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Children and Young People's Experiences of Growing Up with Cerebral Palsy in Rehabilitation

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Abstract

This thesis explores the relationship between children and young people with Cerebral Palsy's experience of rehabilitation and its impact on their psycho-emotional development and sense of self. This thesis identifies that there has been a lack of discussion regarding the impact of undertaking rehabilitation and developing a sense of self as a person with Cerebral Palsy. By conducting semi-structured interviews with 16 children and young people who identified as having Cerebral Palsy about their experience of the rehabilitative process, this research makes three main findings; rehabilitation contributed to participants' psycho-emotional response to their walking ability; rehabilitation constructed a version of independence, which impacted participants' sense of self when the reality differed from their expectation; and, due to their lack of agency in the process, rehabilitation led to participants experiencing internalised oppression based on a belief that they had to improve their functionality through therapy. Based on these findings, this thesis makes a recommendation for further research into people with Cerebral Palsy's experiences of pain and degeneration, and a policy proposal that rehabilitation services should take a lifelong approach to enhance the physical, social, and psycho-emotional well-being of children, young people, and adults with Cerebral Palsy.

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Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature:

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Chapter 1: Introduction and Overview of Thesis

This study explores the impact of rehabilitation on the psycho-emotional development of children and young people with Cerebral Palsy. As a person who has Cerebral Palsy, I believed that having regular physiotherapy from the age of 2 until the age of 18 had a bearing on my perception of being a disabled person in society. As a young child, my parents were given numerous contrasting prognoses of my future ability, from not living beyond a young age to being able to function 'normally'. Rehabilitation was offered - though my parents did not believe it to be optional at the time - as a route to attaining the maximum potential functionality that I could possibly achieve. Accordingly, they pursued, and I attended, Physiotherapy, Occupational Therapy, and Speech and Language Therapy sessions (typically weekly), engaged in home exercises and stretches, and wore orthopaedic splints throughout childhood. In constantly being encouraged to strive to become more functionally able than I was, I believe my sense of self is based on the notion of not feeling good enough for myself and others. I wanted to find out if this was a shared phenomenon amongst children and young people with Cerebral Palsy. Throughout this thesis I have considered the psycho-emotional impact of an impairment that I have, and the process of going through rehabilitation, which I did during childhood - the effects of which I continue to experience. While acknowledging the similarities between me and my participants' experiences, and thus having an in depth understanding of Cerebral

Palsy and the rehabilitative process, I appreciate that my own perspective, as a white middle-class cis-male will have been influenced by the privileges those characteristics enjoy. In researching these themes, I have recognised and continuously reflected upon my positionality and the effect it has had on my interpretation of the data, as I gathered, discussed the findings, and constructed theory based on the experience of my participants.

To study the sociological impact of the phenomenon of growing up with Cerebral Palsy in rehabilitation, this thesis takes a qualitative approach to the data collection and analysis of the views and experiences of children and young people with the impairment. This study combined two research paradigms: emancipatory and biographical research. Following the principles of emancipatory research, which promotes that disabled people should have control over the research process, this thesis seeks to highlight the lived experience of people with Cerebral Palsy by considering the medical, social, and attitudinal factors that influence their sense of self as they go through the rehabilitative process (Oliver, 1992; Barnes, 2004). By taking a biographical approach, this research allows for the individual's construct of their life to be examined within the social context of the phenomenon being researched (Miller and Schütze, 2011). In asking 16 young people with Cerebral Palsy to reflect on their experiences of having undertaken rehabilitation throughout childhood, this thesis seeks to consider its influence on their psycho-emotional development. In doing so, this research bridges the gap in the understanding of children and young people's perspectives of being in rehabilitation and adults' experience of ageing with Cerebral Palsy, and, by considering the psycho-emotional dimensions of rehabilitation, identifies a connection between the rehabilitative narrative and participants' sense of self. The following sections set out the main literature that will be discussed, the research objectives, and the structure of the thesis.

1.1 Introducing key concepts

The study of both Cerebral Palsy and rehabilitation for children and young people with it has been predominantly explored through the medical lens since their discovery in the 19th and 20th Century respectively. Discussing the key concepts of this thesis in turn, the first subsection considers the medical and social constructions of Cerebral Palsy and research on its impact on the lives of children, young people and adults with the condition. The medical approach to Cerebral Palsy focuses on the biological aetiology (cause), diagnosis and treatment options - typically rehabilitation and surgery - of those with symptoms of the condition, which present within their formative years. Social theorists, particularly those within disability studies, have provided alternative perspectives on the lived experiences of people with impairments, focussing on the environmental and attitudinal barriers within society, which they contend restricts disabled people from participating equally. The influence of feminist theory, however, has sought to incorporate the individual experience of impairment and the effect of negative interactions within medical institutions and wider society on people's psycho-emotional well-being, which have been shown to be disabling. Research shows children and young people with Cerebral Palsy experience impairment related effects - such as muscle spasticity, postural control, an impaired gait, pain, and fatigue - social exclusion due to participatory barriers, and psycho-social impacts of feeling seen to be viewed as different by others, which are all factors in their perspectives of living with the condition.

Secondly, the medical construct of rehabilitation and the social critique of it is introduced. Due to the medical nature of rehabilitation, the literature covered discusses the biomechanical underpinning of the therapies provided to children with Cerebral Palsy and the evidence of their efficacy. Though there is limited research on the efficacy of rehabilitation, the literature largely covers the physical improvements of its impact. Meanwhile, the social critique of giving rehabilitation to children, young people, and adults with impairments, has questioned the individualised nature of medical approaches that attempt to ‘fix’ and return people to a standardised ‘norm’ (Oliver, 1993; Barnes, 2003; Abrams as cited in Nicholls, 2015; McLaughlin and Coleman-Fountain, 2014). Finally, the main study into children and young people with Cerebral Palsy’s perspective of rehabilitation has identified that their participation in it is both influenced by the social stigma of having an impairment and is, in itself, stigmatising for creating a different childhood experience to non-impaired children (McLaughlin, 2017).

1.1.1 Cerebral Palsy

Cerebral Palsy is one of the most prevalent long-term physical impairments in Scotland, impacting between 1.77 and 2.11 in 1000 live births (Bugler, Gaston and Robb, 2018). It is caused by brain damage, such as there being a lack of oxygen supply, prenatally, during, or immediately after a child’s birth (NHS, 2021). Children with Cerebral Palsy are diagnosed through their failure to meet movement milestones. The National Institute for Health and Care Excellence (NICE) describe milestones that children should reach as being indicators of typical development, including being able to sit independently by eight months, walk unaided by 18 months, and have a preferred hand for carrying out tasks by one year. For children with Cerebral Palsy, these milestones may be reached at a later stage or not at all (NICE, 2017). Due to the heterogeneous nature of Cerebral Palsy, each child will be impacted differently by both the severity and combination of impairment related effects. However, there are some common traits that impact on children’s physical, learning and psychological well-being and functioning (NICE, 2017). Children are perceived to have physical differences to typically developing children, which impact their muscle control, muscle coordination, muscle tone, reflex, fine motor skills, gross motor skills, oral motor functioning, posture, and balance (Das and Ganesh, 2019). Children and young people with Cerebral Palsy can also experience a number of mental health issues or psychological and neurodevelopmental disorders, and one in four have been reported to experience emotional and behavioural difficulties such as low self-esteem (NICE, 2017).

Meanwhile, the social model of disability, which reconceptualised the phenomenon of being disabled as a societal issue, considers that people with impairments, such as Cerebral Palsy, are excluded from fully participating in society due to environmental, structural, and attitudinal barriers (Oliver, 1990). By moving away from seeing disability as an individual issue, the social model focuses on the cause of disability as being the result of an inaccessible environment, discrimination, and prejudice (Barnes, 2003, Williams, 2001). While this has reframed the research into the lives of disabled people by approaching disability as a social construct, feminist theorists have particularly highlighted the need to recognise the interaction between the personal impact of impairment, such as acknowledging pain for example, and the experience of living in a disabling society (Morris, 1991; Thomas, 1999; Fawcett, 2000). In progressing the social-relational approach to studying disability, feminist interpretation of psycho-emotional disablism has provided a lens through which to consider both the negative effects of contending with environmental barriers, prejudicial attitudes, and impairment effects on individuals' sense of self as a disabled person in society (Thomas, 1999; Reeve, 2004).

Building on social theories of disability, childhood disability studies has demonstrated that children with impairments acknowledge both 'barriers to doing' - recognising that environmental barriers prevent them from participating in activities alongside their peers - and 'barriers to being' - internalising the negative attitudes that can be directed towards their impairment - within their construct of being disabled (Connors and Stalker, 2006). However, it has often been found through their perspectives on these phenomena, that disabled children demonstrate resilience to growing up with an impairment (Davis and Watson, 2001).

Research into the lives of people with Cerebral Palsy has identified that they experience both impairment related effects and the social impact of living with the impairment. Research has demonstrated that young people with Cerebral

Palsy identify pain and fatigue as being the main experience of their impairment effects, and environmental barriers, such as poor access and inadequate transport, which impact their ability to participate in activities equally (Castle et al., 2007; Brunton and Bartlett, 2013). Such experiences in childhood are often both facilitated and inhibited by the support children require from their parents to participate equally, and yet are increasingly negatively impactful as young people with Cerebral Palsy transition into adulthood (Stewart, Lawless, Shimmell, Palisano, Freeman, Rosenbaum and Russell, 2011; Shimmell, Gorter, Jackson, Wright and Galuppi, 2013; Moll and Cott, 2012). At the same time, literature shows that people with Cerebral Palsy also experience challenges to their self-conception due to being perceived as different by others (Hammar, Ozolins, Idvall and Rudebeck, 2009; Shields, Murdoch, Loy, Dodd and Taylor, 2006). In turn, and specifically when young people with Cerebral Palsy get older, these aspects of living with Cerebral Palsy can influence their psycho-emotional selves in respect to their self-esteem and self-efficacy, experiencing inter-subjectivity when relating to others in society (Shuttleworth, 2000; Wiegerink, Roebroeck, Donkervoort, Stam and Cohen-Kettenis, 2006). Meanwhile, in the context of adults with Cerebral Palsy, research has shown that they contend with impairment effects that emerge as a result of ageing with Cerebral Palsy (Moll and Cott, 2012; Paterson and Watson, 2013). Analysis of the impact of this phenomenon demonstrates that the experience of pain, fatigue and degeneration that accompanies getting older with Cerebral Palsy is often unanticipated by people with the condition (Paterson and Watson, 2013). This, Moll and Cott identify, has been found to cause people to experience a biographical disruption due to a decreased ability to function as well as they previously had done (Moll and Cott, 2012; Bury, 1982; Charmaz, 1983).

1.1.2 Rehabilitation

The medical approach to treating children with Cerebral Palsy primarily involves rehabilitation - a term which incorporates the principles of both rehabilitation and habilitation that children with impairments typically receive (NICE, 2017; Pava-Ripoll and Granada-Echeverry, 2016). Paediatric rehabilitation for children with the condition typically includes physiotherapy, occupational therapy, speech and language therapy, and orthotic and surgical intervention (NICE, 2017). This thesis predominantly explores the impact of physiotherapy as it is the most commonly employed rehabilitative service for children with Cerebral Palsy, which they undergo from their early years until they transition out of child health services (Raine, Meadows and Lynch-Ellerington, 2009).

Current physiotherapeutic approaches are based on the Bobath method for treating children with Cerebral Palsy, which grew out of techniques used in the rehabilitation of stroke patients in the mid 20th century (Bobath and Bobath, 1956). The Bobath method is focussed on retraining neurological pathways damaged due to haemorrhages that disrupt the messages between the cerebral cortex and nervous system, which controls movement. Neurodevelopmental Treatment (NDT), which is the basis for the Bobath method, advocates that repetitive exercise can encourage ‘normal patterns of movement’ in the developing child (Zanon, Pacheco, Latorraca, Martimbianco, Pachito, and Riera, 2019; Barry, 1996; Bobath and Bobath, 1956).

As the rehabilitative practice developed, however, differing approaches emerged, which emphasised other elements of rehabilitation, such as strength-based and functionality-based therapy with the intention of improving children with Cerebral Palsy's biomechanical ability to function. Around the same time as the development of rehabilitation, Conductive Education became an alternative approach; attempting to teach children to learn methods of movement associated with typically developing children (Reddihough, 1991). This was based on Andras Peto's approach of learning through repetitive movements and promoting 'goal-oriented' functioning, whereby children with Cerebral Palsy would be encouraged to do while sitting on wooden plinths for long periods per session (Bourke-Taylor et al., 2007).

The evaluation of the impact of rehabilitation on children and young people with Cerebral Palsy has predominantly explored its medical and physical effects. Research has demonstrated that strength-based therapies have been found to show the most significant improvements in their physical function. However, evidence of rehabilitation's impact on children's ability to undertake tasks remains limited (Martin, Baker and Harvey, 2010; Rosenbaum and Gorter, 2011).

The concept of providing rehabilitation to individuals with impairments has been critiqued more broadly, with proponents of the social model of disability arguing that the rehabilitation of disabled people is based on a curative approach related to the individualised model of impairment (Oliver, 1993; Barnes, 2003; Hammell, 2006).The development of the social model of disability marked the move away from the medical model in which people are seen to be disabled as a result of their condition or impairment. Instead, disability theorists have advocated that the focus of rehabilitation should be on adapting the environment and shifting attitudes of those with impairments and wider society towards their acceptance (Nicholls, 2015; Trede, 2012a). However, debate remains over the role rehabilitation has in enabling and empowering people with impairments to attain their own sense of normality (Nichols, 2015; Bezmez, Shakespeare and Lee, 2021).

During the period being researched, children with Cerebral Palsy in the rehabilitative context, however, predominantly remained under a medical gaze and were subject to medical interventions, which aim to promote and attain 'normalcy' (Moll and Cott, 2012; McLaughlin and Coleman-Fountain, 2014). The majority of studies identified, which have taken a social approach to analysing children's perspectives of rehabilitative techniques, have been based within the medical discipline and thus focussed on its functional impact on children and young people's social experiences (McBurney et al., 2003; Skold et al., 2007; Himpens et al., 2013; Gaskin et al., 2012). This method of research has increased children and young people's agency in evaluating the therapies they undertake. Studies into the impact of specific interventions have been found to be viewed positively by participants, given that they often improve their physical functionality in the short-term. However, reviewing the longer-term effects of rehabilitation, children and young people's perspectives on such interventions wanes over time (Himpens et al., 2013). Contextualising the long-term aim of rehabilitation in the lives of children with Cerebral Palsy, Bantjes et al. found that participants in their study made a clear connection between the medical construct of their impairment and the role of intervention in reducing the impact of it (Bantjes, Swartz, Conchar and Derman, 2015).

> *They believe doctors have the power to reduce their disability. The participants describe an acute desire to have their bodies 'repaired' and returned to 'normal' so that they no longer experience the limitations imposed on them by their Cerebral Palsy. Implicit in the way they speak is a view of disability congruent with the dominant medical discourse, but they also speak in ways that valorise discourses of independence. (Bantjes et al., 2015, p.251)*

Further to this, the main study to have been identified that bridges the social analysis of disability with the medical approach to rehabilitation - the SPARCLE project - considered stigma as being influential in children and young people with Cerebral Palsy's approach and response to having rehabilitation (McLaughlin, 2017). In exploring their participants' views on having rehabilitation while going through the process, the SPARCLE project found that children and young people believe it to be a root to reducing their experience of stigma within society but also a stigmatising experience in itself.

Finally, considering the psycho-emotional impact of medical intervention, it has been contended that children are more vulnerable to 'internalised oppression', incorporating societal beliefs about disability that can be disabling, as a result of their deference to medical and parental authoritative figures who hold 'normative' expectations (Reeve, 2004). It has been argued that the impact of giving children constant medical interventions designed to change aspects of their body could leave children disliking them and create a sense of failure if they do not improve (Middleton, 1998; Reeve, 2004). Reeve has demonstrated the effects of internalised oppression in childhood, such as having to manage relationships and societal perspectives of their impairment, being subject to the 'public gaze', which includes being examined publicly within medical settings, and experiencing internalised oppression can have a lasting impact on disabled adults (Reeve, 2003).

The literature pertaining to children and young people's experiences of growing up with Cerebral Palsy and of rehabilitation, discussed in this section, will be considered as this thesis seeks to explore the role of rehabilitation in the psycho-emotional development of children, young people, and adults with Cerebral Palsy.

1.2 Research Objectives

Bringing together the concepts discussed above, this thesis considers whether the rehabilitative process that children and young people with Cerebral Palsy undergo contributes to their construction of their sense of self and whether this impacts their sense of self as young people with Cerebral Palsy without ongoing access to regular rehabilitation. This thesis accordingly has two main objectives:

1. To explore the impact of undergoing rehabilitation on the psycho-emotional development of children and young people with Cerebral Palsy.
    a. To consider the impact of rehabilitation on children and young people's construction of having Cerebral Palsy.
    b. To consider the contributory factors to children and young people with Cerebral Palsy's approach to, and understanding of, rehabilitation.

2. To examine the effect of having access to rehabilitation withdrawn on the sense of self of young adults with Cerebral Palsy.
    a. To consider the long-term impact of the rehabilitative narrative on the psycho-emotional experience of young adults with Cerebral Palsy.
    b. To consider the psycho-emotional impact of experiencing ageing and increasing impairment effects with Cerebral Palsy without ongoing access to rehabilitation.

1.3 Structure of Thesis

This section summarises the following chapters and highlights the main themes that are discussed over the course of this thesis. The thesis consists of; two literature review chapters, Chapter 2 outlines the medical and social analysis of being born, growing up and ageing with Cerebral Palsy, and Chapter 3 discusses the theory behind rehabilitation and children and young people's experience of it. Chapter 4 outlines how I undertook the research and approached the analysis of the findings. Chapters five, six and seven sets out these findings in turn, discussing; the role of rehabilitation in participants' social experiences; the influence of the rehabilitative focus on improving participants' walking ability on their sense of self; and the impact of becoming an adult without access to rehabilitation on participants' physical, social and psycho-emotional well-being. The thesis concludes with Chapter 8, where I draw together the discussions on the main data findings, along with methodological reflections on using biographical research. This chapter finally outlines a proposal for future research into children and young people's construction and conceptualisation of living with the degenerative effects of Cerebral Palsy and includes policy recommendations.

Through the following chapters this thesis argues that psycho-emotionally, participants struggled to reconcile the rehabilitative narrative on normative assumptions of child development, and latterly, of independence, with the reality of being a person with Cerebral Palsy. The data produced three main findings: rehabilitation contributed to participants' psycho-emotional response to their walking ability; rehabilitation constructed a version of independence, which impacted participants' sense of self when the reality differed from their expectation; and, due to their lack of agency in the process, rehabilitation led to participants experiencing internalised oppression based on a belief that they had to improve their functionality through therapy. Given the prevalent theme of pain and ageing that emerged through this study, this thesis proposes that future research should explore the role of rehabilitation in children, young people and adults with Cerebral Palsy’s understanding and construction of living with a condition that degenerates. Considering the policy implications of these findings, this thesis proposes that the aims and expectations of the rehabilitative process should be co-produced with children, young people, and their families, and continuously available to adults with Cerebral Palsy to manage the long-term physical, social and psycho-emotional effects of living with the condition.

Chapter 2: Cerebral Palsy

This chapter explores the construction of Cerebral Palsy within a medical and social context of childhood disability, in order to situate the experiences of children and young people with the impairment growing up in Scotland. This is achieved by considering the key theories on the medical diagnosis of Cerebral Palsy and social research into living with the impairment effects, their interaction with stigma, the social and environmental barriers they incur, and the psycho-emotional effects of disablism within the medical and social spheres that children and young people with Cerebral Palsy grow up in.

The first section considers how Cerebral Palsy can be analysed from a disability studies' perspective. The main theoretical positions for understanding disability include; the individual model of disability, which is characterised by diagnosis, treatment and cure of individuals who deviate from normal functional development or ability; the inter-relational model, which sought to recognise the social context in which people experience having an impairment; and the social model that grew out of a social movement of disabled activists and academics from the mid 20th century onwards, which considers people with an impairment to be disabled by social, attitudinal and environmental barriers that are imposed upon them (Marks, 1997; Oliver, 1990; Finkelstein, 1993; Barnes, 2003). While the medical model focuses upon individuals as being disabled by their conditions or impairments, the social model argues that people are disabled as a result of society. However, the feminist critique of the social construction of disability gave rise to a more nuanced consideration of the impact that both impairment and social barriers have on disabled people. The social-relational model that grew out of this critique introduced the concept of psycho-emotional disablism; the theory that people with impairments can experience negative responses from society, which have disabling consequences on their perspectives of themselves, leading to internalised oppression (Morris, 1991; Crow, 1996; Thomas, 1999; Reeve, 2004). The section then finally considers the development of disabled childhood studies, which has identified that children with impairments experience barriers to participation and barriers to identifying as disabled (Reeve, 2004; Stalker and Connors, 2003; Connors and Stalker, 2006). The models discussed in this section are used in this thesis as a tool for analysing participants' experiences of growing up in the rehabilitative process.

Secondly, this chapter explores the literature on the medical process of diagnosing children born with symptoms of Cerebral Palsy and the qualitative impact of the diagnostic processes on their parents. This will give a context for the family life in which participants in this study grew up. Literature has focussed on the medical cause of Cerebral Palsy, which occurs from damage to the brain before, during, or following birth. It is the most common physical disability in childhood with the current prevalence of Cerebral Palsy in Scotland being around 2 per 1,000 live births (Stavsky, Mor, Mastrolia, Greenbaum, Than and Erez, 2017; Novak et al., 2017; Bugler, Gaston and Robb, 2018). Between the birth and diagnosis of their child, research has found that parents experience a mixture of emotions and a lack of support, in part due to the length of time it takes to make a conclusive diagnosis of Cerebral Palsy (Fernańdez-Alcántara, García-Caro, Pérez-Marfil, Hueso-Montoro, Laynez-Rubio and Cruz-Quintana, 2016). Upon receiving this diagnosis, parents of children with Cerebral Palsy have been found to experience ‘courtesy stigma’ due to societal reactions to their child’s impairment and adopt a co-therapist role in an attempt to reduce the impact of the impairment on them (Greene, 2003, p.1362; Ryan and Runswick-Cole, 2008).

Penultimately, the chapter focuses on the main implications of being a child or young person with Cerebral Palsy; impairment effects, social, physical and environmental barriers, and psycho-emotional effects have all been identified as having an impact on the lived experience of young people with the condition, growing up in society (Brunton and Bartlett, 2013; Shimmell et al., 2013; Stewart et al., 2011; Hammar et al., 2009; Shuttleworth, 2000). The literature concerning the impact of each of these phenomena upon young people with Cerebral Palsy has been predominantly from a rehabilitative perspective. Therefore, the findings of such studies - that young people with Cerebral Palsy experience impairment related effects, such as pain and fatigue, and social barriers, such as restricted access to participation which increases as parental support dissipates – have been used to support the intention of improving services to alleviate the effects of their impairment (Bantjes, Swartz, Conchar and Derman, 2015; Shimmell et al., 2013; Hammar, Ozolins, Idvall and Rudebeck, 2009).

The final section of this chapter considers the literature on the experience of becoming and being an adult with Cerebral Palsy, which has been based on theory pertaining to biographical disruption. Biographical disruption theory, which will be discussed first, laid the foundation for analysing the accounts of people with the onset of impairments who experience significant changes to their social sense of being, and has also been identified as leading to a ‘loss of self’

(Bury, 1982; Charmaz, 1983; Williams, 2001). Research has established that, in early adulthood, young people with Cerebral Palsy experience a biographical disruption that challenges their sense of self when the onset of physical deterioration begins following their departure from childhood rehabilitation (Moll and Cott, 2012). On ageing with Cerebral Palsy, research has further identified that people with the condition experience increased pain, fatigue, and impairment effects, which they had not expected due to it being considered a 'non-progressive' condition (Paterson and Watson, 2013).

2.1 Models for Analysing Disability

There are three main theoretical positions of disability, which will be used to analyse participants' experiences of growing up with Cerebral Palsy: the individualised medical model - promoting individual's return to normalcy; the inter-relational model as defined by the International Classification of Impairment, Disability and Handicap - promoting individual's functional integration in society, and the sociopolitical model - promoting structural changes to society (Barnes, 2003).

The individual model, which was, and continues to be, the predominant medical approach to disability locates the impact of an individual's impairment, for example Cerebral Palsy, within the biological self and is characterised by prevention, diagnosis, treatment, management, and cure of the individual (Marks, 1997). This locates the problem of disability at the individual level and focuses on rehabilitation as the solution (Finklestein, 2001). This medical model promotes the diagnostic labelling of individuals who are considered to have a deficit to normal function (Goar, Davis and Manago, 2016).

The social model provided an alternative to the medicalisation of disability on the basis that 'disability is a social state and not a medical condition' (Oliver, 1990, p.3). It firmly set a distinction between the role of medical intervention with respect to illness and disability, accepting the role of medical intervention and treatment of illness, but arguing that the same could not be applied to disability, as this is a social construct (Oliver, 1990; Barnes, 2003; Williams, 2001). Feminist literature has however criticised the disability movement for being too heavily focused on organisational structure, contending that the social model 'downplays or ignores the cultural and experiential dimensions of disablism' and specifically excludes the impact of personal experience in understanding the 'daily lives of disabled people' (Morris, 1991; Crow, 1996; Thomas, 1999).

2.1.1 The individual model

Disability, from a medical perspective, refers to illness, impairment, and disease. The individual model focuses on the pathology of individual impairment, which is identified as a ‘loss or abnormality’ of function (Marks, 1997, p.87). The medical approach to disability is based on the following principles: ‘health is the absence of disease’; illnesses have underlying abnormalities in bodily function; adverse symptoms are solely caused by illness or disease; patients with illness or disease have little or no responsibility for its causation; and the patient is expected to participate in treatment (Wade and Halligan, 2004, p.1398). These principles can be seen to be reflected in the current treatment approaches across the UK, for example, within the prescription of medicine, rehabilitation, or preventative and corrective surgical intervention.

Broader definitions of health have been offered and adopted to some extent, such as that proposed by the World Health Organisation (WHO). Following the Second World War, the WHO developed a definition, which extended the universal interpretation of health to be the "state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity" (World Health Organisation, 1946). While the WHO's definition progressed the sociopolitical understanding of health, as Badash et al. write, it has been widely critiqued for being too impractical to be applicable in a health and social context (Badash et al, 2017). However, Leonardi argues that by taking a social constructivist approach to defining health, an individual's interpretation of their condition within the social and environmental context can be more reflective of the holistic nature of living with one (Leonardi, 2018). Yet, the rehabilitative models that participants in my study were engaged in, and will be discussed in Chapter three, arguably predominantly follow a deficit model of health.

Coining the phrase, the 'medical model', disabled activists sought to challenge the dominance of an overly medicalised conceptualisation of disability in health and social care settings (Larson, 1999). The medical model was considered to individualise disability and considers the notion of having an impairment as a 'personal tragedy' (Finkelstein, 1996). Disabled activists and academics’ objection to the medical model was predominantly based on its conflation of illness and disability, which suggested that the medical profession could treat and cure impairment (Oliver, 1990). As Barnes suggested, under the medical model, which referred to the medical approach in developed Western cultures, “disabled people become objects to be cured, treated, trained and changed and made ‘normal’ according to a particular set of cultural values” (Barnes, 2003, p.9). This is the predominant approach to treating children diagnosed with Cerebral Palsy, as discussed in the next chapter.

2.1.1.1 The inter-relational model

As an attempt to recognise the limitations of the individual medical model, disability theorists and activists advocated for a more social-relational approach, which acknowledged a person’s impairment but argued that disability was caused by prejudice and discrimination towards them in the form of attitudinal, physical and social barriers to their participation in society (Barnes, 2003). Attempts were made by the WHO to progress the definition of disability in response to campaigning for the recognition of the distinction between impairment and disability, which the medical model failed to do. The ‘inter-relational’ model of disability therefore attempted to bridge the individualistic medical model approach with a social construction of disability (Barnes, 2003, p.14). The premise of the inter-relational model was based on the International Classification of Impairments, Disability and Handicaps (ICIDH) schema constructed by the WHO, which defined impairment as 'any loss or abnormality' of functions, disability as the 'restriction or lack of ability' to perform activities normally (due to impairment), and handicap as a disadvantage resulting from impairment of disability, which limits performance of normal roles. The approach was critiqued, however, for remaining rooted in the individual as it concerns an individual's body, how they function, and their 'participation' in society being dependent upon rehabilitation (Barnes, 2003, p.14). While this schema allowed for social disadvantage to be recognised, opposition to the ICIDH's definition concluded that it was premised on a medical interpretation of normative function, which placed too much emphasis on the medical treatment of socially responsible disadvantages and failed to acknowledge the social factors that cause the exclusion of disabled people (Barnes and Mercer, 2003).

In 1996, in response to the debate surrounding the ICIDH's emphasis on the individual's impairment being the root cause of their experience of disablism in society, the WHO began to revise its definition of disability. As Bickenbach et al. note, the revised definition, initially drafted under the title the ICIDH-2, which was based on the biopsychosocial model of health, sought to recognise three dimensions which together constitute disablement; impairment, activity limitations and participation restrictions, taking account of all areas of a person's life (Bickenbach, Chatterji, Badley and Üstün, 1999). The International Classification of Functionality, which superseded the ICIDH-2 as the published update to the ICIDH, attempted to embrace both the medicalised interpretation of impairment and social theory, considering the conditions that disadvantage people with impairments as being socially created (Imrie, 2004). Published in 2001, the ICF defined disability as 'the negative aspect of the interactions between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)' (World Health Organisation, 2001, p.221). However, while the ICF reinterpreted the effects of one's impairment to be the interaction between their bodily function and their environment, it maintained the medical conceptualisation of impairment as the defective form of functionality, which deviates people from the norm. As Imrie (2004) notes, this drew criticism from proponents of the social constructivist perspective of disability for its ontological categorisation of a 'norm', suggesting that impairment represents a biological difference only inhibiting an individual due to the social, cultural, and economic context in which it is situated. Others, particularly those from a medical sociological perspective, consider the identification of bodily divergence to be a useful classification of function, on top of which the psychosocial determinants of health can be understood (Imrie, 2004). While recognising its wide applicability, especially in policy and medical and rehabilitative settings, Mitra and Shakespeare have called for an update to the ICF, citing three areas of improvements in its definition. Firstly, they argue that the ICF definition should include socioeconomic determinants of health on the same footing as the three original disabling factors, bodily impairments, activity limitations and participation restrictions, thus recognising the two directional impact of health conditions on people's experiences of the personal and environmental factors of disability. Secondly, the definitions of 'activities' and 'participation' are thought to be too narrow in their scope, focussing on the ability to do each, instead of the impact of doing so on the person's life and how they want to live it. Mitra and Shakespeare point to the role that agency should play in appreciating whether an individual is involved in determining the direction of their lives. Finally, they critique the use of the ICF in categorising disability in policy and medical spheres due to its reliance on judging functionality against ‘normative’ standards and by its nature cannot fully appreciate people with impairments and health conditions’ lived experience of disability (Mitra and Shakespeare, accepted 2019, p.3). Without these updates, it is arguable that the definitions of disability discussed in this section remain too focused on the medical construct of impairment.

2.1.2 The social model

In contrast to the medical model, the social model placed the onus onto wider society to address the role of disability within it. It acknowledged that there were social and economic consequences of living with chronic illness and disability (Barnes and Oliver, 2012). The social model was based on the principle that disabling barriers are socially constructed and thus could be removed (Ferrie, 2008). Such a re-interpretation of the social interaction between people with impairments and societies instigated the development of a new framework of disability within academia, which would provide a multidimensional approach to explore the process of 'disablement' (Finkelstein, 1996). At the same time, disabled people and the organisations representing them sought to raise demands for economic equality at a political level and for the 'articulation' of their needs to be central to the social construction of disability (Oliver, 1983). This notion challenged medical traditions, which was labelled as the ‘medical model’, of offering treatment to people with impairment, such as therapy and surgery, in an effort to ‘make disabled people normal’ (Marks, 1997, p.88).

In Britain, the creation of the Union of Physically Impaired Against Segregation (UPIAS) reframed disabled people as people with impairments who have disabilities imposed on them by barriers to their participation and inclusion in society (1975). Oliver is widely recognised as having provided a framework that reinterpreted disability as a social phenomenon. This laid the foundations for what is widely known as the social model of disability (Oliver, 1983). The development of the social model of disability built on the ICIDH distinction between impairment (bodily limitations) and disability (environmental barriers), placing impairment and disability within a sociopolitical framework (Barnes, 2003; Oliver, 1990; Finkelstein, 2001). The strength of the sociopolitical model was to relocate disability within the social-relational dimension of barriers. The effect of the social model has been to promote the principles of accessibility of the environment, i.e., removing physical barriers, introducing flexible work structures and increasing awareness of inclusivity (Oliver, 2013).

The social model's main achievement has been to break the link between bodies and social situation and to focus on the real cause of disability: discrimination and prejudice (Williams, 2001). Shakespeare and Watson cautioned, however, that prevention or treatment of certain impairments should not be perceived as a challenge to the social model perspective of disability, but rather as an accepted construct within a society without disabling barriers (Shakespeare and Watson, 2002). In promoting the social model, Oliver accepted there was still a role for medical professionals in the 'treatment of illnesses in most circumstances', however, it was felt that rehabilitation was driven by an ideological pursuit of a normative form, which is driven by the medical profession ‘at whatever cost’ (Oliver, 1990, p.4-5). Moreover, a central criticism of rehabilitation was that the process was unlikely to lead to increased employment and independent living opportunities for disabled people (Barnes, 2003). Although Barnes argued that challenging the epistemological basis of the social model reinforces the medicalised approach of rehabilitation (Barnes, 2003), the social model’s reduction of the impact of impairment effects is felt by others not to adequately consider disabled people’s experiences and therefore there remains a requirement for rehabilitation in some circumstances (Shakespeare and Watson, 2002).

Acknowledging that the social model is limited in that it does not fully incorporate the impacts of impairment within a society fully inclusive of people with impairments, Watson and Shakespeare argued that in trying to eradicate discriminatory barriers within society, action can also be taken to mitigate against impairment and the effects it induces (Watson and Shakespeare, 2001). In presenting the case for an updated social theory of disability, they point to a multi-dimensional approach offered by Shakespeare and Erickson, which would incorporate the 'bodily, psychological, cultural, social, and politics' aspects of disability (Shakespeare and Erickson, 2000). Watson and Shakespeare also contended that omitting the body from analysis of disabled peoples’ experience of society did not adequately reflect their lives (Watson and Shakespeare, 2002).

2.1.2.1 Feminist critique of the social model

The emphasis towards a social model of disability studies, in its attempt to externalise disabling barriers within society rather than appropriating disability within individual impairment, has been critiqued by proponents of a social-relational approach associated with feminist theorists (Oliver and Barnes, 2012). Morris, for example, argued that a continued denial of the personal experience of disability will lead to the individualisation of difference which will result in a "sense of personal blame and responsibility" (1991, p.118). Feminism has given disability studies a lever for exploring the interaction between the social model of disability and disabled peoples' personal experience of "impairment difference and diversity", illustrating that the two are not mutually exclusive (Fawcett, 2000, p.5; Morris, 1991; Thomas, 1999).

To explore the significance of disabled people's personal experience in understanding the 'nature and social meaning of their impairment(s)', Thomas developed the social-relational model of impairment, which provided a framework for bringing the experience of impairment back into the analysis of the lives of disabled people (Thomas, 1999). Thomas proposed a '*social relational* definition of disability', which recognised that the restrictions caused by impairment do not in themselves constitute disability in the 'social relational sense' (1999, p.40). This was premised on the notion that impairment effects, which impact upon the individual's ability to complete certain activities, only become disabilities if the environment in which they present prevents the individual from accessing their right to participate in society. In this respect, impairment effects constitute elements of both biological and social factors, which can be 'melded together in a holistic fashion' in order to appreciate the lived experience of disabled people. In defending this approach from the potential criticism that the acknowledgement of impairment effects 'let's the medical model in by the back door', Thomas made the case that viewing impairment effects in a social-relational framework allows for both medical sociologists to appreciate the interaction between impairment and social-relational perspectives of disablement, while enabling an understanding of the different forms of oppression that can be attributed to the social interaction of the effect of the individual's impairment (Thomas, 1999). It was Thomas' appreciation of the dualistic nature of the barriers that prevent disabled people, not just from *doing* – as suggested for the theoretical basis of discrimination against disabled people within society – but from her hypothesis that psycho-emotional dimensions of disablism erect barriers to *being*, which significantly contributed the social-relational model of disability (Thomas, 1999). Thomas described the psycho-emotional dimensions of disablism as:

> *... a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being. (Thomas, 1999, p.3)*

Describing in more detail how such practices present themselves, Reeve (2004) considered three dimensions of psycho-emotional disablism. The first dimension explored the impact of physical barriers to inclusion, which Reeve argued serve to reaffirm disabling constructs within society that consistently undermine disabled people's participation in it (Reeve, 2004). Secondly, the social interactional dimension of psycho-emotional disablism includes a variety of exchanges between disabled and non-disabled people, which challenge the right of the former to be treated equally within society. The many interactions that can undermine a disabled person's status, from being stared at, being asked inappropriate personal questions, and having assumptions made about their abilities, led Reeve to consider stigmatisation as a form of psycho-emotional disablism, which erects a barrier to disabled people's interaction with and within social settings (Reeve, 2004). Thirdly, Reeve also considered internalised oppression as a form of psycho-emotional disablism. This provided an understanding of disabled people's reaction to disabling attitudes by acknowledging that they can internalise these values and attribute them to their perception of themselves (Reeve, 2004). By adopting the negative stereotypes, it is suggested that disabled people can believe that their impairment is synonymous with their being disabled by those who hold such attitudes. While this theory has been challenged on the basis that it is thought to reinforce the individualisation of the disability, Thomas would argue that psycho-emotional effects are socially constructed, which amount to the stigmatisation of people with impairments that in turn prevent them from being a part of society for fear of being stigmatised (Thomas, 1999; Shakespeare and Watson, 2010). However, as Thomas admitted, the appropriation of the psycho-emotional dimensions of disablism to understanding the embodied nature of disability depends upon a holistic understanding of the’ 'lived experience' of those with impairments (Thomas, 1999). This thesis aims to do so by considering young people with Cerebral Palsy’s experience of rehabilitation and its impact on the construction of their sense of self.

2.1.2.2 Analysing the lives of disabled children and young people

Building on the academic movement to study the lives of disabled people from a sociological perspective, research into the experiences of disabled children and young people has developed as a paradigm in its own right. Theorists exploring their perspectives of having an impairment have identified specific challenges to their conceptualisation of the barriers they face as disabled children and young people. As its starting position, Davis has argued that the medical approach towards childhood has focussed on a deficit model of impairment.

> *'Medical model' ideas pathologized children who failed to meet standardised developmental targets, viewed disability as the natural consequence of impairment rather than being caused by society, it ignored the structural and cultural barriers that blocked disabled children's inclusion, and resulted in professionals over preoccupied with measuring children's bodies and minds rather than their inclusion into society.*
> *(Davis, 2012, p.415)*

As a result of such pathologization, when discussing disability, disabled children and young people have been found to reflect on their impairment in 'medical terms', due to their frequent interaction with medical professionals (Stalker and Connors, 2003; McLaughlin, 2017). Stalker and Connors found that children and young people showed pragmatism towards the medical treatment of their conditions, simultaneously recognising and opposing a 'personal tragedy' model of impairment (Stalker and Connors, 2003). In contrast to the medical professions' tendency to assimilate impairment with the identification of being disabled, their participants simply accepted that their impairment was a part of their lives.

In researching the lives of disabled children and young people through the lens of childhood and disability studies however, disability childhood theorists have sought to incorporate the principles of the social model into the understanding of how disabled children and young people experience growing up in a society with physical, social, and environmental barriers (Curran and Runswick-Cole, 2014). This discipline emerged from the social construction of disability as a paradigm for exploring the lives of children and young people with impairments as a distinct phenomenon within childhood. Stalker and Connors identified disabled children and young people as having ‘barriers to doing’ (Stalker and Connors, 2003). This, they described as restrictions upon disabled children and young people’s ability to participate in communal activities, such as a lack of physical access to schools and leisure facilities, and support to manage the additional factors of living with an impairment. The disability movement’s achievement was to promote social inclusion of disabled children through the removal of economic, social, and structural barriers (Davis, 2012). However, Shakespeare and Watson found that although children and young people might have identified the social barriers that disable them, they often “actively resisted definition as disabled” (Shakespeare and Watson, 2001, p.21).

Referring to Thomas' social-relational approach to disability discussed in the section above, 'barriers to being' have also been found to impact disabled children and young people, due to "to hurtful, hostile or inappropriate behaviour which has a negative effect on an individual's sense of self, affecting what they feel they can be or become" (Connors and Stalker, 2006, p.21). This was further reinforced by the abuse directed at disabled children by other children in the form of name-calling, teasing or exclusion (Stalker and Connors, 2003). Stalker and Connors identified that whilst it is the disadvantage or exclusion of young children that causes them to realise they are subject to disablism, older children recognised the disabling effects of negative attitudes through interactions with others who present barriers that enforce or reinforce the effects of their impairment (Stalker and Connors, 2003). Disability childhood studies have, therefore, found that psycho-emotional disablism can have a detrimental effect upon the psycho-emotional well-being of disabled children through the attribution of their impairment to their identification as a disabled child (Reeve, 2004).

> *Disabled children may experience more acute internalised oppression because their less powerful position means that they are more vulnerable to the views of the wider society; in addition, their parents may be unwitting oppressors in the process, because their beliefs and expectations will be shaped by the professionals they defer to (Reeve, 2004, p.91)*

Based on the dualist nature of disabled children's account of disablism, childhood disability theory has developed a more critical understanding of how disabled children interact within the social context (Watson, 2012). Evidence showed that the materialist position - that disabled children are oppressed by institutions and structures that fail to include them - is contradicted by childhood resilience to negative attitudes and discriminating practices; demonstrated by their exhibition of agency in the face of victimisation (Davis and Watson, 2002). Therefore, Davis and Watson argue that “In the same way that we need to move away from a model that fixes the identity of disabled children and from pathologizing them on the basis of their impairment, we also need to move away from a model that places all its emphasis on structural disablement” (Davis and Watson, 2001, p.170). This leads to the conclusion that an analysis of childhood disability cannot exist without impairment and that together, disability *and* impairment both constitute disablement. A more holistic account of disablism has been found to be required to analyse the experiences of children and young people with impairments.

> *... in thinking about disabled childhoods, ‘impairment effects’, ‘barriers to doing’ and ‘barriers to being’ all seem to have a place. Our findings suggest that the last of these may have particular significance during the childhood years, when young people are going through important stages of identity formation, which may lay the foundations of self-confidence and self-worth for years to come. (Conners and Stalker, 2006, p. 31)*

By taking account of disabled children's perspectives to both 'barriers to being' and 'barriers to doing', research into their lives can transcend the 'personal tragedy' model of disability and fully appreciate the significance of impairment in their development (Stalker and Connors, 2003). In doing so, research could fulfil the need Davis outlined for an account of childhood, which appreciates the complexity of identity development that disabled children navigate in the social construction of their childhood (Davis, 2012). However, the theories developed through such research discussed in this section have predominantly been based on the experiences of ‘disabled children’, including children with a variety of impairments, such as learning disability, autism, and Cerebral Palsy. While this approach identifies the social-relational phenomenon of having an impairment within a disabling society, this thesis contends, it restricts an in-depth analysis of the relationship between specific impairment related effects and children’s experience of engaging within a disabling society. This chapter seeks to address these issues by considering the specific social-relational dimensions of growing up in rehabilitation for children and young people with Cerebral Palsy.

2.2 Having a Child with Cerebral Palsy

This section focuses on the medical diagnosis of Cerebral Palsy that the participants in this study identified as having had since birth. The first subsection discusses the medical construct of identifying and diagnosing Cerebral Palsy from the 19th century to the present day’s understanding of the impairment. This gives an account of the main medical discoveries that led to Cerebral Palsy being recognised as a specific condition and yet it also demonstrates the complexities and outstanding contentions around the aetiology of the condition, which have led to the latest definition of it being a set of symptoms that become observable as children with Cerebral Palsy develop. Secondly, in response to receiving this diagnosis, usually around the age of 1 to 2 years of age, this section explores the findings of studies into the experience of parents who have given birth to a child with Cerebral Palsy in order to provide a context within which the participants in this study were related to by their parents from birth.

2.2.1 The diagnostic process of Cerebral Palsy

Cerebral Palsy first began to be medically explored in the early 19th century by Little (Panteliadis, Panteliadis and Vassilyadi, 2013). Multiple medical practitioners at the time were observing and documenting the effects of lesions (areas of damage) on different areas of the brain but it was Little, an orthopaedic surgeon, who identified damage that related to a specific group of symptoms being exhibited in children. These children presented with symptoms such as: abnormal muscle tone, i.e., muscles that are tighter or looser than typically developing children, or tone that fluctuates between the two; a lack of postural control; and muscles that go into spasms. Little described these symptoms as Cerebral Palsy (Pietrzak, Grzybowski, Kaczmarczyk, 2016). He observed that there were commonalities among patients between the severity of their condition - namely spasticity - and the degree of their prematurity or difficulty during labour when they were delivered (Panteliadis et al., 2013). It was later acknowledged that the term was a clinical description of the symptoms, typically perceived to be that of an infant with Cerebral Palsy, rather than an exact definition. This was due to the consideration that the condition was “clinically, pathologically and aetiologically heterogeneous"; each child was affected differently by the condition (Stanley, Blair, and Alberman, 2000, p.8).

In the latter half of the 19th century, the various identifiable traits of Cerebral Palsy came to be connected with brain damage at or immediately following birth. Osler, a professor in clinical medicine, studied the connection between asphyxiation during birth and Cerebral Palsy impairment effects (Panteliadis et al., 2013). Osler found that there was a cause and relation between intracranial haemorrhage as a result of lack of oxygen at birth and the development of Palsies including Cerebral Palsy (Panteliadis et al., 2013). Throughout the development of the understanding of the aetiology (causes) of Cerebral Palsy definitions focussed on the symptoms exhibited by children presenting with the condition (Novak et al., 2017). Freud, as a neurologist, contributed three key elements to the modern understanding of Cerebral Palsy (Panteliadis et al., 2013). In studying the brain matter of children diagnosed with hemiplegia (spasticity in one limb) and diplegia (spasticity in two limbs), now forms of Cerebral Palsy, Freud's main finding classified the three variations that occur and cause the condition: congenital (antepartum), acquired during birth (intrapartum), and acquired postnatally (postpartum) (Panteliadis et al., 2013). He secondly identified a correlation between the location of lesions, the areas of the body affected and the degree to which they were affected. Finally, Freud identified the different patterns of movement in children with Cerebral Palsy as forming a collection of movement disorder syndromes (Panteliadis et al., 2013). Following a hiatus in clinical research into Cerebral Palsy, Panteliadis noted that Phelps, an American orthopaedic surgeon, diverted research, and later treatment, from neurological to orthopaedic medicine, which foregrounded therapeutic treatment (Panteliadis et al., 2013). Phelps contributed the categorisation of Cerebral Palsies into five types; “spasticity, athetosis, rigidity, tremor and incoordination (or ataxia)” (Panteliadis et al., 2013, p.289).

Given the competing ideas about the causation and correlation between the defects that occur during birth and the resulting impairment on a child’s development, there have been numerous definitions of Cerebral Palsy since Little first identified the condition. In the mid 20th century, it was the Little Club, formed by a group of leading neurological surgeons and other medics, who came together to define Cerebral Palsy as a specific disorder. They published that Cerebral Palsy was a “persistent, but not unchanging disorder of movement and posture, appearing in the early years of life and due to a non-progressive disorder of the brain during its development” (Bax, 1964, p.264; Korzeniewski, Slaughter, Lenski, Haak and Paneth, 2018). Further definitions have been published that attempt to distinguish Cerebral Palsy from other movement disorders. However, Ferrari and Cioni argued that by 2005, the Little Club’s had remained the most universally accepted and widely acknowledged definition of Cerebral Palsy (Ferrari and Cioni, 2010).

More recently, however, the definition has included the impact of the impairment on the child, describing Cerebral Palsy as “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain” (Rosenbaum, Paneth, Leviton, Goldstein, Bax, Damiano, Dan, and Jacobsson, 2007, p.9). In 2017, it was recognised that "Cerebral Palsy can be derived from any event that will affect the foetal and neonatal developing brain" (Stavsky et al., 2017, para. 4). However, there remains ambiguity as the medical understanding of Cerebral Palsy does not explain definitively why these various causes lead to the symptoms exhibited.

The diagnostic process focuses heavily on the development of movement and involves the observation of movements, which signal that a child responds differently to that of children without Cerebral Palsy (Bobath and Bobath, 1956). Whilst a new-born baby without Cerebral Palsy will develop movements in a progressive manner, typically developing muscle tone that enables them to adopt normative posture to sit and stand independently, children with Cerebral Palsy will exhibit spasticity (tightness) of muscle tone during this process (Bobath and Bobath, 1956). As their muscle tone strengthens, the degree of spasticity affects the severity of a child's impaired motor function i.e., the ability to move their arms and legs to achieve standing, walking, lifting objects effectively and so on. Novak et al. argued that it was difficult to diagnose Cerebral Palsy with any certainty before the age of 12 months (2017), due to the nature of early physical development in young infants, i.e., developmental guidelines indicate that some children may sit up unaided at six months, whereas others may be unable to do so until nine months (Onis, 2007). This led to the common understanding that "a specific diagnosis of Cerebral Palsy in most primary care or paediatric practice settings is difficult to make with certainty during the first 1–2 years of life" (Patel, Neelakantan, Pandher and Merrick, 2020, p.126). However, recent advances in the diagnostic process, such as neonatal magnetic resonance imagining (MRI), combined with developmental assessment tools, have increased the accuracy of diagnosing children with Cerebral Palsy or “high risk of Cerebral Palsy” (Novak et al., 2017, p.899).

The most prevalent indication of a child’s likelihood of having Cerebral Palsy is when they “fail to reach their motor milestones” in relation to childhood developmental guidelines as described above (Rosenbaum, 2003, p.970). To avoid misdiagnosis, it is recommended that children who have been diagnosed with Cerebral Palsy as a result of exhibiting symptoms undergo investigation to attempt to establish the cause. They are recommended to be continually checked to ensure that the initial lesion is not progressive (Gupta and Appleton, 2001). As stated above, however, it is typically the case that a causation cannot be found (Rosenbaum, 2003). Many studies have therefore recommended that investigation continues to explore the aetiology of the child’s brain damage in an attempt to establish causation, in order to determine the most appropriate treatment and/or rule out any genetic implications for the family (Gupta and Appleton, 2001; Novak et al., 2017; Patel et al., 2020; Wood, 2006). This can mean that parents may have to wait a considerable amount of time between birth and diagnosis before knowing that their child has Cerebral Palsy.

2.2.2 Research into parents’ experiences of diagnosis

Since a child will be diagnosed with Cerebral Palsy as a baby or toddler, the initial impact of receiving the diagnosis is predominantly experienced by their parents or primary caregiver. On being given the diagnosis of their child’s condition, it has been reported in various studies that parents of a child with Cerebral Palsy experience mixed emotions (Fernańdez-Alcåntara et al., 2016; Whittingham, Wee, Saunders and Boyd, 2012; Kearney and Griffin, 2001). From reviewing the literature on this phenomenon, it has been found that parents typically express grief over not having the potential opportunities to have the normative experiences they imagined having with a “healthy” baby (Whittingham et al., 2012). Fernańdez-Alcåntara et al.’s study explored the experiences of 24 parents of 18 children with Cerebral Palsy between the ages of 5 months and 6 years, summarising it as an overarching ‘experience of loss’ (Fernańdez-Alcåntara et al., 2016, p.96). This has been found to lead to the notion of ‘chronic sorrow’, in which the parents of children born with Cerebral Palsy experience grief at the loss of the child they were expecting to have (Whittingham et al., 2013, p.1447). Parents in Fernåndez-Alcåntara et al.’s study described feeling distressed by the childbirth and subsequent diagnosis of Cerebral Palsy as this had been unexpected. This was followed by a sense of having lost a child they believed they were going to have (Fernåndez-Alcåntara et al., 2016). The medicalised response of pathologizing a child, McLaughlin posited, contributes to the parents’ feelings of grief and loss by presenting the news of the child’s impairment as a tragedy (McLaughlin, 2005).

Beyond the initial grief experienced, the effect of labelling children as not developing typically, initially or at the point of diagnosis (such as in the case of children with Cerebral Palsy), has been found to stigmatise the baby and the parents (Ryan and Runswick-Cole, 2008). Goffman’s Stigma theory was influential in studying the social interaction between people with attributes that could be stigmatised and those who impose labels upon them (Oliver and Barnes, 2012). Stigma theory has been found to be a useful tool to analyse parents' experiences of navigating the medical and social impact of having a child with an impairment. Considering the effects of the medical model's emphasis on individuals' positions in society Goffman developed 'Stigma Theory', which has been influential in the social interpretation of medical labelling. Writing in the mid-20th Century, Goffman explored individuals' experience of being labelled as 'deviant' in order to understand the impact of societal reactions towards them; individuals who challenge normative expectations of the socially anticipated appearances or behaviours (Goffman, 1963). Goffman relates to such individuals as being 'discredited', whereby the stigmatising feature can be the focus of social rejection to those embodying it (Goffman, 1963). The result of being discredited, Goffman posed, is that those considered normal view the individual with a stigmatising feature as being 'not quite human', which justifies the lower status of them within society (Goffman, 1963). The significance of stigma theory has been acknowledged as progressing social interactionism, which places deviancy as a social inferior status (Oliver and Barnes, 2012).

The theory that the parents are also stigmatised by the diagnosis has been reinforced in Green's study in which she examined the effects of Goffman's 'courtesy stigma' (Green, 2003). Goffman developed the notion of 'stigma by association', or 'courtesy stigma', which impacted those who were close to people with stigmatising attributes (Phillips, Benoit, Hallgrimsdottir, and Vallance, 2011). Green explores the theory that relatives of those with stigmatising characteristics may feel the effects of the stigma and therefore anticipate adverse responses from others towards their disabled family member (Green, 2003). Green, the mother of a daughter with Cerebral Palsy, highlighted the conflicting theories between a belief that the additional practical burdens of caring for a disabled child were the cause of increased emotional distress and a belief that it was due to the courtesy stigma itself. Green proposed that this theory could be applied equally to parents of disabled children with regards to how they relate to others within society. Green referred to three coping mechanisms adopted by parents affected by courtesy stigma: hiding their child's disability from others; feeling they must educate and manage other people's emotional responses to their child; and, in some cases, limiting their interactions with others only to those they feel confident will accept their child (Green, 2003). With Cerebral Palsy being a condition that has visible impairment effects, parents report courtesy stigmatisation as being based on the impact of society's 'othering' of their child due to their perceived difference from children without impairments (Green, 2003, p.1362).

Goar, Davis, and Manago studied the approach of parents of children with impairments and found that deflecting or challenging stigma was influential in understanding their responses to social interactions (Goar, Davis, and Manago, 2016). Their findings showed that parents employed 'medical deflection', minimising the difference between their child's ability and that of typically developing children, while using 'social deflection', privately acknowledging stigma as an exclusionary phenomenon but resisting challenging it publicly, recognising the current structures (Goar, Davis, and Manago, 2016, p. 174). At the same time however, parents in Goar, Davis, and Manago's study invoked medical labels to access support and justify their child’s divergence from expected norms (Goar, Davis, and Manago, 2016).

This section has demonstrated that the literature discussing the history and knowledge of Cerebral Palsy predominantly pertains to the medical construct of impairment, focussing on the neurological root and biomechanical effects of the condition on the body. The literature reviewed demonstrates that the medical understanding of Cerebral Palsy has been relatively static since the 19th century. While there has been little development in the understanding of the medical basis for Cerebral Palsy since it was discovered, it is now accepted that though the initial brain damage that causes it is non-progressive, the biomechanical impact can lead to functional degeneration throughout a person’s life. The effects that Cerebral Palsy have on an individual’s physical, social, and psycho-emotional experiences will be discussed in the following section.

2.3 Being a Young Person with Cerebral Palsy

This section discusses the social analysis of children and young people’s experience of having Cerebral Palsy. Though there has been a lack of comprehensive research into children and young people's experience of having Cerebral Palsy, from a small number of qualitative studies, it is identified that they have highlighted impairment effects, environmental barriers, and psycho-emotional issues. The main impairment effects that have been found to impact children and young people’s embodied experience of Cerebral Palsy are fatigue and pain, which will be discussed in the first subsection. Secondly, social barriers have been found to restrict their participation in the social world. The final subsection considers the research, which has identified that issues of self-image, feelings of inadequacy, and intersubjectivity impact on children and young people with Cerebral Palsy's psycho-social-emotional well-being. This provides the context of considering the social environment in which children and young people with Cerebral Palsy receive rehabilitation.

2.3.1 Impairment effects

Pain and fatigue have been found to be major factors in adolescent and young people's consideration of having Cerebral Palsy (Brunton and Bartlett, 2013; Shimmell, Gorter, Jackson, Wright, and Galuppi 2013). In her review of studies exploring children and young people's perspectives of its impact, Lindsay found pain - specifically hip, back, bladder and upper limb pain - and functioning - feeling fatigued or limited by physical ability - to be significant aspects of having Cerebral Palsy, which provoked feelings of frustration and difference (Lindsay, 2016). Castle et al. argue that the impact of pain and fatigue can be particularly significant in the lives of adolescents with Cerebral Palsy. In their study into young people with Cerebral Palsy's perspectives of experiencing pain and fatigue, Castle et al. found unique issues pertaining to their participants' ability to maintain friendships, which contributed to social isolation, sustain educational performance, and communicate their pain effectively, which had implications for their independence (Castle et al., 2007). Likewise, walking has also been found to be a significant aspect of children and young people's perspectives of having Cerebral Palsy. Gibson et al. highlighted that children with

Cerebral Palsy “learn that walking is part of a preferred non-disabled body and identity” (Gibson et al., 2011, p.67). Participants in Lindsay’s study reported that walking provoked a sense of frustration and was a stigmatising feature, especially when using assistive devices, which she argued threatened participants’ “biography and ability to maintain normalcy” (Lindsay, 2016, p.42). Lindsay concludes however, that walking was less of an issue to participants than social factors in their perspective of living with Cerebral Palsy and highlights strategies children and young people use to adapt to their differing biographies, such as using walking aids and wheelchairs to participate more independently with peers (Lindsay, 2016; Davis et al., 2009).

The notion of having to consider their limitations was described by Brunton and Bartlett as a main theme of their participants’ self-awareness. Participants in their study spoke of coming to understand and realise the effects of their own bodily limits. They identified the level of self-awareness about their limitations was linked to participants’ age, with younger adolescents being less sure of the impact participating in social activities would have on their energy levels and functionality, while older adolescents would explain having to adapt their effort levels and manage other people’s expectations of them depending on their social environment (Brunton and Bartlett, 2013).

2.3.2 Environmental and social barriers

Studies have identified that young people with Cerebral Palsy experience social barriers to developing a positive sense of self. Adolescents with Cerebral

Palsy interviewed by Stewart et al. (2011) identified physical environmental barriers such as being unable to rely on public transport, feeling safe when walking outside (especially when it is wet), access to buildings, and the additional time required to participate in social activities (Stewart et al, 2011; Lindsay, 2016). On the latter, Lindsay considers multiple factors that influence children and young people with Cerebral Palsy's participation; predominantly, the support of family, which can be enabling of their self-confidence and inclusion and yet, at times, overbearing; non-impaired peers were found to be unsupportive; the ability to be included in recreational activities, which contributes to a sense of 'social normalcy'; and resisting discriminatory attitudes, particularly within the school environment, limiting children and young people's ability to complete the work required of them and partake in extracurricular activities (Lindsay, 2016).

Considering the availability and use of support mechanisms to access the environment, Lindsay's literature review found that while support was often reported as enhancing participation in society, formal support was often lacking (Lindsay, 2016). Shimmell et al. found that these considerations became more prevalent as children transitioned to adolescence, with there being mixed feelings about becoming more independent of their parents. On the one hand, adolescents felt their parents contributed to overcoming environmental barriers, yet their support could contribute to preventing social inclusion (Shimmell et al., 2013). Stewart et al. also found that older adolescents could see the value in accepting support when it presented them with the opportunity to be more included and attain similar goals to their non-impaired peers (Stewart et al., 2011).

2.3.3 Psycho-emotional development

The experiences of children and young people extend beyond their recognition of barriers imposed by society. The limited research of children and young people with Cerebral Palsy has found young people to have lower self-esteem compared to non-disabled peers, and issues regarding body confidence (Bantjes, Swartz, Conchar and Derman, 2015; Shimmell et al., 2013; Hammar, Ozolins, Idvall and Rudebeck, 2009). Hammar et al. used Mulderji's phenomenological method of considering young people's experience of body image to compare the self-perspectives of participants with Cerebral Palsy to their non-disabled peers. This method involved asking their participants to rate their interpretations of the bodily concepts, such as: 'the sensitive body', which comes to the fore in, for example, pain or fatigue'; 'the dependent body', which needs assistance to an extent that one feels is unacceptable'; and 'the body in therapy', which is thematized constantly as being in need of training'. Hammar et al. found similarities between the groups in their perceptions of their sensitive body (experience of pain and fatigue) and their physical appearance, but significant differences when it came to participants' views on their bodies being 'unreliable', 'dependent' and more prone to 'catching other people's attention' (Hammar et al., 2009, p.24). This was corroborated by a systematic review by Shields, Murdoch, Loy, Dodd, and Taylor of the self-concept of adolescents with Cerebral Palsy (Shields et al., 2006). This study found that a lower level of self-concept, particularly relating to physical appearance and ability, was more pronounced amongst females (Shields et al., 2006).

Studies into the long-term effect of having low self-perspective have shown it impacts young people with Cerebral Palsy's psycho-social-emotional sense of self. Wiegerink et al.'s review of social and sexual relationships of young people with Cerebral Palsy considered the factors impacting them. The results demonstrate that young people with Cerebral Palsy have a lower self-efficacy (a belief in one's capabilities to undertake social activities) and lower self-esteem in their ability to attract partners, especially among women with Cerebral Palsy (Wiegerink, Roebroeck, Donkervoort, Stam and Cohen-Kettenis, 2006). Similarly, Shuttleworth's study into the ability of men with Cerebral Palsy to develop sexually intimate relationships detailed the compounding reasons behind such barriers (Shuttleworth, 2000). The issues raised by the men in Shuttleworth's study included sociocultural barriers, such as segregation in childhood, overprotective parenting into adulthood, a lack of representation of disabled people as sexual beings in the media, and the culturally defined notion of attentiveness (Shuttleworth, 2000). Shuttleworth believed the overarching phenomenon that explained young men with Cerebral Palsy's barriers to initiating sexual relations and non-disabled people's response to them was intersubjectivity; the perceived 'negative resistance' that the non-verbal communications between men with Cerebral Palsy and non-disabled peers infers (Shuttleworth, 2000, p.269).

The aspects of children and young people's experience of growing up with Cerebral Palsy identified in this section include impairment effects, environmental barriers and psycho emotional-disablism. While such studies have provided evidence of the social-relational experiences of young people with

Cerebral Palsy, the conclusions drawn from such research focused on the potential for rehabilitation to reduce the impact of impairment effects and thus increasing their inclusion within society. This study, however, considers the effect of rehabilitation on children and young people's experiences as they grow up with Cerebral Palsy.

2.4 Adulthood and Ageing with Cerebral Palsy

Finally, this chapter explores the research into the effects of ageing on people with lifelong impairments, such as Cerebral Palsy (Moll and Cott, 2012; Bottos, Feliciangeli, Sciuto, Gericke and Vianello, 2001; Hilberink, Roebroeck, Nieuwstraten, Jalink, Verheijden, and Stam, 2007). Though there has been extensive research into the psycho-social impact of becoming impaired, there has been relatively little exploration of the experiences of people who have had an impairment since birth (Bray, Kirk and Callery 2014). While Cerebral Palsy is a non-progressive condition because the damage to the brain does not get worse over time, the impacts of the impairment can lead to biomechanical degeneration, pain and fatigue over the course of a person's lifespan (Moll and Cott, 2012; Novak et al., 2017). The first subsection introduces the main theories on the biographical impact of the onset of impairments, which have been used as a framework for analysing the experiences of people ageing with Cerebral Palsy, as discussed in the second subsection.

2.4.1 Theorising impairment onset

The impact of impairment on individuals' experience of ageing has predominantly been studied from the perspective of adults who have become impaired through injury or illness (Bray, Kirk and Callery 2014). The most influential literature on this topic has been Bury's concept of biographical disruption, which theorised that the onset of impairment associated effects, and the social barriers that ensue, influences individuals' reaction to their experiences of everyday life (Williams, 2001). As identified by Bury, biographical disruption is primarily triggered by the onset of an impairment, which challenges a person's functional abilities and in turn impacts on their sense of self (Bury, 1982). Bury's study discussed the social impact of biographical disruption as being located within the psychological and emotional effects of an impairment's restriction on individuals' social activities and the changes they subsequently make to their lives due to the 'isolation and dependency, which flow from these disruptions in social intercourse' (Bury, 1982, p.176). As a consequence, Bury believed biographical disruption in adulthood causes "a fundamental re-thinking of the person's biography and self-concept" (Bury, 1982, p.169). Biographical disruption theory attempted to 'break away from an obsessive focus on impaired bodies' while recognising the connection between the body and society (S. Williams, 2001, p.128).

Taking a symbolic interactionist approach, and writing around the same time as Bury, Charmaz (1983) considered the impact of chronic illnesses on people's sense of self. Lawton (2003) highlighted two of Charmaz's main contributions; firstly, Charmaz expanded on the understand of 'suffering', away from just being a physical experience, to encompass social consequences of losing one’s sense of identity because of the negative perception of 'their developing limitations as losses' (Lawton, 2003; Charmaz, 1983, p.169). Charmaz's concept of the 'loss of self' presented the argument that people with 'debilitating' chronic illnesses suffer a loss of identity due to previously identifiable images of their functionality and personality being lost 'without new ones' replacing them (Charmaz, 1983, p.168). Secondly, as a consequence of loss, Charmaz highlighted that other parts of one’s life can be impacted, for example the stigma associated with chronic illness can result in low self-esteem, which can also result in individuals withdrawing from social activities (Lawton, 2003).

Finally, building on the previous concepts, Williams explored ‘narrative reconstruction’ as a model for explaining people’s response to acquiring an impairment (G. Williams, 1984). Based on the experiences of individuals who had lived with their acquired impairment for longer than Bury’s participants, Williams sought to theorise the strategies people use to reinterpret their lives beyond the narrow explanation of the medical phenomenon that took place (Lawton, 2003). This, Williams contended, was in an effort to “reconstitute and repair ruptures between body, self, and world by linking and interpreting different aspects of biography in order to realign present and past and self and society” (Williams, 1984, p.197). Expanding on Bury’s theory, Lawton notes that ‘narrative reconstruction’ highlighted the positive attempts to reframe their impairments following the initial disruption it created (Lawton, 2003).

While these concepts have broadened the understanding of the effects of the onset of impairment on people’s psycho-social sense of self, little attention has been paid to the experience of children and young people with impairments whose biographies, Bray, Kirk and Callery argue, develop as they move into adulthood (Bray, Kirk and Callery 2014). The reason being, Williams contends, is that children who have had an impairment since birth will have normalised their experience of living with it and therefore will be less likely to feel a biographical disruption later in life (Williams, 2000). Bray et al., however, suggest that children and young people with congenital impairments can experience disruptions to one's biography, but that their developing biographies can become interwoven with their parents, making it difficult to distinguish their own understanding of the changes to their bio-psycho-social sense of self on becoming an adult with an impairment (Bray, Kirk and Callery 2014).

2.4.2 Research into the experiences of adults with Cerebral Palsy

The study into the experience of ageing with Cerebral Palsy is a relatively new area of research. The effects of ageing and increased impairment effects have been found to disrupt an individual's physical and social sense of self (Murphy, Molnar and Lankasky, 2000). Such bodily changes, including increased pain and fatigue, can impact a person's experience of daily life and their participation in society (Sandström, 2007).

Moll and Cott have considered the concept of 'biographical disruption' in respect to the impact of ageing on people with Cerebral Palsy (Moll and Cott, 2012). The participants in their study described a process of 'slowing down' as they entered mid-adulthood, which was marked by participants in their 30's losing functional ability, such as walking and undertaking activities they could previously do with ease (Moll and Cott, 2012, p.1280). Considering the impact this has, firstly in relation to work opportunities, Lindsay found a small number of studies have demonstrated that anticipated and experienced discriminatory employment practices, pain and fatigue, and the expectation of needing support in the workplace are the primary concerns amongst adults with Cerebral Palsy. Though limited, Lindsay also highlighted that studies have shown that young people find personal care to be ‘challenging but manageable’, yet this is often reduced by their experience of pain and fatigue (Lindsay, 2016).

While there has been literature written on the biomedical impact of ageing with Cerebral Palsy, the psycho-social effects have been less well researched (Horsman, Suto, Dudgeon and Harris, 2010). Based on the literature reviewed, and as Horsman et al. contend, participants in the aforementioned studies had little understanding or awareness of the impact of ageing with Cerebral Palsy (Horsman et al., 2010). Paterson and Watson’s paper affirmed that the bodily effects of ageing with Cerebral Palsy came as a surprise to many participants in their study. Their research included people in their 40s and 50s and found that the effects of secondary ageing are relatively unknown to the medical profession and, therefore, people with Cerebral Palsy do not anticipate their impacts, which causes anxiety and stress (Paterson and Watson, 2013). Exploring this, Furukawa, Iwatsuki, Nishiama, Nii, Uchida, who assessed participants’ satisfaction level according to subjective well-being indicators, found that people with more significant impairment effects and lower self-reported well-being felt a greater impact between their physical ability and their participation in society (Furukawa, Iwatsuki, Nishiama, Nii, Uchida, 2001).

The majority of the literature reviewed in this section included the recommendation that adult rehabilitation could have a role in supporting people with the social effects of ageing with Cerebral Palsy (Horsman et al., 2010; Moll and Cott, 2012). While previous studies have demonstrated a link between rehabilitation, or the lack thereof, and adults with Cerebral Palsy's sense of self, there has not been substantive consideration of the role of childhood rehabilitation in influencing the development of adults' psycho-social selves. The intention of this study is to fully explore this phenomenon.

2.5 Conclusion

This chapter introduced the prominent models of disability, the medical construct of Cerebral Palsy and its impact on parents and children with the condition. This chapter began by outlining the models of disability that have been developed to provide a framework for considering disabled people's experiences from a medical and social perspective. The premise of the individual model is to diagnose, treat and ultimately 'cure' individuals who are born with or acquire impairments. The 'medical model of disability' was defined in opposition to a social-relational conceptualisation of disability. Objection to the medical model's framing of disability came from a social movement of people with impairments who rejected the notion of disability as an individual problem that excluded people with impairments from mainstream society. However, this approach has been and remains the predominant model for responding to children who are born with characteristics considered to deviate them from typically developing children. This is the basis for the medical intervention for children with Cerebral Palsy, discussed in the following chapter.

An interpretation of disability as a social construction, coined as ‘the social model’, grew out of a movement to redefine what it meant to be disabled within society. Through the organisation of activists and academics, particularly those with impairments, the concept of disability was reconstructed to relocate it to within social structures, which limited an individual with an impairment from fully participating within society. This perspective highlighted disabling barriers that existed due to inaccessible environments, prejudicial attitudes and structural inequalities. While the social model was credited with transferring disability from being an individual problem to a social phenomenon, critics have articulated the need for the movement to recognise the individual’s experience of impairment effects, such as pain and fatigue, and thus the necessary role for medical intervention and rehabilitation. Feminist theorists have progressed upon this model by proposing that psycho-social dimensions of impairment effects can be acknowledged at the same time as promoting a more inclusive approach to reducing external disabling barriers. This gave rise to the social-relational critique of the social model, which recognises the compounding impact of impairment effects and social barriers upon disabled people’s full participation in society.

This chapter reviewed literature relating to the impairment that is considered in this thesis, Cerebral Palsy. As the chapter highlighted, there has been limited progress in understanding Cerebral Palsy and its medical impact on people with the condition since it was first observed in children by Little in the 19th century. Developments in the monitoring of people with the condition have identified that, while the brain damage that causes the impairment effects of Cerebral Palsy is non-progressive, people with the condition can experience deterioration in their functional abilities due to its biomechanical effects on the body.

The chapter then considered the qualitative research on parents' experiences of diagnosis. Due to a child being in their early developmental stages when diagnosis occurs, the process and its impact is significantly experienced by their parents. The literature reviewed in this chapter demonstrated that the medical diagnosis of a child having Cerebral Palsy can lead parents to feel a range of emotions including grief, anger, anxiety, and a sense of loss for the typically developing child they believed they would have. Research has found that the reality of raising a young child with Cerebral Palsy, and the social responses towards the family, can induce feelings of being stigmatised amongst parents, particularly within the medical environment that they are exposed to in their child's early years. Parents' responses to such stigma have been found to combine contesting the environmental and attitudinal barriers that highlight their child's difference and engaging with interventions intended to reduce the impact of the child's impairment effects, such as rehabilitation services.

Section 2.3 considered research into the experiences of children and young people with Cerebral Palsy, which has identified; the impact of physical and social barriers, which limit inclusion; bodily effects associated with the impairment, which highlighted their difference to non-impaired peers; and the psycho-emotional effects of being perceived as having an impairment, which can challenge young people's self-concept and confidence. Reviewing research specifically with young people with Cerebral Palsy, this section demonstrated; that pain and fatigue dominated their experience of impairment effects; that disabling barriers to participating with peers, for example, increased as support structures dissipated; and that they were more likely to report poorer self-image and confidence than their non-disabled peers.

Finally, with recent research finding that young people with Cerebral Palsy begin to feel increased impairment related effects in early adulthood, this chapter reviewed the models of biographical disruption as a framework for examining the impact that degeneration has on young adults' experience of ageing with Cerebral Palsy. Research has identified that the onset of chronic illness creates a biographical disruption, which can lead to a loss of sense of self. Similarly, research into ageing with Cerebral Palsy has found that increased impairment effects in mid-adulthood has led to people with the condition being negatively affected, having grown up with the knowledge that Cerebral Palsy was a non-progressive impairment.

Chapter 3: Rehabilitation

Chapter 2 introduced the medical diagnosis of Cerebral Palsy, which children are given in their early years, and medically identified as having for the rest of their lives. This chapter considers the literature on the theoretical frameworks for understanding the rehabilitative process, which participants in this study underwent throughout their childhood and adolescence before transitioning into adulthood, due to being diagnosed with Cerebral Palsy.

Firstly, this chapter discusses the main approach to the management and treatment of Cerebral Palsy in childhood; rehabilitation (Palisano et al., 1997; Rosenbaum, 2003). Rehabilitation has been dominated by the Bobath approach, which seeks to retrain children's neural pathways through repetitive movement (Barry, 1996). The main alternative approach, Conductive Education, is also discussed for its influence on the rehabilitative landscape in the UK. The section reviews the literature on the efficacy of the main rehabilitative approaches that the participants in this study undertook. This is followed, in section 3.2, by a discussion on the social critique of rehabilitation, two of the significant focuses of which are its lack of consideration of the social context in which people with impairments receive interventions and its attempt to return individuals to a medically conceptualised 'norm' (Pava-Ripoll and Granada-Echeverry, 2016; Barnes, 2003; Oliver, 2013; Trede, Higgs, Jones and Edwards., 2003).

The third section reviews the key theories of childhood and disabled childhood studies, introducing the main concepts of child development, childhood agency and children's rights within the medical and social context in which they grow up. Childhood studies has predominantly been underpinned by developmental psychological theory, which focuses on studying the child as a developing person who goes through stages of becoming a rational, functioning adult (Mayall, 2000). This approach, which viewed being a child as a universal experience, dominated societal consideration of childhood throughout the 20th century and continues to influence social, educational and welfare policies relating to children and families. Alongside the emergence of the children's rights agenda, alternative narratives relating to children as a social group began to be developed by social theorists, such as Jenks, Qvortrup and James and Prout, who objected to the notion of childhood being a 'natural' state (James and Prout, 1997). The growth of childhood studies combined with child right's legislation enshrined the principles that children should be active participants with agency over the issues that affect their lives. This set the framework for considering children as a distinct social group within research, which sought to explain the phenomenon from the position that children are human beings in society. Childhood disability studies brought together childhood theory with disability studies to consider the social phenomenon of being a disabled child (Tisdall, 2012). This introduced a framework for exploring the experiences of disabled children through the lens of the social model of disability.

Finally, this chapter considers the small amount of research that has been carried out into children and young people's perspectives of having rehabilitation. Whether it be therapy or surgery, studies have shown that children perceive there to be benefits to participating in the interventions given to them. However, children and young people in these studies were less able to identify whether there was a lasting impact on their physical abilities (McBurney, Taylor, Dodd, and Graham, 2003; Himpens, Franki, Geerts, Tack, van der Looven, and van den Broeck., 2013; Skold, Josephsson, Fitinghoff, and Eliasson, 2007). This is then examined through the lens of social theory, which has found stigma to be prevalent in young people with Cerebral Palsy's developing sense of self due to medical and social perspectives that highlight how they deviate from typically developing children (Goffman, 1963; McLaughlin, 2017). The section concludes by considering the process of having therapy withdrawn as young people with Cerebral Palsy enter adulthood and the subsequent physical and social impact of not having access to rehabilitation unless sought out (Beresford, 2004; Wright et al., 2015). Literature on the impact of being an adult with Cerebral Palsy identifies that young people with it experience the embodiment of secondary ageing in early adulthood and that this is compounded by the absence of rehabilitation at this stage (Moll and Cott, 2012).

3.1 Rehabilitation of Children and Young People with Cerebral Palsy

This section explores the research into the paediatric rehabilitation process that children and young people with Cerebral Palsy in Scotland typically undergo throughout their childhood (NICE, 2017). As the previous chapter demonstrated, the approach to the diagnosis and treatment of children born with the characteristics of Cerebral Palsy have historically been based within the medical construction of the impairment. The first subsection discusses the main approaches to rehabilitation, which have focussed on physiotherapeutic interventions, that have become common practice for the treatment of children with Cerebral Palsy (Martin, Baker, and Harvey, 2010). Secondly, an alternative approach to rehabilitation, Conductive Education, is briefly discussed due to its significant impact on the development of physiotherapeutic approaches in Scotland (Emerson and Holroyd, 2019). Conductive Education takes an educational, rather than medical, approach to facilitating children's increased function through repetitive movement exercises aimed at developing an 'orthofunctional' personality, characterised by being persistent and determined in physical attainment (Emerson and Holroyd, 2019, p.1349).

3.1.1 The medical approach to rehabilitation for children with Cerebral Palsy

The medical pathologization of childhood grew with the exponential increase in the rate of children with impairments in the first half of the 20th century, specifically polio (Pava-Ripoll and Granada-Echeverry, 2016). This led to an expansion in the role of medicine in the lives of children. The theory emerged that the clinical symptoms of Cerebral Palsy might be improved significantly through neurophysiological physiotherapy, especially if the therapy was started early in a child's life (Panteliadis et al., 2013). This theory was created with two assumptions; that gross motor development, i.e., the process that enables infants to make purposeful movements with their arms and legs was determined by the maturation of the central nervous system; and there existed a 'top-down' control of motor activity (Gerber, Wilks and Erdie-Lalena, 2010; Panteliadis et al., 2013, p.289). This approach was developed throughout the 20th century, predominantly by Bobath and Bobath, a German physiotherapist and her husband, based on their experience of rehabilitating adults who had had a stroke, as they identified a causal relationship between the individual's muscle tone and their movement of affected muscles (Raine et al., 2009).

The Bobath concept has been the predominant physiotherapeutic rehabilitative approach to treating Cerebral Palsy since the mid-20th century, taking a neurodevelopmental approach to engendering 'normal' patterns of movement in babies and children with the impairment (Raine, Meadows, and Lynch-Ellerington, 2009). Other approaches developed in parallel with Bobath included functional therapy, which used goal-oriented exercises to improve children's ability to carry out day to day activities, and strengthening exercises, which sought to improve their muscle tone (Geijen, Ketelaar, Sakzewski, Palisano and Rameckers, 2019). A combination of all these approaches were in common practice in physiotherapeutic rehabilitation in Scotland during the time the participants in this study were growing up, from the 1980's to present day.

Integral to these physiotherapeutic rehabilitation approaches is the Gross Motor Function Classification System (GMFCS), which was created to improve the therapist's ability to make an accurate prognosis of the potential ability of children with Cerebral Palsy. Developed in 1997, the GMFCS was, and continues to be, widely used to chart the progression of children's functions (Palisano, Rosenbaum, Walter, Russell, Wood and Galuppi,1997). The GMFCS was based on the Gross Motor Function Measure (GMFM), which was employed to create 88 (and a simplified version of 66) markers of a child with Cerebral Palsy's ability, such as trunk control, to do tasks indicative of their potential function

(Russell, D. J. Rosenbaum, P. L. Cadman, D. T. Gowland, C. Hardy, S. & Jarvis, S, 1989). A child assessed using the GMFM was assigned a score. In developing the GMFCS, Palisano plotted sample results of children's GMFM scores against their ages in order to chart their potential ability to attain tasks (Rosenbaum, Walter, Hanna, Palisano, Russell, Raina and Galuppi, 2002). Rosenbaum's comprehensive study of the use of the GMFCS over the course of a longitudinal study found that, in crude terms, this meant that a child's GMFM score at 6 months old could reasonably predict what they would probably be able to do at 1 years old and at 3 years old for example (Rosenbaum et al., 2002). Concluding, this subsection discusses reviews of the efficacy of the different therapeutic approaches described, which have used the GMFCS to analyse the impact of therapy on the functional development of children with Cerebral Palsy.

Bobath/NDT

Current neurodevelopmental treatment (NDT) is based on the Bobath model, which was one of the earliest therapies developed for children with Cerebral Palsy (Zanon, Pacheco, Latorraca, Martimbianco, Pachito, and Riera, 2019). The approach focuses on retraining the pathways from the brain to the muscles that are responsible for determining movement (Barry, 1996). It is based on the principle that training the neural pathways in children with Cerebral Palsy will prevent contractures (shortened and hardened muscles) and deformities that would otherwise occur if their posture remained 'abnormal' for long periods (Bobath and Bobath, 1956, p.408). The techniques employed in the Bobath method to minimise the development of these contractures and deformities include exercises that involve the children weight-bearing, stretching and being supported to experience normal patterns of movement (Barry, 1996).

However, reviewing literature on the efficacy of this approach, Martin et al. contended that the efficacy of NDT therapies was difficult to determine due to the tasks being individualised and the process being dependent on the therapist's level of skill (Martin et al., 2010). Of the findings that have been concluded, improvements in GMFM scores were greater amongst children who participated in the more intense treatment groups. This was reflected in a study by Tsorlakis, Evaggelinou, Grouios, and Tsorbatzoudis, pertaining to the effect of NDT on GMFM scores of children with spastic Cerebral Palsy, in particular, which provided statistically significant results where children undertook over double the amount of therapy each week to the comparison group (Tsorlakis et al., 2004). However, due to the 'levelling off' that occurs in children's movement patterns, the potential of NDT, Tsorlakis et al. note, must be contextualised in the retention of functionality as children with spastic Cerebral Palsy age (Tsorlakis et al., 2004 p.743). Based on the findings that NDT has inconclusive benefits for children with Cerebral Palsy, Tyson and Selley have noted that exercise-based activity which encourages functional training, citing gym equipment as an example, showed signs of having more impact than these traditional treatments (Tyson and Selley, 2006).

Functionality based

While physiotherapy has predominantly followed the Bobath method to managing Cerebral Palsy, as Tyson and Selley note, there has increasingly been a move towards a 'functionality' based approach to improving the motor ability of the child, with the intention of enabling them to be able to function in their environment (Tyson and Selley, 2007; Geijen, et al., 2019, p. 232). This approach focuses on the achievement of tasks that can be translated into the child's day to day life, such as dressing, which Ahl, Johansson, Granat argue motivates the child and moves away from the child being a passive recipient of therapy (Ahl et al., 2005). Similarly, functional therapy was found to have significant effects in younger children, leading to "improvements in gait temporospatial measures [walking function], dynamometry, and endurance following functional training" (Martin, et al., 2010, p.306). Based on their systematic review of 34 studies of the most commonly used approaches in physiotherapy, Das and Ganesh found that functional based therapy, which involves intensive activity based, goal-directed interventions, has the strongest evidence for its approach and has the widest application for children with all types of Cerebral Palsy (Das and Ganesh, 2019).

However, reviewing functional physiotherapy rehabilitation approaches, research has found that there is little evidence to support the therapeutic approach that improving impairment effects leads to increased functional ability in day-to-day life (Martin, et al., 2010). As Geijen's review of functional therapy highlighted, the appraisal of a child's ability focuses more on the process of doing the functional task than the outcome the function is intended to achieve (Geijen et al., 2019). Similarly, a systematic review by Geijen et al. found that there has been a lack of consensus over the term 'functionality' and the approaches intended outcomes (Geijen et al., 2019). This is despite efforts to have a universal definition through the use of six criterion of functionality, which include such principals as; therapy being ‘goal-directed’; encouraging ‘active involvement of the child and parents to find solutions’; and being ‘focused on functionality rather than normality’ (Geijen et al., 2019, p.232). The inconsistencies in defining functionality, according to the authors, mean that it is impossible to standardise approaches in the way they were hoping. They referred to the improvements in outcomes for stroke patients, which were achieved due to shared international definitions and standards as an exemplar of good practice that they had hoped could be emulated for children with Cerebral Palsy. In addition to its impact on practice, the lack of these shared definitions and standards means that research into the efficacy of such therapies is compromised (Geijen et al., 2019).

Strength based

The most significant improvements, according to comparative research carried out by Martin et al., came from strength based and functional training (Martin et al., 2010). They found that therapies which focused on strengthening specific muscle groups had the greatest impact on improving children’s GMFM scores. The studies found that improvements were maintained over time, leading to the conclusion that children had incorporated strengthening training into their routines (Martin et al., 2010). There has, however, been controversy around the inclusion of strengthening into the therapeutic approach. Strengthening is the concept of increasing muscle tone through resistance training, which was pioneered by Phelps in the 1940’s (Barry, 1996). Barry described that, whilst

Bobath initially rejected strengthening because of concerns that it would further increase tone in children with spasticity, rehabilitation practitioners at the time took an eclectic approach, drawing on aspects of all the methods described in this subsection and continue to do so (Barry, 1996). Martin et al. concluded that strengthening therapy has the strongest evidence for its effectiveness on individual muscle groups but no impact on improving daily activity or mobility have been found. Furthermore, evidence of its efficacy was strongest among children at the lower end of the GMFCS scale and those whose Cerebral Palsy affected specific limbs (i.e., hemiplegia - one side of the body); meaning their ability to perform strengthening tasks was prevalent before and after the task (Martin et al., 2010).

The approaches discussed in this subsection have been subject to medical evaluation, which has sought to ascertain their efficacy on the physical development. However, as Herskind, Greisen, and Neilsen identified, a key challenge to evaluating the efficacy of therapy is that “it is difficult not to offer infants in a control group any treatment” (Herskind et al., 2014, p.32). A meta-analysis of the efficacy of early identification and intervention in Cerebral Palsy concluded that whilst there was a lack of sufficient evidence to support the various practises of delivering early physiotherapy interventions, the authors concluded that this was not sufficient to exclude the value of continuing to provide them (Herskind et al., 2014). Furthermore, the amount of therapy undertaken by children with Cerebral Palsy is often considered influential on its efficacy (McCoy, Palisano, Avery, Jeffries, Laforme Fiss, Chiarello, and Hanna, 2019). However, exploring the relationship between rehabilitation and the development of children with Cerebral Palsy, McCoy et al. did not find a cause-and-effect link between the amount of therapy and intervention outcomes (2019). Similarly, Martin et al. found that all studies comparing the benefits between intermittent versus routine physiotherapy sessions could not determine a significant difference in outcome, whatever the level of intensity (Martin et al., 2010). Rosenbaum and Gorter highlighted four specific limitations to this approach; the heterogeneity of the condition means it has a 'very wide range of effects'; the treatment of symptoms, such as muscle relaxants, do not affect the underlying condition; there is insufficient evidence that approaches to improve the biomedical aspects of the condition lead to functional outcomes; and, due to the developing nature of the condition in childhood, the treatment often cannot be attributed to the child's development (Rosenbaum and Gorter, 2011, p.457-8). They therefore conclude that the biomedical approach to 'fixing' conditions such as Cerebral Palsy is limited (Rosenbaum and Gorter, 2011, p.457).

3.1.2 Conductive Education

The previous three treatments are based on a medical approach. The alternative approach of Conductive Education, which was developed by Dr Andras Peto in the mid-twentieth century, follows an educational rather than biomedical approach to rehabilitation (Rosenbaum, 2003). This is discussed in this subsection as it was an influential concept during the 1990's, when the participants of this current study were children. The approach advocated teaching children functional tasks with the aim of promoting learning and problem solving in order to overcome the challenges faced by children with Cerebral Palsy

(Bourke-Taylor, Oshea, and Gaebler, 2007). This distinction intended to emphasise the role of the approach in preparing children with neurological impairments to access schooling in Hungary, with one of the conditions at the time Peto was practising being that all children had to be able to walk in order to attend mainstream or special schooling (Reddihough, 1991, p.141).

Peto's background in rehabilitation and psychiatry inspired his creation of the National Motor Therapy Institute, which had limited international recognition until the 1980s (Bourke-Taylor et al., 2007, p.52). The international attention in the institution grew out of the political context that existed between the UK and Hungary towards the end of the Cold war, as markets began to open up between East and West Europe (Reddihough, 1991; Read, 1992). The rise in ideological economic theory that promoted privatisation sought to encourage interest in alternative approaches to healthcare provision. An influential documentary titled *Standing up for Joe* highlighted the growing popularity of the Hungarian institution and prompted a surge in interest from parents of children with Cerebral Palsy (Read, 1992). Central to the theoretical underpinning of the therapy was that repetition would encourage functional development. Children were therefore given goal-oriented tasks to complete to the soundtrack of rhythm and song for younger children and task-analysed verbal instructions, termed rhythmic intentions, for older children (Bourke-Taylor et al., 2007, p.50). Such tasks were performed on two key apparatus - a wooden plinth and a wooden ladder-backed chair (Reddihough, 1991, p.141). The group dynamic used, it was believed, would assist in fostering a sense of there being a 'social unit' and that individual progress would inspire the performance of others (Bourke-Taylor et al., 2007, p.51).

This approach, which is still being delivered in the UK, has been critiqued by various disciplines. Medical reviews of Conductive Education, including Coleman, King and Reddihough (1995) and Reddihough, King, Coleman and Catanese (2008), found no statistical improvement amongst children who had received Conductive Education (Stiller, Marcoux, Olsen, 2003, p.45). However, advocates of Conductive Education continue to argue that the focus on enabling the child to learn orthofunction, which is based on the neuroscience rationale of repetitive activities leading to new neural pathways opening up, facilitates their inclusion in a society (Emerson and Holroyd, 2019). The basis for this conceptualisation of Conductive Education is that it instils a belief in the child that the achievement of orthofunction, whatever the effort involved, equips them to function more independently in society. This is described as the children having an ‘orthofunctional personality’ (Emerson and Holroyd, 2019, p.1349).

The reviews of the rehabilitative methods and the critiques of the rehabilitative approaches, discussed in this section, have identified that there is a lack of conclusive evidence that the concept of giving a child with Cerebral Palsy early intervention, which continues throughout their childhood, with the aim of improving their physical functionality, will lead to lifelong improved functional outcomes that are practicable in daily life. However, the rehabilitative approaches identified continue to be the predominant approach to the treatment of Cerebral Palsy in children with the aim of promoting children’s participation in daily activity and reducing the physical effects of their impairment (Raine, 2006; Das and Ganesh, 2019). The following section considers the social critiques of rehabilitation, which have predominantly focussed on rehabilitations' approach to achieving normative development.

3.2 Social Critiques of Rehabilitation

This section considers rehabilitation from a social perspective. However, there has been a lack of sociological inquiry into rehabilitation (Bezmez, Shakespeare, and Lee, 2021). The predominant social analysis of rehabilitation comes from disability studies' theorists who have critiqued the premise of rehabilitating adults who have acquired impairments back to 'normal', which is discussed in the first subsection (Oliver, 1993; Barnes, 2003). However, recent sociological inquiry into the experiences of people who have acquired impairments of going through rehabilitation suggests that there is a more nuanced process of constructing and negotiating 'normality' that occurs between the actors involved in it; the patient, their families, and therapists (Bezmez, Shakespeare, and Lee, 2021). The critiques discussed in this section lend themselves to the model proposed by Abrams, 'emancipatory rehabilitation', which is latterly considered (Abrams as cited in Nicholls, 2015). Secondly, this section considers the sociological critique of the concept of rehabilitating children who are born with impairments given their lack of prior movement (McLaughlin and Coleman-Fountain, 2014; Pava-Ripoll and Granada-Echeverry, 2016; Weeber, 2004).

3.2.1 Social critique of rehabilitation of adults

The debate on the definition of rehabilitation has been dichotomous, with the medical interpretation on the one hand and the social critique of it on the other. Outlining these two perspectives, Shakespeare, Cooper, Bezmez and Poland refer to the World Health Organisation’s medical perspective of rehabilitation, which focuses on the attainment of physical function (Shakespeare et al., 2018). It asserts that rehabilitation is:

> *A set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments. (WHO, 2011, p. 96)*

This approach has dominated medical therapies towards the treatment of impairment. Introducing the alternative perspective, Shakespeare et al. highlight that the social critique of rehabilitation has predominantly come from disability studies (Shakespeare et al., 2018). Advocates of the social model of disability argue that rehabilitation too heavily focuses on the bodily impact of conditions, rather than appreciating the social and environmental context in which people with impairments access rehabilitation (Oliver, 1993; Barnes, 2003; Oliver as cited in Nicholls, 2015). Rehabilitative methods have largely been disconnected from discourses of a social construction of impairment and disability (Barnes, 2003). Oliver and Barnes, for example, critique the rehabilitative focus on returning people who have been impaired back to normal.

> *Clearly the concept of rehabilitation is laden with normative assumptions clustered around an able bodied/mind ideal. And, despite its limitations in terms of returning people with acquired impairments such as spinal cord injury, for example, to their former status, it has little or no relevance or meaning for people born with congenital conditions such as blindness or deafness other than to enforce their sense of inadequacy and difference. (Oliver & Barnes, 2012, p. 42)*

Responding to both medical and social constructivist accounts of rehabilitative methods to treating people with impairments, Bezmez, Shakespeare and Lee have suggested a more nuanced understanding is required. Based on their account of the rehabilitative process of adults with acquired impairments, the authors argue that the previous critique of the rehabilitative model, that it is a driver in 'reproducing the ideology of normality', is in itself too ideologically motivated (Bezmez, Shakespeare, and Lee, p. 2021). From their findings, it is suggested that the conceptualisation of what constitutes 'normal' is collectively constructed over the rehabilitative period through a process of negotiation between the main actors - patients, their families, and therapists (Bezmez, Shakespeare, and Lee, 2021).

Similar to the social-relational critique of the social model of disability, which links individual experiences of impairment effects and societal disablism, Abrams believes there ought to be an appreciation of the link between therapeutic interventions, when and if required, and the environmental barriers that contribute to an individual's experience of impairment (Abrams as cited in Nicholls, 2015).

This led to Abrams' protestation that; "If we are to do disability studies of rehabilitation, we cannot do so solely through an emphasis on barriers. There is much more to my existence as a disabled person than my exclusion. Much of this existence, especially at the clinical level, is of sociological importance" (Abrams as cited in Nicholls, 2015). In considering the stigma attached to the traditional framing of physiotherapy as being dominated by the medicalised approach, Abrams believes there is room for emancipatory therapy, which would move beyond-functionality based intervention (Abrams as cited in Nicholls, 2015). Emancipatory practice has been discussed as a potential approach to physiotherapy in response to three challenges to the traditional model; the changing clinical role, which is moving towards both a more patient centred approach to care and an increased focus on ensuring there is efficiency in the interventions offered; the gap between practice and evidence; and professionals' identity, which has been difficult to specify between being "technical experts, patient educators, or advocates for patients" due to the first two challenges (Trede, Higgs, Jones and Edwards, 2003, p.3). Shifting to an emancipatory approach to therapy, Trede et al. argue, would lead to a more democratic model that gives more power to patients over the aims and outcomes of therapy beyond the biomechanical approach of traditional interventions, which would mean professionals needing to have more awareness of the social and environmental dimensions of disability and in turn change their role to being more of a facilitator in supporting a person to attain their potential based on their own interpretation of their needs and values (Trede et al., 2003). While, as Trede et al. acknowledge, there are limitations to this approach, particularly its reliance on people having power and knowledge to assert their aims of participating in rehabilitation, it offers an alternative lens through which to consider the role of rehabilitation in people’s lives.

3.2.2 Social critique of rehabilitation of children

Childhood rehabilitation in the UK grew out of the socioeconomic imperative for all adults to become a productive member of society. It was developed through the hospital-based treatment of childhood conditions, such as poliomyelitis, and then within education for children with developmental conditions in the mid-20th century (Pava-Ripoll and Granada-Echeverry, 2016). In an attempt to reduce the ‘burden’ of disabled children upon the social structure, society has developed rehabilitative responses to those that have impairments, such as therapeutic and surgical intervention (Shakespeare and Watson, 1997; Traustadóttir, Ytterhus, Egilson, and Berg, 2015). Critics argue that this was ideologically driven towards fitting disabled children into mainstream society through the eradication of difference (Oliver, 1990; Riddell, 2009). Weeber argues that “The pre-occupation of Western medicine to ’fixing’, rather than supporting, disabilities makes meeting essential ‘nurturance needs’ a secondary concern” (Weeber, 2004, p.25-26). This critique can be directed towards the approach to treating children with Cerebral Palsy because it is focused on a predominantly biomechanical model of rehabilitation.

> *The medical imperative to fix their familiarity with medical procedures, changes to the body that led to pain, produced a practice focused on an opening of the body to intervention, which stories of*

> *promised improvement in function and appearance supported.*
> *(McLaughlin and Coleman-Fountain, 2014, p.80)*

Pava-Ripoll and Granada-Echeverry challenged the notion of applying such rehabilitation to children. They argued that there is a tension between the concepts of habilitation, which should be applied to the developing child, and the rehabilitation of adults in order to restore abilities that they used to have (Pava-Ripoll and Granada-Echeverry, 2016). While habilitation, according to Jindal, Macdermid, Rosenbaum, Direzze, Narayan, and Nayak, refers to the "health care services that help a person *acquire*, keep or improve, partially or fully, and at different points in life, skills related to communication and activities of daily living", rehabilitation refers to "health care services that help a person *keep*, restore or improve skills and functioning for daily living and skills related to communication that have been lost or impaired because a person was sick, injured or disabled" (Jindal et al., 2019, p.1051). Similar to Pava-Ripoll and Granada-Echeverry's contention, Hayton and Dimitriou also identified from a psychological perspective that applying the term 'rehabilitation' to children with motor development disorders, such as Cerebral Palsy, was inappropriate due to the fundamental difference in neurological development between babies and adults (Hayton and Dimitriou, 2019). It is thus argued that "Referring to work with children as rehabilitation adopts adult-centered principles, including an erroneous assumption of prior knowledge that might be reclaimed, with little or no modification to align with typical child development" (Hayton and Dimitriou, 2019, p.3). Similar to the critique of adult rehabilitation, Pava-Ripoll and Granada-Echeverry introduce discourses around the 'rehabilitation of society' as a counter model to the dominant culture of the medicalised approach to habilitating children's bodies (Pava-Ripoll and Granada-Echeverry, 2016, p.840).

Critiques of rehabilitation, as this subsection has shown, have predominantly focused on its premise of attempting to return impaired individuals to a normative state. By considering the social environment in which disabled people have rehabilitation, proponents of this approach have sought to reframe rehabilitation of both adults and children as an emancipatory model to enhance individuals' inclusion in society. However, the main literature discussed in this section primarily relates to either child or adulthood rehabilitation, thus demonstrating a gap in the research on the long-term impact of rehabilitation on the lifespan of young people and adults with the Cerebral Palsy. As the next section demonstrates, the transition between paediatric and adult healthcare presents young people with Cerebral Palsy with unique challenges.

3.3 Children and Young People's Agency in Rehabilitation

This section firstly considers the development of a theoretical framework around the agency of children and young people, and how it has impacted the understanding of their rights within a medical context. From the middle of the 20th century onwards, the theoretical position that children should be considered as entities in their own right gained traction within psychological and sociological literature (James and Prout, 1997; Mayall, 2000; Oates, Sheehy and Wood, 2005). As this began to influence medical, educational, and familial policy, the formalisation of children's rights created a basis on which a child's agency was recognised as being fundamental to their status within society (Tisdall and Punch, 2012). Secondly this section discusses the growth in disabled childhood studies, which stemmed from both the theoretical developments in the social study of childhood and disability, and the rights-based agenda that accompanied them (James and Prout, 1997; Shakespeare, 2013; Traustadottir, Ytterhus, Egilson and Berg, 2015).

3.3.1 The development of childhood agency

The study of the child and childhood has predominantly been based on the notion of the child as a ‘pre-person’ who is on a developmental trajectory towards adulthood (Mayall 2000). The most seminal work arising out of the field of developmental psychology regarding childhood studies was by Piaget, who in the mid 20th century described the ‘four stages of childhood theory’ (Piaget, 1964, p.176-186). This was influential in the understanding of a child's cognitive development and perception of their existence within the world around them (Oates, Sheehy and Wood, 2005). Piagetian theory of childhood development laid the foundation for lawyers, doctors, social workers, educationalists, and academics’ work for, and with, children during the second half of the 20th Century (Mayall, 2000). The child developmental approach to conceptualising the experiences of children growing up in British society was predominantly accepted until the late 20th Century (Moran-Ellis, 2010). It was the overarching narrative within which medical practitioners and educationalists, which Mayall termed ‘the child development industry’, were operating during the period that the participants in this study were experiencing their childhood (Mayall, 2000, p.129). Thus schooling, healthcare practices and research into the lives of children focused on treating them as ‘developing’. Children who did not develop as expected were cast in a separate category of childhood, which inferred that “failure to be harmoniously socialised in society's function meant in effect a failure to be human” (James and Prout, 1997, p.14). Kehily recognised that the impact of Piaget’s research upon the social understanding of childhood was key as “evidence of what is 'normal' or 'typical' became a standard to judge which children were 'subnormal' or 'retarded', not just in physical and motor development, but also in intellectual development” (Kehily, 2013, p.120).

The central criticism of Piaget's theory of child development by childhood sociological theorists was that his ignorance of the social and cultural contexts in which children develop left a gap in the understanding of how children relate to the society around them (Tisdall and Punch, 2012). Such an approach led to the popularisation of children being perceived as ‘human becomings’, implying that children are not fully formed human beings until they have reached adulthood (Qvortrup, 1994; James and Prout, 1997; Walkerdine, 2004). It was this philosophy of childhood that led Qvortrup to debate the status of adults and children as being a perceived power relation, in which adults have assumed a superior position through chronological development. Arguing that there was no legitimate cause for the construction of a power imbalance other than the age at which such power can be exerted on those younger, Qvortrup proposes that children should be viewed as 'human beings', rather than 'human becomings', who construct their own relation to society and inhibit their own social realm (Qvortrup, 1994).

This perspective considered the sociology of childhood from the perspective of children themselves. Intrinsic to this emerging model was the notion that children could be social agents within their development (James and Prout, 1997). Previously, within the medical environment, a child’s body was not seen as different to that of a “small adult”, nor requiring special attention and care, and children were considered a homogenous group (James and Prout, 1997). The initiators of the new paradigm of childhood studies, James and Prout, identified features of a sociology of childhood, which they developed through the creation of a methodological basis for studying childhoods within the contexts that they inhabited. The key features of this approach considered childhood as an intricate combination of the child’s natural status and their social position in the cultural context in which they inhabit (James and Prout, 1990). In doing so, this ‘new’ paradigm reconstituted childhood as a social construction, which should be considered as a ‘variable of social analysis’ alongside other phenomena, such as class, gender, ethnicity and therefore requires cross-cultural analysis. James and Prout concluded that children’s social relationships are ‘worthy of study in their own right’, and therefore children should be considered within the construction of their social lives, those around them and wider society (James and Prout, 1997, p.8-9).

The conceptualisation of childhood in this way was underpinned by, and provided an evidential basis for, the promotion of a child rights agenda, which was popularised by the United Nations Convention on the Rights of the Child in 1989 (Tisdall and Punch, 2012). Becoming the most ratified convention across the world, the UNCRC, supported by the childhood studies' approach to researching children's lives, embedded the fundamental principle that children have agency and should be active participants in decision-making on issues that affect them. The convention provided for a fine balance between protecting children's inherent vulnerability within society, due to the generational position opposed to adults, and ensuring they are treated as human beings with rights. However, a critique of the convention itself is that it "refers to a universal, free-standing, individual child; a child who is on a particular developmental trajectory" (Mayall, 2000, p.245). The shift towards a child rights agenda towards the end of the 20th Century began to have practical implications in society's approach to children, treating them more as human beings with agency over their participation in medical procedures.

Alderson, the leading theorist in the conceptualisation of childhood agency in healthcare, was influential in unpacking a child's perspective of their own healthcare and their relationship to those who inform them (Alderson, 1993). Alderson's seminal study found that children's considerations of health interventions were based upon multiple factors, which have both medical and social connotations (Alderson, 1993). Treatments provided were seen as a 'transformative' process, which resulted in further inclusion in society. As Alderson found, children expressed desires for treatments that would support their inclusion in their peer group. This included the wish for treatments that would 'improve' their appearance, i.e., from having a limp, or for those that could enable their involvement in mainstream activities. Children who considered treatment as a potential cure for their impairment emphasised the possible benefits that this could have upon their social position, an example being increased job opportunities (Alderson, 1993). Yet, Alderson herself admits difficulty in unpacking the associations children made between receiving treatment and their understanding and perceptions of disability (Alderson, 1993).

However, critiques of the sociology of childhood paradigm highlight the challenge to perpetuating its opposition to child development. Tisdall and Punch have identified that the theoretical dichotomy between child development, as being focused on the universal child, and the social construction of childhood, as a context dependent phenomenon, has been too polarising (Tisdall and Punch, 2012). Instead, considering the nature of childhood as being a temporary status on the way to becoming an adult within the social context that children live in may provide a more dynamic approach to conceptualising children's lives (Woodhead, 2009).

3.3.2 Disabled children's agency in healthcare

The models of child development and constructs of childhood have predominantly been based on the notion of a 'natural' child who goes through universally experienced stages of development. This has led to the narrative that disabled children deviate from the 'standard' and therefore exist outside of what is considered to be 'normal' development itself (Curran and Runswick-Cole, 2014, p.1620; Davis, 1995). This construction of 'the child' received criticism from a disability studies perspective, which highlighted that the premise of the exclusion of disabled children from research into childhood experiences was based on the assumption that their impairments barred them from participating in research (Curran and Runswick- Cole, 2014). Attempts have been made to counter such oppressive narratives surrounding disabled children and the presumption that disabled children are ‘victims’ of their impairments by combining principles of both emancipation, empowering disabled people to have choice and control over their lives, and agency, enabling children to play an active role in making decisions about their lives (Oliver, 1990; James and Prout, 1990). In highlighting that disabled children have “been denied the same rights/choices as other children and have been cut off from non-disabled children", Davis advocated that children have agency over their own position in society and this could be applied to the development of a more critical understanding of how disabled children interact within their social contexts (Davis, 2012, p.417).

Most pertinent to this study, the perspectives of children and young people have been largely absent from the understanding of their experiences of medical intervention (Davis, 2012). Davis argues that medical clinicians too often focus on the views of parents and adults, at the expense of understanding and appreciating children and young people’s perspectives of the services they use (Davis, 2012). Building on Alderson’s study into children’s consent to surgery, Shakespeare and Watson posited that disabled children are capable of processing complex ideas about medical treatment if it is presented appropriately (Shakespeare and Watson, 1998). Disabled childhood studies, therefore, have promoted a new approach to understanding and appreciating disabled children as active participants in their lives. The inclusion of disabled children within the process of making decisions and putting interventions in place to improve their quality of life is encapsulated by Shakespeare and Watson's recommendation that practitioners and researchers should "listen to what disabled children say about their lives, respect their wishes and support their choices" (Shakespeare and Watson, 1998, p.26). Stalker and Connors found that "Children simply accept that impairment is part of their lives", adopting a predominantly medicalised approach to discussing their impairment, primarily due to their exposure to medicalised practises (Stalker and Connors, 2003). This has particular application within service design in the development of a system that attempts to put the child at the centre in preference to imposing treatments upon children (Davis, 2012).

3.4 Research into Children and Young People with Cerebral Palsy's Experience of the Rehabilitative Process

This section considers the small amount of qualitative literature discussing children and young people with Cerebral Palsy' experiences of rehabilitation. While the research is narrowly focused on improving services, predominantly being carried out by rehabilitative theorists, it demonstrates a growing recognition of the need to understand children with Cerebral Palsy's perspectives of the therapy they are being given and how this impacts on their developing sense of self as an individual who is seen to require such intervention (Himpens et al.; 2013, Skold et al., 2007; McBurney et al., 2003). The preeminent sociological study into this phenomenon, the SPARCLE project, highlighted stigma as being a dominant cause of, and response to, young people with Cerebral Palsy's engagement in rehabilitation. Latterly, this section considers research on the transition between paediatric and adult rehabilitation, a process which has been found to cause significant disruption and impacts the life chances of young people (Beresford, 2004; Wright, Robb and Shearer, 2015).

3.4.1 Research into children and young people with Cerebral Palsy's experience of having rehabilitation

Qualitative studies of rehabilitation are relatively new and are typically framed around the interventions provided by therapists' themselves (Ohman, 2005). Until recently, research into the experience of children and young people with Cerebral Palsy has been predominantly studied from the perspective of their parents and healthcare providers (Lindsay, 2016, p.153). This subsection considers the limited amount of literature on children and young people's experience of rehabilitation, which has predominantly been undertaken by practitioners within the rehabilitation discipline. Such studies, which have aimed to go beyond the consideration of the physical impacts of rehabilitation in order to explore the holistic effects on the lives of children with Cerebral Palsy, have mainly reported positive outcomes of therapy and surgery (McBurney et al., 2003; Himpens et al.; 2013, Skold et al., 2007).

In relation to therapy, participants in a study by McBurney et al., who's perspectives were analysed over the course of a 6-week intensive therapeutic programme, reported improvements to their strength, flexibility, balance and circulation, with comments such as 'I was able to bend my knees a lot more' (McBurney et al., 2003, p.661). Improvements in functionality were linked to the performance of activities, such as walking, jumping, and using stairs, which participants noted were ‘much easier’ following the intervention. Meanwhile, parents commented on their child’s physical differences, such as ‘He looked better and he looked straighter’ (McBurney et al., 2003, p.661). McBurney also noted that participants felt a positive psychological impact from being able to complete the exercises during the programme. However, this was related to their approach to doing the exercises themselves rather than the outcomes of them. Although exercising was reported to be beneficial, some children did not want to do the home exercises and had to be ‘coaxed’ because some of the exercises actually exacerbated impairment effects (McBurney et al., 2003, p.661). When young people are asked to reflect on childhood rehabilitation however, studies have shown that they predominantly focus on therapy as a negative experience. Gaskin et al.’s study into young women’s approach to physical activity in adulthood has highlighted that their feelings towards rehabilitation in childhood include “frustration from not understanding the purpose of physiotherapy and not being able to achieve treatment goals, functional decline, boredom associated with doing repetitious exercises, [and] uncomfortable physical experiences (fatigue, pain, physical distress)” (Gaskin, Andersen, and Morris, 2012, p.206).

Meanwhile, studies have found significant improvements in children's functionality after having had surgical interventions (Skold et al., 2007; Himpens et al., 2013). A majority of children reflecting on the outcomes of the surgery, who had had it one to three years prior, stated that their functional ability had improved, referencing such benefits as finding walking and dressing themselves easier and being in less pain (Himpens et al., 2013, p.403; Skold et al., 2007). Focusing on the biological impact of the surgery, the main functional outcome reported by the children and young people participating was a reduction in pain (Himpens et al., 2013, p.404). However, limitations to these studies have identified the poor representation of real-life rehabilitation due to the fact that they were time sensitive, barriers to participating in the therapy were ameliorated for the benefits of the study, and the process of documenting their progress was found to have positively influenced the children's rating of the impacts of the therapy (Himpens et al., 2013; Skold et al., 2007).

The sociological impact of the rehabilitative approach on children and young people has been scarcely researched. However, the *Study of Participation of Children with Cerebral Palsy Living in Europe* (SPARCLE) project, which used Goffman's Stigma theory to analyse the role that rehabilitation plays in children and young people with Cerebral Palsy's perceptions of themselves, has developed a theoretical basis for critiquing the social impact of rehabilitation in their lives (McLaughlin, 2017). The SPARCLE project identified two main aspects of medical interventions that induced stigma; surgery and physical therapy, which participants pursued in order to obtain a more socially acceptable body; and the stigmatisation of others based on the perception of their involvement in rehabilitation. The most relevant finding for this thesis was that participants in the SPARCLE project had a constructed sense of their future independence, which was primarily based on being self-reliant and as able as possible, in line with perceived societal 'norms'. McLaughlin, summarising the project, posited that, first and foremost, rehabilitation reduced children's experience of pain from having Cerebral Palsy (McLaughlin, 2017). Furthermore, the process of participation provided children with a sense of pride over the activities they could achieve during therapy sessions. However, avoiding social stigma was still found to be one of the main driving factors in participants seeking medical interventions, with the goal of being self-reliant in the ongoing battle for social position. This led to, for example, participants prioritising walking instead of using a wheelchair, which was backed by self-monitoring and self-discipline in the pursuit of a body that interacted in ways that others 'expected' (McLaughlin, 2017, p.249). Concluding, McLaughlin considered that, instead of being perceived to be passive recipients of rehabilitation, children and young people continuously display agency in 'managing and resisting' stigma while they go through the rehabilitative process (McLaughlin, 2017, p.249).

> *The dynamic of agency and self-disciplining involved in the participants' choices around medical intervention and working on the body, have implications for medical practitioners who work with such young people. One thing that was evident in their discussion was they were encouraged to make their own decisions about what surgery to have and what day-to-day work on the body to undertake. There is no evidence that their participation in intervention was something dictated by others. However, it is useful for medical practitioners to think about how they explore with disabled young people what lies behind their choices. (McLaughlin, 2017, p.249)*

This section has demonstrated that studies into the perspectives of children with Cerebral Palsy have predominantly been undertaken by practitioners within the rehabilitation discipline. This literature has tended to focus on the experience of the medical intervention itself and relate only to the physical impact thereof.

The main sociological study of this phenomenon, meanwhile, has found stigma to be both a reason for children and young people with Cerebral Palsy's engagement in rehabilitation, and contributed to their experience of stigma amongst their peers who do not have rehabilitation. Both approaches of this phenomenon, however, have predominantly explored children and young people's perspectives of rehabilitation while they were going through the process. This thesis considers the long-term impact of having gone through rehabilitation by asking participants to reflect on its effect on their social and psycho-emotional development.

3.4.2 Research into young people with Cerebral Palsy's experience of transitioning out of paediatric rehabilitation

Transition between paediatric and adult healthcare systems has been well documented as being a problematic experience for young disabled people (Beresford, 2004). Transition can present a myriad of difficulties including: a reduction in appropriate support services, therapies and treatments; the removal of peer and support networks; a lack of information about adult support services; and a lack of support from specialist practitioners (Beresford, 2004; Wright, Robb and Shearer, 2015; Moll and Cott, 2012). The problems this creates for young disabled people are compounded by the absence of appropriate consultation and involvement in their own transition (Beresford, 2004).

Studies into the specific experience of young people with Cerebral Palsy's transition between paediatric and adult health services have highlighted; the uncoordinated nature of the relationship between paediatric and adult health services, finding appropriate services to deal with unanticipated impairment effects, and managing stigma and stereotypes in adult health services (Wright et al., 2015; Bagatell et al., 2017). Beyond the poor coordination of the transition process, Wright et al. identified the disparate quality of health treatment within adult services as a barrier to a young person's transition into adulthood (Wright et al., 2015). When young people require rehabilitation, which has been found to be due to often unanticipated issues in adulthood, studies have noted that young people had to identify specific issues in order to access services (Wright et al. 2015; Bagatell et al., 2017). However, Bagatell et al. have identified that on accessing services, practitioners have poor knowledge of the way in which Cerebral Palsy impacts adults and that young people often face being stereotyped or do not have their health concerns taken seriously (Bagatell et al., 2017). In recognition of the preparedness of young people leaving paediatric services, they conclude that the "development of empowerment appears to reflect an additional gap in service provision and skill development that could mitigate the abrupt feeling of being thrust into adulthood" (Bagatell et al., 2017, p.84).

Moll and Cott argue that childhood rehabilitation for children with Cerebral Palsy, which had focused on normalisation, concluded with an approach towards adolescents that there was 'nothing more to be done' (Moll and Cott, 2012, p.1280). Beresford found that current transition models lead to young people and the staff involved in their transition holding low expectations for their future adult lives and that by not adequately engaging them in the planning process, transition fails to take adequate account of their priorities; friendships and social lives (Beresford, 2004). This in turn leads to young disabled people having poorer outcomes as defined as being successful achievements of transition, such as living independently, securing employment, and being in relationships.

Exploring young adults’ experiences, studies have found that young people with Cerebral Palsy felt there was a need to continue to access some form of rehabilitation (Moll and Cott, 2012). Without access to ongoing rehabilitation, Moll and Cott reported that young people with Cerebral Palsy felt that the emphasis on normative function, namely walking, was undermined by the degeneration they began to experience in adolescence (Moll and Cott, 2012). Similarly, Wright et al. highlighted that adults with Cerebral Palsy reported a reduction in their walking ability and increased pain and fatigue associated with ageing (Wright et al., 2015). Such findings have led McLaughlin and Coleman-Fountain to conclude that, without ongoing rehabilitation, the bodies of children and young people with Cerebral Palsy are left ‘always unfinished' (McLaughlin and Coleman-Fountain, 2014 p.76).

The literature discussed in this section demonstrates that young people’s views of medical intervention span both the process and physical outcomes of the interventions, and the role interventions have in facilitating their increased inclusion in society. Considering both approaches to young people’s experiences of rehabilitation will be central to researching the participants in this study’s understanding of the intentions of the rehabilitation they undergo. The studies discussed in this chapter have found that the inter-relational experiences and expectations of young people with Cerebral Palsy is influenced by the fact they have undergone rehabilitation to promote their participation in society (Wiegerink et al., 2006).

3.5 Conclusion

This chapter outlined the case for considering the implications of undergoing rehabilitation in the lives of children and young people with Cerebral Palsy. The chapter began by discussing the traditional medical approaches to rehabilitation that young children with Cerebral Palsy undergo. Therapeutic services, particularly physiotherapy, have been designed to rehabilitate children prior to the limitations of their impairments being fully known (Rosenbaum, 2003). This is primarily based on the neuroscientific consideration that the development of neural pathways, which determine movement patterns of the body, can be retrained through early intervention so that a child's movements can be modified to present as those of typically developing children, and thus increasing their ability to function independently within society (Barry, 1996). This concept was developed by Bobath in the latter half of the 20th century and has become the predominant rehabilitative therapy for children with Cerebral Palsy (Bobath and Bobath, 1956). At the same time, two alternative approaches were developed and adopted alongside Bobath's concept into the overarching practice of physiotherapeutic rehabilitation; one focused on enabling the attainment of functional tasks and the other focused on facilitating exercises that strengthen muscles (Tyson and Selley, 2007; Martin et al., 2010). Reviewing the evidence on the efficacy of these widely used approaches, all therapies discussed in this chapter have been shown by the rehabilitative practitioners carrying out the studies to increase functionality in specific cases depending on, for example, a child’s type of Cerebral Palsy, their baseline function, and the intensity of the therapy undertaken (McCoy et., 2019). This chapter has demonstrated that the literature is predominantly based on research into the biomechanical nature of the impairment and its effect on children’s deviation from typical development, and the role therapeutic interventions can have in facilitating their rehabilitation to more normative physical function. Furthermore, the research has relied on methods and measures developed and used by rehabilitative practitioners themselves, offering a narrow perspective on the efficacy of therapy, only giving a medical assessment of the impact of rehabilitation on the improvement of the impairment, without acknowledging the wider psycho-social and emotional impacts of rehabilitation on the child and the family. Similarly, whilst proponents of Conductive Education extol its benefits in fostering a resilient mindset in children to be functionally independent, evidence of it leading to increased physical ability in children is lacking.

The social analysis of rehabilitation has, meanwhile, critiqued its focus on returning individuals to a physiologically defined ‘norm’, and for not recognising the social barriers that prevent them from functioning equally in society (Oliver, 1993; Barnes, 2003). Whilst there has been limited research into the link between children and young people with Cerebral Palsy’s views of rehabilitation and their experiences within society, the SPARCLE project considered stigma as a theoretical basis for understanding their approach to rehabilitation. It found that participants’ engagement in surgery, day-to-day therapy, and their perceptions of others with similar impairments was rooted in stigma about their different bodies and therefore pursued more socially ‘normative’ function through rehabilitation. However, rather than being seen as passive recipients of rehabilitation, pressured by societal conformity, participants were found to actively balance the effects of stigma in their desire to become more self-reliant, independent adults (McLaughlin and Coleman-Fountain, 2014). This was similarly discussed by Bezmez, Lee and Shakespeare, who considered rehabilitation to be a continual negotiation of ‘normality’ between those receiving and providing therapy (Bezmez et al., 2016). This lends itself to a more nuanced analysis of rehabilitation and its role in disabled people’s lives. Proponents of the social interpretation of disability have sought to advocate for an ‘emancipatory’ approach to rehabilitation, which addresses the medical and social impacts of impairment on the lives of disabled people.

Penultimately, the chapter provided a context for analysing the lived experience of children and young people by introducing the main concepts of childhood studies. A growth in childhood studies introduced a framework for considering the lives of children as a distinct social phenomenon based on the principle that children have rights to participate in making decisions about their lives and for their agency to be respected (Mayall, 2000). This demonstrated the gradual shift away from considering children as immature beings, developing towards the rational adult, which typified the childhood industry for much of the second half of the 20th century. This created an alternative perspective, viewing children as ‘human beings’, influenced by the social, political, and cultural context in which they grow up, instead of ‘human becomings’, which treated a child as capable of achieving standard development independent of their environment (Qvortrup, 1994). Following this shift, sociological inquiry into children's perspectives expanded the theoretical basis for research into phenomena that impact their lives, with medical interventions being particularly considered (James and Prout, 1997; Tisdall and Punch, 2012).

This chapter finally examined the limited amount of research into young people's perspectives of therapeutic interventions. Such literature, which was often carried out by rehabilitative researchers, predominantly found that children and young people were positive about rehabilitation during the process, but the findings typically related to improvements in their biomechanical functionality (McBurney et al., 2003; Skold et al., 2007; Himpens et al., 2013). Finally, the section examined research into the effects of transitioning out of rehabilitation on children and young people with Cerebral Palsy as they move into adulthood (Beresford, 2004; Wright et al., 2015). Similar to the medical nature of the studies into the efficacy of rehabilitation, there has been little evidence gathered on the sociological impact of the withdrawal of rehabilitation on people with Cerebral Palsy as they become adults and navigate the increasing impacts of their impairment effects in its absence (Moll and Cott, 2012).

This study builds on existing research into a potential causal relationship between rehabilitation and young people's psycho-social-emotional well-being. This chapter demonstrated that a gap exists in the research into the role of rehabilitation in the lived experiences of people with Cerebral Palsy across the lifespan. This thesis seeks to determine if and what impact rehabilitation has on young people's sense of self, well-being, and self-esteem.

Chapter 4: Methods and Methodology

This chapter outlines the methodology and methods used to study participants' experiences of, and reflections on, undergoing rehabilitation. The first section of this chapter includes a discussion on the sociological research paradigms of emancipatory and biographical research. In taking an emancipatory approach, this thesis sought to explore the experience of children and young people with Cerebral Palsy from their perspective of having gone through rehabilitation, while the use of the biographical approach enabled for the participants' reflections to inform the understanding of this phenomenon from a social-relational perspective.

Section 4.2 outlines the recruitment and data collection process used in gathering the views of participants in this study. The recruitment of participants involved multiple approaches, which included approaching relevant schools and colleges to invite eligible children and young people to participate, working with third sector organisations who had contacts with families of children and young people with Cerebral Palsy, and through word of mouth. Certain challenges were identified, such as the influence of gatekeepers (parents, teachers, and therapists) who restricted access to eligible children and young people and the limited nature of the demographic. This section also briefly touches on the initial plan to include rehabilitation professionals in the research, and finally provides a summary of participants' characteristics.

The interviews with participants took a semi-structured format with a series of topics being discussed, which gave them the opportunity to expand on issues that they felt were most pertinent to their experiences. Reflecting on this process, the section highlights a number of issues that arose during the interview process, including the vulnerability of participants and the sensitivity of the information they disclosed, the influence of parental involvement, the role of my Personal Assistants, and the potential that I could be considered an insider in the research due to my experience of the phenomenon.

The penultimate section discusses the theory and process for analysing the data gathered from interviews with the participants in this study. This study adopted a Constructivist Grounded Theory approach to anchor the research in the experiences of participants (Charmaz, 1995). This enabled the research to be led by the data, whilst recognising the subjectivity of participants in their accounts. This section highlights that the analytical processes involved in coding and thematically reviewing the data were informed by the topics that emerged during the interview process. Such topics extended beyond the initial theme of the thesis to include broader issues, which impacted upon participants' experiences of growing up with Cerebral Palsy in rehabilitation. Within this section, I reflect on my own positionality as a researcher with Cerebral Palsy who has been through rehabilitation, and the potential impact it had on the study.

The chapter ends with the ethical considerations involved in conducting this study. Three ethical issues are discussed in this section. First, I discuss getting consent, which primarily involved a discussion between myself and participants, who all had capacity to understand the impact of participating. However, where participants were under the age of 16, parental consent was also sought. Secondly, I outline how I ensured anonymity and confidentiality, which was paramount during each phase of the process, but incurred challenges due to the recruitment process and the small demographic of eligible participants in Scotland. Finally, I discuss the impact of having pre-existing relationships with some of the participants, which could have influenced their participation and the information they provided.

4.1 Research Approaches

The two research approaches used to study participants' experiences of undergoing, and having gone through, rehabilitation were an emancipatory and a biographical research approach, which will be discussed in turn. Firstly, this thesis adheres to the principles of emancipatory research, which has sought to give a voice to the experiences of disabled people in research (Barnes and Mercer, 2004). Taking account of emancipatory research's role in attempting to advance the social position of disabled people, and critiques of its paradigm, this section considers the use of this approach in researching the views of disabled children and young people. Secondly, as the literature chapters identified, there is a lack of research into the impact of childhood rehabilitation on young people's developing sense of self. This required that participants reflected on their experiences of growing up with Cerebral Palsy, having gone through rehabilitation. I therefore chose the biographical research model as the methodological approach to gather and analyse participants' accounts of their reflections of this phenomenon.

4.1.1 Emancipatory research

The development of a research paradigm exploring the lived experience of disabled people was in response to disability activists' and academics' discontent that the positivist nature of existing research, searching for a 'true' account of the occurrence of disability, provided an inaccurate representation of its impact on disabled people's lives (Danieli and Woodhams, 2003). With the ontological basis for such research being rooted in a medical definition of disability, located in the body, and the epistemological theory it produced giving a distorted perspective of disabled people's experiences, previous research paradigms failed to recognise the social exclusion of disabled people (Danieli and Woodhams, 2003; Barnes and Mercer 2004). Compounding this, the dynamic between researchers and the research participant was criticised for its hierarchical structure, which perpetuated the production of research that was considered to embed inequality (Danieli and Woodhams, 2003). Therefore, in establishing the emancipatory research framework, the intention was not to undermine the value of knowledge acquisition from the objective perspective but rather to integrate the appreciation of the sociopolitical dimensions of disabled people's lives (Oliver, 2002). Emancipatory research therefore provided an alternative approach that contested the dominant culture in social theory construction at that time. In its place, emancipatory research attempted to rebalance the relationship between the researcher and those being researched in an effort to remove the oppressive nature of social research production (Oliver, 2002). As a result of the emancipatory approach, there were two key outcomes; to enable disabled people to inform the development of research about their experiences, and for those experiences to inform the social structures in order to emancipate disabled people from oppressive culture.

Disability research has since taken on the approach advocated by Stone and Priestley (Danieli and Woodhams, 2003). Their five provocations advanced the emancipatory principles whilst recognising the need to develop a robust research framework. The principles outlined by Stone and Priestley expanded on the political prioritisation underpinning emancipatory research in the field of disability studies to achieve an epistemological basis for the approach. This acknowledged the shift from researching disability as an individualised issue to considering it as a social phenomenon, while at the same time detaching the study of it from requiring an objective standpoint to one which valued personal subjectivity (Stone and Priestley, 1996). In doing so, Stone and Priestley aligned the approach with other emancipatory forms of research to highlight the role of research in progressing the social policy that restricts disabled people from accessing their full rights. This pulled on the feminist principle that personal experience of impairment should be incorporated into a research paradigm, discussed below.

Influence of feminism

In light of the criticisms discussed above, theoretical advances have been developed to incorporate the role that impairment plays in causing disability in the process of 'being disabled' (Thomas, 2004). Disability feminists have contended that emancipatory research should 'include the experience of both impairment and disability', which recognises the variety of 'experiences of oppression among disabled people' in establishing a more holistic account of the impact of personal attributes on disability and vice versa (Barnes and Mercer, 2002). Feminist theory featured heavily in both the critique and the development of the emancipatory approach. There are parallels between the emancipatory research model in disability studies and feminist research; both have been focused on the power relations that serve to maintain oppressive structures. However, as Danieli and Woodhams pointed out, feminist research has adopted a broader interpretation of both emancipation and participation. In doing so, the feminist paradigm has broadened to consider the gendered reorganisation required to promote equality in society by particularly reflecting on the perspectives of researchers in evaluating their position in the research process (Danieli and Woodhams, 2003).

A leading feminist in disability studies, Morris, argued that instead of maintaining the division between disability and impairment, there was also scope to incorporate the perspective commonly attributed to the feminist movement: that the “personal is political” (Morris, 1992, p.164). Prominent opponents to this development have highlighted that the fear amongst proponents of the latter position is “to mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is "really" about physical limitation after all” (Shakespeare, 1992, p.40). In providing her criticism on this approach, Thomas argued that it sustains the male-dominated stance that personal issues should be kept out of politics, which in turn feeds the continuation of “the *social* causes of oppression which operate in areas of life which involve social identity, the intimate, the emotional [and] the so-called 'private'" (Thomas, 1999, p.74). Therefore, gathering a variety of 'experiences of oppression' among disabled people is important in establishing a more holistic account of the impact of personal attributes on disability (Morgan, Barnes and Mercer, 2001, p.54).

Influence of disability childhood studies

Another criticism of the emancipatory research approach is that it only offers a one-dimensional analysis of disability and, by placing the emancipation of disabled people as the central premise of a theoretical approach, it creates a tendency to treat disabled children and young people as a homogenous group (Watson and Shakespeare, 1998). Just as disabled people have been contrasted against the standard afforded to non-disabled people, so too have disabled children been pitted against the characterisation epitomised by adulthood (Reeve, 2004). Research into the lives of disabled children and young people has been relatively underrepresented and has 'tended to focus on their experience of formal support, thus identifying them primarily as service users in need of care and assistance' (Stalker et al., 2012, p.4). Research into disabled children's lives, namely Alderson (1993), Beresford, (1997) and Stalker and Connors (2003) observed that the absence of disabled children's experiences has led to their objectification. Tisdall and Punch reflected on the effectiveness of disability studies to transpose its theory into the political sphere while children's issues remain secondary to those of adults (Tisdall and Punch, 2012). The result has been two-fold; interventions meant to support disabled children were "focussed at the level of individual need", and the absence of their voice led to a lack of "any analysis of the social experiences of disabled children" (Watson, 2012, p.193). Therefore, there has been a lack of theoretical documentation about the lives of disabled children as a distinct phenomenon within childhood (Connors and Stalker, 2006).

Recognising the shift towards a research paradigm that actively included disabled children in investigations of their perspectives, Watson proposed five principles for a new research paradigm. Summarising these, a paradigm for researching the lives of disabled children and young people would include: the revision of the perspective of disabled children's role in researching and constructing an understanding of childhood disability; an acknowledgement of the intersection between childhood disability with other characteristics; an identification of the temporal impact of children's relationship to their impairment and disability; the exploration of the psycho-emotional impact of differing impairments on the collectivisation of disabled children's experiences; and finally, taking heed from disability studies, the prioritisation of emancipatory action against the oppression of disabled children (Watson, 2012). Finally, in addition, Carpenter and McConkey highlighted the paucity of empirical evidence of disabled children's representation in policy and suggested that "more effort should be made to ensure that it represents the range of voices under the rubric of 'disabled children'" (Carpenter and McConkey, 2012, p.254). This study sought to gain an understanding of the experience of children and young people with Cerebral Palsy.

4.1.1.1 Critiques of Emancipatory Research

Reviewing the main principles of the emancipatory approach, Danieli and Woodhams challenged the theoretical framework as the *only* approach to researching the lives of disabled people (Danieli and Woodhams, 2003). Firstly, debating the approach's opposition to 'positivism' as a framework for knowledge production, Danieli and Woodhams questioned the position that viewing disability as socially constructed is an alternate form of positivism (Danieli and Woodhams, 2003). Yet, this view of the dynamic between disabled people as contributors to a social movement and those perceived to be part of the structural barriers has been criticised for being too simplistic. In their analysis of this dynamic, Stone and Priestly suggest that the dualism between an oppressive and oppressed group is a narrow and 'pretentious presumption' (Stone & Priestley, 1996: Barnes & Mercer, 1997; Moore et al., 1998). Similarly, in placing the emancipation of disabled people, especially from a political objective, as the central premise of its approach, there has been criticism directed at it because of its tendency to treat disabled people as a homogenous group (Watson Shakespeare).

Oliver considered the role of research, and in turn researchers, to facilitate the empowerment of disabled people through increasing their participation in research (Oliver, 1992). Critiques have been directed at the equalisation of the researcher and the participant, as enforced by the emancipatory research paradigm. Davis, for example, argues that "by insisting on researchers adopting the social model, emancipatory research may restrict the intellectual freedom of the researcher, and their capacity to interpret the worlds and cultures of others"

(Davis, 2000, p.193). Taking this approach into the research relationship and advocating the social model of disability as a framework through which to consider their experiences, Danieli and Woodhams have contended that participants who do not conform or are not informed may be marginalised or "feel obliged to 'toe the party line'" (Danieli and Woodhams, 2003, p.288).

4.1.2 Biographical Approach

The biographical research approach considers a person's construct of their life within the social context of the phenomenon being researched (Miller and Schütze, 2011). There are two streams of thought concerning this method. The first considers that the biographical data collected is influential in the development of theory through its analysis while the second takes a 'narrative' approach to constructing an individual's life history, in order to place their perspective of their experiences within the events that have happened throughout their lives (Miller and Schütze, 2011, p.16). Goodson argues that life history and other biographical approaches offer a great deal to researching identity (Goodson, 2001). The development of biographical approaches identified the limitations of drawing theory from large collectives of experienced phenomena without diminishing the richness of data from the individuals therein. It sought to provide a method for gathering the personal accounts of those who experienced a social phenomenon (Goodson, 2001). In doing so, Becker argued that life histories provided a method of raising the subjective perspective of people who have experienced issues which have previously been the objects of sociological research (Becker, 1967). Including subjective research into the sociological paradigm challenged the dominance of theoretical objectivity, which tended to maintain existing social power relations (Goodson, 2001). The use of the biographical approach has been supported by feminist researchers as it “can be used to give expression to, and in celebration of, hidden or ‘silenced’ lives” (McLaughlin and Tierney, 1993; Goodson, 2001, p.133).

4.1.2.1 Critique of the Biographical Approach

The biographical approach has been critiqued for its reliance on individual narratives in a number of ways. Firstly, the power to give meaning to the accounts of participants’ narratives has raised concerns about the interpretivist nature of this approach. Plummer, for example, considers that narratives are nothing without the interpretations of those telling, analysing, and reviewing them (Plummer, 2020). For this reason, Shah and Priestly refer to the ‘messy’ and ‘uncertain’ appraisal of biographical research due to the fact that experiences have been “remembered, imagined, selected, and interpreted” (Shah and Priestley, 2011, p.176). Merril and West have highlighted that critiques have been levelled at the approach’s tendency to focus on the granular detail of individual narratives rather than considering the research’s wider phenomenon in a social context (Merrill and West, 2009). Finally, Foucault, Merril and West note, questioned the legitimacy of the biographical method, given the inherent power dynamics within society of which less powerful subjects may not be fully aware (Merrill and West, 2009). Yet, countering this, Plummer highlights the potential for the narrative approach to give a voice to those who traditionally do not have the power or a platform to tell their stories (Plummer, 2019).

Considering the principles of both research paradigms, biographical and emancipatory, incorporating critiques of both, this section identified the opportunities in using these approaches together to research the experiences of the participants in this study. Basing this research in the emancipatory approach and using the biographical method to `investigate individuals' daily life experiences, this study brings to the fore the perspectives of young people with Cerebral Palsy who have been largely absent from research into their experiences of childhood rehabilitation (Roberts, 2015, p.11; McLaughlin, 2017).

4.2 Data Collection

This thesis employed a qualitative research approach to studying the experiences of participants. The production of knowledge through qualitative research is a process of inquiry into the 'social human problem' through developing a 'complex, holistic picture' of participants' views (Creswell, 1998, p.15). It enables the interaction between individuals and society to be studied as an active process that influences the creation of an understanding of their world (Ohman, 2005). Qualitative research, therefore, is based on the lived realities of research subjects. Through the analysis of individual perspectives, a theoretical position can be developed that provides an explanation of commonly experienced phenomena (Creswell, 1998). For this reason, qualitative research has been found to be particularly applicable in researching disability as a social phenomenon (O'Day and Killeen, 2002). O'Day and Killeen argue that by using the research approaches available through qualitative research, such as in-depth interviews, the framing of disability and its impact on participants has evolved to appreciate the diversity of experiences of living with an impairment (O'Day and Killeen, 2002). Likewise, the use of qualitative methodology to explore an individual's experience of rehabilitation can be helpful to understand its impact on people's lives and lead to the improvement of rehabilitative services (Ohman, 2005). The following subsections discuss the process of carrying out research with children, young people and adults with Cerebral Palsy. The first considers the recruitment of participants, highlighting the successes and challenges and reflecting on my own approach to the recruitment process. Also, in this subsection, I refer to the initial plan to interview rehabilitation professionals, which involved recruiting therapists from across the discipline. Secondly, the use of the interview method is discussed in relation to gathering data from participants and explores the issues arising in using this method with children, young people, and adults with Cerebral Palsy.

4.2.1 Recruitment of participants

My data collection took place across 2015 and 2016. In advance of beginning the data collection phase, I developed recruitment materials following principles on the accessibility of information to ensure all documentation was easy to read and comprehend (Tisdall, 2012). This was particularly relevant for the potential recruitment of younger participants, or who may have learning disabilities. The materials were created to inform prospective participants of the intentions of the study, their rights and responsibilities in participating, and the ethical guidelines I would be following throughout the research process.

The initial criterion for participating in this research study was that candidates had to be between the ages of 12 and 35 and have Cerebral Palsy. Following guidelines from the World Health Organisation and the United Nations, the Scottish Government defines ‘young people’ as between the ages of 11-24 (2017). For this study, the lower age range of 12 years old was specified in accordance with the Medical Research Council’s Ethics Guide, which states that in the 1995 Children (Scotland) Act, a child of 12 years or more should be presumed to be of sufficient age and maturity to ‘form a view’. (2004, p.29). Due to the limited access to children and young people, and the small population of children and young people with Cerebral Palsy in Scotland, the sample size was extended beyond the age range of 12 to 25 part-way through the data collection process to encapsulate young people up to the age of 35 who had stopped having therapeutic interventions in their mid to late-teens.

Research exploring the views of disabled people has been critiqued for considering them as being a homogenous group (Watson, 2004). The choice to focus on interviewing young people with Cerebral Palsy, as opposed to those with other impairments, was to acknowledge the specific experience of growing up in rehabilitation as a person with Cerebral Palsy. In an attempt to consider a range of perspectives within this demographic, I tried to recruit participants who reflected a cross-section of the general population of people in Scotland with Cerebral Palsy. I achieved gender parity across participants, some participants identified as LGBTQ+, and a range of ages were represented within the recruitment parameters. There was a mix of participants who attended mainstream and those who went to special school from the beginning of their education. Regrettably, no one who identified as a person of colour was represented in this study. Therefore, it is important to acknowledge, as it is documented that the experience of health care is affected by race and ethnicity, that the findings of these interviews reflect the experiences of white people (Smith, Chaturvedi, Harding, Nazroo, and Williams, 2000).

Considering that this research explores the experience of growing up with Cerebral Palsy from birth, the experiences of parents, including the diagnosis and birthing process as described in Chapter 2, are significant in the reflections of the participants in this study. It is therefore important to note that all participants were brought up by their biological parents, with the exception of one whose mother died during childbirth and was raised by their extended family.

The original plan for recruiting participants to be interviewed was to approach mainstream and specialist schools, third sector organisation providers of support to families of disabled children, and to contact participants through word-of-mouth. I contacted approximately twenty schools across Scotland, including specialist provisions managed by non-profit organisations, such as Capability Scotland. The recruitment document provided to them described that an interview with a young person would be planned in order to accommodate their abilities, including amending the method to incorporate alternative communication styles. Difficulties with accessing potential participants arose at this stage. As Nind identified, when attempting to hold interviews with disabled people, particularly those with communication and learning impairments, choosing and contacting them can involve going through a 'gatekeeper' (Nind, 2008, p.9). In the case of disabled children, this may be a parent, carer, social worker, organisation, or others, which can cause problems in recruitment. It has been suggested that the 'gatekeeper' may block contact with disabled participants due to a belief that they may be unable to participate and/or require protection in research (Stalker, 1998). This was evident in the limited replies I received from schools (see Tisdall, Davis and Gallagher, 2008). Among other reasons, respondents informed me that; either they did not have any pupils with Cerebral Palsy, that I would require approval from the respective Local Authority (a lengthy process), or in one response the judgement was made that “The young people in my school with Cerebral Palsy also have complex additional support needs and would not be able to participate in an interview with you” (Response from a special school).

I subsequently contacted third sector organisations who provide support and advocacy for families of disabled children. From my professional background, I knew these organisations had links to families with a child or young person who has Cerebral Palsy. Due to the established relationship between third sector organisations and families, their advocacy for the research provided it with legitimacy. Therefore, I believed the information coming from such organisations would encourage prospective participants to sign-up to the research. However, while colleagues working in these organisations were confident in identifying potential participants, this approach only yielded two participants. This may have been because the families in contact with such organisations are commonly facing additional barriers to participation, as explained to me by the Director of one such organisation.

I had moderate success when approaching therapy and treatment centres for children and young people with Cerebral Palsy. As part of this process, a local therapeutic centre for children and adults with Cerebral Palsy disseminated my recruitment material around their ‘clients’ (children and young people who attend the centre). This resulted in the participation of one young person who had previously attended the centre for therapy and volunteered there latterly. I met with the Director of another centre who took an interest in my research and was keen to demonstrate the benefits of the provisions available. They invited me to attend a session for young people with Cerebral Palsy to have a full day’s therapy with their trained staff. Three people then offered to participate in an interview, however only two interviews took place as a result of scheduling difficulties. I recognised that this approach had implications for maintaining participants anonymity due to the nature of the close environment. This will be discussed further within the section on ethical considerations below.

Finally, the most successful means of recruitment to this study was through word of mouth and contact with people with Cerebral Palsy already known to me personally. Having knowledge of my research and personal experience of Cerebral Palsy and rehabilitation throughout childhood, there was an expression of interest from others to have their experiences included in the research. Although there are ethical implications to including personal connections, as discussed further below, the nature of the common experience resulted in an appropriate means of collecting valuable data. This was demonstrated by the openness of the participants' contributions, noted by them to be due to the perception that I was a trusted person to conduct the research. This method elicited a majority of the participants for the interview; nine in total. A table of participants' characteristics, which has been anonymised, is included at the end of this section.

4.2.1.1 Including professionals

During the initial phase of recruiting and interviewing children and young people, considering that I was taking a Grounded Theory approach; both were taking place concurrently, it occurred to me that I could triangulate the data I was collecting through interviewing rehabilitative professionals, such as Physiotherapists, Occupational Therapists, and Speech and Language Therapists. Over a short period, I recruited professional participants working outwith the NHS or whom I knew personally. The interviews I conducted with professional participants covered topics, including their motivation for pursuing a career in rehabilitation, their training, the approach they apply to delivering therapy to children with Cerebral Palsy, their views on the principles behind, and outcomes of, rehabilitation, and their views on the rehabilitative provision available to adults with the condition. A topic guide is included in Appendix E.

The data gathered through interviews with professional participants elicited rich information about the rehabilitative approaches used to treat children and young people with Cerebral Palsy and demonstrated the variety of methods captured in the literature review. When writing up the findings from both the interviews with children, young people, and professionals, however, it became apparent that attempting to merge the topics was too broad in scope. I, therefore, made the decision to use the data gathered from professional participants as background information and focus on presenting the themes that had emerged from the children and young people interviewed.

Participant characteristics

The following tables provide an overview of the participants' characteristics and backgrounds to contextualise their quotes in the following data chapters.

Children and Young People

Pseudonyms	Background
Catherine, 30	Catherine has Quadriplegic Cerebral Palsy, which mostly affects her legs, using a power chair for the majority of the time. She is reasonably able with fine motor skills and her speech is not affected to any great degree by her Cerebral Palsy. She lives independently and works in the third sector.
Wendy, 17	Wendy has Cerebral Palsy that significantly affects her physical function. She uses an electric wheelchair with a seating system to maintain her posture. Wendy was in the final year of her special school where she had been since transferring from mainstream at 14. She had hopes to attend college after. She has two sisters, one of whom is her twin

	who also has Cerebral Palsy, but Wendy describes to be more able than her and who helps her a lot.
Sarah, 15	Sarah has Cerebral Palsy, which affects one side or her body more than the other. She walks using one stick, an issue that is discussed during the interview. She is currently studying standard grade at school and lives at home with her mum and twin sister, who is not disabled.
Chris, 33	David is a young man in his mid-20s who has a prominent form of Cerebral Palsy and mild learning difficulties. He has a bespoke wheelchair with a seating system to support his upright posture, his speech and gaze are affected. David lives at home with his mother, who is his primary supporter. He attended college once a week until his transport withdrew.
Rachel, 29	Rachel is a 29-year-old woman with Cerebral Palsy, affecting her legs more so than her upper body. She uses an electric wheelchair out and about, though she drives and uses a manual wheelchair for short distances. It does not affect her speech, but her gaze and thus wears glasses. Since finishing her degree in media, she has pursued further studies and volunteering opportunities but has struggled to find and maintain paid employment and so accesses the welfare system. Rachel lives in her own flat. Her flat is close to her

	family home and maintains regular contact with them but is open to the fact it has been tested at times.
Scott, 27	Scott has quadriplegic Cerebral Palsy and a mild learning difficulty. He went to special school in Edinburgh before moving to a specialist boarding college in England. After finishing college, he now lives independently in Edinburgh with Personal Assistants 24 hrs a day.
Peter, 32	Peter is in his early 30s, he has diplegic Cerebral Palsy, affecting the left side of his body. He is ambulant and gets around independently using public transport. On occasion he may use a walking/trekking pole when walking long distances. His speech is slightly affecting and talks in a broad Glasgow accent. He has an administrative job and volunteers at a rehabilitation centre.
Michael, 28	Michael has Cerebral Palsy impacting his left side more than his right. He also has a mild learning impairment and uses walking sticks to get around. His fine motor skills are functional, and his speech is not affected. Michael lives in a small town in the Borders close to his family where they have stayed for around 20 years. He has a part time job in a food shop working on the tills.
Ian, 30	Ian has Cerebral Palsy affecting all his limbs but more so his lower body. He uses a manual wheelchair around his house,

	where he lives independently, but has difficulty propelling outdoors. Ian works for the Scottish Government, after having graduated from university. He grew up with his family on one of the islands off Scotland. Ian is in a long-term relationship, his girlfriend is also disabled, but they live at opposite ends of town.
Suzy, 31	Suzy is a young woman with Cerebral Palsy, she uses a power wheelchair for the majority of her day-to-day life and has a speech impediment. Suzy graduated university, and now lives on her own in Ayrshire. She employs Personal Assistants to support her with independent living tasks and personal support.
Claire, 15	Claire has diplegic Cerebral Palsy, which mildly affects her right side (mainly her leg). As she explains during the interview, her impairment is not obviously visible to people who are unaware that she has Cerebral Palsy. Claire lives at home with her parents and a sibling, while finishing her Highers with plans to go to university.
David, 35	David has quadriplegic Cerebral Palsy, uses a manual wheelchair to get around and has speech impairment. His mother died during childbirth and was raised by his paternal grandmother. He went to specialist school initially but transferred to mainstream. He now lives with his partner and

	works in theatre. They employ Personal Assistants to support them at home.
Olivia, 25	Olivia is a young woman in her mid-20s with mild Cerebral Palsy, that she describes affects one side of her body more than the other. Her Cerebral Palsy can cause her pain, but it is not always visibly obvious that she has the impairment. Growing up in Sweden, Oliva had the majority of her childhood therapy there, but has accessed health and therapeutic services since moving to Scotland
Gemma, 22	Gemma has mild diplegic Cerebral Palsy, which affects her left hand more than her right. She walks unaided with her foot turned in. She has a husky voice as a result of medical tubes having scarred her throat as a baby. She has recently completed a BA degree in social science and works part time for Lloyds Banking Group.
James, 23	James has significant quadriplegic Cerebral Palsy, is a full-time power wheelchair user and has a speech impairment. He has Personal Assistants to support him to live independently. James currently studies Law in London and identifies as LGBTQI+.
Steve, 31	Steven has Cerebral Palsy, which predominantly affects his right side. Though he speaks with a speech impairment, Steve predominantly uses an iPad to communicate. Steve works for

	the Civil Service and lives with his long-term partner. He is LGBTI+.

Professionals

Pseudonyms	Profession	Area
Laura, working in the profession for approx. 20 yrs	Physiotherapist, private	Glasgow
Naomi, working in the profession for approx. 15 yrs	Physiotherapist, private	Glasgow
Stephanie, working in the profession for approx. 27 yrs	Physiotherapist, NHS	Stirling
Susan, worked in the profession for approx. 35 yrs	Head of Physiotherapy, NHS	Edinburgh
Mary, working in the profession for approx. 36 yrs	Speech and Language Therapist, Education	Midlothian
Rita, working in the profession for approx. 30 yrs	Occupational Therapist, NHS	Edinburgh

4.2.2 Gathering data - interviews

Having recruited my participants for the study, I used the interview method to gather their views of having undergone rehabilitation in childhood, teenage years and their transition into adulthood. A range of methodological tools can be employed to gather qualitative data, such as life stories, case studies, and interviews, which aim to find meaning in the accounts of participants that researchers interpret (Lincoln and Denzen, 2005). However, the options available through the interview method mean it is an attractive source of gathering broad accounts of individual experience (Fielding and Thomas, 2001). The choice for using this method was based on the versatility of its approach as interviews can identify group behaviour, demonstrate population specific concepts, establish common concerns among interviewees and inform hypotheses of observed behaviour (Fielding and Thomas, 2001). Semi-structured interviews were chosen as they enable an open dialogue in which to explore a range of issues. The interviews were therefore able to be more conversational in its style, which proved effective for allowing young people to be more relaxed in discussing the relevant issues. In the same vein, semi-structured interviews allow for both parties to ask supplementary questions to clarify comments or to seek further information based on an interviewees' level of understanding (Fielding and Thomas, 2001). This was particularly helpful in cases where an interviewee's experience had unique qualities that required further understanding due to their specific circumstances, such as explanations of medical definitions.

The level of alteration imposed by the interviewer leads some to consider that semi-structured interviews fall on a spectrum from unstructured to open-ended survey to a combination of quantitative and qualitative approaches with varying limitations of probing (Arthur and Nazroo, 2003). However, to facilitate such interviews with participants, I developed a topic guide which incorporated the main themes I wanted to cover during the course of the interviews. I began with a central theme that rehabilitation could have an impact on children and young people’s physical and social experiences of growing up with Cerebral Palsy. In developing my topic guide, I included discussion prompts, which covered the general phases of the rehabilitative process such as entering therapy, undertaking therapy during childhood, and leaving child services. However, as the analysis shows, in the following chapter, all interviews covered broad themes, including childhood development, the experience of therapeutic intervention, and transitioning into adulthood.

Giving participants agency within the research process was given particular consideration within logistical arrangements. With each participant, I took time to plan and arrange a suitable and convenient interview. This involved giving participants agency in deciding where interviews took place, ensuring that venues were accessible when they were done in public, making provisions for enough time to be allocated, and having the option of accompaniment. Interviews took place in three primary locations: in people’s houses, in cafes and at therapeutic centres. There was one instance where the interview took place online due to geographical barriers.

4.2.3 Reflexivity in data collection

Reflecting on the data collection process, the following issues were identified: the vulnerability of participants and the sensitivity of topics they discussed, which raised the issue of the power dynamic between myself and participants, encouraging me to reflect upon my position in the interview process; the involvement of parents in interviews, which highlighted the challenges of including parents in discussions and the opportunity for participants to give an independent account of their experiences; the involvement of my Personal Assistants throughout the research process, which could have had an inadvertent impact on the data collection and analysis; and finally the potential for me to be considered an insider in the research process due to having experienced the phenomena being researched.

Vulnerability and sensitive topics

Reflecting on the data collection process and its impact on the data gathered, as mentioned above, I was mindful of the balance of power that existed between participants and myself. The participants interviewed for this study varied in age range; the youngest participant was 15 years old and the oldest was 35 years old. I was acutely aware of the power dynamic between myself and my participants. This was particularly pertinent with participants under 16. The power dynamic that exists between children and adults places the child in a vulnerable position when participating in research, especially considering their relational experiences of perceiving adults as authoritative figures in their lives (Hill, 2004). This, Hill argued, makes them susceptible to ‘persuasion, adverse influence and indeed harm’ within the research context, which researchers should mitigate by reducing their appearance as imposing (Hill, 2004, p.63). Kirk for example, suggested there is an inherent inequality in society which places children at a disadvantage when being asked to participate in research (Kirk, 2007). Attempting to redress such an imbalance, Kirk provided strategies such as 'being responsive to children's own agendas' and 'checking children's willingness to participate throughout the interview' (Kirk, 2007). Moreover, research involving disabled children and young people should avoid exacerbating vulnerabilities routinely experienced by them, such as feeling excluded or patronised (Bradbury-Jones, Isham, and Taylor, 2018). I believe I employed these strategies by being responsive to issues brought into interviews by participants and making sure participants wanted to continue interviews if I sensed any discomfort or desire to take a break or stop.

Related to this, as is briefly mentioned above, children and disabled people are often considered to be 'vulnerable' in research. This has stemmed from a traditional construction of both demographics as in need of specific protections (Kirk, 2007). Thackray contended that combined with the perception of disabled people being vulnerable members of society, this can lead to the experiences of disabled children and young people being unheard in research (Thackray, 2017)., Taking the view of those in both disability and childhood studies, I followed the principle that "the right of children to protection is not allowed to supersede their right to express themselves and their views" (Thackray, 2017, p.308).

For one of the home interviews, I gave the participant the option of having their mother in the room during the interview in case it would make them feel more comfortable. This was an option for all participants and was outlined in the recruitment document (Appendix A). However, it was particularly relevant in this scenario as the interviewee was a person who could be regarded as ‘vulnerable’, both for being a young disabled person and for being female. This is compounded by the fact that, as a disabled researcher, I took a Personal Assistant with me to all interviews, and both the PA and I were male (discussed further below). To provide reassurance to participants, and their parents or guardians, full disclosure checks were undertaken prior to conducting any interviews. The participant decided they did not wish their mother to be present, but it was arranged that they would remain in the next room should the participant require them.

An aspect of the interview process that could have compounded the participants’ vulnerability was the discussion topics, which I recognised had the potential to evoke sensitive responses. Sensitive research, as defined by Sieber and Stanley, involves the study of topics that have the potential consequences for the research participant or implications for the broader cohort of participants’ demographic (Sieber and Stanley, 1988). Such consequences, Lee described, can be viewed in terms of posing three types of threat to the participants involved in research and wider society; research pertaining to the private sphere which can be an ‘intrusive threat’, research that threatens to stigmatise or incriminate participants, and research that has political implications that may challenge positions of power or institutions (Lee, 1993, p.4). Broaching sensitive topics in this study could pose an ‘intrusive’ threat because, as Lee highlighted, it may invoke an emotional reaction, which participants may find difficulty to suppress during an interview, threatening their sense of capacity to continue participating (Lee, 1993, p.6).

There were two occasions where the topic of the thesis affected participants during the interviews. The first involved the participant becoming emotional when discussing the impact that therapeutic intervention had on their relationship with their parents. The choice I made was to slow down the rate at which the interview progressed, to give the participant time to talk through the emotions they were having and to check whether they wished to proceed. Upon reflection, I could have foreseen that the topic being discussed might have provoked a strong emotional reaction from participants. I henceforth arranged for interviews to take place in an environment less public than the café where the interview had taken place.

The second occurred during a discussion about a participant's desire to become a father. On multiple occasions he referred to a serious concern he had about having a child in case the child also had Cerebral Palsy; he believed that due to him having the condition, there was an increased chance of his future child having Cerebral Palsy. As the researcher, it was my understanding that this is not the case; Cerebral Palsy is not a genetic condition and therefore not hereditary. The decision I had to make during the interview itself was whether it was ethically appropriate for me to suggest the participant was incorrect or to give my opinion on a medical matter. The potential risk of doing so may have had negative consequences for the participant. Advising the participant that there was not an increased chance that his future child would be born with Cerebral Palsy because he has it, could have been reassuring, but without being fully confident in the facts, I did not want to risk misinforming or misleading a participant. I therefore chose not to correct the participant.

Involving parents

As this study involved the experience of children under the age of 16, I gave participants the option of having a parent present during interviews. The established principle in research with children in the UK is that they should be included in research if they are under 16 years of age without their parents should they wish to do so and have the capacity to understand their participation (Greig, Taylor, and McKay, 2007). Carpenter and McConkey (2012) emphasised the importance of recognising the influence of the family in understanding the development of disabled children's perspectives, particularly when considering their interaction with society due to the justified nature of families to protect their children's interests because of the negative attitudes directed towards them.

The parents of participants were present during two interviews. The first of these was with a participant over the age of 16 who, due to his location, was interviewed via Skype. Their mother supported them to operate the computer upon initiating the interview. I then asked the participant if they were happy for their mother to remain during the interview. This process in itself is cause for reflection. Prior to the interview, due to it being arranged through email, it was not apparent that the participant had barriers to communication and/or comprehension. This may have been because their mother wrote emails on their behalf, though I did not confirm this. The arrangement for the participant's parent to be present could have been due to convenience, if the participant most often communicates with their parent's support. Regardless, when it was agreed that the interview could take place via Skype, I explicitly asked the participant if this was an accessible interview format for them which through prior communication, it was agreed it was.

Having their mother present supported the participant's involvement. The participant gave short answers in response to my questions, mainly in agreement or disagreement. Their mother then supported the participant to expand on these answers. However, in doing so, they also commented on the issues being discussed by providing further explanation about the participant's experiences. While the parent's contributions into the interview were generally matter of fact, describing where the participant went to school for example, it must be acknowledged that their personal perspective influenced the direction and findings of the interview. Reflecting on the impact of this, it is difficult to distinguish the perspective and experience of the participant from their parent's. Had I been aware of the barriers to communication that became apparent through the interview, I believe that I should have determined the format that could have been most accessible for the participant to contribute at their level of ability.

Regarding the second interview in which a parent was present, on reflection, it is possible that the participant's responses were influenced by their mother's presence. The participant attended a private therapeutic centre, which, it was disclosed during the interview, was paid for by their mother. It is therefore a consideration that the participant framed their responses accordingly. However, the mother's contributions during the interview led me to be reassured that the participant was giving their honest account of the phenomenon being researched. In both scenarios, I considered that the benefit of including this participants' perspective in the study outweighed the level to which the data could have been influenced by their parents due to the participants' consent to having them present.

Carpenter and McConkey (2012) have contended that future research explores the views of disabled children and their parents separately to consider the consistency or divergence of views between them. I had considered whether there was the possibility that having parents present might influence the type of data that participants chose to share. During interviews I endeavoured to ensure that the child participant gave answers to questions, which were either preceded or subsequently added to by parents.

Including Personal Assistants

As a disabled researcher my own impairment effects had a bearing on the research process (Williams and Marvin, 2013). Specifically, having a Personal Assistant was an essential part of my research process. This included having my Personal Assistant present during interviews to take notes and work the digital recorder. This is similar to the role of research assistants in qualitative research, which has been found to have an impact on the relationship between the assistant, researcher, and participant (Stevano and Deane, 2017). However, while Stevano noted that the act of carrying out the fieldwork can have an effect on the subjectivity of data collection (Stevano and Deane, 2017), my Personal Assistants were not active during interviews, but accompanied me to undertake the interviews myself. Considering the impact on participants, this had the potential to influence the sensitivity of the information in which the participant decides to disclose. It cannot be determined if this was a phenomenon that influenced the research findings as I am unable to detract the presence of my Personal Assistants from the data gathering process. All participants were informed that my Personal Assistant would attend the interview and were asked whether they were comfortable with this prior to commencing the interview. No objections were raised prior to or during interviews. On reflection, I felt that having my Personal Assistant present during interviews lent the environment to be more conducive to an open discussion as the participant may have felt less pressure than a one-to-one interview may incur.

Insider influence

As the research focussed on a phenomenon I had experienced, which could have been assumed by the visibility of my impairment effects, it was imperative that I acknowledged the potential impact of my role as a researcher with Cerebral Palsy. Such reflexivity is necessary, Mohler and Rudman argue, because the insider researcher status can be attributed to those who are considered to be “highly familiar with the research setting or research participants” (Mohler and Rudman, 2022, p.1511). However, Labaree contends that the insider status possesses ‘the value of shared experiences; the value of greater access; the value of cultural interpretation and the value of deeper understanding and clarity of thought for the researcher' (Labaree, 2002, p.103). While I did not pre-emptively share my experience, in an effort not to influence my participants and affect the objective nature of the data collection, I offered up my opinions on occasion when participants enquired.

As a researcher with Cerebral Palsy, while I could identify with my participants, I recognised their heterogeneity and intersectionality in order to develop an understanding of their lived experiences. The status of researchers, as disabled or non-disabled, has been debated within disability studies. Branfield (1998) argued that without the shared understanding of the oppression faced by disabled people, non-disabled researchers are unable to represent their experiences. However, Shakespeare, recognising that one cannot assume shared knowledge through shared experiences, provides a balanced approach, proposing that "the ideal of emancipatory research suggests that the research agenda should be generated by disabled people, and the researchers – whether disabled or non-disabled – should be accountable to organisations of disabled people" (Shakespeare, 2006, p.186)

4.3 Analytical Framework

This section outlines the Constructivist Grounded Theory approach to, and practicalities of, analysing the data gathered during the collection phase - from recording interviews to writing up the data. Firstly, it introduces the foundations of Grounded Theory, which has become the predominant methodology in qualitative research due to its principle of being an inductive approach to data collection and analysis led by findings (Birk and Mills, 2011). Developments in the theoretical framework, which appreciated the subjective nature of participants' account in research, led to an alternative approach known as Constructivist Grounded Theory, as will be discussed subsequently (Charmaz, 2006). Taking this approach, I outline the process involved to ensure the research was guided by and reflected the issues raised by the participants in this study. This will be followed by a brief reflection on my positionality in the research as a person with Cerebral Palsy who has experienced the phenomenon of having gone through rehabilitation.

4.3.1 Ground Theory and Constructivist Grounded Theory

The basic premise of Grounded Theory is that theory is generated as a result of data collection (Glaser and Strauss, 1967). In contrast to deductive methods of research, which seek to explain or prove a hypothesis, Glaser and Strauss sought to establish a systematic approach to collecting and organising data, which concurrently produced theory (Walker and Myrick, 2006). Divergent approaches between Glaser and Strauss have broadened the original framework of Grounded Theory. Considering its effect on data analysis, the role of the researcher was a key difference in their development of approaches. Glaser on the one hand believed in objectivity of the research during the analysis of data, maintaining the core principle that data should lead the researcher, while Strauss considered that the researcher is an active participant in interpreting the data as it is collected and analysed (Howard-Payne, 2015).

Later, Strauss and Corbin's revision of the coding process to incorporate axial coding, which identifies theoretical trends as they emerge, moved the Grounded Theory approach away from the traditional model of allowing data to guide the emergence of theoretical trends (Walker and Myrick, 2006). While Glaser later contended that this resulted in the determination of categorization by preconceived notions of theory, it was recognised by Glaser and Strauss that Grounded Theory allows the researcher to determine the point at which the variety of data stops yielding new information (Glaser and Strauss, 1967). This provision enables the researcher to conclude that the research has reached a level where findings begin to be redundant in generating new theories. Within my research, this phenomenon occurred to an extent with similar themes emerging in each interview.

The objectivity, which Grounded Theory attempted to harness, was challenged for proposing that theory could be generated from 'objective' data. Charmaz, developing Constructivist Grounded Theory, considered that Glaser, and Strauss and Cobin, viewed the approach as applying a realist model to inductive data analysis (Charmaz, 2006). Charmaz, however, considered Grounded Theory to envelope 'principles and practises', which can be used flexibly through an inductive approach to data collection and analysis (Charmaz, 2006, p.16). Referring to the principles of social constructionism, Charmaz built on the concept that researchers have particular areas of interest to introduce the notion that research can be guided by topics on which to frame the development of theory (Charmaz, 2006). However, maintaining the core principles of

Grounded Theory, Charmaz noted that where the research findings do not fit with the interests guiding the research, the scope of the study should be flexible enough to respond to emerging data (Charmaz, 2006).

4.3.2 Reflecting on the analytical process

During each phase of the research process, I followed the Constructivist Grounded Theory approach. Discussing the data collection phase first, all interviews were recorded on a digital recording device, and I continually kept memos on the issues raised by participants, which in turn informed my subsequent data collection and theoretical sampling (Charmaz, 2006). However, there were issues in using this recording technique. Firstly, on one occasion the device did not start recording and so the interview had to be restarted. Secondly, in interviewing children and young people with Cerebral Palsy, some of whom had speech impairments, the recordings were not always audible. Therefore, in addition to recording, field notes were taken by myself and my PA for the majority of interviews, which aided transcription. However, as Tessier noted, the ability to revisit digital recordings makes their transcription a ‘more complete and more reliable’ version of the data (Tessier, 2012, p. 448). By having the original recording available for the majority of cases, I had the ability to compare the data, which Slembrouck argued takes the pressure off a reliance on notations (Slembrouck, 2007; cited in Tessier, 2012).

Moving on to consider the data analysis phase, I used Nvivo to carry out my analysis of the interviews. Such technology allows for a combination of transcripts, field notes and annotations to be used simultaneously during analysis (Tessier, 2012). In doing so, I developed nodes in Nvivo which supported the categorisation of coded data. I employed coding to organise the data into categories to structure my analysis. Coding enables the analysis to highlight common phenomena that in turn reveal trends within the data (Seidel and Kelle, 1995). However, I was cognisant of Charmaz's argument that researchers inherently influence the research analysis through interpretation during the coding process (Charmaz, 2006).

Through the initial coding process, the primary themes that emerged related to participants' experiences of life as a young person living with cerebral palsy and the way this interacted with their school life and their transition to adulthood. They also talked about the changing nature of their impairment and bodily capacity, living independently, forming romantic relationships, and working. Within each of these overarching themes, subthemes emerged and these enabled a more nuanced analysis of both the commonalities and the divergent views between, but also within, participants' interviews. This concurs with Dey's narrative that with greater categorisation comes greater confidence in the theories derived from the data analysed (Basit, 2003). Therefore, in mitigating against the point above that the transcription process can be subjective, Janesick suggested that the collection and analysis resemble a 'dance', which the single researcher is responsible for 'choreographing' (Janesick, 2003). In taking an iterative approach to the analysis of the interview transcripts, appreciating the interplay between codes and emerging data, four key themes were constructed: social impact of rehabilitation, walking, independence, and pain and degeneration. A criticism commonly lodged at coding, in respect to Grounded Theory, is that the subjectivity of the researcher may bias the interpretation of data and lead to themes being predetermined. In recognising this, however, I followed the commonalities coming through the data to inform my process of categorisation. A coding framework can be found in Appendix F.

4.3.2.1 Positionality

Finally, based on the theoretical framework set out by Strauss and Corbin, this section reflects on my own influence over the research process by considering my positionality. In conceptualising the topic being considered in this thesis, I recognise that it is intrinsic to the research that I, as a person with Cerebral Palsy who had rehabilitation throughout childhood, considered that it could have an impact on one's psycho-emotional development. Having come to the point of wanting to research this topic and pursuing a doctorate in it, I acknowledge that my consideration of the impact of rehabilitation on my psycho-emotional development may have been interrogated to a greater extent than that of, and by, my participants. It is therefore appropriate to reflect on how my positionality may have impacted the research process, as Vernon argues.

> *Thus, reflexivity, the examination of the ways in which the researcher's own social identity and values affect the data gathered and the picture of the social world produced, is a critical exercise for those researching the experience of oppression, particularly to insure the avoidance of colluding with the established hegemony. (Vernon in Barnes & Mercer, 1997)*

From my perspective, the sociological perspective on impairment, as considered by Hughes and Paterson, in recognising the position of the body in society and the potential for it to be considered as an emancipatory concept, is reflective of my conceptualisation of having Cerebral Palsy. Accepting the premise of the social model of disability, I believe that my experience of having Cerebral Palsy is impacted significantly by being subject to a disabling society; particularly by the attitudes of others, denying me from accessing relationships and opportunities on an equal basis, as I perceive it, to non-disabled people. However, I simultaneously believe that my impairment and my conceptualisation of having Cerebral Palsy has impacted on my self-identity and my relationships to others and to society; specifically, my corporeal experience of movement in my physical space, my engagement with objects, the frustration felt when having difficulty doing actions, such as feeding myself, and the pain I attribute to having Cerebral Palsy. Post-structurally, this position is theoretically proposed as a mode for conceptualising the body, and with respect to disablement - impairment, as a product of social discourses.

Subsequently, my approach to reflecting on the rehabilitative process that I went through is to consider it as having had an influential effect on how I have constructed and continued to define my identity as an individual with Cerebral Palsy. Through my extensive consideration of my personal engagement in childhood rehabilitation, biomechanically, I do not believe therapy had a substantive impact on my physical ability; feeling that my physical function was not greatly affected by rehabilitation and that I personally got very little benefit from the process. This is not to say that therapy may not have prevented a decline in my functionality in later life. However, and in appreciating that my specific form of Cerebral Palsy (dyskinetic athetosis) may have been a factor, it is difficult for me to note any physical improvements made from therapy. Experientially, acknowledging both the positive aspects of participating (within the context of being a child in that environment) and the negative memories of the pain it caused, the tensions it created between my parents, and the overbearing role it had on my experience of typical childhood, I have come to conclude that it was detrimental to my psycho-emotional well-being. I am aware that this is my personal perspective of growing up with Cerebral Palsy in rehabilitation, and therefore, in acknowledging my positionality as the researcher, I did not share these views with my participants.

It is for this reason that, while this thesis adheres to feminist theory within disability studies - that the personal is political - which has guided my research agenda, in order to maintain objectivity and a focus on the perspectives of my participants, I have chosen not to consider my own experiences alongside those of my participants when discussing the findings from my research (Morris, 1991; Thomas, 1999).

4.4 Ethical Considerations

Finally, this chapter considers the ethical issues that arose during the research process. The ethics approval process took place in accordance with the College of Social Sciences Ethics Committee at the University of Glasgow in the Spring of 2015. I will now go on to describe the impact of these ethical considerations during the research gathering and transcription phases. Of particular significance to undertaking research to enrich the knowledge base on the lives of young people with Cerebral Palsy, the ethical issues pertained to;

participant's ability to consent, the role of parents in supporting their participation, and the implications of studying a phenomenon impacting a small and specific cohort of young people in Scotland.

4.4.1 Getting consent

The issue of consent was a significant ethical consideration. Alderson and Morrow considered the consent of children to be underpinned by articles within the UNCRC, which highlight the rights of children to 'have their views listened to (Article 12)' and to 'have freedom of thought' (Alderson and Morrow, 2011, p.85). Though there is no legal basis for requiring consent, government guidance in the UK considers obtaining consent to be 'at the heart of ethical research' and thus provisions should be made in accordance with institutional guidance (Alderson and Morrow, 2011).

Consent was sought directly from participants over the age of 16, and additionally from the parents of participants under the age of 16. Alderson and Morrow argued that, in a similar way that consent is sought for medical procedures, social research should follow 'the same values of respect, trust, clear information and good communication' (Alderson and Morrow, 2011). Prior to getting their consent, I reiterated the information included in the recruitment document and on the consent form itself, that participants could stop the interview at any point during the interview if they wished and the information obtained would not be used in the research study. In doing so, I followed the principle prescribed by Beresford (1997) and Davis (1998), that information should be ‘tailored’ specifically to ensure it is appropriate for children and young people (Kirk, 2007).

All participants were given assurance that their identities would be anonymised (Kirk, 2007). However, Alderson and Morrow have pointed out that in certain situations, consent forms are shared with ethics committees, thus violating anonymity (Alderson and Morrow, 2011). I ensured my participants were aware of this prior to giving their consent. One of the participants gave their consent verbally due to their having reduced ability to write. This method of consenting was covered by the ethics committee in their approval of my study guidelines. As Kirk has reiterated, the process of consent should be continually sought during the research process to ensure participants remain content to be included (Kirk, 2007).

While all participants gave their consent prior to being interviewed, reflection on the consent process poses four ethical issues. Firstly, the timing of asking a participant to consent to participate in the interview, having been immediately prior to it commencing, and having only just been through their rights as contributors to research, including the right to withdraw, could be considered to be too restrictive and demanding upon the participant. As there was little time to reflect on the information regarding their participation, participants could have felt pressured into the situation and consented without full appreciation of the implications. While this is acknowledged, all participants said that they understood their rights and continued to consent to be interviewed (Alderson and Morrow, 2011).

Secondly, where the parent of a participant under 16 was required to give consent, the participant was present and agreed to their consent being seconded by their parent. Alderson and Morrow (2011) have highlighted, however, the issue with relying on parental consent is that this could subvert a child's agency and deny them access to participating in research. On reflection of this dynamic between the participant, the parent and I, it could be suggested that the presence of a parent influenced the young person to consent to being interviewed in order to appease their parent. It is acknowledged that this was a concern when such a scenario arose. However, in cases where the parent was required to give consent, efforts were made by myself to give the participant as much control as possible to decide whether or not to take part in the interview. All of the young people that this affected were happy to continue to be interviewed; some with their parents present, the others without.

Finally, there were a couple of situations that caused me to question whether the participant had fully understood the implication of giving consent and sharing their information. In these scenarios, the participants' inclusion in the study was based on their desire and agreement to be interviewed. The logic I applied was that participants' capacity to fully participate in the interview reassured me that they were able to appreciate the implications of doing so; referring to the principle on the competence of children to consent, as Alderson and Morrow have contended, there should be a presumption of ability to do so (Alderson and Morrow, 2011). Therefore, while I may have made prejudicial assumptions based on how the participant presented and communicated their views, given that I did not act to deny participants the opportunity to participate, I do not believe my assumptions had a negative impact upon participants or the study.

4.4.2 Anonymity and confidentiality

The main methods for recruiting participants were through contacts known to me in a personal or professional capacity, engaging them through schools and voluntary organisations, and approaching young people with Cerebral Palsy directly from having personal contact with them. These recruitment methods incurred ethical issues around anonymity and confidentiality, which are expanded upon in this section.

Given that there is a small demographic of children and young people with Cerebral Palsy in Scotland, anonymity was a significant consideration. Thackray highlighted that in discussing specific experiences, disabled children and young people may elicit identifiable information to potential readers of the research they are involved in (Thackray, 2017). This can even occur regardless of pseudonyms. To mitigate this, Gabb argued that it may be appropriate to 'limit' the amount, or type, of description given by participants (Gabb, 2009). However, as Thackray noted, others have disputed whether this is possible (Thackray, 2017). Taking this into consideration, a balance was required to weigh up the potential risks to participants in giving too much of a detailed account of their experiences and maintaining an evidenced-based reflection of the issues participants raised during data collection.

Within interviews themselves, the disclosure of private issues, as Mishna, Antle and Regehr highlighted, can cause a 'dilemma' for researchers who may be privy to information that could suggest the participant was at risk of harm or abuse (Mishna et al., 2004). With disabled children, and disabled people generally, being more susceptible to abuse, the potential reporting of such issues could have put me in a position of having to break confidentiality (Stalker and McArthur, 2010). As this was a consideration, I made participants aware of the measures I would have had to take if any issues were raised - which in the first instance was to consult with my supervisor - and they were, therefore, consenting to participate on this basis. Ultimately no issues were raised that prompted me to disclose sensitive information to a third party during the data collection process.

Confidentiality also relates to the protection of the data gathered. During the process of collecting and analysing data, Thackray has stated that "research participants have a right to know what data is being held about them, how it is being stored and how it might be used" (Thackray, 2017, p.305). As this is governed by data protection legislation, such as the GDPR introduced in 2018, assurances were made that the data gathered from participants would be stored appropriately (within a password protected, electronic file) and the information would be anonymised in the write-up so that the details of their experiences would remain confidential.

As described in section 4.2.1, my most successful mode of recruitment was through word-of-mouth or personal contact. Having been through many of the therapies that were attended by many people who were eligible to participate in this study, it was a natural route to approach those I had made contact within this context. Therefore, my recruitment process involved emailing and contacting friends and acquaintances that I considered to have experiences that may be relevant to the subject matter. There was no selection process involved other than approaching known potential candidates who were of the appropriate age and had Cerebral Palsy. In this respect, confidentiality was maintained because their acceptance or rejection to participate was only divulged to me. There were occasions in which friends who agreed to participate may have discussed this with other candidates at their discretion. While this put participants at risk of identifying themselves to others (Thackray, 2017), I believe the risk was offset by their own agency in doing so of their own accord.

The issue of confidentiality arose when participants' parents were present. On such occasions, it is possible that the presence of a parent inhibited participants from sharing their thoughts freely. However, the presence of parents was always a choice for the participants themselves to make. On one occasion, being presented with this choice was particularly empowering for the young person as they have Cerebral Palsy and a learning impairment and quite emphatically informed their parents that she wanted to be interviewed by herself. Referring to research by McNeilly 2015 and Meerwarld 2013, Thackray disputed the mindset that children with communication issues can be restricted from research as a way of avoiding potential conflicts of confidentiality. She contended that "to exclude the child, or to only hear the child's voice through the parent as interpreter can effectively mean liminal voices remain unheard" (Thackray, 2017, p.310). The inclusion of the familial relationship could have had implications for confidentiality, as they may divulge information not previously known to their family members (Saunders, Kitzinger, and Kitzinger, 2014). However, had the participants' parents not facilitated their engagement in the interview, their experience would have been excluded altogether.

Finally, throughout the research phase, during recruitment, data collection, and analysis, it must be recognised that confidentiality between participants and I had to be extended to my Personal Assistants. This may have been a concern to the participants given that my PA's are not bound to the University's code of conduct. However, the employment contract between my PA's and I includes a confidentiality clause that means information uncovered whilst working with me cannot be disclosed to third parties. This was made explicit to participants prior to being interviewed.

4.4.3 Relationships with participants

As noted in section 4.2, due to having Cerebral Palsy and growing up in Scotland, I had prior access to and relationships with potential participants. Acquaintance interviews, those involving friends or people known to the researcher, provide an opportunity to access data based on the interpersonal nature of the relationship (Garton and Copland, 2010). However, a number of issues arise in conducting research with people with whom researchers have prior relationships (McConnell-Henry, James, Chapman, and Francis, 2010).

Knowing participants prior to researching their experiences has implications in the recruitment process. Johnson and Clark have highlighted that participants who have developed trust with researchers may feel obliged to participate, leading to concerns of researcher ‘coercion’ (Johnson and Clark, 2003, p.422). Pertaining to this study, McConnell-Henry et al. considered that relationships between participants and researchers may impact data collection especially in interviews (McConnell-Henry, James, Chapman, and Francis, 2010). For instance, the personal relationship may elicit more in-depth knowledge than had been expected. This occurred during interviews with participants in this study. However, as McConnell-Henry et al. advise, a prepared interview schedule was used (Appendix D), which kept the role of the interview to that of gathering appropriate data and boundaries were maintained to ensure the participants responses were not influenced by my disclosure of issues not raised by participants themselves (McConnell-Henry et al., 2010).

I believe that the ethical implications of this research were given due consideration and that the issues to have arisen were appropriately and adequately managed. At all times, the best interests of the participants were paramount.

4.5 Conclusion

This chapter discussed and described the methodological approach taken to study the experiences of young people with Cerebral Palsy who had therapeutic interventions during childhood. The chapter described the methods by which these issues were researched and considered the ethical issues involved in this study.

Section 4.1 discussed the research methodologies employed to capture and analyse the views of the participants. Firstly, following a participatory approach I considered to be appropriate at the time of conducting the study, emancipatory research was considered in the choice, recruitment, and interviewing of young people who have Cerebral Palsy, according to the principle of giving disabled people the opportunity to shape the research regarding their lived experiences. Meanwhile, the use of the biographical research approach was discussed for its potential to provide a space for participants to reflect on their experiences of having rehabilitation during their childhoods. While this approach has been critiqued for relying on the memories of participants, which could be influenced by their own retrospective analysis, it follows the principles of constructivist Grounded Theory, allowing for their subjectivity to be incorporated into the research.

The data collection process was discussed in section 4.2, including the successes and challenges in recruiting young people with Cerebral Palsy, and the issues arising during the interviews with participants. The section highlighted that during the recruitment process there were difficulties in accessing and inviting young people with Cerebral Palsy to interview, in part due to the routes to doing so having involved going through educational establishments and organisations. As this section acknowledged, rehabilitative professionals were also recruited and interviewed, leading to rich background information being gathered. However, it was ultimately decided that the research would focus on data from children and people with Cerebral Palsy as the recipients of rehabilitation.

Concerning the interview process, the section raised a number of issues regarding; the vulnerability of participants and sensitivity of topics they discussed, which were considered for their potential to cause unintended harm or distress to participants due to the nature of the subject; the involvement of parents at the request of participants, which the section considered had the potential to limit the information offered by participants; the inclusion of my Personal Assistant in the research phases, which I considered could have had a positive and negative impact on participants; and my role as a potential insider due to having experienced the phenomenon being researched.

The penultimate section focussed on the analytical framework that underpins the research. Considering the developments in Grounded Theory in the context of this thesis, the shift towards a Constructivist approach to framing research around the central themes that emerged enabled the research to develop and expand its scope based upon the initial findings of interviews with participants. This principle led the analytical process through collecting and coding data based on the issues that emerged from interviews. Within this section, I also reflected on my positionality as a researcher with Cerebral Palsy who has experience of the phenomenon being studied, acknowledging that this could have potentially impacted the data collection and analysis process.

The chapter finally discussed the ethical considerations to have arisen during this study. The three main ethical issues included getting consent, which could have been impacted by participants' physical and intellectual capacity, and the role of parents in providing it; ensuring anonymity and confidentiality due to the recruitment process being heavily reliant on word-of-mouth and the small cohort of young people with Cerebral Palsy in Scotland; and the influence of my previous relationship with participants, which could have influenced their participation in the research.

Having set out how I undertook this research, the three chapters that follow present the data gathered through interviews with 16 children, young people and adults, whose Cerebral Palsy. At the time of the interview, four of the participants were still undergoing paediatric rehabilitation, while the remaining 13 had since left paediatric rehabilitation, with the intervening period ranging from a couple of years to almost 20. Participants were invited to reflect on growing up with Cerebral Palsy in rehabilitation from early childhood to present day. Participants, including those who were still children at the time of interview, predominantly spoke about their experiences of childhood rehabilitation in the past tense.

Chapter 5 - Social Experiences of Cerebral Palsy and Rehabilitation

This chapter considers participants' social experiences of having grown up with Cerebral Palsy and having gone through the rehabilitative process throughout their childhoods; from their first memories of engaging in therapeutic sessions to their perspective of transitioning out of paediatric rehabilitation as they entered adulthood. Children with Cerebral Palsy typically enter rehabilitation in their formative years and are likely to attend a variety of weekly sessions of Physiotherapy (therapy), Occupational Therapy (OT) and Speech and Language Therapy (SALT), amongst others, throughout their childhood (Raine, Meadows and Lynch-Ellerington, 2009). When young people with Cerebral Palsy transition out of paediatric services, typically around the age of 16, they are no longer deemed to require regular rehabilitation on the premise that their bodies have matured to their maximum potential physical ability (Herskind, Greisen, and Neilsen, 2014). If an adult with Cerebral Palsy experiences a specific health issue, access to rehabilitation requires a referral from their General Practitioner (Beresford, 2004; Wright, Robb and Shearer., 2015; Moll and Cott, 2012).

Data demonstrated that participants believed that attending therapy was a typical aspect of childhood as it was an expected activity in which they had to participate. While they became increasingly aware that their involvement in rehabilitation differentiated and excluded them from their peers, they predominantly complied with the therapy required of them, based on messages from practitioners and parents that it would enhance their ability and increase their inclusion. However, when rehabilitation withdrew, though it initially offered increased autonomy, its absence and the agency required to access it in adulthood challenged participants’ sense of self as barriers to living with Cerebral Palsy increased.

Section 5.1 introduces participants’ reflections on having rehabilitation during early childhood, both attending therapeutic sessions and being encouraged to do exercises at home. Attending rehabilitation was predominantly viewed as a normative experience by participants. However, within the therapeutic setting participants had little agency. This was reinforced in the home environment with participants being strongly encouraged to complete exercises between therapy sessions.

The second section explores participants’ reflections on the impact of having Cerebral Palsy and rehabilitation on their experience of school and social lives. Participants’ experience of going through school, which predominantly focused on mainstream education, highlighted the social-relational barriers to their inclusion. The rehabilitative process compounded participants' sense of difference from their peers' experience of school. Participants’ transition from school was accompanied by the withdrawal of rehabilitation in teenhood. The common view among participants was that it dissipated without their knowledge.

Finally, section 5.3 considers the social implications of becoming an adult with Cerebral Palsy. Participants continued to experience environmental and social-relational barriers to participating in typical adult life, such as forming relationships and finding employment. Rehabilitative services, which participants only had access to through a GP referral for a time limited period, were incompatible with their social and employment commitments. Participants reflected that this was detrimental to their physical, social, and psycho-emotional well-being.

5.1 Having Cerebral Palsy and Rehabilitation in Childhood

Participants' reflections on having rehabilitation in childhood demonstrated that it was a significant aspect of being a child with Cerebral Palsy. The overall sense from participants' reflections was that their participation in rehabilitation - attending hospital and therapeutic sessions - was a typical aspect of childhood. While participants did not feel that they had a choice over their participation, did not enjoy participating, and felt their agency over the sessions taking place was not heard, they developed an understanding that it was a necessary expectation of them.

This section goes on to explore the data on the role that parents played in facilitating participants' participation in doing therapy outside of the therapeutic environment. Participants predominantly undertook therapy at home because their parents required them to do so, either by direction or physically carrying them out with them. Though participants accepted this in early childhood, as they gained more agency, they showed resistance to doing so. However, parents' emphasis on the importance of therapy, putting conditions on more favourable activities on the basis that participants completed their prescribed exercises, contributed to a sense that their progression through rehabilitation was desirable.

5.1.1 Expected participation in rehabilitation

For the majority of the participants, rehabilitation began early in their formative years and became an integral feature of their routine (Bobath and Bobath, 1956; Rosenbaum, 2003; Herskind et al., 2014). Participants shared that being in rehabilitation was initially part of their personal narrative of having a normal childhood. Sarah's quote illustrates this sentiment, which was expressed by many participants.

> *I mean, growing up, it's, I think it was quite normal, I've not known anything different than as I have… I mean growing up and having to go to physio, OT and doing all this stuff that comes with having Cerebral Palsy or any disability has been quite normal I would say it's not any different than any other kids. (Sarah, 15)*

Rehabilitation was an influential factor in contributing to participants' social identities. Their identification with 'normality' demonstrates a construction of a childhood typical of disabled childhood development (Stalker and Connors, 2003; Shakespeare and Watson, 1998; Davis and Watson, 2001; Watson, 2012). Having to attend hospitals more regularly as required by the medicalised approach to impairment management led to participants associating their impairment with healthcare (Stalker and Conner, 2003). The belief they held that other children were similarly expected to attend regular therapy sessions contributed to their sense that it was a normative activity.

> *I didn't mind the hospital. It wasn't a bother to me. I suppose that's because I've been in hospitals since I was wee, but that wasn't an issue because I thought everybody does it, do you know what I mean? (Claire, 15)*

Though the routine and sense of normality engendered through attending regular hospital settings was accepted by participants, the act of participating in rehabilitation itself provoked more negative reactions, upon which they reflected. For example, Sarah's reaction as a child showed that her experience of the situation was negative, to the extent that she would attempt to remove herself from the situation. When reflecting on this behaviour, Sarah believed it was her negative response that was the unfavourable phenomenon, rather than her being required to participate in something that caused her to experience distress.

> *My physio teases me, every time I go and I've had the same physio growing up, and she always teases me because she always reminds me when I used to go, I used to run away or I used to cry. I was a bit of a terror I think. (Sarah, 15)*

However, at the same time, participants accepted that their participation was expected of them, and they had no choice in attending therapy sessions, as Ian demonstrates.

> *I remember that I didn't like it... so I just thought it's something that I have to do. I kind of accepted it (Ian, 30)*

Participants reflected that childhood rehabilitation was a normative construct in their perception of being a child. Though they may have attempted to demonstrate agency in the process, they had little agency over their participation. Being children in the process, this was reflective of their status in relation to adults, which meant that they did what they were told to do. This dynamic carried over into the participants' homelife, with parents encouraging them to do exercises in between rehabilitation sessions, as discussed in the next section.

5.1.2 Expected participation in therapy at home

Participants were expected to complete regular exercises at home as part of the rehabilitation process. As the literature demonstrated, parents have been found to believe providing therapy at home to be necessary due to the role they adopted as 'co-therapists' (Fernăndez-Alăcantara et al. 2016). Participants spoke of doing exercises at home because their parents either insisted or physically carried out exercises on them. Reflecting on this approach, Ian 'accepted' therapy was a necessary requirement of him, as it was advocated by his parents at home.

> *I did [exercises] because my parents did them, yeah… I suppose it's the kind of acceptance because it kind of had to be done. (Ian, 30)*

The expectation placed on participants to exercise at home regularly demonstrated a further lack of agency. As a child, Michael described having had to do physio at home even though he did not enjoy it. Michael's participation in his stretches did not seem to be controlled by his own motivation to complete them but rather was directed to do so by his mum.

> *As a kid eh, I would almost say that I'm fairly sure my mum did something with me daily, or not you know fairly regularly… Eh, I would say my mum was more strict about, mum would, mum would do my physio, my mum sort of support, helped me do physio… I remember, ehm, getting physio when I was younger and hating it, absolutely hating it. (Michael, 28)*

This lack of consultation caused tension between some of the participants and their parents. Participants gave accounts of their parents stressing the importance of doing their exercises outside of their regular therapy sessions throughout childhood. The encouragement of her parents to do her exercises was felt by Rachel to be an overbearing aspect of her relationship with them. The encouragement from her parents to do therapy at home was therefore viewed negatively by Rachel.

> *It's been a source of stress family wise and life wise. There was probably a part of my childhood that I felt that my mum and dad were just constantly on my case about doing exercises and physio… My mum and dad would be like you need to keep up your physio so we can go places and do things. (Rachel, 29)*

Participants felt a pressure that family leisure time was often contingent on them doing their exercises at home. While a common negotiating position of parents is to set consequences based on their child's compliance in certain tasks, i.e., 'do your homework, then you can watch television', Rachel's parents, for example, placed the onus on her to increase and improve her overall function as a means of enabling the family to do leisure activities. It was communicated that the outcomes of completing these exercises would benefit more than just her as her functionality impacted on the wider family unit. This put a responsibility on Rachel to cooperate in doing her physiotherapy.

While most participants viewed having to do therapy at home negatively, one considered it an opportunity to achieve the aims of therapy. Sarah may have preferred to be doing other activities but made a conscious decision to complete regular exercises at home, placing more importance on the potential benefit from physiotherapy than more desirable activities.

> *You're always going to want to be able to do something like watch TV or go out with friends, but then they're like not going to force you to do it, you've got to decide for yourself if you're wanting to do it, and wanting to make yourself more able and more mobile then you've got to do it yourself. It's that decision that you've got to make, it's, if you want to benefit yourself or not. (Sarah, 15)*

However, as older participants, some reflected on developing more autonomy as they aged. As such, even though participants initially considered therapy to be an activity that needed to be done, they reflected that as they got older, they questioned the necessity of engaging in the process.

> *Then I got into being a teenager and thought 'why do I have to do this?' (Ian, 30)*

Participants' reflections that therapy was undertaken at the request of therapists and subsequently their parents, situated rehabilitation as an imposed phenomenon in which their position as children limited their agency not to participate in it. Parents were often carrying out the responsibilities passed onto them by therapists who perceived the role of parents to be agents of therapeutic intervention between therapy sessions (Fernańdez-Alăcantara et al., 2016). While NICE guidance states that there is no obligation on parents to carry out the physiotherapy, as it was only an offer and not a prescribed service, participants reflected that they had to do physiotherapy based on the guidance of their parents (NICE, 2017). However, the authority held by therapists, and by extension parents, suggested there was a requirement to carry out the exercises. The responsibility on participants to undertake the therapy expected of them, regardless of their feelings towards doing so, had the effect of being an oppressive process advocated by both parents and therapists (Reeve, 2004). The following section considers the effect of being taken out of school to do rehabilitation on participants' social development with their peers.

5.2 Having Cerebral Palsy and Rehabilitation at School

The predominant theme of participants’ reflection of growing up with Cerebral Palsy was their social-relational experience of being in school, on which rehabilitation had an impact. The first subsection explores the two main aspects that participants reflected upon as having impacted their experience of being in school as a child with Cerebral Palsy; being included in their school environment and having friends and peer groups. Data showed that participants mainly recalled negative experiences of being and feeling excluded from their school and social activities because of environmental and prejudicial attitudes towards their abilities as children with Cerebral Palsy. These often conflicted with participants' perceptions of their own sense of their impairments and what they could and could not do.

The second subsection discusses how participants felt about participating in therapy and what impact they felt this had on their social experiences in childhood. For the majority of participants, therapy sessions during school time were an ordinary aspect of the rehabilitative process, which they were expected to participate in. Participants who predominantly undertook rehabilitation in a group setting, either in special school or as part of a cohort of children with Cerebral Palsy in mainstream school, felt that having therapy was a positive experience. However, participants who had individual rehabilitation sessions during the school day viewed taking part in them as a challenge to their sense of identity as a typical child. Finally, participants who were removed from school to undergo surgical procedures felt that it was an infringement on their participation in educational and social settings.

5.2.1 An increasing sense of exclusion

Participants' memories of being in school, which were influential in their reflections of childhood as a child with Cerebral Palsy, were dominated by feelings of being excluded from participating, or unable to participate, equally in school life, due to environmental and attitudinal barriers on the basis of their impairment effects and predominantly using mobility equipment. Secondly, participants reflected positively on the impact of having friends in their childhoods from an early age who understood and accepted the effects of their impairment on their involvement in social activities but recognised the barriers to being included within their peer groups if such friendships had not been established.

As participants grew up in the 1990's and early 2000's, on the cusp of policy changes encapsulated in the Disability Discrimination Act (1995), there were limited accounts of adaptations having been made to ease their access within the school environment (Riddell, 2009). Not only were there physical barriers identified by participants, but also attitudinal barriers. Their impairment was perceived by others to be the cause of such barriers. This was common amongst participants who attended mainstream schools, both amongst peers and staff. Rachel described having to miss out on school trips enjoyed by her peers because the school deemed that her attendance was a health and safety risk.

> *I think from a safety point of view a lot of the time, the school was like "oh you're a fire risk" and I never went on school trips. (Rachel, 29)*

This led to participants being, and feeling, excluded from social experiences that other children without impairment could access. Whilst participants reflected a belief that it was possible to be included, there were external factors which undermined their opportunity to participate equally alongside their peers. Gemma recalled witnessing her mother argue with representatives from her mainstream school when they denied her access to a Halloween party because the hall it was being held in was not considered safe for her as there was a potential health and safety risk involved. Gemma pinpointed this as being when she first felt different to other children.

> *Mum had brought me along to the Halloween party and the head teacher at the time, or depute – can't remember – stopped mum and me said, "sorry, Gemma can't come into the hall" and mum asked why and he answered that there was no provision for her, there was no one there to watch over her. Mum said she'd stay, I'll watch her, if anything happens to her then "I'm her mum". (He answered) "No, we don't have a licence", so they basically turned me away from the party, and I was a bit like, well why? Do you know what I mean? – And I think my mum was really worried, because she'd never had to sit down with me and tell me, "you know... it's because of this". (Gemma, 22)*

Participants' ability to make and maintain friends contributed to their sense of feeling included or excluded because of their impairment. Data showed that participants who had a friendship group from a young age felt that their impairment was more understood and less of a barrier to being friends than those who had not made such friendships at that age. Claire commented that having been in a friendship group since starting primary school, she felt that her Cerebral Palsy was an accepted part of her social-relational self.

> *I've had the same friends since primary 1 and they're horrible people but they're good, know what I mean? They know when, they know how things work and they're not overly like, they know me well enough to know when I can stop, do you know what I mean? We'll go out and they'll say we'll go home now 'cause you're tired. (Claire, 15)*

The fact that Claire's friends were able to adapt their behaviour to meet her needs was understood by Claire to be a demonstration of their acknowledgment of her impairment effects on their social activities. This was the case for another participant who reported that, though her friends often 'forgot' she had an impairment, it demonstrated that they did not acknowledge her impairment as being a barrier to friendship.

While participants acknowledged that making friends at a young age was easier, it, however, became progressively more difficult with age. The data showed that as participants got older and began to engage with more children in school, the difference in their experience of childhood became more evident. There were three issues which created a sense of exclusion; participants did not feel naturally included by their peers, participants felt separate from social groups or social situations, or participants felt their impairment was mocked by their peers. Participants who identified as having felt excluded may have experienced one or a combination of these three issues.

> *It really hit me how different I was. Like, in high school and primary, high school and late primary school. Like, it felt like nobody was coming to talk to me, I didn't have much friends. (Wendy, 17)*

Participants framed their experience of making and maintaining friends within the context of having an impairment. This was predominantly with respect to participating in the physical aspects of socialising with their peers. This was commonly experienced as participants developed through childhood when socialising became more dependent upon participating in physical activities, which they perceived to be a route towards forming friendships. Participants' inability to keep up with non-impaired peers impacted upon their inclusion. James, for example, directly attributed his exclusion from social groups with being treated as unable to join in physically, which he related to being unable to fit in.

> *I had lots of friends, but sadly at secondary school everyone ran off to play football and made new friends and I felt left behind and isolated. Secondary school brought about a desire for everyone else to fit in and I didn't really fit in with anyone. (James, 23)*

As they became older, participants reflected that their peers became more independent from the social structures of school. Participants became aware that their peers increasingly participated in activities that were exclusionary, both because they did not accommodate participants' physical abilities, and presented barriers to accessing such social events, as Ian described.

> *So, they chose to go on an outing to the beach on the final day of school, that again is where you form friendships and stuff, but as you know beaches are not that accessible so I yeah, again because I didn't do those kind of small things, although the kids found me perfectly pleasant and stuff, I just don't think that they got to know me, yeah. (Ian, 30)*

Participants noted that their exclusion from social groups shaped how they perceived their own personality and interaction with others. In response, participants adapted their social selves to be more conducive to their physical abilities. Citing his own preference to avoid crowded social settings, Peter believed that this was to be expected as a disabled person.

> *At the time I didn't know anything different, like now I think it's natural for people with like, especially with the more physical disabilities which are somewhat in your face, it is quite easy to become separate and sort of hang about with like a few people, rather than like big groups of people and maybe don't go out as much, it maybe becomes much harder. Because physically quite a lot of the time you don't feel up to it. (Peter, 32)*

Participants’ experiences of school were increasingly exclusionary. Both barriers to participation and barriers to making and maintaining friendships became more evident as participants progressed through their school lives. At the same time, as the next section discusses, the act of having rehabilitation in school impacted on participants’ school experience and had a lasting impact on their sense of inclusion.

5.2.2 Having rehabilitation in school

Throughout their school experience, it was typical for participants to participate in sessions of the therapies they were offered, including physiotherapy, occupational therapy and speech and language therapy during school time. Reflecting on this phenomenon, participants initially viewed their engagement in therapy as an accepted activity within their school environment, which formed a part of their narrative of having Cerebral Palsy in childhood.

> *I think at an early age about the routine of doing it every Tuesday or whatever going for 2 hours for physio. So it was that thing of being out of class and doing the pretty dull routine stuff that you get every week. (David, 35)*

Participants’ reflections on the impact of having had rehabilitation during their school days showed there was a distinct divide in the perspectives, with those who attended group sessions having felt more included, even though they were participating alongside other children with Cerebral Palsy, while those who had solo sessions reflecting that they felt their participation differentiated them from their non-impaired peers. Pertaining to the former, participants who felt positive towards having rehabilitation in school had either attended specialist education, where the dominant culture in their environment was to attend therapy, or mainstream schools where there were a number of children with Cerebral Palsy who had therapy together. Rachel, for example, described therapy as an opportunity to make friends and find an activity she could compete in equally, due to the fact she was in a supportive environment.

> *Obviously that they had a physio room, I have a vivid memory of doing structured exercises there and the walking bars and just like I think a lot of friendships were formed for me through that kind of environment and also swimming was a big influence in special education I remember being entered into a swimming gala through the school and being encouraged to actively do that. (Rachel, 29)*

Similarly, Gemma, who attended a mainstream school, reflected on the therapy being an inclusive activity given that she was participating with and competing against other children with Cerebral Palsy.

> *I used to love it. My physio would come every, twice a week and I used to get out of class for the afternoon… There were many girls and we used to go again to the club in school. We would go every other Friday, we'd either go to a class or go swimming and I loved it because it was that*

> *time we, you, could be with people who have CP, so you weren't last in the race. (Gemma, 22)*

However, participants who had individual rehabilitation during school time reflected on feeling that it was infringing and excluding. The act of removing participants from their peer group had an impact on their sense of feeling ‘normal’. Participants’ desired activities were often overridden by the therapist’s timetable and/or school staff’s decision as to the optimum period to be taken out of the school day to complete therapy sessions. Claire described being disgruntled by having therapy at school due to the conflict with “golden time”, a period in her school timetable that was for students to have the opportunity to play and socialise.

> *I had this physio person that would come out when I was in primary 4 and she would come in on a Friday afternoon and I was raging because I missed my golden time, and she would take me into the gym hall and do stretches and exercises and stuff with me and I didn't like that because I'm not normal anymore I’m this weird “disabledy” person I can’t do the Golden time things with everybody else… It felt kind of invasive ‘cause like I didn't ask for you to come and do this and yet here you are doing this. (Claire, 15)*

The sense of difference rehabilitation created prompted some participants to be strongly opposed to having therapy in school. Sarah described that, especially in primary school, she would protest her physio taking place in a public space at school due to her desire not to be seen as different.

> *Yeah, at primary school I used to be really keen like, "no! We can go into a separate room and do it," because I think it was again that bit of like trying to be more accepted into the social group that was like school. (Sarah, 15)*

Sarah saw a demarcation between her and her peers when participating in therapy, identifying that doing physiotherapy publicly made her feel stigmatised and less included by peers. Furthermore, Sarah's mum believed that the potential for feeling othered by her participation in therapy was particularly strong for Sarah at a time when children were forming a social-relational identity. Excluding participants from regular classes and recreational periods distinguished them from their schoolmates. Participants associated this form of segregation with their conceptualisation of a 'disabled person'.

The expectation to do rehabilitation also impacted participants' experience of school holidays. The ability of therapists to assess whether exercises had been done between sessions led to participants feeling judged for not ascribing to this role. This had the potential of leading to further deviation from typical expectations of childhood (Weeber, 2004). Rachel detailed incurring negative consequences on returning to physiotherapy, having not completed the exercises expected of her.

> *I always remember, you know you would have time off during the summer holidays and when you went back there would be people in the physio room and I would be screaming 'cause they... and the physios would go oh have you done exercises over the holidays and when you look back obviously not if they've seized up over the holidays. (Rachel, 29)*

Participants, therefore, participated in exercises during school holidays in order to avoid a negative experience on resuming sessions with therapists. With the contributing factor of their parents encouraging them to maintain their physiotherapy during holidays, this had the effect of excluding participants from typical childhood activities.

There were also social implications following surgical intervention. The data highlighted that surgery being undertaken during school time, including holidays, was influential in participants' reflections of it as an exclusive experience. Gemma described having to spend long periods of time resting and in physio to recover from surgery, which directly removed her from her social group. The intention of the surgery was for Gemma to increase her participation in society. However, an immediate outcome for Gemma was the reduction of the ability to be included in society.

> *The recovery period was anytime between 6 months to a year, intense physio and you know it was summer, so it was all like my summer is gone. It's probably the only summer that I actually felt lonely, because I couldn't go out. (Gemma, 22)*

Participants’ reflections of childhood rehabilitation were integral to their social and academic experience of school. In circumstances when therapy was done alongside other children with impairments, rehabilitation offered participants a space to feel included, whereas solo sessions of rehabilitation exacerbated participants’ experiences of exclusion from their peers. However, both approaches resulted in participants being removed from typical childhood education or social experiences. Furthermore, as participants reported it, they rarely had any input into where or how rehabilitation was conducted during this time. On occasion when they agreed to interventions, specifically surgery, its impact on their physical functionality took precedence over their social context, resulting in periods of exclusions, which had a lasting impact on participants’ reflections of childhood.

5.2.3 Transitioning out of rehabilitation

Most of the participants who had left school and were in their twenties and thirties at the time of interview reflected on the reduction of rehabilitation during their time at secondary school. They went from attending regular therapy, to not having it as often, until it eventually stopped. Participants’ comments and wider discussion about the reduction of physiotherapy input as they transitioned out of their late teens demonstrated that the rehabilitative process stopped without consultation or explanation, as Peter’s quote demonstrates.

> *When I was younger, sort of like pre-school, yeah, I had my speech therapy and I had, like, my physiotherapy like at Yorkhill and then, from probably primary school till the end of secondary school, not so much. It sort of just seemed to stop. (Peter, 32)*

Participants did not have a clear understanding as to when or why rehabilitation stopped, recalling the phenomenon as having dissipated over the course of their transition from school. When asked to give their opinions as to why they thought it was stopped, participants generally spoke to there being systemic reasons, such as a lack of resources, rather than commenting on the outcomes of the rehabilitation at that point in their lives. Sarah’s mother, for example, described that after Sarah left primary education her funding for attending a specialist rehabilitation centre had gradually been withdrawn and it was only due to her being able to fund this privately that she was able to continue the sessions.

> *I can start to see the support mechanisms around Sarah reducing quite significantly, so you know, they're less now than what they were in primary school. And some of that is simply because of her own progression so they'll come about naturally, but some of them are because, and I'm not trying to be political here, but some of them are because the authority chooses to reduce things at a certain age… (Sarah’s mother)*

Whether it was political reasons or encouraging individual independence, participants’ reflections were of a speculative nature rather than coming from a concrete understanding of why therapy was withdrawn. Whether or not there is truth in the opinions of the participants, the way that participants experienced this process had a psycho-emotional impact. Participants conveyed disappointment at the reduction and ending of rehabilitation and in some circumstances suggested they resented the lack of consultation about the decrease in support at this stage of their development into adulthood.

> *S: It stopped when I got home and came back up here... I don't like it stopping.*
>
> *I: Would you rather still be doing it?*
>
> *S: Yeah... I liked it so much. (Scott, 27)*

Reflecting on the increased autonomy that the withdrawal of rehabilitation gave them however, participants cited that they enjoyed the opportunity to expand their social lives and had extra time to be with their peers, as Gemma notes.

> *I think at the age I was happy that, that it was away, and I could spend more time with my friends (Gemma, 22)*

The withdrawal of participants' rehabilitation during their adolescence, as they transitioned from paediatric to adult health services, had no clear fixed end point and no clear reason conveyed to them. While participants felt there was a lack of consultation or acknowledgement of their desire to continue therapy, its withdrawal also allowed them to experience more typical activities as they developed into early adulthood. As is typical of all young people, this was a period when participants in this study went through multiple changes, such as leaving school, moving to college or university, becoming more independent from their parents, and, in some cases, having to live independently. At this time many of the participants reflected that they began to experience additional barriers to their social lives. This will be discussed in the following section.

5.3 Having Cerebral Palsy and Rehabilitation in Adulthood

The withdrawal of therapy came at a point in participants' lives when they were experiencing other significant changes, such as transitioning out of school and becoming more autonomous. Conversations with participants illustrated that they continued to face environmental and social barriers to being included in typical adult life. The first subsection discusses participants’ constructions and experiences of work and social lives, which were marked by concerns of physical, social and environmental barriers. Participants reflected that they continued to feel excluded from social experiences, citing fears that they did not feel they fit into established social groups and that the effort required prevented them from accessing social situations. This sentiment was further increased when participants attempted to access adult rehabilitative services as adults, which will be discussed in the second subsection. The social impact of rehabilitative requirements and their effect on participants’ adult lives was rarely considered.

5.3.1 Persistent barriers to social inclusion

Participants' notions of entering adulthood began to shift when social barriers to accessing employment and becoming more independent presented themselves. This resulted in participants reconstructing their idea of being able to fulfil independent functions in society, such as getting a job or living on their own and having relationships, as they had to consider their impairment effects and environmental barriers. Sarah, who was on the cusp of transitioning to adulthood described her concerns for her future.

> *Being a child with CP, compared to being an adult. I think as a child you have a lot more imagination as to what you can achieve, so as a child you can set yourself these ridiculous goals, as in two years I'm going to be totally normal and I'm going to climb Mount Everest. Whereas, as an adult with CP you kind of, not I'm not saying this negative, but you kind of lose that sense of impossible goals. So you have to become a bit more realistic, as in being an adult with CP you've got to think, can I do, can I do, like if you were to have a job like, is it physically possible for me to go to this job, or is it possible for me to live here, is it possible for me to do this, so you lose that sense of, like that bit of your, I don't know how to describe it, but the process where you can do anything. (Sarah, 15)*

Participants discussed their potential to work in adulthood and showed concerns over the actuality of having an impairment and participating in the workforce. Claire, for example, recognised that her ability to work in the hospitality sector would be impacted upon by her physical limitations, even though she acknowledged this should not impact on companies hiring her, which evidenced her understanding of the role companies had in making reasonable adjustments.

> *But like when I'm applying for jobs for now it's like I won't work in Costa because I would have to carry plates and cups and I'm not very good at carrying plates and cups I can't even lift their cups because their awkward shapes, so I don't how I'd do carrying a tray of them. It's like would they put me less, would they be less likely to hire me 'cause I can't do that even though that shouldn't impact them even though it kind of does. (Claire, 15)*

Data shows that once barriers such as the ones to which Claire referred began to infringe on the everyday life of participants, the impact of their impairment on their adult independent identities challenged the constructs that they had of themselves.

> *I work part-time but like, because it suits me, but like the work like, when I used to work full-time, I would work 5 days a week then at the weekend I was knackered and didn't want to do anything. (Peter, 32)*

Participants' narratives demonstrated the long-term effects of having been excluded from mixing with peers due to social and environmental barriers, predominantly as a result of their school and wider society's perception of their impairment. Michael's separation from his peers during school impacted upon his inclusion in social activities later in life. As an adult, Michael attributed his feeling of being an imposition due to having an impairment that was once the cause of his exclusion.

> *So, I was taken into another room with other children who needed, who weren't confident at being out in the, at the school and that, I felt, had a serious effect on me when I, as I got older and went up the school. And to this day still affects me, because there's been times that when I was younger that you would go to the pub and everybody was there, and you feel that you're gate-crashing, and I always felt awkward of, you know yes you'd go across and speak to people, but you would feel that you were either interrupting or you were gate-crashing on a party that wasn't, that you were never invited to. (Michael, 28)*

Participants' views of becoming adults with Cerebral Palsy were influenced by the role their impairment played in them forming relationships. The challenges to friendships and dating were environmental and physical practicalities, as well as social-relational issues. In the case of Ian, for instance, the impact of having to make arrangements to see friends and his partner challenged his sense of being able to socialise and be spontaneous within relationships. He felt that if these challenges were not present in his life, he would have more intimate friendships.

> *I can't just say to people "I'll come for a pint after work", cos I have my PA's and because because they have to know when the shifts are,*

> *have to plan, weeks and weeks in advance it's stupid how, how organised you have to be, and I can't say to, I can't say to [my girlfriend] "do you want to be spontaneous?" and just head for food, because she has PA's I have PA's and all that type of stuff and, so yeah I, I this may sound horrible, I don't know how many friend, friends. I have. I have people I talk to I'm perfectly pleasant to, it doesn't mean to say I am I am I am alone but, I don't have a lot of people I can just sit with and go "I am fucking shit", if that makes sense. (Ian, 30)*

Similarly, participants reflected on having had concerns that having Cerebral Palsy would be a barrier to developing romantic relationships because of how potential partners might react to their impairment (Shuttleworth, 2000). Data showed that this was progressively more pertinent as participants' sense of having an impairment began to have an increasing impact on their approach to forming relationships.

> *Yes, I do have a disability, but it doesn't stop me being, you know, from having from having a relationship, of any of any kind, you know, yes, I would like a a a good strong relationship, but where you can be close with the person, but you also want them to know that you that they respect, and you respect them... It's the same when it comes to, comes to meeting new, new friends, friends of the opposite sex... Anytime that I would try to get to know them, or a relationship, they would always see me as being as a good friend, and that knocked that knocked your confidence. But people people people would be able to go up to brush that off, but I can't, I don't*

> *know if it's because I'm just a, if it's just who I am or if it is part of my Cerebral Palsy, you know, subconsciously, is part of Cerebral Palsy. And we and we, some people are self-conscious of how other people are gonnae react to you in a romantic situation. (Michael, 28)*

Participants continued to experience environmental and social barriers, which affected their social-relational experience of having Cerebral Palsy in adulthood. This was particularly evident in participants' narratives about forming and having intimate relationships, such as friendships and romantic attachments, and their ability to work and live independently. While participants felt that rehabilitation could have been useful in navigating barriers to being an adult with Cerebral Palsy, the practicalities of engaging in therapy in adulthood further impacted upon their sense of self, as discussed in the following section.

5.3.2 Barriers to accessing rehabilitation in adulthood

The social context of participants' adult lives was not considered when accessing adult rehabilitative services. To access rehabilitation in adulthood, participants had to get a referral from their GP. This relied on participants identifying specific health issues, which participants attributed to their impairment and its effects. When participants approached their GP to do this, they suggested a course of physiotherapy. However, the suggested therapy required hours a day of exercise and participants were unable to combine this with their commitments in adulthood, such as work. Olivia, for example, felt she was left with a choice between working or doing therapy.

> *It's like I'm working and I'm working and I'm doing a degree at the same time and it's not like I can do it on my lunch break like do a bunch of stretches, like I was supposed to do them three times a day, and it's not really adjusted to what kind of reasonable life you're supposed to have. (Olivia, 25)*

When participants pointed out such conflicts to those offering the therapy, their realities were often dismissed. This fed into a narrative that physiotherapy was generally geared towards paediatric care rather than being tailored to the needs of adults with Cerebral Palsy. Yet, participants felt it would have been beneficial to have support available to provide them with appropriate advice which suited their situation as adults with Cerebral Palsy, as Gemma indicated.

> *But that would be nice but like not, not one that you feel like you have to go every week as a scheduled appointment, 'cause you can't do that when you're 22, like stuff happens, you have work, and you have uni and you have a life. (Gemma, 22)*

While this lack of support had negative implications for the physical embodiment of participants' experience, the lack of appropriate adult rehabilitation also had a detrimental effect on participants' psycho-social selves. Participants found that the reality of living with Cerebral Palsy provoked them to reflect upon the additional support they needed when it became apparent that the rehabilitation they had had did not sufficiently meet their psycho-social and emotional needs in independent adulthood. Peter believed that psycho-emotional therapy should be part of ongoing adult rehabilitation, alongside physical therapies, for adults with Cerebral Palsy.

> *I think probably the one of the best things that like, like the sort of medical profession probably could do is that like, as well as treat the sort of physical issues, that people with Cerebral Palsy have, also focus on the sort of soft issues that people with like, people with Cerebral Palsy have. So, you've got like, sort of the physical needs, but also, you've got sort of the sort of relationship needs and, maybe even sort of teaching about like your sort of own value and like accepting and adapting to the world around them. (Peter, 32)*

There was a demonstrable shift in participants' approach to rehabilitation as they reflected upon their transition to and experience of adult rehabilitative provision. Whereas rehabilitation had been a constant feature in participants' lives throughout childhood, which they attended even when it interfered with their educational and social experiences, its withdrawal and subsequent absence in adulthood left them feeling unable to access it. When participants attempted to do so, which they themselves had to initiate on encountering a specific issue (through a GP's referral), they were again frustrated by the lack of consideration for their inclusion in mainstream adulthood, such as employment or having active social lives.

5.4 Conclusion

This chapter explored the social-relational aspects of growing up with Cerebral Palsy and having rehabilitation. Rehabilitation was part of the participants' sense of having a normal childhood. Whether or not participants fully understood or accepted why they participated in therapy, most did so due to the expectation of them from therapists and parents. In this sense, therapy sessions, wherever they took place, became another social space the participants were expected to inhabit with little agency and within which they were expected to conform to an adult agenda.

As participants developed through childhood, they experienced social barriers to their education and social lives. Participants felt increasingly restricted from accessing educational and social opportunities and from maintaining friendships. In school settings, participation in therapeutic sessions excluded participants from typical educational and social experiences. While in some circumstances group sessions offered participants the opportunity to socialise with other children with Cerebral Palsy, their removal from their non-impaired peers highlighted their difference. Likewise, the effect of surgical intervention was exclusionary and left participants feeling isolated from their peers for extended periods following surgery.

Participants continued to face barriers to their social experiences as they became adults with Cerebral Palsy. While participants reframed their ability to form relationships, relinquishing some of their internalised beliefs about not being seen as potential friends and partners, the social implications of becoming an adult with Cerebral Palsy influenced participants' notions of developing intimate friendships and romantic relationships in adulthood. Likewise, participants' conceptualisation and experience of employment included reflections on the barriers to being able to do and maintain a job because of the impact of their impairment on the work and its impact on their experience of impairment effects. Within this context, participants' ability to continue rehabilitation was undermined by the structure of adult services. Just as rehabilitation had been built into participants' lives in childhood without due regard for its impact on their social context, the requirements of adult rehabilitative services were not cognisant of its social impact on their lives in adulthood.

Chapter 6 - Walking

This chapter discusses participants' accounts of their walking ability as children growing up with Cerebral Palsy. Participants considered their walking ability was the main aspect of their physical function that identified them as different to other children. For children with Cerebral Palsy, walking is characterised by an atypical gait, including "a slow walking speed, a shorter-stride length and more time spent with double support [on two feet]" (Kurz, Arpin and Corr, 2012, p.600). Studies suggest that around 60 percent of children with Cerebral Palsy are "independent ambulators" (walkers) whilst 10 percent walk using aids to support their walking, such as walking sticks, tripods and walking frames, and 30 percent are wheelchair users (Novak, 2014, p.1143). The GMFCS indicates that children who are able to walk at a certain age will be able to do so within the parameters of their walking ability, while those who cannot, most likely will never have the ability to do so unaided (Rosenbaum, 2003). Considering their long-term walking ability, meanwhile, Morgan and McGinley have suggested that between 25-58 percent of adults with Cerebral Palsy experience a decline in this function (Morgan and McGinley, 2012). This chapter considers participants' physical and social experiences of walking and their reflections on the rehabilitative approach towards it.

Section 6.1 focuses on participants' approaches to walking as they reflected on their childhood development in comparison to that of their peers. Participants reflected that walking became the main identifier of their difference from their peers, which fed into a desire to emulate the style of others. This difference was compounded by environmental barriers which reinforced participants' sense that their ability to walk was not accommodated within society.

At the same time, participants felt that the rehabilitative process was heavily focussed on the pursuit of a more normative walking ability and that by engaging in therapy, their walking ability would improve. The second section, therefore, considers the influence of the rehabilitative narrative, along with parental responses to it, on participants' perspective of their own walking ability. While participants believed rehabilitative interventions, including surgical procedures, would lead to them having a more normative walking style, the outcomes were often less than expected.

The chapter ends by exploring the impact of participants' declining walking ability, due to physical changes as a result of growing or the increased effort required to walk in adulthood, which they had not anticipated. Participants found that they had to limit their participation in social activities or adopt alternative modes of mobility as they entered adulthood. Participants, resultantly, often continued to pursue rehabilitative approaches, such as formal therapeutic sessions or using mainstream gym facilities, with the intention of improving their walking ability and mobility.

6.1 Becoming a Walker

This section explores participants' reflections on becoming a person who could walk. The section firstly considers the social-relational impact of participants' walking ability, as this was a central theme of their experience of having Cerebral Palsy in childhood. The second subsection demonstrates that, at the same time, participants noted that they had to contend with environmental barriers, predominantly in school, which reinforced their inability to walk at the same level as their peers and restricted them from having equal experiences.

6.1.1 Comparative walking ability

Discussing the impact of their Cerebral Palsy during childhood, the data collected revealed participants reflected that their walking ability was the main identifiable difference between them and their peers, both non-impaired children and those with other types of Cerebral Palsy. Walking created an embodied sense of difference. Participants' reflections on walking focused on comparing their walking style to 'other children'. Upon recognising that they walked differently, or were unable to walk at all, participants felt 'othered' from their peers. As participants developed through childhood, their differences became increasingly more of a barrier to them being able to participate in social opportunities alongside their peers.

Participants reflected they felt that in early years all young children had a similar functional ability and that this had allowed them to consider their impairment effects (walking unsteadily, tripping, crawling etc) as typical because the differences between themselves and other children were not so apparent, as Claire noted.

> *I didn't feel like I was any worse than anybody else, I fell a lot, but other people fell too, less than me, but people fell and that's what mattered, and people got tired and I got tired so that's fine. (Claire, 15)*

According to Claire’s comparative approach, all children fell, and all children got tired, therefore as far as Claire was concerned, falling and getting tired did not separate her from other children. While participants reflected that their walking ability was comparable to non-impaired children in early childhood, it became an increasingly identifiable feature of their Cerebral Palsy that differentiated them from people without an impairment, which in turn impacted on their perspectives of their impairment to varying degrees, as David reflected.

> *I think it’s that thing that when you’re about 3 or 4 it doesn’t have a massive impact. Nobody really walks that well; you’re pretty much the same. I think it’s more when other boys start playing football and start doing the sports stuff and you go "Urgh I can’t do that”. (David, 35)*

Retrospectively judging their walking functionality against other children, participants demonstrated that having similar experiences to other children gave them the sense that they were the same as any other child (Davis and Watson, 2002). However, as it became more apparent that their walking ability differed from other children, participants noted that they began to feel othered by their impairment. Participants’ narrative surrounding walking was that being unable to walk in a similar fashion to other children makes you abnormal and ‘other’. Chris demonstrated that there was a style of walking that he considered ‘normal’ and the noticeable difference between this and his walking style was his use of a walker.

> *Cos like everybody can walk normal and like, with no walker and all that. So, I felt a wee bit [of an] outsider. (Chris, 33)*

The inability to walk like others had implications for participants' inclusion with their peers. Claire, for example, described feeling different from other children due to the fact that she had to have assistance to walk.

> *Like we would go out walking to church and stuff and I would have to hold on to the teacher and I couldn't just walk with everybody else. (Claire, 15)*

Participants' inability to participate in typical childhood activities, such as playing sports with peers and being with peers on school trips, highlighted their functional difference. This exclusion reinforced the narrative that to be included with your peer group relies on the ability to walk. Even though most participants had the ability *to* walk, their inability to do so as they perceived others did resulted in the participants feeling disabled by their own walking style. Participants had an internalised belief that there was an ideal way of walking and that they should be able to achieve this. Sarah, for example, put a value on the functionality she observed, and compared her own ability to this.

> *Yeah, yeah, I mean you see other people do it like, walking down the shops like you see people do it, then you think, "why can't I do that?" So yeah, I think it's from seeing other people do it and seeing how easily they can do it and then think about it and not have this trouble that it takes you to do it, and I think "why can't I do it the same way?" (Sarah, 15)*

Participants' developing conceptualisation of their walking ability being an impairment effect was accompanied by 'barriers to being' as a result of negative experiences, such as in Sarah's case of viewing herself in the reflection, or for other participants, which arose from negative comments from peers about their walking style (Thomas, 1999; Reeve, 2012). For Sarah, who was still a teenager at the time this research was carried out, her perception of her walking ability challenged her view of herself.

> *Like stupid little things, when you see yourself walk and you see the, like my [x] is like, slouching most, so when you see yourself walk, and you see yourself as, "that isn't the way I want to be walking", and that frustrates you a lot. Like when you walk past a shop window and you see that, that frustrates you. (Sarah, 15)*

Participants' walking ability did not just differentiate them from those who could walk 'normally', but also from those who *they* perceived could not walk 'normally'. In this situation, participants felt like they had fallen between being 'normal' and being disabled (Bantje et al., 2015). Olivia demonstrates a difference between herself and others with Cerebral Palsy due to the fact she had a better walking ability.

> *So, it's like, something that was like a medical issue primarily and there was like, when people asked it was just like I have a wonky leg or something like that, instead of like well I have Cerebral Palsy, it's like there was, I didn't really fit into the category of what a person with Cerebral Palsy was like. I wasn't in a wheelchair and most of the people that I met at that point who had Cerebral Palsy had, were in wheelchairs, their experiences were different from mine, so there was like, I was like in a kind of grey zone like, I wasn't normal enough, but I wasn't like, I didn't have like Cerebral Palsy the way people expected me to do. (Olivia, 25)*

The degree to which participants were impacted by their walking ability, which was described in a social-relational context, influenced how far they felt they deviated from social norms (Thomas, 1999; 2007). As Thomas described, feeling that non-impaired people have superior ability imposes the sense that an individual’s impairment effects make them disabled in relation to others in society (Thomas, 1999). There was a common view that there is an optimal way of walking that they perceived to be done by non-impaired people and if they were unable to emulate this style of walking then they were failing to be like others.

6.1.2 Barriers amplified difference in walking ability

Participants noted that it was also their experience of environmental barriers that highlighted their difference from other children's school and social experiences. Participants spoke about their experience of being in a mainstream setting and the barriers it imposed on them.

> *I mean yeah, I was lucky enough to get into mainstream school. So, this was 1995, you know. Mainstreaming in 1995 was usually; they hadn't worked anything out... the whole of my 5th year there was one class up a flight of stairs, so once a week I would climb up and down a flight of stairs, which was fun. (David, 35)*

Though participants identified their inability to walk like others inhibited their feeling of being a part of the 'mainstream', they believed that this should not have prevented them from accessing the same educational experience as others. Instead of focusing on the embodied cause for not being able to access mainstream education, participants considered environmental barriers to be the reason.

> *Because I was in a high school of over a thousand pupils and ehm, my mobility was never that great… So, there was, the number of times that I would, could fall over and get crushed. (Michael, 28)*

> *I had a teaching assistant and the way the school was, you had to walk upstairs to get to the playground and every other kid could do it whenever they liked but I would have to wait. (Sarah, 15)*

Participants identified a barrier to their inclusion as people who walked differently was that their access needs were not met. Participants' views of being unable to access school without difficulty demonstrated an understanding of the social construction of disablism. In the process of identifying barriers to their own inclusion in school, multiple participants also evidenced a more general identification of environmental barriers that they felt might have impacted on other disabled children.

> *Annoyed, annoyed, because like what's, yes, I'm capable of doing the stairs and doing things, but if somebody else was to come along what, students that arrive in a wheelchair, what's going to happen, you're going to be stuck in the one department all the time. (Michael, 28)*

In the absence of accessibility, participants described having to find alternative methods of navigating the school environment, which relied on them having to adapt their own physical needs. Michael described that his need for adaptations to get around the school and them not being provided in a timely fashion restricted his access to the school experience he perceived others to have.

> *I remember it took me, months, month to month to get additional handrails put in in the high school so that I could, so I could, so I could just access the classes that I needed, otherwise you were either holding onto the wall to go down, or you were asking to lean on somebody's shoulder while you went down two or three stairs. (Michael, 28)*

Data showed that for younger participants the impact of Disability Discrimination legislation resulted in school premises being made accessible. Claire, for example, felt adjustments to the school's infrastructure had made her feel more included as she was able to traverse the school grounds without barriers, by utilising the bannisters for example. Claire's assumption that everyone used the same access as her made her feel there were no barriers in place. However, although Claire's school had made accommodations, which made it more accessible for her, the awareness of her Cerebral Palsy from other children highlighted her impairment.

> *I didn't don't really feel particularly different ever until I was maybe about primary 4 at the start of primary school their adapted things they put lower bannister and I had people taking me in and out I just kind of assumed that what happened to everybody 'cause I don't know any different, you know what I mean and it was only once people kind of noticed I suppose like it was made a thing of. (Claire, 15)*

The attitudes of others towards participants' physical differences were still a prevalent challenge to their ability to be included and caused them to feel 'othered'. Ian for example recalled being bullied and mimicked because of his walking style.

> *The best and worst of them was when I was in high school, and I was actually a senior and there was a young boy who would, ehm, make*

> *fun of either the way I walked, or he would try to do an impression of how he thought I would speak. (Ian, 30)*

By assessing their functionality in early childhood as being similar to the children around them, participants had minimised the reality of their impairment effects. They were, therefore, able to construct their identity at that stage in their lives as being similar to that of typically developing children. However, as they developed through childhood, the data collected showed that participants acknowledged external barriers, yet also acknowledged that impairment effects impacted their everyday experiences (Thomas, 1999; 2007). Participants' reflections demonstrated that walking presented both a 'barrier to doing', because they felt it restricted them from being included in activities alongside their peers, and a 'barrier to being', as it was perceived negatively by themselves and others (Reeve, 2004). In internalising both these limitations, participants considered their walking to be the disabling factor in having Cerebral Palsy.

6.2 Rehabilitation to Walk

This section considers the rehabilitative approaches that participants undertook throughout childhood. The data showed that participants' reflections on the purpose, activities, and outcomes of therapy predominantly focussed on its impact on their walking ability. Participants recalled that the sense they took from rehabilitation was that it would make them able to walk better than they could. Data showed that while participants felt rehabilitation had had a positive impact on their walking and weight bearing functionality, it had not led to them being able to walk to the degree they had expected.

The first subsection explores the participants' reflections on the focus on improving their walking ability throughout their rehabilitative journey. Secondly, this was reinforced within the familial environment, with participants conveying the belief that their parents wanted them to complete therapy at home in order for them to become better, more independent walkers. Concluding, section 6.2.3 discusses participants' reflections on having been encouraged to undertake surgical interventions with the aim of correcting their walking style.

6.2.1 Therapeutic influence

Participants reflected that their walking ability was the focus of rehabilitation. The notion that their walking would improve with therapy was influenced by the emphasis on it by therapists. The purpose of therapy in their early childhood that participants absorbed was that they could improve their walking ability through biomechanical improvements to their muscle tone and gait. This adheres to the rehabilitative principles discussed in Chapter 3. Within the therapeutic environment itself, which included engaging with therapists, being prescribed exercises, being offered walking aids, and surgical interventions, participants reflected that they came to understand that therapy was intended to improve their ability to walk and that this would lead to their increased functionality later in their life. Rachel reflected that as a child she believed that therapy would enable her to walk 'better' than she would otherwise have done.

> *All I had in my head was that it will make me walk better, that's all I heard it as, like, take some pain away, because Cerebral Palsy, you get sore all the time, you know, my walk would be better and I wouldn't trip up as much, you know my gait was better and stuff. (Rachel, 29)*

During childhood, the narrative that participants believed was that the potential for them to achieve a greater walking ability through rehabilitation was contingent on them putting in the effort to achieve such an outcome. This gave participants the sense that an increased walking ability was achievable. Sarah, for example, recognised that while therapy would not automatically result in her being able to walk as well as she wanted, she could strive to achieve her goal through rehabilitation.

> *It was you'll get better in your walking pattern, and the more you do it and the stronger you get that, the more likely you'll be able to walk 10 miles without a stick, so it was never like yeah, you can do it, like you will be able to do it, it was more like you could do it, if you try hard enough. (Sarah, 15)*

With walking as the objective, on the advice of therapists some participants went to the lengths of attending private rehabilitation settings, which were promoted as providing additional intervention with the intention of improving children's walking ability. Catherine, for example, attended a private therapeutic institution offering Conductive Education, first in the UK and then in Hungary.

> *At the time I didn't object to it, I didn't know any different, and if you think about it in the context in growing up around lots and lots of non-disabled people, everyone else was walking so why wouldn't I be aiming to achieve the same thing... At the time the conductive education was sold to parents of children with Cerebral Palsy as like a sort of miracle cure that would get them walking, and in the context of, in the context of an environment where people put a lot of emphasis on being able to walk, if you say to a 7-year-old, do you want to walk? When everyone tells them that that's a good thing, they're only going to say yes, so I did. (Catherine, 30)*

While participants believed therapy had had a beneficial impact on their functionality, they reflected on its potential to increase their walking ability in contrast to how they believed it would have been without rehabilitation. David, for example, believed physio was beneficial at the time but without a comparison to never having therapy, he was unable to determine whether it was objectively positive.

> *I do think it was beneficial at the time... I don't know what physical benefits that the physio had because I have no way to tell how it would have been without it. But in terms of how I felt about my physicality after [it ended] I don't know either 'cause I had it. (David, 35)*

Walking was a dominant aspect of participants' narrative of childhood rehabilitation. Reflecting on this narrative, participants believed that the therapy they undertook would lead to improvements to their walking ability, which spurred their engagement in rehabilitation. The presumption that participants would embody the goal of improving their walking ability was implicit in their engagement in rehabilitation (Finkelstein, 1996; Barnes, 2003). Being children at the time, and in the context of being surrounded by their peers who could walk, participants complied with the expectation to undertake rehabilitation on the basis that they wanted to improve their walking ability (Alderson, 1993; Bantjes, 2015). This was further influenced by the emphasis put on the attainment of walking by their parents, as discussed in the next section.

6.2.2 Parental influence

Participants reflected that their parents reinforced and promoted the narrative that they should and could improve their walking ability through therapy. Participants reflected that their parents displayed a desire for them to complete the prescribed therapy at home so that they could improve their walking ability and become more independent through being more ambulant. Participants took a sense from this that their parents emphasised a desire for them to be as 'normally' functioning as possible.

Due to the delayed physical development experienced by participants in the study, which is common among children with Cerebral Palsy, participants were able to remember learning to walk and the feelings this evoked. They were then able to recount these memories for this study. For Rachel, the ability to conform to the societal expectation to walk, as desired by her parents, gave her a sense of accomplishment. The fact that her ability to walk, with the aid of crutches, elicited such a strong, positive reaction from her parents, reinforced the importance placed upon the act of walking itself.

> *I could probably remember. I suppose milestones, being able to walk with crutches was quite a big one for me but, I remember getting to that achievement and being able to walk well with crutches was quite a big achievement and I remember the first time I ever took them home and walked from the front door into the kitchen and how happy my mum and dad were that I managed it. (Rachel, 29)*

Participants felt that by encouraging improvement or reacting positively to the accomplishment of 'normative' walking parents projected onto them a desire for them to be more 'able' than they were (Fernandez-Alcántara et al., 2016). The ability of participants to attain this level of functionality affected their perception of themselves, thus causing them to believe that they had to undertake rehabilitation to fulfil their parents' expectations (French, 1994; Reeve, 2004). This embedded the belief within participants' overall conceptualisation of rehabilitation that it was necessary for them to do therapy in order to improve their physical functionality.

> *S: How it would change my relationships? - I don't think it would, for once, for a start my mum would stop nagging at me which would be great. I don't think it would change my relationships, because I don't think people, I hope, that no one is friends with me because of the limitations that I have, so I don't think it would impact my relationships at all.*
>
> *Parent: Why would you want it so bad then if you don't think it's going to make a change to your life?*
>
> *S: It would make a change to my life, but it wouldn't make a change to my relationships*
>
> *I: In what way?*
>
> *S: More confidence in, like, going out and knowing that when you walk into ASDA there's not going to be a bunch of people watching you, or when you go out and then I wouldn't have to bring my wheelchair with me, but independence. So, it would make a massive change to my life, but I don't think it would impact the relationships with people. (Sarah, 15)*

Participants internalised the notion that walking was favourable because it was advocated for by their parents and wider society. The strongest example of this was from Chris, whose mother had passed away, who reflected that his ability to walk against the expectations of his doctors gave him a sense of pride due to the positive reaction it would have evoked from his mother and those who knew her.

> *I'm going to tell you something, doctors can lie as well 'cause the doctors actually said to my mum and everybody else, they said that "[Chris] would never going to walk, he was going to be in a wheelchair all his life" and look at me now. Cause my mum... she's been looking down on me and she done, I done my mum so proud and that everybody I know says that and all. (Chris, 33)*

Reinforcing the therapeutic approach, participants had the ability to recall and attribute feelings to their memories of learning to walk and the response this evoked from people in their lives, particularly parents. Participants had a sense that their parents had a desire for them to have improved function as opposed to functioning how they were. Particularly, improving their walking ability, instead of using mobility equipment, was felt by participants to be actively encouraged by their parents, which in turn influenced the expectations to undergo treatment and complete rehabilitation at home. This was based on receiving positive responses from their parents for achieving improvements (Reeve, 2004). On top of rehabilitation, participants were encouraged by their doctors and parents to pursue surgical interventions, as discussed in the following section.

6.2.3 Surgical interventions

Following a similar narrative to participants' perspective of the therapeutic approach, surgical interventions, which were offered as a 'fix' to participants' atypical gaits, gave participants the expectation that this would significantly improve their walking ability. Yet, on going through surgical procedures, participants reflected that they had not had the impact that they had desired. Participants spoke negatively about the surgical techniques to promote walking. The common outcome was that the expectation of improved walking ability went unfulfilled. Surgery was further highlighted as having a detrimental impact on their body. The surgery some participants were encouraged to undertake was perceived by them to be detrimental to their physicality, their self-image, and their self-esteem. Gemma described her disappointment in gaining a dipped foot through surgery. She stated that her balance was weaker and some of her physical function was more difficult following the procedure.

> *I can't put my foot flat on the floor. And because, but at the time it was... I guess that I thought that I was going to walk normally, and that didn't really happen. I mean I do walk normally, but I just like, the dipped foot was there so that was a big let-down. (Gemma, 22)*

In some cases, the result of surgery challenged participants' perceptions of their own functionality. This was the case for Michael, who had orthopaedic surgery to extend his hamstrings; a technique aimed at improving walking ability. While Michael was unequivocal in the belief that he felt that if he had not had the operation, he would have been the "same old Michael, who walked with one stick”, the chance of being able to walk unaided was the sole hope for having the operation.

> *I view that as being slightly negative as well because my comfort zone is less now than it was previously... Previously before my op I could confidently take a bigger step there than I do now. (Michael, 28)*

While the perception of themselves that participants had prior to corrective surgery (which some of them underwent) was considered by them to be ‘normal’, there was a negative effect when their post-surgical functionality did not live up to their expectations. Surgery had deviated Michael’s sense of himself to being further away from the outcomes he hoped surgery would have achieved. Michael illustrated a direct relationship between the words of his parents and how he felt about himself in response.

> *M: I now see myself as being bent, sort of from your knees downwards. When your mum and dad say stand up straight, stand up nice and tall, you're trying but when you look at yourself in the mirror, you're still very bent. That’s why I choose not to look at myself in the mirror. I don’t really look in a full-length mirror, I don't enjoy that because I'm seeing myself differently.*
>
> *I: How did you see yourself before?*

> *M: As someone that was normal, that's what was normal to me. I could do a lot more than I could now, but what I'm trying to do, I've got different ways of doing things. (Michael, 28)*

The language used by his parents in the phrase 'stand up nice and tall' highlighted the correlation between conforming to functional norms and positive ideals. Michael explained how this led to a direct feeling of negativity when unable to perform as his parents desired. This also conflicted with participants' own view of their functionality, as Michael states. Michael felt more 'normal' prior to corrective surgery; however, this was not supported by his parents.

As identified in the previous section, parents were strong advocates for improving participants' walking abilities through therapy. However, where interventions had not led to the outcome they were expecting for their children, parents expressed regret, which had a negative effect on participants. Rachel, for example, felt that wearing splints directly damaged her feet. This failure led to increased impairments for Rachel, which were viewed negatively by her parents, as it conflicted with their expectations of the splints improving them.

> *One of the things my parents mentioned is splints and it's one of the regrets that they had, they never should have put me in leg splits and one of the reasons they were told that it would help me to walk but actually it's done the complete opposite and it's wrecked my feet to the point where my feet sit squint and they said that "they should have just left your feet and it's not like you can walk anyway". (Rachel, 29)*

Participants reflected that the rehabilitative process had encouraged them to believe that therapy would improve their walking ability. By undertaking the therapy advised by therapists, as children, participants thought their walking impairment would diminish and they would be able to walk more like their non-impaired peers. Parental approaches to the attainment of more normal walking influenced participants' sense that this was desirable. The ability of participants to meet these expectations impacted their psycho emotional well-being. Additionally, while participants believed surgery would further improve their walking ability, and therefore agreed to it, the outcome was often counterintuitive and negatively impacted the physical and social sense of self. This, along with issues associated with growing, led to a decline in participants' walking ability, and how they perceived it, as discussed in the following section.

6.3 Reframing Walking

Participants reflected that during their mid to late teens their walking ability began to decline. As this occurred, participants' constructions of both their walking ability and the role of therapy in achieving improved walking began to change. The decline in their walking ability, which participants had not anticipated, was accompanied by a reduction in the expectations of rehabilitation. In response, participants had to reconsider their approach to walking, making the choice to use a wheelchair to aid their mobility. However, participants continued to pursue a variety of rehabilitative approaches, such as physical therapy or exercise facilities, to maintain or increase their walking ability, or at least an ability to bear weight on their legs. This section discusses participants' reflections on each of these phenomena in turn.

6.3.1 Becoming a non-walker

Data showed that it was common for participants in their teens to experience either a sudden or gradual loss of their ability to walk, and their mobility more generally. Based on participants’ accounts, this was unanticipated and led to a re-evaluation of their physical and social selves, as well as the therapy they had been doing to improve their functionality. For participants, the initial decline in their walking ability was a significant inflexion point in the conceptualisation of having increasing impairment effects of having Cerebral Palsy. On reflection, Ian, for example, felt that his experience of losing his ability to walk caused a fundamental realisation of having an impairment.

> *I suppose the kind of first time, I don't know if I was aware I had CP but the first time I thought there was something wrong as I had a growth spurt when I was 16 or something, and I just completely lost the ability to walk and stuff, and it's apparently quite common in CP. (Ian, 30)*

Such experiences impacted participants’ perspectives of the therapy they had undertaken prior to this. David, for example, believed that the therapy he had engaged in as a child was undone by the biomedical issues he experienced in his teens.

> *I had a problem with my legs, so I spent 2 months almost curled up, my legs bent so anything that happened before that was unbound. (David, 35)*

At the same time as their walking ability declined, participants reflected that the therapeutic narrative around walking shifted. The expectation participants had in childhood was that they would be able to maintain the level of walking ability they had reached through doing rehabilitation. However, it became increasingly apparent that in order to obtain the level of walking ability they had expected to attain, participants would have to devote a considerable amount of time and effort to rehabilitation. David's realisation that the therapeutic requirements would only achieve a minimal amount of walking ability impacted on his belief in the purpose of it.

> *What I took away was that if I spent 8 hours a day, every day for a year I could maybe have got to the point where I could have walked a few steps. (David, 35)*

When it became apparent to participants that it would only achieve an incremental change, participants began to question whether the continued undertaking of rehabilitative therapy was beneficial and justified the potential walking related outcome. Whilst as children participants placed trust in the therapies being offered, and understood it to be what was expected of them, when they had more autonomy over their participation, they judged the potential outcome of doing so against the energy it required to achieve. Upon doing so, this group of participants often opted out of continuing to undertake rehabilitation of their own accord. Catherine, for example, later reflected that she was informed that, if she continued to undertake the therapy promoted by Peto, she would be able to walk around three steps independently.

> *C: When I reached 14 I was still doing Conductive Education which was but more sporadically because it takes a lot of time, and basically, a conductor, so the equivalent of a physiotherapist turned round to me and said that to maintain the level of mobility I had, I would need to do 45 minutes of physio a day, and then three hours at weekends and I was just like sod that, that's far too much effort for what actually means that I can't do things like study and all this kind of stuff.*
>
> *I: What did they mean by maintain? like what mobility?*
>
> *C: As in at that point I could walk maybe 3 or 4 steps without holding on to anything, so to maintain. (Catherine, 30)*

Participants' narratives began to change as it became evident that walking was not going to be the most viable option for getting around. This led to participants having to readjust their perspectives of using alternative modes of attaining their mobility, such as using a wheelchair full time. Participants described feeling that as children they had felt that the use of aids was a failure of therapeutic practises and linked the notion of becoming independent to being less reliant on mobility equipment. Even though participants acknowledged that the use of a wheelchair could be beneficial in increasing their functionality on a practical level, their vision of being an independent adult was premised on no longer needing to use such mobility equipment. Sarah, for example, felt that using a wheelchair would be detrimental to her sense of independence, prompting her desire to find ways of not needing to require it.

> *But as you get older, this might just be me, but I've been, with the equipment, it might be quite a negative way to look at it, but I've always been keen to advance in the way of, I might not need this anymore… It's been trying to get slowly coming away from the equipment and do things as independently as possible. (Sarah, 15)*

Upon reaching adolescence and being faced by additional barriers to independence, participants had to consider mobility aids as enabling. However, becoming reliant on using a power wheelchair challenged participants' sense of accomplishment. Participants had internalised messages of it being a failure to use a wheelchair, and therefore felt guilty about needing to do so on becoming more independent of their parents. An example of this was Rachel, who, when asked how she felt about using a power chair, felt there was a negative social relational effect of needing to use one in adulthood.

> *Not ok about it but I don't think I've really got a choice because I just feel in the back of my head that I've given up, and that's how I'm made to feel, that I've given up. I've spoke to my friends about it, and they were like "it's a way for you to live your life and make it more enjoyable*

> *and not get tired all the time". I think 90% percent of me knows that but that little 10% of me, is like urgh. (Rachel, 29)*

This construct was reinforced by external messages that emphasised the negative value placed on participants' function decreasing as they became an adult. The approach taken by parents demonstrated a continuation of that which was described to be fostered within parents during the initial stages of the child's diagnosis (Green, 2003). Initially this was to encourage the parents to support their child's normative functional movements. However, this approach was continued by parents into participants' adult life. Referring to her parents' approach to therapy, which was to promote the sense of attaining more functional ability, Rachel's experience of requiring a power chair due to decreasing functionality conflicted with her parents' construction of their independent identity.

> *I struggle with my parents because I know they're not happy with the fact that I'm in a power chair, so I guess they're in the mind-set that as long as you do things you shouldn't get worse. So now that I have got worse, I feel it's an area of contention with them... I know they weren't happy when I got it and obviously now that I'm reliant on it, but I get little comments like, "use your manual inside, I know you have to use it outside but use your manual [wheelchair] inside". It's those little chipping away comments that make me go, "you don't really get it". (Rachel, 29)*

While participants had internalised the message conveyed through therapy, that being independent was premised on the ability to walk without aids, a minority prioritised the independence that was gained through the use of mobility aids. For these participants, the prospect of requiring a wheelchair was a much less negative outcome. In deciding to use a wheelchair instead of pursuing the goal of walking, they concluded that using a wheelchair was a more effective way of getting around. For these participants, walking was seen to be inefficient and potentially harmful to their physical selves. Unlike the other participants, they did not express any feelings of failure or guilt around this choice. Instead, they formed a personal perspective of a preferred mode of movement which was not inhibited by the stigma that was felt by other participants about using a wheelchair. This was illustrated by Catherine, who uses a power-chair to get around and actively chose to use a wheelchair instead of walking in order to preserve her energy and abilities to pursue other outcomes.

> *But what I worked out is that, using a wheelchair and very specifically using an electric wheelchair, I can do 75% more in my day than my friends that walk with CP, because of the amount of energy that it takes to walk. And so, I've made a decision repeatedly throughout my childhood and now adult life, that I would rather be able to, to not kill myself and knacker myself out. (Catherine, 30)*

Participants commonly experienced an unexpected decline in their walking ability during their mid to late teens, which brought doubt on the therapy they had done until that point. This was a significant juncture in participants’ conceptualisation of their impairment effects, which caused them to re-evaluate their use of alternative modes of mobility, such as power-wheelchairs. Having been encouraged to pursue walking through rehabilitation, this challenged participants' biographical sense of self as people who could previously walk or were more mobile (Bury, 1982; Bray, Kirk and Callery, 2014). While participants reconciled to the notion that using a wheelchair offered them more independence, they were often confronted with societal pressure against their use. The following subsection demonstrates that this was, in some cases, accompanied by a continued belief that rehabilitation could maintain and potentially improve their walking ability.

6.3.2 Pursuing walking in adulthood

Though the majority of participants recognised that the therapy they had had throughout childhood had not resulted in them being able to walk as they had expected, some participants continued to attempt to access rehabilitation with the aim of improving their walking ability. The internalised message that therapy could continue to improve participants' walking ability remained strong for these participants who sought to do so by maintaining the exercises they would have had through physiotherapy. Michael felt that having therapy, and a therapist, as an adult, would have supported him to do the rehabilitation that he felt would further improve his walking ability.

> *I: So, what do you think having that physio input would do now?*

> *M: Hope. I would like to hope that having physio and improving your, would help improve your stamina, and your, your, your, your ability, your ability to do things more properly and do them for a sustainable period, or a longer sustainable period.*
>
> *I: What do you mean hopefully?*
>
> *M: Well, maybe, when I when I when I when I'm walking I'm I'm concentrating on what I'm doing to get myself to to the next position, where if if you've got a, if you've got a physio there they can watch what you're, how how you're walking and they can say well you know stand, think think what you're trying to do and stand up tall you know, take take take bigger steps when you're when you're walking rather than the tiny baby steps that you are taking. The reason that I know that I'm taking time and use that to continue baby steps is because I know that I'm not gonnae fall. (Michael, 28)*

Due to the absence of regular adult rehabilitation provided by the NHS, some participants accessed private rehabilitation. Since attending a private physiotherapist, which offered tailored, regular physiotherapy, James, for example, described the benefit he had felt to his physical functionality and compared his experience to that which he had had from the NHS when growing up.

> *J: [I've been going] Twice a week for about 4 months. I told her I can see my body improving every day, but no one knows more about CP than her.*
>
> *I: (How does it compare to the physio you had for 18 years)*
>
> *J: NHS physios are not really taught to be creative. And they're taught to give everyone the same advice, stretch this much every day etc. You can't standardise physio for CP, it doesn't work. The new one has come up with, you wouldn't believe the half of it. My legs are over my shoulders and she's swinging my pelvis… She says she can have me walking. I know that's a huge, huge thing for someone who uses a wheelchair, but she's got me standing up against a wall, she can see me convulse in pain and she's like "ignore him, he's being dramatic!" She's treated her own patients for 20 years, she's fantastic. (James, 23)*

In the absence of appropriate support provided by the state, some participants took it upon themselves to purchase equipment and pay to access gyms. While accessing local leisure facilities replicated a normative construct in adulthood, participants linked the need for doing so to the onset of impairment effects related to their Cerebral Palsy and continuing to attempt to increase or improve their functionality. Ian, for example, recognising the benefits of rehabilitation, continued to use gym facilities in place of therapy.

> *It has certainly enabled me to stay on my feet a bit more… The physio itself has helped and the fact that I kind of had to do it to maintain some sort of, some sort of physical thing, that has stayed there. I go to the gym instead of having physio. (Ian, 30)*

In particular, participants emphasised the potential improvements they wanted to achieve through accessing gym facilities. Chris, for example, emphasised that it was his decision to seek out opportunities to exercise with the intention of continuing to strengthen his leg muscles in order to maintain and improve his walking ability and balance.

> *No, I just made that decision on my own, like, and joining up to the gym that was my own decision and bought that bike that was my own decision, and everything was my decision... I got this in my head that I should be using my walker for support for my balance cause my balance is not that good, cause I was born with Cerebral Palsy, so my Cerebral Palsy won't ever go away cause I was born like that but it won't stop my legs getting stronger, so that why I feel like my bike and my walker and my gym help me out on my legs, so they are more stronger. (Chris, 33)*

As adults, participants continued to pursue physical exercise through formal rehabilitation or mainstream provision, such as gyms, with the intention of regaining, maintaining, or attaining a greater walking ability. This was primarily due to participants' sense that walking was achievable through rehabilitation; a narrative that continued to be given to them by rehabilitation practitioners when accessing private services. In doing so, participants had a positive psycho-emotional response to the feeling that they were continuing to achieve, or attempting to achieve, the goal of walking that rehabilitation had instilled in them.

6.4 Conclusion

This chapter focused on participants' reflections on their walking ability while growing up and becoming adults with Cerebral Palsy. Walking was an identifiable social marker of participants' physical impairment. It increasingly became a prominent factor in participants' identification of themselves as different from their non-impaired peers as they progressed through childhood (Bantjes et al., 2015).

Rehabilitation contributed to participants' belief that they could and should improve their walking ability. Both the therapeutic narrative, which led participants to believe that improving their walking ability was possible through therapy, and their parents' encouragement to engage in rehabilitation with this aim, led participants to believe that improving their walking ability was desired of them and was achievable. This resulted in participants prioritising therapy over typical childhood activities, actively choosing to attend intense therapeutic courses within the UK and abroad and agreeing to invasive surgical procedures on the basis that they would lead to participants having a greater ability to walk more normally.

While participants acknowledged that such interventions had had limited benefits, such as the ability to bear weight or take steps, they commonly felt that the outcomes, especially of surgical procedures, fell short of their expectations. This often had negative consequences on participants' physical, social, and psycho-emotional wellbeing. Compounding this, the unanticipated decline in their walking ability, and the resulting reduction in the rehabilitative expectation, left participants having to reconsider their sense of selves as 'walkers'. While the use of wheelchairs had been considered secondary to walking, and continued to have negative connotations and stigma attached, participants, to varying degrees, accepted their necessity to use a wheelchair in order to be independent in adulthood. Even so, as adults, some participants continued to access rehabilitative provision with the aim of improving their walking ability or mobility in an attempt to achieve the goal rehabilitation had instilled in them. Without access to regular rehabilitation, however, participants accessed time limited rehabilitation sessions, used universal provisions, such as gyms, or paid for private therapy sessions, with the aim of maintaining, or even trying to improve, their walking ability. The continued validation this gave them, and positive responses from parents or wider society for attempting to walk better, was influential in participants' approaches.

Chapter 7 - Functioning and Degeneration

This chapter discusses participants' accounts of striving to become independent and the continuous barriers they experienced in living and ageing with Cerebral Palsy. Biomechanically, rehabilitative theory considers that a child with Cerebral Palsy’s manual ability is a main determinant of their potential to undertake daily activity, which is required to be independent (van Eck, Dallmeijer, van Lith, Voorman, and Becher, 2010). Studies into the ability of adolescents with Cerebral Palsy to undertake daily living activities, however, have found that a high proportion require some form of assistance to live independently, including mobility aids and personal support (Palisano, Copeland, and Galuppi, 2007). This chapter finds that the message participants received in childhood from therapists, and in turn their parents, did not reconcile with the unanticipated challenges to living independently with Cerebral Palsy, leaving the participants feeling unprepared for the realities of adulthood. Compounding this, although Cerebral Palsy is considered a “non-progressive” disorder, participants experienced increasing impairment effects, such as adjusting to increased pain levels and functional degeneration, which they had not expected due to the rehabilitative narrative.

The first section demonstrates that both parental messages that their impairment was not a barrier to their participation and the childhood rehabilitative narrative contributed to participants’ belief that they would become independent adults through improving their physical functionality. Participants reflected that on becoming adults there was a need to reconstruct their narrative of being an independent adult with Cerebral Palsy, which inevitably included needing support from Personal Assistants or wider Social Care, employment support and state benefits. On reflection, participants felt childhood rehabilitation had not prepared them for the realities of living as an adult with Cerebral Palsy.

Secondly, as participants progressed into young adulthood, they described experiencing unanticipated early ageing and increasing impairment effects, which impacted and challenged their perspectives of their physical, social, and psycho-emotional experiences of having Cerebral Palsy. Without access to ongoing rehabilitation, participants expressed a need for medical interventions and therapies to mitigate against pain and fatigue, and for some, a continuing need to improve, or at least maintain, their independent functionality.

7.1 Becoming Functionally Independent

This section firstly discusses participants' reflections on the narrative they absorbed as children about functioning independently with Cerebral Palsy. While their parents had enforced the message that their impairment was not a barrier to their attainment of independence, participants had been encouraged to do therapy to develop the functionality needed to become independent. Therefore, participants constructed the notion that they would be able to be independent, without the need for support.

The second subsection considers participants' views of the realities of being independent. Participants reflected that on becoming adults, their construction of their ability to be independent differed from what they had expected as children. Participants felt unprepared when it transpired that they required social care support (formal or informal) and concessions to be made by them or others to participate equally in society, such as employment, as it contradicted their perception of being independent as an adult with Cerebral Palsy. This challenged participants' sense of achievement, which they explicitly linked to the narrative they were given as children.

7.1.1 The functional narrative

During childhood, participants absorbed the narrative that having Cerebral Palsy was not a barrier to their participation in having a typical childhood, either through the absence of being told that it would be or by being encouraged to think that it was not. Likewise, participants were led to understand that Cerebral Palsy would not be a barrier to them being able to achieve their independence as they developed into adulthood. However, at the same time, participants also reflected there was a narrative emanating from their rehabilitation that by completing their therapy they would be more able to become independently functional adults. As children, participants' sense of being an independent adult focussed on not requiring support from another person or the use of aids and adaptations.

Participants reflected that the physical and practical implication of having Cerebral Palsy was not explained to them by their parents. Instead, participants reported that their parents instilled the philosophy that having Cerebral Palsy was not a barrier to their function and participation in society. Sarah noted that her parents did not discuss the implications of having Cerebral Palsy with her in depth, nor talked about it putting limitations on her.

> *I think, no one's ever, like, sat down and had a formal thing, this is what it is, this is what you won't be able to do. (Sarah, 15)*

Participants reflected that they felt their parents urged them not to dwell on the potential limitations that having an impairment could impose. Instead, participants felt that they had been encouraged to think that their Cerebral Palsy was not a barrier to their functional ability to do the same activities as non-impaired children. Ian reflected that his parents' approach was to prevent him from thinking that his impairment was a reason to be treated preferentially.

> *My parents didn't, well they encouraged me, slash, forced me to not to not think about it. In the sense that I couldn't use it as an excuse to not do things, so like I couldn't say I can't tidy my room because of my Cerebral Palsy. (Ian, 30)*

Parental approaches instilled a belief in participants that they could achieve their potential regardless of their impairments. As discussed in the two previous findings chapters, parents both motivated participants to undertake rehabilitation and promoted its potential to improve participants' functional ability. Participants reflected that their parents' approach to them being able to achieve their potential was on the condition that they strived to obtain it, as demonstrated by Rachel.

> *It was always kind of explained to me by my mum and dad that I could do anything that I wanted to as well, but I think there was always a kind of backdrop of as long as you can push yourself. they were always quite pushy but not in a bad way. (Rachel, 29)*

Though rare, some participants' parents had discussed the implications of not becoming more physically functionally able as adults and needing support to live independently. However, participants reflected that the manner in which this was done was negative and made them doubt their notion of independence, which was based on their assumption that they would not require support from others or to use equipment. Therefore, the alternative of only being able to live independently with support was deemed by participants to be their failure. Rachel described having both internalised the concerns and the negative views of her parents over the potential of not being able to function independently on her own as an adult.

> *(Did you envisage having Cerebral Palsy as an adult when you were a kid?)*

> *No, but I know that was a fear in my mum. She would say that to us when I was growing up, "you've got to think about when you are older and how you'll manage when you're older" and I know... I remember that having an impact on me and thinking "shit, I know and can do things now but what if I can't do that when I'm older?" "And what will that mean?*

> *Will I need staff; will I need to have somebody with me all the time?". I kind of felt like the worst-case scenario and I'm kinda coming to terms with that. If I had staff will that mean I failed? I think for them it would. So, it is there. (Rachel, 29)*

Data showed that the majority of participants considered rehabilitation as a route to attaining their conceptualisation of an independent adult identity. This was rooted in their understanding that rehabilitation was intended to enable children with Cerebral Palsy to manage living independent adult lives, as evidenced by Michael.

> *I suppose with therapy they were trying to teach you ways of coping with having your disability, with having Cerebral Palsy and how you would manage, to prepare you for day to day living. (Michael, 28)*

Participants linked the activities required of them in rehabilitation with the ambition of becoming independent. Rachel, for example, reflected that she equated her exercises with the pursuit of being able to carry out tasks on her own, which would result in her being independent.

> *I suppose so I could do things for myself, and I suppose, like,* I *equated doing exercise with being independent. (Rachel, 29)*

Participants' sense of self as an independent person with Cerebral Palsy was based on having participated in rehabilitation. This was especially true of participants who had attended Conductive Education. Considering the literature reviewed, which discussed one of the benefits of Conductive Education was the instilling of a personality that encouraged children to be more independent, participants had a sense that their participation in such therapy had made them feel that they were striving to achieve a greater sense of self. Sarah believed therapy had shaped her sense of self, identifying that it had a positive impact on her confidence and sociability.

> *I wouldn't, physically I wouldn't be myself to put it quite bluntly, I would be so, I'd be a shell of myself, I wouldn't be as confident as I am without physio. Because it gives you a boost of confidence, a boost of independence, that boost of mobility that you need to strive. So, without physio, physically I wouldn't be who I am. Socially it means I would lack so many social skills that have been essential for me growing up, I wouldn't know as many people, I wouldn't have this many, as strong connections as I have now, without physio. So, socially and physically it's, without it I wouldn't be who I am. It's such a key thing. (Sarah, 15)*

Participants identified that the narrative promoted during childhood that Cerebral Palsy was non-progressive, instilled a belief that they would be as functionally able in adulthood as they were in childhood. The impact of degeneration made them contemplate why they could not continue to function as well as they had done in childhood. As an adult, Catherine felt that the expectations raised by therapy were unachievable.

> *As much as our condition is not progressive in terms of the initial brain damage does not get worse, our bodies are screwed. They get tighter and tighter and tighter and tighter and more worn because they don't use them properly, so I am not I am not as physically able as I was 10 years ago, I'm not as physically able as I was. I probably reached my physical, like, peak at probably 4. But, and there's nothing wrong with that but, in a way the medical profession and the therapeutic profession kind of imply that if you do all the shit as a kid, you'll somehow maintain what you've got as a kid, and actually that's bullshit. (Catherine, 30)*

Participants reported that they felt that deterioration was their fault for having not kept up with regular activity or physio. This impacted negatively on their psycho-emotional well-being. Rachel, for example, internalised the construct that if therapy was done ‘enough’ then she wouldn’t experience impairment effects in adulthood. This construct resulted in her belief that it was her responsibility to mitigate against the effects of her impairment.

> *I think you're kind of told Cerebral Palsy that as long as you stay active you shouldn't get worse and this kind of idea that the CP is non progressive and I'm jumping about a bit here, but I think that's why I'm struggling now as an adult, because I beat myself up about it a bit. I think well if I am deteriorating it's my fault because I haven't done enough and that's definitely come from my childhood because my mum and dad had the mindset of “as long as you keep active, you'll be fine”. (Rachel, 29)*

The reality of degeneration conflicted with the expectation that therapy would have prevented degeneration taking place. This reflected the phenomenon discussed in this chapter that participants generally described not having been prepared for its occurrence, as reflected in Catherine’s quote. Catherine’s recollection of not having been told what to expect her adulthood to be like, nor what the interventions she was being given would achieve, gave her the sense that during childhood she had not considered the impact of her Cerebral Palsy on her future adulthood.

> *I don't think I ever thought what being an adult with my condition would mean, ever. Because no one ever talked to you as if you were going to become an adult, and no one ever put any kind of intervention in the context of adulthood or when they did it was inappropriately done, so it was far beyond my comprehension. So, they would say things like, you'll regret not doing that later or you'll feel the benefit of that later, and actually what the hell did they know? - They haven't got a time machine; they can't see what I'm gonna do. (Catherine, 30)*

In retrospect, participants felt that having been encouraged to do rehabilitation as a child, they would have achieved the potential benefits the therapists espoused. Participants reflected on being led to believe that rehabilitation was given in childhood because it was most beneficial to the developing body (Novak et al., 2017; Herskind et al., 2014). They therefore thought there was a belief amongst physiotherapists that the more therapy undertaken as a child, the less the state would have to intervene and support adults with Cerebral Palsy in later life. Catherine's narrative spoke to the philosophical reasoning behind the provision of rehabilitation to young children with Cerebral Palsy and its subsequent withdrawal, describing that she felt that interventions were given to children with Cerebral Palsy in the hope of improvement that would be sustained in adulthood.

> *[Ongoing rehabilitation] doesn't fit with the model that the state works on is that they think that if they put masses and masses, and admittedly it's changing because it's getting less now than when I was a child, if they put masses of masses of intervention into you before the age of 18 they're hoping that somehow it will carry on into adulthood, whereas actually CP being the kind of condition it is, the minute you stop that intervention the decline starts. (Catherine, 30)*

Whilst participants had expected to continue to experience some or decreasing impairment effects that they had normalised in childhood; they did not anticipate there would be increasing barriers to their participation and social-relational identity caused by an increase in these impairment effects. As this happened so soon after finishing therapy, participants had not had the opportunity to create a narrative of having a 'normal adulthood' with Cerebral Palsy. This led participants to believe that, on becoming adults acting independently, rehabilitation was necessary to continue their ability to function.

> *Yeah, right until I think everyone should have physio no matter what age they are, because they only view it as less beneficial the older*

> *you get but, it's still a key part of life that many people with disability that they need that like, they need to have that bit of independence or have that bit of mobility that they wouldn't have without it, no matter, the age you are so yeah, I mean I think I should continue to have it, whether that's, whether I leave school or not, whether I go onto a full-time job or not, that's, still I should always have access to. (Sarah, 15)*

However, participants who had since left childhood rehabilitation reflected that they could have been better prepared for living independently in adulthood. Participants felt that the therapy they had been given had not suitably met their needs and thus their conceptualisation of being independent was challenged. Peter therefore made a case for having tailored independence lessons, which he felt could have enabled him to prepare to live independently as an adult with Cerebral Palsy.

> *Also like, know how, like, independence, more independent living sessions, especially when you're sort of adolescent sort of going into adulthood, I never had any access to that. Is which, maybe if I had a wee bit of access to like independent living classes like maybe learning to cook for yourself and sort of being practical, but in a, like, but with your sort of disability in mind, like that that'd really set you up for later on in life as well. (Peter, 32)*

The data revealed there was a juxtaposition between the societal narrative that participants could have typical childhoods and achieve independence as individuals with Cerebral Palsy, and the therapeutic narrative that they had to partake in rehabilitation to be more able to participate in regular childhoods and become more able to achieve their independence in adulthood. There was a lack of acknowledgement by therapists of the barriers that participants faced, while at the same time they were being encouraged to improve their functionality in order to overcome them. Parents were the main drivers of participants' belief that Cerebral Palsy was not a barrier to their ability to achieve independence, while at the same time they encouraged participants to undertake therapy, which promoted the belief that therapy would enable them to become independent. This gave participants the impression that they would become independent adults without the need for mobility equipment or support. The reality, however, was significantly different, as discussed in the following section.

7.1.2 Being independent with Cerebral Palsy

The data showed there was a disconnect between participants' expectations of adulthood, that they would become more functional and independent, and their unfolding realisation of being an adult with Cerebral Palsy. Following on from the last subsection, participants had a belief, internalised since childhood, that as long as they did what was demanded of them in rehabilitation, they would maintain and/or improve their functionality and be independent adults, as Rachel describes.

> *I think the emphasis has been on independence, it's really strange, and by independence, I mean doing things myself. As I'm getting older*

> *that's changing. It's quite hard. It does affect my mental health a bit, I do have days where I feel I'm fatigued, but also feeling a bit down about it and I can't remember ever feeling that way when I was younger. They say that Cerebral Palsy isn't progressive, but I feel it is, because I feel like I've changed a lot and how I am physically and also how I view it, how other people view it as well. Because I feel when you're a kid with Cerebral Palsy you're also made to think you can do anything and all that inspirational stuff and you can do really well but... I feel different when I'm in my manual, I feel people treat me different. (Rachel, 29)*

Participants felt that there was a disconnect between their experiences of being supported as a child with Cerebral Palsy and that of being an adult. As a child, Suzy for example, felt more supported in childhood, with a general sense that the support networks around her put more effort into equipping her to overcome societal and also impairment related barriers. However, as an adult she felt that there was not the same emphasis or level of support surrounding her.

> *Being a child with CP is so much easier than being an adult. But having CP you have to work hard in every aspect in your life, being disabled you have a lot of barriers in your way… The main difference being a kid you have a lot of people pushing you, but as you grow up these people fade away and if you don't push yourself, you would end up being in the house all day. You have to make your own luck in life. (Suzy, 31)*

The recognition of their impairment effects in day-to-day adult life led to participants coming to the realisation that they would require support in order to live independently and meet their needs as adults with Cerebral Palsy. Participants considered that their challenges around admitting to needing and asking for support in adulthood was linked to the messages they had internalised from parents, rehabilitative professionals and wider society growing up, that independence meant being able to do everything for themselves.

> *If I was struggling, would other people do it? Would they cut the food? They… So that is why I struggle to ask, ask for help and stuff now. Because it's like I've been told you have to be as independent as you can… I still get frustrated at not being able to do things. I felt embarrassed, and I still struggle to ask for help with things that, ehm, I should be able to do... How're other people going to react to that?... But I do struggle with some of the simplest tasks that people can struggle with, or people other people find easy… But you've got to sometimes bite the bullet and say actually I need a little bit of help with that. (Michael, 28)*

Data showed that this had a lasting effect on participants and led to participants considering that therapy should have instilled more of a mind-set of being able to ask for help. For Ian, adapting to the realities of living independently was made harder in part by a reduction in social care resources, which was compounded by Ian’s lack of preparedness about what this would involve.

> *So, to have been encouraged to be so independent to then have to be able to ask for help, it's quite a hard thing to do. So, I think there needs to be a balance struck somewhere because I agree, I can't hide behind my condition, but I think I think now in the kind of inclusive society type of thing where you're encouraged to integrate and all that stuff [you need support]. (Ian, 30)*

Participants' expectations of being independent were challenged when they required the provision of social care. However, on becoming an adult with continuing support needs to be met, participants highlighted the realisation that their lives would need to encompass having ongoing support. As Ian described previously, he was ill-equipped to use the provision of social care, through the employment of PA's, due to the fact that he had not been prepared to do so, on the expectation he would not need them, as he would be able to function independently without them. As participants felt that they had not struggled with certain tasks as a child, the need to accept help in adulthood challenged their expectations of being independent. In discussing the impact of this, Ian explained that he struggled with having to have Personal Assistants (PA's) in order to manage the increasing impact of his impairment related effects.

> *So, to be able to cope with pain and all that type of stuff, I haven't had to do, I haven't had to do that - I had to admit I need more support. (Ian, 30)*

The effects of their impairments, which participants had been able to normalise to a certain extent in childhood due to rehabilitation and familial support, became more influential in their ability to function in adulthood. The data showed that on top of a lack of preparedness to use social care, a degree of uncertainty around their access to it meant participants were unable to achieve a stable position of being an adult who could live independently with support. This was illustrated by issues around Felix's social care package since his transport provision to and from college had been withdrawn.

> *There was quite a lot of discussions and Felix had a care, well he still has a care package, but they've been slowly picking away at that, it's hard to think that they removed, Felix used to get transport, so with some of the cut-backs they took away the transport… [it] took that little bit of independence away that [he] has, for travelling without his mother. (Felix's mum)*

Participants felt that as an adult their independence was challenged by the social and political contexts. While participants accepted that state benefits had the potential to aid their independence as an adult with Cerebral Palsy, they felt challenged by the system meant to support them. Rachel felt that when applying for Personal Independence Payment (PIP) from the Department of Work and Pensions (DWP) there was no acknowledgment that her Cerebral Palsy had associated impacts on her independence and that the increasing barriers to being an adult with Cerebral Palsy was not given full consideration.

> *I just feel like we're under attack or I don't know what I mean by that. I just feel that CP isn't enough... I had my face to face with [the DWP assessor], and I said Cerebral Palsy and she didn't even go "How does that affect you?"... and she was like yeah well but… "well you've had all the time to deal with it so that shouldn't be an issue for you anymore." (Rachel, 29)*

For one participant however, a divergent experience enabled them to maintain the construct they were independent without needing support. While the previous participants had been impacted upon by the biographical disruption to the childhood construct they held of what their independent adult identity would be, Chris continued to maintain this construct due to the informal support provided by his family who lived close by.

> *I don't get any support, I just go to my things, and my brother comes in, and my brother comes in to check on me quite a lot… I like being independent and I, like, I feel like I don’t need any help from anyone, social workers or nothing, so I’m, like, quite independent of my, I look after my own money and all that. I do that quite well and I just feel like I don’t need social workers or any. I can do things myself and all that. I don’t see the point of it. (Chris, 33)*

Chris’ notion of independence was fixed on being able to access his regular social activities and not having social care support. Though acknowledging the support he received from his sibling, he did not see this as a challenge to his sense of independence.

On moving into adulthood and having to contend with the realities of living independently with Cerebral Palsy, participants felt the disconnect between the narrative they had received in childhood and the need for support and assistance to be independent. While this had practical implications for participants in terms of being more restricted in their participation in normative adulthood, limitations upon independence also had psycho-emotional impacts. The data shows that the effects of an internalised sense of independence being contingent on the ability to function in society without aids or assistance from another person resulted in participants feeling unable to access the support they required due to both their own feelings of failure and their anxiety about asking others for help.

7.2 Ageing and Degeneration

This section discusses the data relating to participants' reflections on experiencing pain, fatigue and deformity throughout their lives, and the increasing impact of such impairment related effects as they developed into adulthood. The first subsection discusses participants' reflections on the impact of these effects on their physical and social sense of selves. Studies have found pain to be an inhibitor to adolescents participating in physical activities with their peers (Shimmell et al., 2013). In normalising pain in childhood, participants in Burton and Bartlett's study believed that they had to endure pain in order for them to maintain their participation with their peers instead of seeking ways to mitigate it through more socially appropriate activities (Brunton and Bartlett, 2013). This thesis found that while pain was a factor in participants' lives throughout childhood, the impact of ageing led to more significant effects of pain on their experience of having Cerebral Palsy. The effects of secondary ageing began shortly after leaving childhood therapeutic services. Participants reflected that their social-relational selves were inhibited by being unable to participate in general life in the way they had envisaged. As Paterson and Watson identified, the effects of ageing came as a surprise to their participants (Paterson and Watson, 2013). The second subsection goes on to discuss the lack of appropriate health and rehabilitative provision that participants felt was available to them to manage the secondary impacts of early ageing with Cerebral Palsy.

7.2.1 Recognising the effects of ageing and degeneration

Ageing and degeneration have been relatively under-researched until recently due to there being a focus on the childhood development of Cerebral Palsy and the conceptualisation of it being a non-progressive impairment as the brain damage remains static (Moll and Cott, 2012; Bax, Goldstein, Rosenbaum, Leviton, Paneth, Dan, Damiano, 2005). However, as Colver discusses, findings from research into the experiences of adults with Cerebral Palsy have demonstrated that the effects of premature ageing can lead to pain and deterioration in functionality. Deterioration was characterised by decreased physical function, pain, and fatigue (Colver, Rapp, Eisemann, Ehlinger, Thyen, Dickinson et al., 2015). These findings were borne out in this thesis with participants reporting unexpected deterioration in biomechanical functionality.

Whilst participants acknowledged an understanding that Cerebral Palsy is a non-progressive condition, their experience of ageing with Cerebral Palsy challenged this medical definition, as described by Sarah's mother.

> *Now, CP doesn't change, you know, [but] if anything, the challenges become more evident as she's getting older etc (Sarah's mother)*

While degeneration caused by ageing is a normative construct during a person's lifespan, participants reflected that this started during, or soon after, leaving childhood (Brunton and Bartlett, 2013). The realisation that the effects of having Cerebral Palsy had a greater impact as a person ages contradicted participants' understanding of how they thought they would have developed into adulthood (Moll and Cott, 2012). Rachel summarises the changes she experienced on becoming an adult with Cerebral Palsy.

> *No, everything felt like second nature, it didn't feel like a struggle really [as a child]… It sounds weird but I've had Cerebral Palsy all my life, but it feels like I'm learning it all again, in the sense, I don't know, sometimes I feel like I forget how we do things, like getting dressed and that. Some days I'll be sitting there and be 'why can't I coordinate' the same way… it was just different degrees of severity. I think that was it. (Rachel, 29)*

The physical experiences of participants demonstrated a disconnect between the embodied experience of having Cerebral Palsy as a child, the expectation that this would continue unchanged or would have improved in adulthood, and the actual reality of becoming and being an adult with the condition. The data showed that this reality started to have an impact on them in their early adulthood, as Rachel further demonstrated (Moll and Cott, 2012).

> *A specific example I can think of is the wheelchair service. Because I've always used a really active lightweight wheelchair and around about the time I got chronic fatigue which was around about 4 or 5 years ago, I just started noticing little changes in my CP and I went and spoke to them and said "it's getting harder to manage my chair, has anyone else gone through that" and she laughed at me and she went "have you not read up on it? it what's happen with CP" and I was just like "no?" and it was all just really confusing 'cause basically I got told that, that kind of what happens. (Rachel, 29)*

While pain had been a feature of their childhoods, many participants described that their pain intensified in their late 20's and early 30's. This had a significant impact on their quality of life and their sense of well-being. Ian explained that the experience of increased pain changed his social status. In order to manage his pain, Ian had to forfeit time socialising (Morris, 1991).

> *So, I find myself not saying I don't want social situations but because of all the pain and stuff I get into I have to kind of think, by the*

> *time I go to the pub, and that shuts at 11, then by the time I'm home and I have to get myself into bed and stuff, I could be up until about half past 1 and stuff like that. (Ian, 30)*

Participants had to organise their social lives and work patterns around their increasing experience of impairment effects (Charmaz, 1983; Williams and Marvin, 2012). In order to mitigate against the impact of his impairment on his work/life balance, Peter reduced his working hours, which would have had an impact on his economic well-being and potentially his career prospects (Williams and Marvin, 2012).

> *Obviously, you've got know how like the muscle fatigue that associated with, like, Cerebral Palsy, so for example, like, I work part-time but like, because it suits me, but like the work like, when I used to work full-time, I would work 5 days a week then at the weekend I was knackered and didn't want to do anything. (Peter, 32)*

Participants compared their experience of being in pain and fatigue to that of people without Cerebral Palsy. Gemma's account of experiencing periods as a woman with Cerebral Palsy referenced the additional pain felt as a result, which was compounded by the extra energy she expended to manage it. This fed into Gemma's broader narrative on pain; that her experience of it was greater than that of other young people without Cerebral Palsy, and she felt that this was a normal part of having an impairment. Women's experience of period pain, in general, is often denied or underplayed in order to appease the dominant culture and the internalised stigma around periods (Johnston-Robledo & Chrisler, 2020, p.182). Women with Cerebral Palsy's experience of this is exacerbated by their condition increasing their pain associated with periods. In relating her pain to that of women without Cerebral Palsy, Gemma expressed a social-relational element to her experience of pain. Gemma described the enhanced impact that Cerebral Palsy can have upon commonly experienced pain associated with periods.

> *...my periods, I get tired and because that's what it does, it drains you... but having Cerebral Palsy, it makes you use energy. So, I'll get really bad pain, but the back pain is also there, but the back pain is maybe more than what some other girls' back pain on their period would be. (Gemma, 22)*

Participants also highlighted the impact of the physical effects of their impairment upon their mental well-being. Peter, for instance, reported that the physical effects of his Cerebral Palsy had led to him experiencing depression.

> *Yeah, it's, know how, like, as I said, you've got the physical barriers sometime then, you've got the sort of, I think sometimes you've got mental barriers as well... Like, for example, like, maybe, there's maybe sometimes a wee bit of maybe slight depression because you can, because you're fighting with your body all the time, you know what you want to do, but your body doesn't do it half the time, when you want to do it. (Peter, 32)*

Participants’ experiences of unanticipated ageing and degeneration placed them into a position in which they had to construct a narrative for their next phase of adulthood. Narrative reconstruction has been linked to people’s experience of the onset of chronic illness, discussed in Chapter 2, whereby the challenge to their normative identity caused by acquired impairment leads to a disruption in their autobiographical narrative (Bury, 1982; Charmaz, 1983). When considering this in the context of participants, the genesis of their narrative reconstructions was when they began to realise that their condition (their current functionality and experience of impairment related effects) was unlikely to improve and in most cases began to decline (Moll and Cott, 2012; Bray, Kirk, and Callery, 2014). This had a negative impact on participants’ physical and social sense of selves, which had a detrimental effect on their psycho-emotional well-being. As the next section demonstrates, this was further compounded by the lack of appropriate rehabilitation and medical services available to participants in adulthood.

7.2.2 Accessing rehabilitative and medical services in adulthood

The message instilled by health services; that participants would continue to develop their physical function if they continued therapy, never diminished whilst access to therapy did. As section 5.2 demonstrated, participants felt they had a lack of agency and understanding over the withdrawal of rehabilitation. This subsection explores participants’ perspectives on the removal of rehabilitation and the impact of the absence of appropriate rehabilitation in the context of their increasing impairment effects in early adulthood. Rachel described that the shift from paediatric rehabilitation to adult health services was difficult due to this disconnect.

> *It wasn't an easy road and I got really upset and probably medically wasn't any good places ever so I'd say my childhood with Cerebral Palsy I felt a lot more supported and a lot more believed and now when people look at me from the medical profession, they either obviously don't know what my baseline was so they assume this is how I've always been and that frustrates me 'cause when I try to explain to them that, no this is a result of deterioration because I've had other conditions I feel like they don't believe me or just feel like I'm lazy, they make you feel like you're lazy… How I describe it now, again going back to the always getting over something, it's like wearing a suit of bricks and it's just, what's changed is I can't, I can do the same stuff I can do when I left school, but I feel more tired, I feel more effort for, and that's the bit that I feel has changed. I remember them asking me "what is it that you can't do that you could do before?" and I went "well nothing" but the way I feel about it has changed, the effort that it takes has changed. The support that I need to feel OK is different and some of it is related to CP but some of it is not. (Rachel, 29)*

The data showed that participants had opinions on why there was a lack of appropriate rehabilitation in adulthood offered to them by the NHS. The reasons given by them ranged from there being a lack of resources to support individuals, to participants relating the absence of therapy to the theoretical position of a state investment in disabled children being prioritised over adulthood intervention. Michael considered that a lack of resources in his area determined his inability to access rehabilitation, even though he felt he would have benefited from it, as described below.

> *Because of the lack of resources, or how much resources, lack of resources is what I'm saying. So there, there's not enough, enough physios to do to meet them at, to meet the demand in my area and I don't know if that's ehm across the board all together or if it's just in the [area]. I don't know. (Michael, 28)*

Participants attempted to explain the rationale for a greater number of resources being put in place during childhood than one could expect in adulthood. Olivia contemplated that therapy was more engaged with her when she was a child. Reflecting on the focus on therapy during childhood, Olivia considered that because the child’s body is more malleable, there is more potential to shape it into its best possible condition with the ultimate aim of children becoming independent adults.

> *And I think that's also quite important because like, like physiotherapy and stuff, at least in my experience, are more interested in you when you're like a child and you're malleable but then when you're like an adult and stuff then it's kind of like, well if you need us I suppose you could come talk to us like that kind of attitude, rather than like, let's*

> *invest in your future, then it's just like, yeah let's just make sure that you're like alive like I don't know. (Olivia, 25)*

For many participants, the removal of therapy impacted on their health. As children, they were offered and recommended to undertake therapy, whilst in adulthood this was not available to them, except on request through a GP referral. Many commented on the negative impact this had on their well-being. The regularity of therapeutic interventions in childhood gave Suzy the opportunity to experience movements out of her wheelchair. When therapy was withdrawn, Suzy felt the negative effects on her physicality.

> *Then after 16 you get it all taken away and if you want it you need to be referred by your doctor, then wait on a waiting list. When you finally get it, you only have it for 5-6 weeks, which is not enough. If you are in a wheelchair all day every day you are going to stiffen up and you need exercise, it's the same with speech therapy. (Suzy, 31)*

While the benefits of rehabilitation were not considered to be as strongly felt while undergoing therapy, as discussed above, the absence of it had negative physical repercussions. Participants reported having experienced increasing levels of pain as a result of not doing therapy. This was especially the case for participants with spastic Cerebral Palsy, who noted that their muscles would seize up more frequently when not having had therapy, or been supported to do exercises, for long periods. Upon experiencing these, participants sought out therapy but described the challenges in accessing it.

> *When I was 17/18, I had to refer myself to physiotherapy… I just hassled my doctor, because my spasticity went up, so my spasticity was really bad, so I had physiotherapy when I was about 17/18 for about 6 months. (Peter, 32)*

There was a shift in the power dynamic present in the relationship described by Peter. As a child, the physiotherapist held an authority and made recommendations as to how children should manage their impairment. In adulthood, participants became the authority, having to ask doctors for treatments, which they themselves felt would be beneficial. This led participants to feel that they would benefit from continued rehabilitation throughout adulthood. Catherine explicitly referred to physiotherapy as being a rehabilitative service that, were it available to her on an ongoing basis, would improve her physical, functional and comfort levels.

> *I was in pain as a kid, it hasn't changed and I would say I can tell the difference like if I was to go and have two weeks intensive physio now I would be in heaven for like two weeks after that, cos my whole body would feel a lot looser and I'd be in less pain, but, I've been in pain for as long as I can remember, it's just that the base level of pain that I exist on I've learned to tolerate. (Catherine, 30)*

Participants felt strongly that ongoing therapy would have improved their physical experiences in adulthood. The notion of having access to physiotherapy was felt by participants to be beneficial for their physicality because it would have alleviated their pain. Therefore, there was frustration expressed with the lack of provision provided to adults with Cerebral Palsy. Catherine, for example, spoke of the potential benefits of having rehabilitation in adulthood but doubted that such provision would ever be available to her on the terms that she believed she needed.

> *Because on a very practical level, if I had access to physiotherapy 24/7 I would be in a better physical state than I am, but the state is never going to pay for that kind of intervention for everyone with Cerebral Palsy… Yeah, because it makes life more comfortable, and with not being on painkillers or having to do stupid stuff, if I was to have my own physio 3 or 4 times a week, my life would be physically more comfortable. (Catherine, 30)*

Based on their accounts of ageing and degeneration, along with the medical response to it, participants reflected on therapeutic messages about having Cerebral Palsy that they absorbed in childhood. Participants expressed resentment that that had not been made aware by paediatric therapists that such provision would not continue to be provided as they became adults, nor that there was an inevitability to the degeneration in functionality they experienced as they aged.

Without a specific rehabilitative service to support participants to deal with their condition in adulthood, participants blamed themselves for not doing enough rehabilitation of their own accord. Rachel displayed incredulity at the lack of specialist provision for people with Cerebral Palsy given how it impacts adults, with the result being that she felt that the onus was on her to do more to negate her increased impairment effects.

> *I just feel that there needs to be more support and more... it is one of the more common neurological conditions out there but... but I know I'm not the only one because I've got a friend similar, who's gone through similar sort of fatigue issues and has deteriorated in a similar way and you feel like you're going mad cause you think am I not doing what I should be doing or... (Rachel, 29)*

However, while as children, participants were supported by their parents to complete exercises independently outside of formal therapeutic sessions, they did not feel able to do so meaningfully on their own as adults. Participants' engagement with physiotherapy continued to be dependent on external structures, such as family or medical provision. Taking part in sessions with a therapist, as Michael describes, would have motivated him to be more active in his own therapeutic practice.

> *Physiotherapy yeah, because I find it easier to have somebody to motivate, to give me motivation to do my physio. Whereas it's easy, it's easy when you sit at home to do your physio, to cheat, and the only, the only person you're cheating is yourself. (Michael, 28)*

The data showed that, due to the decline and degeneration of embodied and social functionality discussed in the previous subsection, participants described having an ongoing need for Cerebral Palsy-specific medical and rehabilitative interventions. In childhood, children with Cerebral Palsy are seen by consultant paediatricians who facilitate multidisciplinary teams that collectively treat the child in a more holistic mode. However, as discussed in Chapter 3, adults with Cerebral Palsy access intervention through a GP referral if they have a particular episode of pain or reduction in function associated with their Cerebral Palsy. However, the lack of GP knowledge about Cerebral Palsy was a barrier to participants accessing support. The increasing impact of impairment related effects that participants experienced, which related to their day-to-day experience of having Cerebral Palsy, were often misunderstood, and treated insufficiently. Gemma recounted an experience of trying to secure a solution to her pain from her GP.

> *I went to the doctors a couple of weeks ago and said I was getting really sore back pain and she gave me paracetamol. And I said you do know I've got Cerebral Palsy and she went; "I didn't see that in your notes". (Gemma, 22)*

Participants reflected that their experiences of pain caused by degeneration was subjugated by the fact that they have Cerebral Palsy, and associated, or even unrelated, pain was delegitimised by the medical profession due to their lack of knowledge surrounding the effects of ageing with Cerebral Palsy. When consulting the medical profession about age related impairment effects, Rachel felt they dismissed concerns over the issues she was having. She recounted that the common response to her claims that she had deteriorated were to blame her Cerebral Palsy without any consideration that there might be other possible causes.

> *I feel a bit lost and a bit disillusioned by the NHS because when you get to an adult if you've got a problem you have to go through the GP, as in somebody who doesn't know of anything, and I don't think they take into consideration how Cerebral Palsy can affect you… So, if I said that I felt I've deteriorated or things are getting harder and they would just go, depending on who you spoke to, some doctor would go "that's CP and that's to be expected" and then other doctors say, "that's not CP". (Rachel, 29)*

This means that children with Cerebral Palsy transition from being the central figure in a team focussed on treating their whole person, to a disparate and unfamiliar system of silos (Wright et al., 2015). As a result of medical services being siloed, participants felt interventions focused on one ailment, which in turn had negative consequences for other aspects of other impairment effects. In some instances, such interactions had a detrimental impact on participants. Upon accessing medical services with a Cerebral Palsy related issue, Catherine felt their treatments had iatrogenic consequences.

> *They don't understand that our whole body is, it's a bit weird but they don't understand that our whole bodies are connected so they'll do*

> *intervention in one small part and not realise that because we don't use our bodies as a well-armed chain, if you screw with someone's hand, that might have an effect on their ability to walk because if they use that hand to balance, that would seem really weird to a non-CP person, because they're like ' why would you use your hand to balance? (Catherine, 30)*

While participants sought out therapy or similar provision, most felt that this did not adequately meet their needs as an adult with Cerebral Palsy. The provisions in the current healthcare system were described by participants as not adequately meeting their specific needs. When participants accessed rehabilitation through a GP's referral however, participants were met with a lack of options to deal with pain as a result of their impairment effects (Wright, et al., 2015). Olivia expressed disbelief at this.

> *Basically, she said something along the lines of like, "well you have Cerebral Palsy so your gait is going to be different anyway so there's only so much we can do". Which I thought was kind of a ridiculous thing to say, like well we have to settle for less basically. (Olivia, 25)*

For some participants, as in Peter's case, the effects of rehabilitation itself were felt to have exacerbated the impacts of their condition.

> *I think in mainstream though Cerebral Palsy, although it's the most common physical disability amongst kids, it's not widely practised or taught in, like, even, like, physically… And actually the first time I had*

> *physiotherapy, like when I was, well I was 17/18 when I had that, the first person I said, I seen actually after the treatment I got worse, because the exercises they're doing was making the Cerebral Palsy worse rather than better. (Peter, 32)*

Furthermore, the lack of recognition from medical professionals about the impact of participants' increasing and detrimental impairment related effects on their physical and psycho-emotional well-being was evident in participants' reflections on engaging with health services in adulthood, as Rachel described.

> *if you don't do anything you end up deteriorating and putting on weight. When I had that conversation today, I was at the hospital, I said I'm worried about my weight and the guy said, "how are you worried about it", and I said, "well I can't move as much as somebody obviously with my physical limitations" and he just looked at me as if to say, I don't know what to say. It just would be good to know somebody who knew about the condition and go "I'm stressed. I need a bit of emotional support". (Rachel, 29)*

The data showed that participants would have felt more supported were they to have had specialised interventions specific to the needs of adults with Cerebral Palsy. While Chapter 5 demonstrated that participants felt they had had a lack of agency over their participation in therapy during childhood, as an adult, participants' reflections showed they still required an authoritative figure to advise them on the management of their condition. Gemma highlighted that she would welcome access to Cerebral Palsy-specific advice on how to improve her experience of living with the condition in adulthood.

> *But if I was told by a professional, say a surgeon or something, and they said, "look if you have this physio it's going to make you better" and help me in the future and stuff, I would do it. (Gemma, 22)*

The inability to consult with Cerebral Palsy specialist medical professionals about impairment specific pain affected participants' ability to raise legitimate concerns relating to their social experience. For example, Rachel felt that, while concerns about her sex life were a priority for her, the lack of appropriate provision made her fearful of raising them in the context of non-specialised health care.

> *And again, I'm scared to ask a specialist about that, like you know with my hips and that, I get pain and that sort of thing. But I'm too scared to go "by the way is a sex life a priority to do something about this" and I just don't feel like I've got the right professionals around me to be that open about it. (Rachel, 29)*

Participants felt that there had been a lack of warning from paediatric rehabilitation that they would experience degeneration, pain and fatigue in adulthood. Participants' experiences were exacerbated by the lack of therapeutic and specialised medical support. When participants presented with impairment related issues, they were typically prescribed a short period of rehabilitation for specific, targeted intervention, which did not sufficiently meet their needs, or they were met with treatments that proved ineffective or detrimental, due to a lack of knowledge in adult health services about how Cerebral Palsy affects adults (Wright et al., 2015). Participants therefore felt it would have been beneficial, both physically, socially, and emotionally, to have access to health services who they could consult with about impairment related issues.

7.3 Conclusion

This chapter discussed participants' conceptualisations of becoming and being independent adults with Cerebral Palsy and demonstrated the negative impact of the rehabilitative narrative on their perceptions of the realities of living as an adult with Cerebral Palsy.

After spending childhood undertaking rehabilitation with the belief that their participation would lead to them being an independent adult, characterised by being able to function without support, participants felt unprepared to live as an adult with Cerebral Palsy who required support to be independent. This was exacerbated by the increasing prevalence of impairment effects, such as pain and degeneration, which caused a disruption in participants' biographical narrative and led them to reflect on the readjustment of their sense of being adults with Cerebral Palsy (Bury, 1982; Bray et al., 2014). As a result, participants had to re-evaluate their sense of self as someone who had a lifelong condition with progressively increasing impairment effects, a narrative that was at odds with their previous understanding of Cerebral Palsy as being a non-progressive condition. Considering that this contrasted with what they had envisaged their adulthood would be, participants described that there was a negative psycho-emotional impact on their well-being (Reeve, 2004). The lack of appropriate rehabilitative, medical, and psychological support at this time was felt to further inhibit participants from having a positive sense of self as adults with Cerebral Palsy.

Chapter 8 - Discussion and Conclusion

This study aimed to explore the psycho-emotional impact of rehabilitation on young people with Cerebral Palsy. In taking a biographical approach - asking participants to reflect on the rehabilitative narrative they absorbed in childhood - this study demonstrated that rehabilitation had long term effects on participants' psycho-emotional well-being. After giving an overview of the thesis, recapping each of the previous chapters, this chapter discusses the data findings presented in the preceding three chapters.

Following Reeve's account of psycho-emotional disablism, the findings of this study suggest that rehabilitation contributed to participants' experiences of 'barriers to doing', 'barriers to being' and 'internalised oppression' (Reeve, 2004). It became apparent through data collection that rehabilitation's focus on attaining functional normality and the subsequent reality of living with Cerebral Palsy, led to participants experiencing negative psycho-emotional effects. There were three main contributing factors, which will be discussed in section 8.2.

Summarising these findings, firstly, this thesis found walking was the main aspect of participants' impairments that they believed rehabilitation would improve. Previous studies have argued that children and young people engage in rehabilitation in an effort to reduce the stigma of being different (McLaughlin, 2017). This thesis found, however, that rehabilitation contributed to participants' belief that they could and should walk like their non-disabled peers and that therapy would make them able to do so (Stalker, and Connor, 2003; Bantjes, 2015). Therefore, participants developed an expectation that the daily exercises and surgical procedures they were encouraged to undertake would result in an improved walking ability. For the majority of participants however, their walking ability did not meet their expectation following rehabilitation. This led to participants internalising the belief that they had not achieved the aims expected of them by their parents or therapists. On recognising their need to use a wheelchair to mobilise, though it had been constructed as a failure, most participants came to accept it provided them with more independence in adulthood.

The second finding relates to participants' construction of becoming and the reality of being independent. Rehabilitation's emphasis on functional independence, which prioritised biomechanical ability to undertake daily tasks, led participants to envision themselves to be able to live independently, without support, as adults with Cerebral Palsy. Upon realising that the reality of doing so was more physically demanding and incurred more barriers than they had expected, participants' sense of self was disrupted (Moll and Cott, 2012; Paterson and Watson, 2013).

The final research finding demonstrates that being in rehabilitation itself caused participants to experience internalised oppression. Throughout childhood, the priority that rehabilitation took over other aspects of their experience, without their consent, instilled a belief that there was an expectation on them to improve their functionality. The lack of autonomy that participants reported having had throughout their childhood rehabilitative experience gave them the sense that rehabilitation was a required aspect of their personhood within society. However, while participants had internalised the belief that they should continue to improve, the lack of access to rehabilitation in adulthood challenged their sense of self as adults with Cerebral Palsy.

The penultimate section of this chapter addresses the research objectives of this thesis before discussing the methodological reflections. This study found that the process of using a biographical approach to research the sociological perspectives of children and young people's experiences of rehabilitation had both strengths and weaknesses. The section finally provides recommendations for future research in this field. Building on previous calls for further exploration of the impact of pain and degeneration in the lives of people with Cerebral Palsy, this study proposes that research into this phenomenon takes a lifelong approach, appreciating its impact on the experience of children and young people and their construction of living with the increasing impairment effects of the condition.

Based on this research, section 8.4 outlines the policy recommendation that, throughout the lives of children, young people and adults with Cerebral Palsy, the rehabilitative process should take a more psycho-emotional approach. Such an approach should be grounded in the evidential basis for providing therapy, empowering parents and children to make informed decisions about the aims and potential impact of rehabilitation. There should be continuous access to appropriate rehabilitative services to support young people and adults with Cerebral Palsy as they begin to contend with the impact of increasing impairment effects in order to succeed in living independently.

8.1 Overview of Thesis

This thesis focussed on the psycho-emotional impact of childhood rehabilitation based on the reflections of participants with Cerebral Palsy who had been through the process. Providing the context of this phenomena, the literature chapters, two and three, introduced the theoretical framework of Cerebral Palsy and subsequent rehabilitation of children with the condition, which provided a basis for analysing the experiences of participants in this study. Chapter 2 discussed the medical and social constructions of disability before exploring the development of the understanding of Cerebral Palsy, which has been dominated by the medical approach to diagnosis and treatment of the condition. The chapter went on to consider the key findings from previous qualitative studies exploring the experiences of young people and adults with Cerebral Palsy, which have highlighted the impairment effects, environmental and social barriers, and psycho-emotional impact of living with the condition. Though limited, the chapter concluded by reviewing the main literature on the impact of ageing with Cerebral Palsy, which has found that early ageing, pain, and degeneration are significant, unanticipated features of adulthood.

Chapter 3 discussed the main research on the rehabilitative approaches that children with Cerebral Palsy undergo throughout childhood after receiving the diagnosis, which has been found to be based on neuro-developmental and functional-based therapy that promote normative movement in developing children with the symptoms of Cerebral Palsy. This was followed by the social constructionist critique of rehabilitation and its impact on people with impairments. The chapter demonstrated that, from the small number of qualitative studies into children and young people with Cerebral Palsy's experience of having rehabilitation, it has been found to be viewed as having limited physical and biomechanical benefits at the time of receiving therapy. Meanwhile, the main sociological inquiry into young people with Cerebral Palsy's perspectives of having rehabilitation, the SPARCLE project, has highlighted that stigma was both a motivation for doing therapy, in the hope that it would reduce the social response to their difference in society, and a stigmatising experience in itself as it distinguished them from their peers.

The fourth chapter outlined the overarching methodological framework of this study and the methods used to collect and analyse the data captured from the interviews with participants. Using the principles of emancipatory research, this thesis gave a voice to young people with Cerebral Palsy who have historically been underrepresented in research about their experiences of growing up with the condition, which Chapter 4 highlighted. At the same time, discussing the biographical approach, which was taken to evaluate the long-term impacts of having gone through rehabilitation in childhood, the chapter noted its benefits in terms of giving space for individual narratives to be considered and the risks of such narratives being misrepresented, based on altered perspectives, and open to interpretation (Shah and Priestley, 2011). Penultimately, the chapter outlined the theoretical framework for collecting and analysing the data findings, employing Constructivist Grounded Theory based on Charmaz's inductive approach to developing the key themes of the data (1995). The chapter concluded with a discussion on the ethical considerations of the research, highlighting the potential risks that were involved, such as including parents during interviews, using Personal Assistants during the data collection and analysis phases, and having prior relationships with participants, which could have impacted the research process.

The data chapters interrogated three dominant themes from participants' reflections on growing up with Cerebral Palsy and having gone through rehabilitation: the social implications of this phenomenon, the importance of walking in their personal narrative, and the expectation of becoming an independent adult. Chapter 5 discussed participants' reflections on their social experience being influential in their construction of being a child with Cerebral Palsy; the environmental barriers that challenged their inclusion in school activities, and social attitudes of peers and professionals that led to participants feeling stigmatised for having an impairment. Rehabilitation was integral to participants' constructs of growing up with Cerebral Palsy, as it included attending therapy sessions, most commonly at a medical facility, doing therapy at home, and at school. Within the therapeutic environment, participants' narratives exemplified that the need and intention of rehabilitation was not clearly communicated but the necessity for having it was expressed by therapists and felt by participants. Participants reflected that having rehabilitation during school-time contributed to their sense of exclusion from mainstream activities, particularly if the therapy was done in isolation, having been taken out of class. This gave participants the sense that they needed to maintain their functionality to participate equally in school life. The withdrawal of rehabilitation, which participants tied to their transition out of school, was felt to have been unexplained. Upon attempting to access rehabilitation in adulthood, which was offered as blocks of sessions in an attempt to resolve a particular symptom, participants reported being unable to carry out the exercises prescribed as they were too time-consuming amongst their everyday working lives. Some other participants reported a decline in their mental health because of the lack of provision available to them.

Chapter 6 explored the main impairment effect participants felt differentiated them from their peers - their walking ability - and their perspective of the aim of rehabilitation being to improve it. Participants assessed their walking style in comparison to their non-impaired peers as a progressively differentiating aspect of having Cerebral Palsy. Participants increasingly viewed their walking ability as a barrier to their social experience, such as being excluded from activities with their peers and becoming fatigued more easily as they became older. At the same time, participants believed that the biomechanical purpose of the therapeutic process focussed on the potential it had to improve their walking ability, according to a socially constructed ‘normal’ way of walking. Participants were led to believe that they could and should attain an improved walking ability through their participation in rehabilitation. Parents reinforced participants’ sense that they should complete therapy at home with the intention of improving their walking ability. However, their walking ability did not develop to the point that participants expected through the therapy they had done, and surgical interventions had decreased it further. When it became apparent that they had not achieved the level of walking ability they felt necessary to be independent in adulthood, participants confronted the necessity to use mobility aids and wheelchairs. While participants acknowledged such equipment offered them independence and prioritised such methods of getting around over continuing to exert energy walking, most continued to pursue improvements in their walking ability through a variety of universal and rehabilitative services.

The final data chapter, Chapter 7, explored the data on participants' construction of becoming and being an independent adult with Cerebral Palsy. Throughout childhood, participants reflected that the narrative had been instilled, predominantly by parents, that their Cerebral Palsy was not and should not be a barrier to them being able to achieve independence. At the same time, participants believed the rehabilitation they were having in childhood would enable them to become independent adults. From this, participants had expectations that being an adult with Cerebral Palsy would mean that they would not need to rely on mobility equipment, nor would they require support (formal or informal) to be independent. Participants therefore felt they were unprepared to deal with the reality of being independent when it transpired that they had to rely more heavily on equipment to get around and staff or family members to assist them with daily tasks. This was further highlighted by the final theme that emerged through this chapter, which was the impact of the ageing and degeneration that occurred as participants entered their early adulthoods. Participants reported they had experienced emerging pain in their muscles and joints, a reduction in their mobility and had increasingly low energy to meet the demands of ordinary daily life. Chapter 7 concluded by demonstrating that participants experienced the process of reconstructing their sense of self due to the deterioration in their functional ability. This was exacerbated by the lack of rehabilitation and the poor understanding amongst general health services they experienced in adulthood. The remainder of this chapter discusses the outcomes of the research process.

8.2 Research Findings

The unique angle of this study is in demonstrating the psycho-emotional effect rehabilitation had on children and young people growing up with Cerebral Palsy. In taking a biographical approach, this study suggests that the rehabilitative focus of promoting normative function and the lack of agency participants had in its process contributed to and exacerbated their experience of psycho-emotional disablism as they developed their sense of selves as adults with Cerebral Palsy.

This thesis considers young people's experiences of rehabilitation from a sociological perspective. Shakespeare et al. note that research into the lived experience of rehabilitation has been predominantly undertaken by rehabilitative theorists (Shakespeare et al., 2018). From the literature reviewed, it was evident that the majority of research into children and young people with Cerebral Palsy's experience of rehabilitation came from a rehabilitative domain. While qualitative enquiry into children and young people with Cerebral Palsy's experiences of rehabilitation has demonstrated that they hold views on the therapies they participate in and the impact it has on their biomechanical function, there has been a lack of acknowledgement that rehabilitation as a medical intervention sits within the sociological context in which children and young people access therapy (Moll and Cott, 2013).

This thesis builds on the SPARCLE project, which bridged the gap between social and psycho-emotional analysis of children and young people with Cerebral Palsy's experience of rehabilitation. The SPARCLE project's main finding was that stigma influenced children and young people's approach to, and experience of, having rehabilitation as a means of increasing their independence but also as a way of 'reshaping' their bodies to be more 'normal' (McLaughlin, 2017, p.247). This thesis revealed, however, that rather than mitigating the impact of the stigma children felt within their social context, rehabilitation itself could contribute to participants' experience of psycho-emotional disablism.

As discussed in Chapter 2, Thomas has highlighted that psycho-emotional disablism is characterised by 'barriers to doing' - structural barriers that reinforce disabled people's sense of being excluded from society, 'barriers to being' - social interactions, such as being subject to gaze or hurtful comments, that undermine disabled people's sense of personhood - and 'internalised oppression', which results from negative societal beliefs about disabled people that they internalise (Thomas, 1999; 2007). In exploring children and young people with Cerebral Palsy's rehabilitative experience through this lens, this thesis demonstrates Reeve's contention that disabled people experience psycho-emotional disablism as a result of their interactions with the medical domain. She contends that:

> *The treatment of disabled people at the hands of the medical profession can also have adverse effects on their emotional well-being, leaving them feeling ashamed, vulnerable and objectified (Reeve, 2004)*

This study posits that rehabilitation contributed to participants' experiences of psycho-emotional disablism. Set within the medical construct of disability, rehabilitation's aim is to mitigate against individual experiences of 'barriers to doing' and 'barriers to being' by reducing the effects of their impairment and the social stigma associated with them. The following findings demonstrate, however, that the rehabilitative narrative, which participants reflected on as having promoted the pursuit of 'normalcy' and 'independence', created, and exacerbated, their experience of both 'barriers to doing' and 'barriers to being' by leading them to believe that they would be able to walk better and become an independent adult through therapy. At the same time, being situated within this context from their early years, findings show, the rehabilitative process itself led participants to experience the 'internalised oppression' that their sense of self was conditional on the progress they made to their functional ability.

From the point at which a child receives a diagnosis of Cerebral Palsy, evidence shows the medical model of treating the physical impact of their impairment through rehabilitation is the predominant approach to their early development (Novak et al., 2017; Rosenbaum, 2003). It is based on a model of the 'normal child', which measures children against statistical norms (Gibson et al., 2011). This thesis revealed that participants' ability to walk was the most identifiable aspect of Cerebral Palsy, which impacted their embodied and social experiences of growing up with the condition. Bantjes et al, found that young people with Cerebral Palsy described their impairments in relation to the medicalised 'normative' construct of how bodies are formed and operate (Bantjes et al., 2015). The experience of participants in this thesis would suggest that the messages conveyed to them by therapists, parents, and wider society gave them a fixed notion of normative walking and an expectation that this was attainable to them through rehabilitation (Bezmez, Shakespeare and Lee, 2021). The effects of attempting to meet this expectation and the result of it being unobtainable, however, had a lasting impact on participants' sense of self. This follows Middleton's argument that the impact of constant medical intervention designed to change aspects of their body could leave children disliking them and create a sense of failure if they do not improve (1997). The consequences of the rehabilitative narrative on participants' perception of their walking ability will be discussed in section 8.2.1.

Section 8.2.2 illustrates that rehabilitation contributed to participants' concept of independence and what that term actually means. From a rehabilitative perspective, independence is seen as the ability to successfully carry out a range of tasks. This contrasts greatly with the definition of independence provided by the Independent Living Movement, where the focus is on choice, control, autonomy, and equity (Brisenden, 1986). The rehabilitative approach to treating children with Cerebral Palsy, as discussed in Chapter 3, is focussed on enabling children to attain the functionality required to interact with their world (Rosenbaum, 2003). McLaughlin and Coleman-Fountain contend that within an environment that 'valorises self-reliance', young people with Cerebral Palsy are subject to a disproportionate degree of attention, surveillance, and interventions with the aim of becoming independent, only achievable through extensive rehabilitative practices (McLaughlin and Coleman-Fountain, 2014). This thesis contends that the rehabilitative narrative that participants' function would improve through their participation in therapy led them to believe that if they could learn to walk, hold a cup, dress themselves or complete other activities, they would become independent. This follows Bantjes et al.'s finding that young people with Cerebral Palsy construct their identity within the context of disabled people being subject to both medical scrutiny and a societal expectation to be self-sufficient (Bantjes et al., 2015). This thesis found that this can have a lasting impact on people with Cerebral Palsy's psycho-emotional development if this is not attained and influence their psycho-emotional response to the realities of living with Cerebral Palsy in adulthood.

The key factor in this process was the lack of autonomy participants had as children over the rehabilitative process; its aims and its activities. Section 8.2.3 suggests that this led to participants internalising the narrative that they had to do rehabilitation to improve their functionality, which persisted while access to rehabilitation withdrew in adulthood. During the rehabilitative process, the bodies and minds of children with Cerebral Palsy are 'under the gaze of health professionals' and 'judged against normative standards of physical functioning and appearance' (Moll and Cott, 2012, p.1279). McLaughlin and Coleman-fountain argue that it would be naive to consider young people with Cerebral Palsy as not having agency in the therapeutic process, suggesting that their own desires and constructions of normality - one which encompasses embodied difference - validate their decision to participate in rehabilitation (2014). This follows Alderson's line of argument that children with achondroplasia opt to have limb lengthening surgery due to their own construction of normative height, without recognising the cultural context in which being taller is desirable (Alderson, 1993). This thesis, however, argues that participants had little agency throughout the rehabilitative process - being instructed to participate in therapeutic sessions, being taken out of school to do therapy, and being encouraged to do exercises at home - and their compliance was predicated on their belief that the therapy would result in their increased functional ability. This led to participants internalising the narrative that their sense of self was inextricably linked to undertaking therapy. These contrasting findings emerged through giving participants the opportunity to reflect on rehabilitation having transitioned out of paediatric services.

While rooted in their experience of childhood rehabilitation, the psycho-emotional impact was found to have progressively impacted participants as they developed their sense of being a person with Cerebral Palsy. This reflects Reeve's argument that the lasting effects of childhood experiences of psycho-emotional disablism can lead to internalised oppression.

> *The effects of dealing with the reactions of others to impairment, being stared at and internalised oppression can leave disabled children feeling worthless, ashamed and stressed. These feelings can then spill over into adulthood, affecting life choices and sense of well-being. (Reeve, 2003)*

Upon leaving childhood therapy, participants were no longer considered to require ongoing regular intervention nor had their condition without therapy yet been established. Participants reflected that the lack of access to rehabilitation at this stage in their lives felt counterproductive to the effort they had put into improving their physical function during childhood. At the same time, participants felt that they had been left to deal with the condition they found themselves in without access to rehabilitation and experiencing increasing impairment effects and barriers to independence shortly after leaving paediatric services. This follows McLaughlin and Coleman-Fountain contention that young people are 'under a contemporary requirement to 'self-realise' their transition to adult citizenship' (McLaughlin and Coleman-Fountain, 2014).

There is a growing research field on the social experience of adults with Cerebral Palsy that demonstrates the impact of early ageing and degeneration (Moll and Cott, 2012; Paterson and Watson, 2013). Such studies have found that the cumulative impact of the embodied and social realities of being an adult with Cerebral Palsy were often unexpected and led participants to feel that they had failed to attain the version of adulthood they had envisioned, which in turn has been found to provoke biographical disruptions (Moll and Cott, 2013; Paterson and Watson, 2013; Bray, Kirk and Callery, 2014). This thesis reveals that the rehabilitative narrative also contributes to such disruptions. Participants describe feeling a sense of failure and guilt over not having achieved the normalcy they had been encouraged to strive for and expected to achieve. Participants struggled to adapt to the realities of living with Cerebral Palsy, such as living independently by accepting support, coping with impediments to socialising equally alongside their peers, and performing at work while managing their impairment effects. Studies have argued that young disabled people's ability to become independent is in part down to an individual's self-efficacy - a belief in one's ability to succeed (Palisano et al., 2007). This thesis demonstrates that participants continued to consider that they should undertake rehabilitation in order to improve their ability to participate in adult life. However, access to rehabilitation was limited and was incompatible with their lifestyles with participants having to choose between therapy and studying, working, or socialising. Even when they could access it, participants found it to be insufficient, inappropriate, and potentially detrimental to their physical well-being.

8.2.1 Psycho-emotional response to rehabilitation's impact on walking

This section discusses the impact of the rehabilitative narrative on participants' perspectives of becoming and being a walker. Children with Cerebral Palsy can experience multiple impairment related effects, impacting their speech, ability to eat, dress, and be mobile (NICE, 2017). Participants in this study, however, primarily focused on their walking ability, which involved: experiencing the impairment effects of walking with Cerebral Palsy, such as becoming fatigued and incurring pain; the environmental barriers that highlighted their impairment to walk; and the self and social stigma attached to walking differently to their peers. Reeve, in discussing the dimensions of psycho-emotional disablism, made the distinction between 'direct' - the psycho-emotional disablism people experience through their relationship with themselves or others - and 'indirect' - the inference from structural barriers that they are of less value than others (Reeve, 2012). The contention of this thesis is that the rehabilitative narrative that participants could and should attempt to improve their walking ability through therapy created and contributed to participants' experiences of both forms of psycho-emotional disablism.

The first subsection demonstrates that the narrative they received from childhood rehabilitation, that their engagement in therapy and surgical procedures would lead to improved walking ability, which was reinforced by their parents' encouragement of its attainment, impacted participants' psycho-emotional development. As the second subsection illustrates, participants' accounts of the effect of rehabilitation on their walking ability showed there were inconsistencies between the narrative they had received and the therapeutic progress they made, which caused them to re-evaluate their sense of self when their expected walking ability was no longer attainable or possible.

Aiming to walk

Participants' walking ability was the most referenced aspect of their experience of growing up with Cerebral Palsy. Previous studies have identified that young people experience physical effects, such as pain and fatigue, environmental barriers, such as feeling safe when walking outside (especially when it is wet), and the additional time required to participate in social activities (Stewart et al, 2011; Brunton and Bartlett, 2013; Lindsay, 2016). Participants in this study, however, predominantly focussed on their social experience of walking. Socially, they developed the perspective early in childhood that walking was the main differentiating ability between them and their peers.

Walking holds important social implications within society (Oliver 1993, 2009). Mulderij, commenting on Strauss' 1966 article on the upright posture, noted that standing, or being able to stand on one's own two feet connotes many positive physical and figurative meanings within society (Mulderij, 2000). Gibson highlights that walking "symbolize[s] a whole set of moral virtues – rectitude, dignity, autonomy, not to stoop to anything and to stand by one's convictions" (Gibson, 2012). Through observing the progress that other children were making in their walking styles and the opportunities this gave them, participants in this thesis constructed a comparative sense of their own walking ability. Gibson et al note that children internalise the sense that walking is 'part of a preferred non-disabled body and identity', which has an effect on their ability to develop a positive sense of self from an early age (Gibson et al, 2011, p.67). This was demonstrated by participants in this study, who reflected on becoming increasingly aware of their difference and the negative psycho-emotional impact it had on them. Lindsay argued that children with Cerebral Palsy commonly experience bullying and unwanted comments due to their walking style (Lindsay, 2016). Participants in this study, however, were less impacted by the comments and stares from others. Rather, participants reflected that their own reactions to their walking style, such as seeing their reflection when walking or contemplating why they could not walk like their peers, was the main cause of feeling different. Reeve highlighted that the notion of the 'dys-appearing' body - the body is not socially acceptable - can come to the fore on occasions when its difference is made apparent (Reeve, 2012). For participants in this study, their walking style was an ever-present reminder of their difference.

The contention of this thesis is that rehabilitation was a major contributor to the participants' narrative that walking was optimal, starting as it did in infancy, before they were conscious of social stigma. Bezmez’s study of the rehabilitative approach to walking highlights that there has been relatively little exploration into the link between these two phenomena (Bezmez, 2016). Referring to the persistent dichotomy between normal/abnormal bodies, Bezmez highlights that although rehabilitative practices have shifted focus towards the promotion of daily-life based therapies (such as those discussed in Chapter 3), rehabilitation maintains an emphasis on functional improvement (Bezmez, 2016). This thesis found that, regardless of ability, the majority of participants believed that through rehabilitation they would become better, independent walkers. Walking became the be all and end all of their rehabilitation endeavour and the mark of successful rehabilitation was to become a walker, or as Finkelstein (in Oliver 1996) puts it, ‘a nearly walker’. In addressing their embodied restrictions on their ability to participate in society and the self-stigma they attached to their walking style, rehabilitation’s emphasis on walking influenced the participants in this thesis’ psycho-emotional response to its attainment, as posited by Oliver:

> *In terms set by the rehabilitation enterprise, walking is rule-following behaviour; not-walking is rule-ignoring, rule-flouting or even rule-threatening behaviour. Not walking can be tolerated when individuals are prepared to undergo rehabilitation in order to nearly walk or to come to terms with their non-walking. Not-walking or rejecting nearly-walking as a personal choice is something different however; it*

> *threatens the power of professionals, it exposes the ideology of normality and it challenges the whole rehabilitation enterprise. (Oliver, 1993, p.16)*

Studies have frequently shown that “rehabilitation plays a pivotal role in perpetuating or changing attitudes towards walking and disability” (Gibson et al., 2011, p.67). However, Gibson et al., in their examination of the value of walking amongst children with Cerebral Palsy, have highlighted that there has been relatively little sociological inquiry into the reason behind rehabilitation’s emphasis on it (Gibson et al., 2011). In taking a biographical approach, this thesis reveals that rehabilitation’s emphasis on improving participants’ walking ability exacerbated their negative perspective of walking with Cerebral Palsy. Participants universally reflected a firm understanding that the aim of rehabilitation was to make them ‘walkers’. Participants reflected that rehabilitation instilled the epistemological belief that it would minimise the impairment effects on their walking style to the point where they could emulate that of their non-impaired peers. McLaughlin and Coleman-Fountain argue that the power to influence young people’s engagement in rehabilitation is not just held by those in positions of authority, such as medical practitioners, but embedded in the ‘everyday practices of comparison, belonging, and developing the body people themselves undertake’ (McLaughlin and Coleman-Fountain, 2014). Whilst recognising such comparisons influence the approach of young people with Cerebral Palsy towards rehabilitation, this thesis contends that participants’ engagement in rehabilitation was based on having internalised the narrative from a very young age that the potential to achieve such parity of functionality was not only desirable but physically possible.

As children with little agency in the process, discussed further below, participants were not choosing whether or not to attempt to become walkers, in the same way that children do not choose to become adults. Participants in the SPARCLE project considered physiotherapy to be a positive process of self-improvement, with the aim of working on their bodies being connected to the goal of 'walking' (McLaughlin, 2017, p.248). Being able to reflect on their experiences of doing physiotherapy as children and young people, participants in this thesis, however, portrayed a much less positive experience. They described having felt that they were never doing enough to attain the status of 'being a walker'.

Participants considered the attainment of increased walking ability to be the main achievement that their parents desired from them in their engagement in rehabilitation. It has been found that parents often take on the role of "co-therapists" in delivering therapy at home, at times to the detriment of other aspects of childcare, such as play (Fernańdez-Alcåntara et al., 2016). The role of parents in reinforcing the message that participants could improve through their engagement in rehabilitation contributed significantly to participants' sense of self as a walker. Parents in Fernańdez-Alcåntara et al.'s study were found to focus mainly on their child's potential ability to walk and their cognitive ability. The parents' belief in providing therapy was that it would lead to their child overcoming the disability (Fernańdez-Alcåntara et al., 2016). As young people with Cerebral Palsy, participants in this current study had an ability to recollect learning to walk in childhood as it happened much later in their childhood than their typically developing peers, and thus experienced their parents' positive and negative reactions to their development. Gibson and Teachman argue that such an emphasis on walking is due to "[t]he visibility of bodily differences and alternate modes of mobility not only affects the way others perceive and act toward children with CP, it also shapes the habitus so that children and their parents come to internalize these differences" (Gibson and Teachman, 2012, 478). Moreover, the message that participants in this study took from their parents' emphasis on walking was broader; that they would be more able to partake in family activities if they became more functionally able by completing their exercises and not to do so would be impacting negatively on the whole family's social experiences. Reeve argues that children can be at risk of internalised oppression due to their parents' belief in the expectations of their child's functional progression prescribed by professionals (Reeve, 2004). This thesis supports Reeve's contention by highlighting the impact of the participants' parents' enthusiasm towards them when they made any improvements in their walking and their feelings of failure when they failed to do so.

The process of rehabilitation for the participants in this thesis also included surgical interventions, such as a tendon extension, which were offered on the basis they would improve their movement patterns and functionality. Bray et al. found that children with Cerebral Palsy's perspective of surgery was not impacted upon by their conceptualisation of the impairment they had since birth.

> *Having an impairment or illness since birth is not the primary influence on the experiences of surgery of children and young people, and*

> *their 'time spent with their condition' did not make it easier or harder for them to confront their life or complications after surgery. (Bray, Kirk and Callery, 2014, p.835)*

Through their research, Bray et al. specifically highlighted surgical interventions as having the potential to result in either biographical disruptions if it led to young people's decreased perception of their abilities or, as they coin it, 'biographical enrichment' if the surgery undertaken has a positive effect on the young person's perspective of their own ability (Bray et al., 2014, p.835). While Bray et al found that most participants in their study experienced biographical enrichment following surgery, this thesis found that most participants in this study reflected on having experienced biographical disruption due to surgery not having achieved the anticipated outcomes, which damaged their sense of self. This thesis revealed that rather than just failing to improve physical differences, surgical interventions that had had the intention of enabling participants to walk better were believed to have had the opposite effect with participants finding it more difficult to walk or it having resulted in a negative impact on their posture. This led to a lowering of participants' self-esteem, confidence, and positivity about their future abilities (Bantjes et al., 2015; Shimmell et al., 2013; Hammar et al., 2009).

When 'walking' was unattainable

Studies into the long-term probability of children with Cerebral Palsy being able to walk have demonstrated that they lose this ability over time (Bottos, 2003). The participants in this thesis followed the trend that almost half of adults with Cerebral Palsy experience a decline in their walking ability (Rosenbaum and Rosenbloom, 2012). It demonstrated that the rehabilitative narrative had not prepared participants for the reality that their walking ability would decline in adulthood.

As Bottos highlights, and as was demonstrated in the literature review, multiple studies have shown that “[t]he achievement of independent walking does not mean it will be maintained through adolescence and adulthood” (Bottos, 2003, p.788). Commenting on the potential psychological consequences of this phenomenon, Bottos posited that “[t]he risk of there being a disappointing shortfall between motor achievements and expectations is very high” and the ‘unfeasible expectations’ to walk put on children with Cerebral Palsy could lead to feelings of failure, both of themselves and parents or therapists (Bottos, 2003, p.789). This thesis confirmed this phenomenon, with participants feeling on reflection that while the pursuit of walking, whatever the cost, in terms of energy or frustration, had been worthwhile, the benefits of having done so were far less than they had expected them to be. This led to participants experiencing varying degrees of disappointment at not having achieved the level of walking ability they had expected, predominantly due to the responses it elicited from their parents. Where Gjesdal et al. found that young people with Cerebral Palsy did not expect such a decline in their walking ability, this thesis argues that participants’ lack of expectation that this would happen was primarily due to the rehabilitative and parental narrative that walking could be achieved (Gjesdal et al., 2020). However, participants’ reflections were influenced by memories of biomechanical changes, such as growth spurts or spasmodic episodes, which resulted in their diminished walking ability. Thus, participants were more inclined to express discontentment at the lack of warning that their walking ability could decline than not having met the expectations.

The participants in this thesis, reflecting on their rehabilitation in childhood, described the use of wheelchairs as being secondary to walking. While Gibson et al. note that for children and young people with Cerebral Palsy, walking is not a ‘dichotomous outcome’, highlighting that they may walk in some circumstances and use a mobility aid or wheelchair in others, participants in this thesis did not consider their multifaceted mobility to be a part of their childhood. Stewart et al. described the choices that children with Cerebral Palsy have to make when deciding how to participate in social life and managing the consequences of doing so. The authors use the term ‘trade offs’ to discuss the factors adolescents with Cerebral Palsy have to consider in their day to day lives. Participants in their study would choose to use mobility equipment, as it provided an easier route to social participation whilst conserving energy (Stewart et al., 2011, p.176), therefore ‘trading off’ achieving the goal of walking independently, which they believed therapists viewed as preferable to using such aids (Stewart et al., 2011). This study revealed that making such trade-offs challenged participants’ sense of self - that being as someone striving to walk independently. As Sandstrom highlighted, participants reflected on the dilemma young people with Cerebral Palsy who can walk face, between using a wheelchair for efficiency and the preservation of their status as walkers (Sandstrom, 2007). Participants in this study increasingly realised that the benefits of using a wheelchair outweighed the negative impacts of doing so that they had internalised during childhood. They accepted it was necessary to let go of their childhood understanding of themselves as walkers in order to benefit from mobility equipment that could mitigate the increased effects of Cerebral Palsy on their adult bodies.

This section has demonstrated that the rehabilitative focus on walking as an outcome for children with Cerebral Palsy contributed to participants having a negative psycho-emotional experience. Where previous studies have found that children and young people believe that therapy will improve their ability to walk in an effort to reduce the stigma walking differently in society creates, this study shows that the rehabilitative narrative that therapy will lead to improved walking ability exacerbated participants' approach to its attainment (McLaughlin, 2017). By asking participants to reflect on this narrative having experienced a reduction in their walking ability, which often occurred in their mid to late teens due to physical changes or as a result of surgical intervention, this study has demonstrated the long-term psycho-emotional impact on their approach to the attainment of walking throughout childhood and their response to its decline in their early adulthoods. This was predominantly due to continued parental, and societal, pressure to maintain a level of walking ability over using a wheelchair. Yet, while using a wheelchair had been and continued to be stigmatised, which involved contending with parental or societal commentary on no longer walking, participants compromised on the basis of the increased independence it offered. However, the majority of participants had a belief that they should and could maintain or improve a level of walking ability through the pursuit of rehabilitative means, either prescribed or private therapy or universal gym facilities, having internalised the narrative that this would lead to an improved ability to do so.

8.2.2 Psycho-emotional response to rehabilitation's impact on independence

This section discusses participants' reflections on becoming and being an independent adult with Cerebral Palsy. At its core, Thomas and Reeve note, psycho-emotional disablism affects disabled people's sense of what they want to be (Thomas, 1999; Reeve, 2012). This thesis found that the rehabilitative process contributed to and encouraged participants' sense that they should and could be independent adults through the attainment of functional improvement. Firstly, the section suggests that the rehabilitation they had received during childhood led participants to believe it would have enabled them to become functionally independent adults. When it transpired that being independent as an adult with Cerebral Palsy meant requiring formal or informal support, or struggling without it, and having to use more assisted mobility equipment (such as power wheelchairs instead of manual wheelchairs or walking aids), participants felt unprepared for this reality.

Secondly, this section discusses participants' experience of ageing with Cerebral Palsy without access to ongoing regular rehabilitation. Transitioning out of paediatric health services was a key juncture in their lives. Participants were left without access to rehabilitation while contending with additional barriers to their physical and social experiences as adults with Cerebral Palsy. The lack of warning from rehabilitation that such issues would arise left participants feeling unsupported to meet the demands of being an adult with Cerebral Palsy within a society with environment and social barriers. The reality of living with Cerebral Palsy in adulthood caused participants to re-evaluate their ability and position within society.

Constructing independence

Throughout childhood, participants believed rehabilitation would enable them to become independent, without the need for support or additional aids. Participants' concept of independence was predominantly shaped by their engagement in rehabilitation, and by their parents.

Achieving independence was a key discourse that ran throughout the childhood rehabilitative process. Gibson and Teachman state that "Independence and "participation" are taken-for-granted goals that are reflected in the conceptual underpinnings of rehabilitation" (Gibson and Teachman, 2012, p476). However, the notion of independence is contested. Disability studies has long framed the discussion as being dualistic, between professional practices - typically medical and social care - and proponents of the social model of disability. The former advocates independence being achieved through developing the functional ability to complete everyday tasks such as, dressing, maintaining the household, working, and socialising without the support of another person (Rosenbaum, 2003; Rosebaum and Gorter, 2011). Meanwhile, advocates of a more social model of independence have, since the inception of the Independent Living Movement, sought to define it in terms of the 'personal and economic decisions' disabled people make, which gives them control and autonomy over their lives (Zola, 1983). The result of which has been the growth in the personalisation agenda through the use of direct payments and individualised social care (McLaughlin, 2019). Oliver described the divergence between therapy and disabled people's strategies to independent living.

> *Professional practice aims to give disabled people the skills to do these things unaided, while disabled people are increasingly setting up their own personal assistance schemes to employ others to do these things on our behalf and under our control (Barnes, as cited by Oliver, 1993, p.3)*

The construct of being independent that rehabilitation created was dependent on participants attaining maximum physical capacity and ability. McLaughlin found the societal/mainstream emphasis on self-sufficiency, and particularly an inability to be self-sufficient, impacted young disabled people's interpretation of stigma encouraging them to pursue normative function through rehabilitation (McLaughlin, 2017). While McLaughlin argues that young people's hopes of becoming self-reliant, independent of family, were based on stigma, participants in this thesis reflected on rehabilitation less in terms of inducing stigma about their potential ability to be independent, rather it created expectations of their future selves that they believed at the time to be attainable. Similarly, whereas Mclaughlin reported that participants pursued independence in the knowledge of the barriers they would face as a result of both impairment effects and poor social and welfare support, participants in this study reflected a lack of knowledge or appreciation about the material impact of their impairment and how this would affect their ability to live independently.

A contributing factor to this was parental approaches towards participants, who Gibson argues “are restricted by pervasive concepts of normality, at the same time as wanting to construct alternative realities for their child” (Gibson, 2012). This was reflected in this study, as, based on participants’ reflections, parents were influential in mitigating the impact of both the embodied and social experiences of growing up with Cerebral Palsy, from providing personal care to challenging discrimination on their behalf (Green, 2003). However, at the same time, parents, on the advice of paediatricians, facilitated participants’ engagement in a rehabilitative process, which encouraged their ‘normative’ conceptualisation of living independently as an adult with Cerebral Palsy.

Stalker and Connors highlight that ‘barriers to doing’ can impact increasingly upon disabled children as they attempt to become more independent and the presence of parental support to overcome barriers decreases. This leads to disabled children feeling a level of inevitability that there will be ‘barriers to doing’ in adulthood (Stalker and Connors, 2003). While participants in this thesis, particularly those who had not yet left their family home, posited that they may experience barriers in the workplace or finding appropriate accommodation, most conveyed a sense that the degree of difficulty they experienced living independently was far greater than they had experienced in childhood and far greater than they had expected. In reality, barriers to doing increased as they aged.

On being able to reflect back on the narrative as young people attempting to be independent adults with Cerebral Palsy, participants were able to acknowledge the ‘barriers to being’ that this was creating at the time. In being given an unrealistic idea of independence that transpired to be far different from its reality, participants attributed feelings of resentment and betrayal towards their childhood rehabilitation, which continued to impact their sense of self as adults who had not attained its vision. This had consequences on their adult lives, as Reeve posited could occur (Reeve, 2003; 2006).

Managing the reality of independence

Participants’ sense of self of becoming independent adults was disrupted on their transition to adulthood due to the increased effects of their impairment, which restricted their ability to attain the level of independence they had expected to achieve. Social theory on the impact of transitioning between child and adult health services on disabled children has identified a multitude of barriers to a successful experience (Beresford, 2004; Wright et al., 2015). Such studies have highlighted the structural barriers that disabled young people can experience on transitioning to adulthood, such as a lack of support to manage the practical implications of transitioning, including finding suitable accommodation, employment and social care, and poor health services to deal with the biomechanical changes that begin to occur. Participants in this study also experienced a range of psycho-emotional impacts of transitioning out of paediatric rehabilitation, such as stress, anxiety, and apprehension regarding the continuing barriers to being independent, and distress at their declining functionality on leaving paediatric rehabilitation.

As they became increasingly independent and having to contend with the typical life experiences involved in transitioning to adulthood, participants attributed pain and degeneration in functionality to having to exert more physical effort in order to participate in daily life. During childhood, while participants reflected that pain was a consistent feature of their embodied selves, they generally assumed it to be a natural part of living with Cerebral Palsy, which would decrease through rehabilitation. While the psycho-emotional impact of pain and fatigue were less evident in participants' reflections of childhood, as these impairment effects began to impact their relationships and exclude them from socialising later in life, the psycho-emotional effects became more apparent.

Brunton and Bartlett highlighted that while pain and fatigue is typical for people ageing, it is not generally the consideration of young people who do not have to factor impairment related effects into their participation in society (Brunton and Bartlett, 2013). The participants in this thesis shared that the impact of contending with increased impairment effects, being confronted by pain and fatigue, and feeling unable to meet the challenges of the work environment or to socialise on an equal basis to their non-impaired peers, negatively impacted their experience of the psycho-emotional effects of having Cerebral Palsy in adulthood. It was not the future that rehabilitation had either prepared them for or warned them about.

At this stage in their lives, this thesis demonstrates, participants had to reconsider their sense of self upon finding themselves in the condition that they inhabited after having left paediatric rehabilitation. Studies have shown that people with Cerebral Palsy’s construction of living with their impairment was disrupted as they aged (Moll and Cott, 2012; Paterson and Watson, 2013). Moll and Cott posit that this creates a biographical disruption among young people with Cerebral Palsy when they experience degeneration early in their adult lives (Moll and Cott, 2012). This study revealed that the pervasive narrative of independence that they received from rehabilitation exacerbated participants’ experience of the degeneration that occurred at this stage. As with walking, participants reflected a sense of feeling that they had failed when they believed they had not yet attained the level of independence they had expected to have achieved having gone through rehabilitation.

Williams, who expanded on Bury’s notion that the onset of impairment can result in a biographical disruption, argued that children with congenital impairments were less likely to experience them due to having lived with their condition since birth (Williams, 2001). However, Bray, Kirk and Callery counter this narrative, suggesting that children who have had an impairment since birth experience biological and psycho-social changes upon transitioning to adulthood, which have the effect of causing biographical disruptions to their ‘developing biographies’ (Bray, Kirk and Callery 2014, p.823). This thesis contends that participants’ biographies were constructed by their participation in rehabilitation and thus did not include the narrative that they would experience pain, degeneration or restricted activity in adulthood.

The absence of rehabilitation in adulthood to mitigate against their increased impairment effects has been found to exacerbate this biographical disruption (Moll and Cott, 2012). Participants in this study maintained a belief that continued access to rehabilitation would have been helpful to mitigate their experiences of living independently, predominantly due to the pain it incurred. However, those who accessed adult rehabilitative provision often felt that it had had a detrimental effect, and in some cases was thought to have contributed to secondary conditions, such as chronic fatigue. Yet not being able to access it further exacerbated their experience of pain, which in turn became a barrier to their independence and social inclusion (Charmaz, 1983).

Participants found that the reality of living independently was more physically demanding than expected. They reflected that their biomechanical experience of Cerebral Palsy increasingly impacted on their embodied self, due to the energy and effort required to undertake physical activities, including personal care. Palisano, Copeland and Gallupi's study identified that young people's ability to be independent was most limited by personal care and mobility (Palisano, Copeland and Gallupi, 2007). Participants had to accept the necessity of using support mechanisms, such as formal assistants, in order to achieve the independence in adulthood that they had believed they would have been able to without. Studies have shown that adults with Cerebral Palsy's sense of "self-efficacy, a concept also dealing with ability, was high in people who depend on mechanical assistance, but low when they depend on Personal Assistants" (Sandstrom, 2007, p.439). In struggling to ask for support to carry out tasks they had previously been able to do, participants' sense of self was challenged by the dependency that was a necessary feature of their adult lives.

Participants’ social selves were also impacted by the barriers they faced upon becoming adults with Cerebral Palsy. Rehabilitative studies have identified that young people with Cerebral Palsy consistently have to make choices, trade-offs and plans to facilitate their social participation (Palisano, Shimmell, Stewart, Lawless, Rosenbaum and Russell, 2009). This study revealed that this reduced participants’ conceptualisation of their social lives, by submitting to the reality, to a greater or lesser extent, that they were less able to participate in the activities that they believed they would otherwise choose to do. Similar to Bray et al.’s contention that young people with Cerebral Palsy can experience a biographical disruption, this thesis posits that participants also experienced a loss of self (Charmaz, 1995). Recognising their limitations, participants negatively compared their need to plan their participation to the spontaneity and diversity of options and opportunities they perceived non-impaired adolescents and adults to have.

This finding has shown, as previous studies have highlighted, that participants’ lack of expectation of the barriers they would experience as they attempted to live independently and having to deal with their changing physical and social condition in light of increased pain and impairment effects, often caused them to experience a biographical disruption to their sense of self. This study has highlighted the role of rehabilitation in instilling the belief in participants that they would be able to live independently in adulthood by attaining functional independence through therapy. Not being made aware of the potential support they would require to do so left participants feeling underprepared for the realities of living with Cerebral Palsy in adulthood. Subsequently, having not expected to need ongoing rehabilitation, the absence of the availability of it in adulthood left participants feeling abandoned when trying to cope with their increased impairment effects. Having internalised the belief that they should do rehabilitation to continuously improve their function, participants felt guilty over not being able to regularly exercise in order to maintain their definition of being independent. This is discussed in the following section.

8.2.3 Rehabilitation's impact on internalised oppression

The previous findings suggest that rehabilitation contributed to participants' psycho-emotional disablism, due to the individualised model that therapy promotes. Following on, Reeve considered internalised oppression as being a pervasive form of psycho-emotional disablism as it can leave disabled children feeling worthless or devalued (Reeve, 2004; 2006). This thesis has demonstrated that, in being expected to undertake rehabilitation in order to improve their function, participants developed a sense that their worthiness was contingent on them both being in rehabilitation and in making progress based on professional values and expectations. As therapy was overseen and controlled by therapists and parents, the participants themselves had little agency in the process.

As the first subsection demonstrates, the expectation on participants during childhood to undertake rehabilitation, and the lack of agency they had in the process, instilled a belief that they had to do rehabilitation to improve their functionality. While participants complied, the imposition of therapy at home and being taken out of formal classes to undergo therapy sessions was invasive and hindered their social experiences and inclusion with their non-disabled peers, which had a long-term impact on their sense of self (Reeve, 2004; 2006). However, as the second subsection discusses, while the transition to adulthood offered greater autonomy, which was initially welcomed, the absence of ongoing regular rehabilitation had physical and social ramifications. These led participants to feel unsupported by adult health and rehabilitative services. Their inability to maintain their functionality in its absence, and the degeneration they had not anticipated, had a negative influence on participants' sense of self.

Rehabilitation was an expectation

Participants in this study had been in rehabilitation since early childhood and felt an expectation on them to do therapy throughout their childhood. This study contrasts with the SPARCLE project's findings that participants in their study had agency within the rehabilitative process. Participants in the SPARCLE project, who were in rehabilitation at the time of participating, relayed that they had made active choices to undertake physiotherapy and surgery. This study shows, however, that in being able to reflect back on the process, participants felt they were given little or no agency over their engagement in the rehabilitative process; its aims or its objectives.

Previous studies have demonstrated that children with Cerebral Palsy are in rehabilitation from their early years and were consistently subjected to the medical gaze until they transitioned out of child health services (Moll and Cott described, 2012). Participants reflected upon the medicalisation of their formative experiences, such as going to the hospital for regular appointments, as having been normal within their construct of childhood. Following Qvortrup’s analysis that discussed the domains in which children are unable to demonstrate agency, such as play groups, nurseries, and schools, as they were controlled by the adults overseeing them, this study demonstrated that children with Cerebral Palsy are subject to an additional domain in which they are expected to conform to the demands of adults and are not invited to express themselves (Qvortrup, 1994). Within the therapeutic environment, participants understood that they were expected to undertake the therapy being required of them. On occasions participants voiced their objections, or displayed their discomfort, at having therapy done to them, they felt they were never heard or respected. Any choice or agency would appear to have been highly constrained and controlled. Participants were not afforded the possibility of refusing to comply. This carried over into participants’ response to surgical interventions. Previous studies have noted that young people put faith in surgical interventions when offered as a ‘fix’ to physical differences (Alderson, 1993; Bray, Kirk and Callery, 2014). This thesis revealed that, while it was presented as a choice, participants reflected that they did not see a reason why they would have refused surgical intervention. Considering their developmental stage as children at the time, participants believed in retrospect that they had not been fully apprised of the realistic outcome and therefore their compliance had been given on false pretences, namely that their function would be greatly improved. This was rarely the case; none of the participants reported improvements following surgery.

The emphasis on increasing functionality through rehabilitation was carried over into participants' home lives with parents taking on the role as co-therapists (Greene, 2003). Participants reflected on the role of their parents in encouraging and facilitating their participation in this process with the majority of participants commenting that they had done a level of therapy at home. Building on existing studies, which commented on the influence of parental approaches on children and young people's understanding of their impairment, this study demonstrated the impact of parents' conceptualisation of Cerebral Palsy on participants' constructs of having rehabilitation (Stalker and Connors 2003; Reeve, 2004). While parents' approaches to participants' impairments emphasised their abilities, this was conditional on their progression through rehabilitation. As noted in the literature review, Reeve's notion of parents being 'unwitting oppressors' can be experienced by disabled children as a form of psycho-emotional disablism. Within this dynamic, participants felt that they had to complete exercises under the supervision of their parents, and that partaking in the activities would please their parents and meet their expectations. On reflection the majority of participants felt that they had had to do the rehabilitation expected of them because protesting would have both put a strain on their relationship with their parents, and evoked negative comments from therapists and parents had they not done it.

Participants reflected that they were required to take part in rehabilitation despite their preference for being included in activities alongside their peers. Authors within disabled childhood studies have highlighted that the medicalisation of children’s physical development is prioritised above all other aspects of their being (Davis, 2012). While the narrative, constructed in part by medical and rehabilitative professionals, parents, teachers, and wider support networks, was that being included in society relied on participants’ ability to adapt their physicality to fit in with the dominant culture, predominantly occupied by non-impaired people, the practice of removing participants from mainstream activities was by its nature exclusionary. Studies into children’s experience of barriers to inclusion have argued that the materialist position that disabled children are oppressed by institutions' failure to include them is contradicted by children’s resilience. However, in being able to reflect, participants felt the impact of atypical childhood experiences, including exclusion, was shown to affect their psycho-social development, finding it difficult to initiate and maintain relationships, and to engage in social activities alongside their peers in adulthood. Davis argued that young disabled people’s social skills and self-confidence are prevented from developing because their lives are controlled by others (Davis, 2012). This would suggest that intersubjectivity, which Shuttleworth found to affect young adults with Cerebral Palsy from establishing social relationships, was rooted in childhood (Shuttleworth, 2000). While participants’ sense of being worthy of social inclusion, positive interactions or intimate relationships, developed as they aged, there remained residual belief that their Cerebral Palsy negatively influenced their social selves. Reeve has noted that the lasting effects of internalised oppression can impact young disabled people’s self-esteem and self-perception in adulthood (Reeve, 2006). The following section illustrates that the narrative that rehabilitation was expected of participants in order to improve their physical and social selves persisted. However, the onus on them to access it in adulthood proved challenging, which was detrimental to their sense of self as adults with Cerebral Palsy with increasing impairment effects.

Rehabilitation with autonomy

The reduction of rehabilitation as participants left school and transitioned to adulthood was a critical juncture in their development. Rehabilitation was no longer an integral part of their existence, and this proved detrimental to their physical and social sense of self. This may in itself appear contradictory, but the key factor here is the lack of agency participants had in the process and in the intended outcomes for rehabilitation. Similar to Bagatell et al.'s findings, for the participants in this study, there was a stark switch in the role from child to adult patient (Bagatell et al., 2016). The main contention of this thesis to come through participants' accounts of this period was the limited, or absence of, information and negotiation with therapists about the withdrawal of therapeutic services. With apprehension about entering adulthood on leaving paediatric rehabilitation and having to live with the impact of Cerebral Palsy on their body - which for many was much more significant than they had been led to believe - participants felt they had been cut adrift and discarded by services and left to manage on their own (Bagatell et al., 2017). The main aim of what Finkelstein termed the 'rehabilitation machine' (1988) was to make participants as normal as possible or, as Stiker phrases it 'a demand to be like others' (1999;131). This is what participants were led to believe they would achieve.

In order to maintain the level of ability they had at the point that rehabilitation began to be withdrawn, participants felt the need to keep participating in therapy to the same or greater degree as they had done throughout childhood. Discussing the temporal nature of the achievements, or progress, made through rehabilitation, often due to the impact of pain or age-related degeneration, McLaughlin and Coleman-Fountain argue that young people with Cerebral Palsy have to maintain a ‘degree of self-monitoring and regulation’ if their notion of independence is to be realised (McLaughlin and Coleman-Fountain, 2014). While the outcomes of therapy in childhood were found by many participants to not be as positive as they had expected, participants were disappointed at the withdrawal of rehabilitation when they felt they had not attained the level of physical ability they had expected to have had by that stage. Participants also believed rehabilitation would have been useful in adulthood to mitigate against the increasing impact of their impairment. Without access to ongoing rehabilitation in adulthood, participants’ experience of ageing and degeneration challenged their self-perception as adults with Cerebral Palsy.

There was a juxtaposition between the embodied and social experience of having an impairment that led participants, to differing degrees, to having a transient sense of well-being, dependent on how their physical function aligned with their social inclusion. Reeve, discussing the psycho-emotional impact of disablism upon the construction of disability identities, argues that “[t]he relative strengths of these dominating and emancipatory forces are affected by personal experience, counter-identities as well as impairment; and like subjectivity, the daily experiences of the psycho-emotional dimensions of disability change according to the context disabled people find themselves in" (Reeve, 2002). This was evident in the differing perspectives participants had of their adult selves. Those participants who had engaged with the social model came to appreciate that structural barriers impeded their daily lives, whilst still acknowledging the impact of their impairment (Thomas, 1999; 2007). However, despite acknowledging that they were disabled by society, they still continued to pursue rehabilitative means to reduce their impairment effects. Participants commonly cited persistent feelings that they had to increase their functional ability to succeed in adulthood, such as improving their performance at work, maintaining their friendships or relationships, and living independently with their parents' affirmation. Reeve argues that due to being under the medical gaze, disabled people can become subject to self-surveillance, the concept that "people develop an awareness of how they are seen through the gaze of another and then modify their behaviour via self-surveillance to attempt to make themselves acceptable" (Reeve, 2002, p.500). This typically involved using universal gym facilities, home exercise and time sensitive therapies, while one participant procured a private therapist to continue to attain therapeutic goals rather than fitness.

The lack of autonomy participants had in the rehabilitative process throughout their childhoods had a lasting impact on their sense of selves as adults. This was amplified without access to rehabilitation. Racine et al. (2012), studying young people with Cerebral Palsy's autonomy in transitioning to adult health services, found that they "were sometimes not well prepared within the paediatric–adult transition process to assume full decision-making autonomy". This should not be surprising given that they have been given little or no agency in the rehabilitative process up to this point. Participants not only internalised the rehabilitative narrative that they received during childhood; that they had to undertake therapy in order to continually improve their functionality, but, due to their limited agency over their participation and the prioritisation it had over their social lives, participants continued to feel a societal and internal pressure to maintain physical exercise in adulthood.

A role shift took place when participants transitioned from child services, in which healthcare professionals (such as paediatricians) typically identified what treatment they needed, to adult services, where the onus was on them to identify specific issues when accessing support from their GP (Tisdall, 2012). Previous studies have highlighted that, when accessing healthcare in adulthood, young people have felt patronised, dismissed and that their concerns were not taken seriously (Racine, Larivière-Bastien, Bell, Majnemer, Shevell, 2012; Bagatell et al., 2017). Further to Bagatell et al.'s study, which found that young people with Cerebral Palsy felt stereotyped by adult health service, this study revealed that professionals responded to the concerns raised by participants with a sense of inevitability due to them having Cerebral Palsy, which led them to feel that their experience of having the condition in adulthood was illegitimate.

This section furthers the understanding of children and young people with Cerebral Palsy's autonomy within the rehabilitative process in two respects. Firstly, while the studies mentioned in this section considered children and young people's approach to stigma to be reflective of their agency in the rehabilitative process as it contributed to their hope for functional improvement and social inclusion, this thesis has demonstrated that, in retrospect, participants had little option but to comply based on a narrative they were given that they had to do therapy in order to achieve these goals. Secondly, where previous studies have highlighted the barriers and attitudes young adults face when engaging with health and rehabilitative services, this thesis adds to the connection made between the paediatric approach, which restricted children's agency and autonomy, and the difficulties they experience in expressing and getting their therapeutic needs met in adulthood (Racine et al., 2012). It further demonstrates that the expectation to undertake rehabilitation in childhood impacted participants' psycho-emotional response to not being supported or encouraged to maintain their functionality in adulthood. The onus on participants to do so, and their inability to, resulted in participants internalising a negative perception of their functional decline.

8.3 Research reflections

This section discusses reflections on the data collection and analysis process itself. The first subsection responds to the research objectives this thesis set out to explore and outlines the theoretical developments this thesis has made. Secondly, this section considers the strength and limitation of the research, both of which pertain to the use of the biographical approach. As a result of expanding the sample size to include young people with Cerebral Palsy up to the age of 35, this research relied more heavily on a biographical approach, with participants reflecting on their rehabilitative experience in childhood. While this demonstrated the strength of exploring the perspectives of participants who had experienced the phenomenon being researched and reflecting on its impact, ensuring the reliability of accounts of an emotional topic is challenging as they could have been misremembered or represented. Finally, given the emergence of it as a theme, this section proposes that future research should explore the impact of pain and ageing on the lives of children, young people and adults with Cerebral Palsy is discussed.

8.3.1 Meeting Research Objectives

This section summarises how this thesis has met the research objectives identified in the introductory chapter. The two main objectives that were posited sought to explore the psycho-emotional impact of rehabilitation on the development of children and young people with Cerebral Palsy and the effect of its withdrawal on their sense of self as they entered adulthood. The following responses demonstrate that this thesis has addressed each of the objectives, and in so doing furthered the theoretical understanding of the psycho-emotional impact of rehabilitation on children, young people, and adults with Cerebral Palsy.

1) **To explore the impact of undergoing rehabilitation on the psycho-emotional development of children and young people with Cerebral Palsy.**

This thesis has demonstrated that rehabilitation had a psycho-emotional impact on participants’ childhood development. Reflecting on the biomechanical function, participants believed that the rehabilitative emphasis on functional improvement, encouraged by their parents, instilled in them a sense that they were striving to become more functionally able than they were. Though participants felt they did not have agency in, or understanding of, the therapeutic process at the time, they undertook the exercises prescribed, and accepted exercises being done to them, on the basis that they were told it was beneficial to their functional development. However, socially, participants reflected that the requirement to engage in therapy as frequently as they did, in hospitals, schools and at home, was detrimental to the development of their social-relational selves. Previously, research has focused on the impact of rehabilitation on children and young people while they were going through it, and posited its long-term effects (Stalker and Connors, 2003; McLaughlin, 2014; Reeve, 2012). By taking a biographical approach, this thesis has shown that rehabilitation's focus on attaining improved physical functionality, at the detriment of the child's social and psycho-emotional wellbeing, had a long-term impact on participants' ability to develop a positive sense of self.

a) *To consider the impact of rehabilitation on children and young people's construction of having Cerebral Palsy.*

This thesis has provided clear evidence of the impact of rehabilitation on children and young people's construction of having Cerebral Palsy. The aims and outcomes of rehabilitation that participants reflected on having understood at the time was that undergoing therapy would have improved their functional ability and lessened the impact of their Cerebral Palsy-related impairment effects to the point where they would be able to function independently, without support or the needs for aids or wheelchairs, in adulthood. This adds to Bezmez's argument that while rehabilitation has shifted towards more functional task-based therapy, there remains a focus on attaining ‘normative’ function (Bezmez, 2016). Upon reflection, participants felt that there was a disconnect between the narrative and the results gained in their functional ability. This thesis demonstrated that this led to participants having a negative psycho-emotional response to their own sense of achievements, feeling that they had not committed adequately enough to the therapy. Furthermore, participants had internalised the construct that their impairment effects should and could be reduced and mitigated against, and there was a responsibility on them to attempt to do so through rehabilitation. Building on Reeve’s notion of internalised oppression being a result of psycho-emotional disablism, this thesis has demonstrated the pervasive effect of rehabilitation on participants’ perspectives of themselves as adults with Cerebral Palsy without ongoing access to rehabilitation (Reeve, 2012).

b) ***To consider the contributory factors to children and young people with Cerebral Palsy’s approach to, and understanding of, rehabilitation.***

This thesis demonstrated that children and young people with Cerebral Palsy’s approach to, and understanding of, rehabilitation was heavily influenced by external factors - observations of their non-impaired peers, and messages encouraging their participation in therapy from their parents, therapists, and wider networks. Whereas Shakespeare, Cooper, Bezmez and Poland have suggested that normality is co-constructed within the therapeutic environment by therapists, patients, and their families, this thesis has shown that, upon reflection, considering their experience of childhood rehabilitation, participants felt there was a fixed notion of normality achievable through their engagement in rehabilitation (Shakespeare et al., 2018).

While their initial comparison between their functionality and that of other children was, on reflection, broadly similar, as their non-impaired peers developed ‘normative’ functionality, participants began to conceptualise their impairments as being a barrier to their participation and inclusion in school and social activities. At the same time, participants received messages from parents, therapists, and wider society that striving to improve their functionality - particularly, their walking ability - was desirable and possible through therapy. This expands on Reeve’s contention that parents, acting on the advice and encouragement of medical practitioners, promote a normalised model of development to their child, which they believe is attainable through therapy (Reeve, 2004).

2) To examine the effect of having access to rehabilitation withdrawn on the sense of self of young adults with Cerebral Palsy.

This thesis demonstrated that the effect of having access to rehabilitation withdrawn had a significant impact on the sense of self of participants with Cerebral Palsy transitioning to adulthood. Participants in this study demonstrated a lack of understanding at the reasoning, and an objection to the subsequently understood logic, for having rehabilitation withdrawn at this stage in their lives. For those participants who felt that therapy was predominantly done to them during childhood, the absence of consultation extended, and for those who felt they had been active participants choosing to do therapy, the absence of consultation highlighted participants' sense that they had limited agency in the therapeutic process. While others have highlighted the poor experience of transition, specifically the lack of agency young disabled people have in the process, this thesis has demonstrated the lasting consequences on participants’ ability to access the rehabilitative, health and social care support they believe would assist them to live independently with Cerebral Palsy in adulthood (Beresford, 2004; Wright et al., 2015).

This study builds on Moll and Cott’s findings that adults with Cerebral Palsy can experience a biographical disruption due to their experience of increasing impairment effects - often due to living more independent lives (Moll and Cott, 2012). Participants in this current study believed that, soon after having left rehabilitation, while they had not achieved the aims they had believed they would have at the point of transitioning to adulthood, their function could be improved, and their pain managed by having ongoing access to rehabilitation. Where Paterson and Watson found that the early deterioration experienced by adults with Cerebral Palsy was often unexpected, this thesis has shown that the decline participants experienced in their functional ability and the unforeseen difficulties they experienced, due to a lack of warning of this phenomenon from rehabilitative practitioners, challenged their sense of self as independent adults with Cerebral Palsy (Paterson and Watson, 2013).

a) *To consider the long-term impact of the rehabilitative narrative on the psycho-emotional experience of young adults with Cerebral Palsy.*

The rehabilitative narrative had a long-term impact on the psycho-emotional experience of young adults with Cerebral Palsy. The rehabilitative narrative received in childhood, that exercise and repetition would improve functionality, ran counter to the reality of having Cerebral Palsy as experienced by participants as they transitioned to adulthood. Having not achieved the functionality they believed they would have had at the point of leaving rehabilitation, participants internalised a sense of having failed to attain the aims espoused by childhood rehabilitative therapists and parents. Building on Mclaughlin and Coleman-Fountain's contention that the normative concept of independence promoted by the medical profession is perpetuated by self-regulation, and Reeve's notion that being subject to the public gaze can lead disabled people to practise self-surveillance over their ability to meet societal expectations, this thesis has demonstrated the long-term impact that the rehabilitative narrative had on participants' sense of independence and the stigma they felt when the reality of living with Cerebral Palsy contrasted with it (Reeve, 2002; McLaughlin and Coleman-Fountain, 2014).

b) ***To consider the psycho-emotional impact of experiencing ageing and increasing impairment effects with Cerebral Palsy without ongoing access to rehabilitation.***

The psycho-emotional impact of experiencing ageing and increasing impairment effects with Cerebral Palsy was exacerbated by the absence of ongoing access to rehabilitation. Participants felt that there was a lack of warning from rehabilitative services that they would begin to experience such impairment effects at such a young age. When it transpired that their impairment effects were increasing and they would require greater support to live independently, or have greater difficulty doing so than expected, participants experienced a disruption to their biographical sense of self, having believed that they would have achieved independence through rehabilitation. This thesis expands the theoretical understanding of biographical disruption in recognising the role rehabilitation plays in contributing to children with Cerebral Palsy experiencing one later in life (Bury, 1982; Moll and Cott, 2012; Bray et al., 2014). When this occurred, participants reflected that the lack of access to rehabilitative and specific health services further impacted their ability to maintain a positive sense of self with the condition they experienced in adulthood.

8.3.2 Strengths and limitations

The long-term psycho-emotional impact of rehabilitation on people with Cerebral Palsy has had limited research. This study builds on the works of other authors, such as Alderson (1993), Shakespeare and Watson (1998), Davis (2012), Stalker and Connors (2003), Reeve (2004; 2006; 2012), Beresford (2004), Mclaughlin (2017), who have demonstrated the value of consulting with young people regarding their views of medical procedures and highlighted the need for an understanding of children and young people's perspective on their impairments. However, while acknowledging disabled children and young people experience psycho-emotional disablism, and have posited their lasting effects, the limitation of such analysis is that the research is typically framed in the context of childhood, reflecting on their experiences as they are still children with all the support structures that includes, such as parents, carers, school, therapies, organised activities, and peer networks. Though research into disabled children's lives recognises these will dissipate as they become adults, there is a lack of literature on the impact of childhood experiences on the lifespan of young people with impairments (Stalker and Connors, 2003). In taking a biographical approach, asking participants to reflect on their experience of having had rehabilitation in childhood, this thesis has demonstrated its impact on their psycho-emotional state at different stages of their lives.

Shah and Priestley argue that the 'biographical turn' taken in exploring the lives of disabled people has allowed for their personal accounts to be considered in the context of the social barriers that disable them, referring to Morris' contention that the 'personal is political' (Rustin, 2000). They suggest that there is value in considering this approach in researching the lives of young disabled people because they "have been particularly marked by this kind of public reach - making intimate lives very public and constraining private life decisions" (Shah and Priestley, 2011, p.175). Using such a methodology in this study demonstrated the long-term impact of childhood rehabilitation, with participants being in a position to reflect on the negative effects of having undertaken multiple therapies as children at the instruction of medical professionals and their parents. Using the biographical approach, participants were able to reflect on the connection between the lack of narrative regarding the degenerative effects of Cerebral Palsy and their sense of feeling unprepared to deal with its impact on their lives.

At the same time however, as Thomas states, “Narratives are representations” (Thomas, 1997, p.7). Thus, difficulties incurred through biographical research arose during the research phase with participants who were reflecting on having had rehabilitation in childhood. One of the central criticisms of the biographical approach is that participants in such studies describe their experiences with the hindsight of being an adult (Becker, 1967). For many of the participants, their participation in this study was the first time they had been asked to consider the psycho-emotional impact of rehabilitation. The difficulties some participants had in remembering the feelings that rehabilitation evoked while they were having it, and the emotional toll discussing them, could have limited the reliability of the data they shared.

Additionally, this thesis attempted to take an emancipatory approach by situating the research in the views and experiences of disabled children and young people. However, there were limitations in my approach, which may have prevented the study from being fully emancipatory. Though this study evolved during the data-collection phase, which, for example, highlighted the importance of pain in participants’ experiences, as discussed in the next section, it was limited to the phenomenon that I, a straight white cis-male adult with Cerebral Palsy, originally set out to research. In acknowledging the principles for undertaking research with disabled children, as outlined by Watson (2012), such as specifically engaging with them during the development and design stages of the topic guide and data collection process, greater effort could have been made to include children with Cerebral Palsy during the initial stages of this research project. Co-production in social research, especially with children, young people, and adults with Cerebral Palsy, continues to be an emerging approach, which, if adopted, has the potential to broaden the scope of research to encompass dimensions of their experiences of psycho-emotional disablism, previously underexplored.

8.3.3 Future research

This section highlights the need for future research, which has been identified through this thesis. The emergence of the theme on the cumulative physical, social, and psycho-emotional impact of unexpected pain and degeneration on participants' sense of selves as young adults, and the limited access to adulthood rehabilitation to deal with their effects, demonstrates the need for future research into this phenomenon.

The impact of pain on the experiences of children, young people, and adults with Cerebral Palsy has been relatively under researched. Colver highlighted that experiences of pain in childhood Cerebral Palsy have been at risk of being normalised.

> *...only recently (now that studies ask children about their pain) has it been realised that pain is also a significant feature of the lives of children and young people with Cerebral Palsy and the pain adversely affects their participation and subjective well-being. Once again a life course understanding of Cerebral Palsy is crucial, so that children do not come to view pain as normal, and indeed be conditioned to enhanced*

> *sensitivity to pain which may then persist into adulthood. (Colver et al., 2015, p.3)*

This thesis supports the growing body of research identifying the need to give greater attention to the impact of pain and degeneration on the experience of individuals with Cerebral Palsy. Future research into this phenomenon should take a lifelong approach, appreciating its roots in childhood. Biomechanically, research has identified that there is a need to further explore how to prevent decline in functionality that begins in childhood, as Haak explains.

> *Research is needed in which adult Cerebral Palsy is categorized by a standard typology of Cerebral Palsy and GMFCS severity levels, with independent, longitudinal assessments of standardized outcome measures from childhood through adulthood. Careful assessment of exposures such as early interventions and treatment, exercise, physiotherapy, and environmental factors may help us to learn how to forestall or prevent the functional declines evident in these studies that often start in the late teens and twenties, just as adulthood is beginning. (Haak, 2009)*

Though studies with adults with Cerebral Palsy, particularly Moll and Cott (2012) and Paterson and Watson (2013), have made reference to the role of rehabilitation in their participants' constructions of ageing with Cerebral Palsy, this current study has found that there is a lack of comprehensive documentation on the long-term impacts of rehabilitation, and its subsequent absence, on the physical, social, and psycho-emotional development of young people as they age with Cerebral Palsy. Future research should, therefore, take a lifelong approach to exploring the role rehabilitation plays in people with Cerebral Palsy's construction of their sense of self as the impact of their condition changes over the course of their lives. Doing so could provide more evidence on the whole life impact of rehabilitation in the physical and social lives of young people and adults with Cerebral Palsy.

Such research should focus on the psycho-emotional impact of ageing and degeneration that comes with being a person with Cerebral Palsy. To study such a phenomenon holistically, it is proposed that future research takes a cross-discipline approach, encompassing social, psychological, and medical theory, in order to fully understand the multidimensional experience of becoming and being a young person with Cerebral Palsy.

8.4 Policy Recommendation

This concluding section considers the policy implications for the wider demographic of people with Cerebral Palsy engaging with rehabilitation. Based on the research findings, it is proposed that, throughout a person's life, rehabilitation should be responsive to and take account of the psycho-emotional impacts of living with an evolving condition, which is dependent on the effects of such rehabilitation and affected by increasing impairments effects, due to the physical, social, and environmental context in which children, young people and adults experience having Cerebral Palsy.

Starting from early childhood, this study demonstrated the parental influence on participants' perspective of having Cerebral Palsy and their engagement in rehabilitation. Gibson et al. argue that while giving parents hope, it is important that therapists support children and their families to recognise their abilities and participation (Gibson et al., 2011). Following diagnosis, the potential outcome of therapeutic interventions for children with Cerebral Palsy (as can be derived from the Gross Motor Function Classification System) should be clearly conveyed to parents and children throughout the process as they become evident to therapists. Medical evidence has demonstrated the need to reframe the rehabilitative approach. Novak et al. contended that a continued focus on attempting to "fix the condition" is not realistic and, therefore, working with families to consider the possible prognosis as the child develops is more helpful to attaining achievable person-centred goals (Novak et al., 2013, p.902). They concluded that interventions that adopt the 'body structure and functions' approach should focus on mitigating the bodily impact of having Cerebral Palsy, giving the example of hip dislocation. Such interventions should be evidence-based and focus on the child's strengths and interests "and ultimately seek to help children live an inclusive and contented life" (Novak et al., 2013, p.902). This reinforced Rosenbaum's conclusion that therapy should promote the child's ability to achieve functional independence and move away from facilitating normal patterns of movement, which he considered too often to be 'an illusory goal' (Rosenbaum, 2003, p.972). This thesis contends that an updated approach to rehabilitation should consider the psycho-emotional dimension to growing up with Cerebral Palsy. This expands on Shakespeare and Watson's contention that, rather than attempting to 'normalise', clinical intervention should aim to increase disabled children's quality of life (Shakespeare and Watson, 1998). This thesis demonstrates the necessity of considering such interventions within the context of their contribution to the future quality of life and psycho-emotional response of adults with Cerebral Palsy who were encouraged to pursue rehabilitation during childhood.

As young people develop, rehabilitation plays a significant role in the construction of having and living with Cerebral Palsy. Gibson et al. note that a "challenge for rehabilitation is to determine how best to assist children in maintaining a positive disability identity while pursuing achievable therapeutic goals" (Gibson et al., 2011, p.67). In response to such results, it has been highlighted that there is the opportunity for rehabilitation services, namely physiotherapists, to support young people with Cerebral Palsy to redefine their perspective of living with the condition (Shields, Murdoch, Loy, Dodd, and Taylor, 2006; Shuttleworth, 2000). Considering how rehabilitative services could do this, McLaughlin poses that the limits of such interventions be clearly communicated to young people with Cerebral Palsy.

> *To create a space for at least the acknowledgement that disabled young people undertake painful procedures to respond to the social challenges they face. It may also be useful to explore, as we have seen practitioners do, the limitations to how far medicine can take them, particularly as their bodies age and new cycles of painful intervention are required to try to sustain a 'normal' body. (McLaughlin, 2017, p.249)*

This thesis builds on Reeve's argument, reflecting on the psycho-emotional dimensions of medical interactions, to recommend that rehabilitation considers and supports children and young people with Cerebral Palsy within the social, political, and cultural context of disability and to recognise their experience of "social oppression which operates at both conscious and unconscious levels" (Reeve, 2006, p.103-104). Thus, rehabilitative practitioners should take a more emancipatory approach to enable young people to develop a positive sense of self within the environment in which they grow up (Trede, 2015; Abrams as cited in Nicholls, 2015).

Finally, following their transition out of rehabilitation, the potential that participants' functionality would decrease in adulthood was rarely anticipated by participants. Rather than rehabilitation ending at a certain age, the withdrawal of therapy should be negotiated with young people and their families at an appropriate stage in their transition to adulthood. Furthermore, health care professionals need to respect young adults' need to be acknowledged and valued as competent collaborators in their own transition in order to protect them from additional health problems during this vulnerable phase (Fegran, Hall, Uhrenfeldt, Aagaard, and Ludvigsen, 2014). Given the growing amount of evidence on the impact of ageing and degeneration on young people with Cerebral Palsy and its psycho-emotional impact that this study has demonstrated, it is proposed that rehabilitation should be continuously available to people with the condition throughout their lives (Moll and Cott, 2012; Paterson and Watson, 2013). With Racine et al. finding that adult health services for people with Cerebral Palsy are insufficient and inappropriate, and the current study showing that participants felt their concerns were delegitimized by medical professions, continuous rehabilitation should be provided by therapists with specialist knowledge of the impact of ageing and degeneration on the physical and social experiences of those with the condition. Therefore, this thesis expands on Lindsay's recommendation that "rehabilitation interventions for youth with CP need to address issues beyond mobility and function to enhance their participation, inclusion and well-being" to propose that such an approach to rehabilitation should be available to people with Cerebral Palsy throughout their lives (Lindsay, 2016).

8.5 Conclusion

This thesis has shown that rehabilitation contributes, and can be analysed as contributing, to an individual with Cerebral Palsy's psycho-emotional experience of disablism. The main medical approach to treating Cerebral Palsy impacted participants' psycho-emotional development and the withdrawal and absence of it in adulthood affected their sense of self.

Participants' reflections on growing up with Cerebral Palsy demonstrated a gradual realisation throughout childhood that their impairment differentiated them from their non-disabled peers. Participants' walking ability was the main aspect of their impairment that they felt presented them with 'barriers to doing' - experiencing environmental restrictions, especially at school - 'impairment effects', such as pain and fatigue when attempting to socialise with their peers - and 'barriers to being' - feeling that their inability to walk like their peers made them different and excluded. As participants became more autonomous, and witnessed their peers becoming independent, they recalled having identified unanticipated barriers to living independently, such as daily activities, personal care, maintaining social relationships, securing jobs, and managing support, which impacted their embodied and social experience of having Cerebral Palsy as they transitioned into adulthood.

Participants' understanding of the rehabilitative narrative they absorbed during childhood was that undertaking therapy would lead to improved physical functionality. The focus on physical development through rehabilitation gave participants a sense that their impairment effects would decrease. This underpinned participants' belief that complying with the therapy they were given, the home exercises they were told to do, and the surgical interventions they were encouraged to pursue would lead to an increased walking ability and enable them to live independently without the need for support in adulthood. Parental attitudes towards participants' impairments were significant in their reflections of their approach to undertaking rehabilitation; from being the strong advocates of participants completing home exercises to reinforcing the message that their functionality, and to an extent their ability to embody normative physical presentation, was contingent on their participation in rehabilitation. The ability of participants to meet their parents' expectations was influential in their psycho-emotional development.

The primacy that rehabilitation took over other aspects of their childhood, predominantly their social and educational experiences, fed into participants' sense that rehabilitation was an expected and necessary part of their childhood. Throughout the process, participants reflected on having had little agency over their participation in therapy, the physical impact exercises had on their body while participating, or the time and space it took up in their lives, whether attending sessions, at home or during school. At the same time however, on their transition out of paediatric health services, participants were left feeling that they had not been appropriately supported during the withdrawal of rehabilitation. This inflection point in participants' reflections demonstrated the juxtaposition between their perspectives of being made to do rehabilitation in childhood and their frustration at not having access to it in adulthood.

On becoming adults - realising that their functionality had diminished and that living with their impairment had unanticipated challenges - participants experienced a disconnect between the rehabilitative narrative and their experience of having Cerebral Palsy in adulthood. Firstly, the reduction in their walking ability in their teenhood - either due to physical changes or following surgical procedures - led to participants having to shift their perspectives of becoming walkers. As this happened, the rehabilitative narrative also shifted; maintaining a reduced level of walking ability would require ongoing intensive rehabilitation, which was no longer available. Against this backdrop, while the use of wheelchairs had been considered to be a failure of participants' attainment of walking, participants had to compromise their sense of being a walker with their engagement in society by reducing their participation or by using a wheelchair, even though they continued to feel stigmatised because of it. Secondly, the realities of living independently with Cerebral Palsy, compounded by the experience of increased impairment effects, caused participants to reconsider their physical and social selves. Rather than being able to undertake daily tasks on their own or to participate in adult life without limitation, participants found that they required a greater level of support and experienced far greater fatigue and pain as a result of living independently than expected. This thesis adds to a growing body of research into the lived experience of young people and adults with Cerebral Palsy and highlights that growing up with Cerebral Palsy incurs dimensions of psycho-emotional disablism that can have a lasting impact on young people's sense of self (Moll and Cott, 2013, Paterson and Watson, 2013; Reeve, 2003).

Participants' experience of unanticipated pain and degeneration in adulthood was exacerbated by both the construction of adulthood that childhood rehabilitation had influenced and the impact of the absence of rehabilitation in adulthood, which contributed to a diminished sense of self as an adult with Cerebral Palsy. Participants continued to feel that therapy would be beneficial. They were dissatisfied at the lack of therapeutic provision available to them in adulthood and the lack of cognisance of their social experience of being an adult with Cerebral Palsy. Participants felt their experiences of having Cerebral Palsy were further undermined by the lack of appropriate adult health care, which often left them feeling dismissed or that their experiences of increased impairment effects were illegitimate.

From these findings, this thesis has recommended that the rehabilitative process should take a lifelong approach, in the same way that Cerebral Palsy should be viewed as a lifelong condition and, therefore, treated in the same manner as other long-term conditions (Paterson and Watson, 2013, p.23). This should be supported by continuously available rehabilitation throughout an individual with Cerebral Palsy's life, within which the aims, expectations, and the process itself take appropriate account of the psycho-emotional impact of it on their developing sense of self. By understanding the societal, familial, medical, and rehabilitative approaches to the psycho-emotional development of children and young people with Cerebral Palsy, an appreciation of these influences on their sense of self has the potential to increase the ability of services, family networks, and wider society to support them in constructing their sense of self as autonomous individuals growing up and ageing with Cerebral Palsy in Scotland.

This thesis builds on Thomas' (1997), Reeve's (2004; 2006) and Stalker and Connor's (2003) analyses of psycho-emotional disablism and argues that rehabilitation creates and contributes to children and young people with Cerebral Palsy's experience of 'barriers to doing', 'barriers to being' and 'internalised oppression'. The rehabilitation process, by focussing on the physical, privileges barriers to doing, and that through improving physical capacity the hope is that individuals will be better placed to access their environment and that this will help them better meet their life goals. In doing this however, it can inadvertently introduce or reinforce barriers to being; if young people are not able to significantly improve their physical function, they may believe that they cannot achieve what they want and so their psycho-emotional wellbeing may be negatively impacted.

This furthers the debate around the role of impairment within the social model of disability. The Affirmative model expanded on the Social Model approach of redefining where barriers to equal participation in society existed and brought in the notion that individual impairment could be considered part of a positive disabled identity. As Swain and French highlighted in their conceptualisation of the affirmative model, rather than focussing on the 'pain of impairment', the positive experience of impairment should be given due consideration, in the same way that other characteristics are recognised as being a part of an individual's identity (Swain and French, 2000). Viewing impairment as an ordinary aspect of an individual's experience of impairment, Cameron argues, the affirmative model offers disabled people an approach to considering their impairment as a source of pride, and recognising the value of its difference, whilst accepting it can at times have a negative impact on their lives (Cameron, 2010). Contesting the social model's resistance to incorporate individual experience of impairment and contending that it thus left impairment within the medical domain, the affirmative model poses a non-tragic perspective of impairment. Accordingly, Cameron argues:

> We are who we are as people with impairments, and might actually feel comfortable with our lives if it wasn't for all those interfering busybodies who feel that it is their responsibility to feel sorry for us, or to find cures for us, or to manage our lives for us, or to harry us in order to make us something we are not, i.e. 'normal'. (Tyneside Disability Arts, 1999, p.35.)

The affirmative model suggests that impairments should be embraced, and differences celebrated - the rehabilitation model, conversely, encourages children with impairments to undergo therapy to change or reduce the level of their impairment and to work towards normality. Rehabilitation, therefore, challenges children and young people’s ability to embody this tenet of the affirmative model. Furthering Middleton’s argument that rehabilitation and medical procedures can be detrimental to children and young people’s self-perception, this thesis demonstrated that, having been socialised into not accepting their bodies, the participants in this study later struggled to accept or feel positive about living with Cerebral Palsy (Middleton, 1998). This thesis has shown that the current model of rehabilitation is not neutral; it impacts children and young people’s understanding and conceptualisation of their impairment and of being disabled. Instead, the challenge should be on rehabilitative services to balance the physical and psycho-emotional development of children, ensuring they achieve a beneficial physicality, so that living with Cerebral Palsy is not detrimental to their health outcomes, while promoting a positive sense of self. By enabling and supporting people to construct their own identities, incorporating their impairment, and being disabled, as much or as little as they wish to, rehabilitation and healthcare services would be better equipped to provide more opportunities for children, young people, and adults to develop a more assured sense of self as individuals with Cerebral Palsy living in a disabling society.

Appendix A

Participant Information Sheet

Hi <name>.

My name is Colin Young, and I have Cerebral Palsy. I am working with Glasgow University to look at young peoples' experiences of having Cerebral Palsy and having therapy such as physiotherapy, occupational therapy and speech and language therapy etc. I'm writing to you as you have Cerebral Palsy and I understand you have been to therapy as you've been growing up.

If it's alright with you, I would like to interview you to ask you about your thoughts on the therapies you use. I will meet you on two occasions in a place you choose for around two hours each. I will ask you questions and talk to you about your experience. I will record our conversation and type it up.

If it is alright with you, I will bring my Personal Assistant to the interview, as he helps me to take notes. However, it is okay if you prefer not to have my PA at the interview. The things you tell me will be included in my research report. Your name will not appear anywhere on the report, so that everything you say is confidential. It is your choice whether or not to take part in the research. If you do decide to participate, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you can stop at any time, and you do not need to tell me why.

Contact information:

If you have any questions or would like to talk, please contact me, Colin Young, on xxxxxxxxxxx or at c.young.1@research.gla.ac.uk. You can also contact my supervisor who is Professor Nicholas Watson and can be contacted on nicholas.watson@gla.ac.uk.

If you have any worries about the way the interview was held or if you are not happy with the interviewer, please contact Dr Muir Houston, Ethics Officer, on 0141-330-4699 or email Muir.Houston@glasgow.ac.uk.

Appendix B

Participant Consent Form

Principal researcher:

- Colin Young, c.young.1@research.gla.ac.uk

Principal supervisor:

- Professor Nicholas Watson, nicholas.watson@gla.ac.uk.

I have read and understood the information sheet about this study and have had the opportunity to ask questions about it.

I understand that I do not have to take part, and can withdraw from the study at any time, without having to give a reason.

I understand that I will not be punished for not taking part or stopping.

I agree to my voice being recorded and to have my comments written into a report without my name.

I agree to participate in this interview.

Participant's name: ______________________________

Signature: ______________________________

Date: ______________________________

Parent's/guardian's name ______________________________

Signature (if participant is aged 16 or under): ______________________________

Date: ______________________________

Appendix C

Topic Guide for children and young people participants

This research project explores the experiences of young disabled people constructing an identity in the context of their interaction with external support structures, namely therapeutic services.

To examine the meaning of being a young person with Cerebral Palsy (CP) aged 12-25, it will research their experiences and perceptions of having CP and of growing up with CP in terms of how it impacts on their sense of well-being, their sense of self, their experiences of the services they access, and of their social relationships with family, peers and professionals.

The research project will involve two 2-hour semi-structured interviews between the primary researcher, Colin Young, and the interviewee, conducted within the space of a month of each other. The interview will include themed questions that will initiate discussion on the topic with subsequent questions being optional if the researcher wishes to confirm or expand on the answers you provide.

At the start of the interview, the researcher will explain the format of the interview and request consent from the interviewee for the interview to be digitally recorded.

The research will take a conversational style, guided by the responses given by participants. Therefore, the themes below will act as a prompt, but do not dictate the direction of the interview. Should the interview take a direction irrelevant to the study, the primary researcher will encourage participants to revert back to the primary topic.

Theme 1 – Memories of childhood: as an introduction to the interview, participants will be invited to talk about their most prevalent memories of being a child. This is intended to scope out the participants' consideration of their status as having Cerebral Palsy.

Theme 2 – Development of self: participants will be invited to describe the factors that they believe to have contributed to their identity, including the influencing social-relational aspects.

Theme 3 – Understanding of being disabled: an opportunity to have a theoretical discussion about the phenomenon that is disability, inviting participants to give their views on having an impairment and the role this had on being a disabled child.

Theme 4 – Memories of interactions with health and therapeutic services: focussing on therapy undertaken as children, participants will be invited to describe their reflections on their experiences of therapy; the role it played in their lives and their psycho-emotional response to it.

Theme 5 – Perceptions of their body: developing an understanding of the impact of theme four upon the participant's sense of self, participants will be invited to engage in discussion about their physiological state and the relationship this has to the expression of their identity.

Theme 6 – Shaping of adulthood: given their approach to being a disabled child going through the therapeutic process (as discerned from discussions of the previous themes), participants will be invited to envision their lives as adults with Cerebral Palsy, considering their ideas of being social actors, of interacting with social convention and of appropriating an identity as a disabled person.

Appendix D

Interview Schedule

Theme 1 — Memories of childhood: as an introduction to the interview, participants will be invited to talk about their most prevalent memories of being a child. This is intended to scope out the participants' consideration of their status as having Cerebral Palsy.

Question 1: Tell me a bit about your experience of growing up.
Prompt: When do you remember becoming aware of having CP?
Prompt: What was your understanding of having CP?

Theme 2 — Development of self: participants will be invited to describe the factors that they believe to have contributed to their identity, including the influencing social-relational aspects.

Question 2: What do you think shaped who you are? And how?
Prompt: What role did having CP have on your sense of who you are?

Theme 3 — Understanding of being disabled: an opportunity to have a theoretical discussion about the phenomenon that is disability, inviting participants to give their views on having an impairment and the role this had on being a disabled child.

Question 3: What does it mean to you to have CP?

Prompt: How do you feel your CP is viewed by others?

Theme 4 — Memories of interactions with health and therapeutic services: focusing on therapy undertaken as children, participants will be invited to describe their reflections on their experiences of therapy; the role it played in their lives and their psycho-emotional response to it.

Question 4: What do you remember of having therapy during your childhood?
Prompt: How do you think you were viewed by those giving you therapy?
Prompt: How do you think this impacted your understanding of having CP?

Theme 5 — Perceptions of their body: developing an understanding of the impact of theme four upon the participant's sense of self, participants will be invited to engage in discussion about their physiological state and relationship this has to the expression of their identity.

Question 5: How do you feel your experience of having CP has shaped your view of yourself?
Prompt: How do you feel your experience of having CP has shaped your relationship with the people in your life?

Theme 6 — Shaping of adulthood: given their approach to being a disabled child going through the therapeutic process (as discerned from discussions of the previous themes), participants will be invited to envision their lives as adults with

Cerebral Palsy, considering their ideas of being social actors, of interacting with social convention and of appropriating an identity as a disabled person.

Question 6: When you were growing up, what did you envisage life as an adult with CP to be like?
Prompt: What do you think are the main differences of being a child and an adult with CP?

Appendix E

Topic guide for professional participants

Theme 1 - Training and career: as an introduction, participants will be invited to introduce how and why they entered the rehabilitation profession.

Question: Can you tell me how you got into therapy?

Theme 2 - Therapeutic principles: by asking participants to talk to the overarching role of rehabilitation in the lives of children and young people with Cerebral Palsy, participants will have an opportunity to discuss the principles that they apply to providing therapy.

Question: Can you describe the rationale behind the therapy given to children and young people with Cerebral Palsy?

Prompt: Are the expectations of the therapy discussed with the child/family and how are they managed?

Theme 3 - Therapeutic approaches: in considering the methods used in delivering therapy, participants will be asked to discuss what approach they use to achieve the potential outcomes of rehabilitation.

Question: What techniques do you use when delivering therapy, including exercises and the introduction of equipment?

Prompt: How and when do you determine what exercises/equipment would be beneficial to a child or young person with Cerebral Palsy?

Theme 4 - Therapeutic outcomes: referring to the GMFCS, participants will be asked about the outcomes that they expect and work towards achieving when delivering therapy to children and young people with Cerebral Palsy.

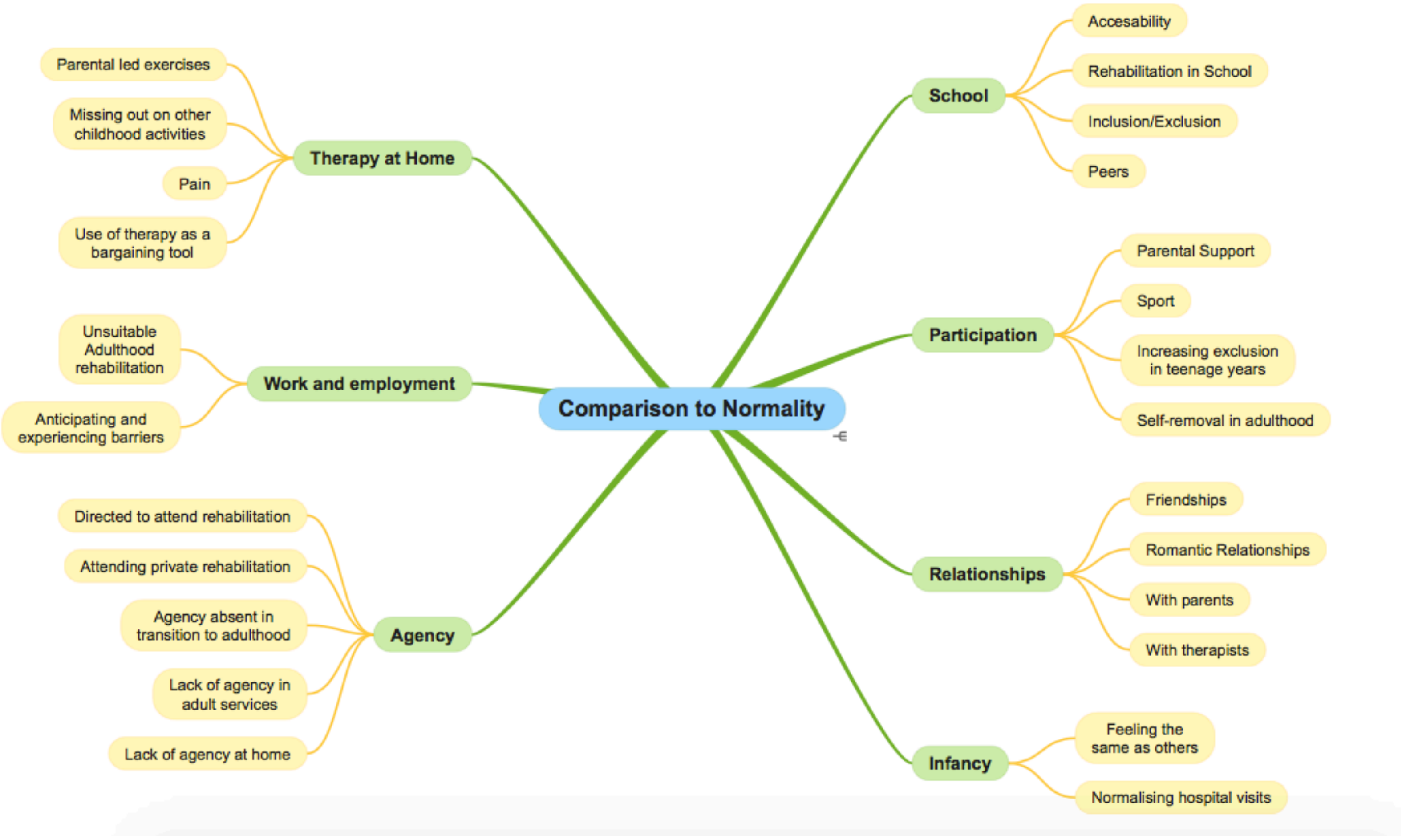
Question: When you're working with a child with Cerebral Palsy, what are the main factors in terms of the outcomes you're looking to achieve?
Prompt: How do you decide when the child or young person has achieved their potential from therapy?

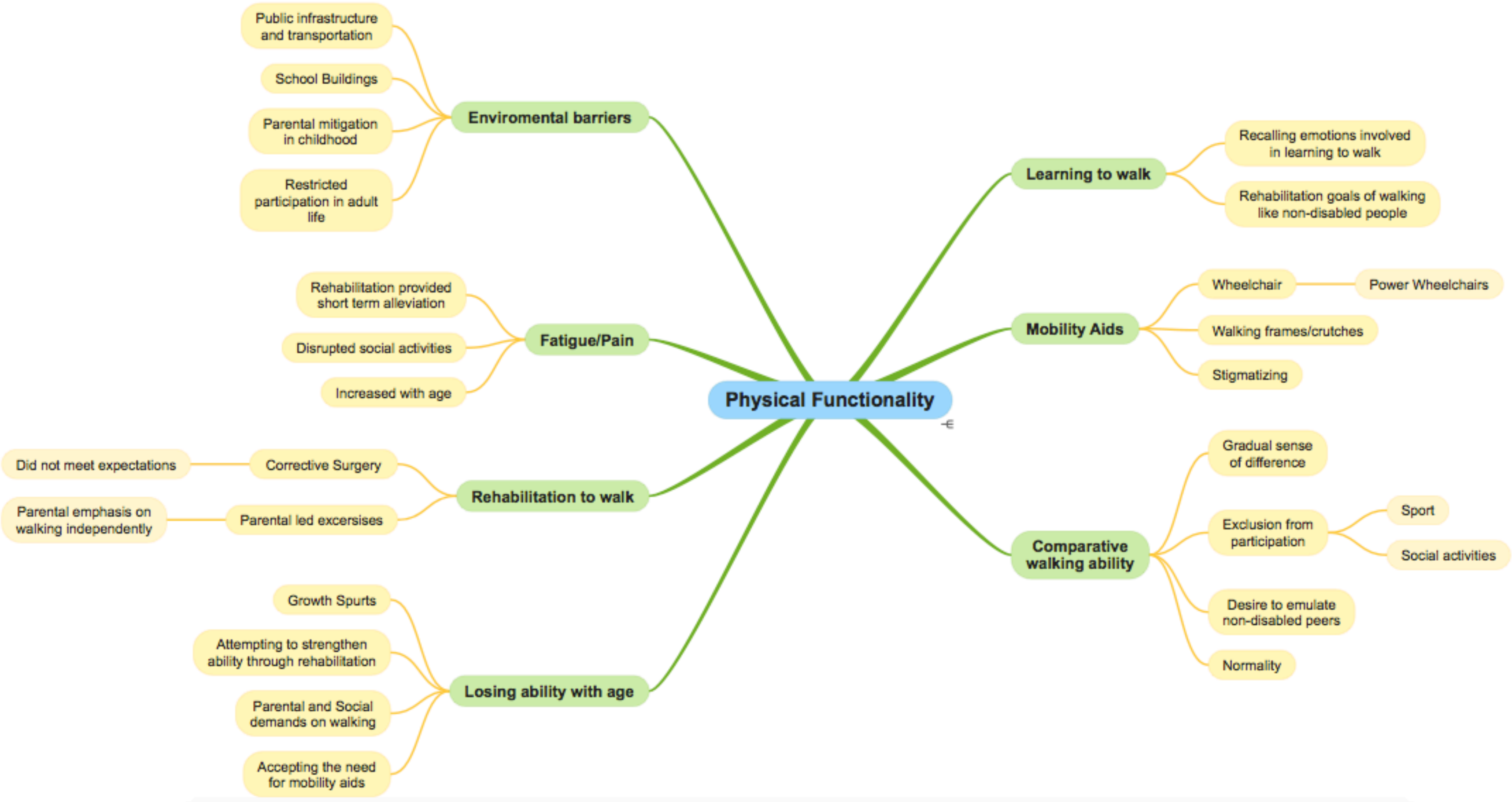
Theme 5 - Therapeutic provision in adulthood: given that rehabilitative professionals typically deliver paediatric therapy, participants will be asked to give their perspectives on the rehabilitative provision available to adults with Cerebral Palsy.

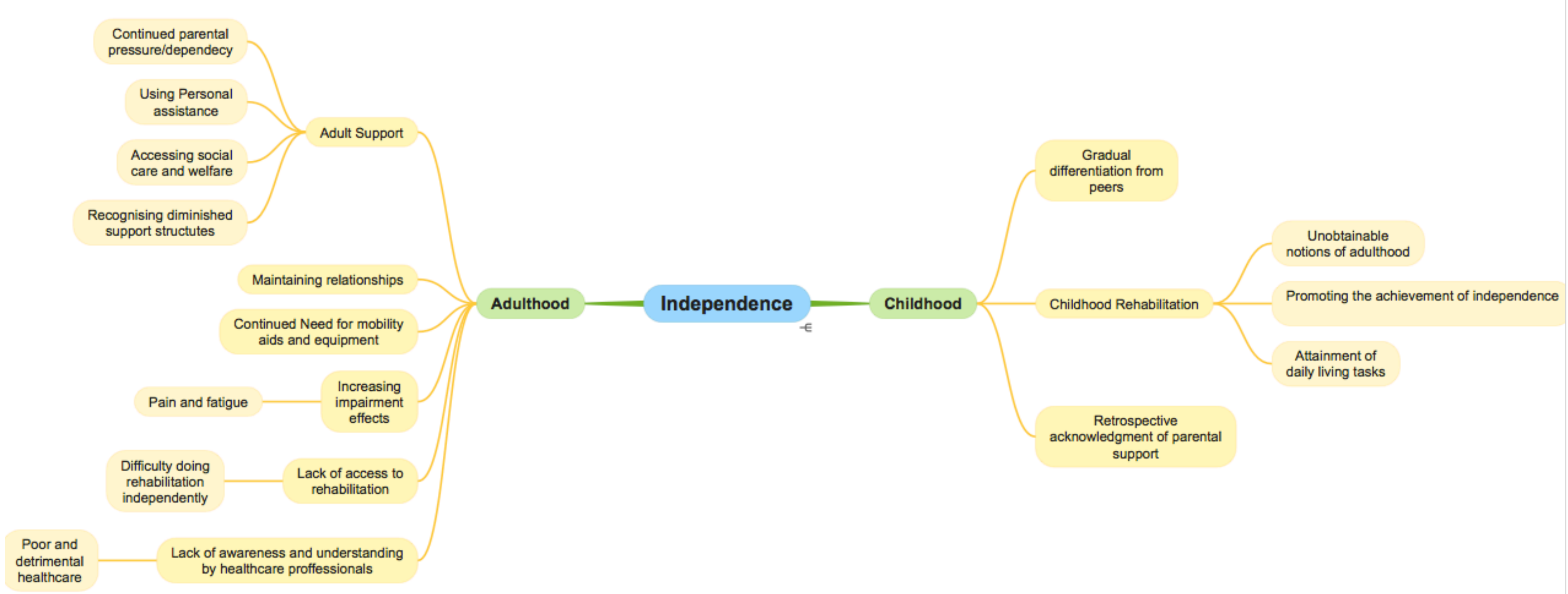
Question: What are your thoughts on the provision available to adults with Cerebral Palsy who have transitioned from paediatric rehabilitation?
Prompt: Do you think young people and adults with Cerebral Palsy would benefit from ongoing rehabilitation?

Appendix F

Coding Framework




Physical Functionality
Enviromental barriers
Public infrastructure and transportation
School Buildings
Parental mitigation in childhood
Restricted participation in adult life
Fatigue/Pain
Rehabilitation provided short term alleviation
Disrupted social activities
Increased with age
Rehabilitation to walk
Corrective Surgery
Did not meet expectations
Parental led excersises
Parental emphasis on walking independently
Losing ability with age
Growth Spurts
Attempting to strengthen ability through rehabilitation
Parental and Social demands on walking
Accepting the need for mobility aids
Learning to walk
Recalling emotions involved in learning to walk
Rehabilitation goals of walking like non-disabled people
Mobility Aids
Wheelchair
Power Wheelchairs
Walking frames/crutches
Stigmatizing
Comparative walking ability
Gradual sense of difference
Exclusion from participation
Sport
Social activities
Desire to emulate non-disabled peers
Normality


Continued parental pressure/dependecy
Using Personal assistance
Accessing social care and welfare
Recognising diminished support structutes
Adult Support
Maintaining relationships
Continued Need for mobility aids and equipment
Pain and fatigue
Increasing impairment effects
Difficulty doing rehabilitation independently
Lack of access to rehabilitation
Poor and detrimental healthcare
Lack of awareness and understanding by healthcare proffessionals
Adulthood
Independence
Childhood
Gradual differentiation from peers
Childhood Rehabilitation
Unobtainable notions of adulthood
Promoting the achievement of independence
Attainment of daily living tasks
Retrospective acknowledgment of parental support

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