess has experienced Cerebral Palsy for all of her life her imagined experience of not having a disability only comes from what she has observed in others. It is interesting to consider the differences that Jess feels are important within imaginary play without Cerebral Palsy and the extent to which Jess’ identity, problem solving and thought processes continue to be based upon her life with a disability. As seen above in the discussion about mermaid play, part of Jess’ experience of disability as part of herself is a negotiation of both difference between her and others and an experience of freedom that she often finds in her imagination.

> *J- it looked funny*
> *N- yeah and why was that?*
> *J- because she’s never normally in a wheelchair, so it would really, it felt like she was the disabled person, not me*
> *N- yeah, and did that feel different to normal?*
> *J- yeah*
> *N- so when you’re pretending do you pretend that you don’t have CP?*
> *J- yeah*
>
> *Jess, Interview 1*

Box 17 Jess, Interview 1- Jess explains how it felt for her sister to be using a wheelchair not her.

Later within her interviews Jess negotiates the idea of falling ill within imaginary play. Jess comments that she wants to fall ill *‘Because then you get all the attention because normally it is Josie that falls ill, I hardly ever fall ill, I’ve only got to fall ill like twice’* (interview 2). Although children with disabilities may be perceived to *‘get all the attention’,* within Jess’ mind she sees illness as separate from disability. This provides further support for the proposal that children perceive their disability as part of themselves.

For other participants such as Abi there are perhaps more connections between being a *'patient'* and having a disability. Abi discusses that in playing her game *'[she] want[s] to be a patient'* and comments that it is *'amazing because someone is looking after [her]'.* It is possible that for Abi one aspect of her disability being a part of herself is that she recognises the level of care that she needs. This may be particularly prevalent for Abi due to her higher levels of medical need compared to other participants. Abi's perception of her disability as part of herself and within her play she chose to be a *'patient'* and wanted to be cared for appears to be influenced by this. As a familiar identity to Abi, she perhaps chooses to play the *'patient'* as a preference within her play.

The difference participants sometimes felt between themselves and their peers is summarised in Lucy's comment that she recalls making when watching tennis players *'I want to be just like them'* (interview 1). It is possible that when making this comment Lucy does not view herself as restricted because of her disability but because of her tennis ability. A similar comment could be made by any aspiring tennis player. On the other hand, it would appear that Lucy seems to experience a sense of difference to the tennis players because of her physical disability. This experience of difference is one that the children have to come to terms with and negotiate within their everyday worlds. It appears that within play the complexities of this negotiation of identity become clear as children wrestle with being themselves, being someone different and enabling a feeling of belonging within their family or peer group.

5.7.2. Engaging in play through watching

One way in which children clearly appeared to play differently to their peers was through the experience of watching play in order to participate. For several of the children the opportunity to watch others playing became a part of their own play experience. There is a possibility that the opportunity to watch led to a vicarious experience of play for each child. Within the participant interviews children talked about a variety of experiences in which they needed to participate through watching. At times children watched play in the same way as their typically developing peers, such as watching YouTube or football games. However, at other times children engaged in play through watching their peers and commenting upon the activity, when their peers were physically participating.

Often participation through watching appears to in some ways be vicarious and is difficult to understand as an onlooker. However, the children's interviews would suggest that they can experience play through adopting a role as a spectator. Jess comments that *'I do watch other people play which is quite nice cos I like doing it and it means I'm not left out' (interview 1).* Although common to many children, both Ben and Tom talk about being part of the crowd when watching matches or races within stadiums and refer to this as part of their play. This everyday experience of vicarious play, and experience of participation through watching, can help to gain a deeper understanding of how children with high levels of physical disability may experience participation through watching other play activities with their peers. Indeed, Lucy discussed how it feels *'good'* to be able to watch her sister playing and this was a part of her own play experience.

Figure 12 Tom watching the train go around the track and creating play characters on the train in his imagination.

The findings raise an important contribution to possibilities of toy play by watching, this appears not to be referred to within the literature. Children within this research reported participating in play by watching their toys and then seeing the toys as moving within their imagination. Tom, within his last interview, chose to play through watching his lego train track. This can be seen within figure 12 and is described by Tom in interview 3 where he talks about how he is *'watching the train go round'* and thinking about the *'characters on the train'.* To an observer Tom looked like he was in his wheelchair watching the train move around the track. For Tom, whilst

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watching he was creating play characters and a play situation which the train featured in. This needs consideration in terms of toys that children with high levels of physical disabilities are given the opportunity to engage with. Within the study children participated in play through watching toys that were cuddly toys or plastic characters such as Buzz and Woody (Toy Story characters talked about by Tom). It is possible that children may like to participate in play through watching other toys which are more complex such as Lego or Playmobil sets (smaller design toys).

More complex play through watching was seen when children participated in watching, instructing and teaching as part of play. This was seen in activities such as building a marble run, which Daniel choose to play as part of his videoed play at the start of his second interview. Daniel discusses how he *'tell[s] [his carer] what to do…because it's really direct…and really accurate'* (interview 2). Although an observer, Daniel demonstrated how he could be an active part of play despite not physically participating. Daniel's focus on being *'really accurate'* demonstrates the care with which he participates in this manner.

Participation in an activity without physical manipulation of the object that is being played with is important for parents and therapists to recognise. As demonstrated by Tom he is able to participate within play and engage with a toy even though he is not physically manipulating it. Participation through watching to interact with objects is also seen within Lucy's play where she creates elaborate play scenarios for her toys. Although there are times where Lucy moves her toys as she pretends they are *'soaring'* or going *'stompty, stompty, stomp'* (interview 1), there are also times where Lucy does not manipulate her toys but still engages in play using the characters. Lucy refers to telling her toys a story, she is able to make use of her communication skills when she cannot use her physical skills to participate in play.

Participation through watching, commenting and teaching as part of play experiences suggests that the participants had developed a strong sense of imagination which enabled them to perceive participation in their minds. It is possible that children with high levels of physical disability develop a more active imagination than their typically developing peers, as this is often a means of them participating within play. The opportunity to participate through watching appears to be important as children often talked about this occurring when they had been left on their own, for example first thing in the morning or on the school bus. As the participants could not easily go to find another play activity or mobilise to find others, their ability to use their imaginations and engage in play through watching may be essential to their participation.

It is important to consider that the findings also suggest there were times in which watching others play did not feel like part of a play experience. There appeared to be times in which children perceived themselves as an active player when watching, and other times where watching appeared to be experienced as tokenistic and excluding. The social and physical environment of the play activity appeared to impact upon each child's perception of watching as either play participation or not.

For some children there is an evident struggle within their mind as to the extent to which they are participating in a play experience while watching. This is seen in the discussion with Daniel about Jenga in box 18. This demonstrates the ambivalence that Daniel feels towards the level of participation he is experiencing. Daniel appears unsure as to the extent to which he is an active participant when watching Jenga. It is clear that Daniel perceives here a difference between *'playing'* and *'watching'* this would suggest that although watching can enable a sense of participation, for Daniel it is perhaps another compromise that he has to make (5.6.3).

N- So are you still playing when you watch Jenga?
D- no
N- no you're not playing? But you're watching
D-Yeah
N- so can you still join in when you're watching?
D- a bit'
Daniel, Interview 1

Box 18 Daniel, Interview 1- Daniel experiences joining in a bit when he is watching Jenga.

Similarly, within her interviews Abi talks about how she changes roles within the way that she participates in netball in box 19. Abi starts talking about the way that she referred to netball before as an activity which she could not actively participate in; when she reflects back on this she refers to herself as either a *'manager'* or an *'audience'.* Despite this, Abi does not appear confident in her ability to participate in either of those roles. In previous interviews Abi seems pleased to help and teach others. In interview 1 Abi comments '*I teach [them] and they go 'ooo ok' and I can say this is my iPad and I go here and everything' (interview 1).* It would seem that when Abi has no other option in participation, being able to teach or act as a *'manager'* as part of a play experience can in some ways enable a sense of joining in. Taking on this role perhaps provides Abi with a new sense of control and power over the play as she becomes an individual who can influence what is happening. This also enables Abi to move from being an outsider of a group who cannot participate to someone who is part of the group and team. This is reflected in the way participants often talked about cheering others or doing things like *'beep my horn'* (Lucy, interview 3) as part of watching play and participating from the side lines.

N- so when, you know when you said you were watching before?
A- yeah but now I play
N- now you play, when you were watching were you still talking to people?
A- No, I was like being a mana… not a manager, I don't know, no not an audience, I just want to play, I want to play but I want to be really safe, so that's why

Box 19 Abi, Interview 1- Abi comments on how she was being a manager or audience when watching netball play.

This would suggest that negotiation of a new roles within play which enable a sense of control, can and did occur for the participants in their watching. Despite this, both Daniel and Abi appeared to be more happy with the opportunity to *'play'* rather than participate in play through their watching. When talking about play in box 19 Abi appears to be referring to play as something which is physically active. Again, there is a contrast between the *'play'* of typically developing peers and the participation which is sometimes experienced in watching. This highlights the possibility of the participants experiencing and perceiving their disability as a barrier to their active play. The participants appear to experience a dissonance between their ability to participate and their awareness of the limitations to their physical participation. This is again reflected through the negotiation of their sense of self as an individual who is able to participate but in a different way, such as by watching.

5.7.3. Extreme emotion- frustration and excitement played out

The playing out of extreme frustration and excitement appeared to be part of play for the participants. There were times in which the frustration of not being able to do something resulted in extreme comments such as *'Kill that' (Jess, interview 2),* when during the drawing of her play experience she made a mistake*.* At other times, extreme excitement led to a big physical response, laughing and exclaiming *'Yay!' (interview 1, figure 13).* Although it is clear that typically developing children also experience a range of emotions and will express these within their play (Prosen & Vitulić 2016), it appears that the nature of Cerebral Palsy and the way that it leads to children's bodies overtly responding to emotion means that an exaggerated frustration and excitement are sometimes played out in their case. It is possible that the opportunity for play provides an outlet in which these extreme emotions can be safely expressed.

Figure 13 'Yay' excitement of Daniel shown with his hands in the air as he wins his iPad game.

Each of the participating children appeared to experience a contention between the frustration they experienced in play and the positive experience of play participation being good and fun.

Some children did not specifically talk about their disability, but expressed a frustration within their play which appeared to be caused by physical limitations. Ben said *'no thank-you'* when play did not go as expected (interview 2). Daniel discusses how play can be *'frustrating…really frustrating because I couldn't do it.'* Daniel talks about feeling *'angry'* in the moments that someone tries to help him with his play but gets it wrong (interview 2). The extent of each child's physical disability as previously

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discussed means that an adult often needs to be present to help facilitate play. The reliance that this then places on other people to correctly follow instructions and facilitate play as the child would like leaves opportunity for extreme emotion to be played out. This can not only lead to moments of anger and frustration, but also to moments of excitement and extreme celebration when the partnership between a child and their helper has enabled them to succeed in their play.

Figure 14 Jess' drawing of her play. Crossed out pictures show where she has stated 'kill that' as she has made a mistake. In the centre of her picture Jess has drawn herself playing an imaginary game where she does not have a physical disability. Bottom left corner moving clockwise the pictures are as follows: 'Playing with Josie' (twin sister) imagination games; 'quite annoying' when we make mistakes; 'fun' and 'free' playing on the floor; 'arty', paint and paint brushes to show creating as part of play; 'musical', playing instruments as part of play; 'laughing' because play is fun; 'cool, funky dancing' Zumba- whilst sitting on a blue bench.

Sometimes extreme emotions and frustration are played out when a child is playing alone. Jess when participating in drawing comments that she *'hate[s] that …. because my hands don't work as good as everyone else so I can't really draw as well'* (interview 2). For Jess the action of making a mistake is perhaps a reminder of her physical disability and therefore is emotionally difficult to deal with and therefore results in an extreme reaction. Jess' comment *'kill that'* comes following a mistake she has made in her drawing (see crossed out drawings figure 14). She comments that it *'makes me feel really annoyed, annoyed with myself'.* Jess' feelings of annoyance at herself could be focused on her mistake but could also be a

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reflection of her feeling about the physical limitations she experiences because of her Cerebral Palsy. Although Jess says *'kill that'* in a way that it is aimed at her drawing, the *'that'* Jess is referring to could be the Cerebral Palsy which stops her hands drawing the way she would like to. It is also possible that Jess feels frustrated because she knows her picture will be seen by others. Although her Cerebral Palsy is a part of her, as seen throughout the findings (5.7.1), there is a constant tension between perceiving herself as successful, strong and independent (5.6.2), and being aware of her physical limitations.

L- I dropped it on the floor!
N- how did that feel?
L- bad, very bad
N- and then what happened?
L- I felt frustrated with myself
N- did you? But then, were you still playing when you felt frustrated?
L- I was still playing
Lucy, Interview 3

Box 20 Lucy, Interview 3- *The feeling of dropping something on the floor is bad but still can be part of play.*

Even when children were being physically supported or were participating in play alongside an adult they still had the opportunity for experiencing frustration. This was seen within Lucy's conversation in box 20. Despite the levels of frustration and anger experienced when play does not go to plan it appears that the children generally are *'still playing'* when this happens. This demonstrates the level of resilience that the children appear to have in their play, they are able to keep playing even when something goes wrong. The feeling of continued participation and resilience experienced by the child is perhaps linked with the extent to which they are familiar with their helper. As discussed in 5.6.1 it is possible for children to experience a facilitated independence when they embody their helper and see themselves as doing something on their own. Alternatively, as seen in 5.6.3 there are occasions when an unfamiliar adult appears to cause stress and demonstrate a lack of understanding which can lead to a play activity not being experienced as play. It appeared that when with a familiar adult the frustration of instances such as *'it dropped on the floor'* can be easily overcome because of the child feels safe within the experience. When with an adult who understands the child and their play well, children are more able to continue experiencing participation, even in the instance of something going wrong.

At the same time as being aware of frustration, all of the children discuss to a great extent the positive emotions and experiences that they associated with play. Play experiences were often described as ‘*good’, ‘fun’,* and *‘happy’.* Lucy describes what it is about playing that makes her feel excited- *‘Playing with my toys and having lots of fun’ (interview 1).* When drawing their play experiences each child often referred to positive emotions within their drawings. Ben talks about how the people playing bulldog in his drawing should have *‘happy’* faces (interview 2). Abi often comments on play activities as being *‘funny, laughing…fun, having fun’* (interview 1). The importance that Abi places on being able to express her laughter and sense of fun in play is also reflected by Daniel: *‘[fun is] where you laugh and giggle and when you’re having a good time (Interview 2).*

J- it makes us laugh lots (laughs)
N-and when you’re laughing lots what does that mean?
J- It means it is really funny and it is a fun game
N- and when you’re playing are there some things that are really fun and some things that are a little bit fun… or?
J- it is all really really fun
N- all really really fun
J- yeah
N- ok. And the times when things are annoying you’re still playing and its really fun but it is annoying at the same time?
J- yeah
N- so it is like both things
J- joined together and there. Like if one thing was here and the other thing was here it would just skim past so it would almost touch but it wouldn’t quite touch because it would just go out [uses two hands and moves them past each other]….
N- …So you know those two things that were just going past each other how would that happen?
J- so they’d just, if it was really fun [showing one hand], but it was just annoying [showing the other hand and indicating a little bit] at the same time (sighs) that’s how I would do it
N- and they would like
J- just go past each other [moves ‘fun’ and ‘annoying’ hand past each other]
N- and what would it feel the most of?
J- fun, probably fun
N- ok, and are there ever times when it feels the most of annoying, not fun?
J- No
Jess, Interview 3

Box 21 Jess, Interview 3- Jess discusses how the feeling of annoying and fun are both experienced at once during play.

The extreme array of both positive and negative emotions played out can be explained and better understood through the tension that children experience within their lifeworld. Jess captures this tension within her discussion about her experience of participating in mermaid play whilst swimming with her family in box 21. This provides further explanation for the tension experienced within each child's lifeworld between their disabled self and the positive experiences they have of play. The frustration and annoyance of having physical limitations appears to in most cases be outweighed by the fun that children experience within their play.

5.7.4. Imagined self without disability – a new spatiality

When each child discussed their imaginary play they did not always specifically say they did not have CP but they would describe themselves moving in a way which suggested they continued to be themselves but without a physical disability. Lucy discusses how in her imaginary play *'My body's just moving how I want it to move!*' (interview 3). This is interesting considering that all the children do not have an experience of living without Cerebral Palsy. It would appear that based on observation of others the children have built a picture of the experience of movement in a way they do not know. When Lucy comments about her body moving *'how [she] want[s] it to move'* it would appear that she recognises there are times in which she has intension to do something physically but because of her Cerebral Palsy cannot achieve a task in the way she would like to. Children did not discuss the experience of trying to get their bodies to physically move or achieve a task such as walking or going and picking up a toy, however, it would seem that for Lucy this has created a frustration which she perceives herself as free from in her imaginary play. Lucy sees the alternative self which she experiences in her imagination as different because of the cohesion it enables between her intention and her action which she does not experience in her reality.

Similarly, Ben focuses on his ability to move and participate differently when discussing his imaginary play experiences. During pretend rugby play on his iPad Ben comments, *'I was trying to trick them so the way that you trick them is to pass left and right, left and right, left and right really quickly'* (interview 1). Tom also talks about physical capability and how he runs and jumps within his pretend play (interview 3). Each participant's use of the first person to discuss their play suggests that this participation is more than of an imagined other; it is part of a new spatiality the children experience in which Cerebral Palsy does not impact their participation. Spatiality is defined as an individual's lived space; the environment around someone which changes their perception of their experience (Simonsen, 2007). Within imaginary play the children are in a new space; they experience a new spatiality in which they can be themselves without the physical restrictions of their Cerebral Palsy.

The children indicate that the experience of a new spatiality in their imaginary play is good. It is unclear as to whether children perceive this self as better than the self they experience in reality. Rather than this being children's focus they appear to draw upon the freedom that participation in their imagination enables as a part of their everyday experience. This imaginary play may be similar to the play of typically developing children when they become and assimilate an alternative character who is perhaps themselves but older. However, it appears to be that the new spatiality that children experience within this play where they have the opportunity to complete actions in the way they intend, is a deeper psychological process, and has a more significant positive impact on their experience.

Jess is one of the children who articulated a new spatiality experienced within imaginary play most clearly. Jess describes that she is *'kind, helpful, (this is in the game and in real life) and independent so that's really good'* and reports that in the game she is often similar *'but I just don't have my disability like I do'* (interview 3). This is captured within the imaginary play that Jess participates in (box 22), as shown in figure 15 where Jess is seen playing independently with her doll. To an observer Jess was sitting and holding the pushchair, occasionally lifting the handle or saying something to her doll but generally appearing to be quite static within the 5 minutes of play. This was a stark contrast to the narrative description (box 22) that Jess then provided of her play. Although static to an observer, Jess was very much actively participating in a play experience with a new spatiality in her imaginary play. This enabled an experience of freedom, movement and ability to care for her baby as a grown up.

J- I'm just jumping her up and down to see her and now putting her back in to have a sleep and I'm rocking her (commentating as watching)
N- rocking her
J- kind of tipping her, tipping up on two wheels to get over bumps and stuff, I'm maybe in the garden
N- ah ok, you may be in the garden, so are you pretending you're walking along with her?
J- yeah
N-so where are you going?
J- we're going to the, we're going to the local park, um this is our garden, we're going to the local park
N-ok, so
J- to, um, give her a little bit of freedom so that she can crawl about…
N- Ok cool, so in this one you're sitting down and you've got the buggy but you're pretending you're walking along with the buggy so when you're lifting up for steps and things like that?
J- yeah, and I'm about to get her out again... And then I'm just hugging her and things
N- so you were saying that she's got brown eyes why were you saying that?
J- because she may not know because she can't see them (whispers) so I was just telling her. So she knows she's got brown hair but she doesn't know that she's got brown eyes
N- ok cool shall I keep it going? (referring to playing the video)
J- yeah, there's a lot of picking her up and putting her down
N- so are you thinking of all the things that a baby might need, when you're playing?
J- yeah
N- and are you talking her on another walk are you?
J- yeah I'm taking her on the same walk because we stopped somewhere and then we kept on going
Jess, Interview 3

Box 22 Jess, Interview 3- Jess is recounting the play scenario that she is going through as she sits on a chair with a dolly in a toy pushchair in front of her.

Figure in 15 Jess is sitting on a chair playing with her dolly in a pushchair. To an observer she is static but in her imagination she is participating in an elaborate play scenario and experiencing a new spatiality, where she does not have a physical disability.

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A similar experience of a different spatiality within imaginary play is seen in Lucy's discussion of her experience. Lucy talks about how her experience of playing football in her head is *'like the sun shining brightly'* (interview 3, figure 16). This suggests a contrasting spatiality and experience of space to the everyday reality. When playing an imaginary game Lucy pictures herself in a space where the sun is shining and she can move around. The reference to sunlight creates a picture of a space that is bright and airy and gives the impression of positive affect. It is possible that Lucy experiences positive affect within this play as she is not limited by physical restrictions she normally faces. Lucy frequently discusses positive experiences both in her reality and in the new spatiality experienced in her imagination. This would suggest that rather than her external reality being less sunny, Lucy experiences a spatiality which she can control in her imaginary play; this means that the experience can always be *'like the sun shining brightly'* rather than an experience of the fluctuating emotion (5.7.3) that children discussed in the everyday reality of play.

Figure 16 A section of Lucy's play drawing which shows her experience of playing football in her imagination in which 'the sun shin[es] brightly'

Examples of a new spatiality in which children imagine themselves without their physical disability are also seen within other interviews. Ben discusses a perception of himself as freely participating in rugby, and Tom talks about how he *'climb[s] up a ladder'* when playing in his imagination (interview 2).

Children within the study also participated in imaginary play where they clearly experienced a different spatiality and lack of physical disability. Imaginary play where they became a hero, famous sports person or a helper appeared to also provide the opportunity for a lived experience of being free from Cerebral Palsy. Lucy reflects on how she helps her sister within an imaginary game: *'Lilly did get somebody, her royal coach, Lucy'* (interview 2). Daniel comments that his imaginary play often involves characters who become *'superheroes like me' (interview 2).* Daniel often talked about assimilating a specific role as a hero within his imaginary play and referred to himself feeling *'like a real ninja…because I might be a ninja'* (interview 1). Daniel makes a similar reference within a subsequent interview where he becomes the character he is aspiring to be: *'I like being a secret agent…I like to be a secret agent'* (interview 2).

Within Daniel's quotes above it is clear that he not only is <u>like</u> a ninja, a secret agent or a superhero; within his play experience he <u>is</u> a ninja, a secret agent and a superhero. His ontology shifts and he <u>becomes</u> a different character as part of his imaginary play. Daniel's experience of his play is one in which he has superpowers which surpass the restrictions of reality and mean that anything is possible. It is possible that for Daniel becoming the hero and the helper and achieving tasks like *'sav[ing] all the people in the world'* (interview 2) were a way in which he was able to process and adjust to the amount of help that he needed from people around him within reality. In becoming a superhero that saves people it is possible that Daniel was also imagining himself as defeating his Cerebral Palsy. Where previously children have talked about their Cerebral Palsy as an embodied thing (*'kill **that**',* Jess, interview 2; *'**it** doesn't hurt me',* Abi, interview 1), it is possible that the Cerebral Palsy becomes a character that needs to be defeated in each child's imagination. The participation as a superhero and accomplished individual who can move freely could suggest that this imaginary play is a picture of Cerebral Palsy being defeated for these children.

Further examples of this are seen in the way that children become other characters within their interviews. Ben discusses how he is *'actually Andy Murray'* when he is playing (interview 2), this suggests he is experiencing physical fitness and strength to move. The participation in tennis could be perceived as hitting away personified Cerebral Palsy in order to defeat it. Tom discusses winning a race with Woody and Buzz (hero characters from an animated film- Toy Story); he gains skills like superheroes in order to be able to participate alongside them.

The duality the children experience of being able to be both themselves and another character within play may be an important part of children experiencing a new spatiality which provides the opportunity to experience freedom from the restrictions of a physical disability in play. This could be seen as similar to the imaginary play of typically developing children where they suspend their reality in order to become a hero. For children within the present study it appears however, that the experience of this new spatiality through becoming a hero is more significant as it provides a perception of control and the opportunity to experience leading play. This could become a duality to the necessary physical help and care each child experiences in their lives because of the level of their disability. This raises the question as to how the participants in the study perceive themselves the majority of the time; it is possible that the lived experience of their lifeworld is a fluctuation between the everyday reality of living with a physical disability and the new spatiality which is experienced in imaginary play.

5.8. Theme 3: Connecting with others in play

There were several times in which children appeared to seek connection with others as part of their play. Children often had good connections with their families; this appears to primarily be because of the extent of support they need to play and therefore the involvement of their families within play. This could lead to a child placing a greater sense of importance on being a part of their family in comparison to belonging alongside their peers.

5.8.1. Using humour to enable connection

When children do not have the opportunity to move freely or access something independently it appears that their ability to communicate humour as an expression of themselves is essential. All of the participants discussed being *‘funny’* or making *‘jokes’.* For Abi, she regularly talked about part of her identity as being *‘mad’* and *‘bonkers’ (interview 2);* this expression of self as someone who is innately funny perhaps enables Abi to feel more confident in her expression of play. Abi comments that she wrote ‘poo’ in scrabble because *‘it just makes me laugh all the time. I love comedy’ (interview 3).* Abi’s use of humour appears to be more than an expression of her character but a means by which she looks for connection and a sense of belonging with others. Belonging is defined as the sharing of occupation with others in a way that enhances wellbeing (Wilcock 2007).

Through writing a humorous word in a game with others Abi was using humour to enable a connection between her and the other players, which led to a shared experience within play. It is possible that in drawing upon humour Abi was trying to draw attention away from her physical disability and the difference in her physical participation between herself and her peers. In being funny and identifying herself as funny Abi was more likely to be able to encourage fun and laughter with her peers; the building of this identity was perhaps of particular importance to Abi so that she had the possibility of being within a group alongside her peers. As Abi is unable to physically participate in the same way as her peers her use of humour provided a skill which she could improve and become one of the best at in order that this became her identity as part of a social group.

For Tom, humour also appears to be a clear means by which he creates connection with others and increases his own sense of belonging to play experiences. When things go wrong within play it leaves open the opportunity for the play activity to finish or for other players to move on. Instead of allowing this to take place, Tom uses these opportunities to create humour and connection with other players (box 23). This leads to Tom experiencing a greater sense of belonging within his play.

[watching video]
T- [vocalising and then squeals/ laughs]
N- [laughing] what happened! Did something go wrong or was it something else?
T- [chooses- 'something went wrong']
N- something went wrong! And you're doing lots of laughing, did that feel funny?
T- [looks- 'yes']
N- so do sometimes things go wrong when we're playing?
T- [looks- 'yes']
N- and is it part of playing or not part of playing?
T- [chooses- 'part of playing']
N- and is it sometimes what makes it funny or is that not right?
T- [chooses- 'they're sometimes what makes it funny']
Tom, Interview 3

Box 23 Tom, Interview 3- Tom uses humour to create connection with other players when something goes wrong.

When Tom sees that something goes wrong he uses laughter and humour as a defence mechanism. In the sense of the saying *you either have to laugh or cry,* it appears that Tom chooses laughter as a way to process mistakes whilst remaining connected with other players. Tom chooses to incorporate his mistakes into his play; they become both a part of his play identity and expression of self, as well as creating an opportunity for re-connection with others and the continuation of the play experience. Through choosing to create laughter around the experience of something going wrong Tom is able to make positive affect an experience of play that could otherwise be perceived as negative. The possibility of creating humour from mistakes appears to demonstrate Tom's resilience in the face of things going wrong. As Tom has a significant level of physical disability it is likely that he may physically attempt to participate in an activity and not be able to achieve an activity with the accuracy or strength needed for the intended outcome. As demonstrated through his humour (box 23) Tom had developed a different style of playing in which he focused on using his communication to create jokes and shared humorous experiences in order to connect with others; this perhaps enables him to overcome the physical limitations to his play.

Tom shows this further through his use of communication; his eye gaze technology, choice making and vocal expression. He chooses to miscommunicate and give an opposite response to what he means in order to cause humour within his play. This enables Tom to share his humour and create connection with another. Tom's use of humour draws adults into the play interaction with him (box 24). Even though Tom initially says that he does not find *'Minions'* funny, this is the opposite of his experience and the importance of *'Minions'* to Tom is clearly seen in the drawing of his play in figure 17. Tom deliberately expressed the opposite view to that of his experience to create a situation that caused humour and connection between himself and the researcher. It is possible that children such as Tom have learnt that they can connect with others through humour. This enables an opportunity to belong and participate with others particularly at times where they may otherwise feel exclusion. Although humour is used to enable connection, it could also be a means of hiding from the frustration caused by having a disability (5.7.3). Through focusing on being funny the children develop a clear role and opportunity for connection as part of their play interaction. This can become a play identity which leads to opportunity for play and belonging.

N- excellent. Have you seen the minions film?
T- (shakes no)
N- no! have you seen despicable me?
T- (nods yeah)
N- do you find it funny?
T- (shakes no)
N- no! does it not make you laugh?
T- (shakes no)
N- you don't do any laughing when you watch minions
T- (vocalises no and starts laughing)
N- ok… are you tricking me?
T- (Nods big yes!)
N- yes, I think you were tricking me
T- laughs and vocalises
N- do you like telling jokes Tom?
T- (nods yes) laughs lots
N- do you like playing like that?
T-(nods yes)
N- it is a good way to make other people laugh
T- (nods yes) [vocalises]
Tom, Interview 1

N- we're going to do your teeth so shall we do a [sad] or [happy face?]
T- [chooses sad]
N- sad, are you joking?
T- [looks no]
N- when you're playing how do you look, do you have a [sad face] or a [happy face]?
T- [chooses happy]
N- (T laughing) I think you were joking!
Tom, Interview 2

Box 24 Tom, interview 1, 2- creates humour and a playful interaction with the researcher by pretending he does not like Minions.

Figure 17 Tom's drawing of his play experience. He is in the centre in his wheelchair, his minions are on the left, buzz and woody at the top, playing the space game by running around in imagination on the right and watching car racing on the bottom right. His minions (left) are really really important to his play, and yet he creates humour by initially telling the researcher he does not know about them.

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This use of humour to create connection is also seen in the other participants' interviews. Jess talks about how she *'tell[s] quite funny stories'* to her peers and Ben talks about being funny and telling jokes. Daniel relays a story of flicking his food in order to make his peers laugh at the lunch table at school. Laughter as an expression of humour was evident throughout the interviews and all the children laughed as part of their play. It is perhaps a shared laughter that creates a feeling of connection and belonging for each child within their play.

There also appeared to be times in which humour was experienced more negatively as it was used wrongly within children's play. Jess discussed an experience of falling out of her wheelchair and how this became a joke between her and her friends. Ben discussed how a peer at school always hugs and kisses him. Ben perceived this to be funny at times but also felt frustrated by this. It appears that the use of humour can at times become a mask in order to hide the difficult experiences that the study participants experience in play. Focusing on humour becomes a way to detract attention from difficulty and to focus on making others laugh. It is possible that the very act of laughing enables children to experience a positive affect and therefore better feeling about the difficulty they are experiencing.

5.8.2. Using voice to be heard in play

Communication appears to be a strength that children draw upon in their play, particularly when their physical disability is limiting physical participation. It seems that particularly for the children who use eye gaze technology the opportunity to use their voice (even if they cannot form intelligible words) meant that they could create connection with others within their play. Both Daniel and Tom discuss making noise as part of their play experience. By doing something that gains others attention they are able to create connection and gain recognition of their play. Daniel comments within his second interview *'I'm not very quiet, I'm not very quiet, I'm quite loud'.* Tom, when talking about playing the piano independently, says that it is important '*because people can hear where [he is].'* (interview 2).

N- What about, do you want to tell me about the game we just played?
D- Yeah
N- ok, go on then, so it was crazy bowling and how did it feel?
D- Crazy
N- Crazy
D- and funny
N- uh huh
D- very loud, very loud
N- very loud, yeah. What do you think about it being loud that is so special?
D- (thinking) it's a bit like laughing because it, you sometimes just laugh loud when you're enjoying the game

Daniel, Interview 3

Box 25 Daniel, interview 3- comments that being loud in his play is like laughing.

Daniel's discussion of the importance of being loud is seen in box 25. Daniel comments that *'it's a bit like laughing because it, you sometimes just laugh loud when you're enjoying the game'* (interview 3). The possibility of being *'very loud'* appears to be closely linked to *'laughing'* for Daniel. Daniel comments later that being loud is a way that he *'let[s] people know that I am happy'* (interview 3). It seems that for Daniel creating a sound to express joy means that he is able to connect with others and let them know about his play experience. This is perhaps important when children cannot independently mobilise or move to find other people within play. Being able to communicate, be loud and create a noise provides the opportunity for other people to notice and recognise the play activity and participation of the child.

Each participant within the study has a significantly better level of communication in comparison to their motor skills. This had an impact on play experience in terms of enabling each child to demonstrate their choices and make their preferences heard. When talking about physical participation in netball Abi commented in her second interview that she *'just asked [her] friend to throw the ball'.* Ben says *'I tell her'* when he is asked how he goes where he wants to when he is playing bulldog with his friends and needs his teaching assistant to move his wheelchair (interview 1). The ability to communicate with others and ask for help when it is needed is explained by Daniel: *'I just say help, and they will help me'* (interview 2). Particularly because of their good communication skills it appeared that communication often became a replacement skill for physical ability which enabled a continued experience of belonging within play.

Using both words and sound of voice appeared to be an important part of play. Where a variety of physical movements were not possible for the majority of the participants they could all use a variety of sounds, tones and pitches in their voice, which could become a part of their play. This was seen in Lucy's use of a sing-song voice within her rocket ship play, where she sang with her peers: *'we go 'zoom, zoom, zoom, we're flying to the moon, zoom, zoom, zoom we'll get there very soon, 5,4,3,2,1'* (interview 1). Lucy describes how they *'pretend that [they're] blasting off and [they] also pretend that [they]'re landing and [it] is a different planet*' (interview 1). Lucy's participation within the play activity does not depend upon her physical ability but depends upon her ability to communicate with others about the experience of being on a *'different planet'*. She discusses how they pretend they can see *'aliens';* she is able to interact with her peers and belong to this play experience because of her ability to communicate and participate in the creation of an imaginary play experience.

Lucy also uses communication and story-telling as part of her play with toys. Lucy plays with them to the extent that they are personified and she is able to communicate with them in a way that enables play. This is seen in box 26. Lucy creates play with her toys where she is able to belong to her toys social group. She connects with *'Conto'*, *'Spot'* and *'Little worry doll'* in the telling of her story in box 26.

> *L- Conto came, conto came and shocked me and spot. Shockedy, shockedy, shock. 'Ah' we screamed! 'It's conto!'. But Conto was crying, he didn't even say a word. Conto is one of my best toys, I, 'Conto is one of my best toys' I said to spot. 'Wow! That's amazing, it sure is' said spot, and I love Conto especially when you cuddle him and then spot we were happily playing together. Conto soared off. And little worry doll came. 'hi spot', 'shh little worry doll! Me and spot are happily playing together'.*
>
> *Lucy, Interview 1*

Box 26 Lucy, Interview 1- is telling a story with her toys as she would on her own. She personifies her toys and they have a conversation with her as a character also in the game.

In this play it appeared that Lucy's toys became more than toys but were experienced almost as peers participating in a play activity with her. Later in this interview Lucy comments: *'Yes I like to do [stories] with my toys because they listen'* (interview 1). It appears that where Lucy is unable to connect with others as part of her play she personifies her toys to the extent that they become like her friends and the social group that she is participating with. This could be only at times, such as when waking up in the morning, when Lucy cannot physically move out of bed and therefore has the opportunity to play on her own. Lucy did, however, discuss taking some of her toys to school; it is possible that the presence of one of her toys enables Lucy a greater perception of having someone to talk to and connect with if she is unable to participate with her peers.

Other participants also personified their toys but this appeared to be to a different extent. Jess comments that her teddy *'goes in a space rocket and he flies to Pluto and he sees this really weird alien with an eye on his nose and an eye on his bottom (smiles), and an eye on his forehead (points) and this alien is his worst enemy (emphasises) and it's about the alien and they both have a battle: teddy bear against alien'* (interview 3). Although Jess is personifying her teddy as a character who can participate and battle an alien, her experience of play with her toy is different as she is not part of it. For Lucy her experience (box 26) appears to suggest a greater level of personification and connection with her toys to the extent that she perceives them as like her friends.

It is possible that toys sometimes become an audience for play when an audience is not there. The use of toys as part of play was common for the participants in the study. It is possible that within the children's mind toys represent a similar being to them, the children often need someone to physically support their play and a toy needs physical facilitation to enable movement. Perhaps the children experience a sense of empathy and commonality with their toys which leads to a focus on play alongside them. Several of the children personified their toys within their play and it seemed that they had developed friendships with characters that their toys represented.

Lucy and Abi discuss developing their communication skills as they have grown older. Lucy commented that *'I kept trying to talk until I learned (smiles) if somebody doesn't hear you, you've got to keep talking'* (interview 3). The ability to communicate and be heard appears to be important for each child. It is possibly most significant for Tom as he currently only uses eye gaze technology and sounds rather than clear speech to communicate. As Tom is still developing his communication skills he uses the skills he has to gain attention and share his play experience with those around him. For Tom and the other participants, the ability to be heard and use their communication skills enables a greater level of connection with and attention from others as part of their play. There are times, however, where communication is not enough to enable connection and because of physical restrictions, often within the environment, the participants remain isolated in their play (see 5.6.3). It is important for both parents and professionals to recognise and encourage communication and humour in the way that they enable connection and a sense of belonging in play. It is also important for these individuals to have a greater awareness of factors which may lead to children experiencing isolation.

5.9. Summary

The findings suggest that the children experienced play through facilitated independence; the embodiment of their equipment and of carers enabled them to experience a sense of independence within their play. There is a tension which the children demonstrated in their lifeworld's between their experience of living with Cerebral Palsy, and a new spatiality experienced in imaginary play- where they played as themselves but without their disability. The children have developed their play skills and negotiated play experiences and participation. Sometimes they experienced having to be on the side lines of a play activity or being unable to participate; at other times children were able to experience participation through the process of watching others play. Children's experience of being themselves was shaped by the way that they connected with others. There were times in which children experienced barriers to playing alongside others. Children used strategies such as communication skills and humour in order to create a sense of connection between themselves and others within play.

5.10. Reflexive account

I found creating the findings chapter the most challenging aspect of my thesis. I felt that throughout the process of analysing the data I had glimpses of an incomplete picture that took a while to uncover and represent as a whole within this chapter. Whereas I initially perceived the process as straight forward, I soon realised that the influence of my own interpretations of the data and the tension of always coming back to the participants' voice was more difficult to navigate than I originally thought. Through discussion with both my supervisors and my peers throughout the findings process I was able to clarify and process the main themes and subthemes that were represented in my data. When discussing my research with others their questions enabled me to explain and frame important aspects of play that the findings appeared to highlight, such as the facilitated independence and imaginary play with no disability that participants experienced.

The start of the analysis process and the initial writing of the findings I found enjoyable and interesting. I was excited by the data that I had gathered and I was interested to ask questions of the data and explore it in depth. My biggest concern at the point of analysing the data of my first two participants was that there would not be sufficient depth for an IPA study. I chose to present the findings of my first two participants at the IPA London discussion group and this enabled me to explore my use of the methodology with others outside of my field. I gained good feedback from those at the discussion and this gave me an increased confidence that I was reaching sufficient depth of analysis with my data. Following this I continued to carry out the analysis process in an idiographic manner as recommended by IPA.

As I continued to interview more participants and analyse their data I found that I had to try and stop myself making premature comparisons between participants. I did this through continuing to keep a reflexive journal throughout the process in order to record my comments and presumptions. For example, in knowing that Daniel had talked about getting *'energy'* from movement and from going *'fast'* I wanted to look for similar discussion about movement within other participants' interviews. Other participants did not talk about moving fast to the same extent as Daniel and this was a reminder of the comparison I was making and the error I had made in my analysis process of too quickly jumping from the individual to the whole. This prompted me to return to the participants' interviews and their own comments and carry out the analysis following the protocol outlined for IPA rather than bringing my own structure or lens to the data. This particularly occurred around presenting the initial findings at the College of Occupational Therapy annual conference (Graham et al. 2016a). Although I presented the findings ideographically, the discussion and questions that followed my presentation led to others making presumptions about general themes and findings emerging from the data. I found that I had to be assertive in stating that I had not finished data analysis yet and therefore the findings would change significantly before the end of the research process. I then had to again make sure I was reflexive in my approach when coming back to the data in order that I was starting with the participants' experience rather than my own interpretation.

Once I had completed the process of ideographically analysing each participant's data I had a summary of each participant's experience (appendix 13). It was from these themes and subthemes that I had gathered for each participant that I was able to draw together overarching themes and subthemes across the participants. My perception was that this would be an easy task in which it would be clear to see the themes in the data. However, this was not the case. It took several iterations, lots of discussion with my supervisors, and several attempts at carpeting in order to come to themes and subthemes which accurately represented the data. There were times in which I had to make decisions about which parts of the data to include as themes within the findings chapter. As IPA follows a process of looking at the weight of the data rather than number of occurrences or consistency across participants (Smith et al. 2009), this had to be considered carefully. I found that the process of carpeting (appendix 14) in order to map out the participants' themes and subthemes allowed me to create groups of themes and more easily decide what was significant in the data.

I spent a long time looking at the duality that occurred within each child's play when using the carpeting approach. At this point of analysis I found that I wanted to pin my ideas on a particular view point and angle. In a desire for the findings to be neat and thought through I wanted to find a duality of experience for each superordinate theme. This initially came from the duality and contrast within each child’s lifeworld between seeing themselves with their disability and seeing themselves as someone who is active and can participate. I tried to create observations of this duality within each child’s emotions and the way that they connect or felt distanced from others. In my first iteration of my findings chapter I created a metaphor of a carrot both inside and outside of the soil in order to represent the idea of a duality where part of the child’s sense of self was exposed and part of it was hidden. This metaphor, however, appeared too far from the data and a true representation of it. I realised, with the support of my supervisory team, that I had wanted to create the framework of duality in order to present my findings in a particular way. I found that through re-framing and looking at the findings through considering each superordinate theme in and of itself I was able to more easily represent the data.

As I started to re-write the findings chapter for a second and third time I discovered that my thinking and processing of the themes and subthemes continued to develop. I continued to go back to the participants’ data in order to make sure that I was representing this appropriately. Re-reading the participant summaries and also key sections of their transcripts enabled me to keep this chapter based within participants’ quotes. I initially found that I reported on themes and subthemes in too much of a descriptive manner and therefore I worked to make sure that each theme and subtheme was interpreted and explained within the text of this chapter. I found that I enjoyed this process of interpreting and representing interpretations of what each participant was saying. An example of this is found in Jess’ discussion of playing like a mermaid (6.3.1), I found that the metaphor that this creates provides an insight into Jess’ understanding of her disability and her processing of this. This was interesting to consider in light of other children’s perceptions of their disability and means by which they represented themselves.

One significant point of reflexivity within the writing of this chapter was around my own positive worldview and the influence that this had on my analysis of the data. I felt that I had a clear picture of my data and was able to represent the participants’ view point, however, feedback from my supervisory team suggested that I had a positive bias within my writing. As acknowledged at the start of this thesis my Christian worldview and desire to see value in every individual does often lead to me interpreting things in a positive light and looking at enablers rather than barriers to participation. I thought I had been aware of this in the process of writing my findings chapter however, on reflection I realised that I had not represented the barriers to children's experiences of play to a great enough extent. When challenged on this I spent time re-reading all the participant transcripts and directly noting the barriers and less positive aspects of play that each participant noted. I have represented these within this chapter in order that I am showing both the enablers and barriers that children report in their experience. The chapter continues to mainly focus on enablers to play as this reflects the outlook of the participants. The majority of the time children discussed things they enjoyed participating in as part of their play activities.

I passionately believed in representing each child's perspective as I felt this was missing from the research literature. I have therefore chosen to focus upon means by which children talk about their experience of being able to play, whilst also trying to represent the barriers that they mentioned, in order that research can represent the view that appeared to be present in the majority of children's interviews. I found that despite the move towards disabled children's childhood studies and the importance of the voice of the child within this movement (Curran & Runswick-Cole 2014), the majority of studies appear to show barriers rather than enablers to participation (Imms 2008, Imms et al. 2017). In this research I therefore wanted to fully represent the child's voice and I was careful within the interviews to not just talk about and focus on barriers to play. I am aware that this could be misinterpreted as a bias within the findings and that my interpretation as a researcher will have a more positive view point. However, I was careful to make sure that I represented both sides by going through my interviews and looking for the more negative aspects and barriers to play. I feel that these barriers are represented in the themes of being forced to compromise in play (5.6.3.), the experience of having a disability (5.7.1), and the extreme frustration that can be experienced in play (5.7.1).

The importance of being able to represent each child’s viewpoint and their experience from their own perspective was emphasised by discussions I had at conferences. I presented some of my findings with a poster (appendix 16) at the European Academy of Childhood Disability (EACD) and College of Occupational Therapy Conferences in 2017 (Graham et al. 2017a, Graham et al. 2017b). When discussing this poster at the EACD conference I found that individuals often saw play as purely physical and therefore found it difficult to move beyond this understanding to consider each child’s experience. I was particularly struck by one specific conversation in which a senior professor did not consider the possibility of each child’s experience, despite discussion about this, because he was adamant that play required physical skill. This raised an important consideration for me in making sure that I was clearly capturing the experience of play that children had even when they were not participating physically and that I represented this in a way which could be understood.

Overall, I was pleased with the point that I reached with my data analysis and the representation of my findings. I found that the process of creating a reflexive diary was helpful in being able to understand my own influence on the presentation of the data. In the process of reflexivity I was able to recognise where my own influence as a researcher went beyond representing the experience of each child. I am confident that the findings chapter presented here represents each child’s experience and interprets this clearly.

6. Discussion

6.1. Introduction: Doing, Being, Becoming, Belonging

The findings (chapter 5) continue to provide support for play as a primary and meaningful occupation for all children, including those with high levels of physical disability. Wilcock (2007) proposed that engaging in meaningful occupation through a process of *doing, being, becoming and belonging* is essential for health and wellbeing. Wilcock suggests that individuals are always *becoming* more of themselves as occupational *beings* through the *doing* of occupation (1998) and connecting and *belonging* alongside others (2007). Through discussion of their experience of play the participants have highlighted new ways in which they participate in the occupation of play through a facilitated independence. This is understood through each child's *doing* of play and the embodiment of both equipment and helpers as part of this. Through play the children appeared to reflect upon their sense of identity and *being;* they experienced a tension in their lifeworld between their identity as themselves with their disability, and the space for a different way of being in their imaginary play. The children developed their identity through an ongoing process of *becoming* within their play; one aspect of this included a recognition of activities that they participated in differently to their peers. There were times in which their Cerebral Palsy limited their physical participation in play, but they engaged in watching, cheering and instructing as a means of participation. Finally, children expressed both barriers that isolated them from their peers and strategies, such as the use of communication and humour, which enabled greater connection and sense of *belonging* within their social world.

The following chapter will discuss the findings in relation to *doing, being, becoming and belonging* (Wilcock 2007) whilst drawing upon other theory and literature. The theory of embodiment (Merleau-Ponty 1945) is of particular relevance to the experience of play for the participants within the study. More recent research that explores embodiment within a healthcare setting will also be drawn upon to further inform the discussion (Benner 2000, Bjorbækmo & Mengshoel 2016, Blanchard & Øberg 2015). Research and theory that discusses the development of self and a sense of *being-in-the-world* (De França 2008, Erickson 1959, Heidegger 1927) enables a deeper understanding of the tension that the current study participants experienced in their lifeworld's. The concept of occupational well-being (Doble & Santha 2008) will be discussed in light of the contributions this study makes in understanding occupational participation (for example, watching play) in comparison to occupational performance (for example, physically participating in play). The study participants demonstrated a resilience to persevere in the face of social isolation, this was part of the ongoing process of negotiating identity and *becoming* themselves. The concept of resilience (Masten 2001) will be discussed in considering this process of negotiation and search for a sense of *belonging* within their lifeworld.

6.2. Doing play: An embodied experience through facilitated independence

The concept of *doing* is described as the way that individuals engage in purposeful action throughout their everyday life; individuals may experience *doing* tasks both that they want to complete and that they feel obliged to do (Wilcock 1998). Children within the study talked about several ways that they engaged in *doing* play. Perhaps most significant to this discussion is the way that participants engaged in *doing* was through the embodiment of both their equipment and their helpers which enabled an experience of facilitated independence (5.6.1, 5.7.1).

As discussed in the methodology chapter (3.5.1), individuals are believed to be embodied beings who create meaning through the experience of *being-in-the-world* (Merleau-Ponty (1945). The Heideggerian view of embodiment is reflected in the experience of the study participants whose lifeworld and view of themselves appeared to be perceived through their bodies. The children experienced play as embodied knowers; a term used within nursing research that suggests that individuals understand meaning through their position within their culture and lifeworld (Benner 2000).

This embodied *doing* play meant that children developed meaning within the context of their lifeworld. This is supported by guidelines, influenced by the international classification of functioning (ICF) (WHO 2007), which suggest six F's for childhood disability: *'function, family, fitness, fun, friends, and future'* that highlight the importance of the context of each child's lifeworld (Rosenbaum &

Gorter 2012). These are also reflected in Powrie et al.'s (2015) systematic review about the broader concept of leisure; some similarities to the present findings can be drawn in terms of the importance of 'fun', 'freedom', 'fulfilment' and 'friendships' in the *doing* of play. Children in the current study appeared to experience interaction with their family and friends in their play through their *body-in-the-world.* The biopsychosocial model of disability supports this in recognising the importance of context to experience (Leonard 1994). It is important to highlight this clearly within the research literature in order that children's experiences as embodied agents in the world are recognised. The following section will explore and discuss the embodiment literature in relation to the participants' experiences of *doing* play, first in the experience of embodying their equipment, then in the experience of embodying a carer. This leads to an expanded understanding of embodiment and a new definition of *doing* play for children with high levels of physical disability.

6.2.1. Embodied equipment

Much of the discussion of embodiment is based upon the experience of our bodies *in-the-world* without the presence of external objects (Merleau-Ponty 1945). Within this study each child's high levels of physical disability meant that the majority of their embodied experience involved the presence of an object such as their wheelchair or walker. There are very few instances where the children experienced play through an embodiment without any external objects. One instance is described in Jess' experience of being able to move around on the floor to play which she describes as *'free'* (interview 2, 5.7.3). This feeling of being free is perhaps closely linked to the experience of moving without the presence of an object; without her wheelchair or specialist seating Jess has no external restriction to her movement and her embodied experience therefore feels *'free'.*

As introduced in section 3.5.1 but less discussed within the literature, is the experience of embodiment in which objects external to the body become an embodied part of an experience (Merleau-Ponty 1945). This is illustrated through discussion of individual's ability to perceive and experience the world through their bodies and objects which become a part of them: a woman with a feather on her hat will avoid walking through a space that may break the feather; a man who is blind perceives his cane as an extension of his hand, which enables him to negotiate space around him (Merleau-Ponty 1945). In the current study this kind of embodiment was often observed in the way that children embodied their equipment as part of themselves when *doing* play. This occurred to the extent that often, unless prompted, the children would not mention their wheelchair as facilitating their ability to move around.

As discussed within 3.5.1, embodiment of objects has been seen within wheelchair use for individuals with disabilities (Giulia et al. 2015, Papadimitriou 2008, Sawadsri 2011). The children within the study experienced an independence that was facilitated through the embodiment of their equipment, enabling them to participate more easily in *doing* play. Although current studies suggest the possibility of embodiment of a wheelchair within play there appears to be no research to date that looks at the embodiment of wheelchairs for children with disability. The experience for children is likely to contrast with the experience of other participants, such as those in Papadimitriou (2008) who participated post spinal cord injury. It is still possible, however, to draw upon such studies to gain an insight into the experience of embodiment for the study participants. Papadimitiou (2008) focused on an emancipatory research perspective where individuals with disabilities are viewed as differently or newly abled rather than dis-abled; they are able to be active agents because of the embodiment of their wheelchair's. The apex of this embodiment during rehabilitation is discussed as being the point at which individuals can do 'wheelies' in their chairs. Papadimitiou (2008) discusses the embodiment process as *'a transformation of one's corporeal schema to include the physical features of the wheelchair'* (p.697). Individuals are thought to recreate their identity in a way that is dynamic and creative – they can embody their chairs to the extent that they are forgotten. This was seen within this study where the use of a wheelchair was often not mentioned or referred to by participants as it was such a part of normality. Although Papadimitiou (2008) discusses embodiment post-injury as opposed to from a disability experienced at birth it clearly suggests that individuals with physical disabilities can embody their wheelchairs in way that becomes normalised and part of facilitating their *doing* occupation within their everyday experience.

Within the present study all six participants discussed or indicated at different points that they felt their wheelchair was a part of them. This perception also appeared when individuals such as Daniel were talking about their experience of using their walker. The embodied experience of using equipment appeared to facilitate an independence and increased sense of intentionality. This is supported by Papadimitriou (2008) who suggests that the embodiment of a wheelchair can lead to a perception of *'I can'* and increased sense of an ability to act intentionally in the world. This is further supported by studies which suggests participation in adaptive physical activities for children and young people with disabilities improves physical, social and psychological skills (Sharp et al. 2012). Equipment and adaptations can therefore be seen as an enabler of intentional movement and *doing,* which becomes a part of each child's sense of self. This was clear for children such as Abi who spoke about being '*independent'* and Daniel who discussed going fast in his walker (5.7.1). It also appeared to be present even for children who use a wheelchair but are not able to use a powered chair independently; many of the children within the study were moved in their wheelchairs by adults for the majority of time, yet appeared to still experience a sense of independence. For example, Ben saw himself as moving independently despite having a helper to move his wheelchair in bulldog (5.6.1).

It appeared that the use of equipment such as computer technology often also increased children's experience and perception of *'I can'* within play. This was seen in children's use of their iPad's in which they often experienced themselves as physically active and where they could sometimes participate independently. This is supported by literature which has suggested computer technology can provide opportunity for play participation and experiences of independence in play for children with physical disabilities (Chantry & Dunford 2010). This is an area which requires further research as to the importance of computer technology equipment and the provision of this for children with physical disabilities.

6.2.2. Embodied helpers

There is a clear body of literature discussing the extent of living as an embodied being with a physical disability and the impact this can have on experience as discussed above. However, there is limited research and discussion within the literature about the embodiment of people, rather than objects, as part of an individual's experience. The findings of this research have suggested that individuals with high levels of physical disability can experience themselves as independently *doing* play even when they are receiving physical support from another to enable that play (5.6.1). This experience of facilitated independence is significant particularly in light of examples above and philosophical discussion of embodiment by authors such as Merleau-Ponty. The extent to which individuals can embody objects and equipment in a way that enables a sense of freedom and a heightened participation (Merleau-Ponty 1945) could also be seen to be true for the embodiment of people. As play is defined by its freedom, choice and control (Bundy 2012) the experience of embodying a helper which was seen to lead to participants perceiving choice and control and may provide an expanded view of play for children with physical disabilities which might not have been previously recognised.

Blanchard and Øberg (2015) come close to describing the embodiment of a therapist by an infant. It is recognised that the embodied experience of a newborn and their interaction with their caregivers will have an impact upon their development (Blanchard & Øberg 2015). The research applies phenomenological theory to therapy practice and suggests that physiotherapists who can actively understand and read a newborn infants cues can become an embodied unit together with the infant (Blanchard & Øberg 2015). It is important to consider the influence of the therapist on the baby, particularly when using physical handling when a phenomenological perspective of both the therapist and infant being embodied agents experiencing the world through their bodies is taken (Blanchard & Øberg 2015). This is further emphasised by Øberg et al.'s (2013) earlier research which suggests that embodied interaction between a therapist and infant can lead to enhanced motor outcomes. This opportunity for embodiment and the importance of interaction between therapists and individuals is also emphasised for adults soon after severe traumatic brain injury (Sivertsen and Normann 2015). These studies provide an insight into the importance of a therapeutic interaction between an individual and a caregiver which could be applied to the experience of embodying a helper during play. Blanchard & Øberg's (2015) research suggests that it is essential that the caregiver is able to read the infants cues in order for them to become an embodied unit. For the present study the children discussed times when embodiment of a helper did not occur within their play because of a mismatch between how the child and their helper as embodied agents were acting. This was seen when Daniel talked about feeling *'angry'* when the carer supporting his play did not follow his instructions (5.7.3), this appeared to interrupt his experience of participating in play. This finding would suggest it is important for parents, caregivers and teaching staff to recognise and understand each individual child's experience of play in order that they have the opportunity for perceived independence as an embodied unit with their caregiver.

Although Blanchard & Øberg (2015) provide a helpful perspective on the possibility of a child and adult becoming an embodied unit the research is conducted and discussed from the adult's perspective. The child's perspective is ruminated and representation of this is attempted, however, at such an early age it is impossible to fully capture the infants embodied experience. The study provides a new and helpful insight into the extent of embodiment that is perceived by the participating children during play. Blanchard & Øberg (2015) suggest that in order to create an embodied synchronised experience as a dyad, both infant and therapist have to relinquish some control to respond to the cues of the other. There is also recognition of the active role of the infant within this interaction (Blanchard & Øberg 2015). Although children with physical disabilities may not always be able to quickly verbally communicate their needs, they have other modes of communication which can be recognised and responded to during play enabling them to remain active participants in *doing* play. An example of this was seen within the use of voice (rather than words), and being loud to connect with others in play (5.8.2).

Within a healthcare setting therapists and other healthcare professionals can endeavour to respond to the cues of those they are working with in order to become an embodied unit. As Blanchard & Øberg (2015) suggests this enables more opportunity for participation on behalf of the child or patient. There are limited studies which discuss healthcare professionals as embodied agents; Bjorbækmo & Mengshoel (2016) mention this for physiotherapists and Benner (2000) discusses the process of embodiment for nurses. Part of the experience of embodiment for nurses is an increased sense of intuition that enables them to understand the experience of the patient they are supporting (Benner 2000). It is possible that when working with children with high levels of physical disability, health care professionals can develop this sense of intuition and awareness of their own *being-in-the-world* in order that they can more readily become an embodied unit with the child. This may lead to an experience of a child sharing co-operative control with another (Parten 1932) - a facilitated participation in which the child experiences themselves *doing* play in a way which they perceive as independent.

The significance of embodiment and living through *‘my-body-in-the-world’* (Merleau-Ponty 1945) is seen within health care experiences discussed above. Despite this, no research to date has specifically discussed the perception of embodiment within a close dyad where the presence of physical support becomes embodied and leads to a perceived independence of the individual. This study provides a unique contribution to the body of literature discussed above in suggesting that the ‘embodied unit’ (Blanchard & Øberg 2015) can become a part of a child’s embodied sense of self when they are facilitated to participate in play. Within the study the children perceive themselves and interact by being-in-the-world through embodying both equipment such as their wheelchairs, and people such as their parents, whilst playing. This brings a new perspective to the concept of embodiment which continues to overrule and cross the cartesian subject/ object divide.

The findings of the present study would suggest an expanded understanding of the concept of embodiment (Merleau-Ponty 1945) in which an individual can embody a person as well as an object. The findings provide the first study in which children discuss their experience of embodying a helper within their play. This is an important expanded understanding of embodiment which could have implications for other scenarios in which somebody supports someone to do something. This could be seen within situations such as: carers supporting adults with acquired disabilities; helpers supporting children with cognitive disabilities; and parents supporting young children to participate. Within all of these situations the individuals being supported could experience a sense of independence if they embody their helper during an activity. It is possible that this could be even further applied in terms of the creation of an embodied unit where individuals do something as a close pair such as racing a tandem bicycle. This raises an important area for further study which may help support the concept discussed by Polatajoko et al. (2007) within occupational science that individuals can perceive participation despite limited performance in an activity.

6.2.2.1. Vista play

In a commentary of Imms et al.'s (2017) research about leisure participation preferences of children with Cerebral Palsy, Copley (2017) suggests that professionals may need to shift their understanding of participation in leisure for children with high levels of physical disability. Copley (2017) raises a challenge that *doing* that is meaningful in the eyes of children with Cerebral Palsy may be different to the *doing* that is seen as meaningful by professionals and parents. Of particular note within this research is the children's experience of *doing* play even when being physically facilitated by a helper (5.6.1). As discussed above (6.2.2) this provides a new perspective to the concept of embodiment beyond the embodiment of objects to also include people. It also highlights a type of play that is currently not captured or explained within the research literature. In order to describe this kind of play this thesis posits the term *'Vista play'.*

The word *vista* originates from both Italian and Latin words for *'see',* it is defined by the Oxford Dictionary (2017) as a pleasing view or a mental view of a succession of anticipated events. The word *vista* has been chosen to describe the play experienced by children when they embody their helpers as they experience an anticipated alternative and pleasing view of their play experience in comparison to the view of an observer. Where an observer sees a child being physically facilitated to participate in an activity, in vista play a child experiences the helper as an embodied part of themselves which leads to them viewing the play as independent. Within this thesis play is defined as an activity in which children experience freedom, choice and control (Bundy 2012). Vista play can therefore be defined as follows (box 27).

> *An internally experienced participation in an activity which is seen as pleasing and enables an anticipated sense of freedom, choice and control.*

Box 27 Definition of ***vista play***

The experience of vista play described by the children in the study suggests that children with high levels of physical disability may experience play more than previously thought. This provides a new avenue for exploration which may contradict the view within several research studies that children with high levels of physical disability are at risk of having limited participation in play and leisure (King et al. 2009, Kolehmainen et al. 2011, Law et al. 2006). Researchers such as Imms et al. (2017) have suggested that contexts such as the presence of an assistant may impact upon the child’s experience of participation. To some extent the embodiment theory discussed here would agree in suggesting that as embodied agents both child and carer need to be able to perceive each others cues (Blanchard & Øberg 2015). However, the concept of vista play introduced by this study provides a strong alternative view; that whilst acting as an embodied unit, the child experiences play facilitated by an assistant as independent. This experience of facilitated independence and *doing* would suggest that the embodiment of the child’s helper leads to the child perceiving a freedom, choice and control which enables them to feel the activity is play.

The enhanced understanding of embodiment has led to the introduction of the concept of vista play. The term *vista* has been proposed within this thesis in order to capture the experience of play in which a child perceives themselves as independent and sees the play from a different view to an observer who would see a child being physically facilitated to play. This experience of play appeared to enable a greater sense of *doing* for the participants and meant that they gained a facilitated independence in which they perceived an embodied freedom, choice and control in their play. This is further supported by the concept of *we-agency* (Salmela & Nagatsu 2017) in which a choice to share agency with another leads to a greater sense of being active within play. This is reflected by Parten's (1932) concept of co-operative control. The findings therefore provide an important contribution to the experience of play alongside a helper for children with high levels of physical disability. They suggest that activities which would have previously been seldom defined as play because of the amount of facilitation required have been seen to be experienced as play by the participants. Within recent literature children with high levels of physical disability are seen to have limited participation because of the extent of facilitation they need to participate in leisure (Imms et al. 2017). This study from the children's perspective provides direct opposition for this and highlights the importance of the experience of participation in vista play type activities for children with high levels of physical disability. This should therefore be both recognised by parents and professionals and explored further in terms of its prevalence and opportunities for participation.

There is a possibility that the experience of embodiment of a helper and therefore vista play is not unique to children with physical disabilities. It is possible for example that a young child whose parent lifts them up to pick an apple would report this experience as *'I picked an apple'* rather than reporting the help they received from an adult. This needs to be further explored within future studies in order to understand whether vista play experiences occur for all children or just those with high levels of physical disability.

6.3. Being ‘me’ in play: Balancing the lifeworld of a disabled self and a different spatiality within imaginary play

Humans are known to be occupational beings; our identity and *being* is often expressed through engagement in meaningful occupation (Doble & Santha 2008, Molineux & Baptiste 2011, Wilcock 1993). In the present study discussion of the experience of play was closely linked to children’s perceptions of their own *being* and identity. The concept of *being* is outlined by Wilcock (1998) as the true essence of oneself that makes one distinctive from others. *Being* is closely linked to an individual’s identity and is often a motivator for an individual’s *doing* and the relationships they form with others (Wilcock 1998). The findings of the present study demonstrated a fluctuation that children experience within their lifeworld in the experience of *being* ‘me’. Children appear to have an experience of being their disabled self (5.7.1) and also of experiencing a different spatiality within imaginary play where they have a sense of self without a physical disability (5.7.4). Spatiality is a concept used to describe the lived space an individual is situated in when experiencing a phenomenon; when in a different space the way that an experience is perceived can be different (Simonsen 2007). Within the current study in an imagined space the participants continue to be themselves but the restrictions of their physical disability are taken away (5.7.4).

The following section will discuss disability and identity theory (Goering 2015, Erikson 1959) in order to outline children’s perspective first of *being* disabled, then of *being* in an imaginary world, before discussing the means by which they reconcile a fluctuating lifeworld.

6.3.1. Being disabled

Within the findings of the present study each child’s physical disability in some way influenced their perception of self (5.7.1). An exploration of the writing discussing the development of identity and a sense of self leads to the works of seminal theorists such as Erik Erikson (1959) (discussed in 2.3.3). Erikson (1959) discusses how children create a concept of *selfsameness* in which they learn to recognise their own identity and characteristics of themselves across time. As part of creating this identity children learn that as themselves they are unique and different from others

(De França 2008). This increasing understanding of *selfsameness* is negotiated by children as they develop; they learn to reconcile their outer and inner perceptions of themselves as they come to understand the characteristics which make them ‘me’ (Erikson 1959). When considering children’s sense of *being* in relation to the findings of this study it appears that children experience significant negotiation between their inner and outer world as they develop their identity.

The findings present the perspective of children who have always had a significant level of physical disability which they have needed to negotiate as part of their life. Erikson (1959) suggests the development of healthy personality occurs through negotiating internal and external perceptions and thoughts. The present study appears to demonstrate the way in which play is a vehicle for expressing this negotiation and outworking a presentation of identity. As an everyday occupation for children (Chiarello et al. 2006), play can be seen to take the majority of children’s time and is common among children both with and without a disability. Children with disabilities have been found to make comments such as *‘I want them [paediatricians] to see that I feel normal’* (Bekken 2014). If play is a part of normality for all children it is not surprising that this may become the grounds for understanding their disability and developing their identity. Bekken (2014) argues that for children with disabilities their being cannot be separated from their doing; this would suggest that for children within the present study their development of identity and sense of *being* themselves has been developed and negotiated through *doing* play.

Every individuals sense of *being* ‘me’ is developed through increasing their awareness of ‘self’ across time (Rochat 2003). Rochat (2003) discusses five levels of self-awareness that develop from infancy to age four or five. This progresses from no awareness of self at level zero; to an ability to understand the position of one’s body (proprioceptive sense) and how this relates to self at level 2; to level 5 where individuals have a self-consciousness in which they can see themselves from the eye of others (Rochat 2003). Rochat (2003) suggests that every individual fluctuates between different levels of self-awareness at different times. Proprioception is our subconscious sense of body awareness which informs our brain as to the position of our body in space. As the participants developed this awareness at level 2 they are likely to have perceived some of the limitations of their own bodies; this could be both a motivation to improve and a recognition of limitation. Self-awareness that has motivated a desire to improve is seen in comments children made about improving their abilities as they grow older. Lucy discusses this in relation to communication and it appears that her self-awareness of her speech led to motivation to develop this skill and then view herself as more successful in her play (5.6.2). As children gain an awareness of their disabled self it appears that this is both mediated by the physical restrictions they feel but also the view of those around them.

The view of identity and *being* 'me' is influenced by social interaction and the context of experience (De França 2008, Wilcock 2007). This is supported by a social model of disability which suggests that perception and experience of disability is shaped by the social world in which an individual lives (Goering 2015). A recent shift from an impairment focused, ableist perspective of disability to an affirmative perspective where individuals are seen through the lens of what they can do, is likely to have an impact upon identity development (Loja et al. 2013, Peers 2009). Children within the study generally appear to view their Cerebral Palsy as an integral and embodied part of themselves (5.7.1). Some children such as Abi appeared to be more influenced by an impairment focused perspective of disability, she was often heard to use language such as *'I can't'* and *'it is not adapted'* (5.6.3). Other participants appeared to be much more influenced by a perspective that focused on what they can do; participants such as Ben and Tom discussed their play experiences with a strong focus on their own strength and success (5.6.2). This highlights the importance of the perspective and language used by those surrounding children with disabilities. It is possible that Abi has developed her identity in an environment in which a more medical and impairment focused model of disability is referred to in comparison to Ben and Tom who may have developed their identity in an environment in which the focus is much more upon what they are able to do. This is supported by recommendations that healthcare professionals should have an awareness of individuals' experiences of their impairments as they are not always negative, and where they are negative this is often because of the reaction of others (Goering 2015).

Zitzelsberger (2005) interviewed 14 women with physical disabilities about their embodiment of their disability and the impact this had on their identity. Women discussed a duality of wanting to be invisible from the point of view of not standing out as having a disability, and visible, from the point of view of having identity as a woman, a mother and as someone separate from their disability (Zitzelsberger 2005). The extent of embodiment of their disability influenced each individual's self-perception and the way they felt others perceived them; at times being different was a significant part of some women's identity, they thrived on being different and wanted to talk about this (Zitzelsberger 2005). This is reflected within Abi's interviews as she would frequently come back to a focus on being different from others. At times Abi viewed this as positive, for example when she wanted to share her experience by teaching others (5.7.2); at other times, Abi viewed this as negative, for example when it meant she could not participate with her peers in activities such as netball (5.6.3).

Although the experience of women with physical disabilities is likely to be in many ways different to the experience of children, there are similarities that can be drawn upon in terms of understanding the complexities of *being* 'me' with a disability. Zitzelsberger's (2005) study highlights that the embodiment of disability can lead to a sense of 'invisibility' in that the women's disability no longer needed to be a focused part of their identity. This can perhaps be seen in the way that children within the study embodied their wheelchairs and equipment to the extent that their narrative was often focused on what they could do and enjoyed participating in, rather than in any external support they were receiving (6.2). Conversely, Zitzelsberger (2005) portrays the women's desire to sometimes view themselves as separate from a physical disability. This moves towards more of a Cartesian perspective of experience in the separation of body and self (Leonard 1994). This phenomenon is explained by Paterson and Hughes (1999) who suggest that society's focus on disability can lead to individuals who are living as embodied beings being drawn towards focusing on disability because society draws attention to this. This view perhaps helps to explain why the participating children wanted to view themselves with no physical disability in their imaginary play. Zitzelsberger's (2005) study supports the idea of fluctuating and merging lifeworlds in which a complex experience of embodiment of disability but also embodiment of freedom outside of the constraints of reality takes place (6.3.3).

The children's views of themselves and the sense of *being* that they had within play were often also related to their emotional expression and self-esteem. This is seen particularly within scenarios when they make mistakes, such as when Jess comments that her mistake *'makes me feel really annoyed, annoyed with myself'* (interview 2, 5.7.3). Birk et al. (2015) argue that self-esteem has an impact upon play engagement and self-determination. Within Birk et al.'s study (2015) those with low self-esteem who engaged in play experienced higher negative affect, and lower positive affect (less enjoyment), than participants with higher self-esteem. This suggests that personality and characteristics brought to play by individuals effect their experience of play (Birk et al. 2015). This can be seen within the findings of the current study in relation to different children's perceptions of themselves and their abilities. Although all the children portrayed themselves as able to participate in play there were some children who more readily talked about the frustrations and restrictions of their play than others. However, there were also times in which children demonstrated a new definition of success in which they mediated success in a way that enabled them to perceive themselves as successful despite their physical disability and mistakes they may make (5.6.2). This could be reflected by research literature which suggests that children need scaffolding support in their participation in play (Jung & Recchia 2013). It is therefore important to be aware of the influence of emotion and self-esteem on the way that children participate in play and negotiate their sense of *being.*

6.3.2. Being in an imaginary space- a new spatiality

For all the participants, the experience of themselves within an imaginary space enabled a new spatiality in their play and led to an opportunity for *being* but without the experience of a physical disability (5.7.4). There were times in which children remained themselves with the only difference that they were physically able to do what their Cerebral Palsy limited within everyday reality. There were also times in which the children took on the identity of a superhero or famous character and referred to themselves as *being* that character (5.7.4). The concept of spatiality, the lived space through which something is experienced, would suggest that the environment of a space closely impacts how it is experienced (Simonsen 2007). For the participants, entering their imaginations appeared to be like the entering of a new spatiality, a space in which the perception of their experience was shifted. Within this imagined space children no longer faced a model of disability which concentrated on their limitations, but they could separate their view of 'self' from their Cerebral Palsy. Both a paediatrician and psychoanalyst, Winnicott (1971) suggested that in play children can process experiences of themselves which occur in reality. This supports the concept that the participants experienced a new spatiality in play as part of processing their everyday realities.

Within imagined play experiences children always appeared to have an experience of independence (5.7.4). Merleau-Ponty's (1945, p.137) concept of embodiment suggests conscious is not about *'I think that'* but about *'I can'* (Simonsen 2007). This would suggest that through the imagined space that children create as part of their play they experience a sense of *'I can'* which is embodied and full. When taking on the character of others children were able to demonstrate powers that would not be possible in reality such as *'sav[ing] all the people in the world'* (Daniel, interview 2), this appeared to lead to heighten positive emotions and feelings of self satisfaction. Eatough & Smith (2006) suggest that emotions individuals experience are closely interlinked with the world and their experience of the world. The experience of an emotion is part of an embodied experience and therefore, as it leads to changes in an individual's body, it also influences the perception of experience and making of meaning (Merleau-Ponty 1945, Eatough & Smith 2006). The experience of participating in a new spatiality within imaginary play is not widely discussed within the literature. It is possible that the positive affect experienced in this participation helps to mediate the negative experiences and frustrations that children sometimes experience within their play (5.7.3).

The phenomenological perspective suggests that through *being-in-the-world* individuals experience an embodied, intersubjective and situational making of meaning (Larkin et al. 2011). Through *being-in-the-world* of the new spatiality experienced in imaginary play it is possible that children are gaining an embodied experience of freedom from their physical disability. The concept of *intentionality* suggests that an experience is always of *something* or in relation to something (Larkin et al. 2011). It is possible that the experience within each child's imagination is an intentional reflection of freedom from physical restriction. The opportunity to embody this experience within their imagination enables the children to experience a physical freedom in their play that may not otherwise be possible. Each child's experience of a different spatiality may have an impact on their embodied experience of reality and their negotiation of their lifeworld. This should be further explored and considered, particularly because children with high levels of physical disability are often portrayed as less able to be active than their typically developing peers within their play (King et al. 2009, Kolehmainen et al. 2011).

All children participate in imaginary play to some extent and becoming a superhero is often a part of children's play (Thiel 2015). It is possible that the imaginary play where children experience a new spatiality where they continue to play as themselves but without any kind of impairment also occurs for typically developing children. Despite this, it is important to note the experience of this play for most of the participants in which they step into a world that is different from the physical restrictions they face in their everyday reality. If children are recognised to be able to experience a new spatiality and freedom to move without physical restriction in their imaginary play it is important that parents and professionals recognise and validate this play.

6.3.3. Reconciling a fluctuating lifeworld

Child development theory suggests that developing a sense of self involves negotiation between internal and external realities (Erikson 1959). This appeared to be a strong theme for the participants in the study where their sense of *being* was a constant negotiation between the self they experience in everyday reality and the self they experience in imaginary play. This is seen in examples such as Jess' mermaid play discussed in section 5.7.1. This kind of duality of self is reflected within other research with individuals with disabilities. Sethi (2012) provides a personal account of negotiating identities between being a 'professional' and also being a 'client'. Zitzelsberger (2005) discusses the tension that women with physical disabilities experienced between wanting to be both visible and invisible with their disabilities. De França (2008) suggests that during middle childhood (age 6-12 years), the age of the participants in the current study, children's view of themselves becomes more complex as they develop an ability to see how they are perceived by others. This appeared to be evident within the children's interviews particularly when they discussed play alongside their peers. Children's desire to compromise in their play (5.6.3) is one indicator of the way in which they want to be perceived as someone who can participate by their peers.

The creation of imaginary worlds, which was seen to be many of the children's experiences, has been found to give the opportunity for being beyond the here and now, and for being and doing vicariously (Root-Bernstein 2014). This can then lead to a newly developed internal reality (Root-Bernstein 2014). Root-Bernstein's (2014) article presents a discussion of world play which is described as a focus on a specific world with multiple characters which individuals return back to time and time again. This kind of play was not clearly observed within the current research however could be related to the findings. The findings in their discussion of a new spatiality within their imaginary play suggest that children often create an imagined play scenario in which they are either themselves without their disability or a hero or rescuer. As Root-Bernstein

(2014) suggests in his discussion of world play, this may lead to the opportunity to be beyond the here and now and to both be and do vicariously. This suggests that children can create a lifeworld in which their sense of *being* is influenced by what they experience within their imaginations.

It is possible that the *being* that children experience within their internal reality is shaped by the corporal standard, a 'perfect' ideal body which is portrayed by society (Loja et al. 2013). Rather than having a separate view of the body as an object, the participating children are always experiencing '*my-body-in-the-world'* (Merleau-Ponty 1945). Within their imaginary world, *my-body* would appear to follow the corporal standard that society suggests is 'perfect'. Within their everyday world *my-body* appears to mean that Cerebral Palsy is part of each child's identity and that embodiment of both equipment and helpers becomes a part of normality. Loja et al. (2013) raises concerns that a non-disabled gaze on those with visible impairments means that their disability is often an embodied part of their identity. It is possible that this non-disabled gaze leads to children's focus on the corporal standard within their imaginary play. Although the experience of embodying a new spatiality appears to be viewed positively by the children, it is possible that this is a result of the pressure from society to conform to the norm.

The embodied experience of activities such as play, is thought to have an influence on the development of self (Rochat 2003), it is possible this was the case for the study participants. Research suggests that children perceive and experience their disability through their bodies and the social world in which their body is situated (Bekken 2014). Our awareness of self occurs through a process which is closely linked to our awareness of our bodies (Rochat 2003). The findings would suggest that the children within this study have come to a place of both understanding their limitations within a physical reality, and a physical freedom they can experience within their imagined worlds. This understanding of limitations is likely to have come as part of their development of self and is reflected in the way that children recognise that as part of having a disability they need more support to participate in activities (5.6.1). This is seen within the way that children play and choose to participate in play where they are ill or the patient (5.7.1). This fluctuation within the lifeworld appears to be reflected in the fluctuation of emotion that children were seen to express in their play (5.7.3). The way that this is negotiated is summarised by Jess (5.7.3, box 21) in the way that the focuses on the *'fun'* of play more than the *'annoying'.* It is important to consider this in light of developmental theory which suggests every individual gains a view of *selfsameness* in which they are able to recognise the consistent characteristics which are about them *being* 'me' (Erikson 1959). Within this study it is possible that the *selfsameness* for the children is both their view of self with a physical disability and the view of self as free from physical restriction within their imaginations. The children have perhaps accepted a lifeworld and a *selfsameness* in which they almost live with two versions of 'self' which are equally important to their experience. This is demonstrated in the way that Cerebral Palsy becomes personified for some of the children (5.7.1, 5.7.3): it is both a part of them and something that they want to separate themselves from.

This fluctuation in the lifeworld and complex and constant move between seeing self through the eyes of disability and seeing self as free from physical restrictions and able to conquer Cerebral Palsy within an imagined spatiality (5.7.4) highlights a tension experienced by children with disabilities which is not currently explored within the literature. Although child development theory and research with adults with disability would suggest a tension in the creation of identity exists; this needs to be further explored particularly for children who have a significant physical disability from birth. It would seem that the positive view of self, redefined understanding of success (5.6.2), and physical freedom experienced within the new spatiality of imaginary play (5.7.4), enable a greater ability to negotiate, embody and normalise the experience of Cerebral Palsy within everyday reality.

This experience of negotiating a dual sense of self within the lifeworld appears to not be present within current literature. Although some studies discuss children’s experience of having a disability (Connors & Stalker 2007), the focus is not on the development of children’s identity. As mentioned within the discussion, early identity development theorists (Erikson 1959) suggest that part of developing a sense of self comes from a negotiation of internal and external identities. For children within the present study they appear to be experiencing a constant fluctuation between their internal and imagined self without a disability and their external self and experience of *being* with Cerebral Palsy. This is particularly important for parents and therapists working with children who have high levels of physical disability to be aware of.

6.4. Becoming an active participant: Developing agency

Becoming is closely linked to the development of identity and a sense of self; it is a process which occurs through *doing* and *being* which enables individuals to grasp more of their potential (Wilcock 1998). As all children develop they go through a process of *becoming* in which they become aware of their sense of self as separate from others in the world, they gain a perception of intentionality where what they do influences the world around them; this has been described as becoming an *active agent* (De França 2008). An individual is considered an *agent* and to have *agency* through being the author of their own actions and having the capacity to act (Buhrmann & Di Paolo 2017). *Becoming* an active participant and developing this identity can be understood through the occupational well-being perspective (Doble & Santha 2008). Doble and Santha (2008) suggest that active participation is not necessarily related to physical activity or task performance but can be about an individual’s experience of an occupation. This is supported by research by Heah et al. (2007, p.41) who suggested that *‘feeling successful’* was an indicator of successful participation in activity in a phenomenological study with children who had disabilities. This section will refer to children as *active agents* in their play; this term is used to describe participation in which children perceive themselves as actively participating and authoring their own actions within their play.

Within this study a sense of *becoming* and negotiating identity was seen within each child’s experience. Anderson (1968) suggests that play is important for child development in enabling children to create their identities, express themselves, and develop their emotional, motor and social skills in preparation for adult life.

There is a wide recognition that play is an important occupation for children and has a positive impact on health and wellbeing (Brooks & Dunford 2014). This would suggest that the process of participating in play can augment children's sense of *becoming.*

The following section will discuss the findings that children perceive themselves as strong and successful in their play (5.6.2) to explore how this is part of children's development in *becoming* an active player. It will also discuss the way that in the face of frustration or potential isolation the participants were able to experience participation through watching (5.7.2). The opportunity for participation by a means that is not physical, such as by watching, is supported by occupational therapy research (Polatajoko et al. 2007, Doble & Santha 2008). The findings provide a contribution to the current body of research in demonstrating children's experience of participation as observers. It appears that this kind of participation occurs through a process of identity negotiation and a shift in perspective in *becoming* active agents in play.

6.4.1. Agency and self

Bayne (2008) discusses the complexities of agency and agentic experiences; suggesting that an individual can perceive agency even when this is not externally true of the experience. This provides support for the perception of agency and independence during the embodiment of the helper discussed previously through vista play (6.2.2). This also would suggest that children are able to develop a sense of agency in relation to the different ways that they participate in play. Researchers such as Lester and Russell (2014) argue that play enables all children to develop their sense of self through an ability to adapt. Occupation, such as play, has been seen to enable individuals to experience meaning making and to create or re-create identity (Hammell 2004, Shank & Cutchin 2010, Wilcock 2006). Within this research children appear to adapt to their experience of Cerebral Palsy through increasingly *becoming* active agents in their play. In this process of *becoming* children appear to develop their own definition of *active agent* in which they perceive agency in situations which may not be perceived in the same way by an observer.

The development of self-agency can be seen within the way that children develop their identities as strong and successful (5.6.2). As discussed within the findings children appear to develop a sense of self in which their agentic powers are greater than others may perceive them within reality. This is seen within children's perceptions of success despite having support to be successful (5.6.2). Coole (2005) highlights that a sense of agency is lived through the body and is dependent upon social interactions within each child's lifeworld. This could support an argument that as children experience success and strength within their lifeworld this represents a greater sense of agency and control over their identity development. It is known that being physically active is positively associated with physical and psychological wellbeing for children with Cerebral Palsy (Shikako-Thomas et al. 2012). Despite this, as the children who participated in the study have significant levels of physical disability, it is possible that the lived experience through the body restricts their sense of agency because of the physical limitations they face. It could be that children then start to negotiate the meaning of success in order that they can *become* more of an *active agent* as a part of their play identity and that as discussed above the sense of *active* is defined by participation rather than performance (Doble & Santha 2008).

Participating as an *active agent* can be seen in the way that the children often wanted to help others within their play (5.6.2, 5.7.4). This desire and satisfaction of helping others by becoming the hero or rescuer in play may lead to greater feelings of well-being. Schwartz and Sendor (1999) found that when individuals with a physical disability were facilitated to become peer telephone supporters they had an increased sense of wellbeing and quality of life. This suggests that enabling children to participate in play in which they take on an active role as a helper may have a positive impact on wellbeing.

Salmela and Nagatsu (2017, p.7) discuss the concept of *we-agency;* this is defined as *'**us** doing something **together**' [emphasis in original text]* the idea that two or more individuals use their self agency to work towards a joint goal. This is interesting to consider particularly for the children within the present study who depend so much on others in order to outwardly act in the world. Where a child focuses on a joint goal with an adult this possibly provides a greater sense of *we-agency.* It is possible that children's ability to *become* themselves relies heavily upon those that are helping them. It is clear that intersubjectivity influences perception of experience (Merleau-Ponty 1945) it could therefore be argued that the children *become* themselves in play not just through personally *becoming* an *active agent* but through a process of moving towards *we-agency* and shifting understanding of what this means for their own identity. This is supported by early play theorists such as Parten (1932) who suggests that co-operative control can still be perceived as 'control' by an individual as part of their play experience.

The present findings add to the current literature in demonstrating the possibilities of *we-agency* and the influence this has on developing a sense of self when one individual has a significant physical disability. This is supported by the input of each child's family and the close interaction they have with their children in supporting their play (5.6.1, 5.6.2, figure 8). Bohanek et al. (2006) suggests that family narratives and shared family history can be a part of building positive identity, self-esteem and self-efficacy. Within this study children's perception of strength and success often appeared to be a direct result of support from their family (5.6.2). The importance of family support and nurture is emphasised by Palmer et al. (2012) who suggests that children with disabilities may need support to develop self-determination skills. If children are to *become* active agents who have capacity for self-determination they need to be provided with the opportunity to make their own choices (Palmer et al. 2012). When considered in light of play being surmised by its freedom, choice and control (Bundy 2012), it would appear that the opportunity for choice is a part of both the child's ability to develop their sense of agency as an active player and part of their very development of self. This is mediated by the presence of their families and those supporting their play to an extent that is not currently discussed in the literature.

6.4.2. Redefining active- playing through watching

Doble and Santha (2008) emphasise that occupational well-being is not just about physical performance in an activity. Polatakjo et al. (2007) support this in suggesting that individuals can fully participate in an activity without being physically active. This is supported by Heah et al. (2007) who found children and parents reported *'being with'* others as an important part of successful participation for children with disabilities. This was seen within the findings where children participated in play through watching others (5.7.2). Similar participation was observed in Tamm & Skär's (2000) study which found that children participated through *onlooker play.* This is further discussed within a research study exploring parents' understandings of play for children with Cerebral Palsy which suggested that children could participate vicariously, through being able to watch a play experience (Graham et al. 2014, Graham et al. 2015). The current findings add to the body of literature in understanding the way that children wrestle with the concept of being *active* participants in play and what this means when they participate through watching.

The vicarious way of playing, meaning that a game is experienced through watching, is seen within gaming culture (Gutiérrez 2013). This was seen to occur more than in the playing of electronic games within the current study's findings. Tom and Lucy were both seen to discuss their experience of playing with their toys through watching rather than physical manipulation (5.7.2), Jess discussed being able to participate alongside her peers through watching play (5.7.2). This concept has recently appeared more scientifically plausible through the research around mirror neurons. Mirror neurons were discovered in 1990 by Di Pellegrino et al. who found that a monkey's neurons fired in the same way whether they picked up a peanut or observed someone else picking up a peanut. This research field has since expanded and there is a general understanding that when watching a leisure activity the same areas of the brain are activated as when participating in this leisure activity (Holmes & Calmels 2008). This activation is thought to occur to a greater extent the more familiar the observer is with the activity (Holmes & Calmels 2008). This could suggest that through being able to observe an activity children could be experiencing the same neurological stimulation as the children who are participating in the activity. If this is the case then as commented on by the participants in the findings (5.7.2) the experience of watching play could feel the same as physically participating in it. This raises an important area for further study in which children's reported experience of being able to participate in play through watching could also be observed neurologically.

Although there were times in which the children discussed playing through watching as an *active* part of their experience. There were also times in which children described watching as an isolating experience and not quite play. This is a concept which needs to be further explored in terms of how children negotiate this *becoming active agents* in their play; at what point they adjust their definitions in order that they can play differently, and at what point the definitions that society places on play are assimilated and therefore mean that an experience is not perceived as active.

6.4.3. Resilience in becoming

As discussed above part of each child's *becoming* involved and continues to involve a negotiation of identity and lifeworld for each of the children who participated in this study (6.3.3). This negotiation appears to be part of a development of resilience in the face of the frustration which they experience because of their physical disability. Rajan-Rankin (2014) define the development of resilience which as an adaptive response to difficult situations. Within childhood literature resilience is defined as *'good outcomes in spite of serious threats to adaptation or development'* (Masten 2001, p.228). Resilience is impacted by person-environment interaction and can be considered alongside a social justice approach as essential to the lives of children and young people facing adversity (Hart et al. 2016). It is important to note that play and leisure participation are seen as part of the basics of resilience for children (Hart et al. 2008); it is therefore unsurprising that the resilience of the children in the current study was fostered in their play. The following section will explore how the findings of the research demonstrate a practical outworking of resilience by the children.

Resilience is a construct that has been seen to help children overcome adversity (Mastsen et al. 2001, Hart et al. 2016) and positively adapt to the onset of physical disability (Lavoie et al. 2016). The participants within this research experienced high levels of physical disability, this impacted their ability to function within everyday activities and can therefore be seen as a difficult situation they need to respond to. Resilience Therapy, designed by Hart et al. 2008 suggests that there are five components which enable a child and those around them to foster resilience: basics, coping, belonging, learning, core self. These components were reflected in the current study findings as part of children's demonstration of resilience. They appeared to have developed a sense of core self which was demonstrated in their view of themselves as strong and successful (5.6.2). They appeared to show an ability to adapt through coping and learning when participating through the embodiment of their helpers as part of vista play, this seemed to enable an opportunity to experience a facilitated independence (5.6.1). However, there were also times in which the children showed less resilience in light of their physical disability and they felt upset and isolated because of the environment that they were in. Examples of this were seen particularly in the playground where Abi felt she could not play netball (5.6.3, box 11,12,13) and Jess was concerned about not being able to access the play equipment (5.6.3). The tension of this experience is demonstrated within section 5.6.3 which discusses times in which children choose to compromise and were seen to show resilience in light of a difficult situation; and times in which children had to compromise and found this difficult. In considering Hart et al. (2008) magic box of components of resilience part of coping is seen to be *'remember that tomorrow is another day'* (p.134). This appeared to occur in the face of frustration and limitations to participation and is demonstrated in the way that Abi initially felt isolated during netball but on another day with a different perspective could recognise how she could participate (5.6.3, box 11,12,13).

Resilience in children is seen to be part of a normative process of development in which children have adaptive systems already in place (Masten 2001). The results of an extensive meta-analysis suggested that resilience is linked to positive health outcomes for children (Schembri Lia & Abela 2016). Specifically, the following characteristics are thought to be evident in children with strong resilience: good relationships with others, strong self-efficacy, good problem-solving and learning ability (Masten et al. 1991). This is also reflected within research specifically addressing resilience in children with disabilities (Lavoie et al. 2016). Lavoie et al. (2016) focused on the experience of resilience of children with acquired physical disabilities and therefore the experience may differ to the children within the present study who were born with their disabilities. In relation to the findings children appear to have positive relationships with their families and caregivers; they have a strong sense of self as an active agent within their lifeworld; and they also demonstrate an extent of problem solving and adaptation to their disability. All of which would suggest that they have fostered strong resilience. Examples of this can be seen in the way that children embody their equipment: as opposed to a focus on frustration of needing someone to move them, the children often focus on the opportunities that their wheelchair or walker enables them (5.6.1, figure 7). Furthermore, the participants focus on family and demonstrate empathy and altruism towards parents or siblings (such as 5.7.1) which would suggest strong and positive relationships. These relationships are considered important for strong resilience (Hart et al. 2008). Further consideration is needed as to the role of the family and their participation in the development of resilience particularly for children with high levels of physical disabilities. The participants within the study all appeared to have supportive families who were willing and able to participate within research, it is possible that an alternative sample may have developed less resilience in the face of their disability through relationships with their family. Recent research suggests that the focus of resilience should start to go beyond an individual's ability to cope with adversity but towards challenging the structures which create adversity (Hart et al. 2016). It is therefore also important to consider the construct of disability within society and the impact this has upon the experience of children such as the participants.

6.5. Belonging through play: Opportunities and barriers for connection

Belonging is a concept which was added to Wilcock's theory of occupational health following its original publication. Wilcock (2007) suggested that *belonging* is about the connectedness of others which provides context to the experience of occupation. Hammell (2004) supports this theory in suggesting that occupation provides an opportunity for connectedness and sharing of self. Occupation from the perspective of individuals with a disability may not always look the same as what is perceived within an able-bodied norm (Hammell 2004). This is clearly the case within the findings of this research where children's participation, particularly within vista play experiences, was often internal and could not be externally observed (5.6.1). Although children appear to experience a connectedness with the helpers who facilitate their vista play experience (5.6.1) it is unclear as to the impact that this has on their sense of *belonging* alongside their peers and in a wider sense. The following section will discuss the findings in light of the opportunities and barriers for connection within each child's experience of play. Children both appeared to enjoy opportunities for connection with others (5.6.1), but also experience times where physical restrictions limited this participation (5.6.3). The findings clearly showed children's use of communication and humour as means by which they developed a sense of *belonging* in their play through connecting with others (5.8.1, 5.8.2).

6.5.1. Opportunities for connection

All of the participants within the study experience high levels of physical disability; this means that they experienced restrictions in physical participation (Shields & Synnot 2016, Imms et al. 2017). However, the findings would suggest that despite physical restrictions the children are still able on the whole to connect with others and gain a sense of *belonging* as part of their play. This is significant considering Hart et al.'s (2008) research which suggest that belonging is an important component of developing resilience when facing adversity or restriction. All of the children drew upon skills they have, such as the use of communication and humour, as a means by which they gained a sense of *belonging* (5.8.1, 5.8.2). There is limited mention of this within the current research literature. One study by Dattilo et al. (2008) emphasises the importance of augmentative and alternative communication (AAC) devices in enabling participation in leisure for adults with physical disabilities. The use of AAC meant that adults could communicate with others and therefore gain an increased independence and involvement within leisure activities (Dattilo et al. 2008). The study participants reflect a similar finding; particularly for Tom, the use of AAC meant that he could participate and communicate his experience of play (5.6.1, box 6). For other participants the ability to communicate verbally had a positive impact upon their participation and often enabled an expressed choice within play (5.8.2). It appears that, in the same way that an individual who loses their sight may train their sense of hearing to enable greater participation (Gougoux et al. 2005), communication provides an increased opportunity for participation for children who have limited physical ability. An ability to communicate needs with others and draw upon communication skills, such as storytelling, enabled a greater sense of *belonging* for the participating children (5.8.2). Parents and health care professionals should therefore have an awareness of the importance of communication skills for children with high levels of disability. It may be helpful to focus on the development of these skills in order to provide children with more tools by which they can connect with others in their play.

There is also limited discussion within the literature in relation to the use of humour within play or as an important characteristic for children with physical disabilities. Clarke and Kirton (2003) briefly discuss the use of humour by children using AAC and their peers without disabilities as part of play interaction. Although Clarke and Kirton (2003) do not discuss the reasoning of this, it is possible that the children within the study pursued these humorous interactions in order to develop positive relationships with their peers. This appeared to be the case within the study's findings where humour was used both to build social connection with peers when engaging in play and also as a demonstration of resilience in light of frustration (5.8.1). Harkness & Bundy (2001) as part of the Test of Playfulness with children with physical disabilities found that the children appeared to have higher scores than their typically developing peers for *'clowns/jokes'* (p.84). This provides support for the current study in suggesting this may be a skill that children with physical disabilities draw upon. This may be both as a way of increasing fun and also as a way of dealing with frustration and difficult situations.

Several studies do address the use of humour in the face of difficult circumstances as a way to avoid or reduce stress and navigate social situations (Demjén 2016, Kuiper, 2012, Martin & Kupier 2016); however, the focus is within different study populations and none of these studies are linked to children with physical disabilities or play. It is possible that, as suggested by the findings and the research within other fields, humour is developed in order to build both resilience and social groups. The use of humour for the participants could be seen to enable a sense of re-connection and re-tuning between a child and the people they are playing with; thus leading to a greater sense of embodiment and participation in the play (Blanchard & Øberg 2015). A deeper understanding of children's use of humour is needed, particularly as a tool to enable a connection with others when other participation is not possible.

Research suggests that emotional expression can impact upon social information processing (Lemerise & Arsenio 2000). If children increase their awareness of social information through their emotional expression then it is important to consider the impact of the experience of heightened emotions (5.7.3) on social processing for children within the current study. At times part of the expression of extreme emotion was perhaps synonymous with the participants using their voice and expression to be heard in play (5.8.2) and therefore connect with others. The findings would therefore support the opportunity for connection and belonging with peers through the expression of emotion.

The opportunity to experience a sense of belonging within one's family is seen to be important for children with disabilities (Hayashi & Frost 2006). This was reflected within the research where family members were important to each child's play. Jess' discussion of mermaid play provides a helpful example of this where she feels a sense of *belonging* in her play alongside her family (5.7.1, box 16). Play alongside family often resulted in positive affect as can be seen in Ben's rugby play with the support of his mum (5.6.2, figure 8). This positive affect can be understood by the emotional attachment and feeling at home which occurs through the dynamic process of *belonging* (Yuval-Davis 2006). *Belonging* within groups of people could be because of age, gender, spirituality or other characteristics (Yuval-Davis 2006). Where the participants in the study experienced their physical disability as a barrier to their *belonging*, in the sense that it was a difference between them and their peers, the focus on being a part of their family and *belonging* to play experiences which were shared with others was therefore important (5.8).

Belonging is considered to be important for all children in their early years (Papatheodorou 2010) and is part of some early years curriculum. Gaining a sense of *belonging* alongside peers at school appeared to be a harder experience for the participants than gaining a sense of *belonging* in their family (5.6.3). Despite this, there were several times in which children demonstrated a strong sense of *belonging* with their peers. This was seen through Daniel's experience of *belonging* and leading a group of his peers in humorous play at lunch time (5.8.1). This is also seen in Lucy's participation in play with her peers at school (5.8.2), and the way that Ben plays with his peers in the playground (5.6.1, figure 7). Developing a sense of *belonging* is essential to the development of identity (Shotter 1993). Shotter (1993) suggests that identity can only be formed through continual interaction with the people in the community one finds themselves in. It is possible that this is what the participating children are doing when they are using their voice and communication to be heard and to create connection within play (5.8.2). Shotter (1993) suggests that the formation of identity occurs best within society when the focus is not upon everyone agreeing but it is on everyone being able to share their ideas and understandings and still *belong* as part of the community. This is interesting to consider in light of the sense of *belonging* alongside their families and peers that many of the participants had (as demonstrated above). This contrasts from the general view within the literature that children are limited in their participation and *belonging* because of their physical impairments (Imms et al. 2017, King et al. 2009, Kolehmainen et al. 2011, Law et al. 2006). If society takes on a perspective which reflects the literature and focuses on impairment and restriction to activity it is possible that children will not be able to express the experience of *belonging* that the findings suggest they feel and demonstrate within their play.

6.5.2. Barriers to connection

Occupational justice recognises that all individuals are unique and have a right to engage in diverse and meaningful occupations to meet their needs (Durocher et al. 2014). This in combination with every child's right to participate in play (UNICEF, Article 31, 1989), would suggest that the participants in the study have a right to participate in play as a meaningful occupation for them. *Belonging* is considered to be an important element of meaningful occupation (Wilcock et al. 2007) and there were times in which the participants in the study appeared to experience barriers to connection and therefore to their sense of *belonging* within play. This was seen relatively few times in comparison to the times in which children discussed a sense of belonging (6.5.1), however it did occur. The feeling of *'I want to be just like them'* (Lucy, interview 1, 5.7.1) summarises the sense in which children sometimes experience barriers to belonging. Occupational deprivation is defined by Durocher et al. (2014) as exclusion from a meaningful occupation through factors outside of an individual's control. The findings of this research would suggest that there are times when the presence of a high level of physical disability and lack of external support within the environment meant that children experienced occupational deprivation.

One factor which is considered to impact upon belonging for children with physical disabilities is access to their environments and the opportunities for playfulness their environment allows (Heah et al. 2007, Rigby & Gaik 2007). Stephens et al. (2017) discuss inaccessible childhoods and the accessibility of environment for children with disabilities. Based in Canada the findings following a survey of children with disabilities and their families suggest that they continue to face several physical boundaries which impact upon their ability to access the community. Stephens et al. (2017) suggest that physical access barriers for children negatively affect their feeling of *belonging* within their community and social world. This is supported by research which suggests lack of physical access can lead to less play opportunities for children with Cerebral Palsy (Rigby & Gaik 2007) and that social attitude and physical environment can be barriers to participation for children with Cerebral Palsy (Imms 2008). Restrictions in terms of physical accessibility were discussed on three occasions throughout all of the participant interviews. Daniel felt forced to go on a theme park ride twice because he could not access his wheelchair (5.6.3); Abi felt like netball was not accessible (5.6.3); and Jess felt that she would not be able to access her new school playground in her wheelchair (5.6.3). The study's findings provide additional support for researchers such as Stephens et al. (2017) in suggesting that restrictions to physical access can negatively impact children's sense of *belonging.*

One further consideration that should be made here is that none of the children requested a child playmate to join their play. This raises an interesting question for the future in terms of how often children with high levels of physical disability have their friends around to play at a time that they have chosen. Children tended to play either on their own, with their parent, carer or a sibling and this was where they gained a sense of *belonging.*

Despite this, the research findings also highlight several situations where children are enabled to participate within their everyday environments and experience *belonging* through the means of adapted activity. This is clearly demonstrated within Abi's continued discussion of netball where she does feel she has had the opportunity to connect with her peers (5.6.3, boxes 12,13); Ben's discussion of playing bulldog in his wheelchair with his friends (5.6.2, figure 7); and Lucy's comments about playing the rocket ship game with her peers (5.8.2). The findings of the study would therefore suggest that children with physical disabilities can experience a sense of *belonging* in their play despite some challenges within environments. Although there is an important need to ensure that each child's environment enables the best possible opportunity for play, it is also important that the voice of the children is recognised in expressing the sense of *belonging* they often experience.

The lived experience of disability (including learning disability, sensory impairment and physical disability) of children age 7-15 was explored by Connors & Stalker (2007); their main finding suggests that children and young people often wanted to portray themselves as similar to their peers.

This appears to highlight the desire for *belonging* among children with disabilities. Several barriers to feelings of belonging were often expressed by parents, more than by children, such as bullying, difficulties with accessing others homes, and frustrations with support assistants not following the child's preferences (Connors & Stalker 2007). This is supported by in-depth focus group research in which children with Cerebral Palsy discussed experiences of bullying and isolation in a school setting (Lindsay & McPherson 2012). Connors and Stalker (2007) suggest that barriers to belonging were often perceived more by parents than by children themselves. This could suggest that adults may focus on barriers more than the children themselves. The current findings highlight two possible instances of bullying: where Ben is excessively hugged and kissed against his wishes (5.8.1); and where Jess laughs at herself with her peers when she falls out her wheelchair (5.8.1). The findings also show one instance of frustration with a support assistant when Daniel comments that he feels angry because his carer has got his instructions wrong (5.7.3). These experiences appear to have occurred as a result of each child's Cerebral Palsy, thus suggesting that in some instances difference because of disability can cause barriers to *belonging* alongside peers.

Connors and Stalker (2007) suggest children with disabilities want to portray 'sameness' more than difference to others for three possible reasons: children feel they have to minimise or deny difference because of peer pressure; children are self-directing agents and thus have a pragmatic approach to their lives and do not see impairment as an important part of their identity; children do not have the language to discuss difference. Within Connors and Stalker's (2007) research they conclude that children portray 'sameness' because they do not have the language and positive framework with which to discuss difference. The current findings would suggest that the participants appeared to be aware of the differences that they experienced and pragmatically embraced this experience in the way that they sought *belonging* in their play. It is clear that the research participants wanted to be like their peers and those around them (Lucy interview 1, 5.7.1) and there were times in which children wished they did not have a physical disability (5.7.1). Despite this, children appeared to be pragmatic in their approach to dealing with difference and had developed several strategies (as discussed in 6.4) which enabled them to be *active agents* in their play with those around them in a way that enabled them to feel like they were participating in a similar way to their peers.

Research with typically developing children has found that they define an activity as less like play when an adult is present (King 1979, Howard 2002, Howard et al. 2006). Researchers such as Imms et al. (2017) have suggested that the presence of an adult supporting the play for children with high levels of physical disability may become a barrier to their participation. The participants within the current study almost always had an adult present or nearby as part of their play experience (5.7.1). As discussed above the children within this research appeared to still able to experience a full sense of participation despite having a helper assist in their play (6.2). Mortier et al. (2011) suggest that support from adult carers has both positive and negative aspects. Tamm and Skär (2000) suggest that the children who had physical disabilities participating in their study often perceived their helper as a friend; Tamm and Skär (2000) propose that this could impact upon children's sense of *belonging* with their peers.

Within the study there were times in which the participants appeared to choose to play with their helper or ended up playing only with their helper instead of their peers (5.7.1). This provides further weight to the current literature in highlighting that the presence of an adult could diminish the possibilities for *belonging.* It is possible that even though the participating children are able to embody their helper within their experience of playing, their peers continue to experience play from a typically developing perspective where the presence of an adult decreases the feeling of play for an activity (Howard et al. 2006). This could lead to typically developing children choosing not to participate in play with their peers who have high levels of physical disability because they have an adult with them. It is important that parents and professionals recognise this and the impact that it could have on experiences of isolation for children with high levels of physical disability.

It is important to consider barriers to *belonging* for all children within play. Every friendship differs in its *content* and the actions that are shared with others, its *constructiveness* and control that is asserted, its *closeness* and depth, its *symmetry* and distribution of social power, and its *affective character* in terms of whether it is supportive or influenced by conflict (Hartup & Stevens 1997). There is a recognition that across the lifespan individuality within friendships will mean that there are times that people experience conflict and a lack of power in their relationships with others (Hartup & Stevens 1997). This suggests that for both typically developing children and children with disabilities there may be times within friendships and relationships with peers that they experience greater or lesser extents of *belonging.* Lundby (2013) supports this in highlighting the complexities for all children in gaining a place in their peer group; throughout Lundy's (2013) discussion it is highlighted that children felt a need to seek out and negotiate relationships with peers. This would suggest that *belonging,* particularly within the context of play which often occurs with peers, can be a challenge for all children. Lundby (2013) suggests that children often engage in consumer relationships in which they give to their peers because they want to make their peers happy in order to create friendships. This perhaps provides an explanation for the way that children in the present study sought out greater *belonging* and participation with their peers when they chose to compromise their play choices (5.6.3).

It is therefore possible that the study's findings reflect a typical experience of isolation and barriers to connection in play. Although the children within the study may experience this isolation because of their physical disabilities it appears that all individuals of all ages have to negotiate a sense of *belonging* within friendships (Hartup & Stevens 1997). Tamm and Prellwitz (1999) carried out a study with typically developing children to discuss the concept of *'If I had a friend in a wheelchair';* their findings suggest that whilst their study participants could recognise physical restrictions in the environment for children with wheelchairs, they had a view that they would include a child with disabilities in their games and that the child would have lots of friends and a high self-esteem. This would suggest that the perception of typically developing children is not one of limitation towards their peers with disabilities but one of inclusion. Despite this, the study took place before the typically developing children had the experience of having a child with a physical disability in their class, thus perceptions within reality may be different. This does however, raise an important alternative view to an impairment driven disability perspective which focuses on children's disability as the cause for restrictions to belonging, in suggesting that children with physical disabilities experience a need to negotiate their *belonging* within the occupations they participate in as much as other individuals.

6.6. Summary of findings

Children within this research have been observed to participate in *doing, being, becoming and belonging* through their experience of play. The findings suggest a move beyond Merleau-Ponty's (1945) extension of self through an object, to an extension of self through the embodiment of people. This has been demonstrated through the concept of *vista play.* The current discussion has highlighted a new perspective of the lifeworld of children with high levels of physical disability in suggesting that they experience a constant fluctuation in their being in which they negotiate both frustrations and perceived freedoms as part of their *being.* Further contributing to the current literature this discussion has highlighted the importance of the concept of *we-agency* and the shared control that enables children to see themselves as active within play. Finally, the discussion has raised the question as to what constitutes *belonging* for children with high levels of physical disabilities; suggesting that barriers experienced may not be as detrimental as much of the literature suggests, and that a focus on skills such as good communication and use of humour may enable a greater sense of *belonging.*

6.7. Implications for practice

It is essential that parents and professionals working alongside children with high levels of physical disability due to Cerebral Palsy are therefore able to recognise the children's experience of play. This includes: being able to understand the importance of the embodied unit; recognising vista play; providing opportunities for expressing an imagined self and negotiating identity as a disabled self; recognising participation in play through watching; and enabling opportunities for experiencing belonging. Practically, parents and professionals can also enable children to develop their component skills in a way that enables a greater participation in independent play, and support strategies for connection. The following section details these practice implications and how they can be implemented.

6.7.1. Understanding the embodied unit

It is recommended that therapists and parents gain an understanding of the importance of creating an embodied unit in order that the children they are supporting can gain a greater sense of freedom within their participation in play. An embodied unit relies upon both individuals reading and correctly responding to cues (Blanchard and Øberg 2015). Therapists and parents need to be able to quickly recognise where there is dissonance between what they are doing and how the child is responding; they need to be able to read and follow cues from the child to recreate a sense of embodiment. On a practical level this will involve practising joint participation in play experiences in which the child is physically facilitated to participate in the play. During the play experience parents and therapists should communicate with the child and asking questions such as ‘how does it feel to have my help?’ and ‘what can I do to make it easier?’ Following the play experience questions such as ‘what were you playing?’ can help to elicit whether the child perceived themselves as playing independently through the embodiment of their helper or whether they perceived themselves as merely being present for a play activity carried out by an adult. The findings of this study highlighted that children felt more comfortable with adults they knew supporting them in their play. It is possible that it will take time to achieve a full sense of an embodied unit with a child.

6.7.2. Recognising vista play experiences

In following an understanding of the creation of an embodied unit it is then of upmost importance that this is recognised as part of children’s experience of *doing* play. In particular, parents and therapists should be aware of the concept of vista play and what this can mean for a child’s sense of *doing.* The greatest difficulty of vista play is that to an observer a child does not look like they are playing; vista play can only be fully recognised from the child's perspective and experience. Therapists working with families can explain the concept of vista play to others in order that this can become a recognised means of participation. As families gain an awareness of vista play it is likely that parents and carers will more easily be able to become an embodied unit with the child.

Practically, recognition of vista play can also occur through conversations with children in which parents and therapists can accept and provide space for children to talk about their experiences of *'I play'* even when they have clearly had physical support to participate. The opportunity to talk about their vista play experiences will both enable the child to feel a recognition of this experience and will highlight and explain the experience further to the parents or professionals they are talking with.

6.7.3. Providing opportunities for expressing an imagined self

It is proposed that children are supported to express their imagined self and to have the opportunity for this to be recognised by parents and professionals in their play. This can practically be enabled through imaginary play opportunities both alone and alongside others. Therapists can make use of children's imagined identity in play whilst engaging them in therapy: this could be done by acting out an imaginary scenario, such as *'saving all the people in the world'* like Daniel (interview 1), whilst reaching for balls to throw at the baddies as part of practising an active stretch. This kind of play could also be incorporated into home programmes which are seen to be more successful the more they are a part of everyday life (Novak 2011). As the findings suggest a new spatiality within each child's imagined world was an important part of their life and identity development, this is important to encourage and recognise. Doble & Santha (2008) highlight the importance of occupational balance between self care, work and productivity, play and leisure across the lifespan. If children are enabled opportunities to express their imagined sense of self they are perhaps more likely to be able to continue this into adulthood in a way that supports their sense of *being* and identity.

6.7.4. Providing opportunities for negotiating identity as disabled self

Children need to be provided with opportunities to negotiate their identity as their disabled self. This is an important area which is not discussed within the research literature. This could involve opportunities within a therapy setting for children to explore what it means to have a disability. Within this research the participants were able to express and discuss how they negotiate this identity through drawing themselves and what they like to play. The opportunity to create play drawings as part of an assessment and rapport building could occur within occupational therapy sessions. As part of enabling children to develop their identity in relation to their disability therapists should focus on what children can do, and what they would like help to make easier, rather than focusing on what children are unable to do.

In addition, the findings suggest that the provision of equipment is important to the way that children build their identity as their disabled self. The importance of each child's wheelchair in their development of identity would suggest that one opportunity for enabling children to negotiate their identity could be through the provision of early mobility. This study further supports the emphasis on this as already highlighted within recent research (Langmead 2012, Sonday & Gretschel 2016). It also further supports the role of an occupational therapist in adapting physical activities to enable participation (Sharp et al. 2012).

6.7.5. Recognising participation in play through watching

It is important that parents and professionals learn to recognise children's participation in play through watching. This is a hard concept for many individuals to reconcile as often the focus on leisure participation for children is physical (Ross et al. 2016, Shields & Synott 2016, Imms et al. 2017). Therapists and parents could validate the experience of participation through watching to children's siblings and peers through modelling how children can participate in a game such as Lego by watching, teaching and commenting. It is also important to recognise that children may choose to play with toys even when they cannot physically manipulate them. Parents and professionals should make sure that children have the opportunity to choose to play in this way.

It is possible that through recognising children's ability to play by watching, parents will experience a sense of relief from the burden of supporting their children to play. Graham et al. (2015) suggest that parents of children with Cerebral Palsy felt a burden because of the level of support that their children needed to play. Although it is recognised that the study participants needed a high level of support in their play, they also demonstrated an ability to play by watching. Recognising this enables children to experience play independently and also enables parents to experience more opportunities where they do not need to be with their child for them to play.

6.7.6. Enable opportunities for experiencing belonging

Through focusing on opportunities that children have for connection it is likely that they will experience a greater sense of *belonging* within their play. The findings have highlighted several ways in which children with high levels of physical disability can connect and participate with others in play (such as through vista play and playing by watching). When adults notice children choosing to compromise their own choices in play because of a desire to connect or continue participating it is recommended that adults talk about this with children. Understanding ways in which children can quickly and effectively communicate their choices in order that they do not need to compromise as much within their play will help children to experience a greater sense of connection with those they are playing with. Parents and professionals can practically support this through teaching siblings and peers ways in which their contemporary, with high levels of physical disability, communicates their choices in order that they can be better understood and enabled to connect with their peers. This opportunity for understanding may lead to less instances of children with high levels of physical disability compromising in their choices in order to engage in play.

Parents and therapists should be aware of the times in which children may worry about feeling isolated or may experience isolation within their play. They can particularly expect to see this within physical barriers to accessibility (Stephens et al. 2017). This was also seen in terms of helpers not adequately responding to the child's cues. Adults can therefore be careful to respond to children’s cues and instructions within play in order that this does not impact their sense of *belonging.*

Another possible strategy for enabling a sense of connection and belonging alongside peers is providing the opportunity for children to participate in play with their peers without an adult present. If the presence of an adult impacts typically developing children in feeling like an activity is play (Howard et al. 2006), then where possible adults supporting children’s play should enable them to participate without an adult alongside their peers. This could be done through the provision of powered mobility, particularly within playground environments, as this will enable children more opportunities to independently engage in play. Where children need the presence of an adult, adults should pay particular attention to following the cues of the child they are supporting in order that play is led by the children and not by themselves.

6.7.7. Enable development of component skills for participation

As children develop their sense of becoming within play therapists can provide strategies for children to improve in their skills (e.g. developing language and physical strength) which enable a greater participation. This recommendation is often made and discussed within the research literature (Ahonen-Eerikäinen et al. 2008, Matthews & Rix 2013, Okimoto et al. 2000). The current study provides additional support for the importance of therapists helping children to develop component skills which enable their play participation and sense of being active in their play. Whilst improving component skills is important, it is also important that this does not become the sole purpose of the play to the extent that the activity stops feeling like play (Goodley & Runswick-Cole 2010). Research from a parents’ perspective has suggested that therapy can be an integral part of the experience of play for children with high levels of physical disability (Graham et al. 2015). However, within this study only one child directly discussed her experience of playing during therapy, this would suggest caution is needed in the manner in which component skills are focused on.

6.7.8. Support strategies for connection

It is recommended that children are supported in developing the strategies that they can use for connecting with others and therefore gaining a sense of belonging within play situations. Children within the present study demonstrated the use of both humour and communication (both verbal and non-verbal) as a strategy for connecting with those around them in their play. Parents and therapists can on a practical level can support children through speech and language therapy in developing effective communication strategies which can then be used to create connection. They can also provide the time needed to enable children with high levels of physical disability to express their needs. This need for extended time to be allowed for children with high levels of physical disability to communicate effectively is highlighted within the Communication Function Classification System (Cooley Hidecker et al. 2012).

6.8. Recommendations for future research

Please see figure 18. The boxes summarise the contributions to knowledge made within the current thesis. The arrows summarise further research as discussed throughout this chapter which needs to take place.

The experience of negotiating identity through a fluctuating lifeworld presents an important finding for further exploration and study, particularly as children move into their teenage and adult years. It is unknown whether individuals with high levels of physical disability will continue to experience this fluctuation in their sense of being throughout their lifespan. Theories of play development would suggest that as children move into their teenage years play becomes much more focused on games with rules and structured leisure and less about imaginary play (Piaget 1951). Despite this, more recent research is discussing the possibility of pretend play across the lifespan (Göncü & Perone 2005). This is demonstrated by researchers such as Root-Bernstein (2014) who discusses the influence of world play on the authoring of books. This would suggest that there are some circumstances in which an adult's imagination may continue to thrive across the lifespan. It is important to further explore the impact of the view that imaginary play stops in childhood (Göncü & Perone 2005) and what this then means for adolescents and adults with high levels of physical disability in terms of their identity negotiation.

Children with high levels of physical disability experienced a fluctuation in their lifeworld between their disabled and imagined self.	•Further exploration of the experience of *being* with a physical disability is needed. •The concept of a fluctuating lifeworld, particularly the presence of an imagined self needs to be explored for adolescents and adults with high levels of physical disability.
Children with high levels of physical disability embody their wheelchair and equipment so it becomes a part of themselves in play.	•The importance of early mobility in enabling children to develop an embodied sense of self needs further exploration. •Further research about the importance of wheelchairs and equipment to individuals who have had disabilities from birth is needed.
Children with high levels of physical disability are able to participate in play through watching, commenting and teaching.	•Exploration of experiences of participating in play through watching for children with both physical and communication difficulties is needed. •Specific studies focusing on ways children participate through watching are needed. Studies should address the activation of mirror neurons and the tension between watching as participation and watching which is tokenistic.
Children with high levels of physical disability experience extreme emotions such as excitement and frustration in their play	•Further research needs to address whether experiencing extreme emotion in play is unique to children with high levels of disability. This could explore the role of emotion in adjusting to the experience of disability.
Children with high levels of physical disability experience participation through 'vista play' an embodiment of their helper.	•The concept of embodying another person needs to be further explored for both children with physical disabilities and other individual-carer dyads in order to understand the impact of this upon participation. •Exploration of vista play for typically developing children. •The importance of vista play for children with high levels of physical disability needs to be further explored in terms of its prevelance and commonality.
Children with high levels of physical disability experience a greater sense of belonging in play than their social world may anticipate.	•Further research should explore the experiences of isolation for children with disabilities in comparison to their typical developing peers. •Research is needed to explore the impact of a helper supporting a child with disabilities on the participation of their typically developing peers

Figure 18 Summary of recommendations for further research.

ORIGINAL IN COLOUR

The experience of embodiment of equipment is an area in which further research could take place. As using a wheelchair appeared to enhance children's sense of 'I can'; this raises the question as to the age in which children with high levels of physical disability should receive mobility or powered mobility they can use independently. This is a current area of debate within literature and practice which is often restricted because of funding (Langmead 2012, Sonday & Gretschel 2016). Further research should explore the importance of early mobility provision for identity development and negotiation for young children with high levels of physical disability.

Further research should take place as to the possibility of participating in play through watching and the experience of this in relation to mirror neurons. Research into mirror neurons would suggest that in watching an activity the same neurons fire as when participating in an activity (Holmes & Calmels 2008). This raises an interesting question as to whether the experience of watching play for the children with physical disabilities is any different from the experience of physically playing for their typically developing peers. Further research is needed which focuses specifically on the possibility of participating in play through watching and the experience that children have of this. This research could include experimental studies which look at what happens neurologically when children participate in play through watching. A comparison of children's reported experience of play alongside a neurological picture of their brain activity during play may provide a greater understanding of what play by watching involves.

In order to gain a greater understanding of the experience of extreme emotions in play it is important to explore the role of emotion particularly in relation to adjusting to having a disability. As emotional expression impacts upon information processing (Lemerise & Arsenio 2000) it is important to consider this specifically for children with high levels of physical disability. It is possible that the expression of extreme emotions is part of each child's adjustment to their disability and the way that they negotiate their sense of identity.

The concept of vista play provides several avenues for further exploration. It is possible that the embodied unit which occurs between a child and their carer could occur between other individual-carer dyads. This should be further explored for participation for other populations. This could include individuals with disabilities and also typically developing children. Further to this, it is essential to further explore the prevalence and commonality of vista play among children with high levels of physical disability. As a style of play common to all the participants it is imperative that this is recognised by each child's parents, carers and friends.

Finally, further exploration is needed in relation to the sense of belonging that children with high levels of physical disability experience in their play. The findings suggest that the sense of belonging the participants experienced as greater than may be expected, this should be considered in depth in relation to experiences of both belonging and isolation and whether this varies from the experience of typically developing peers. In addition to this, researchers such as Imms et al. (2017) suggests that the presence of an adult support may negatively impact play participation. Although the findings would suggest that children do not directly experience a negative impact because of the presence of an adult, it may be that there is an indirect negative effect on children's experience of *belonging.* Typically developing children suggest that the presence of an adult can limit the possibility of an activity being experienced as play (King 1979, Howard 2002, Howard et al. 2006). This may have an impact on the extent of play with peers that participants with high levels of physical disability experience. This was not sufficiently highlighted within the current study and therefore further research should be undertaken to explore how the presence of an adult supporting a child with physical disabilities can impact upon the play experience and participation of their peers.

6.9. Study limitations

The study involved six participants with high levels of physical disability due to Cerebral Palsy, it is therefore not representative of other children with Cerebral Palsy or other physical disabilities. Although this could be perceived as a limitation, it is congruent with the philosophy and methodology underpinning the study which focuses on a small homogenous population with some transferability to this population (Smith at el. 2009). The participants were from different locations in the country and all had different experiences. The participants all had the similarity of choosing to participate in the research; this would involve both their parents and themselves actively responding to the invitation to the study. It is possible the attitude of being able to actively respond to requests within each of the participants' families may have influenced their perspective and experience of play. The experience of play may be different for children within families whose parents play a less active role to support their engagement.

The study aimed to capture the experience of play for the participants. One limitation to fully capturing the depth of this experience was in the communication abilities of the participants'. As the participants have high levels of physical disability they also had some difficulties with their communication. This meant that communication often took longer and needed checking and clarification (Cooley Hidecker et al. 2012). The need for clarification throughout the participant interviews meant that children often did not provide long extensive answers and their response was often interwoven with clarification from the researcher. This impacted the analysis process in being able to understand the flow of each child's experience and being able to quote participant's views which may have been clarified across several sentences. In order to try to address difficulties with communication the researcher was careful to provide as much space as possible for participant responses, this improved as the interviews went on and the research became more accustomed to each child's communication style. In order to reach a sufficient level of depth the study design meant that each child was interviewed on three occasions. Although this did enable a level of depth to be reached with each participant, the differences between participants communication abilities did highlight the limitation this provided for the study. For example, further exploration and depth was reached with participants, such as Jess, who had better communication abilities.

The interviews provided rich data and much of this data was collected following discussion about a play experience that the children had just videoed. Additionally, the children also discussed experiences of play that had occurred in the past. It is possible that this may have skewed the children's perception of their experience in recalling it retrospectively. On the other hand, the consistency of participants' experiences between their discussion of play experiences they had just videoed and discussion of play experiences in the past would suggest that this was not the case.

As discussed within the methods chapter (4) the findings highlighted important comparisons between children's participation in their videos of their play experiences and their discussion of their experience within their interviews. This led to the researcher requesting and gaining retrospective consent from each of the children for the use of their play videos in contributing to the analysis. In future studies exploring the experience of play with children it is recommended that if using this approach consent for the use of videos is sought at the start of the study prior to initial ethical approval. It was a limitation within this study as the participants may have felt coerced to provide retrospective consent which would be detrimental to their wellbeing. Despite this, all the participants readily completed the additional consent forms, suggesting that they did not perceive this as a problem.

6.10. Reflexive account

The process of synthesising the findings and reading in relation to the concepts raised has been both challenging and rewarding. The huge volume of literature which could in some ways be applied to the study's findings is at times overwhelming. It was important for me to be able to find concepts which were relevant and then use these as a foundation for the discussion. The reading around embodiment made a lot of sense in enabling me to understand how children expanded their perception of self in a way that enabled an embodied freedom, choice and control. I found that as I wrote about embodiment and the concepts of Merleau-Ponty (1945) and Heidegger (1927) and based my thinking within the context of a person embodied in their interaction with the world this enabled a deeper understanding and framework which was helpful for the creation of discussion in the rest of the chapter.

I was speaking to a group of friends about my research when someone mentioned the concept of mirror neurons and asked if I had looked at that in relation to my research. At that point it was not a perspective that I had considered and the possibility of it intrigued me. With my master's research still relatively fresh in my mind, in which parents of children with Cerebral Palsy discussed their children participating in vicarious play, together with the findings of this study, where children state participation as an observer; I was interested in the applicability of the neuroscience research to my findings. I have only explored this briefly within this chapter but it appears that the concept of mirror neurons firing when one observes or imagines an activity that this could link to the experience of embodiment that children describe in so much detail within their interviews. I was pleased to have had the conversation and the challenge to consider other fields of research in relation to my findings.

Once I had written about embodiment I found that this closely linked to the development of self and the idea of creating an identity that one can portray to others. In reading Erikson's works I found that the focus upon a Freudian approach was difficult at first to fully understand. I felt offended by some of the references to culture and experience which appeared to be racist in their nature. I was able to overcome this by reflecting on the date of the writings and through the preface of Erikson's work in which he discusses the changes that have occurred since the time of his writing. I felt that I used the broad ideas of identity development rather than specifics from Erikson's theory, but I feel that this represents the way in which identity theory continues to be based upon but has also progressed from this original work.

When writing about *doing, becoming and belonging* I felt an easy flow within my words in the sense that I am often talking about the importance of occupation both as a clinician and when explaining my job to people around me. I often find that when someone talks about how *doing* an activity has been helpful to them I tell them about the importance of occupation for health and wellbeing and the impact that this can have in our lives. This appears to be the case for children within the findings and I wanted to be able to represent their perspective of doing which perhaps looks different to what they may be perceived as doing. This came back to the challenge I experienced in observing the children as appearing to be static within their play when actually they were able to give a detailed and apparently embodied account of their experience. I wanted to be able to demonstrate how the participants were able to reach their right for participation within the occupation of play, even if this doesn't look the same as their typically developing peers.

7. Conclusions

7.1. Introduction

This research study has addressed the experience of play for children with high levels of physical disability due to Cerebral Palsy. The literature review (Chapter 2) highlighted that children with high levels of physical disability are often underrepresented in research (Malkaw 2009) and that limited research exists discussing their experience of play (Graham et al. 2017f). As play is a primary occupation for children (Brooks & Dunford 2014), and all children have a right to play (UNICEF 1989), the study addressed an important area for research.

The research was based upon a **minimal hermeneutic realist ontology** and **social constructionist epistemology**, both consistent with the methodology of **Interpretative Phenomenological Analysis** which was used to inform the research (Larkin et al. 2006) (see Chapter 3: Methodology). Following collaboration with research advocates (Graham et al. 2017e) the research design was created in a way that enabled in-depth discussion of play experience by each of the participants (see Chapter 4: Methods). Six children age 6-11 participated in the research. They each participated in three interviews in which they discussed their play experience. The participants had the opportunity to be videoed playing for ten minutes so that the video could be played back and discussed during their interview. All the children were able to use visual methods to help the discussion of their play experience, this included showing their toys and drawing their play experience.

During the process of participant interviews transcription and data analysis began. The findings of the study are presented in chapter 5. These highlight three superordinate themes- that children experience *making choices and controlling play,* that there are times when they *participate in play differently to their peers* and that *connecting with others in play* was important to their experience. These findings are then discussed in relation to Wilcock’s (1998) theory of occupation and health (see Chapter 6: Discussion). They suggest that children may experience *doing, being, belonging* and *becoming* in play in a way that appears to be different to their typically developing peers. This has not been previously captured within the research literature and presents important implications for the children, their carers and professionals.

7.2. Contributions to knowledge

This research study has made several unique contributions to knowledge. It highlighted that participants with high levels of physical disability due to Cerebral Palsy experienced a **fluctuation in their lifeworld between themselves with a physical disability and a new spatiality of an imagined self without a physical disability.** This appeared to be important to the participants development of identity and sense of self. Participants appeared to re-frame the parameters of concepts such as ‘success’ in order that they experienced a full sense of participation. Carers and professionals should provide opportunities for children to explore their sense of self and their identity particularly with regards to their physical disability.

The findings suggest that participants experienced their **equipment as embodied** when they were discussing their play experience. This is a concept which is considered within adult research literature, however, the current study appears to be the first to discuss embodiment of equipment for children. Therapists should consider this in relation to the provision of early mobility and the opportunity for exploration and participation this can enable.

Children participating in the study appeared to experience **participation in play through watching, commenting and teaching.** Although this has been highlighted to some extent within other studies (Graham et al. 2015, Tamm & Skär 2000) the current study provides further support for the opportunity for children to be engaged and participating in occupation despite having limited physical participation. Children with high levels of physical disability may choose to participate in play in this way and this should therefore be recognised by parents and carers as a possible component of the experience of play.

Seemingly, children with high levels of physical disability appear to **experience extreme emotion within play.** It is currently unclear whether this experience is unique to children with high levels of physical disability and future research should explore this further. It is important that this experience is recognised as part of negotiation of identity and expression of possible frustration and a heightened sense of success because of children’s physical disability.

The **vista play experience** of the children within the current research provides a new type of play which is currently not explored in the literature. This suggests that children can participate in *doing* play themselves through the **embodiment of a helper**, despite having physical facilitation and support. The discussion (Chapter 6) has highlighted the importance of creating the opportunity for an *embodied unit* where the child and their helper can read and respond to the cues of each other in order to enable more of an experience of vista play.

Finally, the study has highlighted the importance of experiencing **belonging and connection** in play for children with high levels of physical disability due to Cerebral Palsy. Children appeared to experience a greater sense of belonging than their social world may anticipate. This highlights an important area which needs recognition both in health care practice, and from parents with regards to children's own experience of belonging. It is unclear whether the strategies children developed, such as using their communication skills and as sense of humour, are unique to children with high levels of physical disability or are common among all their typically developing peers. Further research is needed to explore the strategies children with high levels of physical disability use to pursue and experience a sense of belonging and connection in play.

7.3. Dissemination of the project

During the completion of this research two journal articles have been accepted for publication. A practice analysis discussing the process of using advocates to inform research design was accepted for the British Journal of Occupational Therapy (Graham et al. 2017e). A Systematic Thematic Synthesis of research addressing the experience of play for children with physical disabilities was accepted for publication in the Child: Health, Care and Development Journal (Graham et al. 2017f, appendix 1).

Throughout the research process the study has been presented at several conferences including: the University of Brighton PhD/ Post Doctorate conference; the College of Occupational therapists Annual Conference, both in the form of a seminar (Graham et al. 2016a) and a poster (Graham et al. 2017a, appendix 16); as two posters at the European Academy of Childhood Disability Conference (Graham et al. 2016b, appendix 2, Graham et al. 2017b, appendix 16); also, as both a visual media presentation (Graham et al. 2017c, see enclosed DVD) and as an oral presentation at the International Play Association Conference (Graham et al. 2017d).

The analysis processes was presented and discussed with individuals at the IPA London network group. Feedback was that a sufficient level of depth was reached within analysis. The analysis example is seen within appendix 14.

The study findings are applicable both to occupational therapists and other healthcare professionals working with children with high levels of physical disability. Therefore, further dissemination within child development journals will be sought.

7.4. Summary

This thesis has highlighted several contributions to knowledge including the concept of vista play, the experience of embodying a helper, participation in play through watching and the fluctuating lifeworld that children with high level of physical disability experience. This raises a need for further research to take place and practice implications to be carried out in order to recognise the participation in play of children with high levels of physical disability due to Cerebral Palsy.

7.5. Concluding reflexive summary

In summarising the findings of this research I was confident of the contribution to knowledge that it has made. I finished this chapter just after presenting at the International Play Association conference (Graham et al. 2017d); I was pleased with the feedback that I received there and the opportunity to share my research with key authors in the field. I have also presented my findings to therapists at a school for children and young people with Cerebral Palsy and received good feedback as to how the findings could impact upon the therapists practice. This was important to me and I was pleased that the findings presented new information that they could become aware of and implement with the children, young people and parents they work with.

In attempting to explain what writing a PhD involved to my five-year-old Godson I told him I was writing something very long, about 300 pages. He quickly exclaimed *'300 pages! That is like driving from here all the way to India!'* Indeed, there have been times when the process of this research has felt like a very long journey, but it has been a journey which has felt interesting, challenging and rewarding.

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9. Appendix

9.1. Appendix 1- The meaning of play for children and young people with physical disabilities: A systematic thematic synthesis

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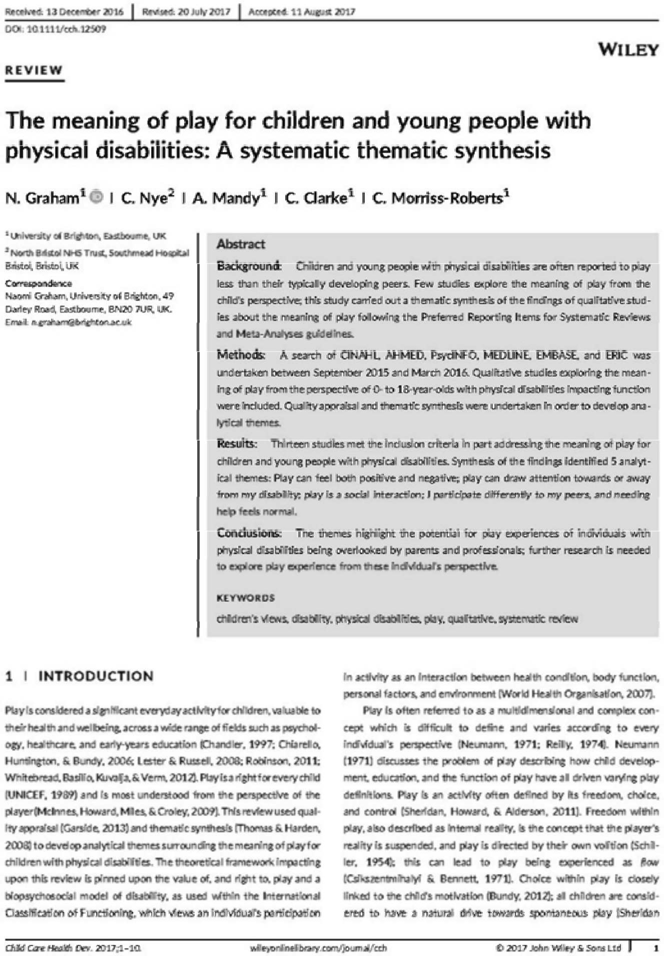

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REVIEW

The meaning of play for children and young people with physical disabilities: A systematic thematic synthesis

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Abstract

Background: Children and young people with physical disabilities are often reported to play less than their typically developing peers. Few studies explore the meaning of play from the child's perspective; this study carried out a thematic synthesis of the findings of qualitative studies about the meaning of play following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.

Methods: A search of CINAHL, AHMED, PsycINFO, MEDLINE, EMBASE, and ERIC was undertaken between September 2015 and March 2016. Qualitative studies exploring the meaning of play from the perspective of 0- to 18-year-olds with physical disabilities impacting function were included. Quality appraisal and thematic synthesis were undertaken in order to develop analytical themes.

Results: Thirteen studies met the inclusion criteria in part addressing the meaning of play for children and young people with physical disabilities. Synthesis of the findings identified 5 analytical themes: Play can feel both positive and negative; play can draw attention towards or away *from my disability; play is a social interaction; I participate differently to my peers, and needing* help feels normal.

Conclusions: The themes highlight the potential for play experiences of individuals with physical disabilities being overlooked by parents and professionals; further research is needed to explore play experience from these individual's perspective.

KEYWORDS
children's views, disability, physical disabilities, play, qualitative, systematic review

1 | INTRODUCTION

Play is considered a significant everyday activity for children, valuable to their health and wellbeing, across a wide range of fields such as psychology, healthcare, and early-years education (Chandler, 1997; Chiarello, Huntington, & Bundy, 2006; Lester & Russell, 2008; Robinson, 2011; Whitebread, Basilio, Kuvalja, & Verm, 2012). Play is a right for every child (UNICEF, 1989) and is most understood from the perspective of the player (McInnes, Howard, Miles, & Croley, 2009). This review used quality appraisal (Garside, 2013) and thematic synthesis (Thomas & Harden, 2008) to develop analytical themes surrounding the meaning of play for children with physical disabilities. The theoretical framework impacting upon this review is pinned upon the value of, and right to, play and a biopsychosocial model of disability, as used within the International Classification of Functioning, which views an individual's participation in activity as an interaction between health condition, body function, personal factors, and environment (World Health Organisation, 2007).

Play is often referred to as a multidimensional and complex concept which is difficult to define and varies according to every individual's perspective (Neumann, 1971; Reilly, 1974). Neumann (1971) discusses the problem of play describing how child development, education, and the function of play have all driven varying play definitions. Play is an activity often defined by its freedom, choice, and control (Sheridan, Howard, & Alderson, 2011). Freedom within play, also described as internal reality, is the concept that the player's reality is suspended, and play is directed by their own volition (Schiller, 1954); this can lead to play being experienced as *flow* (Csikszentmihalyi & Bennett, 1971). Choice within play is closely linked to the child's motivation (Bundy, 2012); all children are considered to have a natural drive towards spontaneous play (Sheridan

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et al., 2011). Internal control suggests the process and objective of the play is controlled by the player (Bundy, 2012). Parten (1932) suggested internal control can also be experienced through cooperative control, when an individual chooses to share their play with others. Bundy (2012) argues a frame of play cues such as an exaggerated use of props, voices, or bodies can lead to an activity being viewed as play. This article follows a definition of play as an activity of freedom, choice, and control framed by cues that an individual is playing (Bundy, 2012; Sheridan et al., 2011).

According to Article 31 of the United Nations Convention of the Rights of the Child, every child has the right to play (UNICEF, 1989). Despite this, the research literature suggests that children with disabilities demonstrate less playfulness than their typically developing peers (Imms et al., 2017; King, Petrenchik, Law, & Hurley, 2009; Kolehmainen et al., 2011; Whittingham, Fahey, Rawicki, & Boyd, 2010). In response to this, health and educational professionals have sought to increase opportunities for playfulness in children with disabilities (Bundy, 2012; Whitebread et al., 2012). This has led to the proposal that academics, health and educational professionals, and parents should recognize the intrinsic value of free play for children with disabilities, rather than purely viewing play as a tool for therapy or education (Goodley & Runswick-Cole, 2010).

As play experience varies according to the perspective of the player, it is important to consider the child's perspective of play (Chandler, 1997; McInnes et al., 2009). Several studies, predominantly in the education field, have researched play from the perspective of typically developing children. These mainly suggest that children view play, as separate to work and without adult direction, as an activity which is fun and chosen by themselves (Berkhout, Bakkers, Hoekman, & Goorhuis Brouwer, 2013; Gmitrova, Podhajecka, & Gmitrov, 2009; Howard, 2002; Howard, Jenvey, & Hill, 2006; King, 1979; King & Howard, 2014; Rogers & Evans, 2006; Wing, 1995). As children with disabilities are thought to play less than their typically developing peers (Imms et al., 2017), it is important to also consider the meaning of play from their perspective. Polatajko et al. (2007) suggests that individuals can be fully engaged and participating within activity despite limited performance; this may also be the case for play.

Participation within play is an important part of a child's leisure activities and is defined as such by the International Classification of Functioning, Disability, and Health: Children and Youth version (WHO, 2007). Although considered a part of leisure activities, play as a concept is defined separately from leisure. Play is typically an internally motivated behaviour marked by a lack of structure, which can occur during work or leisure; while leisure is time outside of work and self-care activities, which can involve participation in an organized activity but might include reflection, relaxation, or spiritual experiences (McLean & Hurd, 2011). This review focuses specifically on play and therefore contrasts to the work of Powrie, Kolehmainen, Turpin, Ziviani, and Copley (2015), whose review focused broadly on the concept of leisure for children and young people with physical disabilities. This review focusses on the concept of play but used leisure as well as play within the search strategy in order to ensure inclusion of all potentially relevant articles.

This study aims to synthesize the findings presented in qualitative studies which help to explore the meaning of play for children and young people with physical disabilities. As qualitative research is often best placed to capture individual feelings or experience of a concept (Garside, 2013) only qualitative data was sought within this review in order that thematic synthesis could occur. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines for reporting systematic reviews (Moher et al., 2009) were followed in the process of writing this article in order to ensure a rigorous and trustworthy review.

Key messages

- Play for children and young people with physical disabilities is different to their typically developing peers.
- Play can draw attention both towards and away from disability.
- Needing a helper within play can feel normal for children with physical disabilities.
- Further research is needed to explore the experience of play from the perspective of children and young people with physical disabilities.

2 | METHODS

2.1 | Search strategy

The following databases were searched between September 2015 and March 2016: CINHAL, psychINFO, AMED, MEDLINE, EMBASE, and ERIC. The following strategies were used.

- CINAHL, MeSH terms:
  - *Population-* child (explode) OR child, preschool OR adolescence (explode) OR "youth" OR young people AND disabled (explode) OR "physical disab*"
  - *Subject of Interest-* AND "play and playthings" (explode) OR "Leisure activities" (explode) OR recreation (explode)
  - *Outcome-* AND "self report" (explode) OR perception (explode) OR "Qualitative studies" (explode)
- psychINFO, AMED, MEDLINE, EMBASE and ERIC:
  - *Population-* child* OR child, preschool OR adolescen* OR youth OR "young people" AND disabled OR "physical disab*"
  - *Subject of Interest-* AND play* OR "leisure activit*" OR recreation
  - *Outcome-* AND qualitative OR perception OR "self report"

University librarians were asked to provide advice regarding the search strategy to ensure a thorough search. The search strategy did not use any limits on the date of publication so all studies relevant to the review in this under researched area of study could be included. The screening and analysis process was carried out by the first two authors (NG, CN) separately and then discussed to refine and agree on both descriptive and analytical themes.

Articles were included if they involved

- 0- to 18-year-olds with physical disabilities impacting their functional ability;
- some discussion of play experience from the perspective of children and young people (not necessarily the primary focus of the study, for example, could be a mention of play within a quote; one theme within a qualitative study which referred to play; or the view of one child with an identified physical disability);
- qualitative methodology (qualitative elements of mixed-method studies considered);
- findings available in English (as no translator was available).

Studies focusing on an intervention were included if the findings discussed play experience which was referred to as play within the article.

Studies were initially screened according to title and abstracts by the first author (NG). This resulted in several articles being excluded through not meeting inclusion criteria (e.g., focusing on a nonphysical disability such as autism, quantitative articles, teacher, or professional perspectives). This provided a method of quickly identifying articles which were not relevant to the review, allowing full text to be read only when necessary (Kable, Pich, & Maslin-Prothero, 2012). This was carried out by NG for pragmatic reasons of use of time; any articles where there was any doubt were included and screened in full. Of the remaining articles, reference lists were screened to include any further relevant studies. Then articles were read in full by both NG and CN independently; agreement was unanimous as to which of the 44 screened articles were included or excluded according to the criteria discussed above (reasons provided in Figure 1).

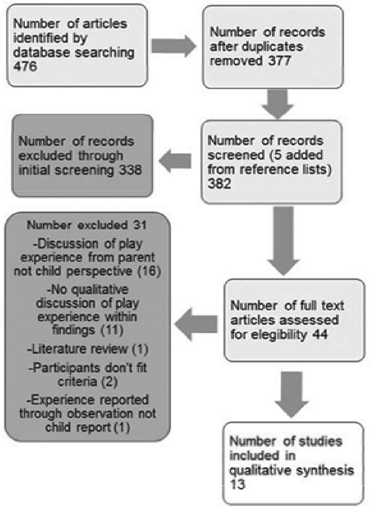

FIGURE 1 Flow diagram demonstrating the search process and identification of articles for review

2.2 | Quality appraisal

Following identification of articles relevant to the review, quality appraisal using Garside's (2013) criteria was undertaken by the first two authors (NG, CN). This suggests reviewing each article according to clarity of questions, suitability to qualitative study, clear context, sampling, data collection, and analysis (Garside, 2013). Issues of trustworthiness such as appropriateness of design, ethical considerations, and reporting of the participant's voice were also considered. Theoretical considerations—such as connection to a wider body of knowledge or theoretical framework—and practical considerations—such as the application of the study to the present review—were also important (Garside, 2013). If an article had poor quality of questions, unclear context, sampling, data collection, and analysis, it was excluded from the present review.

2.3 | Thematic synthesis

Several methods, such as meta-synthesis, meta-interpretation, and constant comparison, are presented within the literature for synthesizing qualitative studies; the most currently used approach is meta-ethnography (Dixon-Woods, Booth, & Sutton, 2007). The Centre for Reviews and Dissemination (2008) also highlights thematic synthesis as one possible method allowing for identification of important or recurring themes. Thematic synthesis draws upon the theory of thematic analysis, which is applied to the analysis of qualitative data (Thomas & Harden, 2008). It involves line-by-line coding of included sections of articles, then grouping together codes to create descriptive themes (Nicholson, Murphy, Larkin, Normand, & Guerin, 2016). The themes identified are then used to explore the research question and create analytical themes relevant to the review (Thomas & Harden, 2008). The first two authors (NG, CN) were aware of the difficulties of aggregating qualitative findings from various contexts however concur with Bearman and Dawson (2013) that a synthesis of research can provide a helpful contribution to practice. The process of independently creating descriptive themes and discussing and agreeing these before doing the same for analytical themes enabled a consensus grounded within the theoretical framework outlined in the introduction; this transparency of process helps to improve the rigour and credibility of this review (Bearman & Dawson, 2013). This occurred through cutting out each authors list of themes and subthemes and in discussion grouping and regrouping them until themes were agreed.

One advantage of thematic synthesis is that it can "go beyond" a description of studies findings (Thomas & Harden, 2008). This is

particularly applicable within this field as very few studies have specific aims to capture the meaning of play for children and young people with physical disabilities. Developing analytical themes allows a broader understanding which would otherwise not be possible.

3 | RESULTS

Systematic searching of the literature and reference lists of identified articles led to the identification of 13 articles relevant to this review (Figure 1). The articles identified are summarized in Table 1. Quality appraisal of the articles suggested all 13 articles were of sufficient quality to be included within the review (see Table 1). Children and young people (age 0–18 years) within this review are referred to as children to describe the participant group more easily. Although seminal work recognizes the differences in participation in play across ages and between children and youth (Sheridan et al., 2011), many studies reporting children's perspectives of play span 0- to 18-year-olds and therefore are all included. When used, pseudonyms from original studies are given.

3.1 | Developing descriptive themes

Each relevant section within the findings and discussion of identified papers was read, coded, and grouped into descriptive themes. Three descriptive themes with 12 subthemes were discussed and agreed upon which captured and described meaning of play from the children's viewpoint. These themes are *play feels positive*, *I can be excluded from play*, and *I sometimes play differently to my peers*. The use of first person was deemed appropriate in order to reflect the perspective of children and young people captured within the articles. The key themes and subthemes are summarized and briefly discussed below, highlighted in italicised font.

3.1.1 | Play feels positive

Within some of the studies, children demonstrated how they can *play on their own*, and this was a positive experience (Burke, 2012; Miller & Reid, 2003). Play was often described by children as *fun, happy and good* (Burke, 2012; Miller & Reid, 2003; Pollock et al., 1997). Children often referred to the importance of *playing with their friends* (Burke, 2012; Mundhenke, Hermansson, & Nätterlund, 2010; Schiariti et al., 2014; Skär, 2002; Spencer-Cavaliere & Watkinson, 2010; Young, Rice, Dixon-Woods, Colver, & Parkinson, 2007). They enjoy competition within play and the opportunity to do this alongside their peers (Miller & Reid, 2003; Schiariti et al., 2014; Spencer-Cavaliere & Watkinson, 2010). Children also referred to their equipment in a positive light suggesting that *equipment helps them play* (Gcaza & Lorenzo, 2008; Miller & Reid, 2003; Skär, 2002; Sonday & Gretschel, 2016).

3.1.2 | I can be excluded from play

Many of the articles also had a focus towards times that the children had felt excluded from play (Skär, 2002; Spencer-Cavaliere & Watkinson, 2010). Children felt that there was a *lack of equipment* or adaptation to support their play (Egilson & Traustadottir, 2009; Gcaza & Lorenzo, 2008; Ripat & Becker, 2012; Skär, 2002). Children often reported a feeling that *no one wanted to play with them* (Egilson & Traustadottir, 2009; Gcaza & Lorenzo, 2008; Miller & Reid, 2003; Mundhenke et al., 2010; Spencer-Cavaliere & Watkinson, 2010; Tamm & Skär, 2000). The nature of each child's physical disability often also led to them being excluded from play because they *needed breaks for care routines* (Pollock et al., 1997; Tamm & Skär, 2000).

3.1.3 | I sometimes play differently to my peers

Some studies also discussed play that was different to typically developing children: Children reported *participating in play by watching a game* (Buchanan, 2009; Gcaza & Lorenzo, 2008; Pollock et al., 1997; Schiariti et al., 2014; Tamm & Skär, 2000). Children often reported participating in *play with adults* (Buchanan, 2009; Gcaza & Lorenzo, 2008; Skär, 2002; Spencer-Cavaliere & Watkinson, 2010). When they had *the opportunity to play with others, children often chose to follow the lead of others*; this enabled them to be able to participate in the play activity (Burke, 2012; Egilson & Traustadottir, 2009; Miller & Reid, 2003; Mundhenke et al., 2010; Pollock et al., 1997; Spencer-Cavaliere & Watkinson, 2010; Tamm & Skär, 2000). Children also expressed that *they have to ask to play* (Gcaza & Lorenzo, 2008; Mundhenke et al., 2010; Pollock et al., 1997; Spencer-Cavaliere & Watkinson, 2010; Tamm & Skär, 2000).

3.2 | Developing analytical themes

The descriptive themes were then synthesized independently, discussed, and agreed upon in order to go beyond the initial meaning of the data and apply it to the context of this review (Thomas & Harden, 2008). The following analytical themes exploring the meaning of play for children with physical disabilities were a result of this synthesis:

1. Play can feel both positive and negative.
2. Play can draw attention towards or away from my disability.
3. Play is a social interaction.
4. I participate differently to my peers.
5. Needing a helper feels normal.

The links between the descriptive themes and the resulting analytical themes is show in Figure 2.

3.2.1 | Play can feel both positive and negative

Children within the studies described many powerful emotions linked to play experiences. Several studies commented on the fact that playing for children with physical disabilities often meant compromise in choice.

> *I mostly play alone. I have no choice. I'm almost never allowed to be in the games, because it doesn't suit the others. Child (Tamm & Skär, 2000, p. 178)*

> *...It usually wasn't me who chose because if I ever did get someone to play with, I usually said 'Okay, you're playing with me, that's good enough, like, you choose. Young person, age 17 (Pollock et al., 1997, p. 29)*

TABLE 1 Summary of articles included within thematic synthesis

Author	Study design	Participants	Comments/key findings	Quality appraisal
Burke (2012)	Multimethod qualitative study. Observation of children playing in playgrounds, participatory photographic project by children including child report.	6- to 10-year-olds, 35 with an impairment, 37 typically developing children from three mainstream and one special education schools. Case-by-case reports (only findings discussing children with physical disabilities are included)	Children construct play cultures by themselves and with each other. Children with impairments are able to make choices and be creative in their play.	Meets criteria; focused on access to playgrounds rather than play specifically
Egilson and Traustadottir (2009)	Mixed methods study, included qualitative data collection through observation and interview about student participation in school. Quantitative data was collected via the school function assessment.	14 children age 6–12 with physical disabilities. Parents and teachers also participated in the study. (Only findings discussing children's perspective included).	Some school settings presented more challenges for student participation. Environmental, child, and task factors all impacted participation.	Meets criteria; focus is on participation within a school setting. One small aspect of the findings discusses play.
Gcaza and Lorenzo (2008)	Case study design over 2 yr collecting views of children at a special school in South Africa about their experience of mobility aid provision.	10 children age 8–18 with mobility impairments, interviews carried out individually, in focus groups, with stories and drawings.	There is a lack of mobility aid devices and the impact of this was reported. Education, play, social interaction, development, and access to services were limited.	Meets criteria; focus is on lack of mobility aids. Play is one subtheme discussed by children.
Miller and Reid (2003)	Qualitative study with constant comparative analysis of children's experiences of virtual reality play intervention programme.	19 children age 8–13 with cerebral palsy participated. Interviews were carried out with these children who were also participating in a randomized control trial.	Perceived experience of flow reported during play, control, mastery, social acceptance, and physical change were discussed by participants.	Meets criteria; reports children's experiences of a play based intervention study and therefore discussions may present differently to other play experiences.
Mundhenke et al. (2010)	Qualitative study using semistructured interviews to explore everyday activities and social support of children with disabilities in Sweden.	33 children age 7–13 yr with physical, intellectual, or neuro-psychiatric disabilities	Children described themselves as being like any other child but requiring social support from family and friends. Some discussion of everyday activities included sadness due to activities that they could not participate in.	Meets criteria; limited discussion of play, reports from children with physical disabilities are included.
Pollock et al. (1997)	Qualitative study, semistructured interviews exploring the meaning of play for young people with physical disabilities	20 participants age 13–18; 10 with physical disabilities, 10 matched participants in terms of sex and age	Play is fun, enjoyable, and relaxing. There can be overlaps between play and work. Supports and barriers to play, for example, being excluded from joining in because of a disability	Meets criteria; focus is on older children. Some findings are reported retrospectively.
Ripat and Becker (2012)	Qualitative descriptive design to interview children with disabilities and their carers about their experience of playground use	20 participants, children and parents, or caregivers with disabilities; children age 7–15 with physical disabilities.	It is important for children to be able to play in the way they want. Occupational therapists should facilitate access to playground environments.	Meets criteria; member checking of data used for 7 out of 11 participants (Only discussion of playground experiences discusses play and is included.)
Schiariti et al. (2014)	Qualitative study, semi-structured interviews about functioning in relation to the ICF	10 children age 10–16 yr with cerebral palsy participated in interviews; 22 care givers also participated.	Participants raised mobility, self-care, and recreation and leisure as relevant areas of functioning for children with CP.	Meets criteria; findings reporting child's perspectives relating to play are included.
Skär (2002)	Grounded theory study using interviews to explore how children with disabilities perceive their technical aids in play situations.	8 children, ages 6–11 yr participated. All used a medical aid such as wheelchair, splints, and crutches.	Play situations were related to technical aids, the play environment, and assistants or parents.	Meets criteria; grounded theory approach suggesting key relations for the play of children with physical disabilities
Sonday and Gretschel (2016)	Qualitative, collective case study designed to explore the impact of powered mobility on exploratory play for children with physical disabilities	2 children with physical disabilities age 8 and 9 who had received powered mobility 2 yr previously	Powered mobility provided the opportunity for children to become independent explorers of their environments.	Meets criteria; case study approach with clear literature review and discussion; child's perspectives are included.
Spencer-Cavaliere and Watkinson (2010)	Qualitative study using interviews to explore the concept of inclusion in physical activity from the perspective of children with disabilities	11 children the majority with physical disabilities age 8–12 yr (one child with no physical disability and severe asthma)	Inclusion within physical play depended upon gaining entry to play, feeling like a legitimate participant, and having friends	Meets criteria; findings are discussed in relation to the literature; reflexive field diary is used.
Tamm and Skär (2000)	Grounded theory study involving observation and interviews aiming to understand how children with restricted mobility play in different play situations	10 children age 6-12 yr with restricted mobility; medical diagnoses such as cerebral palsy, spinal bifida, and downs syndrome.	Different types of play—play with friends, interactive play, onlooker play, play alone, and play with others; recognizes that adults are often present in play	Meets criteria; strongly applicable to review able to capture the meaning of play from the child's perspective
Young et al. (2007)	Qualitative study using interviews of children with cerebral plays to look at what children thought was the most important in their lives. Part of a larger study—Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE)	28 children age 8–13 yr and 35 parents participated. Children had a range of physical abilities, 3 unable to walk and the other children able to walk with varying levels of aid.	Computers, televisions, books, and toys were important in children's home lives where they were relatively free from rules and constraints. Children's perfect day involved being with friends and family and doing their "own thing."	Meets criteria; limited applicability to the present review; findings discussing play are included.

(Continues)

TABLE 1 (Continued)

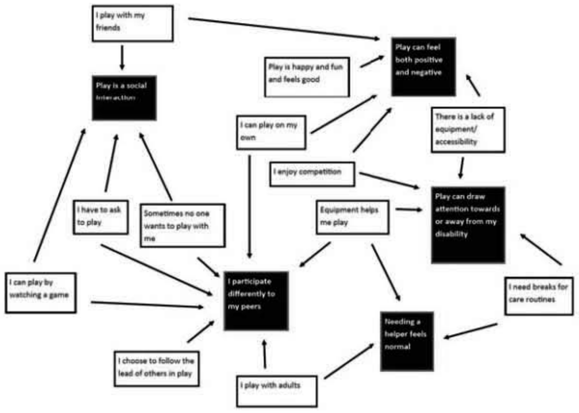

FIGURE 2 Links between descriptive themes and analytical themes [Colour figure can be viewed at wileyonlinelibrary.com]

> *At first they [the other children] thought that I wasn't any good at it. They said, "No, you can't be goalie." Then another guy, who was my friend, said, "Yes, but couldn't he try?!" Child (Mundhenke et al., 2010, p. 135)*

Despite this, when children were included lots of positive emotions were linked to play.

> *And they would let me join in games and that made me feel really, really good and I was all happy and everything. Like sometimes they wouldn't let me join, but sometimes I wasn't okay with it and sometimes I was. Brandon, age 12 (Spencer-Cavaliere & Watkinson, 2010, p. 282)*

> *Well, basically I like most of the games because I like all of them, because they're easy to do and they're fun. That's like, easy for me to do. Vincent age range 8–13 (Miller & Reid, 2003, p. 628)*

3.2.2 | Play can draw attention towards or away from my disability

Playing for children with physical disabilities appeared to have meaning attached to being included with peers and being like everyone else. This appeared to lead to attention being drawn away from the child's disability. The following quote shows how participation in virtual reality means the child stops thinking about their physical disability.

> *You can visualise...all these things like you stopping the winning goal, you scoring the winning point. This is kinda like making a dream come alive. Samuel (Miller & Reid, 2003, p. 629)*

Being with a group of peers known to a child helped to draw attention away from their disability.

> *I hang out more with friends who act like I'm not different. Like, they treat me like I'm the exact same. They treat me... you know, they just don't be like , "oh she has a disability we have to walk slow." They just do it. Girl (Schlarití et al., 2014, p. 858)*

On the other hand, children often spoke about how their disability was made more apparent during play activities. The following quote demonstrates how this happens when groups of children play and one child feels excluded.

> *I watch my friends playing nopentano (form of indigenous skipping using old pantehose) sitting on the floor rug that my mother put outside for me, they talked and laughed together as if I was not there. I sometimes cried when my mother took me inside. (Gcozo & Lorenzo, 2008, p. 19)*

Despite this, for some children, their disability being seen as apparent was positive for their play.

> *They were all cheering for me, "yeah Brandon!" and in kick ball they know I have a disability and they're very cheerful they are like more cheerful for me, they cheer me on, with me, than with the other players. Brandon, age 12 (Spencer-Cavaliere & Watkinson, 2010, p. 285)*

3.2.3 | Play is a social interaction

The importance of play as a social interaction for the children who participated in the study was clear through the way that they referred to play with their friends.

For some, they felt that they missed out on play because they were not able to make friends.

> *I think I was resigned to the fact that I couldn't, for whatever reason, that I couldn't have fun or that I couldn't play or that I didn't have friends. It's only now that I realize how much I've missed. Girl (Pollock et al., 1997, p. 29)*

Being able to participate in play was a shared experience that took place alongside others.

> *Jessica said that being "invited to come and play" would make her feel included because "it makes you feel like they want you to play with them." Jessica, age 12 (Spencer-Cavaliere & Watkinson, 2010, p. 282)*

3.2.4 | I participate differently to my peers

Children with physical disabilities reported how they participate in play in different ways, children emphasized the importance of being able to choose how they played. Children appeared to adapt their play in order that they could join in with their peers.

> *William has strategically self-adapted his play to match his physical capabilities...Carl, like William, finds a way of engaging in peer play that allows him to avoid activities which are difficult and unpleasant but permit him to play with his friends. Researcher's comments for William and Carl, age 10 (Burke, 2012, p.974)*

Children reported participating in play through different means such as watching. This sometimes included more sedentary play like watching the iPad or more active play.

> *...I don't really play at the park because I just want to go home and watch my iPad because I'm more of an inside guy. Um, but, um...that's basically it. Boy, age range 9–12 (Schlarltl et al., 2014, p. 858)*

> *It can be difficult to be in the game so I watch, but I'm still in the game somehow. Child (Tamm & Skär, 2000, p. 178)*

It was also clear that the children had to ask more than their peers as to if they could participate within a play activity.

> *Well, I asked if I could play tag with them, and they said, "no you can't play with us". I went to the teacher, the teacher told the kids to let them play and then I asked after the teacher even said that, and they still said "no, you can't play." Jamie (Spencer-Cavaliere & Watkinson, 2010, p. 282)*

3.2.5 | Needing a helper feels normal

It appeared that many of the studies discussed the need for an adult or assistant to support a child with physical disabilities to participate in play. Facilitation was often needed due to difficulties with physical manipulation (Buchanan, 2009) and access to play (Tamm & Skär, 2000). The need for help was sometimes seen as normal. It appeared that for some children a parent or assistant at school became a friend and playmate.

> *She (the personal assistant) is my pal. Yes, she's actually with me always. Child (Tamm & Skär, 2000, p. 179)*

Once we (he and the assistant) built a railway. Boy, age 6 (Skär, 2002, p. 31)

One further important aspect of children needing a helper within play is that they often directed others to carry out the play where they were not physically able to do so.

> *Corey participated in and contributed to this form of play (pretend play) with signing and by directing his mother to incorporate signs or actions in the songs. Researcher (Buchanan, 2009, p. 276).*

4 | DISCUSSION

This thematic synthesis identified five analytical themes exploring the meaning of play for children and young people with physical

disabilities. There are some similarities to review of Powrie et al. (2015) of the meaning of leisure which was summarized to be *fun, freedom, fulfilment*, and *friendship* (p. 1). Despite this, the themes captured here would suggest that specific play experience is different to the broad experience of leisure. Although positive emotion and friendship are a part of play, the current findings also highlight different experiences of disability, understanding difference, and normalization of help which also occur.

Although play is often described as an activity encompassing fun and enjoyment (Pollock et al., 1997), it is also recognized to be an activity which can incorporate serious and solemn emotions (Sheridan et al., 2011). This review highlights that children and young people with disabilities appear to report greater levels of frustration with play experiences due to exclusion from peers (Spencer-Cavaliere & Watkinson, 2010; Tamm & Skär, 2000). This level of exclusion and negative emotion contrasts to the play of typically developing children, which is usually described as fun and enjoyable (Wing, 1995). It is possible that this leads to children experiencing greater levels of fun and enjoyment when they participate in a play activity that is of value to them. This can be illustrated in the quotes described within the findings section above, such as "that made me feel really, really good" (Spencer-Cavaliere & Watkinson, 2010, p. 282), where children's play experience may be felt with heightened emotion in comparison to their typically developing peers. Further research is needed to ascertain levels of frustration and enjoyment within the play of children with physical disabilities.

The findings suggest that sometimes when engaged within play children do not focus upon their disability, particularly when peers were accommodating. This is an area which requires further research into the perception of disability from the point of view of the player during a play activity. Csikszentmihalyi and Bennett's (1971) theory of play as an activity in which one experiences flow from one action to another could help explain this. If a child with a disability experiences flow within play this may detract from them also thinking about or feeling their disability.

In contrast to this, some of the studies suggested that within play attention is drawn to a child's disability. This was experienced in both a positive and negative light but highlights the impact of physical disability on the meaning of play. Again, the impact of this is upon children with disabilities is not discussed within the literature and is important to explore.

Play as a social interaction is common to both typically developing children and children with disabilities in their understanding of play. Play alongside others is seen as reported as meaningful for typically developing children (Howard et al., 2006; Turnbull & Jenvey, 2006). The current review echoes this, suggesting that children with physical disabilities place similar value on social interaction. This is highlighted in reports of play with peers increasing a sense of inclusion (Spencer-Cavaliere & Watkinson, 2010). Literature suggests that parents of children with disabilities go through a process of normalization in coming to terms with their child's disability (Håkstad, Obstfelder, & Øberg, 2015). However, there currently appears to be little research addressing children's journey of making sense of a physical disability. It appears that being like everyone else in play can be a way in which children develop their identity and sense of self (Tamm & Skär, 2000). This is an important area for future research where play for children with physical disabilities may differ from typically developing children if they are using this to explore and develop their sense of self.

The findings suggest that children participate in play differently to their peers. The idea that an individual can be engaged in an activity without fully participating physically (Polatajko et al., 2007) is reflected within studies exploring how children engage in play vicariously, through communication and through therapy (Graham, Truman, & Holgate, 2014). The idea of adaptation enabling participation is common within occupational therapy practice (Campbell, Milbourne, & Wilcox, 2008). This appears to be a value reflected by children with physical disabilities on a subconscious level, in which they participate in play, a meaningful everyday occupation (Chiarello et al., 2006), in any way possible. The manner in which children participate differently needs further exploration.

Children were found to often feel the presence of a helper was a normal part of their play. This contrasts to the view of typically developing children who reported an activity to be more like play with no adult present (Howard, 2002; McInnes et al., 2009). The need for an adult to be a play partner for children with physical disabilities is frequently referred to (Buchanan, 2009; Graham, Truman, & Holgate, 2015; Hewitt-Taylor, 2009; Skär, 2002; Spencer-Cavaliere & Watkinson, 2010). Despite this, the impact of the presence of an adult on the experience of play is not adequately explored. As discussed within Tamm and Skär's (2000) study, it is possible that the adult can become a barrier to other children playing with those who have physical disabilities because, as observations suggest, the adult may take over the game. They raise concerns this may increase children's dependability upon adults (Tamm & Skär, 2000). As play provides opportunity for mastery and motivation (Shikako-Thomas et al., 2013), and is often defined by its freedom and choice (Neumann, 1971), it can be considered important that adults should follow the child's lead in play experience. This is reflected by parents interviewed by Buchanan (2009), who strongly emphasized following the lead of their child. If adults do not follow the child's lead, it is possible that the meaning of the play experience of a child with physical disabilities will be very different to a typically developing child who has not needed the support of an adult.

4.1 | Limitations

The synthesis of qualitative research studies is questioned due to the influence of the researcher, particularly when using research from a variety of contexts (Bearman & Dawson, 2013; Thomas & Harden, 2008). Despite this, it is argued that helpful contributions can be made if the researchers stance and synthesis process are reported with transparency (Bearman & Dawson, 2013), this review has endeavoured to do this.

In order to gain a wide sample of studies relevant to the review, some involve observations made by the researchers alongside child report. This is helpful to some extent in gaining some understanding of the meaning of play for children with physical disabilities; however, it is limited in that it is not purely from the perspective of the child. It is recognized that the meaning of play varies according to the perspective of the player (Reilly, 1974; Sheridan et al., 2011). Further research should therefore take place from the perspective of children and young people with physical disabilities in order to develop an understanding from their perspective about the meaning of play.

5 | CONCLUSION

The current synthesis has highlighted the potential for play experiences of individuals with disabilities being overlooked by parents, carers, and professionals. The influence of peer and carer perceptions on children and young people's experiences is highlighted clearly within the analytical themes. This has implications for the recognition and value placed on play within early childhood settings, schools, communities, and healthcare settings, for children with disabilities. A greater recognition of a biopsychosocial perspective of disability is needed in order that the participation of children and young people with disabilities is not just seen through a medical lens (focusing on impairment) or a social lens (focusing on social context). It is imperative that further research is undertaken to capture the experience of play, an important primary occupation, from the perspective of children with physical disabilities. This will enable communities to learn to value and recognize each child's experience, allowing them to express their play rather than be viewed with a perspective of limitation.

CONFLICT OF INTERESTS

None to declare.

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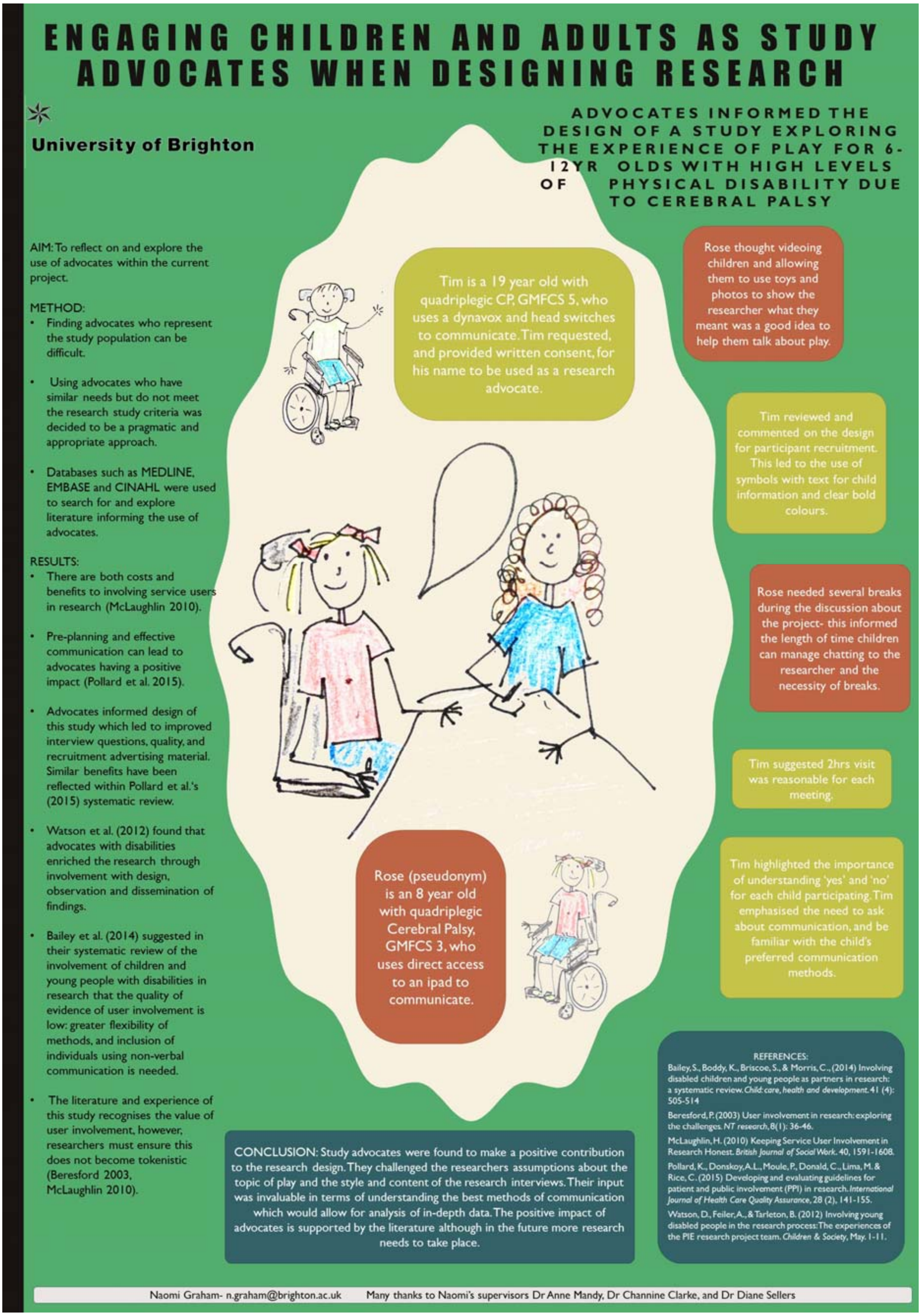
9.2. Appendix 2- Engaging children and adults as advocates when designing research, Poster presentation

Graham, N., Mandy, A., Clarke, C., Sellers, D., (2016b) *Engaging children and adults as study advocates when designing research.* Poster presented at: 28th Annual European Academy of Childhood Disability Meeting, Stockholm.



ENGAGING CHILDREN AND ADULTS AS STUDY ADVOCATES WHEN DESIGNING RESEARCH

University of Brighton

ADVOCATES INFORMED THE DESIGN OF A STUDY EXPLORING THE EXPERIENCE OF PLAY FOR 6-12YR OLDS WITH HIGH LEVELS OF PHYSICAL DISABILITY DUE TO CEREBRAL PALSY

AIM: To reflect on and explore the use of advocates within the current project.

METHOD:
- Finding advocates who represent the study population can be difficult.
- Using advocates who have similar needs but do not meet the research study criteria was decided to be a pragmatic and appropriate approach.
- Databases such as MEDLINE, EMBASE and CINAHL were used to search for and explore literature informing the use of advocates.

RESULTS:
- There are both costs and benefits to involving service users in research (McLaughlin 2010).
- Pre-planning and effective communication can lead to advocates having a positive impact (Pollard et al. 2015).
- Advocates informed design of this study which led to improved interview questions, quality, and recruitment advertising material. Similar benefits have been reflected within Pollard et al.'s (2015) systematic review.
- Watson et al. (2012) found that advocates with disabilities enriched the research through involvement with design, observation and dissemination of findings.
- Bailey et al. (2014) suggested in their systematic review of the involvement of children and young people with disabilities in research that the quality of evidence of user involvement is low: greater flexibility of methods, and inclusion of individuals using non-verbal communication is needed.
- The literature and experience of this study recognises the value of user involvement, however, researchers must ensure this does not become tokenistic (Beresford 2003, McLaughlin 2010).

Tim is a 19 year old with quadriplegic CP, GMFCS 5, who uses a dynavox and head switches to communicate. Tim requested, and provided written consent, for his name to be used as a research advocate.

Rose thought videoing children and allowing them to use toys and photos to show the researcher what they meant was a good idea to help them talk about play.

Tim reviewed and commented on the design for participant recruitment. This led to the use of symbols with text for child information and clear bold colours.

Rose needed several breaks during the discussion about the project- this informed the length of time children can manage chatting to the researcher and the necessity of breaks.

Tim suggested 2hrs visit was reasonable for each meeting.

Rose (pseudonym) is an 8 year old with quadriplegic Cerebral Palsy, GMFCS 3, who uses direct access to an ipad to communicate.

Tim highlighted the importance of understanding 'yes' and 'no' for each child participating. Tim emphasised the need to ask about communication, and be familiar with the child's preferred communication methods.

CONCLUSION: Study advocates were found to make a positive contribution to the research design. They challenged the researchers assumptions about the topic of play and the style and content of the research interviews. Their input was invaluable in terms of understanding the best methods of communication which would allow for analysis of in-depth data. The positive impact of advocates is supported by the literature although in the future more research needs to take place.

REFERENCES:

Bailey, S., Boddy, K., Briscoe, S., & Morris, C., (2014) Involving disabled children and young people as partners in research: a systematic review. *Child: care, health and development.* 41 (4): 505-514

Beresford, P. (2003) User involvement in research: exploring the challenges. *NT research*, 8(1): 36-46.

McLaughlin, H. (2010) Keeping Service User Involvement in Research Honest. *British Journal of Social Work.* 40, 1591-1608.

Pollard, K., Donskoy, A.L., Moule, P., Donald, C., Lima, M. & Rice, C. (2015) Developing and evaluating guidelines for patient and public involvement (PPI) in research. *International Journal of Health Care Quality Assurance*, 28 (2), 141-155.

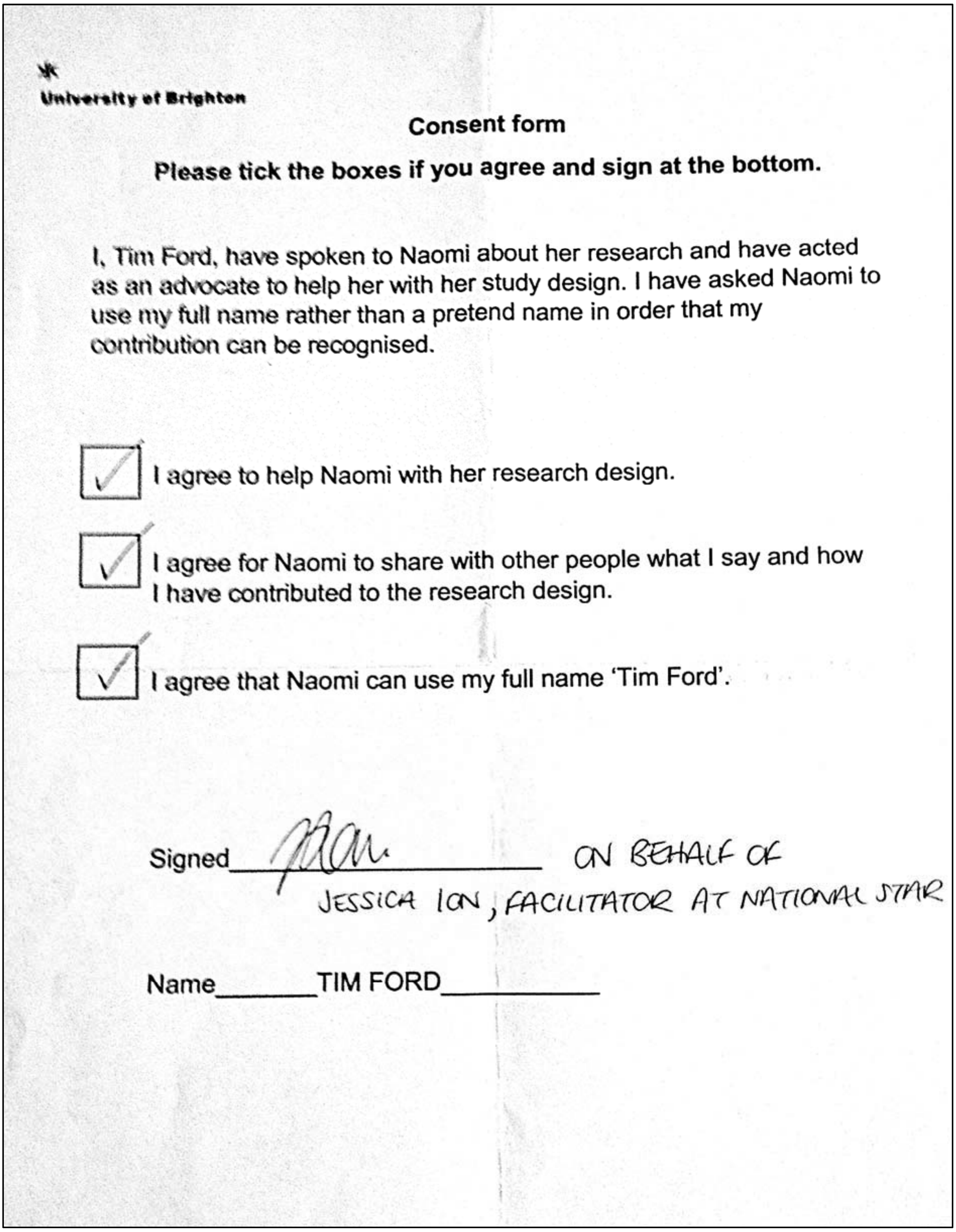
Watson, D., Feiler, A., & Tarleton, B. (2012) Involving young disabled people in the research process: The experiences of the PIE research project team. *Children & Society*, May. 1-11.

Naomi Graham- n.graham@brighton.ac.uk

Many thanks to Naomi's supervisors Dr Anne Mandy, Dr Channine Clarke, and Dr Diane Sellers

ORIGINAL IN COLOUR

9.3. Appendix 3- Tim Ford consent form



University of Brighton

Consent form

Please tick the boxes if you agree and sign at the bottom.

I, Tim Ford, have spoken to Naomi about her research and have acted as an advocate to help her with her study design. I have asked Naomi to use my full name rather than a pretend name in order that my contribution can be recognised.

☑ I agree to help Naomi with her research design.

☑ I agree for Naomi to share with other people what I say and how I have contributed to the research design.

☑ I agree that Naomi can use my full name 'Tim Ford'.

Signed____________________ ON BEHALF OF JESSICA ION, FACILITATOR AT NATIONAL STAR

Name_______TIM FORD___________

9.4. Appendix 4- Participant and parent recruitment flyers

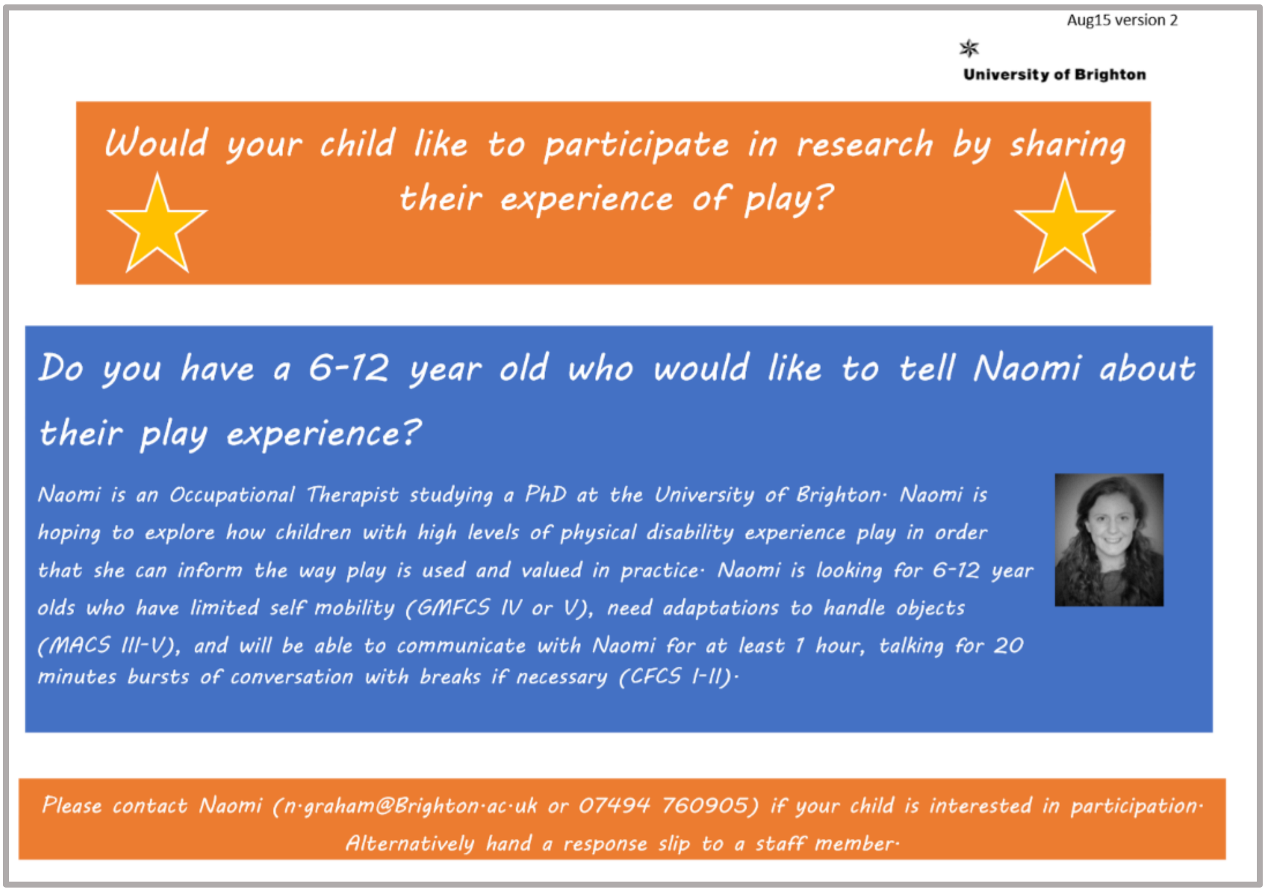
University of Brighton

Aug15 version 2

What do you feel and say about play?

Naomi would like to ask you as part of a research project.

Please contact her on: 07494 760905 Or n.graham@brighton.ac.uk



Aug15 version 2

University of Brighton

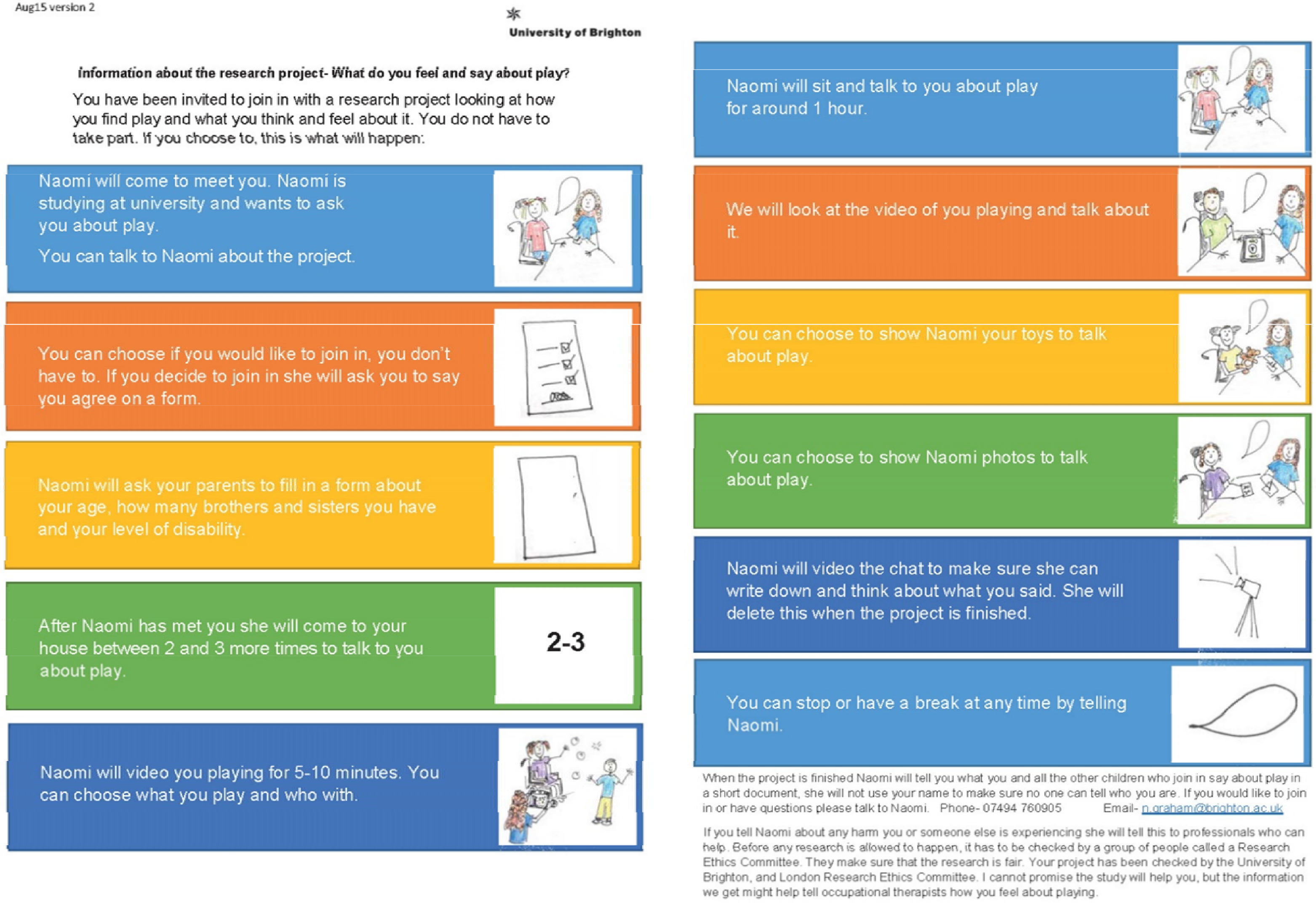
Would your child like to participate in research by sharing their experience of play?

Do you have a 6-12 year old who would like to tell Naomi about their play experience?

Naomi is an Occupational Therapist studying a PhD at the University of Brighton. Naomi is hoping to explore how children with high levels of physical disability experience play in order that she can inform the way play is used and valued in practice. Naomi is looking for 6-12 year olds who have limited self mobility (GMFCS IV or V), need adaptations to handle objects (MACS III-V), and will be able to communicate with Naomi for at least 1 hour, talking for 20 minutes bursts of conversation with breaks if necessary (CFCS I-II).

Please contact Naomi (n.graham@Brighton.ac.uk or 07494 760905) if your child is interested in participation. Alternatively hand a response slip to a staff member.

9.5. Appendix 5- Participant information sheet



Aug15 version 2

University of Brighton

Information about the research project- What do you feel and say about play?

You have been invited to join in with a research project looking at how you find play and what you think and feel about it. You do not have to take part. If you choose to, this is what will happen:

Naomi will come to meet you. Naomi is studying at university and wants to ask you about play.

You can talk to Naomi about the project.

You can choose if you would like to join in, you don't have to. If you decide to join in she will ask you to say you agree on a form.

Naomi will ask your parents to fill in a form about your age, how many brothers and sisters you have and your level of disability.

After Naomi has met you she will come to your house between 2 and 3 more times to talk to you about play.

2-3

Naomi will video you playing for 5-10 minutes. You can choose what you play and who with.

Naomi will sit and talk to you about play for around 1 hour.

We will look at the video of you playing and talk about it.

You can choose to show Naomi your toys to talk about play.

You can choose to show Naomi photos to talk about play.

Naomi will video the chat to make sure she can write down and think about what you said. She will delete this when the project is finished.

You can stop or have a break at any time by telling Naomi.

When the project is finished Naomi will tell you what you and all the other children who join in say about play in a short document, she will not use your name to make sure no one can tell who you are. If you would like to join in or have questions please talk to Naomi. Phone- 07494 760905 Email- n.graham@brighton.ac.uk

If you tell Naomi about any harm you or someone else is experiencing she will tell this to professionals who can help. Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the University of Brighton, and London Research Ethics Committee. I cannot promise the study will help you, but the information we get might help tell occupational therapists how you feel about playing.

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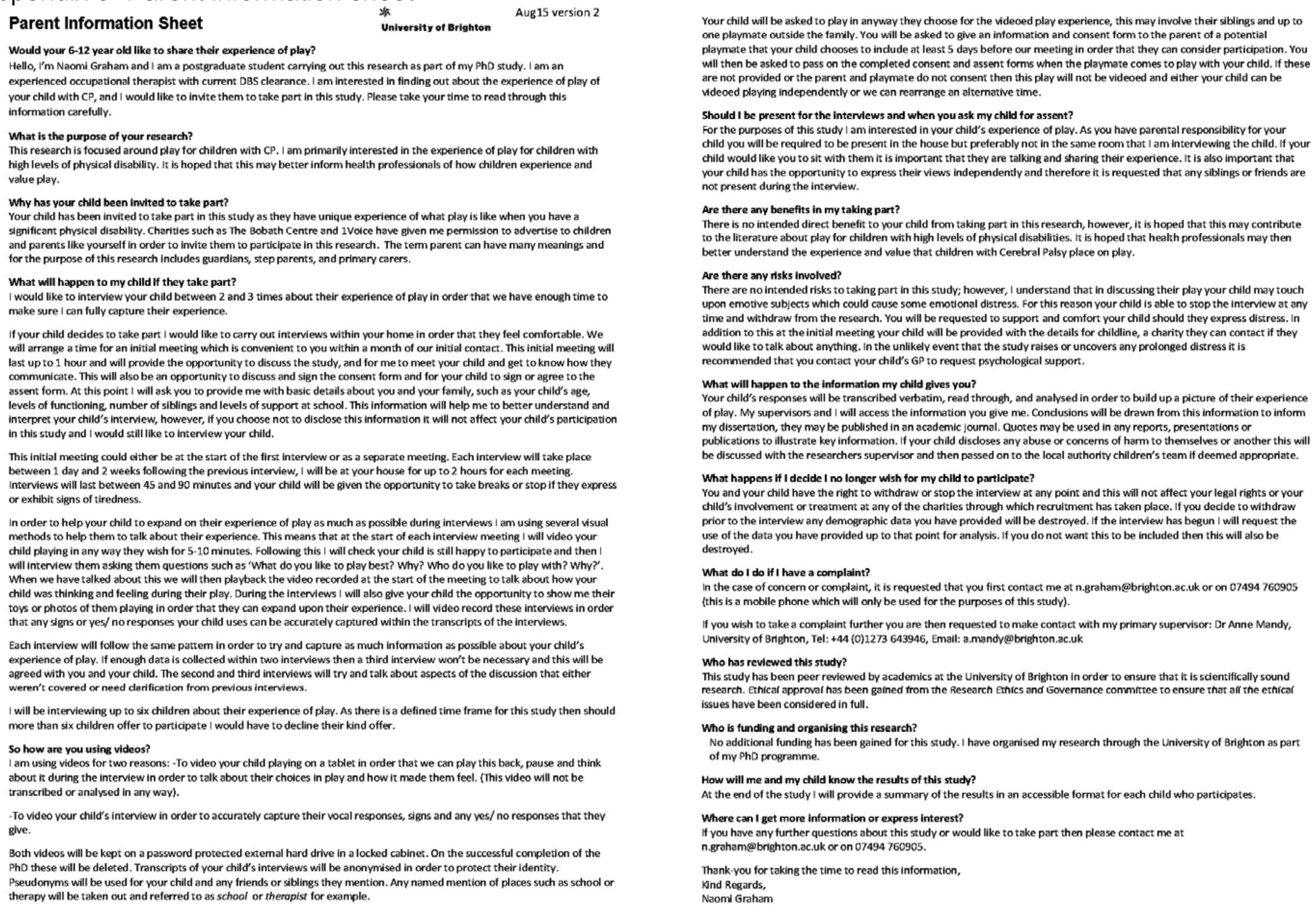
9.6. Appendix 6- Parent information sheet



Parent Information Sheet

University of Brighton

Aug15 version 2

Would your 6-12 year old like to share their experience of play?
Hello, I'm Naomi Graham and I am a postgraduate student carrying out this research as part of my PhD study. I am an experienced occupational therapist with current DBS clearance. I am interested in finding out about the experience of play of your child with CP, and I would like to invite them to take part in this study. Please take your time to read through this information carefully.

What is the purpose of your research?
This research is focused around play for children with CP. I am primarily interested in the experience of play for children with high levels of physical disability. It is hoped that this may better inform health professionals of how children experience and value play.

Why has your child been invited to take part?
Your child has been invited to take part in this study as they have unique experience of what play is like when you have a significant physical disability. Charities such as The Bobath Centre and 1Voice have given me permission to advertise to children and parents like yourself in order to invite them to participate in this research. The term parent can have many meanings and for the purpose of this research includes guardians, step parents, and primary carers.

What will happen to my child if they take part?
I would like to interview your child between 2 and 3 times about their experience of play in order that we have enough time to make sure I can fully capture their experience.

If your child decides to take part I would like to carry out interviews within your home in order that they feel comfortable. We will arrange a time for an initial meeting which is convenient to you within a month of our initial contact. This initial meeting will last up to 1 hour and will provide the opportunity to discuss the study, and for me to meet your child and get to know how they communicate. This will also be an opportunity to discuss and sign the consent form and for your child to sign or agree to the assent form. At this point I will ask you to provide me with basic details about you and your family, such as your child's age, levels of functioning, number of siblings and levels of support at school. This information will help me to better understand and interpret your child's interview, however, if you choose not to disclose this information it will not affect your child's participation in this study and I would still like to interview your child.

This initial meeting could either be at the start of the first interview or as a separate meeting. Each interview will take place between 1 day and 2 weeks following the previous interview, I will be at your house for up to 2 hours for each meeting. Interviews will last between 45 and 90 minutes and your child will be given the opportunity to take breaks or stop if they express or exhibit signs of tiredness.

In order to help your child to expand on their experience of play as much as possible during interviews I am using several visual methods to help them to talk about their experience. This means that at the start of each interview meeting I will video your child playing in any way they wish for 5-10 minutes. Following this I will check your child is still happy to participate and then I will interview them asking them questions such as 'What do you like to play best? Why? Who do you like to play with? Why?'. When we have talked about this we will then playback the video recorded at the start of the meeting to talk about how your child was thinking and feeling during their play. During the interviews I will also give your child the opportunity to show me their toys or photos of them playing in order that they can expand upon their experience. I will video record these interviews in order that any signs or yes/ no responses your child uses can be accurately captured within the transcripts of the interviews.

Each interview will follow the same pattern in order to try and capture as much information as possible about your child's experience of play. If enough data is collected within two interviews then a third interview won't be necessary and this will be agreed with you and your child. The second and third interviews will try and talk about aspects of the discussion that either weren't covered or need clarification from previous interviews.

I will be interviewing up to six children about their experience of play. As there is a defined time frame for this study then should more than six children offer to participate I would have to decline their kind offer.

So how are you using videos?
I am using videos for two reasons: -To video your child playing on a tablet in order that we can play this back, pause and think about it during the interview in order to talk about their choices in play and how it made them feel. (This video will not be transcribed or analysed in any way).

-To video your child's interview in order to accurately capture their vocal responses, signs and any yes/ no responses that they give.

Both videos will be kept on a password protected external hard drive in a locked cabinet. On the successful completion of the PhD these will be deleted. Transcripts of your child's interviews will be anonymised in order to protect their identity. Pseudonyms will be used for your child and any friends or siblings they mention. Any named mention of places such as school or therapy will be taken out and referred to as *school* or *therapist* for example.

Your child will be asked to play in anyway they choose for the videoed play experience, this may involve their siblings and up to one playmate outside the family. You will be asked to give an information and consent form to the parent of a potential playmate that your child chooses to include at least 5 days before our meeting in order that they can consider participation. You will then be asked to pass on the completed consent and assent forms when the playmate comes to play with your child. If these are not provided or the parent and playmate do not consent then this play will not be videoed and either your child can be videoed playing independently or we can rearrange an alternative time.

Should I be present for the interviews and when you ask my child for assent?
For the purposes of this study I am interested in your child's experience of play. As you have parental responsibility for your child you will be required to be present in the house but preferably not in the same room that I am interviewing the child. If your child would like you to sit with them it is important that they are talking and sharing their experience. It is also important that your child has the opportunity to express their views independently and therefore it is requested that any siblings or friends are not present during the interview.

Are there any benefits in my taking part?
There is no intended direct benefit to your child from taking part in this research, however, it is hoped that this may contribute to the literature about play for children with high levels of physical disabilities. It is hoped that health professionals may then better understand the experience and value that children with Cerebral Palsy place on play.

Are there any risks involved?
There are no intended risks to taking part in this study; however, I understand that in discussing their play your child may touch upon emotive subjects which could cause some emotional distress. For this reason your child is able to stop the interview at any time and withdraw from the research. You will be requested to support and comfort your child should they express distress. In addition to this at the initial meeting your child will be provided with the details for childline, a charity they can contact if they would like to talk about anything. In the unlikely event that the study raises or uncovers any prolonged distress it is recommended that you contact your child's GP to request psychological support.

What will happen to the information my child gives you?
Your child's responses will be transcribed verbatim, read through, and analysed in order to build up a picture of their experience of play. My supervisors and I will access the information you give me. Conclusions will be drawn from this information to inform my dissertation, they may be published in an academic journal. Quotes may be used in any reports, presentations or publications to illustrate key information. If your child discloses any abuse or concerns of harm to themselves or another this will be discussed with the researchers supervisor and then passed on to the local authority children's team if deemed appropriate.

What happens if I decide I no longer wish for my child to participate?
You and your child have the right to withdraw or stop the interview at any point and this will not affect your legal rights or your child's involvement or treatment at any of the charities through which recruitment has taken place. If you decide to withdraw prior to the interview any demographic data you have provided will be destroyed. If the interview has begun I will request the use of the data you have provided up to that point for analysis. If you do not want this to be included then this will also be destroyed.

What do I do if I have a complaint?
In the case of concern or complaint, it is requested that you first contact me at n.graham@brighton.ac.uk or on 07494 760905 (this is a mobile phone which will only be used for the purposes of this study).

If you wish to take a complaint further you are then requested to make contact with my primary supervisor: Dr Anne Mandy, University of Brighton, Tel: +44 (0)1273 643946, Email: a.mandy@brighton.ac.uk

Who has reviewed this study?
This study has been peer reviewed by academics at the University of Brighton in order to ensure that it is scientifically sound research. Ethical approval has been gained from the Research Ethics and Governance committee to ensure that all the ethical issues have been considered in full.

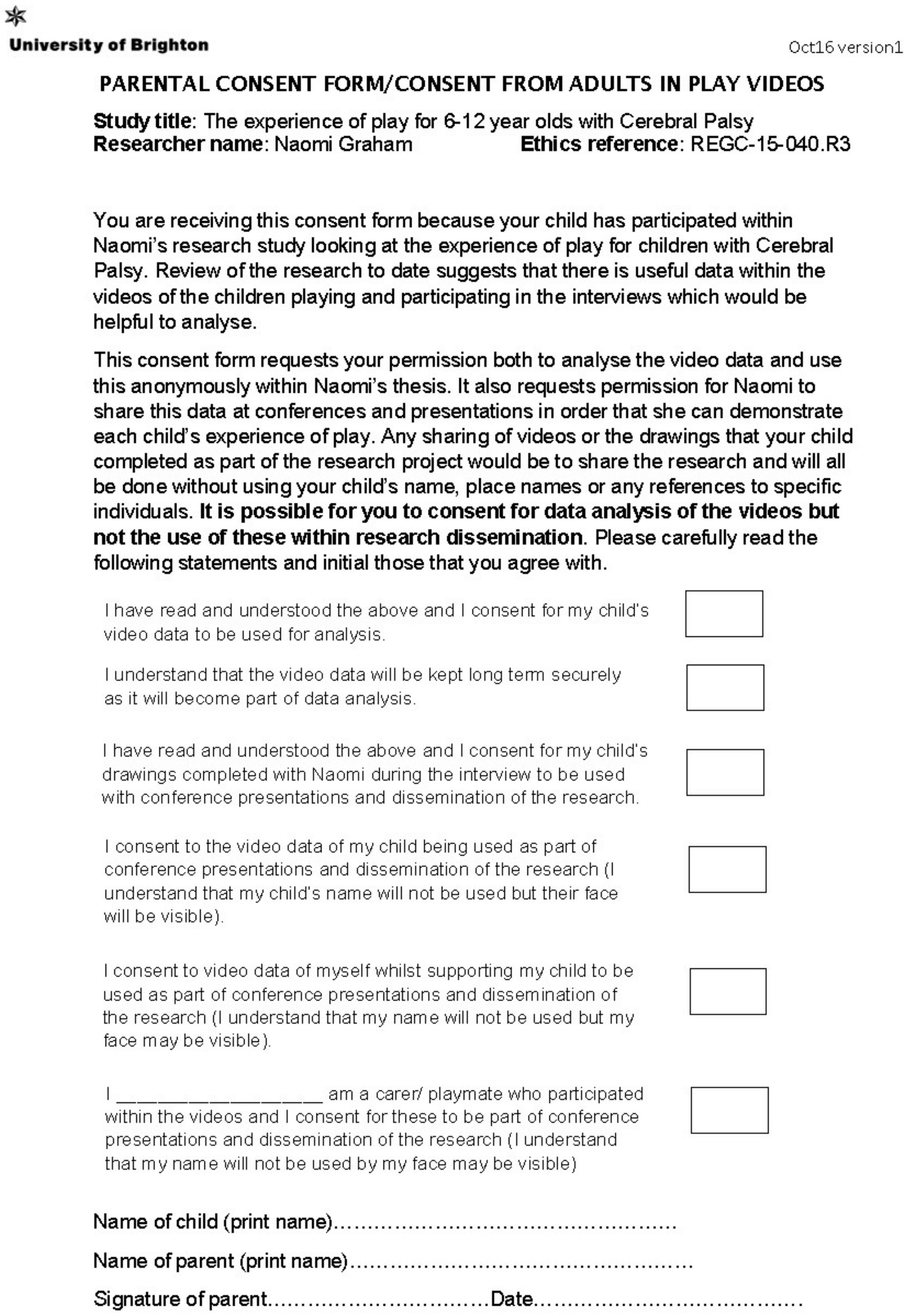
Who is funding and organising this research?
No additional funding has been gained for this study. I have organised my research through the University of Brighton as part of my PhD programme.

How will me and my child know the results of this study?
At the end of the study I will provide a summary of the results in an accessible format for each child who participates.

Where can I get more information or express interest?
If you have any further questions about this study or would like to take part then please contact me at n.graham@brighton.ac.uk or on 07494 760905.

Thank-you for taking the time to read this information,
Kind Regards,
Naomi Graham

9.7. Appendix 7- Parental consent form



University of Brighton

Oct16 version1

PARENTAL CONSENT FORM/CONSENT FROM ADULTS IN PLAY VIDEOS

Study title: The experience of play for 6-12 year olds with Cerebral Palsy
Researcher name: Naomi Graham **Ethics reference**: REGC-15-040.R3

You are receiving this consent form because your child has participated within Naomi's research study looking at the experience of play for children with Cerebral Palsy. Review of the research to date suggests that there is useful data within the videos of the children playing and participating in the interviews which would be helpful to analyse.

This consent form requests your permission both to analyse the video data and use this anonymously within Naomi's thesis. It also requests permission for Naomi to share this data at conferences and presentations in order that she can demonstrate each child's experience of play. Any sharing of videos or the drawings that your child completed as part of the research project would be to share the research and will all be done without using your child's name, place names or any references to specific individuals. **It is possible for you to consent for data analysis of the videos but not the use of these within research dissemination**. Please carefully read the following statements and initial those that you agree with.

I have read and understood the above and I consent for my child's video data to be used for analysis. ☐

I understand that the video data will be kept long term securely as it will become part of data analysis. ☐

I have read and understood the above and I consent for my child's drawings completed with Naomi during the interview to be used with conference presentations and dissemination of the research. ☐

I consent to the video data of my child being used as part of conference presentations and dissemination of the research (I understand that my child's name will not be used but their face will be visible). ☐

I consent to video data of myself whilst supporting my child to be used as part of conference presentations and dissemination of the research (I understand that my name will not be used but my face may be visible). ☐

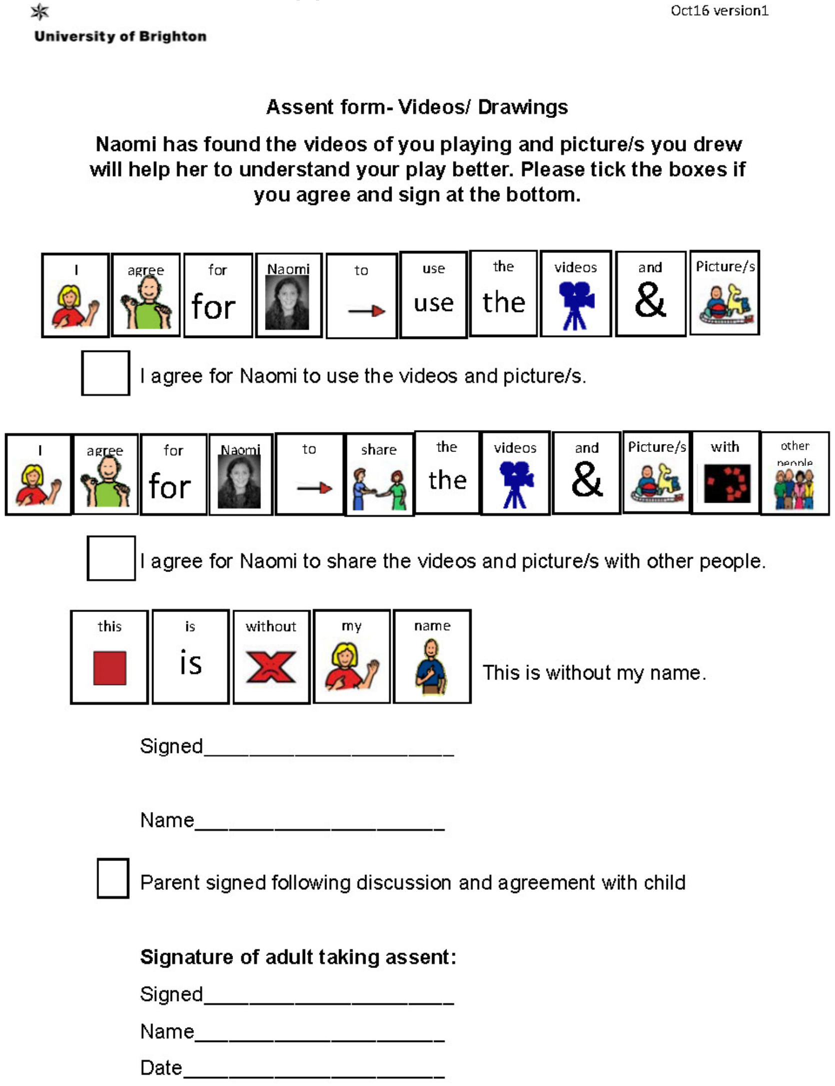
I ___________________ am a carer/ playmate who participated within the videos and I consent for these to be part of conference presentations and dissemination of the research (I understand that my name will not be used by my face may be visible) ☐

Name of child (print name)…………………………………………….

Name of parent (print name)…………………………………………….

Signature of parent……………………………Date………………………………….

9.11. Appendix 11- Additional consent form for use of videos



University of Brighton

Oct16 version1

Assent form- Videos/ Drawings

Naomi has found the videos of you playing and picture/s you drew will help her to understand your play better. Please tick the boxes if you agree and sign at the bottom.

I agree for Naomi to use the videos and picture/s

☐ I agree for Naomi to use the videos and picture/s.

I agree for Naomi to share the videos and picture/s with other people

☐ I agree for Naomi to share the videos and picture/s with other people.

this is without my name

This is without my name.

Signed______________________

Name______________________

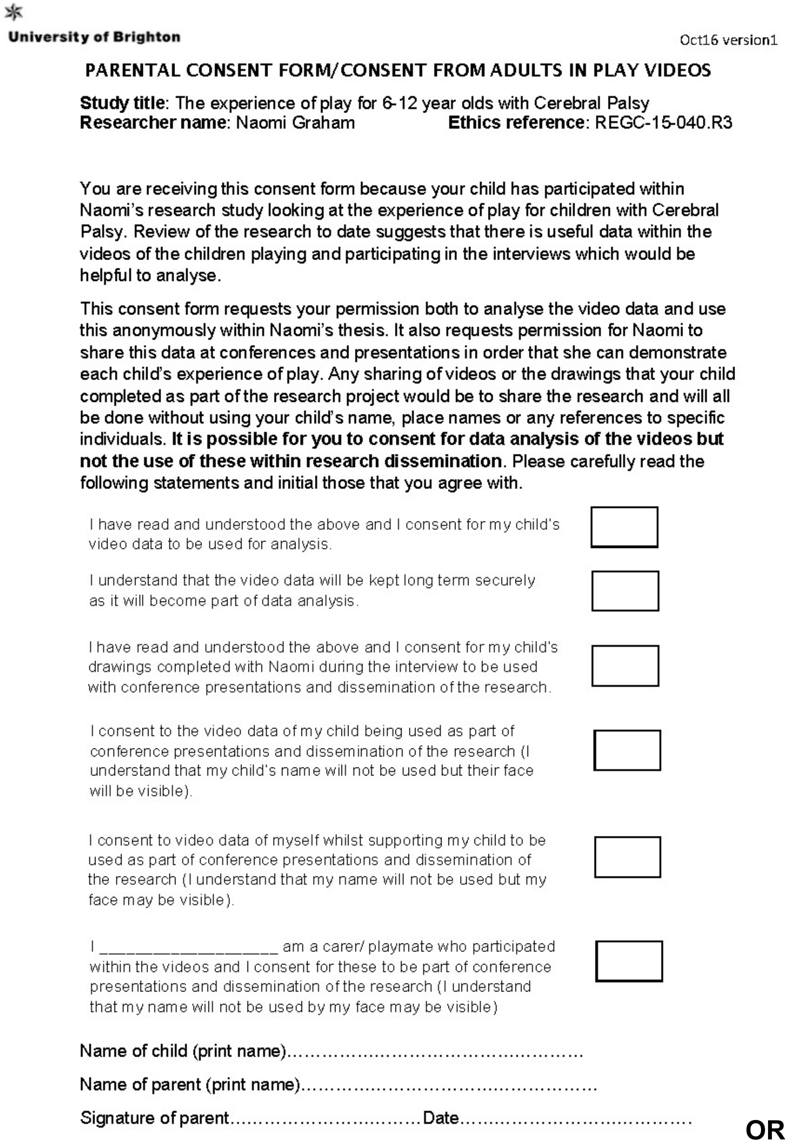
☐ Parent signed following discussion and agreement with child

Signature of adult taking assent:

Signed______________________

Name______________________

Date_______________________



University of Brighton

Oct16 version1

PARENTAL CONSENT FORM/CONSENT FROM ADULTS IN PLAY VIDEOS

Study title: The experience of play for 6-12 year olds with Cerebral Palsy
Researcher name: Naomi Graham **Ethics reference**: REGC-15-040.R3

You are receiving this consent form because your child has participated within Naomi's research study looking at the experience of play for children with Cerebral Palsy. Review of the research to date suggests that there is useful data within the videos of the children playing and participating in the interviews which would be helpful to analyse.

This consent form requests your permission both to analyse the video data and use this anonymously within Naomi's thesis. It also requests permission for Naomi to share this data at conferences and presentations in order that she can demonstrate each child's experience of play. Any sharing of videos or the drawings that your child completed as part of the research project would be to share the research and will all be done without using your child's name, place names or any references to specific individuals. **It is possible for you to consent for data analysis of the videos but not the use of these within research dissemination**. Please carefully read the following statements and initial those that you agree with.

I have read and understood the above and I consent for my child's video data to be used for analysis.	☐
I understand that the video data will be kept long term securely as it will become part of data analysis.	☐
I have read and understood the above and I consent for my child's drawings completed with Naomi during the interview to be used with conference presentations and dissemination of the research.	☐
I consent to the video data of my child being used as part of conference presentations and dissemination of the research (I understand that my child's name will not be used but their face will be visible).	☐
I consent to video data of myself whilst supporting my child to be used as part of conference presentations and dissemination of the research (I understand that my name will not be used but my face may be visible).	☐
I __________________ am a carer/ playmate who participated within the videos and I consent for these to be part of conference presentations and dissemination of the research (I understand that my name will not be used by my face may be visible)	☐

Name of child (print name)……………………………………………

Name of parent (print name)……………………………………………

Signature of parent……………………………Date………………………………….

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9.9. Appendix 9- Interview Schedule used as a guide during interviews

How does talking work best for you, do you want me to guess what you're saying or wait until you've finished saying it?

I'd love you to be a bit like a teacher, I would really like to know what's inside your brain and what you think and feel about the things that we chat about. There is lots of time to think and explain what you're thinking.

Please tell me a bit about yourself: what makes you you?
(what does your CP mean to you?)

What's important to you?

Who is important to you?

Please tell me what play means to you?

Please tell me about how it feels to play something that you really love?

Please tell me about how it feels to play something that you do not love as much?

What happens when your body does not move in the way you want it to for playing?

Can you tell me about joining in with other people's games?

When watching the video: Can you tell me what it felt like playing that game?

Can you tell me what you were thinking playing that game?

How does this show me what playing is for you?

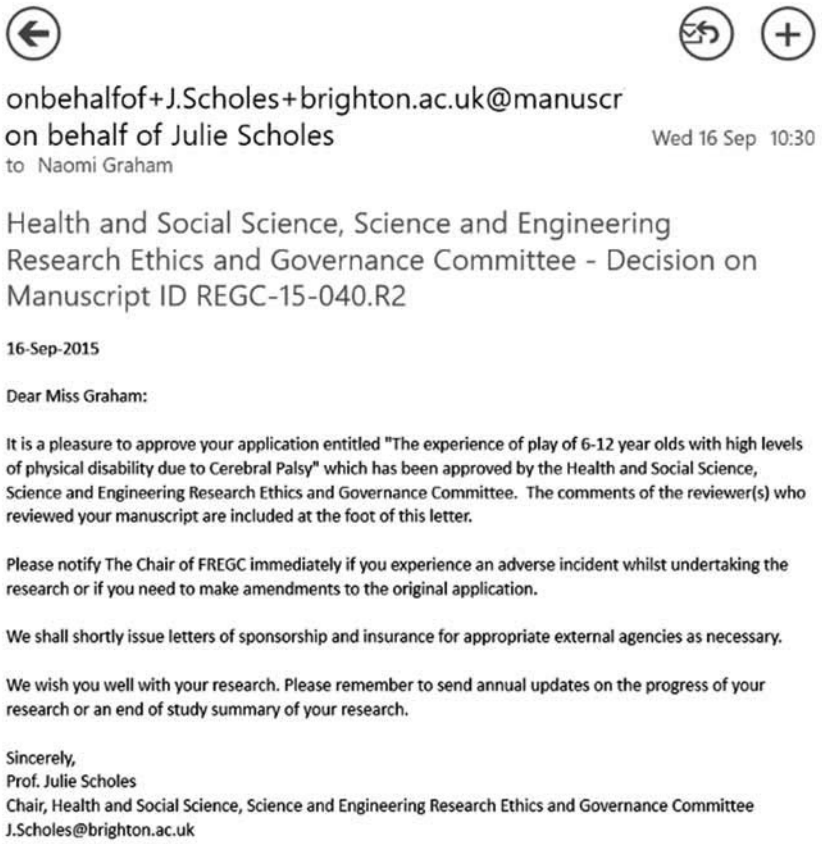
Can you see anything you did not expect in the way you are playing in the video?

Prompts- can you tell me a bit more about that?

How does that feel?

Can you be the teacher and explain what that means?

9.10. Appendix 10- Ethical Approval from the University of Brighton



onbehalfof+J.Scholes+brighton.ac.uk@manuscr
on behalf of Julie Scholes
to Naomi Graham

Wed 16 Sep 10:30

Health and Social Science, Science and Engineering Research Ethics and Governance Committee - Decision on Manuscript ID REGC-15-040.R2

16-Sep-2015

Dear Miss Graham:

It is a pleasure to approve your application entitled "The experience of play of 6-12 year olds with high levels of physical disability due to Cerebral Palsy" which has been approved by the Health and Social Science, Science and Engineering Research Ethics and Governance Committee. The comments of the reviewer(s) who reviewed your manuscript are included at the foot of this letter.

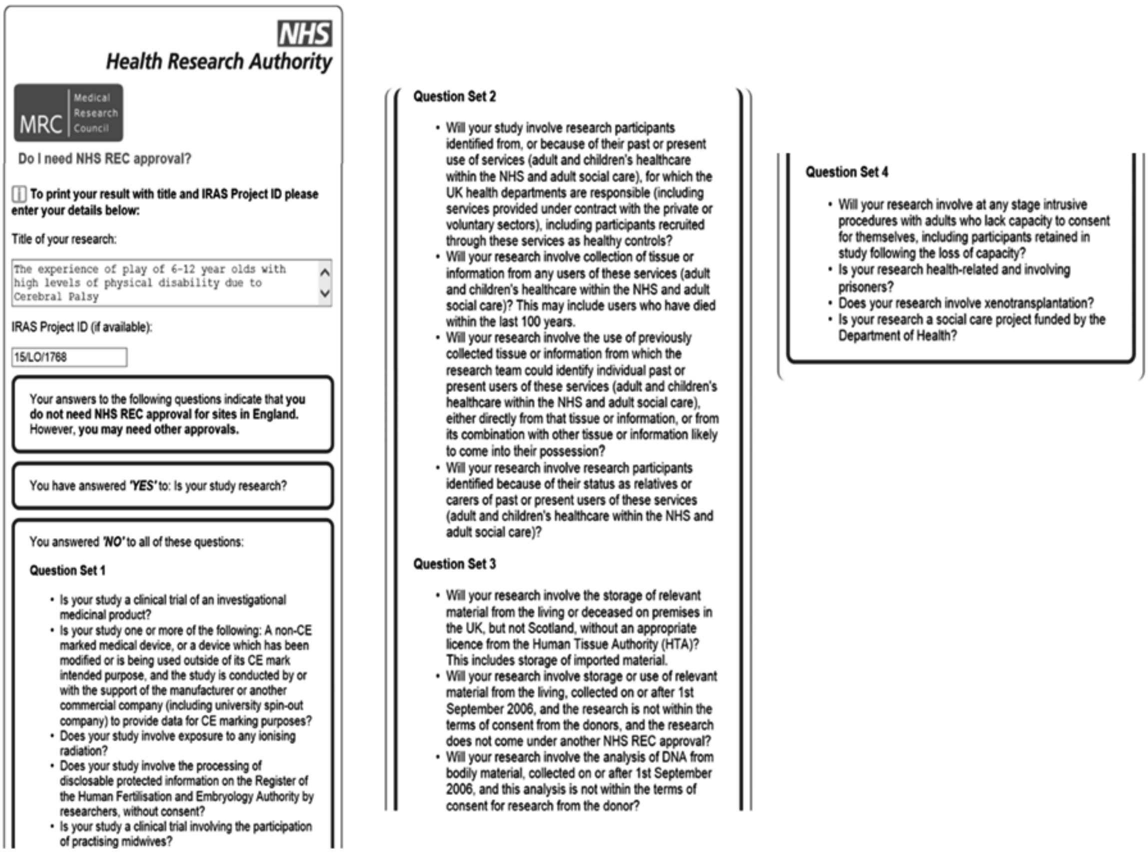
Please notify The Chair of FREGC immediately if you experience an adverse incident whilst undertaking the research or if you need to make amendments to the original application.

We shall shortly issue letters of sponsorship and insurance for appropriate external agencies as necessary.

We wish you well with your research. Please remember to send annual updates on the progress of your research or an end of study summary of your research.

Sincerely,
Prof. Julie Scholes
Chair, Health and Social Science, Science and Engineering Research Ethics and Governance Committee
J.Scholes@brighton.ac.uk

Certificate showing IRAS approval not needed



NHS
Health Research Authority

MRC Medical Research Council

Do I need NHS REC approval?

To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

The experience of play of 6-12 year olds with high levels of physical disability due to Cerebral Palsy

IRAS Project ID (if available):

15/LO/1768

Your answers to the following questions indicate that you **do not need NHS REC approval for sites in England.** However, **you may need other approvals.**

You have answered ***'YES'*** to: Is your study research?

You answered ***'NO'*** to all of these questions:

Question Set 1

- Is your study a clinical trial of an investigational medicinal product?
- Is your study one or more of the following: A non-CE marked medical device, or a device which has been modified or is being used outside of its CE mark intended purpose, and the study is conducted by or with the support of the manufacturer or another commercial company (including university spin-out company) to provide data for CE marking purposes?
- Does your study involve exposure to any ionising radiation?
- Does your study involve the processing of disclosable protected information on the Register of the Human Fertilisation and Embryology Authority by researchers, without consent?
- Is your study a clinical trial involving the participation of practising midwives?

Question Set 2

- Will your study involve research participants identified from, or because of their past or present use of services (adult and children's healthcare within the NHS and adult social care), for which the UK health departments are responsible (including services provided under contract with the private or voluntary sectors), including participants recruited through these services as healthy controls?
- Will your research involve collection of tissue or information from any users of these services (adult and children's healthcare within the NHS and adult social care)? This may include users who have died within the last 100 years.
- Will your research involve the use of previously collected tissue or information from which the research team could identify individual past or present users of these services (adult and children's healthcare within the NHS and adult social care), either directly from that tissue or information, or from its combination with other tissue or information likely to come into their possession?
- Will your research involve research participants identified because of their status as relatives or carers of past or present users of these services (adult and children's healthcare within the NHS and adult social care)?

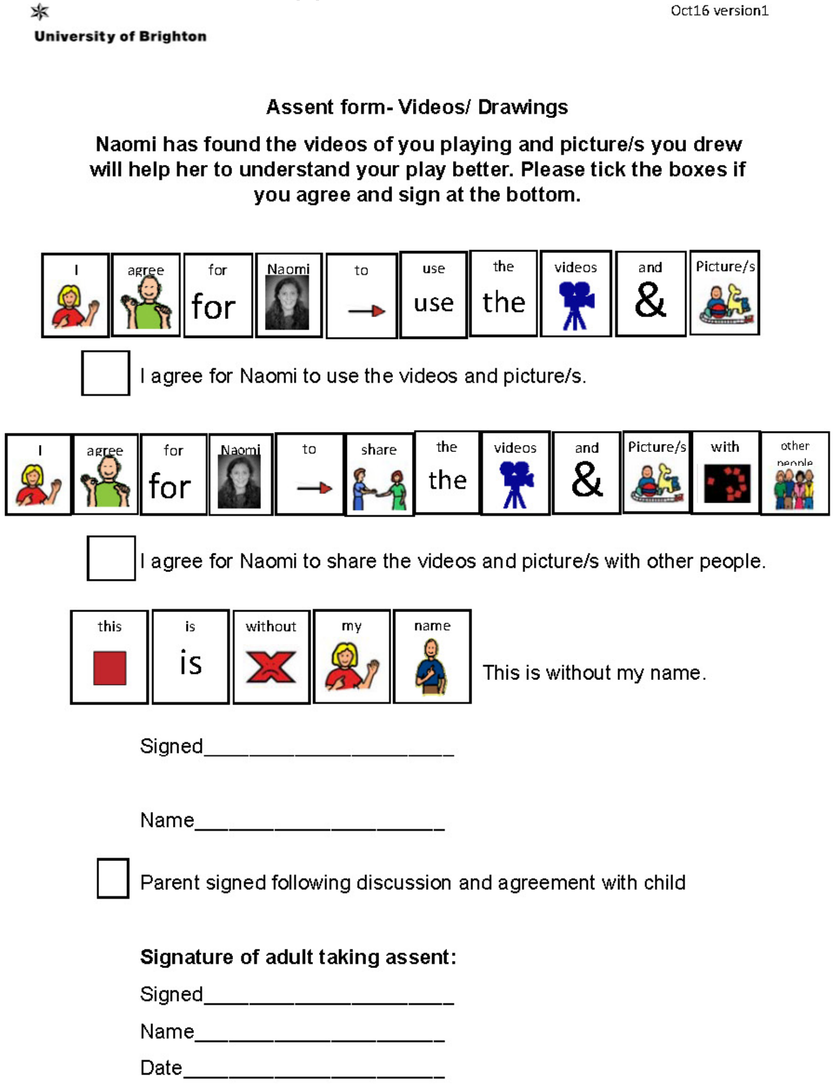
Question Set 3

- Will your research involve the storage of relevant material from the living or deceased on premises in the UK, but not Scotland, without an appropriate licence from the Human Tissue Authority (HTA)? This includes storage of imported material.
- Will your research involve storage or use of relevant material from the living, collected on or after 1st September 2006, and the research is not within the terms of consent from the donors, and the research does not come under another NHS REC approval?
- Will your research involve the analysis of DNA from bodily material, collected on or after 1st September 2006, and this analysis is not within the terms of consent for research from the donor?

Question Set 4

- Will your research involve at any stage intrusive procedures with adults who lack capacity to consent for themselves, including participants retained in study following the loss of capacity?
- Is your research health-related and involving prisoners?
- Does your research involve xenotransplantation?
- Is your research a social care project funded by the Department of Health?

9.11. Appendix 11- Additional consent form for use of videos



University of Brighton

Oct16 version1

Assent form- Videos/ Drawings

Naomi has found the videos of you playing and picture/s you drew will help her to understand your play better. Please tick the boxes if you agree and sign at the bottom.

I agree for Naomi to use the videos and Picture/s

☐ I agree for Naomi to use the videos and picture/s.

I agree for Naomi to share the videos and Picture/s with other people

☐ I agree for Naomi to share the videos and picture/s with other people.

this is without my name

This is without my name.

Signed_____________________

Name_____________________

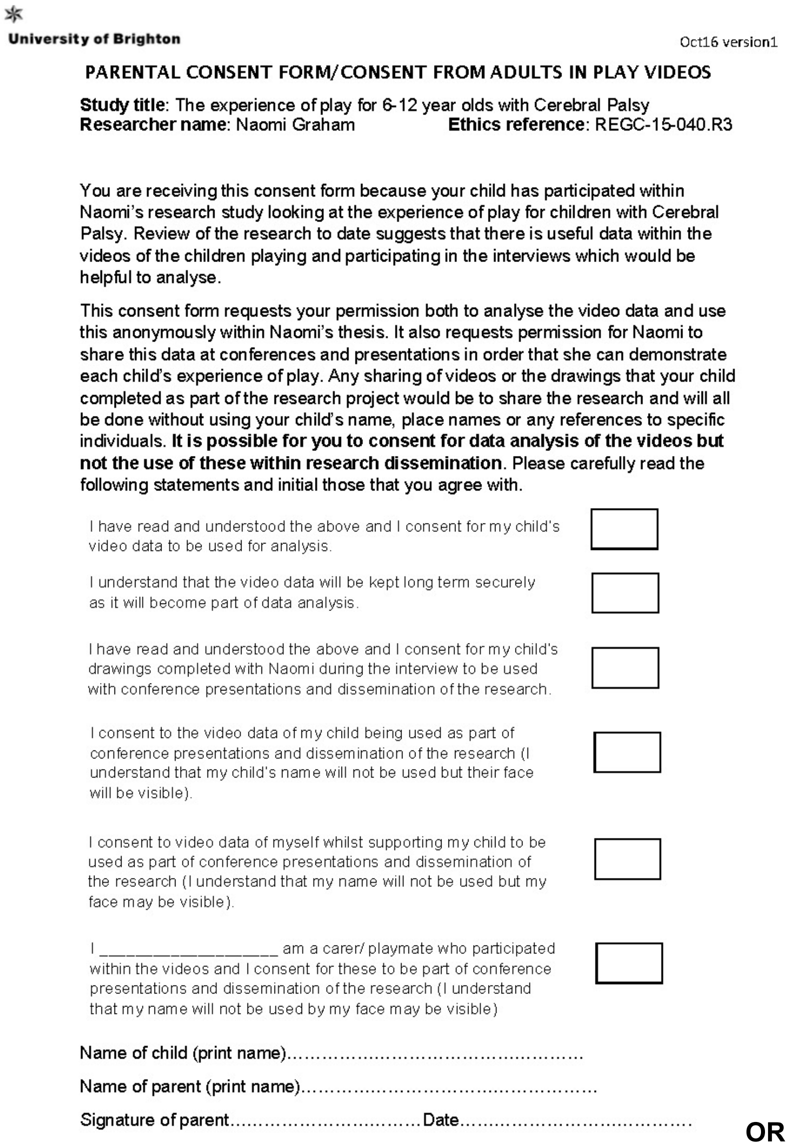
☐ Parent signed following discussion and agreement with child

Signature of adult taking assent:

Signed_____________________

Name_____________________

Date______________________



University of Brighton

Oct16 version1

PARENTAL CONSENT FORM/CONSENT FROM ADULTS IN PLAY VIDEOS

Study title: The experience of play for 6-12 year olds with Cerebral Palsy
Researcher name: Naomi Graham **Ethics reference**: REGC-15-040.R3

You are receiving this consent form because your child has participated within Naomi's research study looking at the experience of play for children with Cerebral Palsy. Review of the research to date suggests that there is useful data within the videos of the children playing and participating in the interviews which would be helpful to analyse.

This consent form requests your permission both to analyse the video data and use this anonymously within Naomi's thesis. It also requests permission for Naomi to share this data at conferences and presentations in order that she can demonstrate each child's experience of play. Any sharing of videos or the drawings that your child completed as part of the research project would be to share the research and will all be done without using your child's name, place names or any references to specific individuals. **It is possible for you to consent for data analysis of the videos but not the use of these within research dissemination**. Please carefully read the following statements and initial those that you agree with.

I have read and understood the above and I consent for my child's video data to be used for analysis.	☐
I understand that the video data will be kept long term securely as it will become part of data analysis.	☐
I have read and understood the above and I consent for my child's drawings completed with Naomi during the interview to be used with conference presentations and dissemination of the research.	☐
I consent to the video data of my child being used as part of conference presentations and dissemination of the research (I understand that my child's name will not be used but their face will be visible).	☐
I consent to video data of myself whilst supporting my child to be used as part of conference presentations and dissemination of the research (I understand that my name will not be used but my face may be visible).	☐
I ________________ am a carer/ playmate who participated within the videos and I consent for these to be part of conference presentations and dissemination of the research (I understand that my name will not be used by my face may be visible)	☐

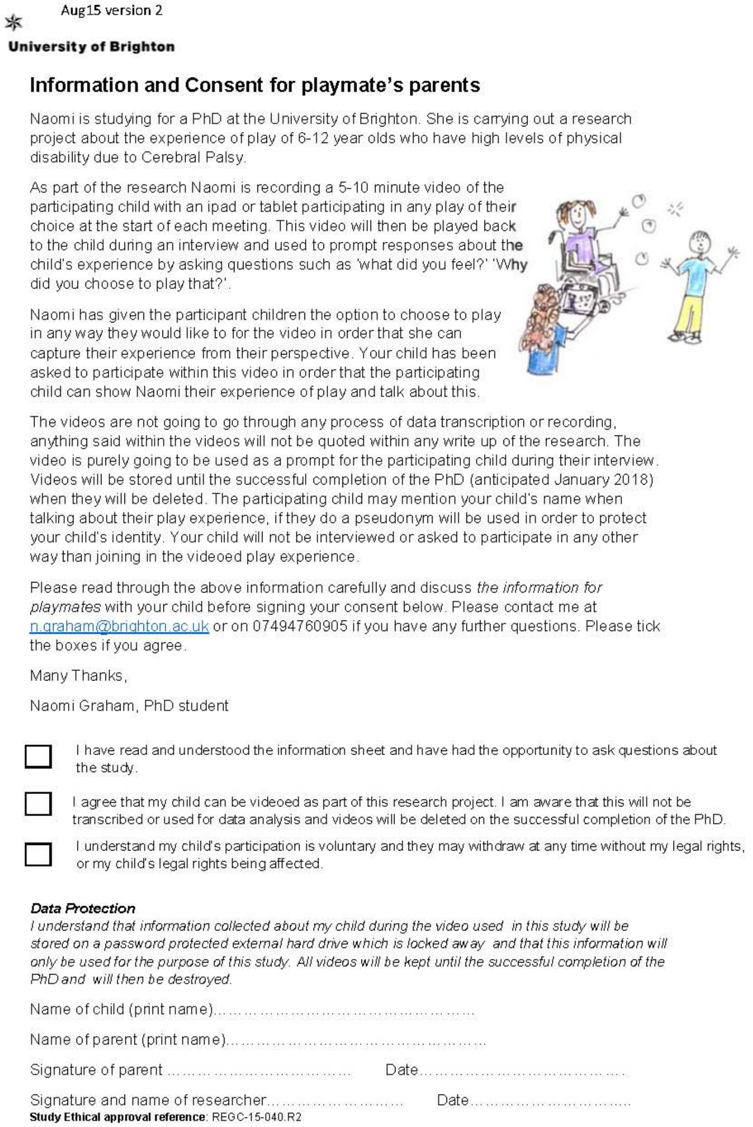
Name of child (print name)……………………………………………

Name of parent (print name)……………………………………………

Signature of parent……………………………Date…………………………………

ORIGINAL IN COLOUR

9.12. Appendix 12- Playmate information and consent



Aug15 version 2

University of Brighton

Information and Consent for playmate's parents

Naomi is studying for a PhD at the University of Brighton. She is carrying out a research project about the experience of play of 6-12 year olds who have high levels of physical disability due to Cerebral Palsy.

As part of the research Naomi is recording a 5-10 minute video of the participating child with an ipad or tablet participating in any play of their choice at the start of each meeting. This video will then be played back to the child during an interview and used to prompt responses about the child's experience by asking questions such as 'what did you feel?' 'Why did you choose to play that?'.

Naomi has given the participant children the option to choose to play in any way they would like to for the video in order that she can capture their experience from their perspective. Your child has been asked to participate within this video in order that the participating child can show Naomi their experience of play and talk about this.

The videos are not going to go through any process of data transcription or recording, anything said within the videos will not be quoted within any write up of the research. The video is purely going to be used as a prompt for the participating child during their interview. Videos will be stored until the successful completion of the PhD (anticipated January 2018) when they will be deleted. The participating child may mention your child's name when talking about their play experience, if they do a pseudonym will be used in order to protect your child's identity. Your child will not be interviewed or asked to participate in any other way than joining in the videoed play experience.

Please read through the above information carefully and discuss *the information for playmates* with your child before signing your consent below. Please contact me at n.graham@brighton.ac.uk or on 07494760905 if you have any further questions. Please tick the boxes if you agree.

Many Thanks,

Naomi Graham, PhD student

☐ I have read and understood the information sheet and have had the opportunity to ask questions about the study.

☐ I agree that my child can be videoed as part of this research project. I am aware that this will not be transcribed or used for data analysis and videos will be deleted on the successful completion of the PhD.

☐ I understand my child's participation is voluntary and they may withdraw at any time without my legal rights, or my child's legal rights being affected.

Data Protection
I understand that information collected about my child during the video used in this study will be stored on a password protected external hard drive which is locked away and that this information will only be used for the purpose of this study. All videos will be kept until the successful completion of the PhD and will then be destroyed.

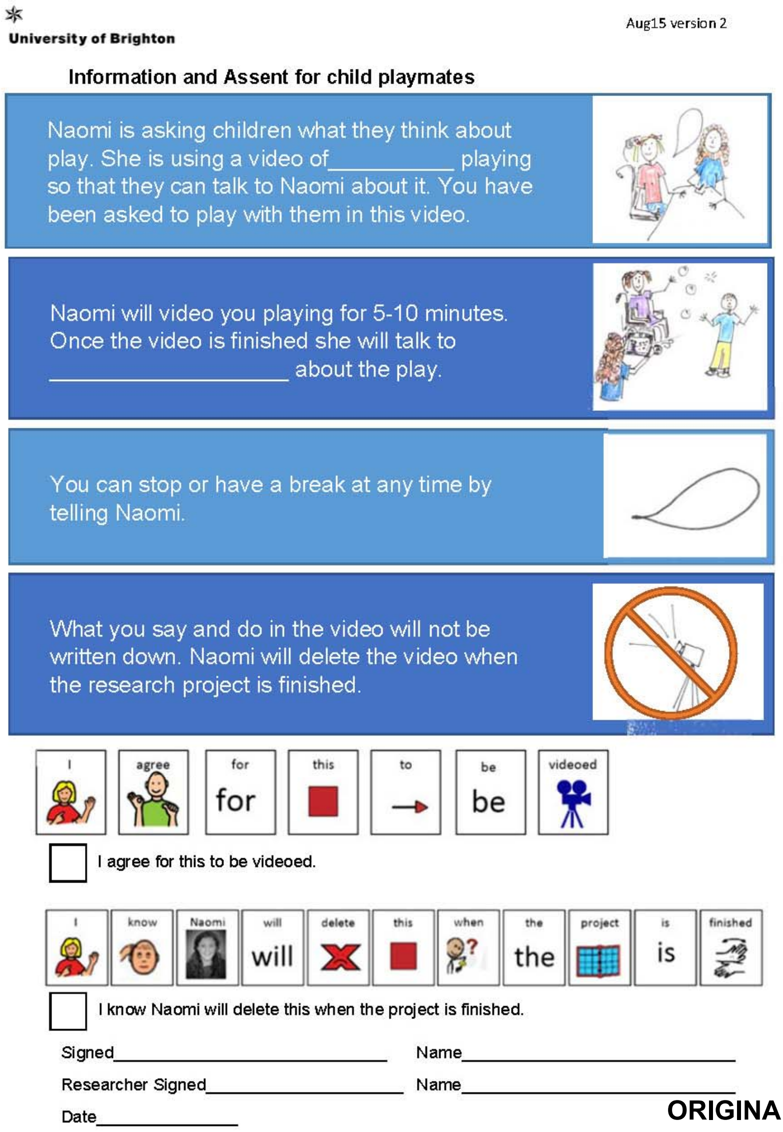
Name of child (print name)……………………………………………

Name of parent (print name)……………………………………………

Signature of parent ……………………………… Date…………………………………….

Signature and name of researcher……………………… Date…………………………….

Study Ethical approval reference: REGC-15-040.R2



University of Brighton

Aug15 version 2

Information and Assent for child playmates

Naomi is asking children what they think about play. She is using a video of__________ playing so that they can talk to Naomi about it. You have been asked to play with them in this video.

Naomi will video you playing for 5-10 minutes. Once the video is finished she will talk to ____________________ about the play.

You can stop or have a break at any time by telling Naomi.

What you say and do in the video will not be written down. Naomi will delete the video when the research project is finished.

☐ I agree for this to be videoed.

☐ I know Naomi will delete this when the project is finished.

Signed____________________________ Name____________________________

Researcher Signed____________________ Name____________________________

Date______________

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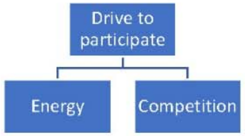
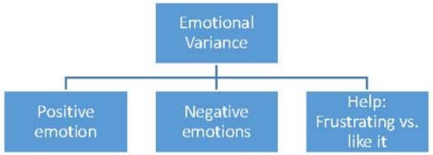
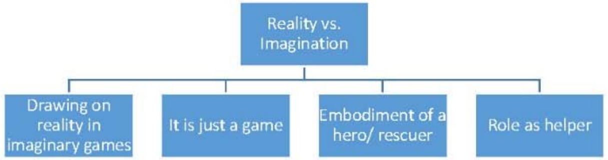
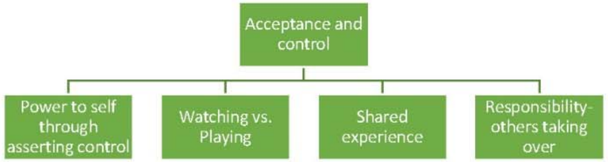
9.13. Appendix 13- Summary of participant’s interview data

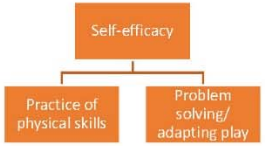
Daniel











Daniel has a ***drive to participate*** in play, it gives him **energy** and he enjoys the **competition** to win or achieve an outcome. Daniel’s sense of energy and speed perhaps reflects times when he embodies freedom within his play and no longer feels constrained to the limitations of his physical disability which means he cannot move fast or freely. Daniel appears to seek sensation through choosing to play in ways which will move his body such as going on rides at theme parks.

Daniel finds much ***emotional variance*** in play, he often experiences **positive emotions** and will express this with a loud ‘Yeah’, describing feeling ‘happy’ or ‘joyful’. Daniel also attributes more **negative emotions** to his play, particularly surrounding times which are ‘frustrating’ or when he feels ‘angry’. Daniel finds that he both **likes and feels frustrated by the need for help** in order to play. He likes that people are there to help his play but can find it ‘a bit annoying’ when they play the game in a different way to how he intends.

The meaning of play for Daniel is often placed within a ***shared experience***, Daniel often requires support to play and this is reflected within his interviews. Daniel takes value in **play belonging to him**- often referring to ‘my games’ and his ‘own imagination’. **Being heard** is important for Daniel in the way that he portrays himself in play and he often likes play activities where he makes lots of noise.

In play Daniel finds meaning through ***reality vs. imagination***. He often **draws on reality in imaginary games**, making use of his pet rats, or films that he has seen. Daniel also sees that playing is not the same as reality and talks about how **‘it is just a game’**. Daniel’s embodied play experience involves **becoming a hero/rescuer** in which he plays out stories and does things like ‘save all the people in the world’. Daniel also sees his **role as a helper** in play, mainly when he needs to instruct others as to what to do.

Daniel seeks ***acceptance and control*** through his play and enjoys **experiencing power to self through asserting control**. Daniel sometimes struggles with this control when he is torn between **watching and playing** and this impacts the level to which he can participate. Sometimes in this **shared responsibility- others take over**; this can be positive and wanted by Daniel, but at other times can cause a play activity to no longer be play.

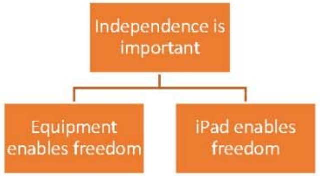
Daniel has a strong sense of ***self-efficacy*** through **practice of physical skills** and through **problem solving and adapting play**. Daniel is good at explaining how he changes a play activity in order to play in the way that he wants to. Daniel demonstrates resilience in the way that he will continue to pursue play and problem solve despite facing barriers such as dropping a toy or bumping into something.

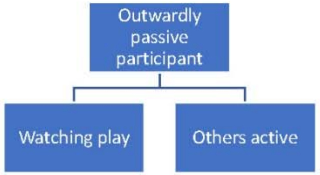
Analytical thoughts:

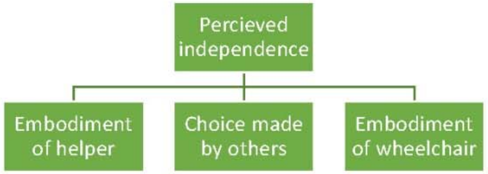
- Daniel becomes the hero/ rescuer in his play- is this because he spends so much time being helped that within play he needs the opportunity to help others?
- Daniel appears to get a heightened sense of play when he is feeling more physical freedom by fast movement etc. Is this because increased movement will give increased sensory feedback and therefore will be easier to process and experience- What about this in relation to theories about embodiment? Proprioception is recognised as giving an individual an indication that it is their experience as subject.
- Daniel frequently comments that it is just a game- is he at an age where play is no longer seen as cool? Or he is aware of the difference between reality and not reality
- When Daniel is playing in his imagination he doesn’t have CP does this give him more freedom/ a sense of control that he doesn’t normally have.
- Daniel appears to know that through practice he can improve physical ability he infers that he did lots of practice particularly when he was younger but it appears that now he is more accepting of the role of a helper and the need for a carer to physically assist him.
- Daniel experiences something as his own experience despite a helper- is he embodying his helper? What might this mean for definition of play as an activity.

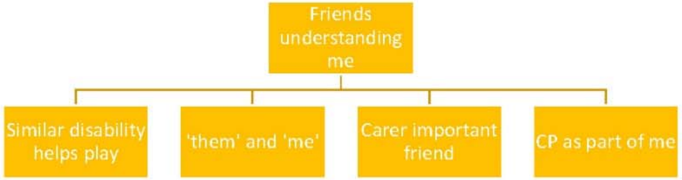
ORIGINAL IN COLOUR

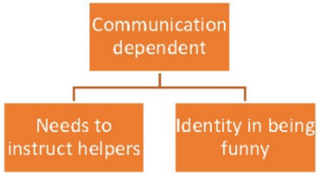
Abi

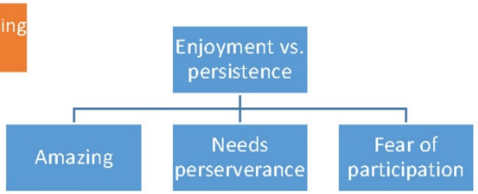












Abi feels that ***independence is important*** within her play. Her **Equipment enables freedom,** particularly her mouthpiece and her wheelchair, Abi's **iPad enables freedom** as it is the only independent play opportunity she can most easily access.

Often within Abi's play she is an ***outwardly passive participant***, despite this, Abi reports feeling a part of play through **watching others play** netball and through **others being active** in play such as her dogs licking her.

Abi experiences a ***perceived independence*** she reports herself as independently participating within play activities despite having a helper supporting her to physically achieve them. This suggests that to some extent Abi **Embodies her helper** when she is playing. She often depends upon **Choices made by others** particularly in the set up of her play such as the position of her iPad. Abi appears to **embody her wheelchair** and would often refer to her chair as an integral part of her.

Abi's experience of play often depends upon ***Friends understanding her*** Abi expresses that if others have a **similar disability it helps play** as they then more easily understand each other. Abi also discusses being apart from her peers in terms of **'them' and 'me'** when referring to her friends at school who do not have a disability. Abi sees her **carer as an important friend** and her **CP as a part of her** which has a strong influence on how she plays and identifies with others.

Abi's participation within play appears to be ***Communication dependent*** she often has to use her communication skills to **instruct helpers** as to how to play and she sees her identity in **being funny** and being able to express how mad/ bonkers she is.

Abi faces a contention within her play in terms of ***enjoyment vs. persistence*** Abi often describes play as being **Amazing** but also describes the level of **perseverance** she needs to be able to keep playing when it is difficult for her to participate. Abi also discusses a **fear of participation** particularly in terms of netball and being worried about being hit by the ball. This again affirms Abi's sense of her CP being integral to her identity and an underlying sense of fragility she seems to have which impacts what she feels she can participate in in terms of play.

Analytical thoughts:

- Abi particularly seems to embody her helper when playing. She often refers to herself as doing something even when she has physical assistance
- Abi seems to perceive play as physical and often talks about others being active in play and not being able to participate
- Abi seems to find comfort in the idea of others being similar to her and yet also being unique. She has a learnt response which is like an adult has told her what cerebral palsy is and she often refers back to this in her interviews.
- Abi wants to do well and this translates to play in terms of wanting to succeed and wanting to be independent.
- She is often outwardly passive- how much does this reflect the children? They see themselves as participating even when they are often done too (e.g. dogs licking, riding in kayak etc).
- She frequently refers to herself as being mad- is this a strategy to hide the CP ? to make her more interesting in order that she can find friends who identify with her because of humour? Or is this just part of family identity?

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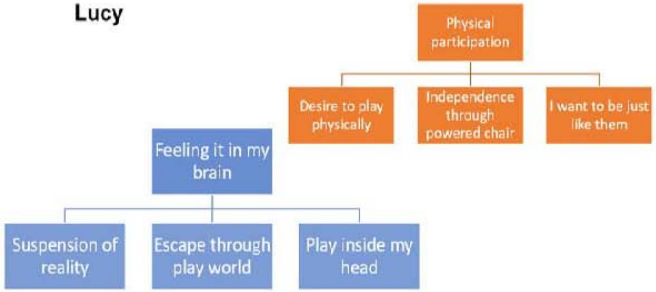
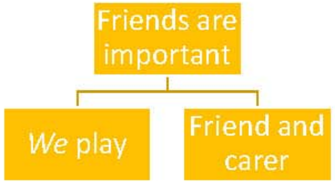
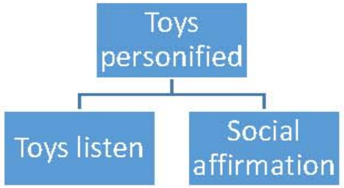
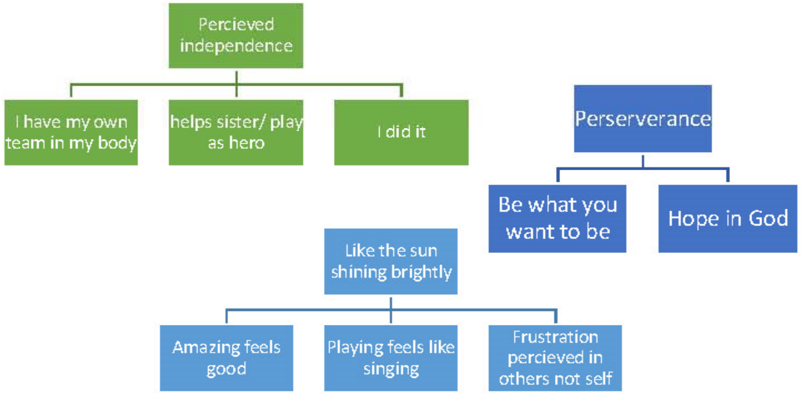
Lucy









Lucy feels that ***physical participation*** is an important part of play, she often comments on a **desire to play physically.** She is able to achieve **independence through using her power chair** when she is playing. Despite this, there is a recognition that Lucy cannot participate in physical play in the same way as others, Lucy reported saying to her Mum in a comment about tennis players that she **wants to be just like them.**

As well as seeing play as a physical activity Lucy also finds that she ***feels it in her brain.*** Much of the play that Lucy discusses is imaginary play based. Lucy **suspends her reality** and is able to **escape through her own playworld.** Although it isn't always clear it, appears that when Lucy is discussing her imaginary play she is able to **play inside her head** without the restrictions of a physical disability.

As a part of Lucy's imagined play world her ***toys are personified***, Lucy's toys become real characters that she experiences and is friends with. Lucy appears to feel affirmed because her **toys listen** she finds **social affirmation** in the relationships she builds with them. Imagined scenarios that Lucy plays with her toys often enable her to be the **hero of the play.**

Lucy often refers to her ***Friends as important*** she will make reference to the fact that '***we* play'** and that she participates in play with others. Lucy sees her carer as both a **friend and carer.**

Lucy demonstrates a ***perceived independence*** within much of her discussion about play. Lucy comments that she has her **own team in her body** that enables her to participate. She will tell stories of **helping her sister** and directing her particularly in playing physical games. Lucy often makes use of phrases such as **I did it** when explaining play that is supported by a carer. This suggests that Lucy is displaying a perceived independence in which she sees herself as able to play independently despite having some help.

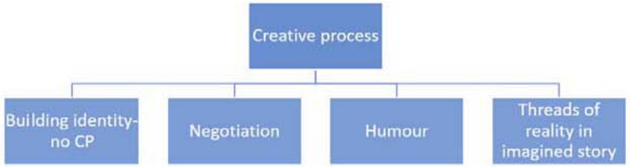
Perseverance within play is key to Lucy being able to continue to participate. She feels that it is important to **be what you want to be** and she often discusses how she has **hope in God** which appears to enable her to persevere.

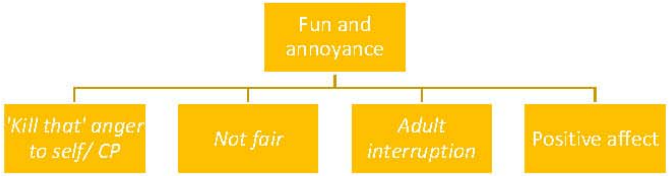
Lucy feels that play is **like the sun shining brightly** she comments that it is **amazing and feels good.** Playing can **feel like singing.** It appears that Lucy likens positive emotion to play in a way that doesn't necessary account for frustration during play, like Lucy is choosing to try and respond positively to play activities. She is able to **perceive frustration in others but not herself** during play.

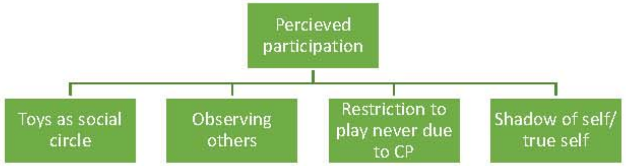
Analytical thoughts:

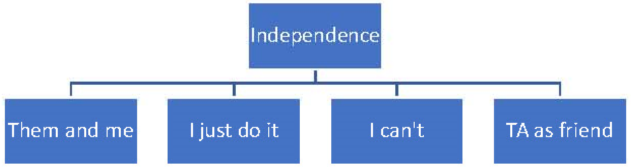
- Interesting about personification of toys and discussion of God- gives hope for participation with friends and ability to keep carrying out play.
- Imaginary play/ playworld provides an escape in which Lucy does not seem to have CP and can participate in physical play as she likes
- Society/ children often refer to 'Games' as almost an interchangeable word for play (not sure where to put within themes)
- Physical participation is frequently referred to- is this Lucy's perception of what play needs to consist of? Does she realise she often misses out on this?
- Positive affect often linked to play even when negative things can be experienced in a play scenario.
- Is that view that play always has to be good and therefore Lucy can only see negative emotions linked to play in others or when probed?

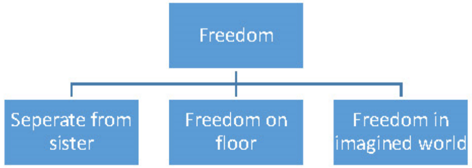
Jess











Jess discussed her play like a ***creative process***, she had created a sense of self and had **built an identity with no CP** for herself. Within imaginary play Jess often used **threads of reality within imagined stories.** Play experienced with others often involved **negotiation** and it appeared that **humour** was important to play for Jess and how she portrayed herself.

The emotions of play experienced by Jess are like two moving cars which narrowly miss each other of ***fun and annoyance.*** Jess' play experience often involves a combination of both **positive affect** and then more negative feelings such as that play is **not fair** and a sense of wanting to **'kill that' and express anger towards herself or CP.** Feelings of annoyance were also often discussed for Jess when **adults interrupted** her play, even though this was normally to keep Jess physically safe. Despite feelings of annoyance Jess appears to focus on the fun experienced during play and commented that fun is always the bigger of the two emotions.

Jess often had a sense of ***perceived participation*** and a feeling of fully joining in and being a part of something despite sometimes perhaps being on the edges. Jess often talked about her toys in a way that was personified and it appeared that she saw **toys as a social circle.** Jess often talked about participating in play through **observing others** and would be able to give details of how her sister or a friend participated in a play activity. When Jess talked about restrictions to her play these were **never due to CP.** For example, Jess talked about using a bow and arrow sideways like a crossbow as part of a game rather than as an adaptation so she could participate. Jess' feeling of participation, particularly within imaginary games appeared to highlight a **shadow of herself** which she appears to represent within reality.

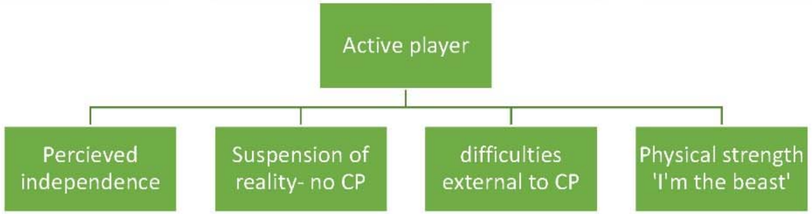
Independence within play is an area in which Jess faces contention. She often feels that with her peers it is **'them and me'** when she is playing. Jess often talks about how she can **'just do it'** when she is participating in play. This contrasts to her comments of **'I can't'** and the restrictions that her disability seems to place on her play in comparison to her peers. For Jess she experiences her peers participating very separately to her particularly when they run around in games- something that Jess feels she can't participate in. As Jess experiences a feeling of social isolation and perceives that 'they' don't want to play with her Jess sees her **TA as a friend** who will always be around to play with her.

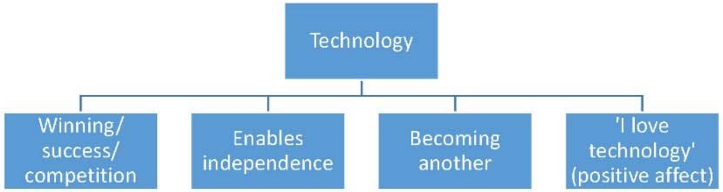
Jess' experience of play is often one of ***freedom.*** Jess experiences freedom as an individual **separate from her sister** and often makes distinctions between her play and the play of her twin. Jess experiences **freedom in her imagined world** where the characters that she creates can interact in the way that she wants them to. Jess also talks about how she experiences **freedom on the floor;** this is a very physical freedom and one of the only times that Jess can mobilise and move around a space independently in her play.

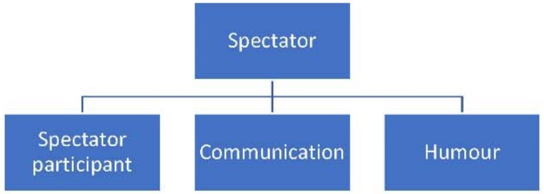
Analytical thoughts:

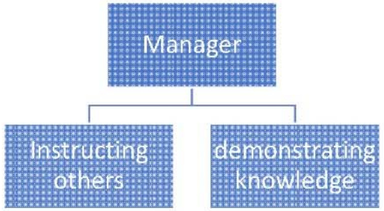
- The way that Jess creates her play scenarios is interesting- it seems that she always returns to the same imaginary character with her baby Annabel. Is this a life imagined for the future? Or is it an opportunity to escape and play without having CP?
- Jess describes the emotions of her play experience very interestingly- she has to negotiate and choose to have fun despite the interruptions of adults and feelings of annoyance.
- There is a lot of perceived participation particularly seen through the language- in some sense Jess will talk about herself as subject (e.g. *'I used the bow and arrow')* but often her sentences will start with I and then when she is asked to describe the play experience she will use 'we' or her sister or a friends name and then give detail of the specific activity.
- Jess talks about playing with friends and yet when asked about it appears to feel very social isolated- she often discusses 'hope' and 'wishes' that things will change although appears to have a bleak view on her friendships currently.
- Jess wants to be independent and this is clear in the way that she plays and the play that she talks about. She perceives play as something that is difficult to describe and just happens but with herself as subject- *'I just do it'*.
- Jess unusually doesn't make use of a powered chair very often and it appears that one of the only times she gains a true sense of freedom is when she is playing on the floor. The ability to move around by herself appears to be significant in Jess' play experience.

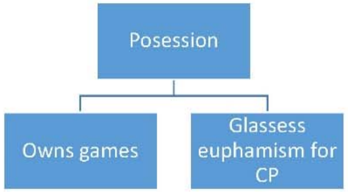
Ben











Ben feels that he ***belongs to a team,*** much of his discussion about play experience is discussed within the context of sport. The participation within a team reflects Ben's desire for **independence versus his need for help**; this is reflected in the way in which he can **embody his helper and they become part of the team.** Ben appears to find participation within a team and perception of belonging to a wider team full of **overwhelming excitement.** This appears to be connected to the sense Ben has of being **part of something wider** than himself. Ben often identifies with teams and locations which may be perceived as popular or well known and this appear to be part of this sense of belonging.

Ben sees himself as an ***active player:*** when Ben discusses play it often has a physical output of some kind. Ben displays a **perceived independence** in his discussion of play activities; despite support from an adult or automatically controlled technology Ben sees himself as independently acting within play. Ben often **suspends reality and imagines himself with no CP,** Ben frequently discusses becoming another player and actively participating in the game as them. When Ben has difficulties achieving what he'd like to in a game he often talks about this as **external to CP** for example, not having the instructions or the ball being slippy. Ben sees himself as physically active and wants to portray his **physical strength** through phrases such as '**I'm the beast'**.

Ben makes use of ***technology*** in order to enable him to access play. Technology allows the opportunity for **winning, success and competition** all of which seem to be essential to Ben's sense of an activity being playful. The use of technology **enables independence** and means that Ben can participate in play on his own. Playing popular sporting games means that Ben can easily **become another** in the way that he suspends his reality. Ben comments **'I love technology'** and the opportunity to be able to use technology for play appears to be associated with positive affect.

Ben often experiences play as a ***spectator,*** Ben is able to **participate as a spectator** and will often make use of **communication** or his sense of **humour** in order to be more of a part of the play.

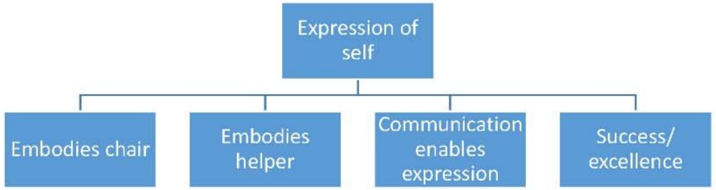
Ben on occasion puts himself in the role of ***manager*** of the play that he participates in. Ben will often **instruct others** within play in order to enable play to occur in the way he would like it. Part of Ben's experience also seems to be that he wants to **demonstrate his knowledge** through doing this Ben is affirming his role as manager and leader of the play.

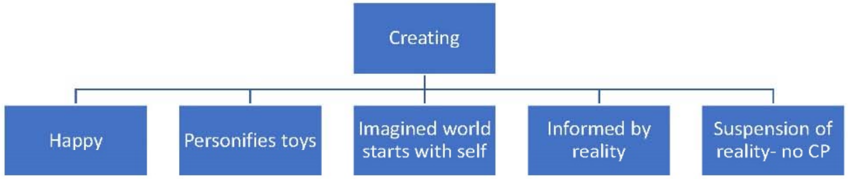
When talking about rugby Ben talks about the importance of the ***possession*** of the ball. Possession of things seems to be a part of Ben's play experience that helps him to feel more of a part of it. Ben **owns games** and often discusses what he owns. Ben interesting talks about owning glasses frequently, it appears that his possession of **glasses may be a euphemism for CP.** This enables Ben to express his disability.

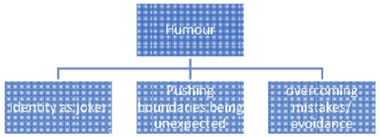
Analytical thoughts:

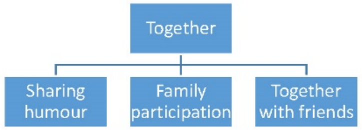
- Appears to focus very much upon physical play
- Language of possession/ winning/ belonging to a team enable a description of Ben's play experience
- Being a part of something wider/ popular appears to enable Ben to vicariously experience and enter into play- this means he can feel very excited/ frustrated if he is able or unable to attend an event.
- Ben appears to not mention his CP unless prompted, he does mention glasses though and talks about these as something distinct to him- is he using this as a euphemism for CP or not? It is about saying that CP isn't so bad and it is just a thing like wearing glasses?
- Ben appears to hold in tension a need for others to help him and a want for independence, this is something that needs to be brought into discussion.

Tom









When playing Tom experiences a tension between ***help and independence,*** he requires support from an adult in order to participate in most play activities. In communicating what he would like Tom often makes **compromises for ease** and might go with the first choice offered to him for a play activity. Tom's experience is that **technology enables** his play and means that once he is set up he has the opportunity to participate in something independently. Tom often experiences independence in play through being a **spectator participant** he enjoys playing through doing activities such as watching motorbike racing. Tom **normalises help** that he needs in order to be able to communicate and express his choices for play. Despite this Tom has a strong **desire for independence** and often **perceives independence** despite the presence of an adult supporting his play.

Tom uses play as an ***expression of self.*** Within play Tom perceives his wheelchair to be a part of him; he **embodies his chair** and particularly when drawing play does not draw himself without it. Tom also often **embodies helpers** within his play and will express activities as being led or carried out by him despite having physical support from a helper. In order to express himself in play Tom relies on communication and finds that **communication enables expression** of himself and his preferences. Tom sees himself as having **success and excellence** he discusses always being accurate in his choices and expression despite the normal compromises that have to occur during play.

Tom's experience of play appears to be one of ***creating*** Tom expresses positive affect at the opportunity to play and sees this as **happy.** He creates a suspended reality in which he **personifies toys.** Tom's suspended reality and **imagined world start with himself** he uses himself and the objects physically available to him to influence his pretend play which is **informed by reality.** Within imaginary play Tom is creating play in which **reality is suspended and he does not have CP** this enables a greater sense of physical freedom and ability to move.

Humour is essential to Tom's play experience. Tom places a large amount of his **identity as a joker** he uses humour and laughter in order to express his play. Tom within his play is often **pushing boundaries and being unexpected** because he knows this can be seen as funny and can lead to laughter. Humour is also important within Tom's play experience as it is a way to **overcome mistakes and avoid** things which are difficult. Tom chooses to laugh at mistakes and see them as part of the play rather than to become frustrated and distance himself from them.

Play is an activity which is often done ***together*** within Tom's experience. He wants to be able to share humour with others and often uses this to enable others to engage in his play. Tom has a strong sense of family and family participation and playing together is important to his experience. Tom also plays together with friends and at times his toys become his friends but he wants the opportunity to participate with others.

Analytical thoughts:

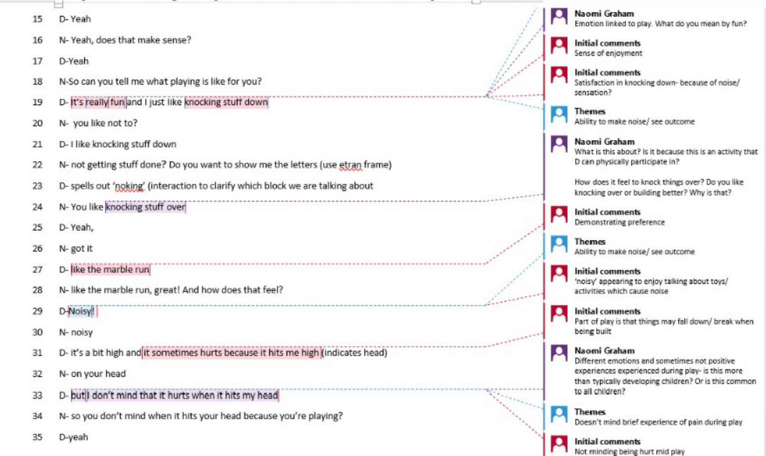
- Play through humour- choosing to communicate the wrong thing in order to cause laugher. Way to adjust/ process mistakes.
- Laughter- contagious- captivates others and means they join in participation
- Embodiment of helper
- Needs a good communication partner
- Creates a world starting with but going beyond self
- Perception of self as different- e.g. missing/ different hands, expressive mouth.
- *Together*- sense of being a part of a social world.

9.14. Appendix 14- Example of data analysis and analysis process

Daniel interview 2 [Descriptive comments, *Linguistic comments,* conceptual comments]

Original transcript	**Initial noting**	**Emergent themes**	**Connections between themes**
N- So do you do pretending as part of your playing sometimes, pretending to be things? D- sometimes N- can you tell me about that? D- I like being a secret agent…I like to be a secret agent N- Do you? D- and go on missions, and I sometimes imagine my rats N-so how does that feel? D- Good, because it is your own imagination N- good, what's important about it being your own imagination? D- you can get… (Thinking) I don't know N- you don't know D- but it is just really fun, yeah N- so can you tell me about one of your missions? D- well there was a man stealing birthdays N- stealing D- birthdays N-birthday cake? D- no birthdays, the whole birthday N- oh the whole birthday D- He is an alien and I've got a gun hook, no I've got a hook, no I have a gun but there's a hook on the end N- yeah D- I can go up to the ceiling and attack him and then I press the button to make the birthdays come back N- okay, D- Yeah N- so you rescue the birthdays? D- yeah N- and how does that feel? D- a bit sad, N- oh D- because you think you're going to lose your birthday, Yeah. And my birthday was nearly gone and that was bad because you just die. N- yeah, D- Yeah N- so why, why would it have been bad if you lost your birthday?	Pretending is sometimes a part of play. *Change of tenses- I like to be- suggests a shift in reality.* Becoming a character who can move around freely? *Own imagination.* Imagination belonging to Daniel. Really fun- Positive emotion associated with play experience *'he is' as if alien character is real.* Reality suspended- Daniel has tools he needs to defeat enemy. Use of technology within play- press the button. Go up to the ceiling- Freedom to move- embodied experience. Variety of emotions experienced- sadness- as if the situation is real. *Changing between you and my.* Concept of death.	Sense of self-pretending Becomes a character Belonging to self Play as fun Reality suspended Moving differently to reality Embodiment of a hero/ rescuer	**Sharing play** Asserting 'my' game **Reality vs. imagination** Embodiment of a hero/rescuer
D- you would probably never grow up, no, you would die N- because you wouldn't be able to grow up? D- no, you would die N- you would die, I see D- because it is a bit like the man, the gun did that. N- so does that make it even better when you save the day? D- Yeah, you can get it back, the whole people in the bag N- tell me that again? D- I save all the people in the world N- okay, you take it? D- I save everyone from this world N- You take everyone on the rope? D- no N- on the road? D- No I help everyone N- you help everyone D- because their birthdays are gone N- Okay because their birthdays are gone they've been taken by the man. D- Yeah N- So how does that feel when you help everyone? D- Amazing.. Amazing Interview 2, lines 81-141.	Growing up is good and something Daniel wants to experience. Linking to something else that Daniel has watched? *Blame on object not person- the gun did that. 'I save' present continuous tense- clearly being the hero within the situation.* All the people- sense of making all things right. *From this world- what is in this world that needs saving from- referring to reality or the game? I help everyone.* Owning ability to be able to rescue everyone- feeling amazing.	Role as helper	Role as helper **Emotional variance** Positive emotion

Example of analysis process within a transcript, Daniel, Interview 2



D- Yeah
N- Yeah, does that make sense?
D-Yeah
N-So can you tell me what playing is like for you?
D- It's really fun and I just like knocking stuff down
N- you like not to?
D- I like knocking stuff down
N- not getting stuff done? Do you want to show me the letters (use etran frame)
D- spells out 'noking' (interaction to clarify which block we are talking about
N- You like knocking stuff over
D- Yeah,
N- got it
D- like the marble run
N- like the marble run, great! And how does that feel?
D-Noisy!
N- noisy
D- it's a bit high and it sometimes hurts because it hits me high (indicates head)
N- on your head
D- but I don't mind that it hurts when it hits my head
N- so you don't mind when it hits your head because you're playing?
D-yeah

Naomi Graham
Emotion linked to play. What do you mean by fun?

Initial comments
Sense of enjoyment

Initial comments
Satisfaction in knocking down- because of noise/ sensation?

Themes
Ability to make noise/ see outcome

Naomi Graham
What is this about? Is it because this is an activity that D can physically participate in?

How does it feel to knock things over? Do you like knocking over or building better? Why is that?

Initial comments
Demonstrating preference

Themes
Ability to make noise/ see outcome

Initial comments
'noisy' appearing to enjoy talking about toys/ activities which cause noise

Initial comments
Part of play is that things may fall down/ break when being built

Naomi Graham
Different emotions and sometimes not positive experiences experienced during play- is this more than typically developing children? Or is this common to all children?

Themes
Doesn't mind brief experience of pain during play

Initial comments
Not minding being hurt mid play

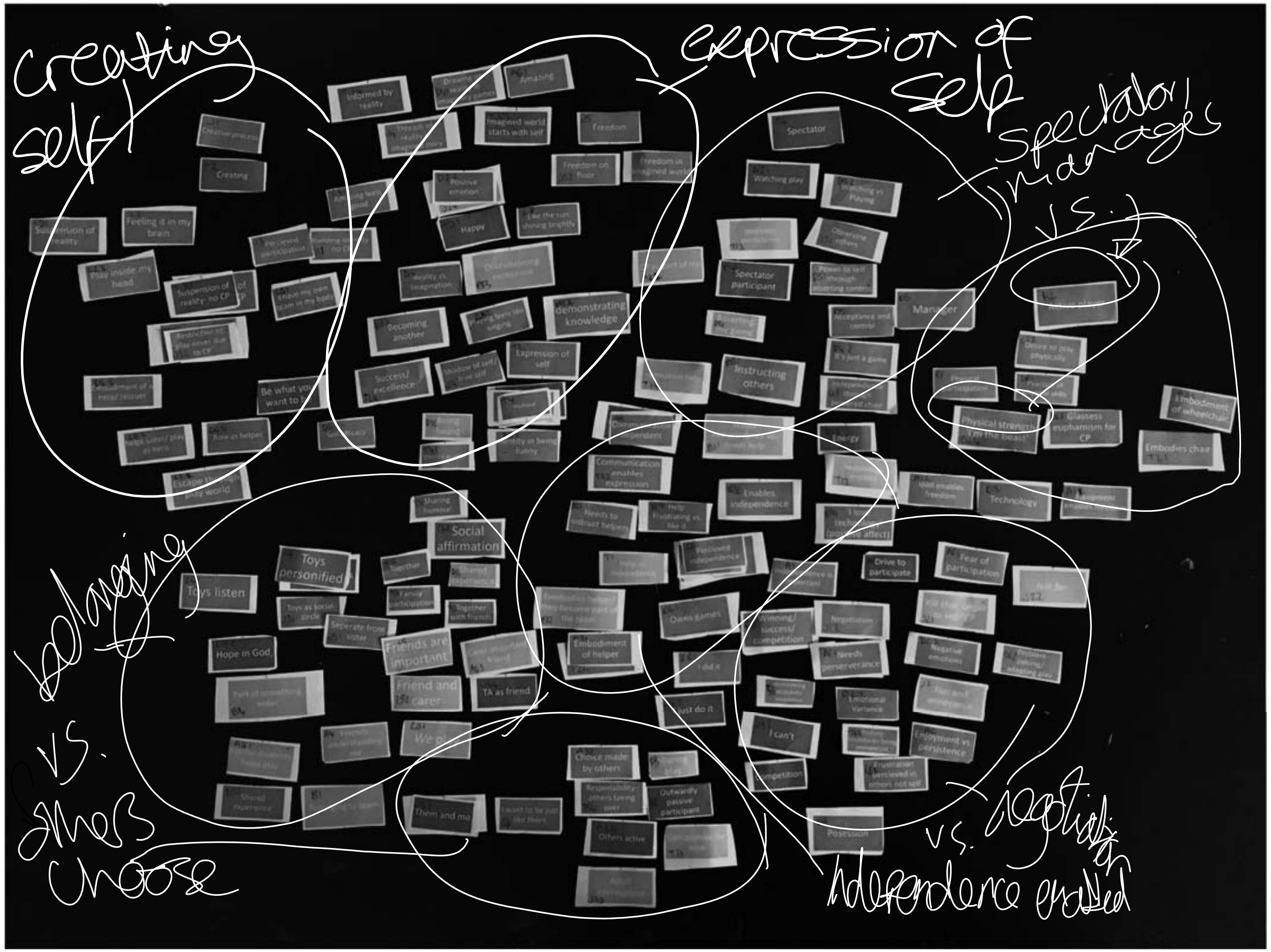
ORIGINAL IN COLOUR

Abi, interview 1 [Descriptive comments, *Linguistic comments,* conceptual comments]

Original transcript	**Initial noting**	**Emergent themes**	**Connections between themes**
N- and who do you like to hang out with at school? P- I don't, I'm on my own at the moment, I'm on my own N- You're on your own at the moment, ok P- Because they're playing netball N- oh okay P- Yeah	Perspective of being alone at school. *I 'don't' perhaps indicates some level of choice.* *Solitude belongs 'my' to Abi- a choice to being alone.* Hanging out on her own. *At the moment- transient timing, not on won all the time.* States being alone like a fact. *Refers to everyone as a whole not specific friends. 'playing' continuous.* Them and me	On own	**Friends understanding me** Them and me
N- at play time? P- Yeah, and then I can't play it, because it is not adapted. N- yeah, it is not adapted P- no N- that's frustrating P- Yeah	Playing is physical (and she refers to not adapted) Abi sees herself as excluded from the play. Physical game with rules. *'Can't' more of a definitive statement of not being able to access.* 'not adapted' feels like quite an adult phrase.	Lack of adaptation	
N- So does everybody play netball? P- Yeah, Yeah N- ok, and you just, where do you go? P- I'm on my own really, I watch them, yeah N- You watch them, ok. And is there, what other things are important to you? P- um, Because I've got a disability, my TV N- Your P- TV N- your TV P- Yeah,	Emphasises being alone. *Use of the word 'really' is she not on her own but feels along?* How likely is it the whole school is playing netball? Is it specific friends she can't play with? Isolation when others are participating. Watches play. *Watch 'them' Abi is separating herself from others in terms of the way that she participates 'I' watch- still control and choice over what she's doing.* Choosing to watch others.	Watches to participate	**Outwardly passive participant-** Watching play
N- because you've got a disability your TV did you say? P- No, I've got equipment N- you've got equipment P- yeah	CP integral to who Abi is. *'Because I've got a disability'* Identity appears to be firmly rooted within disability. What's the connection between disability and TV? Being able to watch/ participate passively enables more play.	CP integral to identity	**Friends understanding me** CP as part of me
N-ok, so you've got your wheelchair, what else have you got? P- standing frame N- Standing frame P- I don't use it really. I've got my, what's it called? my chair N- Your chair P- my new chair	Equipment linked to disability. Equipment necessary for Abi. *'don't'- expressed choice and preference not to use. 'my' chair belongs to Abi.* Chair is more desirable because it is new. Chair enables more participation?	Equipment needed for play	**Independence is important** Equipment enables freedom

Original transcript	**Initial noting**	**Emergent themes**	**Connections between themes**
N- the start of year 6, ok that's when you started playing netball. And does it um, so when you're watching netball.. P- (interrupts) I play netball, because I drive, so that's why N- you like it	*I play netball- Abi stating participation.* Participation through driving not watching. Driving wheelchair appears to be linked to independence in being able to move around and participate. Freedom to move important to participation?	Wheelchair enables freedom and participation	**Independence is important** Equipment enables freedom
P- yeah N- so when, you know when you said you were watching before? P- yeah but now I play	Two weeks later has been able to participate through driving around- this is seen more as playing. Contrast between watching and playing.	Participation through watching	
N- now you play, when you were watching were you still talking to people? P- No, I was like being a mana… not a manager, I don't know, no not an audience, I just want to play, I want to play but I want to be really safe , so that's why. Can I have a drink?	*Watching was still participation- struggling to complete sentence here and use a word for it.* Trying to find a role which involves watching e.g. manager/ audience. Abi was able to participate through watching but was trying to find herself a role. Desire to participate but feels more fragile than other children?		
N- so why do you feel safe now? P- because I have to , I want to be safe, I don't want to hurt my head and stuff N- Yeah. Here you go (gives Abi drink)	Has to participate in play or has to be careful? Strong link between physical play and possibility of being hurt.	Fear of injury	**Outwardly passive participant-** Watching play Others active **Enjoyment vs. persistence** Fear of participation

Abi interview 3



Example of 'carpeting' process, negotiating and grouping themes. This was done through laying out each of the themes and subthemes created as a result of each participants interviews and moving these around and grouping them with possible commonalities. The following table demonstrates the grouping which occurred as a result of this version of 'carpeting'.

Superordinate themes	***Be what you want to be*** **Expression of self vs. re-creating self**	***I'm the beast*** **Spectator vs. active player**	***I want to be just like them*** **Belonging vs. others choose**	***I do it and I can't*** **Negotiation vs. independence enabled**
Subthemes	Success and excellence	Physical strength and participation	Toys personified	Communication enables choice
	Free and happy	Embodiment of wheelchair	Social affirmation in belonging to something wider	Embodiment of helper-perceived independence
	Humour as expression of self	Spectator participant	Shared experience-drawing others in	'kill that' anger to self and CP
	Vista play: creating internal self with no CP		Outwardly passive participant	Drive to compete and negotiate control in play
	Role as a hero or helper		Choice by others	
	CP as a part of self		'them' and 'me'	
	Restrictions to play not due to CP			

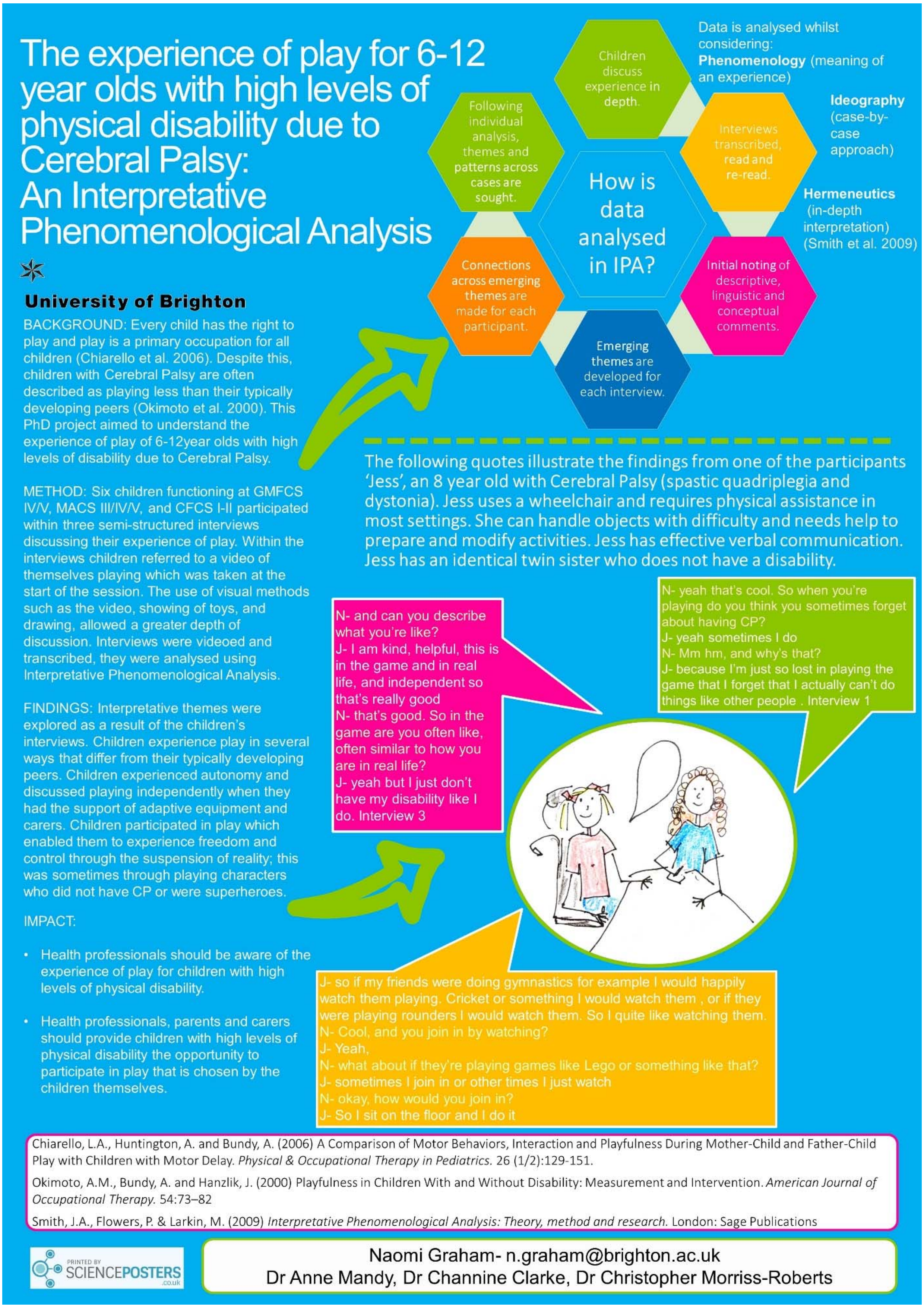
9.15. Appendix 15- Further quotes to illustrate findings

1. Making choices and controlling play	2. Participating differently to peers	3. Connecting with others in play
1.1. Facilitated independence- helpers become an embodied part of self	2.1. Disability as a part of self	3.1. Using humour to enable connection
'N- So do you have a chair that you use by yourself? B- Yeah a wheelchair N- a wheelchair, and is it one that you can drive? B- yeah N- or does somebody push you? B- Usually somebody pushes me.' (Ben, interview 1). *'N- And what do you with the ball? A- throw it. N- throw it, and then what does [Abi's dog] do? A- catch it, he catches it, you throw it back, yeah. N- ok, and how do you throw it? A- I can't throw it, so someone holds my arm and then I, and hand, and then I throw it.' (Abi, interview 1).*	*N-So sometimes when you wanted your hands to do something, your eyes, it was tricky to get your hands to do something because your eyes could always see, it took a little time to get your eyes to go to the place you wanted them to can you tell me how that felt? P- ok N- ok, P- yeah, good N- So you're very good at keeping trying P- yeah, yeah (Abi, interview 2).* *'J- well, no it's only when I'm eating lunch she leaves me, she comes back. So I sometimes play with her. N- ok, does she help you find other people to play with sometimes? J- she plays with me N- So what things do you do as well as catch? J- So I sometimes, what do I do? I'm not actually sure. Sometimes I just sit there quiet. N- and is she your friend or is she just your helper? J-she's my helper.' (Jess, interview 1).*	*'When I have lunch I get my food and I bang like this (indicates banging table) and it goes up in the sky… when the teacher goes I go like this, (indicates hitting the table) and then (pretends to look up) and then I'm just looking and then I did nothing N- okay, you're just looking D- No then I say, I did nothing, nothing at all. N- okay so how does that feel? D- a bit cheeky.' (Daniel, interview 2).* *N- go, why does it not want to play?! oh it's gone slow-mo! Why is it doing that? T- (laughs a lot and finds it funny) N- (both laughing) what's it doing going really slowly? Does that feel funny? T- [looks yes] (vocalising, waving hands around) (Tom, interview 1).*
1.2. Seeing self as physically strong and successful	2.2. Engaging in play through watching	3.2. Using voice to be heard in play
'I go on a normal [emphasis] horse so I sit on it and I'm quite good, I just do it . It's not that difficult for me actually, it's actually really easy now because I've been doing it for (whispers)- I started when I was four and now I'm eight, I've been doing it four years so I am pretty good at it.' (Jess, interview 3). *[Playing tennis as Andy Murray] 'N-So how does that feel? B-good because I get all sweaty when I run around.' (Ben, interview 2).*	*'N- And do you ever play by watching Lilly do it? L- yes N- So how does that feel? What do you do when you're watching her? L- Good. N- yeah, how do you join in, do you do cheering maybe? Or do you just watch her do big kicks? L- yes!' (Lucy, interview 2).* *'J- so if my friends were doing gymnastics for example I would happily watch them playing. Cricket or something I would watch them, or if they were playing rounders I would watch them. So I quite like watching them. N- Cool, and you join in by watching? J- Yeah.' (Jess, interview 1).*	*'We pretend and that there are aliens we pretend that we, we pretend that we can see aliens as well, we, yes, we pretend that, yes, we pretend that our friends are aliens as well.' (Lucy, interview 1).* *'N- yeah. And you look like in that picture that you were doing really big bashes with your hands. Were you choosing to do big bashes or was that just happening? T- [chooses- choosing to do big bashes] (starts giggling) N- You were choosing to do big bashes! And why is that? T- (still giggling) N- are big bashes more fun or not really? T- (still giggling) [chooses- more fun] N- more fun! Is that because, um, you can.. does it matter that you can hit it hard or not really? T- [Chooses- hit is hard] (still laughing) N- Yeah, hit it hard. Is that because does it make a louder noise or not really? T- [chooses not really] (stops laughing but continues to vocalise through conversation) N- not really. Is it because people can hear where you are or not really? T- [chooses- because people can hear where you are] N- Yeah, because people can hear where you are. Is that because people can hear the piece you're writing or not really? T- [chooses hear the piece you're writing] (Tom, interview 2).*
1.3. Choosing to compromise vs. having to compromise	2.3. Extreme emotion- frustration and excitement played out	
'In the classroom when nobody is in the classroom, me and Miss Salt play world cup.' (Ben, interview 1). *'One day some people came to the game place and they couldn't think of what game to play first but then God spoke to them and he said 'you can choose which game you want to play first' said God. 'But only in your mind' said God.' (Lucy, interview 2).* *N- your mum was choosing so was she playing or were you playing? T- (vocalises approximating me) [chooses you playing] N- you were playing. Did you mind that your mum was helping or not really? T- [chooses not really] (vocalises) N- not really. And if you didn't like it could you ask to change it? T-(vocalises) N- If you didn't like it would you keep playing or would you ask to change? T- [chooses keep playing] N- you'd keep playing? (Tom, interview 2).*	*'L-I dropped it on the floor! N- how did that feel? L- bad, very bad. N- and then what happened? L- I felt frustrated with myself. N- did you? But then, were you still playing when you felt frustrated? L- I was still playing N- ah and who helped you? L- Laura [carer] did. N- and how did that feel? L- good.' (Lucy, interview 3)* *'N- So if I was an alien and didn't know what fun was what would you tell me? A- it's like funny, laughing.. yeah N- what else? A- Laughing, laughing, fun, having fun, yeah. N- ok, and how does it feel in your thinking when you're having fun, what do you think? A- all of my mad stuff – Nutella! N- uh huh, all of the mad stuff! A- eating Nutella!… N- Ok, and how does it feel in your body? A- Amazing when I'm having fun.' (Abi, interview 1).*	
2.4. Imagined self without disability- a new spatiality		
[Talking about wheelchair driving game] 'A- yeah, or you jump or you flip. I could do that I want to. N- how do you think that would feel? A- Good, how do you do a flip in a wheelchair? N- How do you think?… A- I don't know, amazing.' (Abi, interview 2). *[Talking about imaginary play with minions in which Tom is participating] T- [climb up a ladder] N- you climb up a ladder. Does that mean it's really big or is it not very big? T- [chooses really big] N- it's really big! And do you imagine all this in your head or is that wrong? T- (looks yes) N- yeah, and when, is that like playing or is that not playing? T- [choose play definitely].' (Tom, interview 2).*		

ORIGINAL IN COLOUR

9.16. Appendix 16- The experience of play for 6-12 year olds with high levels of physical disability due to Cerebral Palsy: An interpretative Phenomenological Analysis.

Poster presented at COT and EACD 2017 (Graham et al. 2017a, 2017b)



The experience of play for 6-12 year olds with high levels of physical disability due to Cerebral Palsy: An Interpretative Phenomenological Analysis

University of Brighton

BACKGROUND: Every child has the right to play and play is a primary occupation for all children (Chiarello et al. 2006). Despite this, children with Cerebral Palsy are often described as playing less than their typically developing peers (Okimoto et al. 2000). This PhD project aimed to understand the experience of play of 6-12year olds with high levels of disability due to Cerebral Palsy.

METHOD: Six children functioning at GMFCS IV/V, MACS III/IV/V, and CFCS I-II participated within three semi-structured interviews discussing their experience of play. Within the interviews children referred to a video of themselves playing which was taken at the start of the session. The use of visual methods such as the video, showing of toys, and drawing, allowed a greater depth of discussion. Interviews were videoed and transcribed, they were analysed using Interpretative Phenomenological Analysis.

FINDINGS: Interpretative themes were explored as a result of the children's interviews. Children experience play in several ways that differ from their typically developing peers. Children experienced autonomy and discussed playing independently when they had the support of adaptive equipment and carers. Children participated in play which enabled them to experience freedom and control through the suspension of reality; this was sometimes through playing characters who did not have CP or were superheroes.

IMPACT:

- Health professionals should be aware of the experience of play for children with high levels of physical disability.
- Health professionals, parents and carers should provide children with high levels of physical disability the opportunity to participate in play that is chosen by the children themselves.

How is data analysed in IPA?

Children discuss experience in depth.

Interviews transcribed, read and re-read.

Initial noting of descriptive, linguistic and conceptual comments.

Emerging themes are developed for each interview.

Connections across emerging themes are made for each participant.

Following individual analysis, themes and patterns across cases are sought.

Data is analysed whilst considering:
Phenomenology (meaning of an experience)

Ideography (case-by-case approach)

Hermeneutics (in-depth interpretation) (Smith et al. 2009)

The following quotes illustrate the findings from one of the participants 'Jess', an 8 year old with Cerebral Palsy (spastic quadriplegia and dystonia). Jess uses a wheelchair and requires physical assistance in most settings. She can handle objects with difficulty and needs help to prepare and modify activities. Jess has effective verbal communication. Jess has an identical twin sister who does not have a disability.

N- and can you describe what you're like?
J- I am kind, helpful, this is in the game and in real life, and independent so that's really good
N- that's good. So in the game are you often like, often similar to how you are in real life?
J- yeah but I just don't have my disability like I do. Interview 3

N- yeah that's cool. So when you're playing do you think you sometimes forget about having CP?
J- yeah sometimes I do
N- Mm hm, and why's that?
J- because I'm just so lost in playing the game that I forget that I actually can't do things like other people . Interview 1

J- so if my friends were doing gymnastics for example I would happily watch them playing. Cricket or something I would watch them , or if they were playing rounders I would watch them. So I quite like watching them.
N- Cool, and you join in by watching?
J- Yeah,
N- what about if they're playing games like Lego or something like that?
J- sometimes I join in or other times I just watch
N- okay, how would you join in?
J- So I sit on the floor and I do it

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