“…it's about sometimes falling between two worlds…”: A narrative exploration of adulthood experiences living with ‘mild’ Cerebral Palsy.

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Abstract

Motive for research: This is a thesis primarily for those with Cerebral Palsy (CP) and it can be situated amongst an academic debate which has left a significant number of disabled people's voices outside of discussions around impairment and disability.

Research aims: This thesis introduced these unheard voices and in doing so explored adulthood experiences of 'mild' CP, including how mild diagnoses are constituted and possibly contested in medical, social and personal spheres. A focus on mild is important when exploring the experiences of those with CP given that 'mild' is in common usage and yet its meaning or value is not entirely obvious.

Methods: This research drew on a narrative methodology, producing 24 loosely structured, online interviews. The interviews, though led by my participants, were approached with a topic guide allowing for analysis across narratives. My methodological choices were influenced by my positionality as a researcher with the same condition as those I spoke to. Mild was left as a self-defined term meaning conversations were not fixed around a singular understanding of CP.

Findings: The three findings chapters are: 1. The value of mild, seeing mild as a fluid identity, sat within a discourse of luck and comparison . 2. The strategic use of mild, including discussions of mild as an embodied experience. 3. The realities of living with mild CP, supporting the idea of mild as ambiguous and creating liminal bodies as they negotiate an imagined future ageing with a lifelong, 'non-progressive mild condition.

Discussion/ conclusions: My discussion understands the value of mild within the spectrum of disability, and in turn how these fit within the prevalent normative environments. The research aims to recognise the fluid nature of mild impairment and social disablement, using my participant narratives to be a starting point to rewrite expectations around ageing with CP.

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Author's declaration

I declare that this thesis is a presentation of original work, and I am the sole author. This work has not previously been presented for a degree or other qualification at this University or elsewhere. All sources are acknowledged as references.

1. Introduction

Chapter introduction

This chapter introduces my thesis by first setting the scene, including outlining my motivations and hopes for the thesis. I then provide a roadmap for each thesis chapter, before moving on to a justification of carrying out the research and what it aimed to do. I briefly outline the originality of my research so that I may return to this in my discussion and conclusion chapters. I then continue to 'set the scene' by providing an outline of Cerebral Palsy (CP), including how it is understood clinically and the diagnostic procedures commonly used. This will help to make clear the current bias towards biomedical commentary found around discussions of the potential impact of CP. I then move the discussion to a more specific discussion of 'mild', including an etymology of mild and how mild is applied to CP. Understanding the social and medical understanding of what mild 'means' is vital to later understanding the value that my participants may or may not place on mild. I hope this research highlights the personal, emotional and physical work achieved by those who are required to negotiate their place in our society, often feeling somewhere between or not fully part of either the disabled or able bodied world, as they negotiate a mild diagnosis which may in itself be seen as ambiguous and the real impact of their impairment unknown.

1.1. Setting the scene

Much of the current discussion of CP fails to account for how CP assumes meaning across the life-course, which includes how individuals negotiate the idea of mild. Much of the research focuses on childhood. This thesis works towards trying to meet this gap in the literature with the voices of some of those individuals. I was initially motivated to pursue this research as I felt alone in my experience of mild CP, feeling as though I was experiencing the able-bodied world through a disabled lens. Therefore, I approached the research with the aim to explore what living with mild CP meant to others, whether this was similar or very different from my own experience. This being primarily a PhD in Sociology, I aimed to bring together the theorists who aim(ed) to understand the body, its positioning in our world and the embodied experiences of navigating this, to form a sociological understanding of CP. I saw this as enabling me to seek a deeper understanding of the relationship between the social body and the physical body and think more critically about the relational nature of disability and impairment.

As this is a thesis which focuses on the adulthood experience of CP, I have striven to include current studies that are engaging with adults with CP, as I hope this knowledge will be the stepping stone for further new knowledge on CP beyond the paediatric clinic. I also aim to continue to strengthen the bridge between disability studies and (medical) sociology. Although these debates cannot simply be transcended, I hope that my analysis and discussion points highlight the value of bringing these two schools of thought together. CP, like many other physical disabilities, is experienced both corporally and socially, and those that live with it deserve to be listened to and receive social and medical support. Thus, when looking to understand their experiences, the value of an approach which incorporates consideration of the current medical and social frameworks of understanding, alongside subjective feelings, cannot be underestimated.

Considering the scope of the project and the stark differences across different countries' medical systems, it was necessary to limit my recruitment to those in the UK, although I was approached by and therefore become aware of many more people who identified with and wanted to speak on mild CP who I was unfortunately unable to include in the interviews. This points to the possible benefit of a wider comparative international study. The interviews were conducted with men and women in the UK, aged between 26 and 65. Due to Covid-19 restrictions and to facilitate accessibility, the interviews were conducted online. I am deeply grateful for those that spoke with me; our conversations held such personal and analytical value, the complexity of which I hope I have managed to convey. Mild CP carries a multitude of meanings and these meanings can be fluid. Mild is not a fixed identity and the embodied knowledge of this fluidity of impairment and disability has been historically overlooked in debates surrounding the disabled body.

I hope readers of this thesis develop a new or deeper understanding of living with CP. For those that live with CP, I hope they may feel less alone, seeing at least an element of their experiences mirrored in the words of those I spoke to. Their stories may act as a stepping stone to an awareness of the complexity of living with CP and 'mild' conditions, and challenge society's desire to primarily classify CP in terms of physical functionality, ability, or social integration.

1.2. Why focus on mild?

This research allows disabled people to be kept at the centre of the research, and their biographical and narrative accounts will help to keep the context of their life and therefore the context within which they experience their CP and negotiate the value of mild. This is important, as although there is common usage of mild when talking about CP, the meaning remains unclear.

The focus of this research will be the lived experiences of those who have CP, a lifelong or long-term disability or health condition, assigned as ‘mild’ in its diagnosis. There are overarching debates within and across sociology and disability studies as to the degree to which research should focus on the individual or on the wider contexts of the body and disability (Shakespeare, 1998). There appears, therefore, to be a need to bridge these two perspectives and contribute to the empirical research that speaks to these two areas. Furthermore, the focus and aim of this research will also be to include in these debates the sociology of diagnosis. There arguably needs to be a more complex analysis of the real-life experiences of those with ‘mild’ but long-term physical disabilities and health conditions. As well as the need to make explicit the social experience of impairment with the structural issues of inequality and the power relationships that these depend upon, I also wish to highlight and challenge the distinction between so-called able and disabled bodies, and how this distinction is made, notably through medical diagnosis of conditions and disabilities, and moreover the work that is done through these diagnoses via the distinction of the severity of the condition or disability. By its very nature, ‘mild’ diagnoses are ambiguous, in-between, liminal in some way and within this context traditionally signify the presence of an impairment with a lesser degree of disability. To even come to a decision of what constitutes a mild diagnosis is contested and dependent on medical and social discourse. This research will draw upon this work of medical discourse, and classification work by Durkheim and Mauss ([1903]1963 , Parsons (1951), and Douglas (1966,1997) and consider such sociological frameworks alongside the sociology of diagnosis (Brown, 1990) and of disability studies, rather than seeing these as in some way separate to one another. To this end, the central ontological talk for this research will be to ask what the label of ‘mild’ disability or health condition constitutes, and in doing so to explore the social, political, and personal consequences for those who are given these diagnoses. This research adds depth to our current academic understanding of a lifelong disability and reminds us about making such experience normative rather than exceptional.

1.3. Thesis roadmap

CP is more often than not viewed through a paediatric lens, further realised by the clinical classification of the condition as non-progressive. This leaves detailed discussions of the impact of CP in adulthood missing from academic and social understandings of CP. Furthermore, the over-reliance on clinical descriptions of CP, without sufficient consideration of how individuals may self-identify with other descriptions of their disability, including a discourse around 'mild', means that the lived experience of individuals with 'mild' CP are also currently missing from research spaces. The following section will outline the structure of this thesis including the content of the substantive chapters, which tell the story of adults with mild CP.

Chapter 1 will set the scene for the research and introduce the topic of mild. This chapter will consist of an outline of the research focus and aims, and an overview of the current dominant commentary surrounding CP, namely its clinical classification. It will also provide a justification for the focus on mild, from an etymological and academic point of view. In deconstructing mild in this way, I will begin to establish mild CP as a worthy area of academic study as well as demonstrating that the idea of mild was not something that I imposed upon my participants, but rather it carries meaning for them outside of the interview.

Chapter 2 will present a review of the literature from foundational sociological writers, writers from medical sociology specifically and disability studies. This chapter will then close by discussing the papers that currently focus on mild CP, highlighting the significant gaps within this, and a lack of discourse around the experiences of mild CP. This chapter will be foundational to my analytical chapters, as I use this space to unpack the theories and models which underpin my approach to understanding disability and how the social model of disability is taken forward by namely Carol Thomas to form a social-relational model of disability. A detailed exploration of why and how I feel this model best complements my participant narratives will be left for this chapter, however, a key component of this chapter will also be an attempt to bridge tensions between medical sociology and disability studies to arrive at a more comprehensive and multidimensional starting point for understanding mild CP through the words and experiences of my participants.

Chapters 3-4 will outline the methodological choices I made in order to collect these perspectives, detailing not only the practical steps I took, but also give an account of how my positionality as a researcher living with the same conditions as my participants influenced the recruitment and data collection processes. I will close these chapters by making the link clear between my interview topic guide (the questions that formed the interview conversations) with the analytical themes I will then go on to present. I chose to group my methods into two chapters in this way, as it allowed me space to fully discuss the more original elements of my methodology and the standpoint from which I began the research, whilst also being able to give a clear overview of the steps I took to recruit, conduct my research, and complete my analysis.

Chapter 5 will introduce the participant demographics to lead to the three subsequent empirical chapters.

Chapter 6 presents the first empirical material which explores both why people chose to take part in the research, and it also includes material on how they considered themselves to ‘have’ mild CP. This will introduce the complexity that the mild label encapsulates, which is vital to recognise when examining the empirical material this will lead into an analysis of the value of mild, and where it sits within the spectrum of disability experienced by those with CP. Given the subjectivity of what constitutes ‘mild’ and the way it is experienced, it then follows that the second empirical chapter (Chapter 7) discusses how rather than carrying a singular meaning, mild becomes something which can be strategically employed to enable the social negotiation of binary environments. The final findings chapter (Chapter 8) builds on this to explore the effect of mild on the life course, specifically the realities of living with a ‘non-progressive’ mild condition and the imagined futures that derive from this. A summary of the analytical findings will be presented in Chapter 9.

What remains for Chapter 10 is to interweave these stories of mild into the current sociological and disability discourse (contained in chapter 2). By introducing these missing voices, my discussion chapter will locate a summary of my findings within the literature and in doing so point to the applicability of the research findings to everyday lives, social policy and academia.

My final chapter, Chapter 11, will reiterate the originality of this research, looking forward to the future study that may arise from it, whilst also reflecting on limitations of my research and how I may have approached this topic differently.

This research was carried out *with* people who self-identify as having mild CP, and its findings are presented first and foremost for them. Initially motivated by a personal desire to hear from others who may identify with my own experiences of CP, in doing the research I have brought together multiple voices that paint a complex and vivid image of the realities of living with mild CP.

1.4. Why do the research?

This research is focussing on life with mild CP, a condition for which the impairment is not always reflected in the disability, nor the disability reflected in the impairment. That is to say that a ‘mild’ impairment may not relate to a mild disability and a more severe impairment cannot be always assumed to result in a higher level of disability. Rather disability could instead be seen as being on a continuum, and therefore contextual. This research is set within a clinical context which has a higher concern for what people cannot do rather than what they can. The focus for this research is on the latter. My approach was not to ask participants to explain what they struggled with, but to share their experiences, which may contain struggles within them. This shift away from seeing disability solely within a framework of risk and precarity could contribute to how disability is understood. I was not looking to disrupt or challenge ideas of what it can mean to be disabled merely for disruptive sake, but rather I was looking to improve care. Care is an element of disability (and indeed everyday life) which I will return to later in my discussion chapter.

A key imperative to conduct this research is that not enough work has been done to challenge the assumptions that society holds as normal and the expectations placed on adult bodies. A space needs to be made for contradiction, change and fluidity around disability and impairment. Currently, understandings of lifelong 'non-progressive' impairments are largely fixed at the point of diagnosis, and disabled identities are formed by the medical checklist that determined their diagnosis. Allowing for change and fluidity will not only expand our social understanding of disability but also improve medical care provision. There should be fewer assumptions that care is not needed post-16, and an acknowledgement that adults with CP continue to live with their CP beyond childhood.

Thus this research aims to demonstrate the complex negotiation between how the individual sees themselves and their disability, the way others see and respond to them. Other people's negative response to impairment becomes the basis for disablement. Though the intention may not be ableist, the result is to make assumptions. This goes further than making surface observations of someone, rather it presumes to know the abilities of a person and therefore how they 'function' within society. The judgments may not even be made consciously, but they are there and they do work to distinguish between those that appear to occupy a 'normal' body, and those that do not. These norms shape the normative environment which people with mild CP must navigate and within which the value of mild is negotiated.

1.5. Aims and research questions

Research questions

I began this research with the following questions in mind:

1. What are adulthood experiences of mild Cerebral Palsy?
2. How are 'mild' diagnoses constituted in medical, social and personal spheres?

3. To what extent are diagnoses of mild Cerebral Palsy contested?
4. How do people living with 'mild' Cerebral Palsy manage and negotiate their disability, body, and identity?

These questions highlight that the focus of the research is to look at how mild is made sense of within every day, medical and academic settings; how ideas of mild may be challenged or contested and how people with mild CP negotiate this alongside their sense of self and the personal value of mild for them. These questions will be helpful to return to throughout the thesis, as once unpacked, they contain within them several related sub-questions. For example, how is the adulthood experience of CP influenced by a person's experience in childhood? What is the normative environment that shapes how mild is constituted? How might people with mild CP use the term mild, and in what ways may they conform or resist expectations around this? And finally, what is the reality of life with a condition termed as non-progressive?

Each of these questions could have been investigated in their own right, however within the scope of this thesis, this research attempts to bring these questions together to present original narratives on life with mild CP. A key aim of the research was to allow the participants to have a role in shaping the topics that were explored, and the focus they chose in their narratives reflects this. The research questions above provided a framework from which to analyse the empirical material. Although there is not one singular answer to these questions, continuing to seek answers opens discussions around the role and value of mild, something which is yet to be explored in relation to CP. A key goal for this research, therefore, is to highlight this overlooked experience of CP and disability more generally. A more detailed overview of the aims is outlined below.

Aims

As outlined above, the aim of the research being proposed was to explore and make visible the lived experience of those who have what is regarded as a mild but long term or life-long physical disability or health condition (CP). The ambiguous nature of a mild diagnosis is seen in the difficulty there is in defining what 'mild' is. The focus was to carry out research drawing on a narrative methodology, to unpack broader ontological questions such as how are disabilities and long-term health conditions defined? What occurs when an individual is given a diagnosis of having a 'mild' form of disability or long-term health condition? Furthermore, how do individuals with this contested diagnosis manage their disability, their body, (and potentially their identity), within a social world built upon fixed categorisations and social groups? The notion of social order, classification and the division of the sacred and profane are well theorised by Durkheim, Mauss ([1903] 1963) and Douglas (1963, 1966) and their theories can be drawn upon to understand how the complexity of people and bodies may not entirely fit into certain spaces. Therefore, the research is aiming to highlight the complexity of lived experiences with the lifelong disability of CP within our normative and binary society. For the purpose of clarification, I approached the research with the following foci: recruiting adults with a medical or self-diagnosis of 'mild' CP (without an intellectual disability) for the purpose of collecting interviews. I aimed to identify narratives through these interviews, to then later synthesise common (and where relevant, conflicting) stories across individual narratives. I hoped that these narratives would be drawn upon to ask questions of the social, medical and political positioning of 'mildly' disabled bodies. A narrative methodology was drawn upon and adapted to the best fit to the research questions and importantly in response to the empirical material. My methodological chapters below outline this process in greater detail, however it is relevant to highlight here the many more participants I was able to recruit than I had anticipated, which suggested that mild carries a meaning to people that is not always reflected in the literature, hopefully suggesting an originality to the research. The interview space allowed people to express their feelings in a way which I have then aimed to make accessible for others to learn from (Riessman, 2007).

1.6. Originality of the research

The desire to learn about how people live with impairment has arisen through a critique of focussing on curative medicine. This shift has allowed for the space to consider the complexity of the experience of impairments including ideas such as mild. It is important to also recognise these as embodied experiences of disability, to allow me to consider how bodies interact with their social environment to produce disability (Shakespeare, 2006). My research is trying to contribute original thought to this by locating this experience sociologically and connecting it to the life-course. There have been increasing efforts to include studies on adults with CP, which will be explored further in my reviews of the literature below, however none are yet to focus solely on those with mild conditions.

The people I spoke to have been previously unheard voices and their stories are able to highlight the everyday realities of living with mild CP. Being able to bring attention to these realities is part of the originality of this research, bringing these stories in discussion with sociological understandings of disability and health. Current literature which explores ideas of CP does not focus on mild forms of the condition and mild CP is mentioned only briefly in a handful of studies from the UK. However, this research is not only original in topic; I also chose to not add descriptive limits to what 'mild' could mean to people. Therefore, the group of people I went on to speak to have a range of manifestations of CP with varied ambulatory abilities, as this in itself suggests that our current understandings of disability are limited and confined by normative ideas of functionality and ability. This is a further original element to the research, and I believe allows for a widening of our understanding of how people live with CP and how they make sense of their impairments within their everyday lives. My participant demographic table reflects this variety of ‘levels’ of impairment, although the majority of the people I spoke to were unable to or felt it not relevant to provide a diagnostic ‘Gross Motor Function Classification’ level, which is often used as selection criteria for CP research. The collaborative nature of the interviews, and the way in which my positioning as a researcher allowed people to feel able to share their experiences with me which they otherwise may not have done (which I will return to in my methodology), leads me to hope that original insights into their experiences have been facilitated. These insights on life with mild CP, therefore, will contribute original thought on how to support those with mild CP to navigate medical and social care, and therefore encourage deeper understanding of the barriers that having mild CP can have on how people access care. This research has given sociologists an opportunity to continue to learn about the relationship between disability and impairment from a point of view that has not yet been fully explored, from people’s past and ongoing lived experience of a multifaceted and fluid experience of disability and impairment.

I would like to pause here to reflect on the ideas presented thus far before continuing to justify my focus on CP and further describe how CP is currently understood. This research has aimed to carry out research for those with mild CP, with myself as a researcher with mild CP, to ultimately learn about how ‘mild’ is described, used, and negotiated in the lives of those who see themselves as having mild CP. This research aims to begin to fill gaps in our current understanding of how CP, as a clinically non-progressive condition, is not experienced the same way between people or even by the same person. CP is a complex disability that although medically classified as largely made up of physical impairments, has significant social and emotional implications for those with CP and their families. By looking at CP, I hope to not only contribute to knowledge around the disability but also challenge fixed notions of what being disabled is.

1.7. What is CP?

Despite this being a qualitative study of the subjective knowledge of mild CP, it is not possible to begin to understand how mild CP is realised and experienced without first acknowledging the common discourse when people speak of CP, that ultimately still largely arises from biomedical understanding of the condition and its disabling impact. Therefore, this section of the thesis will discuss the ways in which CP is clinically classified and presented. It will begin with a justification for including clinical literature and its place in the conceptual framework for this thesis. It will then explore the clinical understanding of CP. This will then lead to the closing paragraph discussing the diagnosing of CP, including the most commonly associated measuring and classification system, the Gross Motor Function Classification System (GMFCS) and the role this can have in the categorisation of the varied manifestations of the physical impairments associated with CP. I feel that it is important to start here to begin to understand where 'mild' may fit within medical classification of CP. The following section has an important place within this thesis, as it sets the scene for how CP is understood particularly in medical but also lay spheres, the subsequent chapters will also then periodically return to the clinical definitions and understandings of CP, to continue to contextualise how mild is then also understood.

1.7.1. A justification for including clinical literature

The clinical literature that describes and makes sense of CP has considerable influence in defining the space in which CP is discussed. Regardless of the extent to which people draw on the medical discourse to describe their own experience in their everyday lives, CP is still first and foremost understood within biomedical classificatory systems. Although my research aims to move away from the constraints of a biomedical framework, it would be impossible to fully understand the empirical material I will be presenting without acknowledging the medical context from which societal and individual understandings of CP are based. Hence, it is possible to justify the inclusion of clinical literature into the conceptual framework of this thesis, as they are too interwoven into everyday understanding of CP. Hence, this review will open with a brief history of CP, providing the wider context to the brief history of mild and subsequent review of the current literature dealing with mild CP specifically. This general history will include topics such as the historical understandings and treatment of those with CP, for example the role of social segregation in education and in wider social spaces. There will also be a consideration of the expectations of the disabled body, and how this has changed overtime.

Although necessarily limited by the scope of this thesis, these important overarching ideas will lead onto a closer examination of the question 'what is CP?' This will include contemporary clinical definitions of CP, and the categorisations or groups of symptoms into 'types' of CP, as individuals do define aspects of their experience, in relation to such categorisation, which is not neutral. This includes the question of severity, which will tie this section back to 'mild' help to situate where mild sits within clinical labels. Importantly, I will use this to consider why these clinical classificatory systems are necessary in the first place. Building on the concept of severity, I will then explore how 'severity' is determined. That is to say I will look at the diagnostic processes around CP, including the

GMFCS studies which have explored the experiences of receiving a CP diagnosis, and the meanings, feelings, and emotions that people attach to this, including a late CP diagnosis. This section will therefore provide a means of understanding if and how there is a clinical identification of mild CP. This review will then move on to explore what a mild diagnosis is presumed to mean for adults living with CP, including the literature around ‘functionality’, Quality of Life measures, and the ‘social integration’ of those with CP. All of these elements focus on the individual rather than the societal response to CP and disability, showing how the individual, in effect, becomes responsible for their own vulnerability and precarity, despite relatively few studies of the above topics directly involving the voices of those with CP.

It is important to make clear here now that, where possible, the literature included in this review will focus on the experiences of adults with CP. This is however going to be a fairly difficult task as so much of the current discussion remains around childhood experiences of CP rather than adulthood. Although more studies on adulthood are emerging, this review will demonstrate the gaps that remain in this area. Nevertheless, key available literature regarding CP and adulthood and ageing with CP will be included, such as studies looking at CP from a life course perspective, studies on CP and motherhood and/or parenthood. These studies will be used to explore the knowledge that available studies are providing and the extent to which these challenges ideas of how trajectory and mild CP is perceived. This review will show the significant gap that exists for studies around mild CP and even more so, for studies around mild CP and adulthood. The literature review in chapter 2 which attempts to locate mild within current studies highlights this gap in more detail, and also begins to suggest how mild is used in more complex ways that the clinical classification of CP would suggest. This therefore points to the importance of this research as an opportunity to hear about mild CP from those that experience it.

There is a small amount of grey literature which needs to be acknowledged as so few studies have studied mild CP. This includes the information that is available in the public domain (especially in lay terms) for those with mild CP, parents, carers and schools. There are also blogs which are developed by those with CP, which outline their experiences and create a site for public discussion. I also wish to acknowledge the online communities within which mild CP may also feature. Although it is not possible to include specific posts from members, I feel that it is important for me to acknowledge member sites such as those on SCOPE and the social media groups from which I initially joined as someone with mild CP, and then later recruited from for my research, which over the years have provided a source of knowledge for me and others within these online communities around a topic that is so strikingly under researched.

To avoid this section of the thesis becoming a standalone feature, I will pause throughout the review of the literature, to reiterate how the ideas that arise in the literature fit within the narrative arch of the thesis. It is important that the conceptual framework of this thesis fully explores the complex interdependence of biomedical knowledge and embodied knowledge that underpin life with mild CP.

1.7.2. Clinical presentations and classifications

CP includes a group of permanent disorders of movement and posture that cause limitations to activity. CP is heterogeneous and thus has various classifications but is often classified on clinical findings and motor impairment (Saranti et al, 2024). There are standardised classification systems, working towards an early diagnosis, which will be explored in further detail below. However, they help to make up a wider "therapeutic regimen", focussed on the prevention of motor problems, improvement of movement, communication skills and the prevention of secondary impairment. The incidence of CP ranges from 1.5 to 3 per 1000 live births worldwide (Saranti et al, 2024, p.49).

CP is typically diagnosed between 1-2 years of age, and it's manifestations are most commonly classified into one of the following groups: spastic, dyskinetic, ataxic, hypotonic or mixed (these are also correlated to the body part affected) (National Institute of Neurological Disorders and Stroke, 2024). There is a commonly held idea of CP as non-progressive (Manji, 2014). Doctors classify cerebral palsy according to the type of movement disorder involved: spastic (stiff muscles), athetoid (writhing movements), or ataxic (poor balance and coordination). Although the brain injury is thought to not worsen over time, CP can place great strain on the body and cause additional strain and contribute to co-morbidities on the body particularly in later life (National Health Service, 2023).

More than 80% of individuals with CP are expected to live beyond 58 years. Survival and mortality rate depends on the severity of the impairments (increases with the severity) and the type of motor impairment (Saranti, 2024). It is important to introduce survival statistics here, as it points to a significant and growing population of people who have been historically under cared for and listened to, the adults with CP. It also begins to challenge the idea that the focus on the impact of CP remains on children. It is not too difficult therefore to see why adults with mild CP may have largely been lost within the current medical and social care systems. There is currently little room for discussion of where someone with mild CP may fit within these classifications, other than being seen as less impacted by CP than those with a more severe impairment. For those living with mild CP, they are often left with both their medical diagnosis and how they come to make sense of this. This means that their experience of a certain CP diagnosis may differ from the expected and assumed experience. Therefore there can be multiple understandings held of the same body, with the medical knowledge often holding more weight than embodied knowledge. This thesis hopes to begin to bridge the gap between these understandings. Medical knowledge of CP often begins at the point of diagnosis, as it is how severity of impairment is clinically determined.

1.7.3. Diagnosing CP – GMFCS and other diagnostic measures

A key source of information regarding the GMFCS (including the Expanded & Revised version) is CanChild (2024). The Gross Motor Function Classification System - Expanded & Revised (GMFCS - E&R) is a 5-level classification system that describes the gross motor function of children and young people with cerebral palsy on the basis of their chosen movement with particular emphasis on sitting, walking, and wheeled mobility. There is emphasis on usual performance in home, school, and community settings, i.e., what they usually do, rather than what they are known to be able to do on a 'good day'.

The GMFCS - E&R is a widely used method for classifying the movement ability of children with cerebral palsy. To date, use of the GMFCS - E&R has relied upon a health professional to classify a child. The newly developed GMFCS Family and Self Report Questionnaire presents an option for parent involvement in classifying children's motor abilities. The questionnaire is available for four age groups of children and youth: 2 to < 4 years, 4 to < 6 years, 6 to < 12 years, and 12 to 18 years (CanChild,2024). Children who have motor problems similar to those classified in "Level I" can generally walk without restrictions but tend to be limited in some of the more advanced motor skills. Children whose motor function has been classified at "Level V" are generally very limited in their ability to move themselves around even with the use of assistive technology. This hierarchy is reflected in the etymological connotations of mild. That is, mild is etymologically understood to be less severe or to have a lesser impact (there will be further discussion of this below), however it is not necessarily reflected in the stories of my participants as their experiences were not as linear. It is important to acknowledge that the GMFCS does not include the judgements about the quality of movement or prognosis for improvement, therefore it arguably can only be a starting point within its temporal context for how the impairment of CP may impact people.

The GMFCS is not the only measuring system for CP, another being for example, the Manual Ability Classification System (MACS). This focuses on someone's ability to use their hands for daily activities, again this information is usually relayed by the parents as an assessment is carried out on how their child 'performs' in their everyday activities (CP Scotland, 2025). This needs highlighting to reflect the context of physical functionality and ability in which CP is understood. Compagnone et al (2014) compared the GMFCS-E&R and the MACS, along with a third communicative function classification system in children (including those aged 18) to argue that they complement one another well and when used together can provide a clearer functional profile of CP. What remains interesting is for those I spoke to, only two were able to provide their classification number on the GMFCS, with some providing a self-estimate of where they may fall upon this. Therefore, this raises questions of how applicable classification systems such as these remain relevant for the everyday lives of those with CP, and specifically for those with 'mild' CP, they may provide more of an objective measure of functionality, however only if their functional ability is actually reflected in the boundaries of the measures. The measures place value on the physical ability of the individual and in doing so the physical independence of the child within their physical environment. For those I spoke to, independence was not always measured in the same way especially as they find a space for their experience of mild CP.

Consequently, the question is raised, how relevant the measures remain throughout their life course. Jahnsen et al (2006) were studying the GMFCS and the consistency between self-reported and professional classifications. Specifically, the reliability of reporting and the changes in this assessment of function levels over time. To assess this, they compared patient-reported assessment of their own function with a physiotherapist. More than half reported stable functioning levels, with changes attributed mostly to the physical or social environment. Similarly, McCormick et al (2007) looked at the stability of the GMFCS in adults with CP determining the stability of the GMFCS between ages of 12 and 18 in the US rated based on their last interaction with a rehab specialist and compared to childhood records. They found that the levels observed as a child were highly predictive of adult function. This suggests that there is some relevance to these measures for establishing patterns in diagnosis to impact CP in adulthood, however they may only be helpful for those who are able to identify with them and should be used in conjunction with subjective and personal knowledge of their own bodies.

The measures may begin to outline the anticipated impact of the impairment and provide a clinical identification for milder forms of CP, however this can only go so far in presuming the meaning for a mild diagnosis in adulthood. Again, the focus on functionality leaves out a significant proportion of the experience of CP, including the social and personal impact of the condition, even when first identified as having a lower level of impact for the child. The future disablement experienced by those with mild CP may not be accurately categorised as 'mild' or being less impactful of their everyday lives. These classifications are focused on impairment and have less to say about disability, which is the focus of my thesis. A mild diagnosis is presumed to mean that the CP will have less impact and produce less barriers on participation of everyday life. The diagnostic measures that suggest this focus on the relatively higher levels of physical function that are presumed to be associated with a mild diagnosis. This section has highlighted these measures to begin to outline the clinical landscape in which CP is understood. There is however a wider understanding of the term mild, which is also relevant to this thesis. The following section will present an etymology of the term mild, focussing on how it has been historically understood in a medical-social sense, and its relevance to CP.

1.8. What is mild: a brief etymology

This is not an exhaustive etymology of mild, rather, I focus on the relevant understandings of mild established over time. This section works here, following a discussion of the clinical processes surrounding the diagnosis of CP, as it introduces the interactional nature of mild, which can then be shown to be informed by lay and social understandings of what 'mild' means. These understandings arguably reflect, or at the very least inform, the ideas of the hierarchical nature of the GMFCS. A less impactful impairment is assumed to carry less of a disability, in other words, mild is presented as the opposite of severe, thus 'mild' could be seen as a bridging idea between impairment and disability. This binary relationship is recognised by my participants, seen later in the analysis, in the discussion of "luck" and the heavy focus on comparing yourself to people seen to have more 'severe' forms of CP, or those who appear able bodied, and how this influences their interpretation of themselves as having or once having mild CP.

This etymology will begin by exploring the historical etymology of mild, bringing this into discussion with sociological literature concerning classification and social boundaries to situate 'mild' within everyday discourse. Drawing on an understanding of how 'mild' is made sense of outside of CP, I will outline how it is used and acquires meaning within the diagnosis and categorisation of CP. This will be used to conclude the chapter in a final discussion of how my empirical questions were designed to fill gaps in the knowledge of how 'mild' CP manifests itself within the personal and social lives of the participants.

'Mild' needs to be treated as more than type of CP, and instead as a lived experience, through which individuals negotiate meaning. As such, my analysis of the empirical material works towards a better understanding of the relationship between the impairment and the embodied experience of CP. Disablement is at the centre of this experience, although this is often overlooked in favour of more quantitative categorisations of diagnosis (Atkin et al, 2023). Hence, 'mild' provides an analytical lens through which to better understand CP, and importantly, locates experiences within the context of a negotiated life course, rather than an expression of linear biological ageing. This chapter will begin by reflecting on the etymology of ‘mild’. This lays the foundations for a reconciliation of critical sociological debates with discussions about the meaning of ‘mild’ in relation to how individuals with CP make sense of their health and wellbeing.

Such examples show dimensions in disability, of which mild is one, and move away from presuming that CP, and potentially other lifelong early acquired impairments, remain static and stable. This thereby enables a consideration of diagnoses as a dynamic and personal experience negotiated within social and normative contexts. The value of adopting a mild lens facilitates this by first questioning the relationships between individuals and their diagnosis and second, demonstrating how disabling experiences are historically, socially, and personally known, rather than an easily defined and predictable experience.

Using mild as an analytical tool, therefore, raises useful questions, when making sense of disabling experiences, such as why does this categorisation of mild exist, and what role does it play in both the experience of CP, as well as disability more generally? At times a tool for self-identification and embodied agency, mild is also a classificatory system, reflecting power relationships and hierarchies, and the tensions that can result from this. The thesis, by prioritising individual narratives, facilities the voices of those regarded as disabled. It foregrounds their experiences and offers an opportunity to listen to their accounts. This is not always the case in an area dominated by more medically oriented discussions.

1.8.1 Etymology and definitions

It can be helpful to first take a step back and look at the origins and connotations of ‘mild’ to demonstrate its medical and social history, alongside its linguistic origins, as there is often a cultural nature to the etymology of words (Williams, 1976). This etymology will be understood within the context of sociological theory to suggest reasons for the application of ‘mild’ as a diagnostic and social label, when understanding disabling experiences. This will help to facilitate an account of disability that is better connected to people’s narrative experiences and negotiation of social (and temporal) contexts.

‘Mild’ comes from the middle English form ‘mylde’ and ‘milde’ from the 1500s. It originates in Middle Dutch, Middle Low and High German. The Oxford English Dictionary provides the following definition: “Gentle and conciliatory in character, disposition, or behaviour; not easily provoked; not giving offence to others; not rough or fierce in manners. Of manners, behaviour gentle, conciliatory.” Oxford English Dictionary (2021).

This suggests that there is an expectation for that which is labelled as 'mild' to be inoffensive to others, the responsibility for which is placed on individuals. When applied to disability, and specifically the social management of impairment, this highlights the social-relational aspect of disability and impairment (Thomas, 2004). It also raises the possibility of having mild consequences of a condition, which can then be used to distinguish from more severe expressions, within individual narratives, as a way of making sense of experience. This will be further explored in the presentation of the empirical material, but for now, my account highlights an association of mild with (in)visibility. This invisibility is often presumed to be associated with less demanding symptoms in everyday life. However, for those living with mild CP, how they feel and experience their condition may contradict this. Hence, as 'mild' carries the expectation that the impairment is socially discrete, this may mean that the extent of their disability, and in turn, medical/social needs are overlooked or oversimplified.

Further definitions of 'mild' offer more insight into why 'mild' symptoms may be overlooked. For example, "Of a person's attributes, characteristics, etc.: moderate, slight; not marked or extreme." Oxford English Dictionary (2021). The significance of this definition is two-fold; it attaches moral significance to mild, as it describes an individual's character, and it also highlights how something considered mild is often seen as less "marked" and therefore presumably less evident. This has links to the visibility debates surrounding disability (Spirtos and Gilligan, 2022), also see discussion in chapter 2 regarding (in)visibility debates, (pp.40-41) and can be further understood within the anthropological/sociological literature that discusses the physical body as means for understanding the social world. Mild is categorised as 'slight', and applied to disability, this could mean impairment is unremarkable, leading to the presumption that so too is the disability. Douglas (1996) conceptualises the body in two forms: the physical and the social. One influences the other; the social influences the way the physical is perceived, and the experience of the physical body is mediated by the society. The two bodies reinforce the categorisation of the other. This helps to explain how a lay understanding of 'mild' as the opposite of extreme, could reflect the *medical* framing of mild as the opposite of severe. An understanding of one helps to uphold understanding of the other. However, because these social boundaries are maintained through a collective acceptance of the meaning of 'mild', it leaves open the possibility of individual transgression of these margins (Douglas, 1966). With order comes margins, and with margins comes the possibility to transgress them. Boundaries can be made visible through a discussion of where the margins of the boundaries lie, discussions which are evident in my empirical material. Therefore, how mild is understood socially influences how people make sense of their experience with mild CP, and this is further made sense within the context of the medical use of 'mild'. Therefore, mild offers the opportunity for comparison. This can be at a level of conditions, such as x is milder than y. However, it can also have a more strategic role in how individuals understand their disabilities.

As I will go on to explore in my empirical chapters, employing mild as a description of their CP can have differing consequences, depending on the social/interactional or even physical context in which it is used, or the choice to use mild may alter throughout their lives. There is a spatial element to the use of mild (influenced by the *physical or social* environment that they may find themselves in) and a *temporal* element (for example, they may choose to no longer use mild to describe their CP in a certain context, where they once may have done so in the past).

1.8.1.1. The use of mild in medicine

The medical use of mild also has a history which begins in the late 1600s. It was used initially to describe symptoms of pain or certain illnesses, notably Smallpox by the English Physician, Thomas Sydenham. It was deemed possible to have a mild form of Smallpox, and as such it was now possible to use mild to categorise health conditions. With this, the phrase 'milder' was introduced, still within medical discourse, which further suggests how 'mild' played a role in the introduction of medical classificatory and comparative systems: ""inoculated Cow-Pox is a much milder and safer disease than the inoculated Small-Pox" (see Riedel, 2005 and Boylston, 2013 for a discussion of mild cases of smallpox and subsequent vaccination development). This clearly situates 'mild' within historical work done to map and classify disease and illness onto the body. Sydenham's work on epidemiology meant that the body, and all its known possible diseases (at the time) could be mapped out and labelled within an "anatomical atlas" (Armstrong, 1983, p.2). The anatomical atlas gave structure to the different elements that constitute a body. The relationship between the different elements of the body is established, hence the body becomes readable and understandable. That the body was made of cells and tissues did not come until the 19th century, which itself is an interesting point. Sydenham was looking to classify symptoms and attribute them to disease, rather than classify disease per se. With this came a pathologizing of the body (Armstrong, 1983, with new techniques for observation and assessment. Hence by the 19th and 20th Century, power is understandable as the relationship between the individual body and the clinical gaze meaning that there is now a clear focus and therefore a pathologizing of the individual through the medical gaze. The body is now subject to closer scrutiny, and with it the individual begins to understand their bodies against this medical framework. Mild in this way in effect becomes part of classificatory systems that attempt to define individuals. My accounts suggest another use, in which 'mild' can be used to legitimise experience and may even in some instances be empowering. This implies a more personal and individual value, although this could set up a tension with more classificatory accounts. To close, I wanted to highlight how ‘mild’ has been documented to have been used in Old English by the late 1500s, as an adverb meaning “mercifully, graciously” (Oxford English Dictionary,2021). The assumptions that are attached to the phrase “not hard to endure” suggest that ‘mild’ has been used to indicate something which has little impact on the body. Highlighting this here foregrounds my participant’s frequent understanding of themselves as feeling that they are “lucky”, or importantly, having an awareness that they may be perceived by others as being “lucky” to have mild CP. Luck is in many ways a comparative phrase, an assessment made in relation to the experience of those around you.

1.8.1.2. ‘Mildness’ in relation to ‘moderate’ and ‘severe’

> “Mildness - "state or quality of being mild" in any sense, Old English mildnes "mildness, mercy," from mild (adj.) + -ness.” (Oxford English Dictionary,2021).

Mild and “mildness” is therefore made sense of in relation to moderate and severe classification. CP can be ‘milder’ than what it has the potential to be, in comparison to other manifestations of CP. With synonyms of, faint, slight, vague and minimal, within a lay understanding, ‘mild’ is often presumed to have relatively minimal impact. This is another example, of where mild can be an absolute comparison between different experiences of the consequences of CP, while also being used to distinguish between different consequences at a more personal level and then temporal trajectory. These presumptions can and will be challenged within this thesis, drawing on the challenges made by the participants. Alongside these challenges, however, it remains possible to recognise how mild can be used in a comparative sense, to aid an understanding of disability for both the individual with CP and society more generally. Furthermore, a deliberate use of mild in a comparative sense also highlights a performative Goffman (1956) use of mild. By which I mean that where participants choose to describe their CP as being ‘mild’, they may be doing so with some awareness of its connotations. They are therefore using ‘mild’ at the same time as managing their bodily movements to ensure that they are able to conform to social expectations of what mild means (see later discussion of managing potential stigma in chapter 2). Among many other uses of the term (which will be explored in later chapters), the participants described their CP as ‘mild’ to reflect something about their abilities and go some way in tackling disabling assumptions. Hence, there is direct and indirect comparison of the impact of their impairment within their own narratives of CP, as well as the societal narratives constructed around able and disabled bodies. If mild is seen as a performance, then understandings of mild are established through social interaction, and it can then be asked how these topics make their way into public and social discourse. Therefore where mild is likely referring to the impairment in the first instance, it can also assume meaning in relation to the impairment effect and the more social and disabling consequences. There are a lot of different layers here, reflected in the participants' accounts. This begins to build a picture of a multi-facetted definition of mild, which I will use my empirical material to further interrogate. Mild is regulatory in the sense that it provides a universal language with which to talk about CP. Similar to QoL measures, the categorisation of CP as mild moderate or severe provides benchmarks against which to (attempt to) measure impact. QoL measures are not only empirical heuristic measures of experience but also reflect epistemic power relationships (Atkin et al, 2023), and thus in the same way, the categories of mild, moderate and severe give the impression that there is a common, quantifiable, experience. Again, this is something which was challenged throughout the interview discussions and will be developed further in the analysis of the empirical material.

1.8.2. Mild outside of CP

With establishment of the general medical and lay discourse surrounding mild, I want to consider how these maps onto other lifelong conditions which can be categorised as ‘mild’. I will use two examples, ‘mild’ acquired brain injuries and Thalidomide.

There is a heavy focus in the literature on ‘mild’ brain injuries or cognitive conditions, for example mild traumatic brain injuries, (TBIs) , as symptoms are not always visible. However, there is a question raised here as to whether visibility should be the main measure of the ‘mildness’ of a condition. When in fact, 'mild' clinical TBI frequently results in long-term disability. This suggests that mild TBIs are a site for translational research (Yamamoto et al, 2018) as diagnostic and classificatory labels of ‘mild’, ‘moderate’, severe can be misleading. Hence this example gives further support to the need for ‘mild’ to be subject to further academic reflection and debate and furthermore highlights the originality of this research in that it draws on sociological theory and equally the expressed experiences of those with CP to move away from biomedical interpretations of diagnoses and furthermore highlights the complexity of categorisation techniques within both medical and social spheres. Therefore, mild is a dynamic experience, which is realised through historical and contemporary understandings of disability and impairment. There are conceptual links here to a mild diagnosis of CP, because although CP is considered to be a non-progressive condition, the mild diagnosis does not have a clear set of criteria with which to understand people’s experience of mild CP. It can be difficult to define memory loss, as well as what is normal ageing and what is a symptom of dementia. The same can be said for the bodily changes seen in those with mild CP, there are gaps in medical understanding of the impact of CP on the body. It is useful to remember that medicine has significant social influence in western society, and as such is a site for social control so is able to shape people's understanding of ageing and reinforces ideas of biomedical understanding of conditions. Beyond medical discourse there are social impacts for diagnostic labels (, and thus there is a social aspect to the diagnosis. For example, Swallow (2020) suggested that a mild cognitive impairment (MCI) diagnosis implies an 'at risk' status even though knowledge of the patient's future is uncertain.

Patients therefore have to negotiate their illness classification; they are managing uncertainty but also navigating the wider social and political context of ageing. Swallow (2020) argues that classification processes can be complicated leading to 'messy patient narratives', beginning to introduce ideas of liminality. These are especially useful concepts to draw upon as part of the analytical framework for this thesis. It provides empirical examples of the theoretical work of sociological thinkers such as Durkheim and Mauss ([1903] 1963) whose work provided foundational thinking in classification and categorisation literature and has helped to guide my exploration of the ways in which classification of diagnoses and bodies are closely linked, and are established and reinforced through bodily norms, shaped through social expectations on the body. This literature is important when considering the impact of classificatory systems, as often a diagnostic label becomes a master status for the person living with the impairment (Beard and Neary, 2013). The consequences for this vary for the individual and can be best understood in relation to empirical material. However, Beard and Neary (2013) provide a useful conceptualisation of the processes of diagnosis as being a "diagnostic creep", using the example of the expansion from MIC to Alzheimer's disease (AD), which may broaden to encapsulate asymptotic forms of AD. This discussion is therefore highlighting the ways in which sociology can help to understand the complexity of the diagnostic processes surrounding a mild categorisation, which can later be recognised in relation to the experience of those living with mild CP.

The concept of severity is also shown through the example of Thalidomide. Over 60 years ago Thalidomide was prescribed to pregnant women to help with morning sickness. Thousands of children were born with a range of impairments. All organs and tissues of the body can be impacted by Thalidomide, and severity can vary, and impairment can manifest in many ways (Vargesson, 2015). Thalidomide holds similarities with CP in the varied ways in which it can present, and also the limited knowledge of the future impact of the condition. The literature does however reflect the complexity of health issues and social context, there are ongoing health concerns and an increase or start of medical concerns, related to Thalidomide syndrome, for example increased pain and musculoskeletal problems alongside ageing (Newbronner and Atkin, 2018). 'Mild' adds another layer of complexity to knowledge of ageing with a lifelong condition, and as suggested above, it can be difficult to differentiate between normalised ageing, and ageing accelerated by living with a physical impairment. It is also important to note that Thalidomide embryopathy was classified into groups according to the particular physical manifestations present, and furthermore there were severity classifications established of mild, moderate, severe and most severe (Hinoshita, 2020). Hence, severity is reflective of physical categorisation, groupings which attempt to make experience of the spectrum of severity quantifiable as well as benefit payments.

Before moving onto a closer focus of how 'mild' is used within CP discourse, it is important to highlight how mild is a pervasive aspect of medical discourse and how quickly this can then become part of the lay understanding of a condition and its effects. Seen in the public and medical discourse of Covid-19, a 'mild' form of Covid-19 indicated that the virus was manageable and did not require significant medical intervention (NHS, 2022). With Covid, the application of the term mild to symptoms cannot be presumed to be synonymous with a mild illness or impact, namely due to the occurrence of 'Long Covid' (Wilson, 2020). Hence, there is a subjectivity of the interpretation of symptoms as 'mild', which problematizes the applicability of the term mild as a classificatory tool. This will be interesting to explore in relation to the purpose of classification, when using the word mild. It can be asked, for example, what is the value of using mild given that it is so subjective? This subjectivity, however, could imply a more personal value, in which "mild" is used to give meaning to experience. Here I am introducing a sense of trajectory and an understanding that meaning is negotiated over the life course. This requires agency, realised in a social context that is also looking to define experience. This is perhaps where the tension of the use of mild occurs and is consistent with the idea that mild can hold multiple and possibly conflicting meanings. My work here is attempting to lay the groundwork for a language, in which people can express themselves, in ways consistent with their experiences. This would suggest the importance of the word mild, explored in further detail in the discussion.

These are complex questions, which I will endeavour to provide a response to, especially when presenting my empirical material. Before I do this, I will reflect further on these ideas by exploring debates about sociology of diagnosis, which provides a conceptual link between sociological and classificatory literature. The positioning of mild in social and medical discourse is contested and often unclear. It seems to at once reproduce and challenge a normative classificatory system. Diagnoses are fixed categories as well as something that doctors do and assign to people (Blaxter, 1978). Jutel (2009) argues that diagnosis guides medical care. It organises the clinical image of disease and determines medical interventions. A mild diagnosis therefore says something about the positioning of these individuals in the medical and social world, as there is social as well as medical meanings attached to a mild diagnosis. These are individually realised, in addition to being socially enacted.

1.8.3. Conceptualisation of ‘mild’ in relation to CP

In biomedical spheres therefore, it is presumed that everything must be defined in relation to and within the boundaries of classificatory measures. For CP, this classificatory system is namely the GMFCS, an attempt to standardize experience and provide a legitimate experience of mild. The applicability of this will be considered critically through my participants’experiences. The ICD-11 (WHO, 2024) also provides classification of CP, under the branch for disease of the nervous system. Spastic CP is the only group to be recognised as having severity, (mild, moderate, and severe). More broadly, the ICD breaks down CP into: Dyskinetic cerebral palsy, Ataxic cerebral palsy, and Worster-Drought syndrome, familiar categorisations within CP diagnosis. Grouping symptoms in this way forms an image not unlike the autonomy atlas. Medicalisation of the body therefore creates boundaries of experience through labelling, and although not always perceived negatively, sociological literature relating to bio-power and narratives of resistance (Mishler, 2005) provides alternative points of reference through which to make sense of a mild diagnosis. Therefore, a diagnosis is a product of negotiation, between medical categorisation and interpretation of that classification. It is recognised that CP has a range of manifestations, with severity determined by the functional impairment ” (Eunson, 2012). Alongside the GMFCS, there is also the Manual Ability Classification, focussing on how children with Cerebral Palsy use their hands to navigate everyday objects (Compagnone et al, 2014)).

This classification has however been reinforced through the biomedical literature, for example a cross-sectional registry-based study of 1,888 adults with CP, as part of a Swedish CP follow-up programme (Pettersson and Rodby-Bousquet, 2021). The median age for those in the study was 25 years old. The study compared the GMFCS with the Communication Function Classification System (CFCS), which describes the effectiveness of communication, including all types of communication such as facial expressions and alternative communication. For CFCS Level 1 score, people were more likely to live with a partner, be in mainstream education, and in competitive employment. Compared with the GMFCS Level I, where people more often lived with a partner than those at GMFCS Level II-V, and having a more severe disability was associated with a decreased probability of having a partner. Hence literature such as this reinforces the use of these measures and seems to legitimise the associations made between ‘functionality’ and achievement personal milestones (and how this interacts with disability). This understanding of functionality needs to be looked at critically, to highlight the fluidity of disability, a key aim for the research is what the nature of disability is for those with mild CP and how this plays out socially in everyday lives. Hence why I am focussing on testimonial experience to unpack this. I will be providing the opportunity for different expressions of mild to be realised, and ones which connect to experience and active agency.

This raises the question of how applicable the GMFCS is to the diverse experience of CP. Rosenbaum et al (2008) noted that prior to the GMFCS, levels of disability was described as mild, moderate and severe, and they found inconsistencies in the way they were used, and the meanings attached, especially in relation to children's motor function so therefore it is sensible to not entirely discount the potential that the GMFCS had to provide some predictability and political validity to diagnosis. This raises an interesting tension between a measure of impairment, which is confused with a measure of disability. This is common and points to the value of the presented account of mild, is that it offers an account of mild more consistent with disability. However, the reason for the need for social and medical validation need to be examined critically and meaning attached to quantitative scales need to be explored. There also needs to be more transparency with the process of diagnosis, to understand how certain levels are assigned to individuals, and the expectations attached to this. It is clear therefore that 'mild' has been medicalised in relation to CP, the diagnosis has impact beyond the body, it can shape and influence life with CP. The classificatory systems do not account for the idea that definitions of mild are often contested, something which in my thesis, by relating to testimonial experience, I hope to recapture. There are examples of patient resistance and active agency which is not being considered. It is interesting to ask why 'mild' is used relatively frequently in the literature in relation to acquired brain injuries and intellectual impairments more generally, and yet less so in relation to CP, when considered at its most basic diagnostic category, CP is damage to the brain. It potentially highlights the liminality of 'mild' in relation to CP, and the confusion around where it lies as a lay or medicalised term.

Examining mild has therefore helped to begin to access the etymological and later medical meanings attached to a mild diagnosis. It is therefore possible to ask in my analysis what 'mild' is able to accomplish, not only as a description of a condition, but as a rhetoric and discourse. In this way, I will explore the ways in which a mild diagnosis is lived. Literature from the discipline of the Sociology of Diagnosis will be drawn upon to explore this further later in the thesis. As it shows for example how a medical diagnosis can also be conceptualised as a social diagnosis. A diagnosis is set within certain political and historical circumstances. It is determined by a series of stakeholders (be that the clinicians, the institutions guided by classificatory measures, or the lay public), the interests of each sometimes overlap, for example the need to state a diagnosis to access government benefits (Brown et al, 2011). Hence, a diagnosis represents impairment, but it also defines experience, sometimes to the detriment of considering the active agency of those living with CP. It is important when reflecting on why we have diagnosis, to acknowledge that social and political context have an important role. It is equally important to locate this discussion historically. Diagnosis does have a purpose and in some cases a value. It can empower by legitimating the illness experience and it can also define access to effective care pathways. As diagnosis of CP 'levels' or 'types' is by its nature categorical, it can also be used to determine and legitimise differences in the way that CP is assumed to be experienced in people's everyday lives. However, these differences may not be as categorizable as hierarchical systems such as the GMFCS may be used to suggest.

1.8.4. Introducing related sociological literature

I will now recap the links to sociological literature to highlight the usefulness of incorporating sociological concepts into an understanding of mild. This will introduce the foundational sociological concepts which form part of the analytical frameworks for how I understand 'mild' within the empirical material. Concepts such as social classification and categorisation, liminality, and bio-power, will guide investigation into what constitutes mild. I will attempt to provide alternatives to established biomedical models of disability and impairment, studying how people interact with the notion of mild within their experiences of CP, how a mild diagnosis can be debated and contested within and outside of medical spheres. 'Mild' can pose a disruption to binaries, boundaries, and categories, and sociological literature supports analysis of this. For Durkheim and Mauss ([1903] 1963), the social world was structured by classifications and humans' ability to differentiate is based on this classification. The differentiation of CP is not necessarily problematic, it is the assumptions attached to this, and the oversimplification of experience that can be the product of social classification. It allows for an expression of power relationships, which can be problematic as they have the potential to reinforce normative assumptions of disability and the binary of disability to ability. Hence, understanding the role of social differentiation is important for considering the relationship between related categories. When framed within medicine, it helps to understand how severity classification of CP can have an impact on the disablement.

Furthermore, if it is accepted that social classification is the basis for solidarity, this could be the basis of unity and resistance, in which definitions of mild are questioned and used to redefine someone's experience Medical diagnoses are often a reflection of social and political debate and the discourse surrounding a 'healthy' and 'able' body (Gardner et al, 2011). Hence, the concept of the medical gaze can be understood in relation to the idea of a social diagnosis (Brown et al, 2011), again, a concept which acknowledges the role of social, structural and temporal influences on a diagnosis. The influence of the medical gaze occurs alongside a construction of a social diagnosis.

Douglas (1996) distinguishes between the physical and social body, arguing that one influences the other, the social influences the way the physical is perceived. Hence, the experience of the physical body is mediated by the society, and the social and physical body reinforce the categorisation of the other. Hence, this provides further analytical insight into how a diagnosis of a physical impairment can impact on the social positioning of the individual and vice versa. Given that the notion of mild is contested, this suggests that the diagnosis itself may lead to feelings of liminality for the individual. Examples from the empirical material will be explored in later analytical chapters, what I would like to highlight here, is the ambiguity that surrounds the meaning and experience of a mild diagnosis. Thresholds between a diagnosis can be unclear, and thus people may feel that they cannot be easily assigned to cultural or social positions (Turner, 2004). Having a secure position in society supports the legitimacy of someone's experience (Douglas, 1966). Society does not of course exist in a vacuum and order is never neutral, meaning that margins and boundaries are not rigid (Douglas, 1966). There is again an opportunity for resistance, and for experiences to not fit medical and social classifications. Boundaries can be made visible by things that do not fit, or that are out of place. Therefore, by analysing the experience of 'mild' CP highlights the complexity of CP diagnosis.

I do not wish to attempt to provide a definition of mild, this is neither achievable nor productive, instead the focus needs to be on establishing shared understandings of mild from those living with CP. It will be asked how important the diagnosis of mild is, as either part of the medical diagnostic descriptor, or when mild is a description of impairment that people use for themselves. A diagnosis is about relationships; the relationship between the individual and their diagnosis, the relationship between those with the same diagnosis, and influencing factor of wider social structures. In this way, 'mild' may take a performative role, helping those with CP to find people and spaces to identify with, but also using mild to present a certain way for a given purpose.

1.8.5. Highlighting the analytical gap

To conclude this section, I want to reiterate a key analytical gap in the literature, an understanding of 'mild' from the perspectives of those with CP. The body is only understandable in terms of the language that is available. This language inscribes the body. Ways of seeing the body have been alternated or entirely replaced throughout history. A change in the description of the body can lead to a change in understanding the body and vice versa (Armstrong, 1983). This is indicative of the malleability of mild. The GMFCS and other systems of measurement attempt to create objective categorisation of experience through the grouping of bodily movements. There is potential for there to be tension in the mismatch between lay and professional understanding. And the objective nature of the measures, may lay in juxtaposition to the subjective use of the term 'mild'. Tracing the use of mild in historical discourse helped to trace an understanding of the body with CP, although the questions remain to be asked, why this categorisation of mild exists, and what role does it play in the experience of CP as well as disability more generally? Answers to these questions will be suggested throughout my thesis but will always be rooted in the empirical material. In that way, critical sociological theory (alongside that of critical disability studies) will be brought into discussion with the testimony of those with CP to reimagine the meaning and use of mild. This will allow for a reconceptualisation of experience, as well as a critical reflection of the surrounding discourse. The stories shared with me will provide new ways of seeing mild.

Chapter summary and central thesis argument

This chapter has opened my thesis by outlining my research aims and outlining a roadmap for the thesis. I have outlined where I hope that original ideas can be taken by the research, namely this research involving new voices, speaking to an experience that has not yet been at the centre of an academic study on CP in the UK. I have also aimed to justify my focus on CP, from an academic perspective, a main component being that this research challenges normative ideas of what it means to be disabled and contributes to arguments put forward to bring together ideas from sociology and disability studies more closely. I also gave a brief etymology of mild, and used this to highlight the multi-faceted and temporal nature to definitions of mild, which will be illuminated through my participants' narrative extracts. Knowledge of this academic work is currently missing from academic and social understanding of disability and impairment, which leads me to my central argument below, which I will continually refer to throughout this thesis as my narrative thread.

The story I am striving to tell in this thesis is based upon the idea that mild discourse is missing from the debates of disability, sociology and the social rhetoric surrounding disability. Hearing from new voices about how they experience a 'mild' disability contributes to the challenges made against the still largely binary relationship presented between impairment and disability, and has introduced a necessary complexity to current social and biomedical understandings of CP. I hope this begins to pave the way for a much-needed expansion of the language currently used to make sense of disability. My participants articulated a need for a discourse around mild, one that supports an easier negotiation of the non-linear trajectories attached to living with mild CP, as well as enabling them to share their understandings of the connections between their bodily and social experience of CP, outside of the impositions of clinical and societal expectations of what they should or should not be. Mild, lifelong disability needs to be talked about, and those with mild CP need to be the first people we listen to. I will make reference to elements of this central argument for my thesis, to demonstrate how the ideas connect together, and to ensure that the overall 'story' of the thesis can be followed more easily. For the upcoming chapter, the subjective meanings of mild are largely at odds with the current social and clinical understandings of CP and these experiences of disability, and the body is not yet fully explored in disability/sociology, my second chapter below discusses the analytical framework upon which I will use to make sense of this disparity.

2. Literature review

Chapter Introduction

This literature review focuses on developing a social relational model of disability to best capture the experiences of individuals with mild Cerebral Palsy (CP). The aim is to bring into dialogue and potentially reconcile the long-standing theoretical tension between medical sociology and disability studies, arguing that an approach acknowledging both social oppression (disablism) and the reality of impairment effects is necessary. The discussion reviews core sociological theories on the body, classification, and social order (citing scholars including Durkheim, Parsons, Douglas, and Goffman) to establish that disability is socially constructed against norms of "ordinariness" (Davis, 1995; McLaughlin, 2017; McLaughlin and Coleman-Fountain, 2018). Finally, the review explores the social model of disability and its critiques, positioning the social relational model, particularly Carol Thomas's (2004b) work, as a bridge that integrates concepts of structural and psycho-emotional disablism with the lived, embodied experience of impairment.

As the discussion in the previous chapter has shown, CP is still largely understood through biomedical and clinical literature, which highlights an analytical gap of engaging with the lived experience of CP. It is, however, no longer sufficient to analyse the experience of living with CP from only a clinical, paediatric perspective. To do so would be detrimental to the advancement of care services for the majority that live with CP into adulthood. As would be expected, those with CP have unique experiences in adulthood which interact with their impairment on a social and embodied level. Therefore, to limit understanding CP in adults to a largely biomedical framework of understanding risks dismissing the social barriers negotiated by those with CP, on both a collective and individual level. I am specifically wanting to use this social-relational model of disability as a framework to help me to understand the participant narratives in my analysis, as the value, presentation and understanding of mild is shared through the interviews, which are the product of reflections on their life. This lived experience is rooted in social interaction and the interplay of this with impairment effects, which are both experienced on a fluid trajectory throughout their lifecourse.

2.1 Medical sociology and disability studies: transcending debate

I would like to begin by acknowledging that there exists a debate within the literature between medical sociology and disability studies. By first highlighting these tensions, I am aiming to then provide further argument for the need to transcend these tensions, by suggesting how I am able to attempt to bridge this through my research. My research can contribute to the strengthening of this bridge as it draws from both disciplines, and does so in a meaningful way which expands the scope of understanding people's everyday lived experience of certain disabilities and impairment effects. I am aiming to contribute to arguments which recognise a social nature to disability, but that also recognise that people have a body through which they experience this disability and society. The tensions between medical sociology and disability are not unique to CP, although the focus on mild CP allows me to go further in my critical thinking of how disablement, impairment, and medical and social barriers contribute to the lived experience of those with mild CP. It also allows me to bring together (and transcend) debates relating to the mutuality of medical sociology and disability studies.

Medical sociology has a history of analysing disability but in a way which is critiqued for focussing too heavily on the personal tragedy and the societal response to disability/chronic illness including everyday embodiedness. Medical sociology places disability in more of a medical model framework where the impairment becomes individualised. Disability studies try to move away from this individualisation of disability which is then in turn critiqued for ignoring the realities of living with an impairment. It can, therefore, seem a challenge to connect the two disciplines (Thomas, 2022). Scambler and Newton, for example, claim that the "lifeworlds" of families cannot be understood solely through "the biological, social or psychological impacts of the disease process" (2010, p.102). They argue for a more complex theoretical framework, in tandem with the traditionally fought dichotomy between impairment and disability, to claim that whilst oppression is recognised in their participants' worlds, it is secondary to the biological effects of the condition.

Our ideas of disability are formed within cultural ideas of 'normality', or 'ordinariness', concepts which are also subject to analysis in both medical sociology and disability studies (Davis, 1995; McLaughlin, 2017; McLaughlin and Coleman-Fountain, 2018). In a study examining young people living with serious health conditions, Atkin and Ahmad (2001) discuss how they attempted to take control of their lives and how they valued a 'normal' life, yet this was threatened by health complications along with life transitions, social relationships, intersectional sexism, racism, and disablism. This research attempts to draw from both sides of the debate, particularly considering the relationship between physical impairment, disability and how people live (and embody) their lives within these. The debates between medical sociology and disabilities studies, I will argue, need not be as dichotomised as they are often presumed to be. Instead, I would like to explore how it may be possible to draw on concepts from both these fields to produce a useful conceptual framework to understand the experience of 'mild'. These concepts are outlined below and introduced here to allow me to refer back to them later in the thesis.

McLaughlin et al (2023) highlight how disability is frequently overlooked as a central sociological topic. Arguing that maintaining the boundaries between medical sociology and disability studies risks limiting the scholarship that can arise from this area of research. Both sides of this debate seem motivated by a similar desire to better understand the experience of disability and impairment in order to more successfully advocate for disabled people. Consequently, maintaining open dialogue between the two disciplines allows for an exploration of disability from a multiplicity of angles. This literature review will endeavour to recognise but not dwell upon these tensions, as the purpose of this review is to provide space to synthesise these. Recognising that disability can be understood as socially relational and at the same time acknowledging the individual impairment effects, helps to overcome these tensions. By recognising that the social nature of disability can remain at the centre of disability discourse without being undermined by also acknowledging the impact of impairment.

2.2. Sociological understanding of the body

2.2.1. Sociological thought on classification and social order

Sociologically, the physical body and the social worlds that people live in are traditionally conceptualised as two distinct yet deeply interwoven components of how people experience society. I will be drawing on sociological literature which considers the relationship between the material world (felt through the physical body) and society (constructed within social interactions), as mediated and shaped through the construction of classificatory processes and hierarchies. Sociological scholars discussing classification and social order aim to establish the social relationality of bodies and the dichotomisation of one group from another. In doing so they highlight the normative environment that this social relationality is established and reinforced within. These debates are fundamental to the origins of medical sociology, as people deemed unwell or ill become sequestered from mainstream society.

Durkheim and Mauss' ([1903] 1963) work was fundamental to establishing a theory of social classification and the role of categorisation in the distinguishing of one group from another. Classification, they argue, is based on an innate sentiment of sociability, and thus has social and moral consequences for bodies. This "classificatory function" (Durkheim and Mauss, [1903] 1963, p.2) leads to another hierarchy, distinguishing one group from the other, and potentially marginalising the group deemed to have a relatively lower social status. Similar classification work is arguably achieved at the point of diagnosis of a mild disability. Simultaneously diagnosing an individual as disabled (rather than able), and mildly disabled, (rather than severely disabled). Thus, my research has the potential to contribute to ideas that categorisation is not purely for the purpose of group formation, but to achieve something socially significant. That is to attach socially significant meanings and labels to bodies, and in doing so establish their relational placement to one another. This brings forward the idea that bodies do not simply exist in the same spaces together, the social positioning attached to groups or individuals places them in a social relationality to one another. Relating this back to mild CP, mild disability sits outside of the socially constructed, normative boundaries established in society, and can pose a potential point of disruption for medical and social classification which upholds this normative environment. Such disruption highlights how bodily boundaries carry social consequences, directly correlated to how successfully bodies (in this case, non-disabled and disabled bodies) are able to conform to and maintain their assigned role.

Parsons' (1951) work on the sick role discussed the legitimisation of the unwell body, and the social acceptance or rejection of the ill body, depending on the success of conforming to the sick role. Medicine (and medical categorisation) is established as a legitimising force, as the sick role becomes a place where 'legitimately' ill individuals can find themselves whilst unwell. Unwell individuals are placed in a particular relationship with society. Illness is legitimised through medicine, and to be socially accepted, there must be a desire and ability to be well again (Parsons, 1951). This is where the sick role becomes relevant to this research. It maintains a hierarchy of ableness and highlights how the social world is based on the notions of conformity and deviance. People must be able to conform ideally to the able world or alternatively be successful in the sick role. My research talks to this dichotomy of able and disabled, and demonstrates how this may encourage comparison between other disabled people and able-bodied people, whilst challenging the extent to which this was possible for people with a chronic but mild physical disability. Mild CP cannot easily fit within the able-disabled binary, as the mildly disabled body disrupts the dichotomy. The permanent nature of CP within the lifecourse, and the fluidity of disability and impairment effects challenges the temporary nature of the sick role. Therefore, Parsons' work establishes how the categorisation of bodies in the medical sphere is both socially constructed and reflected in the social order of society.

The social significance of the placement of bodies is something also considered by Douglas, who has been equally influential in establishing the discipline of medical sociology. Douglas makes a distinction between the profane and the sacred, and the two, social and physical, bodies (1966, 1970). Social categorisation is again establishing hierarchies. Where bodies do not fit neatly into social categories they are seen as "out of place" (Douglas, 1966, p.36). The research will draw upon and expand on this notion (for an initial discussion of the application of Douglas to disablism, see Oliver, 1997), highlighting the complex position of being mildly disabled, as such bodies appear on the margins of classificatory boundaries. If it is true that the "physical body is a microcosm of society" (Douglas, 1970, p.101), this research can explore how the mildly disabled body and society are interconnected and reflective of one another. Social expectations impact on the physical body and the physical body shapes social expectations and hierarchies. Therefore, the mildly disabled body highlights the fragility of the relationship between the physical and social body – medical and social marginalisation of those with mild CP is an example of how the body, and therefore the person, can become a social 'taboo'.

Mild CP bodies are marginalised and in being marginalised bodies they pose a threat to identity management and the social norms, by the way in which the body is used and managed and how disabled people experience the world. Identifying with having mild CP is even further transgressive as it confuses a more dichotomous distinction between being 'able' and 'disabled'. That which is threatening becomes taboo (Douglas, 1966); for example, the adult in need of support and help to be dressed transgresses the socially established notion of what an adult body should be capable of doing. The need to receive care in this way, becomes taboo. As will be discussed in more detail below with the work of Elias (1939), historically, as more bodily needs and functions were monitored and controlled, social and cultural behaviour was also increasingly monitored and boundaries set for right and wrong. Social norms were established for behaviour, importantly, although this regulated the public body, body management became an internal endeavour.

Hence, the individual becomes responsible for their own body management and is blamed for when this is not possible (for example, the limitations faced by people with certain physical symptoms of CP), highlighting once again how bodies that cannot be neatly kept within social boundaries can therefore carry stigma, risk and shame. The potential psycho-emotional impact of this stigma and shame is explored later in this literature review (See Reeve, 2003, 2004, 2006; Thomas, 2004b), but for people who do not fit neatly into binaries of able and disabled (see another example with ambulatory wheelchair users) they are marginalised and their experience is denied, misunderstood, or challenged. There is therefore a complexity in the everyday life of disabled people (and in the way they interact with non-disabled people) which is not captured in the binary thinking of being either able or disabled. This includes the spaces in which people may be considered, or consider themselves, to be disabled.

This symbolic imagery of two bodies, the physical (individual) and social (cultural) body (Douglas, 1997), is foundational for the social relationship theory. There is an interdependency between the social body (i.e. society and social norms) and the physical body. Society is a collective phenomenon, it has a system of meanings, which impacts on how the physical body will be experienced (embodied). The social body limits the way the physical body is perceived. There is a continual exchange of meaning between these; one reinforces the other, hence the physical body can be restricted in expression. Mild CP bodies challenge the social order, and it becomes difficult to ignore the physical bodily experience and its relationship to the social experiences of individuals in groups. If the body is seen as a representation of society, then a healthy body comes to represent the accepted and normal social unit, and the sick body disruption. This further builds on Parsons' line of thought, displaying how norms and hierarchy are socially constructed, and the body becomes a symbolic medium to display this.

In summary, the body becomes a metaphor for society and a means for expression of the cultural and social expectations on the body. The body therefore has a social role as well as a physical place in society. Individual bodily experiences are therefore culturally determined and there is a cultural imperative for people to be able to take care of and regulate their own body.

To conform to social norms, there is a need to maintain normative bodily regulation. The tension that is created between this exchange of meaning between the physical and social body is highlighted through exploration of the mildly disabled body, and the way in which people both individually and collectively regulate the way their body behaves. When the boundaries of normative social and physical behaviours are crossed this can indicate a threat to identity and marginalisation of the individual due to the unsettling of norms, even for everyday behaviour. For the debates within medical sociology, this body of literature has posed that transgressive and misunderstood bodies can exist, and so, such bodies become subject to heightened surveillance within both social and medical spheres. Despite this external surveillance placed upon the 'risky' disabled body, simultaneously the everyday experience of living with disabilities is dismissed and overlooked. Especially as the complexity of this is lost in dichotomised grouping of bodies, as either disabled or able bodied, depending on the way they are perceived by others. This perception is tied at least initially to the physicality of the disabled body, and how it may move or be used in a different way to the norm that is expected.

For Elias (1939), bodily and social boundaries were established and maintained through a process of normalisation (a 'civilising process'). This process described how the 'micro' everyday bodily behaviours are shaped by 'macro' (social/contemporary/historically contextual) expectations and norms. Transgression of social norms lead to public sanctions on those that were unable to achieve individual self-regulation. This is relevant to the social relational model of disability, as the ability for disabled bodies to do this can be limited by impairment. Furthermore, as the body is experienced on a social and physical level there can be an embodiment of social transgression. There is a social and historical context to normative environments that cannot be dismissed, to do so would ignore the social and physical barriers faced by disabled people. The challenges/barriers faced when managing a body with a mild disability, and navigating a socially/temporally contextual normative environment are not acknowledged. Discourse surrounding the embodiment of mild CP requires engagement with invisibility debates, and self-management of the body to successfully 'pass' as able bodied. Social templates of how to achieve this are unclear at best, further contributing to the 'risk' of transgression of social norms and boundaries (although my narratives also demonstrate how this uncertainty can also open up opportunities for resistance).

The body, therefore, is something that we have and at the same time something that we are. The body can be influenced, trained and 'civilised' but at the same time is also subjectively experienced. There are wider social and historical influences that impact on the body, which means that the body is considered as both an individual and social experience. The same can therefore be said about the experience of living with mild CP. There are links to be made between this historic move towards a more civilised body, and the way in which medicine and medical practices provided opportunities for further regulation of the body on a macro and micro level. As medical sociology discusses, biomedical understandings of the body provide prescriptive ways of living successfully, establishing the body which can conform to societal ideas as 'healthy' and in need of less medical intervention (Davis, 1995; Thomas, G.M., 2023).

2.2.2. Medicalisation of the body

As I have begun to introduce above, foundational sociological thought on social classification and order can be bridged with ideas informing medical sociology. This socio-medical lens helps to highlight how medicine can be used as a regulator force. Understanding the processes of medicalisation of bodies and the social imperative to hold bodies to normative standards in this way also helps to make sense of the potential social consequences that limitations from the impairment can place on the body. This helps to make sense of the social consequences of the limitations from the impairment, placed on the possibility for self-regulation of the body. Shilling (1993), by drawing on Elias' idea of the civilizing process, proposes a theory of the 'civilized body'. This is concerned with understanding the individualisation, rationalisation, and socialisation of the body - in other words how people relate to their bodies - to explain the experience of an embodied individual within a particular historical period. Bodily behaviour holds temporal context and expresses social and cultural expectations. The product of this civilising process is a regulated 'social' body that has replaced the unregulated natural body. However, the civilising process should not be only seen as a judgement of the in/superiority of societies or bodies, meaning the recognition of this social civilisation was not solely highlighted in order to explain contemporary understandings of how bodies were assigned social class. Elias' observations can be used to recognise an ongoing process of relative and reflexive refinement of social rules and thus social bodies. The body has become increasingly individualised, rational through continued socialisation according to norms and expectations. A regulated and successfully socialised body replaces an unregulated ‘natural’ body. The physical and social regulation of the body became increasingly internalised; an individual endeavour for which the onus then falls on the individual to achieve. People are then blamed (and marginalised) when this is not achievable. A mildly disabled body, therefore, cannot always be neatly kept within social boundaries, leading to stigma, risk and shame (Shilling, 1993). Shame is arguably attached to stigma and the avoidance of shame motivates self-discipline of the body (although again the scope for disabled bodies to achieve this internalised regulation may be limited).

A further body of literature that considers the societal perception and management of the body is that of dramaturgical sociology. Reflecting on this body of literature will help me to further analyse the management of the body, and the ways in which, for those I spoke with, the act of presenting oneself as having ‘mild’ CP, can involve performing as less disabled in certain contexts. Mild therefore can be used as a way to mitigate impairment effects. Particularly, the presentation of self and performance of self-identity (Goffman, 1956). Goffman’s work can be used to map out presentations of ability and disability. Social interaction is a “kind of information game” (Goffman, 1956, p.20), of revealing falsities, hiding of the self, and identity management. This raises questions as to what extent managing a mild disability involves similar information games. Moreover, Goffman highlights how these performances play into social roles within society. Defining a social role as “the enactment of rights and duties attached to a given status” (1956, p.27), and arguing that, “when an actor takes on an established social role, usually he (sic) finds that a particular front has already been established for it” (1956, p.37). The research can also ask to what extent there are ‘fronts’ prescribed to the mildly disabled for them to follow or conform to. With these ‘fronts’ can also come social scripts, which shape the way a disabled person may manage their body and interact with the social world. This begins to highlight the relational nature of disability and the way in which disability and impairment can be considered to be both social and physical in their nature and impact.

From a socially relational perspective, Goffman’s work describes careful and deliberate management of how people perceive attempts to ensure that their disability/impairment is interpreted in a certain way i.e. as something that does not prevent them from reaching expected social and physical milestones. There are performances of a socially approved version of the self which can carry significant negative impacts on the disabled body; impairment effects are there and impactful (see detailed discussion of impairment effects below). Therefore, a disabled identity is not inherently stigmatising, it is the way others respond to (or may be potentially anticipated to respond to) a disabled body that can cause stigma and so the disabled body is once again interpreted as outside of the norms; there is an embodied nature to disability (McLaughlin et al 2017). An ageing body with mild CP carries the physical consequences of maintaining a socially accepted version of what ‘mild’ means. There is space for resistance through the presentation of the self (seen for example in the way that people I spoke to chose to not use mild as a self-description of their disability later in life).

Stigma emerges when others challenge the norms expected within social interactions. Therefore, to return to Goffman, it is not the impairment itself that is inherently stigmatising, but rather the way in which the impaired body may be responded to within an interaction. Meanings that are attached to bodies through such interactions can deem the body as being outside of the social norms. Often work is therefore required on the behalf of the disabled person to manage this discomfort for others (McLaughlin’s, 2017). People with mild CP may strategically embody mild to avoid the potential stigma of not doing so.

2.3. Sociological understanding of embodiment

The management of stigma has been a central concern of medical sociology: there is an embodied experience of impairment and people may strategically embody what society comes to expect mild to mean, in order to appear as such. This then does the work of demonstrating that their impairment does not impact them and importantly will not pose significant social discomfort to anyone else. Feelings and emotions are attached to bodies, these have a social origin as well as deriving from the body. Society is represented through the body; there is a social construction of medical knowledge which can be mapped onto the body (e.g. for people with mild CP, the medical response to their impairment can change over time). A disabled and non-disabled person can experience their body very differently. Restricted functionality (in a physical and social sense) can make it more difficult to live in a body without doing so reflectively. Identifying (or not) with mild becomes a point of reflection.

Western thought places the body and the mind as separate entities; the body is habitually and symbolically connected to the world (Annandale, 2014). The concept of the ‘lived body’ however shows that bodies are both social and biological, they allow us to have a physical experience but also form feelings and emotions to these which can alter the way we interact with society. These feelings can derive their meaning from cultural contexts, but they also have their origin in the body (Annandale, 2014; Shilling, 2005). The way disabled and non-disabled people experience their body can be vastly different; bodily experience can be culturally constructed, however most people carry a sense of embodiment, in that there is a connection between their mind and their body which cannot be separated. People are “embodied social agents” (Nettleton, 2013, p102). What is important to understand is how restrictions on the ‘functionality’ of the body (in a literal and social sense) make it difficult to live within the body without doing so reflectively (ibid). The experience of disability and disablement becomes a point of reflection, something seen in the way my participants openly and extensively reflect on the value and impact of mild for them throughout their lives. Bodies are made up of habits and behaviours, these become normalised thus go unquestioned. An inability to conform to this highlights their existence (Bendelow and Willams, 1998). Non-disabled people are given a template of how to use their bodies which is determined by social and cultural expectations and norms. Being positioned outside of these norms, disabled people can face difficulty navigating social spaces without such easily accessed templates. Charmaz and Rosenfeld (2006), conceptualise this as ‘the looking glass body’, not only about the body appearances, but also about bodily experiences and those experiences coming from the body; this has value when attempting to reconcile medical sociology and disability studies.

For McLaughlin and Coleman-Fountain (2014) the disabled body can become an ‘unfinished body’. They argue that disability is shaped by social and medical narratives producing an ‘anomalous body’, different from the norm, but fixable. Here the concern is to understand how such narratives and the behaviours associated with them influence the stories told by young disabled people with CP in the northeast of England. Their findings showed that the medical and social responses to bodily differences became part of their stories and influenced their bodywork. They became bodies that were unfinished, fixable and flawed. Therefore, a narrative of an unfinished body is produced; they manage their bodies as integral to their emerging identities. This can also pose a threat to undermine and highlight the labour entailed with producing an ordinary body. This gives new light and knowledge to disabled embodiment, in relation to ongoing changes in the body and helps to understand the changes to the way people relate to the idea of mild and the varying degrees to which a mild disability influences their identity.

Similarly to Nettleton (2013), they say that “…disability brings a different temporal relationship to the body” (McLaughlin and Coleman-Fountain, 2014, p.83). Specifically looking at the impact of surgery and the ‘damaged body’, they reflect upon how the body is monitored as a child and as it transitions into adulthood remains unfinished. This also highlights how there is a materiality to the body, CP is seen to not stay the same with age in my accounts, disability has a temporal character, and the idea of normality is fragile. This points to the importance of ensuring that discussions around the body need to be based in bodily experience and not simply theorised about; there needs to be an effort to engage with empirical data on the body and individual's feelings about this (Nettleton and Watson, 1998), particularly as bodily changes can often impact our social relationships. This highlights the value in pursuing participants’ perspectives on how they experience their body from themselves. Hence, embodiment and the lived body gives me a paradigm to work within, which focuses on the experience of the body from the perspectives of those who inhabit the bodies. This thesis is looking to contribute to ideas around how embodied difference is negotiated in everyday lives, and specifically how people with disabilities and those around them negotiate this (Thomas and Sakellariou, 2018).

For some disabled people this means returning to the idea of ordinariness, with literature such as McLaughlin and Coleman-Fountain (2018), highlighting the ways in which disability can impact an individual's scope to negotiate their identity, especially for young people. Their identity is shaped by both individual creative expression but also normative constraint. This opens up discussions relating to the assignment of value to bodies in society, where judgments of value are shaped by ideas of norms and what is meant to be ordinary (ibid). In their 'pursuit for ordinariness' young people with disabilities may encounter stigma and other prejudice, and although not all may wish to conceal their difference, they may engage in bodily management techniques, which again are modelled against ideas of normality. Once again therefore, people with disability may feel the need to reflect further on their body and the way it is used and behaves within normative environments. Chronic illness means that people reflect on their bodies in ways that may or may not be on their own terms. The study of people's bodies highlights the fragility of bodies and its appearance and how we are impacted by its contingencies (Charmaz and Rosenfeld, 2016). This highlights how the symptoms of a chronic illness or lifelong disability may change throughout the day (or their lives) and the significance of this becomes clear when it is considered how what people do with their bodies matters to their social position and identity. Furthermore, they matter according to the way they are valued though the societal meanings attached to them.

When discussing embodiment, it is therefore important to remember that the individual is living within a particular temporal setting, which will meaningfully influence how they experience their social and physical world. Moreover, illness can highlight the limits that our bodies place on the material world and in doing so risk highlighting how disabled bodies may break the bodily etiquette that people are socialised into since childhood (Bradbury, 2008). In the same way as illness, therefore, my accounts of mild CP, point to an employed disability which often results in a certain vigilance over the body in an effort to present the body and the self in certain ways. The extent to which there is a desire to do this, and the ways in which this may be achieved, is shown to differ across the narratives that I later explore. Hence there is support for adopting a life course approach to disability in order to become aware of the larger picture regarding the relational nature of social expectations, which then need to be negotiated and navigated by disabled people within an able bodied world.

2.3.1. Embodiment of risk in motherhood

I would like to build on this discussion of embodiment by using motherhood and pregnancy as a brief case study, to help to bridge and illustrate the potential of a more social relational approach to disability. Motherhood and the pregnancy journey stood out as an applicable case study to include here, as the navigation of these experiences were at the centre of their narratives for people who had children. The narratives show an under researched area of study on a largely gendered experience of being a parent with CP (hence the focus on motherhood rather than parenthood more generally. See section 7 of my analytical chapters for further discussion of this.

The journey to pregnancy and eventually motherhood, is based on power relations where women particularly experience tensions between their own knowledge of themselves and their bodies and the dominant medical understandings of the body which may be prioritised over women's knowledge of themselves. To question medical knowledge and processes around pregnancy and birth creates the potential of risk. Women can embody the risk that they may pose to themselves and the baby. Frederick (2014) made the statement that "...as a mother with a disability, the chance of being investigated by social services is ominously high." (p.31), which makes it undeniable that disabled women face stigmatizing attitudes. There is a belief that they cannot perform mothering competently. Within cultural values attached to motherhood, there are expectations that mothers devote intensive time to looking after their children, and disabled mothers pose a potential threat to this. A woman's disability is used to determine her safety as a mother and her ability to provide safety for her child – to care. The middle-class, married women who meets normative prescriptions of "good mothers" are less likely to experience the gaze of the state" (Frederick, 2014, p.34).

In order to be critical of the expectations placed on women for achieving a perfect motherhood, there must be critical consideration of the values of normalcy placed on disability, which is reflected in these responses to disabled mothers (Frederick, 2017). Disabled mothers must navigate and negotiate in a medical framework which favours safety and labels those that cannot provide that with a risky label. And yet these women are often also unable to access medical spaces due to inaccessibility and by the idea of what an ideal pregnant body is. This therefore begins to introduce a more social relational account of bodies, which I will return to in a short while below. Thomas (1997) is a foundational paper which discusses women's engagement with the risk discourse often found within medical spheres. This leads to a pressure felt by disabled women to demonstrate that they are or could be 'good enough mothers'. There is a history of mothers/parents being involved in 'protective' services, despite mothers experiencing the same impairment in different ways, 'safety' is a common word used in the medical discourse around the suitability of disabled women to become mothers (Frederick, 2014). Having a disability becomes synonymous with not being able to adequately care for the baby, even though evidence does not suggest this (Deeksha et al, 2023).

Frederick (2014) argues that rather than asking if disabled people should have children, we should be asking how we can help. Those that fit the normative assumptions of being a good mother are less likely to experience the gaze of the state. They especially highlight the power relationships between mothers and social workers who have the power to claim expertise on the suitability of them as mothers.

Views on disabled mothers are helpful for exposing underlying beliefs about normalcy that is prevalent for all. Disabled women are labelled risky mothers under the scientific regime which values the successful management of risk and the prevention of disability (Frederick, 2017). These mothers are rendered invisible and lost in inflexible and inaccessible medical practices; they are not intended for motherhood as they do not conform to the normalcy project, yet at the same time there is little room for responding to their needs. Once again, bodies that cannot easily conform to the norms are looked upon as ‘unruly’, and the need for medical surveillance is deemed necessary. They are at once highlighted as a risk and yet their own needs remain invisible (for women with CP, this can include increased fatigue, worsened spasticity and bladder function following pregnancy, across all levels of impairment (Condran et al 2024)).

Once again, for Frederick (2014, 2017) safety is a key word used around the suitability of disabled mothers. Surveillance is heightened as having a disability becomes synonymous with being an unfit mother, and inability to care for a baby. There are norms attached to femininity and motherly love which are assumed to be unattainable for disabled women. The question shouldn’t be, should disabled women have children, but instead how to help them. My research shows that disabled women can and do have children, in fact motherhood was often central to their personal and disability narrative, this was not discussed however without recognition that pregnancy, birth and parenting is impacted upon by the CP. Beliefs about who is a suitable mother further highlights societal norms. The interviews I held with mothers with CP, as we shall see, demonstrate an embodiment of this ableist discourse. However in some cases, there is also a resistance to this. Disabled embodiment of risk is produced and experienced within an ableist context that results in a charitable gaze and invokes the medical model to signify impaired, and therefore, limited bodies. The stories of disabled people are however marked by strategies of resistance that embody individual and collective struggles for recognition (Loja et al, 2013). How my participants use ‘mild’ as a self-description of their CP is explored in my analysis as one of the ways in which women who become mothers with CP navigate their diagnosis and the social and medical responses they receive towards their physical disability. These are shown in my analysis (see section 7.2 for my analysis of the embodiment of risk in motherhood as told though the narratives) to be largely challenging or negative responses, to the idea of a woman with CP being able to successfully carry a child or succeed at motherhood, in a way which aligns to the normative ideas of what a ‘good’ mother is, as discussed above.

Ahlvik-Harju (2016) conceptualises these norms as the “normalcy narrative”, which they use to explain the basis of how normal, less risky bodies are upheld as desirable for motherhood. The disabled pregnant body is therefore disruptive to this and socially disturbing. This provides a link back to the more general point that able-bodiness is taken for granted as the norm, and begins to demonstrate the value of adopting Thomas’ social relational account (explored in detail below). The discussion needs to move on to what the experience of disabled mothers is (not debates around if it is or should be happening) because current lived experiences of disabled pregnant women, or mothers are being overlooked. In summary, there needs to be a question raised, however, about which ideal, ‘normal, less risky’ body disabled pregnant women and mothers are compared to. Ahlvik-Harju (2016) challenges these cultural norms (the ‘normalcy narrative’) which presents the able-bodied (male) as the ultimate normative standard from which all other bodies are judged. Writing in the area of feminist disability studies, they argue that there are normative standards for embodiment that people must conform to, or face being marginalised. The disabled body (and its non-comformative ways of being) is therefore disturbing. The normalcy narrative is the comforting narrative of embodiment, and deviations from this are not accepted. Able-bodiness is taken for granted as the normative standard in society. Ahlvik-Harju (2016) concludes that this norm needs to be reimagined.

To bridge this back to the more general discussion of medical sociology and disability studies, the ideal body is always presented as achievable, and as seen above, the non-ideal (disabled) body remains “unfinished”(Shilling, 1993; McLaughlin and Coleman-Fountain, 2014), so to then be unable to achieve this is seen as a personal failure. The body and the person are devalued. Disabled toilets, lifts, disabled badges/spaces establish an expectation of what being disabled is, however using them separates people out and may alter how people interact with one another. This physical world is still built with primarily able bodied people in mind, to which adaptations are then made in addition. The social relationality of disability regulates bodies, by categorising people into groups of normal and abnormal, these bodies are currently held up as what you do not want to be. My participant narratives about these so-called ‘abnormal’ bodies are much more dynamic and complex than this dichotomy allows for, hence, these narratives may serve as counter narratives to the ‘normalcy narrative’ (Ahlvik-Harju, 2016) and challenge that idea that the best body is one which is physically independent and controlled. To briefly link back to Parson’s for ‘ill’ or ‘sick’ bodies, that sit outside of this ideal, the response remains to try to classify them into another socially acceptable boundary.

Diagnosis of ‘abnormality’ or disability is a way in which this categorisation and management of bodies is still achieved.

2.4. Sociological understanding of the diagnosis

A key socio-medical process that upholds normative ideas is the identifying and labelling of bodily difference, resulting in a diagnosis. A diagnosis is carried with the individual as they navigate their lives. In this way, diagnosis can provide a means to understand the self and others, but they can also reflect societal interpretation of impairment and disability. Therefore, before further exploring these social relational aspects of disabilities, it is important to understand another foundational concept when considering CP. CP is still largely understood through diagnostic categories, on a linear spectrum of mild to severe, that is independent to dependent. Stories of the experiences of living with mild CP have the potential to both disrupt or reinforce this, for example, some who identify as having mild CP do so because they do not currently rely on medication or other medical intervention. However, there are other permanent wheelchair users, for example, who also consider themselves to have mild CP. Understandings of CP are led by diagnosis and the sub-categorisation within a diagnosis (e.g. spastic diplegia, quadriplegia). This diagnosis carries expectations of the future. Biomedical expectations are placed on the physical body, which may have consequences for the way that the social body is perceived.

Social construction of diagnosis and illness is a key theme in medical sociology; by seeing illness as socially constructed, it allows for an examination of how social forces shape understanding of and responses to health, illness, and healing (Brown, 1995). They aimed to further refine social construction of diagnosis, to argue for a sociology of diagnosis. Rather than looking at the social construction of medical knowledge and the paradigms of professional belief, the discipline of the social construction of illness deals with the illness experience and how this is experienced on the personal and group level and the dynamics between these. Medical sociology loses the strength of its explanations when it denies social causation. For patients, diagnosis provides a personal, emotional way of knowing what is wrong.

Diagnosis for sociologists can be a way to track medical knowledge. Brown (1995) takes this further to say that diagnosis is a sociomedical archive; a historical catalogue of actions of those in the health care system, seen in diagnostic manuals, which can show the history of medical regulation, which has historically given labels and meaning to illness. Diagnoses have been analysed as “the classification tools of medicine” (Jutel, 2009, p.278). A diagnosis is a vehicle for social classification that places bodies in certain positions in society and in relation to other bodies (Blaxter, 1978; Brown 1990; Jutel, 2009; Jutel and Nettleton, 2011). This research could help to uncover the nature of the relationship between mildly disabled bodies, and other abled and disabled bodies, through personal narratives of embodied experiences. Diagnostic activity is a prescriptive process but there is a social element to diagnosis also. Diagnosis is both a list of diseases as well as a process, something that the doctor does. The act of describing illness is affected by the descriptions available at the time, as well as the purpose for diagnosis. Categorisations are somewhat the result of the process (Blaxter, 1978). The question is raised therefore, how do diagnoses fit into pre-established categorisation of illness or impairment?

Naming something is often the start of social labelling, which holds the power to lead to or legitimise social control of certain bodies and individuals (Brown, 1990). A diagnosis (medical labelling) is socially powerful. “Diagnosis is a language of medicine.” (Brown, 1995, p.39), meaning that diagnosis locates the normal and abnormal which legitimises medical boundaries and supports the social construction of bodily boundaries. In a 2011 paper, Brown et al, looked at reformulating the sociology of diagnosis by proposing the concept of ‘social diagnosis’ – the interplay between larger social structures and the ways in which illness is manifested on the individual and personal level. This connects illness to the act of diagnosing which is set within social and political conditions. It captures the individual experience, the collective nature of a diagnosis and the larger social structures that influence this and the diagnosis, locating an individual and group in relation to social structures. The concept of a social diagnosis means to consider the larger social structures and the social factors that contribute to the diagnosis. This can be drawn upon by medical sociologists, public health and medicine, as listening to a patient story allows access to understanding of the story behind the diagnosis. For disability studies, this carries the implication that a social response to the effects of a disability can reflect how the impairment is understood and interpreted by others. For CP, this understanding is still largely based on biomedical assumptions of what bodies with CP can do, should do, and how the CP may manifest physically. A diagnosis therefore can shape or form part of the disabled person’s identity, and the rejection or acceptance of the implications of this diagnosis in relation to identifying with ‘mild’, may be seen to be on a non-linear spectrum, embodied and strategically presented by the individual to avoid stigma, misclassification or judgement from others. This therefore begins to establish links between the literature of social classification and diagnostic order with literature of social relationality, which I will now go on to explore.

2.5. Establishing a social relational nature of disability

I have moved through classical sociological theory, which underpins the origins of medical sociology, to understand tensions with disabilities studies, which I will now explore in further detail. We live in norms and endeavour to be normal. To understand the disabled body you must understand the norm and the normal body. The construction therefore is with the normal, not disability; the problem is not the person with the disability but in the way that normalcy is created to mark the disabled person as the problem (Davis, 1995). If there is an ideal form of body, those that do not meet this fall short of the ideal, seen in direct comparison with one another. The idea and identification of a norm is upheld by those that deviate from it. The process of normalisation divides up those in society who can adhere to this and those that cannot. The notion of a normal body provides the possibility of a disabled body and therefore a body which faces barriers to its social integration. Ableist attitudes are an example of this, as the barriers to social integration occur due to the rejection of the individual by society. This next section of the literature review will open up the discussion to include understandings of the disabled body more specifically. Beginning with the social model of disability as a significantly valuable development in the acknowledgement of society's part to play in the disablement of people with impairments. I will build on this to introduce and firmly establish a social relational understanding of disability to provide a theoretical framework for my analysis.

2.5.1. Where did it begin: the social model of disability

Berghs et al (2019) outline the social model as founded in the findings of the Union of the Physically Impaired against Segregation (UPIAS) which originated in 1972 in the United Kingdom. UPIAS concluded that disability is imposed on the individual in addition to the impairment, seen through the isolation of disabled people from society. This meant that medical models alone could not sufficiently provide a framework for understanding disability. Oliver (1996) conceptualised this into a social model understanding of disability. Put simply, the social model of disability saw disability as a result of the social barriers faced by people with impairments. It was not the impairment itself that was the cause of the disablement, but society. There is a distinction therefore between physical impairment and the social environment. People with impairments are socially excluded from an already inaccessible society which in turn establishes and reinforces disabling barriers. This connects back to writers such as Parsons and Douglas, and their understanding of how the social categorisation of bodies is reflected in the dichotomising response to unwell, and consequently taboo, bodies. Introducing discussion of the social organisation of bodies alongside models of disability helps to further develop some of their ideas and give them meaning within disability studies, which provides the more critical edge in which disability is foregrounded.

2.5.2. Value of the social model

The value of the social model of disability centres around its distinction of impairment from disability, recognising that societal barriers, not individual embodied conditions, create disability. The social model promotes equality and inclusion and challenges physical, attitudinal, and systemic barriers, which are seen as a barrier to social justice. The onus to improve is placed on society rather than fixing the person with the disability. Disability becomes a problem because of the way society treats people with embodied impairments. The impact of the social model was significant in the UK alone. It laid the groundwork for the Disability Discrimination Act (1995) and Equality Act (2010), which made disability a protected characteristic, therefore systemic prejudice and discrimination became a legal issue and connected to human rights. The social model also influenced the United Nations Convention of Rights of Persons with Disabilities (CRPD), which states that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (Bergh et al, 2019). Although it is true that the social model argues for a removal of barriers or a shift in attitudes towards disability, its influence suggests a much more radical impact on the discourse and management of disability in society. Disability was now recognisable as a social oppression, linked to but separate from, and importantly not necessarily resulting from the impairment. It is the disabling environments containing physical and social barriers, which exclude disabled people rendering them powerless and voiceless (Watson, 2004). Therefore, the social model challenges ideas that disability is an individual experience; social barriers become the central cause of collective disablement and thus arises a common oppression to fight.

2.5.3. Critique of the social model (paving the way for a social relational model)

It has been discussed (through research such as Watson, 2004) how the social model of disability has been a useful political tool, and Oliver himself has made the point that since the social model is a political model by nature rather than an exhaustive framework from which to understand disabled people's lives (Oliver, 2013). However a tension emerges because, by focusing on the oppressive nature of the social, individual experience and embodiment has the potential to be overlooked. A bridge, therefore, has to be built between the disabling physical environment, the social interactions which can confirm social positioning of one group to another, and the lived experience of the impairment, which I hope my empirical material is able to attest to. The social model has been criticised for being over simplified and not capturing the complexity of experience and the diversity within this. The social model relies on the binary of disabled/non-disabled – those that are disadvantaged and those that are not. Disabled people are categorised as such and thus the label of being disabled carries certain meaning. From this, it has been argued that an approach is needed which incorporates the experiences of disabled people but also acknowledges the impairment and the impact that this has. Corker (1999) called for ethnographic and qualitative research to present a picture of the realities of being a disabled person whilst capturing the socio-historical context within the disabled person's narrative, which in itself can act to track the experiences of disabled people in contemporary society. Understanding of disability would therefore be grounded in the experiences of disabled people. This needs to start by listening and hearing their stories, which need to be accepted as they are even if they do not fit into pre-established boundaries.

Shakespeare (2006) gives a balanced discussion of the strengths and weaknesses of the social model, with its strengths centred around the positive impact the social model has had psychologically for disabled people. This begins to link back to the embodiment of disability which is picked up by Thomas in her discussion of the psycho-emotional element of the social-relational model. The social model helped to strengthen opportunities for improved self-esteem, foster a positive collective identity, create a powerful shift in the use of language surrounding the experience of disabled people, and introduce the psycho-emotional elements of disablement (i.e. disability is understood as oppressing and therefore having a negative impact on the social and emotional wellbeing of disabled people). For Shakespeare (2006), however, the weaknesses of the social model lay in the lack of engagement with impairment and the secondary effects of impairment, which can often be experienced with lifelong conditions.

In the reality of disabled people's everyday life, it is hard to distinguish between social barriers and impairment. Writers such as Thomas G.M (2023) further support these critiques, highlighting how impairment is central to the world of disabled people and taking a purely social approach to disability risks discounting experiences such as pain. Disabled people can therefore be disabled by both their bodies and social environment; this should not be internalised as a fault of theirs and no moral meaning should be attached to this. Thomas (2023) uses the example of disability and stigma as a way to bring together medical sociology and disability studies. As discussed above, disabled people are defined by pity and stigma when their embodied selves do not fit with how others interact with them or how they use their bodies. As a result of this, disabled people can be excluded from social life and marginalised. This provides a conceptual link back to the assertion of Goffman (1963) that stigma is based on a language of relationships, therefore stigma is rooted in interactions. I draw on these ideas within a social-relational approach to disability to discuss how mild (and the social value of it) is understood relationally, to non-disabled people as well as others with CP.

2.6. Social relational model of disability (with a focus on Carol Thomas)

I will now use this space in the literature review to explore a potential solution to the tension between disability studies and medical sociology, before looking forward from this to establish a theoretical framework of relationality which will guide my analysis of the narratives of mild CP. Thomas (2004b) began her argument for a social relational model of disability by emphasising the relational elements to the social model of disability, which Thomas argued needed to be expanded on and not overshadowed. Thomas puts forward the argument that in a society which disables impaired people, unimpaired people are understood as being in a position of power. This opens up the idea of disability as a social relational phenomenon. Disability can arise from interactions between those that are deemed as powerful and those that are relatively powerless due to being marked out according to physical or cognitive differences. Therefore, disabled peoples' lives are restricted by the social structures formed by other (non-disabled) people. This ties into my earlier discussions within medical sociology. To briefly highlight these links here, a social relational understanding of disability takes into consideration the relationship between the social world, and its normative social structure, and the way in which this is mirrored or impacts on the physical body. Consequently, there is a social exclusion of people with impairments from social life (played out within different spheres e.g. education, motherhood). This also links back to the notion of a 'lived body' (Nettleton, 1998; Annandale, 2014) and the way in which life and bodies are experienced differently, and can be limited by impairment. The disability/impairment dichotomy is therefore not helpful because impairment does contribute to disablement.

Hence, the processes of social classifications identified by Durkheim and Douglas can be taken further within a social relational framework, to include reflection on the realities of the ways in which disabled people are put in a position to have to navigate these socially imposed bodily boundaries, and how this is negotiated on a more nuanced, interactional level. A lived example of this could be the need to navigate legality around workplace 'reasonable adjustments' or manage knowledge of the self with medical knowledge within doctor/patient interactions. The potential disabling nature of these interactions have a social structural basis, but also are shaped by the individual interactions between people (able vs disabled/powerful vs powerless). Thus, macro social categorisations identified by sociologists also have a more micro but still interactionally significant impact on everyday lives of disabled people.

2.6.1. Why and how do power relationships exist between those that can or cannot meet socially constructed standards of normality?

Disabled people exist in a world which is built first and foremost for able bodied people, and at the same time need to manage and live with the impact of their impairment (Ahlvik-Harju, 2016). Thomas distinguishes between these two things as impairment effects and disablism. Impairment effects are the direct and unavoidable impacts of the impairment. These can be physical, sensory, emotional experiences which cause barriers to the social world (Thomas, 2010, 2012). Impairment effects therefore have a biological basis, although still experienced and felt within a cultural or historical context. Hence they are seen to be bio-social in nature, felt in the way that the society responds to disability. Importantly, Thomas makes the observation that impairment effects can occur at any point in the life course (Thomas, 2010). This opens up the real possibility for there to be a fluidity to impairment effects across an individual's life. This begins to challenge the assumption that a clinically 'non-progressive' disability like CP will be experienced in a linear way across the life course. It also creates space for the discussion of impairment such as pain and fatigue, which have consequences for the way in which people can access society and use their bodies, alongside understanding the changing social and material circumstances, in which an individual experiences their impairment.

The social relational model of disability, therefore, builds on the idea that there is an identifiable disablement of people with impairments, but makes the argument that the impact of impairment on everyday life should also not be underestimated or overlooked. Engaging with impairment effects is necessary to understand the disability that impaired people may face. Thomas conceptualises this as disablism, that is the avoidable social limitations imposed on disabled people. This includes barriers experienced in everyday life, limitations to their future aspirations and their "psycho-emotional" wellbeing (Thomas, 2004). Importantly, Thomas identifies that these are imposed on those categorised as 'impaired' by those deemed 'normal' (Thomas, 2004). This does two things, it firstly further reiterates how disablement is socially constructed and relational; it can be manifested in individual interactions or seen epistemically in larger social structures. It secondly takes into account the impact of the social classification identified by Durkheim and Mauss ([1903] 1963). It demonstrates how the categorisation of people with disabilities separate from those who are able bodied, carries social, emotional and material consequences and forms the basis of exclusion too. This reminds us that there is not one singular definition of, or way to understand, disability. Disability is instead the product of socially constructed meanings and assumptions attached to certain bodies and not others. Disabled people must navigate this social world alongside managing the effects of their impairments.

Thomas made the argument in her 2010 work, that the ways impairment effects and disablism are intertwined are not yet fully understood, “I found that experiences of disablism and impairment effects were closely intertwined in their lives, particularly in their encounters with non- disabled people and the structures that inhabit the landscapes of ‘normal life’” (Thomas, 2010, p.47). This reiterates the connection between impairment and disability, and provides a foundation for understanding them as two interconnected experiences. Impairments have tangible bodily effects which are experienced within a culturally contextualised understanding of disability and impairment. These constructions are formed and reinforced by medical professionals. Here there is a link back to the sociological understanding of diagnosis. The labelling of illness and disability is not (and arguably can never be) an objective endeavour, as a diagnosis is constructed of temporally contextual medical and social paradigms. Hence why I reflect on the value of mild later in my analysis, as I make the argument that mild does not hold one singular meaning, to either those with CP or the medical professionals that they may come into contact with. However, there is an overwhelming attempt to classify bodies into what is expected of them by others. Tensions are felt by those with mild CP when they may not meet other expectations of what having mild CP should look like. This supports Thomas’ observation that although other people can cause or “do” disablism to one another, there is a biosocial reality (Thomas, 2010) of impairment effects which impacts everyday life. It is the reality of these experiences which I strive to bring light to through my empirical material. Thomas’ work was a key stone in challenging beliefs around disability and how disablism could lead to psychological distress, or psycho-emotional disablism, which placed disability alongside racism, sexism and other forms of socially constructed prejudices. Disablism arises from the relationships disabled people have with others and impacts on wellbeing and sense of self (see further discussion below of the “psycho-emotional” element to the social-relational model).

2.7. How does the social relational model of disability build on from and link to the social model of disability?

Once again, the social model suggests that while people might live with an impairment, it is the physical and social environment that causes disability. The social-relational model acknowledges this alongside the impact of people’s physical impairment, the built environment, and other people’s attitudes which can all influence the experience of disability. It is important to recognise how the social model was instrumental in establishing the onus on society and non-disabled people to make spaces inclusive for those with disabilities. The social-relational model builds on this to provide an extended framework for understanding disability. The social model established that disability is something that is experienced socially and can be found within the social structures of society. The limitations that disabled people face should not be blamed on the individual themselves, but rather there is a need to look outwards to the disabling material and social environment; the problems lie in the way society is politically and culturally organised around a normative environment.

Thomas' work makes more explicit the social relational foundations of this disablism; how prejudice against disabled people, often led by an ableist attitude leads to ableism (discrimination in favour of able bodied people). While the social model can help distinguish between disability and impairment, it has been critiqued for not allowing greater insights into the effects of 'impairments'. Thomas argues for viewing disability as a social oppression, whereby those designated with 'impairments' are oppressed by those without, extending the social model of disability into a social relational model. Disability therefore encompasses structural and inter-personal dimensions which make visible the power relationships between able and disabled people. Thomas understands that people also continue to experience the impact of impairment on their body. This could include pain, increasing impairment and increased fatigue, as secondary effects as a result of the original impairment. A static understanding of diagnosis which does not engage dynamically with the individual across their life course, will not capture the ongoing and changing impact of their impairment.

Thomas identified with the idea that disability was a social phenomenon, but one that cannot be understood in isolation; there is an understanding that the experience of living with a disability necessarily involves the recognition of impairment effects. "People who are disabled also have to work harder to maintain their sense of normality against daily assaults" (ibid, p. 71). Disabling practices directly impacts on impairment effects and disabling social interactions make disabled people aware of how others feel towards them (Shakespeare and Watson, 2010). In turn, and possibly to adapt to the responses of others, disabled people's perception of themselves and their disability can change over time. It is important therefore that all aspects of the disabled person's life are looked at, and where needed, their needs are operationalised into research (Shakespeare and Watson, 2010).

2.7.1. What does the social relational model of disability say about the nature of oppression?

To acknowledge disability (something that comes into effect from social barriers), there is not a need to dismiss impairment and how these might interact with one another (Thomas 2004b). There are both external dimensions of social oppression as largely discussed above, for example seen in the disabling interactions with others, or the physical barriers faced by people with disabilities in the material world. What needs further discussion is the internal oppression felt by disabled people which can lead from this. Thomas' work includes a discussion of the psycho-emotional element to disabilities, that is oppression felt on the 'inside' as well as externally. Due to these disabling interactions, judgements from others or challenges faced to their self-identity, there is potential for disabled people to feel of lesser value, unattractive or otherwise marginalised or unchosen. The social relational model brings attention to the impact and effects of the social behaviours between the non-impaired and impaired, the power relationships which underpin this, and the impact this has on the sense of self. One clear example which I form a case study from in my analysis, is the disabled woman's experience of becoming pregnant and giving birth. My analysis demonstrates how pregnancy, birthing and motherhood are central to the narratives of the women I spoke to that had children. During the interviews, reflections on their own experiences with this brought to the surface both stories of unequal doctor/patient power relationships, but also the presentation of the self as a competent and successful mother (in spite of or even due to their CP), as a narrative of resistance, the tensions within this are highlighted through a social-relational model. This experience of feeling the need/expectation to embody stereotypes of what it means to be mild through their motherhood can be understood as internalised oppression (Reeve, 2002). This form of disability shapes in profound ways what people can be, as well as affecting what they can do as a consequence (Reeve, 2002, p.32).

Reeve (2006) builds on the idea of psycho-emotional disablism, arguing that one of the most significant components to self-identity is how people respond to one another. Specifically, the disablism caused by the attitudes and behaviour of disabled people towards one another (Reeve, 2006). These interactions are built upon perceived hierarchies of impairment (that is, who is considered to be more disabled than the other), this has an impact on how people will self-define their disability. This will be seen clearly in my analysis, when I discuss the ways in which determining oneself as having mild CP is not done so in isolation; rather it is a decision come to through comparison to others and an assessment of how 'mild' both the impairment and the impact of this impairment has on their everyday life. The people I spoke to not only acknowledged the comparison that they made between themselves, others with CP and able-bodied people to determine how disabled they felt. They also drew on their own life experiences, for example, being in education, having children and being married, as a measure of how much they identified with mild as a result of reaching these milestones. Their narratives of mild each centre on an understanding of themselves, and themselves in relation to others.

As Reeve goes on to discuss, the psycho-emotional effect of disablism is not only seen between disabled people, but also plays out on a broader interactional level with the able bodied world and the people that are deemed to inhabit it. “When interacting with the social world outside the home, for some disabled people, it is the experience of psycho-emotional disablism which is more exhausting than dealing with environmental barriers” (Reeve, 2003, p.8). This highlights the multiplicity of disablism, and the dynamic interactions that underpin this. Not only do disabled people experience exclusion from physical environments due to accessibility and/or their impairments, but they must also adapt to managing the responses of others, and the often disabling curiosity and potential judgments that are attached to this.

Social interactions can be understood as a transactional process (for an example of sociological discussion of this, see Goffman and his work on presentation of self and stigma management). Our identity is formed and reaffirmed through the responses of others. Therefore, when this is not achieved, this affects both the identity and self-esteem of the disabled person, as well as reinforcing negative stereotypes about an already marginalised group (for a widely discussed example in popular media see when someone is deemed ‘not disabled enough’ to use a disabled parking space). Once more, external oppression can lead to internalised oppression. Also, to briefly return to the etymology of mild, the connotations of mild sit within the idea that it is not as impactful relative to more severe forms of CP, therefore it would be assumed to have fewer disabling effects. This places people with mild disabilities on the margins of two socially constructed groups, those that are deemed able bodied and those that are deemed disabled. These groups have values attached to them, with more value placed on the former group. In certain environmental or interactional contexts, it may be desirable for the disabled person to be perceived more as an able bodied person than a disabled person, as ultimately, to be of value in this normative-based society, means to be physically and mentally independently capable, “therefore, it is not surprising that disabled people can feel devalued and disempowered” (Reeve, 2003, p.91).

It is appropriate to pause here and reflect on how the ideas of core theories in sociology and medical sociology bridge with and differ from Thomas’ ideas on the social relational nature of disability. As established above, medical sociology is well rehearsed in debates on chronic illness and disability, but has been criticised for having a bias for individual tragedy and more of a focus on personal failing and stigma. The sociological theorisation of stigma and the way in which it is formed through and within social interactions can be seen to provide a basis for the psycho-emotional foundation of the social-relational model of disability. However, medical sociology arguably does not engage sufficiently with the structures of oppression that impact disabled people.

The social model of disability encouraged a move away from this, identifying the disabling conditions in the material world as largely distinct from the individual's impairment. Writers such as Thomas, Shakespeare and Reeve see this divide as unhelpful and risking the oversight of impairment impacts (effects). Debates around social oppression can be focussed on heavily to the detriment of acknowledging and being critical of embodied and physical impairment. Thomas and writers in support of her line of thinking, recognise these impairment effects whilst maintaining a discussion of unequal power relationships and structural oppression. Therefore, reintroducing impairment back into the discourses around medical sociology (whilst keeping disablism at the forefront of discussion) helps to continue the development of disability studies and/or the sociology of disability. This is important when it is argued that disability is still often overlooked as a sociological topic in its own right. Hence, critical and open dialogue is needed between these disciplines to explore the complexity of experience and bring attention to the marginalising of disabled people (McLaughlin et al, 2023). I would like to include in this also the marginalisation of disabled researchers who are key to facilitating an open and honest space for discussing the realities of living with a disability (Shakespeare and Watson, 2010).

This reality is not yet completely captured within medical sociology which, it has been argued, as a discipline leans on theories of social deviance (Thomas, 2012). In this context, occurrences of social deviance are transgressions of categorisation of normal and abnormal; the abnormal becomes pathologised. Thomas (2012) reflects further on this, referencing Parson's notion of the social deviance attached to being ill. Parson's sick role allowed people to temporarily live outside of the ideal; a designated sick role regulated the dysregulated and the deviant. In this way, medicine was serving a social function. Goffman's work also relies on this distinction between the normal and deviant to explain stigma as a product of certain social interactions which position disabled people at a social disadvantage to non-disabled people. Thomas' work is arguing to incorporate a sociology of disability further into the mainstream discussions of sociology. This would encourage engagement with oppression faced by disabled people alongside other epistemic oppression such as gender, race, or social class. With a focus on disablism (but with a recognition of the impairment effects) this would move disability out of the margins of the sociological discipline, and allow for a more inclusive discussion of the systematic inequalities faced by disabled people (Thomas, 2012).

2.8. What does the social-relational model say for the relationship between impairment and disability: relocating CP within a social-relational understanding of disability

Before closing this section of my literature review, I wanted to consider how the social-relational model will help me to develop my understanding of the relationship between impairment and disability, as presented in my participant narratives. Thomas (2002) drew on debates of disability as a social phenomenon, which opened up discussion of where and how this social oppression occurred. Oppression is felt internally as well as through external discrimination and it is important to consider the impact this can have on social interactions. There is a socioemotional element which has effects on sense of self, self-esteem and security. This internalised oppression (Reeve, 2002) shapes what people can be and therefore what they do. The psycho-emotional is not just a private element, rather, social interactions are mutually constructive.

The nature of the impairment also plays a role in shaping the disability. As discussed above, it can be understood as an embodied socio-psycho experience in which the individual is socially marked due to a visible impairment as unacceptable or unsettling. The impairment effects (Thomas, 2004) therefore, can have a direct and marginalising effect on social life as they force the body to be set outside of ableist norms. A recent example of this studied in relation to CP is falling or the 'fear of falling' as studied by Shah et al (2015). Their study found that falling or fear of falling is felt by over half of their study population of people with CP. They found that people used their own management strategies to try to manage this impairment effect. This, therefore, is a further example of how disability is embodied, as their impairment is managed to limit this potentially socially limiting experience. Self-management techniques included the strategic use of a wheelchair or avoidance of certain activities which may increase the risk or possibility of falling.

The study acknowledged that falling for adults happens sooner for those in the CP population, so adults living with CP may benefit from specific fall prevention and recovery support which is currently limited. This also highlights the need to manage the impairment effect as the person ages with CP. While the initial brain damage is non-progressive, there are tangible changes experienced in the adult body which are associated with physical (and psycho-emotional) consequences. The impact of this is exacerbated when experienced within a society and material environment built for non-disabled people. Adapting to this largely still inaccessible world can lead to functional loss, pain, fatigue and other psycho-emotional issues. These impairment effects and psycho-emotional embodied effects of ageing are significantly under acknowledged in linear thinking regarding the relationship between disability and impairment. It is therefore helpful and appropriate to adopt a lifecourse approach to understanding the realities of living with a lifelong disability. This helps to capture the socio-historical context of what is happening as people age with CP, but also within the context of the rest of their lives.

My participants' narratives provide a window into understanding how people are experiencing CP across their lives so far, and how this is shaped by and continues to shape their understanding of themselves as having mild CP, all within their own timelines. This becomes especially important when understood within a social-relational framework, as the use (and therefore the social/transactional value) of mild is better understood with consideration of how people are shaped by their cultural environment and the relationships they build with others within this. Furthermore, considering my participant narratives of mild within a social-relational model of disability helps to locate the value of this research within contemporary discussions of medical and social responses to bodily differences. Specifically, how medical and societal responses to bodily differences shape the stories that people tell of their bodies and how they make sense of their disability and identity as a disabled person (McLaughlin and Coleman-Fountain, 2014).

The discussion above leads to the possibility for me to be able to locate some of the narratives of mild within (in)visibility debates relating to the experiences of those with so-called 'invisible disabilities' and how they pose a challenge to binary assumptions of what being disabled or non-disabled looks like based on the physical body. Furthermore, the difficulties attached to finding a position in disabled and non-disabled social spheres when a body is "not looking the part" (Calder-Dawe et al, 2020, p.146). I feel that it is significant to make the point that this experience, although an important observation, can only be said to apply to some of my participant's bodily experience of their impairment. As discussed in my analytical chapters, multiple participants who self-identified as having mild CP were permanent wheelchair users, which directly challenges the notion that a mild disability or impairment is one which is less visible to the outer world. This highlights problematic assumptions that disabilities should be easily and visually recognisable and returns to the idea that bio-medical diagnostic processes do not fully capture the lived experience of a lifelong condition such as CP, particularly when understandings of CP are realised through dynamic and fluid interactions between the individual, other people and their material environment.

This brings us back to the appropriateness of a social-relational model of disability to understand mild CP. What mild is, is challenging to classify (medically and socially), so acceptance from others (and even the self) requires an understanding of the complexities and interconnections of impairment effects and disablement. This is challenging to navigate as a disabled person with mild CP, especially as it is often the case that people are ignorant of the details of disability, and yet hold an idea of what it should look like (Calder-Dawe, Witten and Carroll, 2020), which disabled people are obliged to try to conform to in order to achieve successful social integration. This creates an important bridge to the next section of this review, which explores the way in which mild CP is currently discussed within the available literature, as when CP is discussed it is still largely done with a clinical focus. I will use the next section of this review to present the literature that exists on mild CP, to later make the argument in my analytical chapters that current discourse of mild CP does not reflect the social and everyday complexities of living with mild CP. To close this section, I would like to reiterate what I am taking forward to use in my analysis from the social-relational understanding of disability:

1. The acknowledgment that impairment effects and disablement are two aspects of living with a disability, whilst being open to discussing the ways these overlap.
2. The interactional connections between the self, the body, other people and the physical environment (and therefore how disability can be embodied).
3. The potential for diagnosis to be used strategically, reflecting on the role of diagnosis in navigating social spaces.
4. The observation that space is not uncritical. Physical and social (interactional) space influences bodily experiences and in the same way, bodies influence space.
5. Challenges to the linear nature of impairment and its relationship to disability, which are shown to have a much more dynamic relationship.
6. The social significance of language and having access to the words to be able to express the realities of living with a disability. The social relational model expands on the critically important elements of the social model of disability which gives disabled people a way to collectively express the injustice and barriers that they face. This is more important than ever with the continuing political and social targeting of disabled people.
7. Expanding on the interactional nature of disability highlights the unequal power relationships that underpin understandings of disability and able bodiness, whilst also highlighting the transactional nature of disability, that is navigated *within* disabled spaces, as well as outside of them.

2.9. How is (mild) CP understood (with a focus on clinical literature)

2.9.1. What is known about 'mild CP'

This proportion of the literature provides an account of how current literature frames the debates around CP and thus highlights the gaps in the discussion around mild CP. CP in adulthood is an emerging topic within academic literature, spanning multiple disciplinary and epistemological boundaries, including rehabilitation and physiotherapy services, and psycho-social studies. Most studies are still to be found within paediatric journals or aligned in some way to childhood studies and aim to support paediatric services for those with CP, rather than a move towards social studies and the everyday experience of CP in adulthood.

Highlighting gaps in the literature will help build the foundations for the discussion of the ways in which social science, sociology and disability studies may be able to close gaps in the understanding of mild CP in everyday life. It is also relevant to keep in mind on a broader level how research narratives can be utilised in social science and sociological disciplines to access meaning making achieved by those with early-acquired, lifelong conditions, and specifically how narratives, as a negotiated social event, can be a productive interactional space to collect in-depth reflexive data, and how narrative analysis can allow for a fuller and more complex awareness of the needs of those with mild CP.

I approached this review of CP literature with the aim to understood CP in adulthood, to what extent has this been attempted to be understood sociologically, and therefore what is currently understood about mild CP in adulthood. In total, I found four studies specifically focussing on mild CP in adults (Eken et al, 2016; Morris et al; 2002, Gao et al 2017a; Geo et al 2002b). Although other studies did discuss mild CP and include participants with mild CP. (Gaskin, Andersen and Morris, 2010; Howe, 2008; Guffey, 2015; Healy, 2020; Howe, 2009; Shuttleworth, 2000). Studies that had a deliberate inclusion of participants with mild CP, or studies where the majority (over 50%) have mild CP, for example a comparative study between GMFCS levels, were Damiano et al, (2013); Reid, Carlin, Reddihough (2011); Spirtos and Gilligan (2020); Munger, (2011).

For the primary studies looking at mild CP in adulthood, the majority of studies measured physical 'functioning' of the body with mild CP, and epistemologically, the studies were based in rehabilitation, occupational therapy, behaviour and movement studies, neurology and child development. A significant proportion of studies of mild CP were built upon the physical measurement of 'function'. Eken et al's (2016) findings suggested that walking endurance could be improved with training, but that endurance itself did not reflect on participation. This is the space in which more qualitative-based studies would be helpful to understand in more depth the meaning of participation for those with mild CP. For example, this highlighted how the walking endurance of person with CP may not necessarily reflect the disability they may face, as measuring walking endurance does not take into consideration the social and physical accessibility of the space (as discussed in Guffey, 2015).

Similar questions arise from the Morris et al (2002) study, which acknowledged patient report of worsening movement in fingers, but cited no other evidence or worsening neurological condition.

This clearly highlights the critical discussions that need to continue around who is assigned the 'expert' in the case of lifelong conditions. It is vitally important to understand disability from the lives of those that experience it, and assumptions and firm distinctions cannot be made between physical presentation of impairment and disablement. Impairments are part of the social experience of disablement, they are both socially and physically experienced, and a lesser impairment does not always lead to lesser disability.

Therefore, in-depth, participant-led studies have the potential to be able to take studies such as Howe (2008) further, as this paper (examining the classification and subsequent exclusion of bodies in sport) links to discussions of Douglas and body regulation, and the processes of classification explored by Durkheim. Gaskin et al (2010) looked at how personal feelings of inferiority can be both helped and hindered by participation in sport, as participation in certain able-bodied sport spaces, they feel, limits their access to disabled spaces (suggesting certain public spaces can become normalisation spaces) and the acceptance of their peers from either group.

This feeling of being 'stuck in no-man's land' was echoed by Munger's study (2011), although only giving an in-depth analysis of one participant who had mild CP, their insights point to the complex and real consequences of the label and experience of mild, such as a struggle to be accepted, facing encouragement to integrate into non-disabled worlds, and employment discrimination. As the Spirtos and Gilligan (2022) study found, (looking at young adults, not specifically mild CP) for those with CP there was an awareness of a sense of liminality between boundaries of disabled and able and deliberate 'disability identity management' to manage themselves in social settings.

Therefore, particularly as one of the papers in the review found a proportional increase in mild CP (assuming this to be the diagnosis of mild CP) during the 2000s (Reid, Carlin, and Reddlhough, 2011), this strongly suggests the richness of knowledge that could arise from a study with a singular focus on mild CP in adulthood, and a study which prioritises the thoughts feelings and knowledge of those with CP. The diversity of experience within the term mild is instantly clear through a comparison of the clinically posed GMFCS level of mild, levels I-II (Habersack et al, 2022), which includes walking independently, and the participants in my study who, although not aware of their GMFCS level, were a permanent wheelchair user or a required assistance with walking which is clinically associated with GMFCS levels III and higher (Habersack et al, 2022; Palisano et al, 1997).

Hence, this section of my literature reviews has demonstrated the relatively small number of studies looking at mild CP, and a real absence of a sociological focus on my research topic. This is not only because there is a lack of relevant studies, but those studies alone have begun to highlight the varied experience of disability that is currently being overlooked. With the changing medical landscape and increased acknowledgment of survival rates, and more precise and early diagnosis, there may lead to an increase of mild cases of CP, this places even greater importance on establishing what the value of mild may be. The following sections of this chapter will broaden the literature out to establish what sociology has to say about CP in adulthood. This is necessary literature to be aware of due to the lack of research on mild CP in adults, it gives an idea of the literature I had access to when embarking on my interviews and thus outlines the current sociological discussions around CP beyond childhood.

The following section will now look at relevant literature looking at adults with CP within sociology. This literature is being introduced to refer back to throughout my thesis, and it will also give me the opportunity to reflect on what mild can contribute to these discussions.

2.9.2. The emerging social and medical identity of an adult with CP

The adult body with CP is something which is becoming of increasing interest to the medical world. Often framed in a sense of transition, studies look back in hindsight to reflect upon the transitions that adults may have experienced (I will discuss this in my third analysis chapter, chapter 8). The notion of transition often places, therefore, the studies and resultant discussions within a clinical and paediatric setting. It is here that the studies point to gaps in medical knowledge, this appears to be the motivating factor to the emergence of this medical identity. The sense of reflection is recognition of the increased survival rates of those born with CP (Moll, 2012), as the likelihood of this increases, so does the need for research to fill the gaps in physicians' knowledge.

This is a new type of ageing population, and one that does not follow the trajectory of those ageing with able bodies. This difference appears to be a cause for uncertainty and risk attachment to the bodies, a theme that will be discussed later in the thesis, the ageing body with CP can longer simply be seen as a continuation of childhood bodies, and the studies draw on this difference as a potential point of comparison between child and adult bodies with CP. The studies examined for this review, often gave specific and limited areas for research, focussing on levels of functionality and productivity (also a theme to be discussed further) compared to those of able bodies. Arguably, this new and emerging identity leaves sociological questions as to how this new identity will fit into the medical rhetoric that CP is a non-progressive disability? As well as this, and before this can be discussed, there needs to be a conversation surrounding what this new social group (and therefore new study population) will look like? What adjustments will be needed in societies to accommodate them, and how can they be better understood within everyday society, rather than merely within a medicalised setting?

Kumar, Perez and Friel (2023) look at the complexities of ageing with CP, highlighting healthcare challenges faced by adults with CP, these include management of long-term motor impairments, difficulty finding clinical experts, and a lack of rehab options. They also look at the ways in which it may be possible to maintain functional independence, social integration and communication participation. They help make the point that although the brain lesion that causes the movement disorder is non-progressive, the neurodevelopmental disorder worsens from secondary complications of existing sensory, motor, and cognitive impairments. They highlight the importance of long-term healthcare to prevent functional decline.

Again picking up on the lack of current knowledge held on the healthcare of adults with CP, Yi, Jung, and Bang (2019) take more a psychiatrist perspective, focussing on rehabilitative medicine and writing on adults with CP and their experience and transition to adulthood. To gain a full understanding of the healthcare needs of adults with CP, in order to create space for developing healthcare services focussed on adults. They argue that Psychiatrics need the knowledge of this to "prepare for the aging population " although this does not focus as much on the social side of ageing with CP, studies such as this are important for continuing to advocate for adulthood in CP as a worthy area of study. There may be a bridge to be made between these broader observations of the need to acknowledge adults with CP, and the need to include those with mild CP. Life with CP as an adult is full of personal and medical unknowns, which studies only relatively recently acknowledged it as an area of study in its own right (despite papers acknowledging increased survival rates for decades (Hemming et al, 2005). I would like to argue that the same needs to apply to those with mild CP. Adults living with mild CP are navigating both a future of unknowns (from a lack of knowledge on adults with CP) as well as needing to navigate the social world as somewhat of an unknown or misunderstood body.

When something is uncertain there are often unknowns, and adulthood within the context of CP has been shown to be a space for unknowns. It may be useful to consider where this comes from, and several papers point to attempts to carry out research from cohorts of adults who received a certain form of paediatric intervention. This therefore could be the point at which the adult body with CP becomes uncertain. Previously under-researched and relatively under-recognized, (as demonstrated through its recent emergence), the adult body appears to be discharged from hospital services and the minds of those in the medical and health and social care almost in its entirety. With exceptions for those with severe forms of CP, this theme is here to highlight the lack of continuity between childhood and adulthood care and research. It seems relevant therefore to seek the impact of childhood intervention through biomedical research on those that experienced the transition into adulthood. What is often lost here, however, is the context to this end result that is being increasing considered; what racial, economic, gender read, and political circumstances can impact the way in which an individual experiences CP in their adult life, and how might these factors change the level of uncertainty and riskiness they face in society? Sociological research could be helpful here to realise how the demographics of an individual may have an impact on the outcome of medical intervention, and in turn may impact how they "function" as an adult with CP. Risk or precarity is something which I will return to in my analysis to make the link clearer between disability and risk through the empirical material.

Consequently, bringing mild into discussions could bring to light the impact of certain diagnosis, and, drawing on a sociological perspective, suggest that mild is more than simply a label, it may say something about how a person may qualify for or be considered to require care, as well as challenging the relationship between the biomedical and social experience of disability.

2.9.3. Functionality/productivity of the ageing CP body

Functionality is a subjective word, shaped by the context of its use and who sets the expectations of the levels of functionality, these are sociological questions that are arguably not fully explored or recognised by the papers in this review. Interestingly, broader literature makes certain assumptions about functionality, as something that can be objectively defined, hence problematising functionality (and capability) will form a discussion point of this thesis. Overwhelmingly, the focus on functionality is centred upon an individual's ability to walk, or alternatively, how successfully an individual is able to use adaptive and assistive technology, such as a wheelchair, to increase their capacity for function and in turn productivity (Mesterman et al, 2010; Eken et al, 2020; Reddihough et al, 2013). This hypothetical productivity is often measured numerically, and presented in corresponding percentages, reflecting a set of determinants for an individual's success in an able-bodied world. However, this leaves space for important sociological questions such as: How well does the wheelchair fit into an individual's life? Does the degree in which it does or does not fit in the way determine the display of the disability and thus impact the way in which people are displayed in their society? In this sense therefore the wheelchair becomes animated by the individual and the spaces in which it is placed - no longer a seat or a place to sit or be, but rather becomes a signal of disability, for some freedom and independence for others a social barrier and social symbol of their deterioration and inability to be rehabilitated (which will be discussed below). This displays clearly where sociology has a place to examine this interaction with wheelchair users and beyond, as it does not appear sufficiently complex to only consider how functional someone is by other people's notions of productivity. It could even be argued that it may be useful to carry out studies where functioning is self-defined by the individual and hence their levels of productivity could be considered within the original abilities and limitations of each individual, as well as focussing upon the quality of life and quality of movement.

Linking this discussion back to mild CP and my sociological framework, I feel this literature demonstrates the value of looking at the ways in which people with mild CP negotiate their social and physical world, as well as looking at how aids such as wheelchairs can contribute to the socially performative elements of disability. It also shows how the performativity of mild CP is not simply an individual experience but is the result of the interaction between the person with mild CP, their environment, and other people. This is negotiated within normative environments.

2.9.4. Rehabilitation of the ageing CP body

Rehabilitation appears several times throughout the studies, often cited as the end goal of the research. There are comparisons made however to able bodied individuals, of similar ages, that may not be entirely useful when taken out of the medical context that these discussions are often placed within. This also raises the important question of rehabilitation to what? This has presented the opportunity for me to challenge normative assumptions about the able body through my research. The lack of knowledge of adults with CP appears to rely on an idea of continuity between the condition of the individual as a child, and their condition as an adult (Balandin and Morgan 1997). There is, however, a lack of research to confirm that this continuity exists, and instead lay and personal experiences often suggest that the non-progressive nature of CP is not seen in their day to day lives (Benner et al, 2017) (this is discussed in the final theme). Again there also seems to be little attempt to consider the quality of people's lives once they would have received this rehabilitative treatment. Sociology can play a part here, raising questions as to the necessity of the treatment in a social sense, as well as challenging the idea that rehabilitation should focus so heavily on the physical body. Once the notion that those with CP will decline is challenged it becomes a viable area for research, a possible area for intervention (where sought by the individual) in the same way it is seen in paediatric services. This literature also raised questions to me around why functionality is limited to walking ability, and instead rather should functionality be self-defined?

Here introducing experiences of mild CP helps to challenge the notion of deterioration based solely on a linear trajectory. The impairment effects felt by mild CP are arguably fluid, and therefore, as will be shown later in my analysis, the applicability of mild to their experience of CP may alter. The strategic use of mild (as I will describe in later chapters) to reflect how they feel CP impacts their day-to-day life, may therefore better reflect this change in their impairment, rather than only seeing it in terms of linear functional 'decline'.

2.9.5. Personal insight/the lay experience

Self-identification of the experience of CP as an adult, including ideas surrounding functionality is currently on the periphery of discussion. Where it is attempted to discuss this, papers focus their research aims on exploring the psychosocial nature of CP. This introduces the idea of CP as an experience - a dynamic experience, something which can alter and interact with the ageing experience. Such research again points to a lack of a sense of coherence, recognising the need for more knowledge, not simply for physicians but for the people living with CP. Disability intersects with ageing and with the society individuals are in - the ageing process is not homogenous, even with the same disability, or gender, the ageing with an early-acquired disability happens in many different forms. What is lacking here is the recognition that ageing in general is not simply a biological changing of physical states, but also an emotive process, one that can evoke a changed sense of self, and unique feelings towards your ageing body. This individuality is often lost, the meanings that people with CP attach to their experiences with their body are not explored in a way which allows them to be legitimised and become part of the discussions of how to respond to the ageing process alongside CP. Furukawa et al (2001) looked at the "subjective well-being" of adult CP patients, although the paper is useful for pointing to the importance of social positioning of those with CP (e.g. workplace), it frames the experience around the idea of 'social integration' which reminds us of the happiness of disabled people is still measured by the degree to which their bodies are able to conform, or the extent to which they are able to achieve inclusion into the able bodied word. There is a pressure to pursue normality (Munger, 2011). Munger's PhD thesis is a fascinating read, based on the psychological experiences of adults with CP in the US. Through interviews and diary study, the research looks at stigmatisation and how this interacts with their self-identity and social-psychological wellbeing. Participants described instances of being treated differently or of stigmatisation in their everyday lives. Where they had become integrated within a disabled community this helped them manage their sense of self, however the opposite was also found for those who had not managed this integration with such social groups, especially within an able body focussed society.

Shah, Bradbury and Taylor (2020)'s study tells the stories of women's experiences of premature ageing and sexual and reproductive healthcare for women with CP. Speaking to 45 members of an online international community (Women Ageing with Cerebral Palsy), they sought to understand the bodily and lifestyle effects of CP for women. Studies such as this highlight the importance of giving women their own voice, particularly in relation to sexual and reproductive health services, and the importance of giving a public and social platform for women's experiences to be heard. Jones (2009) publication gave their personal reflections and recommendations for ageing with CP among other disabilities. It contained the lived experience of a 64-year-old woman ageing with CP (health scientist for CDC) and other multiple disabilities, reflecting on coping with secondary conditions and functional decline, fighting pain and fatigue and misdirected medical advice, arguing for the benefits of a strong partnership between adults and those with CP. They very tellingly summarise with the following: "Growing up with CP is hard on the body" (Jones, 2009, p.12). This observation is currently largely overlooked in the literature, particularly from the perspective of those with CP. As being able to listen to people in this way is so rare, I would like to summarise some of the difficulties she faced which included: limited options at school; frequent falls; fear of dropping her baby as a new mother. During this, doctors often failed to put symptoms together and see the bigger picture of her disability. Jones notes 'functional' decline and lifelong pain, noting that a willingness to adapt and change is needed, as well as feeling able to ask for help. Their recommendations include, collaborative doctor-patient relationship, acknowledgment that the impact of CP can have similarities and differences and these impairment effects (Thomas, 2004) interact with musculoskeletal functioning. Hence there needs to be an incorporation of knowledge of modern medicine with lived experience, beginning by involving more people with CP in research.

I would like to close this section by highlighting a paper by Jacobson, Löwing, and Tedroff (2020), who looked at the health-related Quality of Life (HRQoL), fatigue and other health variables in young adults with CP. In doing so, they explored the associations with the GMFCS-E&R and physical activity. Overall, they conclude that the HRQoL scores were in line with the 'norm', however self-reported physical health was lower in GMFCS III-V compared to levels I to II. Interestingly, mental health was, inversely, lower in GMFCS-ER levels I to II compared to GMFCS-E&R levels III to V. Pain prevalence was 49%, and pain was present across all GMFCS-ER levels. Fatigue, as well as sleep problems, had 41% prevalence, with fatigue severity decreasing with increasing level of physical activity. This suggests that pain and fatigue are important to address in high motor-functioning individuals also. This study highlights the relationship between medical classification and the everyday embodied experience of mild CP. It is important to understand how CP is understood in the clinical sense, so that it may be considered alongside the embodiedness of my participants. It is also interesting how the study refers to those on the lower end of the GMFCS as 'higher functioning'. I hope that my research begins to show the subjectivity of such phrasing, and show how, even when a GMFCS can be assigned to an individual, the impact of these impairments can vary and the medical notion of 'high functioning' needs to be challenged. The use of 'mild' CP and understanding the value that mild can have alongside the GMFCS labels is one way in which this may be possible. Mild is used in more complex ways than its clinical classification would suggest, showing the value of looking to the experiences of those with CP to explore this further.

2.9.6. An acknowledgement of grey literature

For those that are living with CP into adulthood, there are examples of information that is available in the public domain (particularly in lay terms). Key examples include the NICE guidelines (NG43, 2016), Quality Standards for Cerebral palsy in adults. This guideline covers care and support for adults with cerebral palsy. It aims to improve health and wellbeing, promote access to services and support participation and independent living. It includes recommendations on access to services and ongoing review support with communication, vocational skills and independent living, electronic assistive technology and physical activity, managing spasticity and dystonia, assessing and monitoring bone and joint disorders, mental health problems, difficulties with eating and nutrition, respiratory disorders and pain. It also refers to the transition for young people into adult care services, a process which is expected to be managed through the NICE guideline on cerebral palsy in under 25s, and the NICE guideline on transition from children's to adults' services for young people using health or social care services (NG43, 2016). This guideline covers diagnosing, assessing and managing cerebral palsy in children and young people from birth up to their 25th birthday. It aims to make sure they get the care and treatment they need for the developmental and clinical comorbidities associated with cerebral palsy, so that they can be as active and independent as possible. Interestingly, the GMFCS is not validated for use in adults. However, the GMFCS level at age 12 has been shown to be a good predictor of mobility into adulthood, especially at the milder and most severe levels. It is used here in the absence of a validated system for use in adults because it is readily understood by people with cerebral palsy, their families and carers, and health professionals involved in the care of adults with cerebral palsy.

CP Scotland has also produced guidance to act as support for adults with CP. This documentation argues that statutory services for people with cerebral palsy are concentrated in children's services and education. Thus, there is no specialist therapy service for adults with cerebral palsy in Scotland, apart from the adult services provided by Cerebral Palsy Scotland. They argue for the need for change. Arguably in a subject where little is known, steps forward for change have to come from the knowledge of those with mild CP. One area of which this is especially the case is in discussions around CP and fertility, pregnancy and motherhood/parenthood. Since carrying out this literature review and reviewing the contents of the empirical material, I also feel it is necessary to reflect on the literature on motherhood and CP. A search of the literature shows a focus on parents with children with CP, rather than those that become patterns with CP. There is the following literature which does explore this topic (Shah, 2006; 2020; 2022), although it remains very much a work in progress (Shah et al are also currently recruiting for an upcoming study, looking at women's pregnancy experience: Rights and Choices for women with cerebral palsy (RICH)).

Chapter summary

This chapter has outlined existing literature from sociology and disability studies which I can then use to develop a theoretical and analytical framework and situate my empirical material . In doing so, it highlights the gaps that remain, in relation to a discussion around mild CP. This literature review has begun to show that CP is a complex condition, and one which deserves sociological focus. What remains from my research is to demonstrate that this complexity extends to the 'meaning' and value of mild. It was important for me to not simply see mild as an intersection of CP, but rather to allow mild to become the focus of study in its own right. Mild carries strategic and transactional value (when considered within the social-relational nature of disability) that is not reflected in the existing literature. My research aims to convey this value. An overarching idea to emerge from the existing literature is that CP continues to have an impact (all be to varying degrees) into adulthood. The use of mild allows there to be a critical analysis of the felt reality of these impairments, which are clinically categorised as 'nonprogressive'. Where a condition is seen as nonprogressive it may be presumed that the impairment also does not progress or alter. A framework that challenges this idea, and instead put disability and impairment on an interconnected continuum allows for an experience and understanding of disability that considers the context of disablement (a large feature of this being its social relational nature). My narrative research will aim to keep disabled people at the centre of the telling of their experience of disability and impairment, recognising them as the experts of their own CP (Liddiard et al, 2019). Arguably, not enough work has been done to challenge the assumptions that society holds around the concept of normal, and the expectations placed on adult bodies (Shilling, 1993). A space for contradiction, change, and fluidity has to be expected and allowed to have a place in society, as current assumptions that see disability as a static experience, risk being deterministic and not fully appreciative of the dynamic and interactional aspects of living with a lifelong early acquired condition.

To link back to my central argument, I would like to make the point that, mild, lifelong disability needs to be talked about, and those with mild CP need to be the first people we listen to. More broadly, my argument overall thus far is:

- Mild CP is an important and worthy area of study as it allows for a more complex analysis of living with lifelong physical disabilities.
- Mild appears in discourse surrounding CP, and yet its multiple meanings and therefore value is yet to be established.
- Sociological concepts around classification, embodiment, bodily boundaries and management can help to establish what this value may be.
- The social-relational model of disability will be central to my theoretical framework for the narrative analysis of the interviews.
- The use of mild appears to currently be largely overlooked as, and such its complexity is lost from disability debates.
- Disabled people are required to navigate a largely ableist society, negotiating their place within normative categorisation of bodies. Therefore, the social-relational understanding of disability makes a point vital to my analytical standpoint, that although social disablement is still experienced and challenging this must remain critically important, people with a disability experience the world through their bodies, bodies which carry impairment effects, which interact with the social disablement they may face.

3. Conceptual methodological chapter

Chapter introduction

It has been established in the previous chapter that, in line with my central argument, ‘mild’, lifelong disabilities need to be talked about. I went into the research with the aim to allow my participants to share, and for me to listen to their stories. Although I recognised that my position as a disabled researcher with the same condition would need to be acknowledged during the recruitment process, I feel retrospectively that I underestimated the importance that this would have for my participants, and the role that my methodological choices would play in the way I was able to access this group of people. Therefore, in an effort to be as transparent and clear as possible, I have broken down my ‘methods’ into two chapters, the first being a conceptual methodological chapter, which will introduce me as the researcher, focussing on the reflexivity I strove to maintain. Before looking at the ontological and epistemological position I took for my research, and then how this formed my approach to this narrative enquiry. My second methods chapter will be more traditional in its content, detailing the practice steps I took to complete my empirical research and analysis. including my selection criteria for the research, although decisions around this held in themselves an unexpected response from the participants, which I will detail within the chapters. The following chapter will aim to show why I feel I was an appropriate person to bring the complexity of CP (as I have been pointing to in previous chapters) to the forefront, and why I chose to draw on a narrative approach to do this.

I would like to open with this brief definition of narrative: Biographical narratives create a knowing spatial 'presence', which as it enfolds, offers an expression of who we are, accessible to others (Riessman, 2007). I will refer back to this through the two subsequent chapters, however I would like to highlight the idea of 'knowing', of 'expression', and of accessibility. These three concepts become central to my methodology, striving to help my participants felt known, and their feelings expressed. It is my goal during the interviews to create a space of trust, I feel like this is supported by the mutual (albeit personal) knowledge of CP, and I aim for this research to make this knowledge accessible to others to learn from. As this chapter will outline the methodological foundations and choices made in relation to this research, there will be discussion of the debated discourse surrounding narrative inquiry and where this research is situated within these debates. As a reminder of the research aims of this study:

- Consider ways a 'mild' diagnosis is constituted in medical, social and personal spheres.
- Highlight how adults living with 'mild' CP experience their disability within their society.
- Make visible lived experiences of adults with a mild physical disability through the telling of personal narratives.

Hence, the research methodology has been embedded within the aims of the study, recognising the contribution that narrative inquiry can bring when seeking to understand the meanings attached to concepts previously largely considered within biomedical fields. Narratives are a broad and well debated topic, and it is essential that tools are decided upon that best fit the research questions. Integrating theoretical debates and operational decisions is vital to create a solid and appropriate methodological approach. Once again, the research questions that later guided the interview topic guide and the methodological choices made during the research. These are:

- What are adulthood experiences of mild Cerebral Palsy?
- How are 'mild' diagnoses constituted in medical, social and personal spheres?
- To what extent are diagnoses of mild Cerebral Palsy contested?

- How do people living with 'mild' Cerebral Palsy manage and negotiate their disability, body, and identity?

When these research questions were being developed, care was taken to try to avoid (as much as possible) my personal experiences pre-empting the questions that participants might ask, when making sense of their bodily experiences. However, on reflection, there is a commonality threaded within these research questions of context, of situatedness. This is something that has been reflected in the empirical data, but it is important to note here, during the process of doing the research. The chapter focuses on this and maps the impact of my positionality as a researcher. It begins with considering the theoretical assumptions, implied in a narrative approach.

3.1. Introducing the researcher

I approached the research having completed my undergraduate degree in Sociology at York, as this degree had been impacted upon by my disability (which I often described as 'mild CP'), when given the opportunity to pursue a PhD, I felt motivated to seek others 'like me', or to find out what mild 'meant' to people. Although I quickly recognised that those questions or goals were not the most academically productive, as mild has such varied and fluid meanings which are arguably better understood as the value that mild holds or is given by the individual and those around them, I approached the research with an awareness that mild meant more than simply a diagnosis. The reflexive section within this chapter details my reflections as a disabled researcher, carrying out research with people who have the same disability.

3.2. Ontological and epistemological perspective

This section will look at the ontological and epistemological perspectives that I drew upon to develop my methodological approach. There will be an inclusion of feminist material towards the end of this section, despite a purely feminist methodological approach becoming less relevant as the research developed. I wanted to include it here still, as I draw on feminist writers to reflect on the way I managed the delicate interview space.

3.2.1. Constructivist approach

Narrative inquiry emerged as a move away from positivist approaches to qualitative research, creating and valuing links between culture, history, and identity that can arise from listening to the experiences and voices of historically marginalised groups (Riessman, 2005). Combining life histories (complete or partial) with socio-historical contexts allows the researcher to access meaning and sense-making, done by participants as they (re)tell their stories (Junqueira et al, 2014). Bruner (2004) considers these stories as simultaneously animating and being animated by life. The research takes forward this notion that life is constructed by and through narrative reconstruction to aim to create a collaborative environment within interviews, allowing participants to share their experiences. Reflexivity is at the core of this interaction – life stories are reflexive both in their telling and once they have been told. There is a central goal to understand, understanding not in the sense of testable hypotheses and assumptions (Mishler, 1990), but rather to strive for better understanding and embracing of the possibility of multiple constructed realities and subjectivities, made visible through individual narrative telling (Sharp, 2018). Analytical meaning, therefore, becomes the product of the understanding between the observations made by the participant on their own life, and the ways in which this is interpreted by the researcher (Josselson, 2011). Thus epistemologically, it is important for there to be space within data analysis for multiple understandings to reflect multiple realities, potentially even within the same narrative, and across multiple temporal spaces.

Throughout this research, there will be a reflection on the different ways in which temporality can be understood in relation to the participants' narratives. Drawing on Beal's (2013) work, who considers temporality as a philosophical underpinning of the narrative. It does more than place a telling in time, for Beal there is an element of historical context to narratives, meaning that there is a dynamic and fluid relationship between people's experiences of the past, present, and future. The links between these temporal spaces are often made by the participants. The constructivist approach therefore also places the authority on the participant for telling their story (Riessman, 1990). This is not to suggest that narrative interviews are fact-finding projects, this will be discussed further, but rather that social reality is created through the way in which people present themselves, and the response to this. For Riessman (1990), social reality is crafted through language, an assertion that can arguably be applied to the interview setting. Language becomes a 'cultural resource' for the narrative retelling. Through the retelling an impression of a person is developed, mediated by the presence and response of the researcher and their questions. The specific impact that the researcher may have on each individual interview cannot be measured, and arguably cannot ever be, however it remains tangible. It is something that is not only seen in the transcripts themselves but also across interviews - common questions are asked, some are added or removed, or asked in a slightly different way in order to shape them to the participants' telling style. (Riessman, 1990). Questions may also be asked in a different order to one another across interviews, in this way, chronology is given a subjective and somewhat individualised meaning.

It is worth noting here the link made in the literature between narrative ontology and identity. Social Constructivism for Mishler (1990) requires an inductive approach to research, and the acknowledgment that life history narratives play a part in identity formation and presentation. Narrative interviews are a space in which the relevancy of events in participants' lives can be considered in relation to the research questions and aims. Hence, knowledge arises from interaction with individuals, the environment, and the researcher (Moll, 2012). The methodological underpinnings for this research are drawing on this discourse to allow for and encourage heterogeneity amongst participants through their uniqueness of experience (this is arguably even more of a key factor to consider when participants and I share, in terms of broad diagnosis at least, the same disability). Therefore a key point to take forward from the ontological and epistemological justifications for this research is the collaborative nature of the data collection and analysis, which seeks understanding as well as knowledge. It may become necessary to consider how the methodology has played a role in the participants' identity formation processes as they appear during the interview. The interview environment was more unique as we were discussing personal and individualised life events which at the same time were also deeply social and experienced within specific temporalities. Narratives which typified this were that of fertility, pregnancy and motherhood. Although not only applicable to women's experiences, the less traditional version of a structured, question and answer interview is often argued for by feminist writers, hence my acknowledgment of such writers below.

3.2.2. Is there a role for feminist ethics here?

To briefly consider the helpfulness of drawing on feminist methodological practices, Oakley (1981, 2016) has extensively reflected upon this, and in particular in relation to narrative inquiry. Reflecting on their own work in 1981, Oakley (2016) argues that feminist approaches to research allows women the space to construct and communicate their knowledge of their lives and experiences, with the aim of being emancipator. This idea has been taken forward in the practices of this research, not just for the women that participate, but has influenced the ontological and epistemological directions of this study and was a significant motivation for aiming to avoid a traditional question-answer format. Morris (1992) takes a similar stance, seeking a feminist approach to disability research. Although this is done not as simply the recognition of a double disadvantage for disabled women, but to make the argument for the need to account for disabled women's subjectivities, and how feminist methodology can help to make the personal political, given that women's experiences are not simply a neutral or universal experience (de Beauvoir, 1949; Morris, 1992). The diverse nature of experience was important to acknowledge to avoid making assumptions based on shared knowledge between myself and the participant. Furthermore, the heterogeneous nature of disability, even when arising from societal responses to the same impairment, highlights the suitability of a narrative approach which embraces the often complex, destabilising (Morris, 1992), and emotional elements of interviewing and research.

There is not however the goal to create a rigid feminist methodological approach, rather there is an important acknowledgment within this discourse, that "... language can never fit perfectly with individual experience" (DeVault, 1999). This also makes an important point about reflexivity. Rarefying experience through methodological application presents a testimonial language, which is not entirely a person's own. This creates a tension, which research is required to negotiate. This is important to remember, as there is a back-and-forth process of the participants answering questions in relation to the language used on the Participant Information Sheet (see appendix 1), the researcher's explanation of study motives and considering this alongside their own set of language. For example, I needed to incorporate 'impairment' into the language I used to describe CP as this way a phrase I had previously chosen not to use for my personal disability, although several of my participants did, and I also found it necessary to use it to distinguish between the physical impact of the CP and the social disability. Hence, researchers can also learn from the language that the participants chose or do not choose to explain their experiences (DeVault, 1999). This is a significant point for consideration for this study, where the definition of 'mild' was left as a self-defined term, and thus discovering participants' understanding of this label becomes part of the endeavour of the interview. This is not an individual endeavour however, a narrative methodology, drawing on certain feminist tools, allows for and arguably can necessitate a more conversational style of interview; one in which the participant and researcher collaborate together in search of fuller answers (DeVault, 1999). Hence, they develop methods for listening around and beyond the words of the interview, allowing the researcher to see parts that were excluded. This can mean it is hard to maintain a traditional methodological approach to interviews. The interview dynamic in this case is disabled researcher and disabled participant, discussing personal experiences of disability. This dynamic has opened up the opportunity to recognise the unsaid, and possibly develop a form of conversational shorthand, however with this dynamic arguably places further importance on being aware of your short-sightedness, the job of the researcher remains to recognise and understand the ambiguity and the contradictions presented in the narratives (DeVault, 1999).

Rather than beginning the interviews with or trying to establish a singular definition of the term 'mild', the aim is instead to contribute to a fuller understanding of the term, to consider its possible complexities, and to reshape current understandings of what it means to have 'mild CP'. As I have mentioned previously, I feel that this understanding best comes from listening to those who experience mild CP, that means prioritising the stories to be found in their narratives. Narratives (and narrative analysis) are broadly debated in terms of how they can be drawn upon for data collection and analysis. Due to the topic of the research, I needed to consider how I would ensure that I actively listened for their personal experiences of mild CP, and not conflate them with my own. I needed to balance this however with ensuring that I continued to align to my research methodology of valuing the subjective nature of research and allowing myself to play a role in the construction of the interview narrative where appropriate through my conversations with the participants.

3.3. Reflexive nature of the research

This section – as part of my broader reflexive approach - is a collection of reflections of experiences of doing narrative interviews, and more specifically, interviewing people with the same condition as myself, within a narrative methodological framework. The central idea for this is to provide support for the idea that there is value in shared experience between researcher and participant, and even further value when this shared experience becomes part of a conversational style of narrative interview.

My research is looking at the embodied experiences of 'mild' cerebral palsy in adulthood (see chapter one). This has come to include the social and emotional feelings attached to CP, and how these intersect with the physical realities of lifelong, early acquired conditions that does not always fit neatly into the boxes of disabled and non-disabled. As I also identify as having mild CP, I will be discussing the impact of sharing a diagnosis (at least in terms of medical categorisation), for both myself as a researcher and how the participants responded to this dynamic. Researcher reflexivity is a central aspect of any research and arguably something that is vital to incorporate and acknowledge, not only in ethics applications or analytical write up but also to the participants themselves. As I have found, where the researcher and participant positions, in this case as disabled people, cross over, there can be found a site for conversation and reflection, though not necessarily comparison, and there is space to share what might otherwise not have been shared.

By asking participants to focus on telling personal stories, they are in turn given permission to focus on themselves. I believe that considering narratives as a site for conveying feelings, emotions and memories, allows for a biographical approach to interviews, without necessitating a chronological telling of participants' experiences. On a theoretical level, this also allows for the agency of individuals to become apparent and to be acknowledged, at the same time situating this agency within social and cultural networks, and in turn the power relationships that shape participants'experiences. This becomes foundational to the sense making processes carried out in the interview and analysis.

As part of my analysis, I am also considering the possibility that people manage several narratives at once- whether that be historical/medical/personal narratives such as motherhood or partnership when they share their stories. These narratives are dynamic and fluid and change with time. Being that mild CP is at the centre of these narratives, this also gives support for the argument that the concept of mild is temporal and influenced by time, space, and place. The shifting and multiple narratives are not only a theoretical observation but are seen in the bodies of participants. The scars, the operations that have now been deemed ineffective or in some cases harmful to the body with CP as it ages. Therefore, the concept of understanding CP, and the discourse surrounding a diagnosis is something that also changes. What was once considered the right path to take carries consequences for the social and emotional experiences of those with mild CP. Consequently, a narrative is not simply a story with a plot and a clear beginning, middle, and end, but rather it seems that it is a tangible presentation of people's understandings, people's feelings, and the *sharing* of a memory or an extract from a certain time in their lives.

I presented my experiences under a presentation titled, 'This is not a traditional Q&A interview' (York St John, 2021, Postgraduate Researcher (PGR)) conference, as I used this phrasing at the start of all of my interviews, to reiterate that although I am asking for participants stories for the purpose of my thesis, which they are aware of and are willing to contribute to, I am also willing to share. There is a starting position of commonality (even if that starts and ends with the label of mild CP). In moving away from the traditional participant-researcher relationship, I hope to provide methodological critique of the traditional dynamic, not to provide criticism or discount it as an interview technique, but to simply discuss a different type of interview environment, and what this might be able to bring to the experience of the interview for everyone involved, including the eventual reader of my findings also hope to contribute to the discourse of the likes of Barnes (2003), Barnes and Mercer (1997), Oliver (1996) and Thomas (2010) all within critical disability and disability studies, who advocated for research done for and with rather than only to and on disabled people.

3.3.1. Reflections from my own application of a narrative methodology

I would now like to spend some time looking at four key areas of reflection that I have chosen from my experience of advertising, recruiting, and interviewing, which was carried out between December 2021 and June 2022. I hope by considering these elements of my research experience, I will be able to point to the ways in which sharing the same condition as the participants has allowed me to develop a more critical methodological framework, hopefully supportive of in-depth data covering the experiences of disability, disablement, and the often contradictory and fluid experiences of Cerebral Palsy as both a diagnosis and disability.

3.2.1.1. The dynamic transparency of researcher positionality

The first reflexive element of my research experience is the dynamic transparency of the researcher's (my) positionality. In the first advertisement for my research (a post made on my behalf to the charity Adult CP Hub's Facebook page) I chose to not state that I also had CP, and I also purposely did not include a definition of the term mild (among many reasons) to avoid my ideas, assumptions, and experiences limiting those that may identify as being able to take part. I felt it was sufficient to clearly state my relationship with CP on the participant information sheet, as I was fearful of allowing me and my CP to somehow become a focus for the research. The response, although not negative, was one in which people often told me about what it was like to live with CP, commenting on the post about the types of CP there are, and the nature of a CP diagnosis, seemingly assuming I would not already know. As well as a strong desire to be given a set of criteria regarding the nature of the term mild. I responded to this with a more in-depth explanation of where my motivation for the research originated from, my position as a researcher also living with CP (see appendix 2), and hence why I considered the need to keep mild as a self-defined term.

The response from that point on still surprises me now. I completed 24 interviews (beyond my initially planned 15 interviews) in 7 months, ahead of my original project timeline, and the running theme among those that took part was that their interest in the study was linked in some way to my own experience with CP. A further related experience to highlight here is, after I collaborated with the charity Adult CP Hub and SCOPE to advertise my research, I was contacted by a social media group called adult advice UK and asked if I would like to advertise my research with them, which I readily accepted. I also asked if it would be appropriate, either now or once the project was complete for me to join the Facebook group myself for personal networking. What was interesting here was that the response was 'unfortunately we only allow people with CP and their carers/partners to join the group, to allow for a safe space to share'. Therefore, something had led to the assumption that I did not have CP. I'm still not sure where that assumption came from, but it highlighted to me that such assumptions are still being made, maybe based on a picture, or what you are working towards in your life. It also highlighted the importance of prioritising felt and lived experience rather than simply the subjective visibility of disability or outward impairment signs.

3.2.1.2. An unknown impact – the researcher's naivety

I would now like to move onto the understanding I have developed around my initial naivety towards the impact of the interviews for myself. I first noticed this in relation to my limited understanding of the variety of manifestations of 'mild' CP. In comparison to my ability to largely walk independently, there were those that used a wheelchair permanently, or struggled significantly with communication. Mild therefore it seems was not just a physical indication of CP but a feeling, a positioning of the self that often changed with time and experience, or even social settings, evidenced I felt during the interview. It may be useful to reflect here on the work of Garland-Thompson (2005), who from the perspective of feminist disability studies, focuses on patterns of meanings attached to a condition, rather than only looking at the functionality of a body. In this way, mild could be considered a tool for understanding, a way to see how those with mild CP might be brought into a "politics of appearance". What was important for me to recognise early in the collection of my interviews was that mild can and arguably should only be taken as saying something about how that individual feels about their CP, the impairment effects or maybe the way they consider others might perceive them, rather than there being a common set of physical criteria to which the participants refer to when they use the term mild. This way of thinking is often in direct opposition to the biomedical and clinical categorisation of CP, and it is within this opposition that power can arguably be regained, where individual voices can have a real impact on how the ways in which CP, and mild conditions in general are presumed to be experienced.

I will also take away from the interviews, the decisions participants made, to share with me emotions and feelings they have yet to share with anyone else, specifying that this was because I also had CP, so would, to some extent at least, understand. I recall phrases from participants such as from Holly: "I only ever tell people who are going to understand". The experiences and feelings that people shared with me, either about themselves, medical staff, or their CP, I will never forget and still find emotional to think about now. As well as people's desire to support me, to share with me tips for my future, based on their own experiences, or things they wish they had been able to tell their younger self. The emotionally heavy conversations and memories that developed from this space of sharing held both personal and analytical value to me. I was presented with possibilities of how my CP will be in the future. Upon hearing these futures, whether experienced or imagined, led me to realise that analytical detachment from participants during our conversations would not be possible in the way I initially thought it might be.

3.2.1.3. Navigating my involvement in the interview interaction

With such personal connection to the research area came the need for even further careful consideration as to how I was going to navigate my involvement in the research interviews. Having established that my first-hand experience of mild CP drew me to the project, my involvement in the research in this sense at least was unavoidable, however I did not fully anticipate the ways I might become a partner to the conversation of the interview. I vividly remember filling out the ethics application and spending a great deal of time considering how I needed to acknowledge my 'insider' knowledge. My decision then, was to take more of a step-back approach to narrative interviews, to say the minimum, and only answer questions at the end of the interview. However, this did not turn out to be the reality of my research. At first I worried I was doing the interviews wrong somehow, until I realised that rather than compelling myself to not contribute I was now making the decision as to the degree of my involvement based on the moment, the individual interview and person – some needed more, and some less contribution from me, but the knowledge that I had CP seemed to break down a barrier. What I would like to suggest and highlight, is the multidimensional role of researcher-sharing in narrative interviews. Led by unique analysis that can come from shared experience, there can be more room for a flexible approach to constructing interviews. One of stepping back and stepping into the interviews rather than a straightforward inside/outside dichotomy. This conceptualisation has afforded me an additional lens with which to view my own conduct as a researcher, as well as the value of the interview and its impact on the participant.

3.2.1.4. My management of post-interview contact with the research participants

A fourth and final observation from my experiences so far is directed towards my management of post-interview contact with the research participants. After the interview, I had requests for friendship, professional connection, or to stay in touch, even just the acknowledgement that it felt good to talk to people that understood the 'weird' parts of CP. I too often felt this, however the practicalities of staying in touch need to be handled delicately due to the recruitment and advertising techniques I employed, including posts to social media sites and charity forums (all with approval from the retrospective moderators). I remain a member of these groups as I was a member prior to the research in most cases, therefore the right steps going forward is still something that I am navigating. The work of Oakley (1981) and Vernon (1997) helps to unpack the complex but often necessary consequences of researcher-sharing during the interviews. Although talking about your own experience does not add bias or influence where it was not already there, as no research can arguably be free of this, a collaborative and conversational interview environment does require a balance to be made, with liberation for the participants at the centre of all decisions. What is clear is that the traditional participant-researcher relationship cannot always be so easily formalised as it once maybe could.

3.3.2. Ethical implications: a focus on reciprocity

Although arguably this section of the methodology chapter makes up part of the reflexive exercise, I wanted to make specific note to the concept of reciprocity and its ethical implications, to reflect upon what the participants could and hopefully did gain from the interviews. As well as to reiterate the ways in which the interview rapport often developed into a temporary interview partnership and how this joint venture has required ethical consideration mirroring discourse within current academic literature, concerning researcher positionality and first-hand reflections of the qualitative research experience.

Shah (2006) discusses the ontological privileges of being a disabled researcher carrying out research on disability, namely that shared experience of oppression and disablement helps to lay the foundations for interview rapport (Berger, 2001). There is a risk of ‘over rapport’, but other researcher demographics (in my case, age and cultural differences) help to create enough distance between researcher and participant, that shared stories do not overwhelm each other.

I feel privileged to have been able to use our shared experience for me to empathise with my participants and develop rapport (Finch, 1984). Berger (2001) advocates for narrative autoethnography as shared experience potentially allows access to emotions which is not necessarily discussed in the literature. Sharing creates an exchange, an opportunity for the researcher’s views to be challenged, tested. A conversation reveals the participants personal debates and negotiations with themselves, others, and the social and physical world, and allows the researcher opportunity to check understanding and gain feedback from the participants (see my brief discussion of the pilot interview and development and changes made to interview guide in the following chapter). It is a fluid engagement, with hopefully understanding gained on both sides. I also attempted to mirror the language of participants as seen in my own shift in the use of the term ‘impairment’, as initially I avoided using it due to my perceived negative connotations. However, after multiple participants independently used the term to refer to themselves, I adopted the term in my own language to reflect their use.

This raises the question of, who gains from the interview, and what is it that they gain? Vernon (1997) argues that reciprocity requires the researcher to be prepared to answer questions, show “vulnerability through self-exposure” as the participants are being asked to do. It is important that the researcher is aware not all participants will require or request sharing in the same way as others, thus researcher-sharing should only be done when asked or appropriate, and direction should be taken from participants and introductory conversations. Barnes and Mercer (1997) – a critical methodology allows for support of emancipatory methods, with a key focus on not only the inclusion of disabled people but putting disabled people in charge of the process.

I was asked in the York St John PGR Critical Conference: ‘what did I think the participants gained from the interviews, and how did I know this’. My answering related to the importance of having a safe space to share and talk. For those who wanted to, a chance to share, and find commonality with someone who also relates to the notion of mild (or for whom ‘mild’ has had a place in their life and understanding of their CP, even if this label is rejected by the participant). As well as the knowledge that their input in the research can hopefully have a tangible influence on the thoughts of CP.

Concluding thoughts

This short discussion has hopefully highlighted the need to avoid underestimating your influence as a researcher, and to be fully aware of where this influence comes from. It might not always be appropriate to share as I did, but coming from both a place of knowing, as well as acknowledging that I cannot know everything, allowed me to learn from participants and question my own assumptions, whilst at the same time being able to empathise rather than only sympathise. This is an ongoing reflection for me but it has helped me recognise that taking an approach to narrative interviews where sharing is not avoided but rather embraced and often encouraged by the participant themselves has the possibility to allow for a more in-depth data collection and a more holistic approach to the narrative interviews. Hence, I will return to the value of embracing researcher-participant sharing during narrative interviews within my discussion.

3.4. Defining narrative for this research

3.4.1. Narrative enquiry and academic debate

Before a definition is provided of a narrative for the purpose of this study, it is useful to outline the key theorists that are being drawn upon in order to establish an understanding of a narrative. To first re-establish the social constructivist foundations of this study’s methodology. The constructivist approach allows for the realisation of multiple realities understood by the participants. The realities are arguably constructed by individuals and influenced by the research environment (Sharp, 2018). Moreover, stories are a way to preserve memories as well as reflecting on experiences, as explored above, this can become a co-constructed event during recruitment and analysis processes. Thus, a social constructivist approach is taken to consider many different perspectives, and how these might change over time, as well as how participants come to terms with their experiences. It also allows for an acknowledgement of the impact of societal views on narratives. Insight is given into how participants built their narrative of experience in relation to others in their temporal and social space, and the social and cultural meanings attached to those by their contemporaries. Therefore, when stories are retold during the study's interviews, how are these narratives told in relation to contemporary templates and understandings of disability? Narrative analysis allows the assessment of data in relation to social construction, whilst recognising change and evolution over time (Hunter, 2010).

In order to develop a deeper understanding of the conceptualisation of a narrative, writers in the area of narratives will be drawn upon to demonstrate the key work employed to conclude as to the definition of a narrative for the purpose of this study. Mishler's (2005) work helps to build the justification for using narratives to understand the experiences of impairment and disablement. Writing about narratives of resistance, Mishler (2005) looks at the socially grounded accounts of patient illnesses, where patient refusal of treatment becomes part of their illness story, told to and by others, and speaks in some way to who they are or were. Mishler makes the argument that critique of social structures would be made stronger with the incorporation of 'marginal experience narratives' that may be in the form of 'narratives of resistance' - these are the stories of the oppressed and underrepresented. These stories provide alternative knowledge sources; they destabilise truths and historical structures. This is the product of a thought experiment, considering the possibility of patient illness stories as resistance narratives, which relies on viewing medicine as one of the 'oppressive social institutions', open to critique. Although this arguably reads as one dimensional, it does highlight the hierarchical relationships and power imbalances that may exist within medical settings, and how these may be negotiated. The narratives of resistance allow space for the patient to be considered as something other than a fixed social category of 'sick' (Parsons 1951; Varul, 2010), disabled patient. Instead a narrative or illness story contains contradictions, medical problems not described in lay terms, and there is therefore a 'complexity and fullness' to the patient.

For Frank (1993), illness can produce claims for self-change, and the illness narrative is built on the idea that personal experience is able to be presented as public events. Hence, illness can be a juncture for change, and thus narratives can lead to change. Telling narratives can change their lives, for Frank (1993), experience is made ‘real’ through talking, it comes into public existence through telling. Although these narratives are personal and told by lay people, writers such as Bury (2001) argue that lay and narrative knowledge is lessening the authority of meta and medical narratives. In their work, Bury identifies narrative tropes to understand how people with chronic illness move between lay and expert models of knowledge. For example, the process of ‘normalisation’; a twofold process which involves maintaining a pre-illness identity alive (for example by continuing with usual activities, or minimising symptoms). At the same time, normalisation can also mean the ways in which illness is incorporated into their newly changed lives, it becomes a new normal.

This suggests that the self is not merely passively released during the interview, rather a narrative interview or personal telling is an “active lived process” (Kelly and Dickinson, 1997). Narratives can help us make sense of experience but are also a way that we represent our experience to others, which then respond to this representation. This is what makes them interesting. This also connects to my idea of multiple realities, meaning that the self cannot be wholly separated from the narrative telling. The understanding of the self (in relation to the research topic) is realised through participant experiences and the meaning making of these events. Hence said more simply, there is an argument that participants can actively realise and make sense of their self through their telling during the interview. They are not simply talking about themselves, they are actively making sense of and attaching meaning to their experiences as they tell and re tell their story, in this case their life with CP. The telling becomes part of themselves, they are giving autobiographical accounts of who they are and were, and others around them. The self becomes a narrative self (Kelly and Dickinson, 1997), which is told through an ‘autobiographical discourse’. Therefore, arguably, each participant builds their own discourse as they speak of their own disability and impairment. Mild is an aspect of this discourse, and when placed at the centre of the conversation, it opens up discussion of the relationality of disability and disablement, with others, the self, and physical and social environments.

This demonstrates the way in which participants’ narratives are interwoven with the psycho-social context (Thomas, 2010). Thomas (2010) argues that epistemologically, the stories are considered to be socially constructed, giving a unique insight from the point of view of the participants, rather than the medical and clinical models of knowledge. Ontologically this ties into the acknowledgement of multiple realities, understood under a social construction framework. With multiple realities comes a multiplicity of truth. Narrative truth is not necessarily fact, neither is it expected to be, it is a constructed reflection of truth. Rather than focussing on ‘facts’, the goal of narrative methodology is to explore how events are understood, made sense of and organised. Meaning is constructed through social discourse, (Josselson, 2011) and the links between the meanings of the participants, and the understanding and interpretation of the researcher. Arguably Frank (2014) conceptualises this in terms of the 'dialogical' nature of narrative ethics, meaning that narrative analysis is carried out iteratively rather than sequentially, where understandings are built upon one another.

3.4.2. Characterising narratives

Stories are a significant part of people's lives. Whether you are the teller or the listener, stories have a significant impact on everyday lives. Stories are crafted on a macro and micro level, within societies and institutions and between individuals (Riessman, 2005). Storytellers experience their world and, importantly, interpret it, leading to observations and tellings of how things are and should be. The task of a researcher who undertakes narrative inquiry is to establish where the narratives lie in interview data. For Riessman, (2005), a narrative can take many forms, the commonality being the storied nature of the text. Research interviews have been conceptualised as "Speech Events" (Mishler, 1991, p.35), drawing a focus to oral histories of personal experience, which is the form of narrative sought by this study, more specifically the personal histories (and possible futures) of life with 'mild' CP. Here lies justification for adopting a narrative methodology, as narrative interviews and narrative analysis aids the researcher in being able to make connections between meaning and meaning construction to the experiences of the participants. I considered this to be of particular use when considering the significance of the term 'mild'. It is arguably not enough to see 'mild' as being simply another concept by which to analyse disability, but rather that the definitions, use, understandings of, and responses to the term, carry a sociological and actual consequence for disabled people. Thus, a narrative focus has hopefully allowed for the negotiation and navigation done by the individual, by others, and by society in relation to a 'mild disability' to come to light and be closer to a sense of understanding of not merely what meanings are attached to disabled people's experiences, but also critically examining what is means to 'understand', and how understanding is as temporally and socially influenced as the disability itself. Hence to return to establishing the nature and form that narratives may take, it is important for the researcher to recognise that not all talk is narrative. As Riessman and Quinney (2005) have discussed, the term 'narrative', has been largely adopted into mainstream culture, commonly referring to the practice of people telling their own story. However, for Riessman and Quinney (2005), plots and character development are not prerequisites of narrative talk in the case of a research interview. Instead, the focus can be on the understanding that can be taken from what the participants share during the interview. The role of the researcher, therefore, also becomes clear, as they are given the privilege of bringing these stories together. They are able to establish the significance of individual stories, reflecting on cultural and social templates that are drawn upon as stories are shared, and ultimately bring focussed recognition to the thoughts, feelings, and knowledges that are behind the participants' experiences.

3.4.3. Illness (and disability) narratives

Alongside general literature of narrative methodology, there is an established and growing discourse surrounding the 'illness narrative'. Although the conceptual differences of illness and disability may need exploring further, it is useful here to briefly reflect upon how narratives have been drawn upon when approaching research on illness and disability. Frank is a key writer on this topic, looking at how people who face illness are drawn to storytelling as a form of meaning and sense making. Frank (1993) sees stories as an opportunity for patients to tell their story of who they are and the meaning of their suffering. "The lesson here is that stories take care of people" (Frank, 2014, p.80). Thus taking forward the notion that pain, suffering, and illness places you where you need to be, and the transience of suffering is important to consider; there is a wider happening beyond the body (although the pain remains real). The question remains, however, how this may be applicable to chronic and permanent conditions and disability. Thomas (2010) reflects on the relevancy of narratives for illness and disability by integrating the idea of identity through the concept of 'personal identity formation'. Thomas looks upon illness narratives, and narrative methodology more generally, as conceptual tools to consider the psycho-emotional aspects of disability and experiences for disabled women, as well as her personal experience with disability. Reading Thomas' work has helped me to reflect upon the role of the researcher in the characterisation of the participants' CP narratives. Researchers are not simply question-askers, they also tell a story, arguably retelling the stories that are shared during the interview. The researcher cannot tell the participant what stories are important, but rather 'amplify and spread' people's stories, (Frank, 2014 p.82). Drawing on a more recent study, Spirtos and Gilligan (2020) used narrative interviews and analysis to explore the research question, 'what are the disability related identity experiences of young people with hemiplegic CP?'. Narrative inquiry was used to prioritise the participants' stories and helped to construct their lived experience through the narrative. They argue that there is an inherent link between narrative and identity, thus the telling of life stories leads to an understanding of the conscious and unconscious aspects of their identity. This study is relevant to this exploration of the literature, as they drew upon a specific form of Narrative Analysis, that being the Biographic-Narrative Interpretive Method (BNIM), which establishes a more formulaic approach to narrative analysis, beginning with a singular open-question to start the interview and encourage the participant to lead the interview from there (Wengraf, 2001). There is often a second interview to ask to follow up questions, guided by the life elements shared by the participant. Where my methodological aims depart from the BNIM method, is the temporal (re)ordering often carried out on the interview data that is collected using this analytical approach, rather than keeping the data in the form in which it was collected.

A possibly more relevant approach to analysis is one outlined by Bingley et al's (2008) paper, which focussed on narrative study of palliative and end of life care. They argued that simply valuing the story is not sufficient analysis, it must be ensured that the method is appropriate for the study aims and the story. Participants are reliving interactions and thus they carry social meanings both in the moment and in the retelling. The interaction with the researcher could lead the participant to reflect on the story/event in a different way such as when participants became emotional. Thus they argued that the narrative should not be limited by fixed conceptual boundaries, it has to be determined with the context of the interview and the individual telling. Riessman's (2003) reflections regarding narratives in a medicalised setting also mirrors the importance and value of a focus on the individual case, something which is often to some degree dismissed as anecdotal. For medical teaching, a detailed example substantiates 'textbook' knowledge (something reflected in the interviews). Hence, the illness narrative provides a way for patients to explain and contextualise their interrupted lives, and 'changing relationships with the social world' (p.7). Furthermore, a theoretical framing that is valuable to explore is Riessman's (1990) analysis of illness narratives as performances. Drawing on Goffman's (1959) dramaturgical theories, Riessman argues social actors (participants) perform a desirable self when faced with difficulty, although importantly, the illness narratives that are the product of this, present a preferred self not the actual self. As telling stories is constricted by words and language, vocabulary. Story telling is constrained by "narrative templates" (Frank, 2014, p.83) given by society. These templates become relevant in different cultures and times and space. Hence suggestive of the idea that the illness experience, and in turn the experience of impairment and disability, is not fixed. On a macro level, this suggests how appropriate application of narrative ontology can help to better understand health care experiences for the patient, carers, and medical staff and how it can contribute to policy and practice improvements. I would now like to reflect on how this discussion of the literature moves the thesis on, including the aspects I have lifted from the debates. Having outlined key literature and theory surrounding narratives, I will now narrow this to an understanding of how a narrative is conceptualised for the purpose of this study. In the broad, macro sense, narratives are recognisable as personally and socially negotiated, a data collection tool, and pieces of data themselves, which are both set in a specific time and part of a fluid trajectory. Therefore they allow for both a macro view and micro understanding of social structures and personal experience simultaneously. A piece of narrative in the interview may take various forms but is generally seen as an extended piece of talk, which can include the interviewer's responses, speaking to an event, retelling an aspect of their lives. This could be something that they have talked about before, or this might be the first time they have spoken to someone beyond their closest social circle. A narrative is therefore a space for personal expression, situated within a loose interview structure. The interview transcripts therefore capture a guided conversation with large amounts of talk from the participant. The challenge remains to establish how to identify the nature of a narrative for the purpose of analysis.

3.5. Operationalising the 'narrative' in this study

The research required more than asking participants to tell a singular story. The interviews were looking to collect versions of life stories, centred around the participants' understandings and experiences of 'mild'. This is key to understanding the way in which a narrative has been operationalised within this research. I was not only asking participants to retell specific events but recall events that are significant in their understanding of their own disability as mild, this is key and is consistent with the use of narrative. In short, the interviews were attempting to make 'mild' (and the experience of a mild disability) narratable. This concept of what is narratable is drawn from Frank's (2002) analysis of the dialogical nature of narrative analysis. In a society in which being able to verbalise experiences legitimises them, allowing people to share their stories through these interviews allowed the participant to make their experiences narratable. Their experiences, therefore, become valuable and are given meaning. Hence, this concept of narratability can become part of what 'a narrative' means for this study; both the experience of CP in adulthood, and importantly, the experience of mild CP in adulthood becomes part of a valued aspect of people's life stories. Furthermore, by allowing people to narrate their own experiences, there is a sense of reality that is attributed to a testimonial experience that is otherwise largely overlooked. The participants' own words are valued as analytical and analysable expressions of feeling and experience.

This therefore provides a foundation for defining a narrative in the context of this study. A narrative, drawing on the work of Mishler (1999) and Thomas (2010) is considered a space for participants to express their experience/reality in a way which can confirm or broaden previously held expectations and representations (Thomas, 2010) of them. Within the interviews, this is seen through the ways in which the participants take charge of their own story and rarely rely on chronology to guide their telling. Rather, their stories often take the form of something close to Mishler's notion of "narratives of resistance", alternative knowledges told by marginalised voices. This is further reflected in the analysis of the narratives, the broader social context becomes vital to contextualise the interview data, to make clear the power relationships behind currently held representations (Thomas, 2010), in this case of the relationship between clinical diagnosis, disability and impairment. Thus, I am using the lens of ‘mild’ to make experiences narratable, as ‘mild’ enables me to focus the interviews, around which individuals can tell and narrate their stories. This is consistent with my commitment to giving voice to (and representing) testimonial experience.

With the acknowledgment that opposing knowledge should be heard, and that marginalised people should be able to compose their own representations, it becomes clear how a methodology guided by the narrative discipline is relevant and helpful to this study. Allowing participants the opportunity to tell stories allows for these stories to be analysed as a whole. With no fixed assumptions made about participants’ relationship with the term mild, the study looked to connect participants’ experiences to their life story. Although the analysis of the data can arguably not be entirely removed from personal and cultural frames of reference (Thomas, 2010), this does not lessen the value of asking for life stories located and guided by the participants. Researcher involvement in analysis and the interviews themselves should instead be acknowledged and reflected upon, with the recognition that the narrative researcher is not simply collecting data but will “enter into a relationship with the respondent...” (Frank 2002, p.16).

A significant aspect of reflecting on researcher involvement is making clear what Frank (2002) refers to as the researcher’s standpoint. The interviews within this research do not always take a traditional narrative formation. This is due in large part to my standpoint when approaching the interviews. A researcher’s standpoint is seen to reflect in your approach as a researcher – reflecting your unique experience and your membership of certain communities (Thomas, 2010). In my personal circumstances, this meant sharing the same condition with my participants, hence I could not make claims for neutrality or naïve objectivity. Instead, it was often this shared starting point that encouraged response to and participation in the research.

My standpoint as a researcher also meant that the interviewees asked for my input as they engaged me in conversation in order to ensure that their story was heard, to seek to compare our experiences or simply to share emotions that possibly were not given space to be shared before then. I could not ignore this, as it would be broken rapport. Nonetheless, I was keen to ensure the interviews did not become an open dialogue but responded to create the space to enable the person to narrate their story. This adds originality to my account and offers an interesting methodological reflection on the interview process, particularly as individuals were responding to my disability, while relating their own. My questions to the participants, therefore, were a part of this conversation which helped to elicit the life story between myself and the participants, who started from a shared experience of CP, hence the more conversational nature of the interviews. They were used to clarify my understanding of participants' experiences, and to help to avoid assuming an understanding due to my personal knowledge of CP. This highlighted a need for the questions from the researcher to be reframed as part of the conversation created within the interview. That is not to deny the researcher-participant relationship, but to recognise that researchers can hold multiple identities within an interview setting. Initially and foremost interacting with each other to meet the aims of the study, a conversation then emerges, guided by research aims but led by the participants' experiences.

It is important to be transparent as to the ways in which research aims were met and key research questions given the opportunity to be answered through the interview material. This was achieved through an interview topic guide. There is a debate as to the use of topic guides in narrative interviews, with those in support of methodological purity arguing against the use of guides at risk of not allowing the participant the opportunity to share their experiences uninterrupted, with focus on areas that they deem necessary. However, within these methodical debates are those who argue that the interview is rarely a place where ordered and chronological speech is reproduced. The interview is instead a space for producing subjectivity for both interviewer and interviewee (Harding, 2006). This inter-subjectivity in interviews, can subsequently result in a "degree of emotional exchange" potentially meaning that the participant feels a sense of recognition (ibid).

Hence, there is arguably a vital interplay of speaking, listening and understanding on both sides of an interview interaction. There is in this sense a co-authorship to narrative interviews, which is based upon narrative questions (ibid). Rather than merely acting as explanatory questions, narrative questions allow for the participant to feel heard and listened to in the researcher's response to what they are being told. A specific example of the way in which the interview topic guide was used flexibly was through a focus on childbirth or motherhood or mental health following the initial interviews highlighted these as potentially valuable conversation topics (see appendices 3 and 4 to see the development of the interview topic guide). Therefore, a topic guide provided a 'checklist' with which to focus the interviews, that remained unfixed and open to change. The topic guide became a suggestive conversational guide for both the participants and me. Hence, where the topic areas may remain similar for the purpose of comparative analysis, they were not necessarily used in the same way (Crinson and Leontowitsch, 2006; Morgan, 2016). Each participant's definitions of mild were different, hence the way in which the participants related to the term varies, and my questions or conversational responses adapted to this. Thus, there is a collaborative element here, which would not be found in semi-structured interviews, or a formalised interview schedule. Rather, drawing on narrative method allows for the story to emerge from the interaction, exchange and dialogue between interviewer and participants, whilst ensuring that the telling and reflection of life experiences remains in the participant’s own words (Muylaert et al, 2014). Following rapport-building introductory questions, the research focus was introduced with the open-ended question: “What does ‘mild CP’ mean to you and your experiences of Cerebral Palsy?” The depth of response to this question varied, however it often posed as the question to which they returned to most frequently throughout the interview. The topics were there to ensure that potential comparison or debate were generated through the data. In effect, to understand the idea of ‘mild’ required the research to explore narrative accounts, relative to each other. Hence the use of the topic guide, which provided a framework for engagement, while having sufficient flexibility to enable a sensitivity, consistent with individual experience that enabled them to narrate their story. Interestingly, my interviews provide an account of what it is like to experience CP but using the idea (or lens) of "mild" to understand and make sense of this experience.

Chapter summary

Narratives tell of human life and human experience, and this is contradictory, complex and multi-layered (Josselson, 2011). Hence this is reflected in the narratives that are produced, the aspects of people’s narratives are interconnected, and a narrative is seen as a way to make sense of these connections (Josselson, 2011). They are an opportunity for people to reflect on their initial and current feelings and reactions, with hindsight and space created by time, allowing the opportunity to place these biographical instances into their social and historical context. So narrative is a product, a story that contains the understandings of historical awareness, temporal spaces, and social influence. The interview environment brings in the context of the relationship between me and the participant, which contributes to the dynamic nature of narratives. Mishler (2006) provides a useful conceptualisation of narratives as stories with meaningful connectedness. This goes beyond chronological or biographical organisation and allows for a (re)interpretation of the past, with consideration for the consequences for the present and potential future. A large part of the researcher’s role is therefore to make this connectedness clear, and place experiences within public spaces as part of macro analytical ventures.

Stories are part of everyday lives in part at least due to their collaborative nature. They are a discursive practice beyond simply recalling. Narrative analysis, therefore, is a method to access cultural and social experiences (Bingley et al, 2008; Sharp, 2018). Their collaborative nature must therefore be mirrored within interviews. The recollections and retellings could therefore arguably be seen as not only shared between the researcher and the participant, but in part co-constructed between them. During the interview, the probes and open questions posed by the researcher aim to support the facilitation of participant reflection. Being an active participant in the interview, Sharp, (2018) argues that researchers do not carry out narrative interviews merely to gain a story, but to play a part in the retelling of experiences, often therefore exploring participants' feelings and emotions at sites of transition and change in their lives. This notion of 'retelling' exemplifies the importance of including mild as a point of analysis. For those I spoke to, their experiences were either not yet heard or misunderstood. This research gave them an opportunity to make people aware of their experiences and 'retell' their stories authentically. Hence, this leads me to begin to outline how I carried out the research, that is to outline the practical steps I took to collect their stories.

4. Methods chapter

Chapter introduction

I approached the interviews with two sites of knowledge, that lay in the academic literature and my own personal experiences. This inevitably had an impact on the design of my methods, data collection and analysis plan. Namely, I knew I needed to create space so that the varied use of mild could be realised. This chapter will aim to give a clear overview of my methods, starting with study design and sampling. This includes recruitment criteria and recruitment processes, including the recruitment sites from which I found my participants. I will then outline my data collection methods, which were online, accessible interviews and the use of a topic guide to help to guide my research conversations. I will close by reflecting on my analytical approach. I also include a brief reflection on ethical considerations, although carrying out ethical research, I have hoped to show, was an ongoing endeavour.

4.1. Background (aims and objectives)

As I have outlined my aims and objectives in previous chapters, I will offer a summary here. Drawing on a narrative approach, I am looking at the experiences of adults with mild CP, to deconstruct the value of mild CP and the meanings attached to it whilst also looking at how mild may be strategically negotiated within normative environments.

4.2. Study design

I would like to briefly acknowledge here why I chose to pursue more interviews than I initially intended to. I initially suggested that I would recruit between 10-15 interviews, however by the end of recruitment I had completed 24 (including a pilot interview). This was not merely to collect more empirical material, but rather it was because I realised the potential variety for the people I could talk to and the stories they could share. I was also surprised by the amount of people identified in some way with the notion of ‘mild’, and subsequent analytical chapters will provide more detail for how this focus on ‘mild’ was a key motivator for people wanting to take part in the research.

4.2.1. Sampling strategy

In order to operationalise my original research questions, I determined that I needed to recruit participants at different stages of their life course, who regarded their CP as mild, without placing limits on what ‘mild’ might be or mean.

The advertisements contained a selection criteria for the participants, the key criteria being that the participants identify as having ‘mild’ CP. This was purposely kept as a self-defined term, to allow the interviews to become a space in which to discover what mild CP meant to them as individuals, rather than measures such as physical ability.

The selection criteria were as below:

- Aged 18+
- Identify as having mild CP
- Currently live within the UK
- Have access to the internet and a digital device such as a mobile, laptop or computer

As I mentioned previously, initially when this criteria were posted, there were several comments on the Facebook post asking for a definition of the term mild. In response to this, I made an additional response, detailing my justification for not specifying a set criteria, and for not defining what I felt the term ‘mild’ to mean. (See appendix 2 for my justification for keeping mild as a self-defined term, that I shared with those in my recruitment groups). It felt vital to ensure that mild remained a self-defined term, to avoid excluding participants, or limiting them to numerical or physical measures.

4.3. Recruitment

4.3.1. Social media as a key recruitment site – utilising ‘private’ Facebook groups

Prior to beginning the study, I was a member of Facebook groups that provided online support to adults, and in one case specifically women, with CP. I was aware that these groups were my target participant demographic, and thus once I had gained ethical approval for the study, I approached the moderators for these groups to be able to advertise my research with them. Social networking sites such as Facebook have been recognised as a useful vehicle for accessing hard to reach populations (Curtis, 2014), although they come with particular ethical considerations, and it can be helpful to reflect on these to continue with a reflexive approach to research. Once I had completed the necessary paperwork in order to advertise with the charity Adult CP Hub (now renamed 'Up'), I submitted the online advertisement to be posted on my behalf to the group. I received instant feedback and there was notably a large amount of indirect communication, where respondents replied to the post rather than emailing me directly as indicated to do so on the advertisement.

Thus there were concerns for their privacy and the sharing of potential participation in the study (Bender et al, 2017), however it was reiterated to the people in the group that they are asked to email me as the researcher to express interest in the study, and the comment section also allowed members of the group to 'tag' one another to the post, to highlight the study to them, exposing a number of people to the post (Curtis, 2014), snowballing recruitment played out online. My initial posts to UP and Women Ageing with CP led to me being approached by a third social media group, Adult Advice UK. Alongside this, I also advertised my research on the research messaging board for SCOPE, before which I was required to complete a Research Request form, which helped to confirm that the study would be suitable for the audience I intended, and that the advertisement post was visually accessible (see appendix 5 for my advertisement poster adapted for SCOPE).

Recruiting in this way suggested that the respondents, and eventual participants, had a degree of computer literacy, although by the same nature prevented access to the study for those that did not (Hirsch et al, 2014; Bender et al, 2017). Participant consent forms and information sheets were also shared online via a privately shared Google Drive folder. There were a small number of technical issues arising from this, for example incompatibility of the consent form, however this was mitigated with the use of email. With any online space, there is a heightened consideration of how to determine the authenticity of those you speak to. However, this was somewhat mitigated due to the use of closed/private Facebook groups, that required screening questions before admission (Hirsch et al, 2014). Although nothing can be assured, the use of virtual interviews also lessened any potential risks to safety when interacting with the participants. On balance, online recruitment was appropriate and beneficial for this study, leading to a shorter recruitment period, however, as is the risk with targeting specific groups for recruitment, there was an over-representation of White British women (Whitaker et al, 2017) which needs to be acknowledged in the study's final analysis.

4.4. Data collection

4.4.1. A fluid interview topic guide

I have previously referred to the changes I made to my topic guide following my pilot and initial interviews (see figures 6 and 7)). This was something which I felt was important to note again here, as it demonstrates the value of carrying out in depth interviews led by participants, in order to ensure that the research is meeting a need of the people I am speaking to, whilst also showing how an interview topic guide can be successfully integrated into a narrative methodology. Rather than being restrictive, it can offer me a point of comparison and allow me to explore common topics that are still relevant to the individual I spoke to. By keeping the topic guide flexible, I was able to track development in my understanding of mild CP by the changes to my topic guide.

4.4.2. Why in-depth interviews?

Alongside the previous sections of this chapter discussing the definition of a narrative, it is useful to briefly reflect on the nature of the interviews themselves, the environment from which the narratives and stories have been formed. To reiterate, this study looked upon narrative interviews as guided conversations, meaning that as each interview was completed, an awareness developed as to which questions were most thought-provoking for the participants. The overarching goal for the interview and interview questions was to encourage the participants to talk as freely and openly as possible (Kelly, 1996). Therefore the interviews were mostly built upon loosely structured, open-ended questions (Kelly and Howie, 2007), see interview topic guides, 3 and 4 as an example of this.

This fluid structure is reflective of the interactionally dynamic nature of the researcher-participant relationship (Sharp, 2018). The researcher can therefore be seen to have an active role in the interview, asking questions and encouraging responses. My first question, "What made you first be interested in taking part?" opened the interview in a broad manner, allowing me to begin to understand the thoughts, feelings and experiences that the participant was bringing to the interview, and often, what was going to be at the core of their narrative. Their answer here was often something that could be returned to throughout the interview, the connecting thread between the experiences they shared with me; the reason they wanted to take part in the research allowed us to return to the current moment and reflect on what brought them to where they are now.

The depth of the interview goes beyond the questions and answers and often continues once the recording has ended. This ‘small talk’ that often begins once the interview has ended can give vital context to the stories that have just been told (Jovchelovitch and Bauer, 2000). I found it useful to continue the recording whilst I asked the demographic questions at the end of the interview. The participant was aware that the interview was still being recorded, and it often led to the capture of additional stories or further elaboration on what has already been said. Where an interview was longer, or particularly emotional, I asked if the participant would be able to answer the demographic questions via email, which allowed them the time to reflect on their answers and the interview itself.

Building upon the notions of collaborative interviews found in feminist literature, there is broader methodological discourse relating to an overall conversational style throughout the interview. It is important here to note that when initially planning interviews with hypothetical participants, I envisaged and even actively aimed to avoid contributing to the interview, to avoid my potentially closely related personal experiences muddying the interview data. Instead I was looking to use open ended questions and remain uninvolved as far as possible to allow the participants’ stories to take the forefront. However, although collecting participants’ stories remained the priority, and I adapted my involvement with interviews according to the level of involvement taken by cues by the participant (Gubrium et al, 2012), I realised that a narrative interview need not be led by a distant interviewer, but rather participant stories can be facilitated by a conversation. A conversation can result in further talking and thus provides context to what is said in the interview. This context should therefore include the actions of the listener, the researcher as well as the participant (Gubrium et al, 2012). Hence in this way, the conversational style interview provides guidelines for the level of transcription as well as providing empirical insight into the researcher-participant dynamic within this type of narrative interview. The context to the participant’s involvement in the research is also worth acknowledging their reason for wanting to take part. For Thomas et al (2009), the narrative interview is one in which the social world is viewed from the point of view of the participant. In order to seek the subjective and collect the related social context needed to interpret the stories you hear, you need reflexivity. A narrative conversation therefore takes on a loose temporal order and is a space for communicating feelings, explaining past responses to life events, and an opportunity for participants to evaluate their experiences. This work done by participants in the interview is however a co-construction, a dialogue between the interviewer and participant. There may even be some aspects that go without saying, although there is a need for the researcher to double check their understanding of what is shared. Therefore, this allows for a fluidity in methodological approach, with the assurance of ethical rigour and an assessment by the interviewer as to the appropriateness of technique, this is a continual task that can be developed and become more fine-tuned with each interview experience (Owens, 2007).

To engage in this collaborative effort, the researcher must not be hesitant to ask questions, although traditional forms of narrative interviewing often describe a singular question that triggers the participant to tell a biographical story in relation to the research topic, with the interviewer asking minimal questions to deepen understanding or to maintain the participants' telling (Polkinghorne, 2007). This approach to narrative interviewing has produced insightful data and is particularly helpful where a researcher aims to collect participants' life stories and often craft a chronological understanding of their story and life experiences. Building upon, but moving slightly away from this narrative formation, once in the interviews I felt that more of a reciprocal conversation and involved approach to interviews best suited the people I spoke to. This conversation was therefore at times semi-structured in nature. I approached the interviews with broad, flexible, and non-exhaustive ideas of topic areas that may be useful to provide understanding and ultimately answers to my research questions. There was therefore a delicate balance to be made between participants being "gently steered towards themes" (Thomas et al, 2009) whilst also following participants "down their trails" (Gubrium et al 2012, p.24). In practice, this balance varies between interviews and needs to be led by contextual cues that also help researchers be critical of our assumptions (ibid). Gubrium et al (2012) argues that there is a need for more acknowledgment of the relational aspect of interviews, and question responses can help to show the relationships between the researcher and participant. Furthermore, the storytelling itself is relational and collaborative. The story should be seen within its surroundings, be that the social historical, or interview settings.

Geertz (1973) provides a useful concept that helps to further operationalize theories and discourse around conversational or reciprocal approaches to interviews. The role of the researcher is to coax rather than to probe; the latter being responsive to what participants say, the former more collaborative, and a product of empathetic listening, guiding the direction of stories. Interviewers are therefore 'feeling' their way through the interview. Approaches to this are again specific to the researcher and participant relationship during the interview, and so, "The interviewer is, therefore, a tool for obtaining knowledge." (ibid, p.303).

4.4.3. Online interviews

Covid 19 necessitated the need for online interviews and moved face to face interviews into virtual spaces (Oliffe et al, 2021). Therefore it is beneficial to consider the benefits and concessions of the online space. The most common issues with technology are unstable video and audio streams, as well as a changed pacing to the interview. The concessions however do not outweigh the benefits to be found in this approach to interviews. The main ones being increased confidentiality of talking in a safe space or home environment, and the ability to speak to people who might otherwise not be able to due to geographical distance (Moises, 2020; Oliffe et al, 2021). This was especially the case with social distancing within Covid 19 restrictions.

The meaning of a narrative is not simply discovered at the end of the story or section of talk, it incorporates the story as a whole, the meaning of participants' narratives can unfold within non-chronological parts of the interview too (Jovchelovitch and Bauer, 2000). For Smith and Sparkes (2008), the body is also seen as being inscribed with the narratives. It could be asked if carrying out the interviews online restricted the way in which the body can be used as part of the telling of the narrative, e.g. zoom backgrounds, not being able to see assistive equipment, for instance wheelchairs. Therefore, the boundary of a narrative is not always clear-cut. The participants' narratives become a series of stories, consisting of large sections of talk and interview exchanges (Gubrium et al, 2012). They may not have a plot in the traditional sense, being linear or sequential, however there are still stories to be heard, and they are arguably tied and interrelated (Josselson, 2011) to their experience of 'mild'. Narratives can appear unexpectedly, for example from a fixed question, and participant digressions shift power (ibid), the participant leads the interview, and their narrative becomes a product of their answers to my questions, as well as the stories and experiences they wanted to share with me.

Interview Accessibility

An element that is especially important to consider in relation to the participant demographics for this study, was the accessibility of the interviews. One of the interviews was requested to be carried out over email, rather than using videoconferencing software. The participant requested this due to a speech impairment that meant they felt more comfortable carrying out the interview in written form. Ison (2009) has written on the topic of facilitating the participation of those with verbal communication impairments (specifically those due to CP) within research, using email interviews to allow for this, offered as an alternative for the traditional verbal interview. They argue for adopting a funnelling approach to questions, beginning with broader questions, and building on the topics discussed by the participant.

I feel that the email interview that I completed with the participant was as in-depth and conversational as the verbal interviews. Although this email conversation needed to contain more questions asked by me, and it became less about sharing experiences than others had been, I felt that it was still possible to gain a sense of the participant as a whole, with their use of punctuation and colloquialisms. Moreover, the participant was able to be given more control over when was best to respond to the questions, and thus arguably give reflective answers (James and Busher, 2006). Therefore, although there needed to be a change to the interview setting, and the nature of the interview was unavoidably more structured, I feel that a narrative was still produced, and stories were told and shared in a way that was suitable for the participant, and most importantly allowed them to participate. As a consequence of completing the interview via email, the interview was largely pre-transcribed. This is something I found personally beneficial, as I transcribed the interviews myself, with the assistance of an encrypted transcription software, Otter.ai.

4.5. Analysis

4.5.1. Operationalising: my approach to narrative analysis

What remains then is to establish how my understanding of what a narrative is, and how the theoretical underpinnings above, can be operationalised. This can help to create the frameworks by which the analysis can be guided, to ensure that the participants' narratives are fully and clearly heard as they are. Overall, my approach could be categorised as based in a necessary fluidity, moving between overarching themes and individual sections, lines, or quotes from the data. The overall aim of the analysis is to categorise the data in a way which connections are established, and the attached meaning to stories made sense of, to hopefully provide analytical insight and more complex conceptualisation of disabled adults' experiences. However, the voice of the participant will always remain at the forefront, along with the feelings and emotions held within the stories, and the interview environment readable within the transcripts. Hence, the fluidity allows for a more holistic approach to narrative analysis, where each of the life stories are considered as a whole, and sections of text interrelated as being in relation to one another (Josselson, 2011), and to piece these analytical insights together to carry out a cross analysis between stories in order to move towards broader narrated concepts. The parts, therefore, lead to a fuller understanding of the whole, and the whole, a more complex understanding of the parts (ibid). Thus, the cross analysis leads to the discovery of patterns, as well as points of contradiction and departure from overarching patterns. These categorisations are then analysed in relation to a set of research questions. Hence, the need for guided interview conversation that also allows space for the participant to lead the interview down paths they see relevant to their answers. This process is not a straightforward or linear one, much like the narratives themselves, and so blurred boundaries must be looked for and accepted in order to present participant narratives in a meaningful and accessible way (ibid; Hunter, 2010).

Therefore a toolkit is developed to approach narrative analysis in the best way for the data, and to do justice to the participants' vulnerability, openness and willingness to share. When an impairment is storied/narrated in this way, there is potential to be able to examine agency as well as social structures surrounding people's feelings and meaning making (Smith and Sparkes, 2008). Asking about personal feelings has been relatively under-achieved with adults with CP, with questions on feelings aimed towards evaluation of health services and similar. Which although vital, can sometimes miss the questions of how services and social life with CP makes them feel (ibid). The analysis of this data must then be able to capture the ways in which (mild) impairment is part of personal and social narratives. As a researcher this also cannot be overlooked, as the study is approached from my own personal standpoints, and the embodied stories shared between myself and the participants are recreated and constructed within certain material, psycho-social, and interactional structures (Thomas, 2010). The stories are socially constructed, so too must be the analysis, therefore arguably the emotions felt during the interview, and the effect for both researcher and participant must also be incorporated. The analysis can no longer be objective or neutral, but rather should be reflexively involved.

Key to the objectives of narrative inquiry, the interview data manages to locate experience within the context of people's lives, in which their stories of who they are become important to understanding the idea of 'mild'. This has been achieved by rejecting a chronological approach to interviews. Instead, recognising interviews as intersubjective emotional events, which lead to dialogue led by narrative questioning (Harding, 2006). Anderson and Kirkpatrick (2016) argue that the richness of data shouldn't be lost in the analysis, hence the stories must be identifiable within the data. On reflection of this, I would like to argue for ethical and analytical consistency whilst avoiding methodological rigidity. Meaning that, in line with the ideas of Thomas (2010), there is value to be found in crafting your own analytical approach as a researcher, drawing on aspects of existing debates. This has allowed me to take a more holistic view of the data. By being transparent in my role in the interviews, and my use of similar questioning frameworks, it has given me a starting point with which to understand both myself and the participants within the wider social patterns, power relationships, and structures that underlie the individual and shared everyday experience.

4.5.2. Analytical process

Key to my analytical approach is the attempt to offer a more detailed analysis of my participants' experiences rather than simply describing them. This will be presented in my later empirical chapters. For clarity as to how I came to my conclusions in my analysis, the steps I took are outlined below (although this is of course an iterative process, and acted as a guide to ensure I was approaching each interview analysis in a similar way):

1. Understand each story (familiarisation of the material).
- Find themes in each story/interview.
- Keep looking back over the interview as a whole.
- Make note of significant parts of passages.
- Group into broad categories, with examples passages.

2. Find links within the interviews (connect the 'bigger picture').
- Re-read passages within the categories and look for links and interrelationships.
- Note any contradictions within and between the narratives.

3. Establish overall narratives - (categorisation of findings).
- Cross analysis between passages and across interviews as a whole, to find patterns or see differences.
- Analyse the stories in relation to a set of research questions.
- Consider what this analytical thread meant for the everyday life of those with mild CP (to ensure the applicability of the research findings to the current body of knowledge).

It was important that as I wrote up my ideas, I looked for and accepted and acknowledged overlapping threads. Thus, I believe that it is important to consider how analysis of the empirical material may highlight more than one overall story, particularly as we tend to use essentialism and over generalised scripts when discussing disability. My account challenges this. In order to prevent overly segmenting the material, I believe that it is important to recognise the possibility of multiple stories which reflects the multiplicity of mild (Moll, 2012). Rather than destroying the interviews and restructuring into chronological order, I aim to use broader conceptual themes which contain specific narrative examples from the interviews in order to explore how mild is understood, discussed, and employed across the life course, and especially in adulthood. Regarding the interviews themselves, I was concerned with being able to narrow down a justification for how using an interview topic guide aligned with drawing on a more narrative approach to my methodology. However, reading the interviews in their entirety, side by side, I have come to recognise the way that they have worked together quite well. Rather than taking a question-then-answer approach to the interviews (like semi-structured interviews), the interviews and therefore the responses seem more layered, each in a way that is personal to that. I largely covered similar topics with my participants (due to the topic guide and because I was covering general themes which are common amongst many people's lives), which allowed for analysis. However, the degree of focus on these topics varies hugely across the interviews. For example, for some, school is a passing memory, whilst for others it could be central to their narrative. The same for family relationships or how their parents responded to their disability. Therefore, I am hoping to do justice to this by having the following conceptual frameworks, developed from and using topical examples from the empirical material to explore these. Having the privilege to explore such personal life stories, makes it evermore paramount that I was able to fully consider and mitigate potential ethical concerns in my methods decisions.

4.6. Ethics

I carried out an in-depth ethical assessment for this research, which detailed my considerations of the potential ethical concerns with the research and ways to mitigate. As I have previously discussed the ethics of reciprocity, I will focus here on the more practical steps I needed to take to ensure a robust and ethical study design.

As the research was very likely to deal with personal topics, I wanted to ensure that my participants were able to participate in and be aware of the personal and in-depth nature of narrative interviews (Bold, 2012). I therefore detailed the potential experience of the interviews within my participant information sheets (see appendix 1). This included that the interviews would include opportunities for breaks as they may need, particularly as I anticipated that the interviews would be around 1 hour for each participant. Interestingly, none of my interviewees decided to take or ask for breaks, despite some of them being over an hour long, instead they often chose to complete stretches during the interviews. I hoped that this pointed to a level of comfortability in the interview environment.

Each interview was conducted on an encrypted device, and after each interview was complete, I ensured that I anonymised, handled and stored the data in line with the University policy (University of York, 2001a, 2001b). As an interview 'debrief' I also followed up with each interviewee as to how they were feeling after the interview and if they were still happy for me to use their interview in my analysis. This was a further opportunity to gain consent for their participation, which I felt was necessary, as the participant may have wanted to reflect if they were still happy to consent after they had completed the interview and knew what they had shared with me. I sought initial consent prior to the interviews via a participant consent form (see appendix 6) (University of York, 2021).

Due to this research having a strong personal connection to myself, I also ensured that I drew upon my supervisory and personal support networks to manage my emotions and feelings following the interviews. I also reflected on my role in the interviews and the dynamic of the researcher-participant interview relationship, as can be seen in previous chapters (British Sociological Association, 2017, p.4). I recall finding the process of completing the ethics application form an extremely useful as well as important exercise (see my ethics approval email, appendix 7). It allowed me to begin to anticipate what the interview environment may look like and vitally gave me the opportunity to consider at least some of the ways in which my participants may experience it.

Chapter summary

The interviews became a space and opportunity to reframe the focus from trying to define mild, to asking what the value of mild is for those that identify with the term. Although the participants shared with me their ideas of what mild meant for them, it was not my role to determine a singular or static meaning for what mild means. They had a personal understanding of what mild meant for themselves and for those around them prior to the interview, therefore mild was not a concept that I was imposing onto them, it held meaning for within and outside of the interview. These subjective meanings produce the value of mild, which originate from multiple socio-cultural and biomedical understandings of CP and the experience of lifelong physical disability/impairment more generally. Importantly, these understandings are shown to be negotiated through the response of others and a negation of social networks, which often, although not always, places people in a liminal position in various social spaces. This is sometimes difficult to disentangle, which is why it was important for me to locate my analysis in people's narrative experiences, which attempt to articulate this entanglement. This begins to situate the analysis within a framework of social negotiation, liminality and an understanding of people with mild CP as bodies on the margin. These ideas will be explored further throughout my empirical chapters, but I wanted to include it here, to demonstrate the importance of showing the link between my analytical approach and the knowledge that has arisen from the narratives. I am arguably doing more than just prioritising the voices of those with mild CP, I am also beginning to redefine 'the expert' on CP. This is important when for CP, like the majority of conditions, the expertise is presumed to lie with medical professionals. In line with my central argument, I hope that the material in my analytical chapters offers new/alternative understandings of CP and chronic impairment/disability.

The extracts from their narratives included throughout the following chapters were chosen as they either typified a theme that is being explored, or they are helpful to explore a particular articulation of experience which is helpful for a deeper understanding of this negation experienced and achieved in their everyday lives. As outlined in the methodology chapter, the choice to focus on mild CP generated unanticipated responses. Initially, there was a clear expectation that I would provide further details as to what I meant by mild. This response prompted me to make explicit the decision to leave the definition of mild to be determined by the participant. Mild was therefore purposefully left as a self-defined term. The early response to this choice was further explored by some of those that I spoke to, in response to my opening question, ‘what made you be interested in taking part in the research?’ I present some of the responses to this question in chapter 7.

5. Introducing the participants

Chapter introduction

This chapter is here to introduce the participants who have (I will argue) begun to pave the way for a much-needed expansion of the language currently used to make sense of disability. Their experience of a ‘mild’ disability contributes to the challenges made against the still largely binary relationship presented between impairment and disability. In the following section, I will give an overview of the demographics of my participants, before provide context for why discussing mild CP may be important for them.

5.1. Participant demographic table

Appendix 8 is the Participant Demographics Table, as I asked these questions at the end of the interview, I selected the questions most relevant to the stories they had shared with me, to avoid unnecessary collection of personal data. Where participants asked, or where they answered these via email, I quoted their responses to maintain a sense of themselves and demonstrate the varied ways in which people may use or not use mild, and yet still weave mild into their narratives. Here, I will give a brief overview of my participants’ demographics:

- 5 identified as ‘male’
- 15 identified as ‘female’ (including 1 identification as a ‘cis woman’)
- The ages ranged from 20s-60s, with 4 participants between 23-29, 6 between 30-39, 8 between 40-49, 5 between 50-59, and 1 aged 65.
- They were predominantly white (including white British and white Irish), with 2 participants identifying as other than white.

The description of their CP diagnosis included a range of responses, which both included and excluded ‘mild’. For example, some chose their clinical classification such as ‘spastic diplegia’, or ‘quadriplegic’, whereas others chose ‘mild right hemiplegia’. Hence mild is used in parallel with clinical classifications, in some cases, such as the quadriplegic classification, this may traditionally be incompatible with the notion of mild as less impactful (as outlined in my earlier etymology). This makes the study of mild more fascinating, as it adds a further layer of complexity to their stories.

5.2. What story are they telling?

I would like to offer here a reminder of my overall argument, taken from my understanding of the overarching narratives my participants shared. My argument consists of three main elements: firstly, that **mild holds value,** a value that is socially utilised, resisted or contested according to how it may be employed or embodied, it provides purpose and meaning to experience, prior to its social utilisation. This leads to the second aspect of my argument, that **mild is employed strategically**, to present the body in certain ways and to achieve impression management through the embodiment of mild. The strategic use of mild occurs and is negotiated within normative environments. As this embodiment of mild varies across the life course, there is also a temporal nature to mild. This introduces the third element of my argument, that **mild is experienced through non-linear personal trajectories,** which contextualise people’s experiences of mild. In summary mild is effective as a classificatory tool, but more than this, discourses surrounding mild have real consequences for how disabled people position themselves against others in society. Mild confronts the fragility and contingency of normative disability binaries, with a strong sense of liminality articulated through their narratives of mild which speaks to a life on the margins. Mild is, therefore, a lived experience, realised through a performativity, which requires negotiation through social relationships. Narratives, by connecting body, identity and society, offer insights into the epistemic potential of mild.

In other words, this thesis presents an understanding of mild CP from the perspective of those living with the disability. It breaks down how mild is made sense of, how mild is used, and the actual lived experiences of a condition that is consistently considered non-progressive and therefore its disabling impacts still assumed to be static and relatively less severe. In doing so, this research presents the experiences of mild as a fascinating and rich category of analysis which requires increased medical and social care support and understanding. People living with mild CP deserve deeper recognition for the ways in which they negotiate socio-medical misassumptions, misunderstandings and ignorance, resisting barriers formed through normative and ableist social structures. This is an opportunity to listen to voices previously largely unheard and learn from their expertise to have a better understanding of how people with mild CP are often left feeling like that they are, as Polly stated, “falling between two worlds.”

Chapter summary

This has been a relatively shorter but still important chapter to give an overview of the people I spoke to. It has given me the opportunity to demonstrate the diversity in the ‘types’ of CP that people may live with and yet still consider themselves to have mild CP. This raises further questions, including what makes them see themselves as having a mild form of CP and why this may be important to their understanding of themselves and their disability, which will be explored in my subsequent findings chapters.

My first findings chapter will explore the value of mild including how this can support the idea of disability as a continuum, and the value of mild within this. I will also include a discussion of the discourse around mild such as ‘luck’ and how this is made sense through comparison of others. Mild can be employed to reflect an understanding of the self in relation to others. It will begin doing this by discussing how participants identified who had ‘mild’ CP (in others) and what a mild diagnosis suggested for them.

My second findings chapter will look at this strategic use of mild, as a communicative device to say something about themselves as well as their social and physical capabilities. People may embody mild, as they are aware of the able-bodied norms that exist in society which shape our understanding of disability and ‘ability’. A clear example of this is in relation to pregnancy and motherhood (which in itself carries an embodied risk), hence examples of empirical material discussing this will be presented to show the everyday consequences of lying with mild CP.

My final findings chapter will look at the everyday realities of living with mild CP in more detail. Including how mild CP is experienced within temporal trajectories. There are realities of ageing with mild CP (clinically seen as ‘non-progressive) that need to be acknowledged, which impacts on their imagined future, which may become increasingly difficult to navigate. This leads to my conceptualisation of mild CP as a potential liminal identity and a discussion of how the normative environments which somewhat predetermine the value of mild, also maintain the binary of disability and impairment which create this liminal mild space.

6. Findings chapter I – the value of mild

Chapter introduction

I initially asked my participants what interested them in taking part in the research and what mild CP meant to them to provide me with a starting point for the interview and something to return to. This is important particularly as, in the absence of clinical definitions of mild, it becomes a self-defined identity, but one which often draws on bio-medical understandings of severity of impairment and what this means for the experience of the disability. A diagnosis is at once deeply personal and yet shared within social spaces which creates a conflict of experience. It is difficult to deny the embodied nature of mild. The analysis will show how mild CP can make people feel contradictory (or be viewed by others as such). The negotiation between individuals in a normative society is made explicit through the experiences of those I spoke to. This creates a dynamic and tension in which a diagnosis of or identifying with mild CP is both a 'blessing and a curse' for the everyday lives of adults with CP. This is unpacked through discussion of the narrative extracts I outline below. The debate arguably should not be centred around what the definition of mild CP is, or to even try to find a singular meaning for mild CP, that endeavour would not do justice to the complexity of their experiences, particularly as those I spoke to have been subject to systemic ignorance and invisibility by these in their social and medical network. Hence, striving to hear and understand their voices is critical for reframing debates around the body and bodily experiences of impairment and disability, building on the work that has come before, but drawing on voices not heard before.

CP has many manifestations, of which mild is one. However mild in itself holds multiple meanings. Returning to my central argument, my participants articulated a need for a discourse around mild, not least to determine its value, which is the basis for this first analytical chapter.

The goal of these findings chapters is to set up a deconstruction of mild, as relevant to those diagnosed with CP, locating the idea of 'mild' as an integrated aspect of participants' more general lived experience. This chapter has therefore aimed to introduce the participants, highlight their motives for taking part in the research, and to begin to delve into why they perceive themselves as mild. This, however, is not simply an individualised experience, but also rooted in their social environment and their knowledge of others' experience of CP. This, and the idea that mild CP has a temporal and interactional basis, will be explored throughout my analytical chapters below, to present the juxtaposition of being both able to use mild to 'fit in' with an able-bodied world, whilst also having the potential for mild to hold a sense of liminality. To reach this conclusion, I will explore the three aforementioned analytical chapters or 'threads' from the narratives. Their sense of self and ideas of what mild means to them are subjective and personal, which is what the following section will explore. This section of my analysis is aiming to make the point that the people I spoke to understand what mild means at the start of our conversations; mild therefore is not a concept that I am imposing onto them or their experience. Mild has a meaning for them, and thus our shared knowledge of how CP impacts us as individuals created a shared understanding from which to launch these conversions. Arising from conversations in my pilot interview, I asked each participant as an opening question what made them interested in taking part in the interviews. My narrative methodology was a choice made to give me access to their subjectivities and importantly, how they felt about their lived experiences (Valeras, 2010), hence asking for their motivation for taking part in the research was a foundational step to understand the approach they took to their story telling.

> Polly: I think it's the specific focus on mild CP, mild CP being kind of vague. I mean, it's self-described, which is, which is absolutely fine, because that gave me the confidence to kind of volunteer a lot.

For Polly (42 female, spastic hemiplegia, left sided CP), the 'self-described' nature of mild for the participant criteria gave her confidence to speak to me. There is both the element of mild as 'vague' as well as being self-defined.

Polly begins to introduce the idea of mild CP as a misunderstood condition (resulting often in a group of misunderstood people who are given a mild diagnosis) produced and reproduced by misplaced expectations of what CP is as a whole.

> "…because when you say you've got mild CP, and then you walk into a room, I've had people expecting me not to be able to walk into a room."

This lack of research focussing on mild CP is something that is recognised as a motivation for taking part in research by Daniel:

> (Daniel,33 male, quadriplegic): "… I think there's a lot of concentration on the more severe forms of CP, whereas the mild Cerebral Palsy tends to get sidelined…"

For Daniel, the concentration on other manifestations of CP has meant that mild CP has been 'sidelined'. This is an important articulation of the research landscape surrounding CP, that is often understood in terms of the more severe experiences of the condition. The interviews allowed for a focus on a misunderstood and under researched experience and thus formed a space for people to share knowledge that may otherwise have been overlooked. This highlights the importance of having a better understanding of the value of mild for both personal, social and academic spheres.

This reminds me of Amy’s observation that certain more well recognised symptoms of CP, such as swallowing difficulties “just really don’t apply to me”. For Amy (27 female, mild athetoid CP), this renders her overlooked in research and in medical spheres:

> “I just feel like I'm very invisible within research and therefore kind of within healthcare as well because GPs don't really know what to do.”

For Amy and others like her, there is a lack of representation of her experience of CP within academia, and this translates into her feeling erased from the medical spheres also. This highlights the great value in the academic discussion of mild CP and moreover, it makes explicit the lack of nuance in the way that people with CP may be cared for by their primary doctor, often the first point of contact for adults with CP to discuss any concerns with.

> “And there aren't really any services that are particularly equipped to deal with mild forms of Cerebral Palsy because what do you do? If the answers aren't there in the research, then then you can't build a healthcare service on or not an evidence based on”

Amy’s narrative here contains an important observation, she highlights not only the need for an alternative discourse, but also highlighting a key issue, that the right questions have not yet been asked to try to understand the experience of mild CP.

> “Yeah, so that's what really got my my interest really just like a generally in sense of where are the people with mild Cerebral Palsy? And not just in healthcare… But also like in general life … I find it really hard to find people who have similar experiences to me so yeah, just that that I feel very aligned to maybe if I can put my perspective out there maybe like someone else might”

Amy goes on to share further details on her motivation for taking part in the study, suggesting that she is unable to see herself reflected in personal spheres as well as being included in research, be it in personal, in health care, or in research. The value of a shared experience should not be underestimated, even with a condition such as CP where the everyday experiences of the impairment and disability is likely to vary. This also begins to highlight the relational nature of experience. Seeking shared experiences points to the interconnected web of experience outside of the interview and of the meanings that mild holds for people beyond the interview conversations. Mild therefore holds value which can be vital to understand in order to work towards a more nuanced understanding of the impact of impairment and subsequent disability. The extract from Amy points to a reflection attempting to locate her own subjectivity within the social practices of defining and dividing experiences of disability. Throughout this analysis, mild will be shown to be, both socially and medically, considered a social-relational term, and as such its meaning is often formed and reinforced through comparison of others. Mild carries assumed meanings which are highlighted and unpacked during the interviews. The depth and complexity of mild is shown through the participants' accounts, that situate themselves as individuals within the context of normative environments and able-disabled binaries which are maintained through social and biomedical boundaries. Invisibility in medical and social spheres is reflected within the feelings of invisibility amongst individuals. Comparison was one key way in which the people I spoke to made sense of their disability through comparison and what they are or are not able to do, which is in turn reflected in medical diagnostic categories.

Hence, this section has aimed to set the scene of the interviews and to begin to highlight some of the key motivations for the research. It also establishes expectations about CP, of which mild is not usually associated, yet it emerges as an important aspect of people's experiences, as they give purpose and meaning to their experiences. Primarily, this research aims to understand and listen, to be led by the stories told by people with CP, and in doing so, begin to understand the bigger picture of how mild CP is experienced and responded to medically and socially. People responded to my choice to focus on mild CP, and in doing so highlighted the value it holds outside of the interviews, in the everyday lives of people with mild CP, as well as in a wider sense within society as a whole. Theoretically, mild is introduced as a category of analysis, and similar to Garland-Thompson (2020) argument that feminist theory should be introduced into the disability sphere, mild can work to extend the diversity of our understanding of disability, including its relationship to impairment. The next section of this analysis will look more closely at the multifaceted nature of the value of mild, and the discourse that is developed around it.

6.1. Who has mild CP? (participant perspectives)

It remains important that I am able to justify a focus on mild CP not only on its academic value, but also for the value this research may have for my participants and others with mild CP.

I hope by doing so I begin to introduce the subjective nature of 'mild' and the importance of leaving mild as a self-defined term. I also hope this begins to introduce mild as an analytically rich point from which to better understand disability.

> Alex (56, ‘male’, ‘spastic diplegia’): I mean when I read out your mild you know it's one of these things are so subjective. In certain instances, I don't really class myself as having a disability. But that's dependent on you know, my circumstances, you know, comfortable environments, you know, that, you know, minimises the impact, you know, a CP has.

Here, Alex introduces the fluidity of disability and the felt impact of his impairment. His feelings towards being disabled changes depending on the environment he finds himself in; ‘comfortable environments’ minimise the impact that CP has for him. This directly challenges the assumed static nature of CP, and moreover it makes explicit the relationship between the felt impairment effects (Thomas 2010, 2012) and the physical environment. CP is negotiated differently within specific contexts.

In order to understand the value of mild, therefore, the physical and social impact of disability need to be considered simultaneously.

Mild appears therefore to enable an articulation of this comparison, and reflects work around self-assessment, taken from awareness of the physical and social environment. So, mild can be placed at the centre of a web of awareness, of the self and the body in context. The use of mild also begins to introduce an alternative or parallel discourse in which to understand CP. This alternative discourse is needed to account for the largely misunderstood experiences. Although mild seems to present as an alternative shared language for people to use as to legitimate their experience, there seems to be some ambivalence in doing so. It is important to recognise the complexity of how people legitimize themselves and their experiences, particularly as further in this analysis they emerge as a group that carry precarity socially and medically.

To link back to Alex’s initial observation that there is a subjectivity to diagnostic labels, Adam reflects this when he said,

> “CP is a term used to describe a whole range of physical impairments that can vary in terms of severity.” (Adam, 65, ‘male’, ’athetoid’)

Adam’s description is a useful reminder that CP is an umbrella term that encompasses a variety of impairments and lead to many different experiences of disability. It also highlights that CP can be framed in terms of ranges of severity, pointing to mild as a relative term and therefore understood in comparison to other ‘severities’ of CP. Adam then goes on to explain why he deems himself to have a mild form of CP:

> I would argue that my example of athetoid CP is mild because I can do almost everything that I want to do - walk, run, play sports, talk, read, write - with some things being more difficult

> than others but still doable - whereas I know of people who are more severely affected and can’t do as I do.

It is interesting that Adam uses both the label of mild, and the official medical diagnosis ‘athetoid’, suggesting that although mild may not be acknowledged in the medical literature as medical classification of CP (Manji, 2014), people do choose to use it alongside their official medical diagnosis. This suggests an overlap of the lay and medical spheres, as well as potentially an overlap of the social and biomedical classification of CP. Used in this way, it appears to be a qualifier, used as an additional description for his diagnosis, especially as Alex then goes on to explain how/why he classes himself as mild, based largely around his abilities and the relative lack of hindrances (at least at a functional level) that CP poses to his everyday life. Alex also evidences his self-classification through the comparison of others with more severe forms of CP, hence again he places himself and the bodily impacts of CP as being in some form of functional hierarchy. This is recognised through measures such as the GMFCS; however it is interesting how these markers of levels are replaced with the term ‘mild’, providing an alternative discourse to understand the impact of CP. The notion of discourse will be explored later in this analytical section.

Alex was not the only person I spoke with that drew on their abilities to enable them to categorise themselves as mild. Amy said when describing why she saw herself as having mild CP:

> is the fact that it wasn't immediately picked up on. I had levels of impairment or difficulty, which like, restricted my life quite a lot and really impacted me like, on an hourly basis, let alone daily basis, there's so many aspects of self-care that I really struggle with. But I manage to live independently, and I can do most things. And I don't rely on any kind of health care services or clinicians long term. And so that for me, is where I put myself in the mild category. (Amy, 27, ‘cis woman’, ‘mild athetoid cerebral palsy’)

I wanted to include Amy’s narrative here also as it poses several points of discussion on the ideas Alex’s narrative introduced. What is immediately striking about Amy’s narrative is the apparent contradictions that she describes, if these are taken at face value and only considered within the normative binaries of our society. Within our world which places high value on physical ability and makes direct correlations from this to independence, Amy’s memory of having high levels of impairments and which restricted her everyday life, would normatively deem her to have a high reliance on others. However, Amy shared that she was able to live independently. Amy therefore uses a different frame of reference to understand independence, one that is set within a different understanding of ability and disability away from the normative binaries. Her struggles are not separated from her ability to be independent, rather daily struggles exist alongside her ability to sustain her own independence. She also refers to the lack of need to engage with long term health care services, which she directly correlates to her sense of self as having a mild form of CP.

Mild therefore, appears here to be used as a signifier for this more nuanced understanding of independence, that moves away from physical ability. Mild does not simply signify a lack of or less struggle, rather it seems to signify an alternative from the biomedical norm of severity. Amy attempts to reconcile the real disabling impacts of her CP with the concept of independence. In this example, she gives a clear outline of why they consider themselves to have mild CP, and therefore what they understand mild to be. It was not immediately detectable, it allows for independence, and they do not rely on long term health care/interventions.

There is an interesting tension emerging here, in which mild provides meaning, which can be empowering (and perhaps transformative), but is enacted within a discursive context, which attempts to define experience. This is one of the principal dynamics occurring within my accounts, which also includes negotiating trajectory, while having an ageing/impaired body. These dynamics, which I explore in greater detail below, help to explain why experience is not fixed or essentialised but part of the struggle for resistance.

Hence, mild seems to unsettle previously foundational assumptions of CP that a ‘mild’ experience of disability is one that has little impact. It also shows that when people are given the opportunity to orient themselves towards a certain diagnosis, mild seems to fit as a description for a multiplicity of experiences, even where the impairment seems to have a significant impact on their everyday lives. In Amy’s narrative mild symbolises independence despite the struggles they may face. Amy attempts to reconcile her diagnosis with independence. Such reconciliation can carry with it a complexity, made explicit by Sue’s articulation of how she considers herself to have mild CP.

> So I'm a little bit of a complex case, I believe, because I have got CP obviously, and I am wheelchair bound. Which may be some people listening this will be like, Well, if you're wheelchair bound, how is your CP mild? But growing up, I kind of realised that my, the way I express myself and my articulation is quite rare for people with CP. And also, you know, I, I'm in control of a lot of things, I mean, control of our muscles and in control of my tone. I mean, it's not perfect…But you know, I, a lot of people will see be they're not as independent as I am. (Sue, 23, ‘female’, ‘spastic diplegia, ‘affects legs more than arms’)

Sue’s observation that, “growing up, I kind of realised that my, the way I express myself and my articulation is quite rare for people with CP” highlights a temporal element - a shift in understanding of the self over time. The complexity is anticipated and the source of the complexity identified - the label of 'mild' being used to refer to a body which is unable to move independently or without aid. More can be said about the way in which functionality as a social construct is tied in with independence and the relationship between the social and physical movement of bodies. Aids such as wheelchairs point to bodies that do not work in the usual way (Thomas, 2002), there are assumptions that a body such as this would not be capable of independence.

Sue's independence is conceptualised in a different way to the traditional notions of physical self-sufficiency. Sue recognises that her ability to express ideas and articulate experience would be assumed rare considering her limited physical ability. She therefore tells a narrative of mild which is centred on resistance to normative assumptions. Work is done to navigate the impact of her mild diagnosis. The idea of narratives of resistance speaks to power and oppression, allowing historically oppressed voices to resist stories told of them (McKenzie-Mohr and Lafrance, 2017). Sue provides an alternative account which arises from the experience of everyday life with mild CP. Sue negotiates this by finding points of independence away from the norm of physical care and walking, making sense of and in doing so reconstructing what mild means for them, which here centres around the notion of bodily (and therefore) social control of the self.

Therefore, Sue's narrative has begun to demonstrate a destruction and reconstruction of normative assumptions, whilst making sense of their diagnosis. Many of those I spoke to were able to draw on their awareness of normative assumptions and discourse, using these assumptions and knowledge of how they and their diagnosis is perceived to employ mild strategically. This returns to the idea that people's stories have been told within a trajectory, that is an understanding of how their experiences are temporally related to one another.

Therefore, the extracts above remind us that although mild is likely to usually be referring to the impairment in the first instance, it can also assume meaning in relation to the impairment effect and the more social and disabling consequences. There are a lot of different layers here, implicit in their accounts of why they defined themselves as having mild CP. This introductory chapter, I hope, has therefore helped to develop a muti-facetted definition of mild, upon which I then use my empirical material to further interrogate.

6.2. Making sense of their mild diagnosis

The narrative extracts shown above suggest that mild has a value outside of the interview. My participants came to take part in the research to share their experiences and feelings towards mild and what it meant for them in relation to their CP. This confirmed to me that mild was not simply a category that I was imposing on them, but rather that mild carries meaning and more so social value. It is not simply a neutral term. There are many ways in which people made sense of themselves as currently or previously seeing themselves as having mild CP. They either currently or have previously identified with the idea of mild. This section of my analysis will therefore begin to present the ways in which mild is understood as they emerged from the narratives from those who identify with the term.

Firstly, mildness seems to be involved in the deconstruction or reconstruction of diagnoses. Brown (1995) introduced the idea that there was a social construction of diagnosis. This asked the question, what is the social definition of a condition? The social definition of 'mild' has a contested definition, as the extract below suggests, this means that it is influenced by the historical discourse around disability, as well as the changes in physical symptoms and importantly, how much my participants deemed it necessary to use 'mild' as a way to navigate certain social spaces. Hence mild could be used to deconstruct and challenge people's assumptions surrounding CP and the limitations this is presumed to place on the ability for people to achieve certain life milestones such as having children or being in a romantic relationship.

> Molly (43, female, dystonic spastic CP):
> When I was younger, I think, cause I'm 43, and I think, like I grew up in the 80s and 90s and being disabled, the view on disability was quite negative then, and that is still negative now we'll still got a long way to go. But it is getting better and so throughout my kind of teens if if I didn't talk, you couldn't tell that I was disabled so it was kind of, like the doctor, because the doctor had said it was mild Cerebral Palsy, like I can do stuff, I had coordination issues, but it was mainly with my speech. And I think it was al-the word mild was like that protective, 'I'm not really disabled. It's only mild Cerebral Palsy.' And you know as I got older, now I've had my kids and you know life happened, you know people still frown on a disabled person. [[inaudible]] but it's certainly mild Cerebral Palsy. And it was, I kind of used it, that word, as a defence mechanism. But actually as I've got older, the ageing process for Cerebral Palsy, is horrible. Good Luck with that [I: thank you]. And as I get older, the physiotherapy I had back in the 80s, and 90s, is really detrimental on my health now. So I've got issues with my hips. [I: yeah]. I'm kind of my balance and coordination because of that [[inaudible]]. So getting [[inaudible]] shaky. And it isn't mild now. [I: yeah, I understand]. And I need to; I've got a wonderful life. I've got two wonderful kids. I've got a good partner. I don't need to hide behind it anymore.

Disabled bodies seem to exist in spaces outside of the mainstream, with female disabled bodies seemingly experiencing more critique and social commentary than others (Meekosha, 1998). This will be explored in further detail later in the analysis with the case study of disabled mothers. Molly's narrative is another which is temporally and historically situated; this establishes important themes which I will return throughout the analysis. It is interesting how Molly specifies the examples of having children and having a partner. The examples seem to exemplify an awareness of the normative milestones which are expected to be reached in an able-bodied adults' lifetime. It is even more interesting that she uses these examples whilst she is discussing how she no longer uses mild as she had previously. Her reasons for no longer using mild are the changes that she has noticed in her body as she has grown older and losing certain physical abilities that she once had. Therefore, Molly articulates that she once used mild as something to "hide behind", which she no longer needed to do. In this way she could be seen to be reconstructing her own diagnosis, simultaneously reflecting on changes that she has experienced in her physical body, whilst challenging ideas that a higher level of disability may necessarily present more social barriers than mild CP. Hence 'mild CP' seems to be a social diagnosis as much as it is a medical one (Blaxter, 1978). Considering that Molly discusses societal attitudes, it is telling that she uses the phrase,

> Molly: "I kind of used it, that word [mild], as a defence mechanism".

Blaxter (1978) discussed how a diagnosis is a product of the process of diagnostics, something which is ultimately impacted on by the contemporary classification of medical conditions. Something can only be named using the labels available, and the classificatory language used will depend upon the purpose of the categorisation. Hence mild is seen to be deployed in personal diagnostic work, where people (with an awareness of the historical, political and social contexts), will use mild to present themselves in particular ways possible to conceal the social and physical consequences of their impairment.

> Adam (65, male, athetoid CP):
>
> One thing I forgot to mention in my previous answers and particularly applies here is communication - both written and verbal. My speech is affected, and I do find talking hard work and sometimes I have to repeat myself or use a different word with the same or similar meaning. Again, I would still regard this as being borderline 'mild' because I can talk eloquently and make myself understood most of the time.

For Adam, although he recognises his struggles with speech, this for him does not impact on his ability to be understood in most circumstances. Despite speech impairments, Adam is able to navigate the interactional space to ensure that he is still understood and thus for him this reflects the mildness of his CP. The fact that he coined the phrase, ''borderline mild" highlights the boundaries within these categories such as mild or moderate, and there is also a need to justify your place within these, which again points to the fragility of boundaries. There is again an awareness that he may not be perceived as mild by others, and therefore this reconstruction of their diagnosis is achieved to challenge these assumptions.

This is also seen in Alex's (56, male, spastic quadriplegic) articulation of how relevant mild is to his understanding of his CP, importantly, both socially and personally.

> Interviewer: how important do you think this that concept of mild is to your understanding of your CP? Do you use it very often? Do you say I have mild CP? Or do you just have a CP? Is it easy to describe it in a medical way first, but do you ever use the phrase mild itself?
>
> Alex (56, male, spastic quadriplegic): No, to be honest, I don't think it's relevant. You know, because, you know, no, that's quite simple. I've never actually used the term mild CP. You know, because I kinda feel that I then leave it up to you know, you know, you know, people to make up their own mind. You know, because, as I said, my perception is going to be entirely different you know, of somebody else's. So, I don't really get into, you know, maybe, you know, depending on the discussion about, you know, the spectrum, you know, of you know, CP, you know, from, you know, the variant, maybe just maybe some variant , maybe one affected hand right through you know, the extreme end…but that's not generally a conversation I have. You know, if somebody just said you know, so what happened you know, I went just CP some [[inaudible]] and move on and I try to make it that it doesn't define, you know who I am. I mean, obviously, it's a word, you know, more then, you know, happy to have that discussion. But you know, generally, you know, have the brief discussion and move on. It's not something I use often is you know mild, or you know it's not."

This highlights that mild may not be relevant to their everyday lives or how they interact with others, offering an alternative approach to interacting with able bodied people. Not in a way that dismisses the diagnosis but doesn't prioritise it. Is this a 'privilege' to be able to do this? Possibly surprisingly, mild is not important for him (despite him being able to theoretically classify himself in that way), which may be because he recognises the use of mild for others, and therefore Alex is able to make a comparison of himself to them. Therefore, the employment of mild in this way may be a way to distinguish between severity without the virtual hierarchy of traditional biomedical definitions of symptoms. The experience of impairment and disability is a complex web of comparisons including physical, verbal and the psychological impact of the condition, with importance not always on the word itself, as there is not one single definition, but rather in what it can signify and how it can distinguish. Mild appears to aid negotiation of normative social environments as well as to negate an understanding of the self, more specifically to determine the extent to which he considers himself to be disabled.

> Interviewer: Would you consider yourself to be disabled? Do you think you're a disabled person? Or would you not see yourself as that?
>
> Ruth (42, female, spastic diplegia): Yeah, my condition is but as a person I'm not disabled. Do you understand me?
>
> Interviewer: I do understand that yeah. Would you like to explain it a bit more than just for the purpose of the interview?
>
> Ruth: Yeah. Well, in society, they call me disabled, but for me I'm not disabled because I can still do things. I just need a little training and if I just need to learn, but my brain wise, my mind is not disabled.

In response to my questions relating to this, Ruth (a 42-year-old female with spastic diplegia, who notes that she uses a wheelchair for convenience) notes her impairment but does not identify with the label of disabled, saying, "I'm not disabled because I can still do things". Therefore her explanation does not fit within the binary between able and disabled, specifically as her mind is not "disabled". Despite CP being a neurological condition, Ruth's ability to communicate and make sense of the world leads her to reject the idea of being disabled. Her ability to navigate the social world, even when their ability to navigate the physical world in the normative sense is impeded, means that she is placed in a liminal position to the dichotomy of impaired or non-impaired, and disablement may not therefore necessarily follow impairment in the way that the social model suggests. That is not to place criticism on the social model as an invaluable tool for placing onus on society to strive for equity and inclusion. However the social model does still rely on a separation of impairment and disability. For Watson (2004) this dichotomisation extends to one between resistance and conformity and power vs powerlessness. Watson makes the argument for the need for an analysis that does not rely on such dichotomies. Arguably then there needs to be a new understanding of power as something more flexible and lift the concept of disability from binary opposites to accommodate experiences such as Ruth's. Disablement therefore arises from impairment and oppression (the physical impairment and the social response to it). There is not one universally understandable disability; there are differences between people that can become marginalised if the only focus is on disablement (Corker, 1999). Moreover, Huges and Paterson (1997) argue that the distinction between impairment and disability needs to be realigned. The body is at the centre of political and theoretical debate and yet too far removed from the discourse with the social model. They argue that the body needs to be re-understood from reactionary to emancipatory. This therefore argues for the expansion of social models and an embodied idea of disability impairment. The narratives extracts have begun to suggest a resistance to the assumptions attached to a mild diagnosis. These struggles for social and physical bodily control, independence and personal emancipation from societal binaries are embodied. Their impairment is beginning to be explored through their narratives where it is currently absent from theory. The impaired body is part of a certain social and medical history, and it holds value for understanding how mild is used alongside medical classifications of CP.

> Lucy (43, female, spastic diplegia, and notes that she uses aids in the bathroom and shower): it's probably in medical terms I probably am classed as mild [I: mmm. But mentally it's a major stumbling block for me because I've always like I've never felt accepted. [I: right] Because I've always been different from all the other kids at school, so I'd always be left out [I: yeah]. But then I'm almost shunned from the disability community [I: yep] because they look at us and say well, you're not disabled… I won't even attempt to go to the shops now because I can't stand the scrutiny… Yeah, it's another one of those thing where I find it really strange that the doctors will look at the mechanics, but no one's ever said to me 'oh I think you need counselling'. I know, [I: mmm], I need counselling.

For Lucy, her personal feelings towards her CP cannot be reconciled with the medical definition of mild. This is beginning to raise an interesting tension between the medical diagnosis of mild and how it begins to assume strategic meaning in the lives of participants. In effect they have to make 'mild' work for them, along with their need to legitimise their sense of 'mild' through their social relationships. The diagnosis is a starting point rather than an end point. Having 'never felt accepted' from able bodied or disabled groups, this disconnect has a significant tangible impact on her everyday life. Noting the 'scrutiny' that she is aware of from others when outside of her home, Lucy describes an acute recognition of the support she needs but not being able to access this. There is a gap therefore in support which urgently needs to be filled. This gap is not just left in terms of physical support or medical care, but also how she feels marginalised in social spaces and also lacks support for her mental health, which is directly impacted upon by the effects of her impairment. Lucy's narrative presents a helpful picture of the way that the physical body ('mechanics') may be looked at separately from the psychological impact of living with the condition. The body, therefore, is a project realised in both the public and private spheres (Bieńko 2018), and as such the body is a main instrument of experiencing the world and the self. Negotiation of the social world is determined largely by the physical presentation of the body; therefore, the body becomes a site for social and cultural tensions. The degree to which people experience this tension appears to rest on the ability for people to conform to normative expectations and a normative presentation of the self and the body. For example, Sue provides commentary on the way in which CP impacts her everyday life and builds her definition of mild from the way that she is able to live a 'normal' life. Her subjective sense of ‘normality’ is negotiated through a lack of pain and whilst recognizing the role of her wheelchair, she can also reconcile this with normality.

> Sue (age 23, female, wheelchair user, with spastic diplegia which impacts her legs more than her arms) : I'm not the typical. I mean, these are outdated stereotypes anyway. But what I'm putting across is, I live, you know, every day, I feel like you know, I live I live I live a normal life and I've always been taught and growing up I was always encouraged that I was able to do anything. You know, my parents used to say to me, there's nothing you cannot do with just you have to do things differently. So growing up, I really felt privileged that everything I've learned how to do in life hasn't been that hard. Yet. I mean I can't run…so yeah, but my CP being mild what I mean by that not going around the houses 20 times is I don't have any pain day to day I don't I don't know I just feel like I'm living my life but I'm just sitting down

Sue’s response to what ‘mild’ meant to her shows an ability to establish which parts of the diagnosis are important to them. Sue states: “I’m not the typical”. This points to an awareness of the assumptions around what a CP body is and how Sue may be different to this. Sue also highlights how the way she navigates her disability has been mediated by others, having recollected: “I've always been taught and growing up I was always encouraged that I was able to do anything”. Similar to John, responding to a diagnosis is not just a personal journey but an interpersonal one that is heavily influenced by the response of others, in particular parents. However, what is vital to highlight here is the ‘privilege’ Sue felt for her abilities. There is a privilege attached to normalcy and being able to navigate the physical world successfully.

> Sue: … ‘my CP being mild what I mean by that not going around the houses 20 times is I don't have any pain day to day I don't I don't know I just feel like I'm living my life but I'm just sitting down’

Interestingly, a study from Sienko (2018) found that pain made the most significant difference to the health status of adults with CP, and emotional support made the largest contribution to the variance with satisfaction of life. It is interesting to remember that Sue is a permanent wheelchair user, and therefore our conversation made clear the ways in which people recognise their difference in relation to others with CP as well as with an awareness of how they may be interested by others. Sue challenges commonly held ideas of what a more severe form of CP may involve (e.g. using a wheelchair), with their ability to live their life not lessened (although still impacted on) by the wheelchair. This challenges the normative assumptions around the mildness of CP and the ambulant ability of the individual. Hence there is a resistance here to normative milestones, and people are forced to navigate their own subjectivities within these. As mentioned, this opening section is about generating meaning and purpose, in which a person can locate their experiences in a framework, which enables them to generate values, irrespective of the precarity they experience. This meaning, however, has to be socially negotiated and performed in relation to an audience, which may require some persuading.

> Tina (39, female, spastic diplegia): That was getting in the 80s. So that's kind of like my experience of growing up is like, 'Oh, you have mild CP, because although it just affects the bottom half of your limbs, you can still walk. You are still mobile so therefore you are [I: Right yeah, so it was based on what you can and can't do.] Mild. You cognitively everything, milestones that you're hitting everything. You know, all your milestones, speech, everything like that. Is fine. It's not affected. So you have a mild CP.'

For Tina, her past experiences are set within the backdrop of the 1980s, giving a historic setting to her diagnosis, and drawing on the idea of trajectory once more, she later goes on to say,

> Tina: I definitely say as I've gotten older, I'd say I would put myself sort of more in the moderate category.

Hence here, where achieving biomedical milestones was once enough to categorise her as mild, as demonstrated by her stating “you can still walk” as a key part of the diagnosis and that this determined, from a biomedical perspective at least, the mildness of the impairment. However what Tina does here is highlight the fluidity of mild and the fragile boundaries of classification. For Durkheim and Mauss ([1903] 1963), classification is expressed culturally, supporting the idea that the able-disabled binary is more of a cultural classification than purely a biomedical one.

> Tina: I think just as as you get older, you just realise the wear and tear on your body just takes its toll.

This directly challenges the idea that mild CP is static. The ability to walk may remain but the impact of this continues with age. There is a trajectory of biological ageing that runs alongside the trajectory of the disability. There is a fluidity to a mild diagnosis that is not yet being recognised, often arising from the physical consequence for moving the body in particular ways, and this experience can be best understood through the observations people make of their own bodies. It is critical that these self-observations are listened to .

> John (52, male, spastic diplegia): I was very angry when it was first told, because because it made so much sense for everything and I guess what's wrong hospital getting tests for all sorts of stuff that were probably not necessary. If somebody had said, actually, you will have bladder urgency or you will have more difficulty with your bowels and stuff. If you're spastic diplegic so if they had been able to put that together rather than then go on to like a specialist neurologist and a specialist and then nobody can separate that they're still chasing almost. But there's nothing there's nothing medically wrong there's nothing there. So I was very angry. Probably angry with my parents for a while because I kind of had that trigger memory but I do remember

> like reading that vaguely and why would you not pick up on, why did nobody like I just make so much more sense so 20 odd years of things happening to my body that didn't make sense.

John shares the anger he felt being denied the knowledge of his impairment and moreover being denied the language to explain what he was experiencing. This points to the knowledge that a diagnosis can provide, as it provides the ability to prepare and respond to the bodily experiences of impairment effects. Stating that before the diagnosis there were “things happening to my body that didn’t make sense” suggests that there was a process of meaning-making, and there was previously a lack of personal control over knowledge of the self and the body. John also introduces the role of the parents in determining an early diagnosis. Noting that his parents did not “pick up on” the possibility of a diagnosis further shows how a diagnosis is not simply a biomedical observation, but is an interactional transaction between his personal knowledge of his body, the interpretation of others around them and the processes of medical classification. It is a cat and mouse game to determine a set of expectations, and sense-making that is deeply emotive and personal yet medically and socially negotiated. There is a constant comparison against normative expectations of able-bodiedness and impairment.

Therefore, this section has looked at the ways traditional understandings of traditional and biomedical classificatory systems may be deconstructed or challenged, through alternative understandings of disability provided by those I spoke to. Mild holds value in being able to provide this alternative. These challenges however were made within normative structures of ability, disability and the privilege of being able to present as fitting within the binaries. This suggests that there is a performative nature to ‘mild’, which will be explored in upcoming narrative threads. The sense of normality is largely based on the visible physical functionality of the body; however the narratives have shown how this does not paint the full picture, with the biomedical classification of CP and mild cannot be assumed to be able to predict a linear trajectory. This raises an interesting conceptual point about managing the way the body is presented to others, associated with normative views about what it is to be disabled. These narratives are demonstrating more fluidity, in which they have to resist how their experiences may be interpreted. There, however, continues to be a sensitivity to these normalising discourses, which have to be incorporated as part of individual narratives. The complexity of experience can be understood through the self-observations of those I spoke to, highlighting the importance of considering how the impairment is both expressed by the individual as well as how others in society respond to it. These responses can be seen as sites for cultural expression on both a group and individual level. Norms shape understanding and meaning attached to a diagnosis. The next section of my analysis will explore this in further detail, looking at the ways in which people articulated the social value attached to mild and the discourses that are produced from the notion of mild.

6.3. Social value of mild and discourses of mild

For some of my participants, being able to speak of having mild CP gave them more than a diagnosis, it aided them to negotiate themselves a place in society and make sense of (define or redefine) the self. Hence there is an importance to language, in enabling individuals to name their experiences, although in introducing the social value of mild, there is a reminder that this requires social negotiation, which at times, is able to facilitate and challenge participants' use and definition of mild. This section will explore this social value of mild.

> Amy(27, female, Mild athetoid cerebral palsy): "Yeah, I think for me, having that word Cerebral Palsy was but for one, it was a huge relief, because I was starting to worry. Is this getting worse? Do I have something like Parkinson's? Do I, like what what is wrong with me like because there's plainly something’s wrong? And what I really struggled with was when I couldn't do things, or I was a bit messy or a bit clumsy? The language that I had to articulate that to my peers who would maybe like tease me a bit or like, look me up and down? Or you know, it wasn't like blatant teasing. It was like 13-year-old girls, you know bitchiness, I don't know if I can say that type of thing.

For Amy, therefore, having the language from her diagnosis gave her social power, and reasoning to be able to answer the questions she asked of herself and to be able to “articulate” that to her peers. A mild diagnosis can help people make sense of their experience for themselves and for others and offer an explanation that will help them to navigate social interactions. Hence this also shows how biomedical terminology can manifest in the mind and body and carry social and spatial concerns for the individual, becoming embodied experiences (Parr and Butler, 2005). This highlights connections between people and their experiences of the biomedical and the social. The social model is invaluable, but the physical and social impact of disability cannot be ignored. The heterogeneity of the experience cannot be ignored, neither can the personal characteristics of those that have the disability:

> Interviewer: Not quite fitting in type of thing?
>
> Amy: Yeah. And if you if you don't have the language to articulate why you're different, I used to, I mean, it worked for me when I was like six or seven years old to say, I've got

> a wobbly finger. That's how I used to say, the main thing that I could notice was that I couldn't keep my fingers still. [I: right]. So I used to say I've got a wobbly finger and that's fine when you're six. When you're 13. And you've got girls being like, what like what the like, not even saying things, just looking at you. Or when you fall over on the bus like uurgh, or when you're like your or you can't do your shirt up after PE and they're just looking at you. I wish I had the language to say I've got cerebral palsy. And I think that would have given me a bit of power, like in my head even if I didn't say it out loud. But I didn't have that. And I didn't even have the word disability to like, rely on because I didn't know that I was disabled. So being 13 and not being able to do your shirt up after PE and then having to say, Oh, I've got wobbly finger. Like, that just sounds weird. And so I think purely from a social angle, like that would have given me something to fall back on.

In the example here, Amy discusses how she was able to draw on her diagnosis of mild CP explain to others why her body may not move in expected ways. Moreover, she reflects on how a late diagnosis prevented her from having the language available to explain this when she was younger, which she found increasingly difficult as she moved through childhood and into adolescence. It is also interesting that Amy seems to correlate the diagnosis with being identifiable as disabled. Therefore, having the diagnosis gave her access to another 'sphere' of activism and formed new connections between her body and how she was able to understand herself (this poses as an example of the strategic use of the diagnosis, which I will explore later). Furthermore, a diagnosis was able to make her 'understandable' to those around her. Amy particularly highlights the benefits of this socially, although it is important to be critical of why a diagnosis is needed in order for people to navigate certain social spaces. This highlights the social relational element of disability (Thomas, 2010). It also highlights the potential complexity with the clinical diagnosis of CP (Jones et al, 2007), and introduces questions around the impact of a late or mismanaged diagnosis (Nettleton et al, 2004), which is arguably more common amongst 'milder' manifestations of CP.

However, the impact of a diagnosis is arguably more complex than simply giving a name to felt symptoms. Although for people like Amy, it can form part of their toolkit to navigate social interactions, as something to "fall back on", a diagnosis also has the potential to create boundaries around experience, which can be difficult to cross without potentially meeting the questioning of others. I am aware that there is this overlap with diagnosis and negotiating the social value of mildness. To say you have 'mild' CP carries certain connotations and meanings which then automatically places people within both medical and social boundaries. There were multiple examples of participants telling stories of times where they felt empowered and disempowered by their CP and other people’s response to it. Independence takes on new meanings, the focus for that independence also changes from the normative meaning of independence for able bodied people. Hence, there were also some participants that were aware of and discussed their abilities in comparison to their peers, who they saw as able bodied. Here, degrees of independence helped to simultaneously establish and blur the boundaries between mildly disabled and able bodies. This returns to the relational nature of a diagnosis, and the way in which an individual’s perception of where they ‘fit’ within the world between able and disabled (Spirtos and Gillian, 2020).

Classification could create a sense of community. Thus a confirmed diagnosis can be elaborated into the idea of a community, relative to the context in which a person lives, which in turn generates ideas of what a community constitutes. Diagnosis is more than a fixed spatial characteristic but represents a dynamic and temporal process of agency and self-identity, which to assume meaning, requires the continual negotiation of boundaries that define inclusion and exclusion, as it becomes realised relative to structural differentiation. Diagnosis is, therefore, actively reproduced and negotiated through relationships and networks. Self-identification occurs in response to negotiated power relationships, the outcome of which provide normative definitions of who can - and should - be regarded as being part of a community. This could be helpful in understanding biopower, in addition to narratives of resistance, a concept which will be explored in later chapters.

Amy seems to describe her everyday interactions between herself and social and physical space. Space is not just uncritical - the space influences the bodily experience, and the bodily experience shapes the space. Space is at once experienced and negotiated physically and socially (Parr and Butler 2005). Therefore identity can be shaped by and within these ‘bodily spaces’ set within discourses of biomedicine, the body must be disciplined against the social and physical norms. For Amy this also meant considering the social context, as the explanation required during her childhood was no longer sufficient as a teenager. Other people’s responses were different, therefore the explanation needed to be different. Alongside this it is also important to acknowledge that the functioning of the body moves beyond just the physical. The inability to get dressed in the same way as others did not hold the same social consequences as a young child as it did as an infant, therefore ‘functionality’ is also socially contextual. Words are important and needed to navigate and negotiate. Having the right language would even allow her to use her diagnosis to her advantage and to be able to ensure others could understand what she was saying. This also highlights the relational aspect to mild and the value it holds as a comparative tool to others, both disabled and able bodied. Thomas (2004) argued relationality was a key concept for discussions around disability, seeing a disability as relational in terms of severity and in terms of impairment and disability and in terms of relation to other people and society. Thomas (2004) argues that the foundations of the social model of disability are based on social relations and that this idea of disability as a relational concept needs to be developed. The social model has overshadowed this aspect of the framework by removing the body completely. This is important when considering how ‘mild’ fits in the debate, to not let use of the word itself overshadow the insight that can be taken from the interviews. A framework of social relationality extends the work on social inequality and injustice, and it allows for the consideration of the impact of *impairments* for disabled people whilst maintaining the social nature of disability. It also allows a layered approach to disability itself (as socially motivated).

> Ben ((41, male, mild right-sided hemiplegia, spastic cerebral palsy):): I mean, everyone I've known CP has been told that ‘I really don't think they're going to walk I don't think they'll to do this’. And a lot of I think, is managing expectations. I think when the physios or the doctors say that they're fully aware that actually there's a reasonable chance, but it's better to say [[inaudible.
>
> Interviewer: Yeah they don't want it to come back on them
>
> Ben: Yeah, I think so…. especially when I was younger, I did disable sports and things like that. But I always thought it was I was always able to compete with able bodied people as well. And it felt weird to be shunted out. I think it's a lot better these days. But then Yeah, so there's a lot of that. And I think it's a lot of it is is, yeah, not so much to other people. So they couldn't do it. But yeah, so to prove to myself that I could maybe

Ben’s account above begins to re-define ideas of power, ableism, privilege, visible and invisible. Is ‘visibility’ a useful concept to move the discourse towards? Still based on concepts of how ‘seen’ a disability is? Seen by who? In what circumstance? Where does ‘mild’ fit in this? Does invisible mean indiscernible? If so, indiscernible for who? These questions potentially tie into the idea that disability is based on a continuum in the sense of physical symptoms, socially and on the level of discourse (medial and lay people). It might be understood in an academic and lay sense that disability and impairment can alter and change, but arguably there is not sufficient language to describe this in an everyday sense. There is potentially a disparity that needs to be filled. The response to the idea of ‘mild’ and the stories that arise from this might reflect this. The good day/bad day dynamic is as far as the discourse has gone in a long time. Ben articulates a desire to challenge the assumptions made around the causal relationship between impairment and disability, through his defiance of the biomedical expectations placed on people with CP at the point of diagnosis, Ben instead presents impairment as being somewhat on a social continuum, fluid and changeable.

This also opens a discussion of the change of independence with ageing, as for some the use of mild creates a boundary for reflection (for them and for me), i.e. how it was once deliberately used as a symbol of independence and relative ability, and now (often with age) this was not considered necessary or wanted. There were also the experiences of changes in their symptoms, often worsening with age. This introduces further complexity, in which an ageing and impaired body exists in time, although a person's response to this also exists in time. With age, therefore, their CP was not as mild as they once considered it to be. So, there is an additional layer of experience to ageing which moves beyond biological expectations and assumptions. As people's understanding of themselves and their disability as they age, is constructed through interactions with others and their response to their disability (Thomas, 2012, see further discussion of this in chapter 2, section 2.7). Mild could be part of a language of relationships, and that in some circumstances, and for some participants, mild works to manage actual or potential stigma from impairment (as well as disablement). This may be another way to bridge sociological and critical disability studies. Having mild CP seems to allow for a level of physical independence, but only so long as social independence from stigma is also established. Using mild may be a way to manage potential stigma, and foster understanding – about who they understand themselves, and how others understand them. Hence, their personal narratives are used to shape how they are interpreted in their social world. Quackenbush (2011) argued for personal narratives to be incorporated into disability and sociological discourses. Recognising the marginalised position of disabled people in culture as a whole they draw on rhetorical theory, looking at dominant discourses, but also the alternative rhetorics in disability narratives. This raises questions such as, who can speak and who cannot? Who is othered or objectified? How do identity and the physical appearance of the body determine if and how someone is spoken to or about? Is the body heard or silenced and ignored? And how might people resist these discourses? It also highlights the comparative work that is the backbone of how people understand themselves compared to others. The following section looks at how this comparison can manifest into discussions of 'luck'; that is those that may feel 'lucky' to have mild CP compared to other people with CP.

This cements the social value that a diagnosis can hold, and the social processes which determine the relationships between classificatory categories, of which participants cannot escape from, irrespective of their attempts to make mild work for them. Mild also invites comparison, while introducing the idea of luck, to the extent that things could be worse.

6.4. A discourse of luck and comparison – a comparison game

These dominant discussions are based on norms. We live in a world of norms, and most endeavour to be normal. We rank our own and each other's bodily and mental abilities and measurements and on a spectrum of normal to abnormal. A comparative process, based on norms, has been established for most parts of society (Davis, 1995). Mild arguably sits somewhere between these two binaries and thus mild can be used to not only how they understand themselves but also how they may be perceived by others.

> Lucy(43, female, spastic hemiplegia): In my eyes I'm Frankenstein with all the scars and all the rest of it… I've had some right horror experiences when it comes to like dates and whatever. But all I can say is I've kissed plenty of frogs, but I've found me prince.
>
> I: aww, well he sounds lovely your husband.
>
> Lucy: he is. Honestly he needs a medal the size of a dustbin lid for putting up with me.

Lucy's extract is a fascinating embodiment of this sense of normalisation, viewing herself as "Frankenstein" and viewing her scars as a physical indication of the ways in which her body is an anomaly. It is also interesting how Lucy connects this view of herself with her experiences with romantic relationships. Framing her husband's care as "putting up with me". This also suggests that other people prior to her husband did not respond to the impact of her CP positively, despite their definitions of their CP as being mild, and that this seems to have contributed to her sense of self. There is a sense of fortune attached to Lucy's narrative; after having the negative social experiences, she has found a relationship which then inadvertently places her closer to the norms of adulthood. Lucy also introduces the issue of medical intervention and how it may be responded to by those with CP and others around them.

The topic of surgery arose in several other narratives, such as Adam's below, which made sense through the notion of 'luck'.

> Adam: In that respect, I have been incredibly lucky, you know, any surgeries I've had , you know, on all have been, you know, pretty successful. I'm, you know, no regrets… I don't know if it impacts me too much because that is my norm… Well, you know, as my norm and I don't really feel that, you know, I mean, okay, if he asked me to run up a flight of stairs, you know, then you know, obviously, that's going to impact me, and I do use a wheelchair and walking stick…

Adam sees himself as "incredibly lucky" for having successful surgeries, and does not regret having this medical intervention, however, parallel to this, Adam also refers to the impact that CP continues to have on his physical abilities. It becomes interesting that Adam's sense of luck is tied to the success of his surgeries whilst he still lives with impairment effects, suggesting that the idea of successful intervention or rehabilitation needs to be discussed with the individual. The idea of what may be an anomalous body is seen differently by those with CP than those without. Disability is shaped by social and medical narratives producing an 'anomalous body', different from the norm, but fixable. McLaughlin and Coleman-Fountain's (2014) study found that the medical and social responses to bodily difference become part of their stories and influence their bodywork. They become bodies that are unfinished, fixable and flawed. Therefore a narrative of an unfinished body is produced; they manage their bodies as integral to their emerging identities. This can also pose a threat to undermine and highlight the labour entailed with producing an ordinary body.

The idea of an anomalous body is upheld by the medical gaze and medical-social control over the body, therefore able and disabled categorisation are a way to make sense of bodies. Mildly disabled bodies become the anomaly within this, however. There is arguably a medicalization of different embodiments and medical intervention. The body is monitored as a child and as it transitions into adulthood it remains unfinished yet still the subject of social monitoring. Those with mild CP are arguably more likely than those deemed 'severe' to be without medical care after childhood, and yet they may continue to feel the same, if not more, social scrutiny as the meaning of mild is unclear. Some of my participants reflected on the place for surgery reflecting the presence of a narrative of the damaged body; there is a materiality to the body that does not stay the same with age. Therefore, disability has a temporal character, and the idea of normality is fragile. There is a discursive establishment of normal bodies through medical classification, but also an individualised responsibility and embodiment of health: "disability brings a different temporal relationship to the body" (McLaughlin and Coleman-Fountain, 2014, p. 83). Ageing is done differently and there is a medical gaze, but agency remains. Such agency is reflected in Christine's narrative below:

> Christine (56, female, walks independently and uses a FES machine since retirement): And so he said, 'Have you ever had another operation?' And I went, 'No.' He said, 'Have you been offered an operation?' And I said, 'Yes. When I was 12, they wanted to, to lengthen my Achilles tendon.' And he said, 'because of your age, you made the best decision of your life. Because the the research or the ability to do stuff back then...', I'm not that old. But it feels like you know [[inaudible]], [I: certainly technology a lot a lot has changed]. Yep '...was such that it would have it would have seriously affected your life and the way that you you've developed and things.'...

Temporality is vital to Christine's narrative, with her story having the potential to be very different had she taken the choice to go ahead with surgery, due to the medical knowledge at the time sometimes leading to interventions which resulted in further difficulties rather than helping. Moll's (2012) research presented the idea that for adults with CP, there was a trajectory of the 'disordered body' upon which the highs and lows of living with CP is played out upon. This idea of trajectory is something which will be explored in the upcoming analysis section. Here, it is interesting that Moll also found that normalisation was also a recurring theme in their life stories, led by the focus on rehabilitation, particularly in reaction to childhood walking can pose psychological challenges. As this sense of normalisation appears to run through Adam and Christine's narrative, the idea of norms may not always be made explicit, but it appears to drive this idea of luck. Arguably, the notion of the disordered body needs to be reconceptualised in a more positive way, including the conceptualisation of a theory on ageing with a disability. Clinically there needs to be a continuum of care established to manage CP long-term including secondary health problems (Moll, 2012). The scars (or lack of) are brought into conversation with the present, the decisions of the past are reflected upon, regretted or looked back upon within the present. This is not just reflective of their past experiences but is also based on the expectations of others. I will now discuss this further in relation to mild as a source of comparison.

Chronic illness means that people reflect on their bodies in ways that may or may not be on their own terms. Charmaz and Rosenfeld's (2016) study of people's bodies highlights the fragility of bodies and their appearance and how we are impacted by its contingencies. Disabled bodies are under larger scrutiny and yet more invisible. Disabled people become more highly self-conscious under certain circumstances and must overcome obstacles faced when trying to establish a competent identity (seen in Lucy's extract above). People also have an inherent desire to compare themselves to others. The idea of the norms assumes or puts forward the assumption that most people fit within this norm (Davis, 1995). This is important to our understanding of mild, as the multiple manifestations of mild can make it difficult for people to feel fully disabled or able bodied, and yet it can in other ways allow people to be closer to the norms of able-bodied people. The use of mild may therefore show an awareness of this expectation to be able to conform to a certain group.

The relational nature of a diagnosis also points to the presence of power relationships. It is important to not only identify where these may play out, but also to consider what these power relationships attempt to do. For example, they may attempt to uphold normative expectations of disabled and able-bodied people. This includes the medical discourse which surrounds mild CP (depending on the socio-medical context). The outcome of these power relationships is however negotiable. For example, medical discourse may assume a particular use of mild, which a person with CP has to negotiate and respond to, while at the same time having the opportunity to use it for strategic purposes, to make sense of their experience and in some cases, use it as the basis of resistance. This introduces further complexity, in which an ageing and impaired body exists in time, (although a person's response to this also exists in time). This is however also a risk, as it creates the continuing possibility that others may define their experience, as part of social negotiation. This is negotiable, which is why my analysis is important in outlining this negotiability. Therefore, the response of the individual with CP and those around them will adapt and change alongside the impairment. The strategic use of the term mild provides new ways of understanding, new points of reference to understand what mild means for them and the experience of their body and disability. Rather than having a disability or not, there is a continuum established, which can weave uncertainty into the responses of medical professionals. There is also a fluidity in people's understanding of their own 'roadmap'; individuals have to begin to understand their impairment through trajectory, which is personally realised and socially negotiated, hence this is a continual dynamic.

> Sue: I think there were a lot of moments where I kind of sat up and thought, Well, okay, maybe I've just got to accept my life and, you know, try try it. For so many years. I wanted to give up, even being, you know, not not being alive, but I just, I just didn't see a point. It was like, Oh, well, I'm disabled, I might as well act it then stay in the house do nothing and just blerg! And just so I think when I was about 16, it took me a long, long time to grow up. And I mean, psychologically, physically, everything. I was just the self-loathing, and why me lasted for far far too long. And I think I kind of pinpoint the time. But I remember having a conversation with my mum, we were in the car, and I always laugh. It's not funny but I do always laugh. She said to me, one day, she said, you're just going to stop moaning, and you're just going to accept yourself for who you are. And you're just going to get on with it. You know, life has dealt you this pack of cards, you could be worse. You could be now you may not wake up tomorrow, so just try! … My mum always used to make me watch Pride of Britain Awards in like, the seven seven bombings. And she always turned to me and go, Ah, so are you better or worse to that person? I always used to be like, yeah, I'm better than they are. But she was trying to make me realise that I did have potential to have a great life if I just wanted to start living it.
>
> Interviewer: this is quite a lot of like comparison to other people either enabled or disabled with CP or without and sort of that comparison and the levelling out when a how different are the same you are to somebody else reflects on how you feel about your CP or your yourself in general.

> Sue: It's plagued my life comparison has plagued my whole entire life. And it made me somebody who I didn't like for many, many years. Because I like I said, I shunned being disabled and I almost used to want to hide away from the fact that I was disabled.

In this extract the participant articulates their discomfort in being between able and disabled. They categorised themselves as being more or less disabled than others, using their own measure of disability (in this narrative there was a strong narrative thread focussed on their ability to talk and have a voice). They say that they once “shunned” being disabled and their CP (acknowledging their impairment), placing themselves in competition with others. This suggests that comparison is an element of ‘mild’. People can feel a sense of hierarchy based on the comparison of physical ability. It is interesting that they saw themselves as being less disabled due to their ability to talk, when medical classification tends to focus more on physical ability, which in this participant’s case may mean that they would be categorised as more severe than mild, as a permanent wheelchair user. Sue says the quotes: “why am I here? I'm not like that person. I'm not, I'm not that bad, you know, why am I in this?” highlighting the thought processes surrounding categorising themselves as mild, and how this can be tied to a sense of self. Mild is embodied, and a sense of liminality is therefore embodied through the use of mild. The following quote from Sue: “Oh, I’m not disabled, I'm more like the able-bodied people. But then I always used to punish myself and you know, hate myself used to be like, you’re not like them are you, but it was self-induced. No, it was always like, Oh, well, I'm not you know, I can speak so I'm not like you oh, well, you can't walk though can you?” reflects the conflicts that can be felt when they try to make sense of their position within this liminal space between able and disabled. Added to this is the context of the participant’s age. In this extract they are reflecting on when they were younger, hence they could have been said to be in a liminal space in this way also, and hence this testimony shows the ways in which they made sense of what mild meant to them and how their feelings towards their diagnosis and impairments have changed as they have grown older.

As in the example above, participants discuss times of conflict with their relationship to the term mild and whether they feel they ‘fit’ the category. This confusion could be explored further to allow space for other possibilities of the experience of impairment and disability, a multiplicity of meaning. Mild is a conflicted and contested word and may be a way for people to manage and make sense of their experience without downplaying it. There are also temporal aspects to changing feelings towards ‘mild’ – some because of physical change, others more a conceptual readjustment.

> Sue: And then but then on one side of the coin the thing I should have accepted, which would have made me accept myself, I shunned, cause if I would have accepted, it's so ironic, because if I would have accepted the CP or would have been like, oh well I'm so lucky. But by not accepting the CP, I was always setting myself up for a fall, because I was never going to be as good as my able-bodied counterparts. So looking back on it, it was really a stupid thing to do. Because if I understood disability, wasn't this big taboo. And it's really ironic that somebody with a disability looks on other people with disabilities and is actually discriminatory. But as a child, something in me said it was fine. But like I said, it's, it was really actually I think, damaging to me, that I would say, Oh, we're not disabled, I'm more like the able-bodied people. But then I always used to punish myself. and You know, hate me used to be like, you're not like them are you, but it was self-induced. No, it was always like, Oh, well, I'm not you know, I can speak so I'm not like you oh, well, you can't walk though, can you?

Sue presents much of the conflicting feelings that people shared with me during the interview. She almost places the onus on herself for not being able to accept her CP and seeing herself again as being 'lucky'. Sue draws on the idea of taboo to make sense of this. Hence this highlights the discourse and potential stigma that surrounds disability, which Sue appears to suggest that she once internalised. She goes on to describe the comparison she once made between herself and able-bodied people, saying that she used to see herself as not as good as them. This makes clear the potential for people with CP or disabilities more generally to feel separated from able bodied people in this binary fashion, hinged on their functional and physical abilities. Therefore here it seems like Sue now wishes that she had recognised her relative 'luck' because of what she is able to do, rather than focus on the ways she deemed herself to be unable. The way in which she suggests her negative feelings towards herself, and her disability were "self-induced", that she saw herself as "discriminatory" towards other people with disabilities and able to recognise what she was able to do (talk) but this was constantly compared with what she was not able to do (walk), details great conflict in her sense of self and the embodiment of her disability. Narratives such as this make it clear that a diagnosis needs to be understood as both a medical and social system of classification. This is not carried out simply in a hospital but is a lifelong project, negotiated with the self through the awareness of and comparison to others, both able and disabled.

> Sue: But like I said, I had the biggest problem with my disability growing up, more so than anybody else. When it was really hard to come to terms with that fact, it was really hard to learn. Oh, actually the only problem you know, you are your own problem. You are your own worst enemy. Because the things that used to go on, not that I want people to feel

> sorry for me, by the way…. that I used to think about myself and reinforce about myself. Nobody could ever say anything worse. Which is really sad. But yeah, I was my own worst critic, my own worst enemy. And I was just waiting for any opportunity to then shove back in my own face when it was like aah can't…

Sue continued to recall the thought processes that she worked through in order to reach a level of acceptance about her disability. Even aware of how others may read her interview, “not that I want people to feel sorry for me” and the fact that she saw herself as her own worst enemy suggests three things. Firstly that people with lifelong disabilities can and do change how they feel about themselves and their disability, and do their own diagnostic work, making sense of where they are in relation to other people. Secondly that there is a clear discourse around disability, having a mild condition forces people to consider how they may be ‘lucky’ compared to others, it complicates the simple able-disabled binary. Thirdly it highlights that there is a material and discursive value to mild. The extracts have shown that mild holds value in verbal interaction with others and provides a tool to navigate the idea of taboo - it also holds value for how they understand their corporeal body, although this value can change.

Chapter summary

This chapter has outlined the ways in which the value of mild is negotiated and how this can mean that mild may be both the trigger for or the product of comparison between able bodied and disabled people, or between other disabled people. It therefore was important to enable my participants to share their understanding of the connections between their bodily and social experience of CP, outside of the impositions of clinical and societal expectations of what they should or should not be (as I outline in my central argument).

What has been learnt for people with mild CP?

As I have previously described mild as a lived experience, I would like to bullet point key ways in which this chapter has contributed to knowledge of living with mild CP. In other words, what does this chapter mean for people with mild CP? I will strive to reflect in this way at the end of each of my analytical chapters:

- It highlights something which people with mild CP will already be aware of, and that is that the value or place for using mild to describe their experiences will differ according to the context in which they are discussing their disability. This will be built upon in my second findings chapter below.

- Mild provides an alternative language to describe their experiences, which they can draw upon when trying to make sense of their bodies and capabilities. For example, it may be useful for wheelchair users to still view themselves as having mild CP when considering their verbal abilities. This directly challenges commonly held ideas of what ‘mild’ is (compared to severe). This creates an interesting dynamic for them in their everyday lives, where they may be able to have influence over the expectations and judgements of others.
- Mild may also help them to understand their experience against that of other people with CP. The value of this lies in being able to seek community, or make sense of their disability, particularly as they navigate growing up and getting older with CP.
- Analysing the value of mild highlights the expectations and views of what being disabled is. It makes these judgments visible.

7. Findings chapter II - the strategic use of mild

Chapter introduction

A discourse of mild needs to be established because mild is being used in medical and everyday understandings of CP. This chapter looks at examples where mild may be used strategically in an embodied sense, including the specific example of fertility, pregnancy and motherhood. Hence, having established the meaning participants give to mild and its value in understanding narrative experiences of disability, I now explore its possible strategic use, although more personal in intent, is mediated through social relationships.

7.1 Embodying and employing mild / the strategic use of mild

The way disabled and non-disabled people experience their body can be vastly different and bodily experience can be culturally constructed (Nettleton, 2013). There is also a connection between the mind and body that cannot be separated, which helps to understand the connection between the self, the body and identity and the experience of disability from a framework of embodiment.

> Polly (42, female, spastic hemiplegic CP - left sided) … So I'm 42 now. And I'm feeling it. Now. When I was in my teens and 20s The main problem was not being able to wear high heeled shoes. I mean, there were other things but … it was just it was just that and I realised how privileged that is to sort of say that. I mean, I've never been able to do that magic trick of walking down a flight of stairs in the middle of a flight of stairs without holding on to anything. And when people do that, I'm like what!

> How do they do that? It’s like a magic power. I watch them and I go oh my god. Anyway, so, you know, I've always been a bit wobbly. I've always been prone to falling over. I've always had to hold on when I'm walking downstairs. My entire daily life is on the flat And then I went to [[university]], and I felt extremely disabled. Because it was more exertion, it was more hills. And I, that was the first time, it sorts of hit me that mild CP meant more than, well, I can't wear high heeled shoes.

Here, Polly interprets herself differently depending on the environment she finds herself in. The normative environment changes, hence, there is a degree of strategic decision making here, as part of making mild work for her. This is also played out within the physical changes to her body as she ages with CP. Polly directly points to the disabling nature of the physical environment but also embodies this. Polly states: “that was the first time, it sort of hit me that mild CP meant more than, well, I can't wear high heeled shoes.” This quote suggests how the body is habitually and symbolically connected to the world and speaks to concepts such as the ‘lived body’ discussed in texts such as Annandale (2014) and Shilling (2005). The concept of the lived body is that bodies are both social and biological, which allows us to have a physical experience but also form feelings and emotions to these which can alter the way we interact with society. These feelings can derive their meaning from cultural contexts, but they also have their origin in the body. Society is represented through our bodies.

> Polly … But it's different now, because of the wear and tear. And because I've had two children, and my body knows about it. And I still think that I'm doing pretty well. But it's just that everything is a little bit harder. So everything I've always had is a little bit more difficult and COVID as well, but we can perhaps talk about that later the impact of sort of use it or lose it on your mobility… ‘it’s like a magic power’

This is demonstrated in Polly’s extract above; both Polly’s social, personal and social environment impact on the ways she feels her impairment. There is a clear embodied trajectory here, intersected with events such as becoming a mother and the impacts of COVID-19. Looking at the two of Polly’s extracts together, she articulates ways in which able bodied and disabled people experience the world and spaces differently. Changes appear with age, a fluidity that is made clear through the static physical architecture. Studies such as Carroll et al (2021) support this idea. Relatively little being known about how CP impacts the life course and participation in everyday life as adults, their interviews focussed on the engagement with community activities. Participants’ experiences of growing older were influenced by individual agency, family and the social context as well as wider sociocultural contexts. The effects of CP diagnosis can ‘unfold over time’. I will explore this in my third analytical chapter when I discuss the experience of mild as a temporal trajectory.

This again suggests that living with a disability is as much a social negation as it is a negation between the physical body and the environment. This section of the analysis explores the embodiment and selective use of mild. Something which is explored in Eve's extract below:

> Eve (40, female, with spastic diplegia, a stay-at-home mum and notes the use of a cane): Yeah. And it wasn't something I realised until recently of how much I say it [mild]. I kind of downplay it. [I: Yeah]. And especially as a youngster, I didn't want people to think differently of me. It was hard enough being different never mind them thinking it…I used to put more prevalence on the term mild, because I wanted to downplay it. But now it's more because I want to achieve more, if that makes sense. So I'm kind of like it is mild, because I'm able to do whatever I put my mind to. I worked in Spain for four years. I've had two beautiful children. I got married. I walked out my only requirement on my wedding day was my dress had to be big enough that you didn't see my walking. And everyone was like, Why are you asham-I said I'm not ashamed of my walking but I want one day where it's me. It's not me with the walk; I don't want to walk at the video and see me stumbling.

Here, mild is conceptualised as being linked to doing more (rather than less), and the ability to overcome, directly linked to achieving traditional milestones. Drawing on the work of Douglas (1970), here there seems to be an example of an exchange of meaning between the person with CP, their body, and the environment (specifically walking down the aisle on her wedding day). Focussing on this event specifically, it is a moment that carries a lot of meaning, emotion and is often at the centre of most marriage ceremonies. Therefore, it is interesting that Eve says she wanted one day "where it's me", suggesting that she distanced herself from her CP. Although it cannot be assumed they always do that, it is interesting to explore as the idea of not wanting to be seen "stumbling" relates back to the idea that the way the physical body behaves carries with it social consequences. Hence, the idea of mild is at the centre of this exchange of meaning. As there are restrictions to how the physical body can express itself (Douglas, 1970), for Eve here, impression management was central to this participant's account. In this account Eve has not mentioned their impairment changing, and yet the way they respond to it does change, and their use of mild can reflect this. Goffman's (1959) dramaturgical model is useful here. The intended impression can change; they can be fleeting or ongoing. We create an impression through 'sign vehicles', language and body language and expressions (the ones we give (deliberate) and the ones we give off). There is a pre-established element to it, almost rehearsed; people such as Eve are aware of their social role to play in mediating the impression they give, which they do through the use of mild, and the way in which social relationships can develop from this. A lack of control over the body could give them away at any moment. Mild suggests a certain degree of control over the body, as for John below, as this control lessens, so does his use of mild:

It is interesting therefore that an increase of falling with age for John meant that he no longer used the phrase mild in relation to his CP.

> John: I probably don't use it [mild] as much I'm probably again now that I'm older because it impacts more. Like I definitely have been falling more.

This not only reflects temporality but also demonstrates the strategic use of mild and where it may or may not be deemed applicable. Ben's narrative is another example of this:

> Interviewer: So how important do you think like the term mild is to like your CP? Or is it something that you specifically say to people? Are you just like I have CP or is it you know, how is it?
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> Ben It varies. I mean, I think I haven't, I've started talking about a bit more and try and sort of advocate a bit for not just CP, but disabilities in general, particularly if the stuff until now is more important. But before I didn't used to tell people unless it was needed to so
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> Interviewer: Was there a a reason for that, or did you just?
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> Ben: Yeah, well, I used to get a bit a bit I couldn't. I didn't want it to be me… So I started being a bit more open about it now. And quite often I'll just say cerebral palsy, but I think sometimes that again, I'm probably doing that for the shock value. It's not about me again, it's just to make people think…, I think to say mild I guess, mild means that you are Yeah. I dunno. It's not an exact term, is it? So yeah, probably probably mild is a good thing to say and something that I should use more.

Ben's reflection that "I didn't want it to be me" suggests that he previously did not want to be defined by his diagnosis or use the discourse of disability and impairment. Therefore, how much is revealed and in which way depends on the context of the interaction. Hence, there seems to be a degree of impression management through the use of mild, which can directly reflect how people feel about their CP in that given moment in time. This is something which Ben has demonstrated can change throughout a person's life and is drawn on where and when it may be needed. Mild carries with it purpose and meaning, although not one that can be singularly defined. Its fluid nature reflects the complexity of the relationship that people have with their impairment and disability.

> Interviewer: ...Do you actually say, I have mild CP to people in your everyday life?
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> Polly: No I do use it, I use that I use the term all the time. That's how I would describe my CP to anyone really. I think if I'm being absolutely honest, I use mild as code for, it's okay.

> You don't need to treat me any differently. ... And when I say I've got mild CP, but before the pandemic, I used to commute into central London four days a week. And that is code for you know, like,
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> Interviewer: don't panic?
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> Polly: Don't panic is exactly right. You know, treat me I mean, it's like internalised ableism, almost. But I want them to understand that I have a level of function. That means I am upright, and mobile. ... And I use the word mild all the time. I never say I have CP. I always say I have mild CP. Always

Polly here describes an awareness of the expectations of what CP is, and thus how she uses ‘mild’ as a way to signify to others that their expectations may be inaccurate. Polly also again highlights the confusion that can surround ‘mild’, which further suggests that it disrupts people’s assumptions of what CP is in a mild form. She also then specifically goes on to talk about how she uses mild to say, “it’s okay you don’t need to treat me any differently”. Hence, mild here is employed to bridge the gap between knowledge of disability and a lack of knowledge, as well as able and disabled people. Polly is aware of how others may feel about her CP, or the way that CP may change the way people interact with her (again linking to the idea of ‘mild CP’ as a social as well as physical diagnosis), and thus the use of mild succinctly communicates to those around her how she wishes to be treated, hence it links to my discussion of internalised ableism in chapter 2, section 2.7. It is also interesting how she says the sentence: “I never say I have CP. I always say I have mild CP. Always”. This highlights how ‘mild’ is playing an interactional role and assisting Polly to present herself and her disability as she chooses, which appears to be closer to an able body than a disabled body.

Goffman’s (1956) work can help to see how there is a performance element to using mild in this way. A performance is an activity done throughout the impression management. It is important to see how other people co-participate in this impression making, with the physical environment also sometimes having influence on the way in which ‘mild’ is used to portray a certain experience and image of disability. In this way, the use of ‘mild’ in certain circumstances may become rehearsed, and although the precise use of mild may be adapted with age, using mild in this way becomes part of the routine of navigating being disabled. Polly acknowledges the internalisation of ableism, supporting the idea of the embodiment of mild. Ahlvik-Harju (2016) argues that the world responds to an embodied version of us, and we respond to the world through our embodiedness. There is a dichotomy of how bodies are perceived such as normal, abnormal, accepted or rejected. Society has normative standards for embodiment which bodies are expected to conform to, and those that don’t are ignored, oppressed or marginalised by society. This is legitimised by dominant discourse and representation, typifying cultural narratives. These narratives shape our material world, shape who we are and how we interact with others. Their paper focuses on the normalcy narrative which celebrates able-bodiness, in the rational, male subject (ibid). This becomes the norm, and anything outside of this by default abnormal. It raises the question: Why are disabled bodies so provoking, unsettling, or disturbing? People's comfortable narratives of disability are disrupted by seeing the unexpected, their response does work to restore the balance. The comforting narrative is one that speaks of an able bodied, young male. This is the ideal, in relation to this norm, other bodies are deficient.

This highlights the politics of appearance and the marginalisation of bodies. Female bodies have been medicalised and subjected to stand out against the dominant standards. Interestingly, there are no examples I can draw upon where men's narratives spoke to the relationship between masculinity and the disabled body. This is something that I believe is worthy of further study in relation to navigating parenthood with CP. Disabled bodies exist as part of a wider discourse of bodies - at society level, there is a compulsion to shape, regulate and moralise the body and this can be corporally manifested. There is a devaluation process that applies to the body and the people within the body - people feel of less value because of their bodies and disabled bodies are in a constant state of need to be repaired and normalised. Life stories of those with bodies differing from the norm can pose as a counter narrative to normative discourse. Therefore, disabled people tend to be excluded from every day. Bodily difference therefore cannot always simply be viewed neutrally, but rather there is a need to recognise that this may cause difficulty. Stories of different embodiments needs to be acknowledged. Binary categorisations of able and disabled are not helpful for understanding embodiment in this context - we can better understand the histories of embodiment as open-ended. Bodies are always unfinished (Frank, 1995; Shilling, 1993).

> Polly: Yeah. And I don't think it's a value judgement on people who, who can't pass as able bodied. I think it's a sort of survival mechanism. You know, I don't want you to know that I'm disabled because I don't want to be vulnerable. You know random work colleague or doctor I've just met, or you know, so it's, it's personal to me. It's not like that I think that able is better It's just the world that I'm functioning in... I'm not very good yet at giving myself credit for being a disabled person. Because as much as I act, I'm still a disabled person, whether I'm pretending to be able bodied or not. And it is pretending you know, I'm under no illusions, it's, you know, in London, when the commuting, you have your head down, you're walking, and you walk really fast and everybody walks really fast. And if you keep up with the crowd, and you just get on the train and help people out the way and sit in the seat, and it's, you know, whereas So, yeah, I sometimes have Botox injections in my, in my eye muscle for the squint. So I know that you can have Botox injections for CP. But for me, it's, it's to correct the squint. And when I go through the injection, they put a great big

> eyepatch on on your eye and they say, so should we take it off? Or do you want to leave it on? And when I'm going out into like Central London, I always, always, always leave it on. Because I want the world to see that I can't see properly. And people are genuinely quiet, you know, they they recognise what that means they let you have a seat that you know. Whereas I'm not so confident that I would get the same empathy with a walking stick. And that sounds a bit weird, doesn't it? But I don't know why that is. But like if you're wearing an eyepatch. Oh, today, I had an accident. I've hurt myself one off, and I need a bit more care. [I: it's like temporary?]. Yeah. Whereas if I've got a walking stick, I still don't trust some people are going to be lovely about it. And some people might shout abuse at you.

Polly insinuates the need to present herself in certain ways because of certain social contexts. I want to focus on the following sentence: “I'm not very good yet at giving myself credit for being a disabled person. Because as much as I act, I'm still a disabled person, whether I'm pretending to be able bodied or not. And it is pretending you know, I'm under no illusions...” as it makes explicit an awareness of the decision to present herself as being able bodied. Moreover, it highlights how having ‘mild’ CP, in the case of Polly, gives a privilege of being able to ‘pass’. Importantly, she is able to distinguish between the performativity abilities of having ‘mild’ CP without undermining their experience of disablement. There is a negotiation of the presentation of the body with their identity. Valeras (2010) discusses ‘hidden’ disabilities, and how this presents a choice of whether to reveal a disability or not and if so in what way. The extent to which this decision is a choice, rather than presentation work deemed necessary in the social or interactional context, needs critical reflection, however their findings argued that hidden disabilities play a part in understanding who people are. There is not a clear box for some people with ‘mild’/hidden disabilities to be in, showing how identity discourses are enabled by power relationships (Valeras, 2010). The deliberate use of the term mild and strategically employing certain mobility aids, which could also be seen as “sign vehicles” (Goffman, 1959) to make her disability more visible, further shows how the malleability of mild can play a central role in the discourse of disability identity. The power relationships that uphold ideas of disability and ability can therefore be drawn upon by those with CP, using active agency to support their presentation of self, although Polly’s reference to other people’s responses to the visible impairments asks the question of if this is accepted by others too or not. Disability stereotypes shape everyday experiences between able bodied strangers and disabled. People may be ignorant of disability but still feel able to identify what disability looks like from looking - this leads to ‘medicalising behaviour’ from others (Octavia Calder-Dawe et al, 2019) and suggests that this produces a dynamic by which there is a negotiation of their embodied knowledges. The use of (or rejection of as some examples show) mild is therefore also an important way for people to resist ableist norms. I will now discuss the idea of resistance in more detail below.

Resistance

Mild therefore is emerging as something other than the usual disabled patient story. Within this includes the notion of resistance. In this case referring to the resistance to normative assumptions and discourse around impairment, disability and 'mildness'. The concept of Narratives of Resistance is most notably introduced by Mishler (2005). Basing their research on socially grounded accounts of patient illnesses, Mishler specifically focussed on patients' refusal of treatment. This refusal becomes part of the patient's story, a story which is told to others as well as by others. For Mishler, the treatment refusal says something about who the patients are, that in some way, and most importantly for my study, challenges the status quo. Narratives of Resistance was the product of Mishler's thought experiment, to consider patient illness stories as a resistance narrative, with medicine taking the role of an oppressive social institution. Reframing the relationship between patients and medicine in this way highlights power and hierarchical relationships, and thus within this context, the patient's refusal of treatment becomes not only part of their story but more broadly they form part of a narrative critique of social structures. It is here where the concept of narratives of resistance is formed, as Mishler argues a critique such as this could be made stronger with the incorporation of marginal experience narratives, meaning the stories of the oppressed and underrepresented. These can include narratives of resistance, and provide alternative knowledge sources. They also destabilise truths and historical structures. Narratives of resistance therefore allow space for the patient to be considered as something more than a fixed social category, there is a complexity and fullness to the patient, as they are able to tell a story which may challenge assumptions about their experiences and interpretation of their own health trajectory.

> John: I am not the type of person that kind of I suppose mostly I I don't feel limited by what I can and can't do. I but I probably thought like okay, well I'm gonna take it sounds cliches but like take all opportunities, so I really enjoyed University,

Mishler (2005) put forward the idea of patients narratives of resistance as a product of the failure to listen to the patient's experience and accounts of their illness. There is a hierarchy of power in medical institutions and there are tensions that come with this. It is possible that the 'mild' narrative is not the usual patient story. Therefore, 'mild' has epistemic value; it allows for consideration of how people take control, understand and make sense of their diagnosis, showing that people with mild CP are not passive to their diagnosis, or the assumptions that are attached to this.

> Molly: But yeah, I think as we get older, we we do come become more accepting of who we are. And it is what it is. You know people who care and respect me don't care if I have mild Cerebral Palsy. Or if I've got, if I can't walk that day. They really don't care. and I think like I said, growing up in the

> 80s and 90s, and early noughties, and going through that period where society wasn't as accepting of disability, I didn't talk when I was out in public, because that was a giveaway. I hid it as much as I can. I'm too tired to hide it now. I really can't.

For Molly, her experience of disability has changed both because of her own personal acceptance of her disability as well what she perceives to be a shift in the public response to disability. There is much to unpack in this extract, beginning with the situation of her disability within a social network and how the care and respect of others can help to support the acceptance of her disability. Mild does not hold the same influence within these circles. She then reflects on her choice to not previously talk when in public spaces, her speech being an indicator of her disability. She discusses actively hiding her impairment in the ways it was possible for her to do so. She closes with the observation of: “I'm too tired to hide it now. I really can't”. This points to the work which needs to be put in both physically and socially to manage the physical and social body, particularly to conform to normative ways of being, and a desire to move away from this with age. Molly therefore paints a relationship trajectory for how she rescinded to and managed her CP in public spaces.

She also goes on to give further explanation of why she no longer chooses to apply the word mild to herself:

> Molly: You've got other things to think about, yeah…. And it's like, I absolutely understand why some people need to use that word, and some people don't use mild Cerebral Palsy as like a shield. Some people, you know, they're quite happy with the description of that word. But I think my life experience and how that word has been used in a detrimental way, I just don't like using it… There's stuff that is annoying, but actually I quite like it, I quite love it. Now that I know now, I know I'm worth more than just a label. and it's made me humble if anything. It's made me more tolerant, and a better mother and a better friend.

Although Molly recognises, like many others I spoke to, that people with CP will employ mild differently, she considers the ‘detrimental’ ways that she once used mild to hide her impairment to avoid experiencing disablement. Her reflection of: “I'm worth more than just a label. And it's made me humble. It's made me more tolerant, and a better mother and a better friend” begins to critique the use of mild to enforce bodies into boundaries. She now sees herself beyond her ability to present as having mild CP, particularly as she adopts other roles in her life such as motherhood, she sees her experience of CP as being a positive influence on this. It is interesting how arguably by engaging in these roles such as ‘friend’ and ‘mother’ prevents her marginalisation as a person on the boundaries between able and disabled. Other social roles have reduced her need to be as aware of how she is interpreted by the wider society. She has a place within her own social world in a way she did not have before, therefore mild for Molly does not need to be employed or used to negotiate normative structures. This also begins to introduce the temporal nature of people’s experiences. They experience CP as part of a trajectory, which is far from fixed and is certainly not linear. Telling her story provided an opportunity for reflection and distance to make sense of the body (Frank, 1996). Mild has been presented to be contested, and this is important to keep in mind when we think about the ways in which people classify themselves as mild.

7.2. The embodied risk of motherhood

I would now like to continue to build on the discussion of motherhood, as a site of embodied practice of mild which hopefully brings a lot of the previous analytical discussion to this point together.

Demographically, from those that I spoke with, 6 women had children (with one woman briefly mentioning future childbirth) and 4 men had children. For the mothers I spoke to, their identity as a parent is at the centre, or at least important to, their narrative. They almost tell the stories of their experiences of mild CP through the lens of motherhood. They often distinguish between their experiences pre-and post-birth and reflect on the ways in which their relationship with their body and their CP has changed (and continues to change) over this time. Disability/impairment therefore is located in broader experience, including motherhood. This can mean a move away from the notion of disability as a primary identity, although it remains important, as it is shown to mediate the experience of motherhood. I will begin however by looking at how those with CP navigated the relationship with their own parents, and the reflections made around how this incepted with their experience of CP. I think this is an important place to begin, as even those that did not have their own children, still had stories to share concerning motherhood, through their own childhood and young adult experiences.

The modern pregnant woman is surrounded by a complex web of discourses and expected practices around surveillance and regulation of her body. Thus risk becomes central to the pregnancy discourse, with most of the advice given working towards containing that risk for herself but most importantly her baby (Lupton, 1999). This raises questions around, what are the normative assumptions around good motherhood (or parenthood)? This is a key question to answer, looking at it from the angle of disability, in order to understand the ways in which motherhood has been experienced by those with mild CP. Birth can be a risky act for anyone, but for those with CP the potential risks are often misunderstood. For the women I spoke to, the perception of risk was often embodied, it was felt in the way that women's bodies were perceived and treated by clinical and medical professionals. Hence, this section of my analysis will use the empirical material to consider what the normative assumptions are around motherhood (that come to light when looking at motherhood from the angle of disability), looking first at the stories told around the attitudes of health care professionals.

> Lucy (43, female, spastic hemiplegia): Because obviously I got CP because the cord was round my neck and the whole time, I just had that in the back of my head. What happens if that happens? What happens if that happens kind of thing. [I: right yeah] And no one could relay them fears [I: no] for us because no one's ever sort of looked into why it happened, or was there something that could have been done differently? Because I was born in the seventies it was just sort of like 'yep yep brushed under the carpet'

Lucy's extract speaks to a feeling of precarity and risk, temporally understood in reference to her own birth. There is also a historical context to consider, where Lucy highlights a lack of knowledge of how her own birth may have led to her CP and a background of feeling dismissed by medical professionals. This arguably makes pregnancy and fertility even more fraught due to modern day birthing practices being heavily reliant on medical apparatus and expert help.

> Lucy: One of the worst was obviously being married, are we gonna have kids, are we not? I literally sat on the fence for years because I was like, I don't want a kid to go through what I've had to go through. And when we eventually sort of took the plunge and I was pregnant and was going to see the midwives, I was like 'so, how will I do this?' And it was just like tumbleweed.

Due to uncertainty around her own birth, and ultimately the cause of her CP, Lucy was looking to medical staff to help lessen precarity surrounding her child's birth. Within this account, Lucy reflects on how she struggles with the boundaries between what she is able and not able to do, discussing the difficulty that this can cause when presented with something she feels unable to do, especially where she felt that her parents overemphasised the value of overcoming the impairment effects of CP. This also highlights liminal positions that 'mild' CP can place people in. They have the ability to conceive and carry a child, but are treated, arguably even more so than able bodied pregnant women, as unable to make their own choices regarding their birth. This is justified against a framework of risk, danger and precarity which can then manifest itself within the present body and past experiences of these women. The assumptions and responses of these clinicians are articulated against a framework of risk. For those with CP, pregnancy is often automatically categorised as being high risk, and the consequences for the way that pregnancy and birth are experienced can be seen within the empirical material. The notion of danger surrounding pregnancies and birth for women with CP, therefore, can become embodied risk. The feelings of danger are exacerbated by the unknowns that surround pregnancy. Although 'unknowns' are another common feature of pregnancy and birth, the element of CP can contribute to this, due to a lack of understanding of how-to best support women and their partners during a pregnancy.

> Lucy: Yeah. The worst was the consultant. He picked up my bad arm, which I can hardly lift up myself, and dropped it and went 'okay you can give birth naturally'. And I was like excuse me? Like what planet are you on? It's like I can barely lift my leg up properly and you can't tell us how long I'm going to be in labour for. And again had to complain. My pregnancy was so stressful [I: mmh] it was unreal.

Lucy continues to describe the interactions she had with her consultant at the time of pregnancy, which seems to result in a disparity between the knowledge Lucy holds of her own body and the medical opinion of the consultant. This is an example of denied embodied knowledge, and the need for disabled women to negotiate the "scientific motherhood regime" (Frederick, 2017, p.74). Hence, disabled mothers are positioned to be able to reveal these underlying beliefs around normalcy which all mothers are content with. This highlights a paradox - they are labelled as risky mothers and yet they are rendered invisible by inaccessible medical approaches and by the consumer market of motherhood which prizes the able body.

> Lucy: obviously it doesn't help when you've got a young kid and you're like always up during the night to [I: I know I'm dreading that, yeah]. But then with muscle spasms and everything else on top [I: mmm] it was a nightmare when he was first born because I would literally just be drifting off to sleep, and he's awake wanting another feed. And I dug my heels in, and I breastfed him for ten month [I: oh wow]. But it was horrendous. To the point that I actually though I'd had a stroke at one point because I was slurring my words that much [I: tired]. It was pure lack of sleep.

There is however a tangible impact of motherhood, which can be made more complex by impairment. Therefore it is important to not simply remove or ignore the materiality of the body from the discourse of disabled motherhood: “I dug my heels in, and I breastfed him for ten months [I: oh wow]. But it was horrendous” reflects the determination of women in general to follow normative motherhood expectations, but in this case may also reflect the lengths women may feel they need to go to present themselves as the usual mother and ordinary women (Grue and Laerum 2002), being able to ‘do motherhood’ in the usual way becomes ever more important for mothers with mild CP.

I want to avoid making the claim that the women I spoke to were powerless in their influence over their birthing or motherhood experience. Amongst the medical unknowns, the women articulated what was known to them, based in their own efforts to prepare for birth. There is resistance to the normative assumptions of what a disabled parent is, and what they are capable of being. The women remain aware of the possible risks and precarity of pregnancy, and they are able to identify the tangible consequences of clinical prejudice, as well as the real consequences of ‘mild’ impairment. Hence, to close my analysis, I will return to the meanings attached to motherhood and how these women are negotiating their own birth/pregnancy as well as beyond raising their children. There are some potential gender differences to be explored in terms of the impact of ‘mild’ CP on the experience of parenthood, which will help to broaden this analysis to better understand the possible social and gendered intersections of the experience of ‘mild’ CP. All but one of the men I spoke to who were fathers did not feel that their CP had an impact on their ability to be fathers.

> Interviewer: Do you have any children or anything like that?
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> Ben: Yeah, I've got two children.
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> Interviewer: Has it has it ever affected you as you've become a father at all?
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> Ben: Erm no not really

Hence the importance of highlighting this as largely a gendered issue, is to acknowledge the specific ways in which CP may impact on the biologically female body (Shah et al, 2022). As well as physically, there are also the social expectations placed on women which can be at odds with disabled women. Grue and Laerum (2002) argue that one reason why disabled mothers may be treated with scepticism by others could be because disabled people in general are still viewed as needing people’s help, they are the receivers of care rather than being reliable carers. Women are traditionally presented as embodied subjects. Whether publicly or privately western women find it difficult to forget their bodies, including their appearance. During pregnancy this embodiment comes to the forefront (Leder, 1990).

> Polly: And the fatigue of having a baby. You know, the waking up in the night and all that stuff that happens. I was really not okay. And some of that was having CP and never having really never having really acknowledged it. I think acknowledgement is a really important point with sort of lived experience of mild CP, because because it's mild, and you're operating in the Able world, more or less, and on a good day with a headwind, somebody looks at you like oh there's an able-bodied person going about their day. Nooo. However, I definitely bought into that, and just just cracked on. But then when stuff happened, where CP hit me and hurt me and disadvantaged me, I've got so used to pretending that it wasn't a thing.

Polly's narrative helps to connect ideas of the mild discourse, the notion of living in a world which is not fully yours and connects this with the presentation of the self and an embodied performativity. There is a normative standard for successful motherhood, which is centred around an able-bodied woman being able to independently navigate the world coded for able bodied people. As a disabled woman this forces Polly to 'ignore' her CP in order to present herself and her ability to confront these standards successfully. For Polly, it is not only the physical intersections of her CP and pregnancy, but the social consequences too.

> Polly: I very nearly didn't have the second baby. Because I didn't think that I could physically manage what I'd been through with the first baby. So if I've always said to my husband, you know, if I'd been able bodied, I'd have had more kids. Which is quite big. It's quite a big thing to say.

This highlights a disparity between her personal desires and how suitable she is recognised as being for being a mother. Pregnant bodies are generally liminal, existing between one body and two. Douglas (1966, 1969) talks about an in-between, things that cross conceptual boundaries. Arguably a disabled pregnant body is this. It challenges ideas of bodily margins (social and physical) and once again creates an anonymous body. This positioning is impactful, and can leave disabled women feeling trapped between their desires as a person and their abilities/social perception as someone with CP. The impairment may be mild, but the disability is not, instead CP shapes their trajectory even when mild it is still impactful.

> Polly: But it was it was eminently clear after [[son’s age]], who is now six, I couldn't, couldn't be pregnant again. And to be absolutely honest, if I was to get pregnant, again, I'd have a termination because I cannot my body, my body cannot do it again.

Their decision is made for them. There is some distinction between the self and the body, and yet the experience is imminently embodied. Bodily capacity shapes the way forward on their motherhood trajectory.

> Molly: I think at that time I was probably, so my kind of late teens early / early twenties was probably my best kind, I was in my best physical health… I loved being pregnant. Absolutely loved it. I think emotionally and socially there was a lot of questions about why I was having kids. People don't understand that Cerebral Palsy isn't genetic.
>
> Interviewer: Oh yeah that was one of the first questions I remember my mom asking the doctors like is it genetic? Can she pass it on to any children?
>
> Molly: No it's not… it's not genetic. And then it was, is it fair having children with a disability? But I ended up being pregnant and I carried my children fantastically. But I think again because I couldn't give birth now. I know that the way my body is now if I was pregnant… I don't think I could move. You know, I think I would be sitting down for 9 months. At that time you know because I was physically okay than the kids are sixteen and eighteen, so they're older children I suppose. Buy yeah, I think for me it was more the social

The ideal parent, and in particular the ideal mother, is upheld by assumptions of what a mother should be, and how motherhood should be experienced. The women that spoke with me had an awareness of this and reflected on how social norms and expectations were upheld by clinicians and the social world around them. They, and their bodies, were seemingly assessed for their suitability for motherhood by those around them. Molly’s account highlighted the way in which the judgement and assumptions of others could become embodied within their diagnosis of mild CP. She made the distinction between physical and social consequences of pregnancy with CP. Although she loved being pregnant, this was contrasted with the social consequences of being pregnant within a social world which prioritises able bodied mothers. She specifies that there were questions raised by others as to whether she was ‘fair’ to have children, a question rarely asked of able-boded women. Molly’s account also shows how these questions are not only raised based on the mother’s perceived lack of physical ability. Despite having a seemingly successful pregnancy physically, Molly seems to note how socially the notion of a disabled woman choosing to carry a child and become a mother was still not accepted. Furthermore, Molly reflects on the emotional consequences for this; the responsibility was placed more heavily on her to justify her choices around becoming a mother. The normative assumptions around the genetic suitability of parents are also raised here. Although CP is not considered to be a genetic condition, the notion that it may be assumed to be was enough for those around her to question her suitability as a mother. In order to navigate these normative ideas, that an ideal mother is one which strives to pass on the most ideal genetics possible and to avoid passing on harmful ones, Molly reflects on her use of 'mild'. By using the term mild, she was able to counter assumptions that she was not capable of being a 'good' mother. This raises again the question of what a good mother is and supports the idea that those with a disability are automatically disqualified from achieving this status.

Interviewer: Like other people's attitudes and reactions to it rather than how you managed it?

> Molly: Yeah. I think with the kind of like the word mild, I was defending being a good mum, good mother, because I had mild Cerebral Palsy. Why is that a thing? There are people out there that are more disabled than me that are doing fantastic job at being parents. Why am I still hiding behind this, oh I've only got mild Cerebral Palsy? My kids, I am biased, but they are the most amazing kids, and the most tolerant kids as well.…There's stuff that is annoying, but actually I quite like it, I quite love it. Now that I know now, I know I'm worth more than just a label. and it's made me humble if anything. It's made me more tolerant, and a better mother and a better friend. So although she's [[her CP]] a little bit bitchy that's fine.

What is interesting in this particular narrative is the way in which Molly is able to reflect on the way in which her use of the term mild has changed from when she first became a mother and is able to almost resist the negative assumptions around the impact of CP on her children. Although still able to recognise the impact of CP on her life, with time she has been able to reconceptualize her CP as a positive influence on her life and those of her children, hence working to directly resist and transcend the boundaries created by some of good/bad, able/disabled mother. The notion of the 'good mum' introduces a moral element to the discussion - and raises the questions, should disabled women be mothers and if so, can they be 'good ones'? Disabled women have been found to experience higher surveillance of health care workers and social services (risk) - this demonstrates the impact of their need to fight for a place in the world; there is a consequence to them being seen as risky that goes beyond the corporeal body (Frederick, 2014). As this has been shown to be less of a concern for men, this is perhaps a reminder of how gender assumptions continue to be internalised and how these require a response, irrespective of whether they have an embodied impairment or not.

Thomas (1997), considers disability to be a social phenomenon, resulting from social barriers and social exclusion, with pregnancy interwoven with the experiences of disablism and focuses on women's experiences to understand how disablement manifests within reproductive spheres. Starting from the study of personal experiences - sociological tradition that individuals experiences are effective at illuminating society. The women’s stories highlight the problems faced within healthcare services, medical and social structures and the social relationships they form. There is a key medical discourse that risk should be avoided.

> Polly: Yeah, because babies, right, they start off small, relatively light, and they just get chunkier and chunkier and chunkier until you're like. So, you know, there's a lot of right, you hold the baby, you put it on your hip, right? And then you're off because of babies here and you're not off balance. So there was a lot that I didn't expect with having a baby. Like, you know, you're expected to keep that baby safe. And my body was not. I did alright, my son is still alive. But, you know, like he used to, he used to run. Yeah, he was he was a runner, and I couldn't catch him. And I realised very early on that if he wanted to give me the slip, there was nothing, particularly when he was like two or three. There was nothing I could do. And that's quite a scary thing.

Polly articulated a fear of being judged as an adequate mother - something experienced to lesser and higher degrees by most women, however disabled women are particularly vulnerable to this as physical disability, independence and care giving abilities questions translates to a questioning of their mothering abilities. Power relationships raise questions of if they will be good enough mothers. They face vulnerability and insecurity; it becomes a social debate on a larger scale beyond the individual woman or partners. The management is not just focussed on the pregnancy, but on the mother herself.

I would like to close on an alternative narrative to display the complexity of the experience of pregnancy and motherhood.

> Eve (40, female, spastic diplegia): When I was pregnant, I had the best walk ever.
>
> Interviewer: Really? Did that straighten you out?
>
> Eve: Because I had to walk backwards, you know walk backwards, and I didn't have as much pain pregnant, lower back pain and stuff. Obviously, everything you have the oxytocin and all that releasing so my bones weren't hurting as much my muscles weren't hurting as much, I could have more energy later on. But yeah, definitely pregnancy affected my health now and ageing. I was an old geriatric mum at 32

Eve's narrative opens by describing the positive impact that pregnancy had on her body, allowing her to walk with a straighter gait and experience less pain. There is an understanding of the self in medical terms but alongside this is a retrospective acknowledgement of the legacy of pregnancy on her health and how this intersected with her CP and her general ageing and knowledge of the discourse of risk around motherhood. So therefore, the complexity of motherhood needs to be understood. It is a three-dimensional experience, of which CP can provide complexity; however this section has shown how this is constructed as a moral question of their ability and suitability as mothers.

This section has discussed, therefore, the ways in which mild can be employed. Used strategically by people to be able to navigate a social world which builds up restrictive boundaries of how people should be, determining how bodies should present and behave in certain physical spaces. Mild therefore, although not used by everyone I spoke to, was recognised as holding meaning for people beyond another classificatory system. It becomes the basis of comparison and a means of communicating where people consider themselves to fit on the spectrum of experience. Those I spoke to redefined what it meant to have mild CP, navigating their everyday by drawing on their knowledge of the assumptions of others and where they may resist these. Mild is contextual, and the decision to draw on this discourse can change throughout the life course. The value of mild seemingly changes between each temporal or physical space, which can leave people vulnerable to being on the margin of societal understanding.

Chapter summary

Hence, this chapter has explored the ways in which mild can have a strategic use. This helps people with CP to negotiate where they 'fit' as well as using mild to signify to others how they wish to be perceived. It is interesting how life 'milestones' such as becoming a mother can be used to exemplify the ‘mildness’ of their CP. Mild in this way has been shown to be an embodied experience and one that, to link back to my central argument, can support an easier negotiation of the non-linear trajectories attached to living with mild CP. The use of mild is adapted according to changes in their bodies as well as changes in how they perceive themselves. The perception of the self is again something which can be influenced by their life achievements. Consequently, mild is once more shown to have a fluid identity which requires constant social negotiation. What has been contributed specifically here, is the way in which this negotiation is embodied and can become part of a wider gendered experience of disability. The lens of mild allows us to recognise the everyday interactions between disabled people and their social world, and the potential precarity that surrounds this.

What has been learnt for people with mild CP?

- Mild is something which is felt within and navigated through the body. It is a label which may become more or less relevant to them as they age, and it is important that this is given space to be fully realised.
- It highlights the emotional work carried out by people with mild CP in order to achieve ‘recognition’ as having mild CP. This shows how mild is not just something you might innately be, but something that you manage your body to *appear* to be.
- With the motherhood example specifically, it shows that we have a long way to go to ensure that our maternity services and care are as accessible as possible, and that the rhetorics around ‘risky’ mothers are more harmful than protective.

8. Findings chapter III - living with a mild condition

Chapter introduction

A key motivation for the thesis was to highlight the complexity of disability and impairment, especially when they are considered ‘mild’, and to challenge readers’ assumptions around what it means to live with a ‘mild’ diagnosis, by highlighting where normative assumptions still remain within the binary of able and disabled. I now wish to contribute to this discussion by introducing the concept of trajectory as an anchor for my analysis and discussion. This is a useful concept to centre my analysis around, as we all live within our own trajectory, set within wider social and historical temporalities. Hence, we often make sense of our trajectory in relation to others. ‘Mild’ is currently often used as a comparative word, understood in relation to severe disability, or able-bodiedness, and as an expression of the anticipated impact of CP. However, the people I spoke to highlight a significant gap in understanding around the fluidity of impairment and disability, and a failure to acknowledge the complex processes of navigating a world still ultimately shaped for able bodies. A narrative of mild CP contains within it resistance, conformity, and ambivalence to a proposed trajectory that moves away from the binary and into discussions of negotiation and sometimes ultimately rejection of social and biomedical normative thinking.

8.1. The realities of ageing with a ‘non-progressive’, ‘mild’ condition

As I established within my earlier etymology of mild, mild CP is presumed to carry less substantial long-term impacts as people age, and yet the examples I present below suggest otherwise. This returns to the idea that a mild impairment cannot be assumed to carry a mild disability, and yet people with CP and their families lack information about the transition to adulthood, creating further barriers to adult life with mild CP (Freeman et al, 2019). This chapter looks at the realities of ageing with CP, which includes a turbulent transition period between paediatric and childhood medical services.

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> Lucy: For me as I’ve been an adult there’s just there’s no information. [I: mmm. There’s no care. It’s like as soon as you hit sixteen [I: yep] that’s it you’re out the door, off you go big bad world and everyone keeps on saying it’s a nonprogressive sort of issue but that’s a complete and utter lie because as I’ve got older, I’ve progressively worse and I’ve now got additional sort of issues because of that. I’ve got lovely Heberden nodes on my fingers because I can only use one hand, so this hand’s now got osteoarthritis in it, it’s yeah. I just wanted to have my sort of like say [I: oh yeah brilliant] and this is the perfect sort of platform to say, ‘these are the issues that I face, please help.’

It is clear from the extract above that Lucy links the lack of information available to the lack of care she has received for her CP in adulthood. Lucy clearly articulates the lack of care services for adults, presenting biological age as a watershed of access to support services, at least for people with less ‘severe’ types of CP. However this runs parallel to the progressive physical changes that are felt by those ageing with CP. Interestingly, Lucy saw the interview as a place to have her voice heard, and specifically to make clear the issues she faces as an adult with CP. To be listened to and acknowledged is key to their wellbeing. Mudge et al (2016) aimed to further understand the experiences of ageing with CP, with a focus on adult’s experience with health services. They found that impairments to CP change over time, and for many the severity of the disabling impacts increase with age. There is a need to have a 'listening health care professional' (ibid, p.1) to recognise the patient's expertise and have a positive impact on their sense of autonomy. Mudge et al (2016, p. 7) also identified that "All participants acknowledged an accelerated ageing process associated with CP…".

> Polly: Yeah, you just rub along, don't you? [I: yeah]. And I just wish I'd been a bit more. I'd acknowledged it a bit more, particularly at physically taxing times in my life. Because the ostrich approach of head in the sand, I'm fine. It hasn't served me like it served me well up to a point and then it really stopped serving me well. So I think I think it's I've had to change my mindset and start thinking of myself as a disabled person. [I: do you think that's been difficult?] Well I've always been a disabled person from day one. Like, I was a premi in 1979. And that's probably what caused it. But it's never not been a thing. But in terms of impact, it's definitely disabling. Now, whereas before I live in my life, I'm in the 20s, got a job, blah, blah, Carry on, carry on.

Polly's extract suggested that ignoring her CP only worked until the impairment increased. She has always been a disabled person - but not always felt the same level/impact of disability experiences are set within medical and social trajectories, which encourage or make people feel as though they need to rub along in an able-bodied world. The ability to do this lessens, and the impact of trying to do so increases. Bagatell et al's (2017) study was concerned with the transition into adulthood for those with physical disabilities, especially CP. Issues include health care, education, employment, independent living and community engagement. Although focussing on the transition period in the US, they argue for a holistic approach to transition focussing on building capacity and empowerment, and further education regarding CP to better understand that despite focus on the paediatric experience, CP carries lifelong consequences into adulthood.

> Eve: I think milestones, I mean, we lived on an offer with mom and dad until about five years ago. And like, we've had our own places in between and stuff like that. And we've got our own place. I've got the kids we married at a later stage than a lot of my friends did. And I kind of go Yeah, but I was ready for it now. Yeah, that makes sense. Right? If I if I'd done it to their milestones, I wouldn't have been ready.

A diagnosis can help people make sense of current and past experiences and may also help create a sense of preparedness for the future. Social and medical trajectories are established alongside the medical classification of symptoms. However, a 'mild' diagnosis may make visible the dynamic and complex nature of a life course trajectory for disabled people. This is because the expectations of living with a mild disability may simultaneously move people away from a normative able bodied person's life trajectory, and at the same time, carry different expectations to that of somebody given a more severe diagnosis of CP. A nuanced understanding of the impact of these expectations needs to develop from the participant interviews, however, there is an overarching idea emerging that a mild diagnosis moves people away (to varying degrees) from normative milestones. This highlights the relational nature of a diagnosis, as a diagnosis needs to be understood both in its contemporary setting as well as in the way people make sense of this as they age with CP. Understandings of mild change with time, and hence a diagnosis must be understood temporally, within political, social and personal contexts. For some people with mild CP therefore, understanding of their own diagnosis and what this means for their experience of disability remains fluid and malleable throughout their lives. This is an important analytical observation, as it also highlights the vulnerability of medical knowledge and the fluidity of social responses to a CP diagnosis within their contemporary social and medical settings.

> Sue: Yeah. When I was younger, I saw it as a huge disadvantage. I thought that it meant I thought it rendered me useless. I thought I was just, you know an error, you know, it's just like, oh, well you disabled that's it then, end of. Whereas now, it's like, Ah, you're disabled. That's amazing. And it sounds really weird to say. But I wasn't. …But yeah, my parents looked into an operation to try and help me walk, but it wasn't because they wanted to change me it was because I wanted to change me. … But now, if someone said to me, Oh, if you could, you know, if you could wake up tomorrow and walk, would you? It's like no, because being disabled and having CP is me. It's who I am. And I think if I didn't have my disability, frankly I think I'd be pretty boring, and I think it's what makes me edgy now I'm 24. … And I think to be honest, if I woke up tomorrow, and I could walk I think I'd be gutted!

Sue refers back to the idea of surgery and rehabilitative care and how this is navigated within the social and family networks of the individual rather than just a case of individual decision making. They seem to articulate a reconceptualisation of the self. Seeing CP as making them "edgy" presents them as distinctive and even when presented with the hypothetical possibility to no longer live with CP, they remark that they would be "gutted". This shows a temporal shift in the way that they relate to their CP and a change to the way the impairment effects are embodied. It is interesting how Sue's narrative shows the ways in which she was required to negotiate this understanding of herself and her CP within the context of growing older, thoughts around the possibility of medical intervention, feelings of low self-esteem, and comparison to others. Sue's narrative here seems to present a clear example of the way in which mild CP is understood within embodied trajectories.

Ageing therefore becomes another site, similar to motherhood, to bring my analytical points together, as there is a continual re-negotiation of mild, but one that is connected to normative assumptions associated with the life course, which enables disabling and ableist assumptions to come into play to redefine a participant's understanding of mild. This sense of growing older, while a personal reflection, is also connected to a sense of embodiment.

> Matt (58, male,right side spastic hemiplegia): That's the other thing isn't it is. And especially at your age, I was very conscious about what not wanting to have the spotlight on me at my age about my disability. I think as you get older, you accept it more because you haven't got to prove anything to anybody in the pub or, you know, when you your age, you want to be you want to interact for who you are, rather than Oh, you know that person, we've got to give them space because they've got a disability. And when you're younger, you're very conscious of that. As you get older and you realise, you know, you're not you're not needed in society as regards to playing a role as regards to the younger generation. It doesn't seem to matter as much. You've done it, you've been it, you just want a quiet life. But you want a life that's pain free.

In Matt's extract above, I am reminded that these interviews were a conversation between myself and the participants – he refers to me and my age and uses it as a point of reference for his own retelling of his experiences, and then as a point of comparison to how he feels at his present age. Matt presents not only a personal change in the way he sees himself, but notes a shift in the way he wanted to be socially perceived,

> Matt:I think as you get older, you accept it more because you haven't got to prove anything to anybody.

He connects this to having made other achievements as an adult, and therefore not needing to present himself as being able to work similarly to an able-bodied person.:

> Matt: you just want a quiet life. But you want a life that's pain free.

This is a stark reminder that growing older with mild CP is not only a social experience, but one that is impacted on by the effects of CP. There is an ever-present biomedical trajectory that intersects with the social elements of living with a lifelong condition. Christine also describes the intersection of biological age and ageing with CP. Interestingly, she describes a ‘lightbulb moment’; a point in her life where she realised that the fatigue she was experiencing was not simply because of a busy lifestyle or a personal lifestyle choice, but was also the result of her CP.

> Christine: I also didn't realise, and I don't know if you've spoken to anybody else who's my sort of age. But you don't realise that actually, when you're absolutely shattered in the afternoon about two o'clock. It's fatigue. It's not because you've been burning the candle at both ends, or you haven't been sleeping enough. And that was a lightbulb moment too.

This reiterates the tangible lifelong impacts of CP but also begins to suggest there needs to be room in the medical and social discourse around CP for an understanding of the impacts it can have. Moreover, this section has highlighted the problems that can arise with the social and personal understanding of CP when an adult life with CP is not considered or anticipated. Particularly in medical spaces, their future with CP is left unimagined.

8.2. An imagined future

The idea of an imagined future is strongly connected to a sense that a future has occurred, which raises an important question of how participants connect their sense of the immediate with the idea of future possibilities, including the extent "mild" enables them to make sense of this.

When a diagnosis of CP is given to parents, caregivers, or the person with CP (as is sometimes the case with late diagnoses), they are also given a set of expectations and predictions (which often form into a given trajectory). It also tends to offer a more binary and absolute definition of disability, whereas disability is experienced more as a continuum (see discussion chapter 12), and this is apparent in the narratives of those I interviewed. Individuals have to negotiate this diagnosis and give meaning to it, as it follows them throughout their lives. A diagnosis, therefore, achieves more than medical classification. It can also provide a roadmap of anticipated social, physical and emotional impacts of their CP. This trajectory is set within expectations of the future and makes sense through reflections on the past. I asked some of my participants if they had considered the future when they were younger and if their current lived experiences have been what they expected. Adam’s response to this question highlights the emotional work done by people to understand and come to terms with a lifelong disability.

> Interviewer: If you did consider the future, has it been what you expected it to be?

> Adam (65, male, Athetoid): I remember being told that I’d get better one day! Of course what they meant was that I would be able to learn to do things rather than the ‘I’d wake up one day and I would be the same as everyone that I thought would happen! … I was never really told that my disability would be lifelong, and I only found out when I asked the school nurse. It was quite a shock, and it took me while to come to terms with the situation.

Adam recalls being unaware of the lifelong nature of CP and needing time to adapt to this. Even with knowledge that their CP would cause lifelong impairment, this is an interesting narrative to start this section with, as it highlights the effect of expectation, and of knowing what to expect. Adam outlines a re-understanding of events and is also to recognise the intended meaning behind the idea that he will one day ‘be better’. This also suggests multiple possible trajectories, one where CP can improve, and one where it may hold lifelong consequences, seen in this way it is possible to understand how Adam needed to come to terms with a new understanding of his disability and therefore himself.

> Interviewer: Is there something that you know now about your CP or just about life that you wish you'd known when you were younger? Or has it sooner?

I asked this question to encourage the participants to be reflexive, and to better understand the knowledge that might be helpful to know before people with CP reach adulthood, or to better prepare them when given a diagnosis.

> Katie (32, female, spastic diplegia): Probably how it would affect me getting older, and how or how it would change with age, I think because, you know, there's such a thing or such a like misconception that people think oh, CP is a child's condition and then it's like, when you get to 18 It's like, well, magic you're cured. But actually, you get to 18 and things just go terribly wrong terribly quickly. And it's like, I think when I was younger, if that well, if I's have one known that I'd had CP. But I think around the like I say, knowing how it would change and that it's not going to be you know, thinking back to a child, it's not going to be like that forever. And this is not exactly what's going to happen. But this is roughly what to expect. stay true to yourself, and you know, you know, what you believe in and, you know, try not to let your disabilities you know, get in the way of what you want to do, because you can always find a way around it.

Katie’s narrative above exemplifies how knowledge is power, and that there is a potential disservice to people with CP to deny that the impact of CP will go beyond childhood. Mild is assumed to create lesser barriers to a ‘successful’ adulthood. The reality of this however is much more complex.

As shown, there is currently no buffer to help the transition between paediatric and adult services, arguably clear and accurate information and acknowledgement of the potential impacts across the trajectory of their impairment could go some way to acting as a buffer, providing the opportunity for some preparedness. This would be particularly helpful as changes within these periods of time are often not linear or straightforward. Katie closes her narrative suggesting resistance to the idea that impairments are fixed and cannot be worked around and cannot be something to be simply overcome. Katie was not the only one of my participants to recall reflecting on what their future may look like as an adult. This suggests that there is value in seeking information from adolescents and clinicians should be aware of their goals and support them to realise these (Cussen et al, 2012). Sue details the questions she asked of her future, focussing on questions to herself and her future abilities and possibilities.

> Sue: Oh, my god, yeah. Everyday. All day, every day? What am I going to become? Am I gonna have a family? Am I gonna have any friends? Am I going to be able to get a job? What am I going to be able to do? Were they you know, will they be stuck in the house all day, every day? Will I be living with mom and dad till I'm 50? Yeah, all day, everyday Emma. I used to [[inaudible]] on it in the first thing I do when I wake up would be like, Oh, well, what if I can't, you know, cook? What if I can't? You know, Will I ever be able to have a dog? You know, it was just I always used to worry as well. I always used to think am I gonna to be dependent on my parents for life? That was one of my huge worries because sometimes, and I don't know if you've had this from anybody else, sometimes I forget I'm disabled.

Charmaz and Rosenfeld (2016), discussing chronic illness, point out how illness reminders often fade from memory if long lapses occur between episodes. Although they argue that this is more applicable to the chronically ill rather than disabled people, it is an interesting conceptualisation of the way in which people may be reminded of their condition. For those with CP, reminders could come from the body or their social environment.

8.3. Stories of liminality

I would now like to integrate the idea of liminality into my discussion of these imagined futures. In particular how expectations for futures are created, in which the present threatens to determine the future through embodied liminality. For those that may struggle to make sense of who they are in their present (and what their CP means to them), it follows that their futures may also be unknown. Mild does not fit into pre-existing classifications of experience. Higher levels of disability, shown through the struggles with self-care in everyday life, still made sense in relation to a mild diagnosis. 'Mild' is largely a self-defined term, and it seems therefore that medical discourse and classification is often too reductive, mild in that sense reflects the need for more flexible expression of experience. This can also be seen to reflect the difficulty that people can have in finding their position between the able and disabled world. Although most participants were able to articulate what mild meant to them, socially they often felt that having 'mild' CP meant that they were continually between and negotiating their own validity in certain physical and social spaces.

Concepts such as taboo highlights social structures, hence if mild is seen in this way the confusion and uncertainty surrounding mild could be utilised as a way to highlight the normative classification of people with mild CP and how this attempt at negotiation may still leave them on the margins. Willet and Deegan (2001) discussed this feeling of people with a physical disability that in a modern society there is not a clear and stable role given to them. Drawing on the idea of the rites of passage and liminality, people with a disability are symbolically on the margins of society. Society is disabling and systematically oppressive for people with disabilities, worsened by the boundaries of classification which do not allow for a complexity of experience. Moreover, they make the argument that traditional notions of liminality and rites of passage can help people in contemporary society to make sense of their social status as disabled people with a physical disability. Having a physical disability, they argue, means that disabled people are in 'a situation of permanent liminality', as a physical disability places them socially somewhere 'betwixt and between' normalised ideas of physical functioning. Those with disabilities are often still at the margins of society: "We argue here that individuals with disabilities are in the potentially unending, liminal stage of a symbolic rite of passage." (Willett and Deegan 2001 p.137).

A disabling society justifies keeping the physically disabled liminal by adopting profane reasons for this separation; the ambiguity around mild and mildly disabled bodies can mean that those that embody mild are marginalised within society (Calder-Dawe et al, 2020). The physically disabled are tainted with a profane status outside the sacred space of the community (Douglas, 1915). The way the body behaves is learnt social behaviour shaped by social expectations; the bodily practices and habits we take as being natural to the extent that they are overlooked. This brings together ideas of embodiment and social constructivism (Mauss, 1934). Individuals with disabilities are considered taboo and must be set apart (Douglas 1966). Rites of incorporation in a disabling society become impossible because they would contaminate the large group, arguably leading to a comparatively invisible marginal group of people outside of straightforward social and medical classification. Invisibility can come in many forms, from being overlooked in social situations, to being symbolically removed from social circles. However, the people I spoke to were not simply helpless, their liminal status has the power to redefine and reshape the disabling society. Disability in a disabling society also exposes the disabling building blocks of society. This brings me back to the importance of a discourse of mild as alternative language allows for a discussion and eventually the challenging of problematic norms.

8.3.1. Consequences of being liminal bodies

It is vital to go further than only recognising the liminal status of those with mild CP, to look at the consequences of living on the margins of social and medical acknowledgement. These consequences are projected forward in their everyday experience of mild CP, which I will now explore below.

> Lucy: No one has never ever said to us. And as I said growing up it was great that my parents would always push us and say 'there's no such word as can't' [I: mmm]. But my god was it a hard pill to swallow, [I: yeah] when I was like a teenager and stuff… And I always feel like that, that I'm not good enough for anything. [I: oh I'm sorry you shouldn't have to feel like that] and you've always got to do three, four times the amount [I: mm] as what a normal person does just to get the same kind of, I dunno accolade or whatever like same kind of praise, and no one understands the frustrations that you have… it's like even now I'm walking around, I've got my Ugg Boots on, but I haven't got any socks on, why? Because I can't put them on. [I: right yeah]. And my own stupid pride, instead of going to my husband, sticking my foot out like my five-year-old going 'can you put my socks on' I'd rather just, do without it. [I: mmm] I know it's stupid but it's the only way I can cope with it. I can get through it.
>
> Interviewer: no I don't think it's stupid, it's how you manage it isn't it, nothing's stupid.
>
> Lucy: But again because I work I when the GP im saying I'm having these issues, I need help. I'm admitting I need help, which is a massive step for me to say. [I: mmm] Please help. And they turned around and said that because I work, I'm not entitled to anything.

Lucy pointedly discusses here the impact of living with a chronic condition that is misunderstood. What was once helpful encouragement from parents, becomes "a hard pill to swallow" when the same management techniques do not continue to work for her as she ages. This links back to trajectory and is a reminder of the precarity and uncertainty of having a long-standing chronic condition. Lucy feels alone and misunderstood in her struggles with participating in everyday self-care activities which seemingly come easily to able bodied people. She also struggles to navigate the interpersonal impacts of her CP, for example requiring physical care support from her husband. However, these struggles are dismissed by her doctor based on her ability to engage with employment. Lucy is stuck between the able and disabled world, feeling unable to seek help from those around her. Depending on the interpretation of others, she is deemed more or less disabled and therefore more or less in need of help. This highlights again the importance of listening to those affected by CP, rather than simply determining health needs based on an individual's ability to achieve certain milestones.

> Matt: sometimes mainly that I feel like I'm a fraud. Because it can be mild, but then when you have a bad day, you almost feel like everybody's against you…”

This complexity of experience leaves Matt feeling like he is “a fraud”. He struggles, due to his fluidity of his condition, to be contained within the boundaries of able and disabled or the hierarchy of severity classificatory systems. This returns my account of mild CP back to my opening discussions of the classification of CP, and mild as a classificatory tool.

> Matt: and if we ask [for help], they almost look at us if say, well, can't you do it yourself? Can't you walk? Organise it yourself. And sometimes you want that responsibility to take it away from you, but also is, you know, your own limitations of your own disability

Similar to Lucy, there is tension with asking for help, tied into the idea of mild and the assumptions around this that others hold. The use of mild can in this way be restrictive. Others struggle to understand liminality and the fluid nature of chronic conditions. This also links to Goffman’s analysis of everyday life, and that bodily control is necessary to avoid stigma. The body mediates social and personal identity and (re)produces social hierarchy – to pass through any environment unproblematically is a skill. Disabled people therefore may find it difficult to live by the normative rhythm of society (Shalinsky and Glascock, 1988). Their liminal status justifies the way they are treated, as they are defined in terms of the ritual process rather than as a whole social person. They may not always have the same landmarks to guide them.

> Matt: Maybe, maybe it's a mask that we hide because of what we have, we have different thoughts. You know, we don't have the same run of the mill thoughts, we look at able bodied people, and sometimes with awe and envy. And all we can do is smile. Rather than, you know, we're envious of them, or we've been in awe of them, or we want to be liked by them, or we just want to fit in. And so our natural reaction is to smile. And then

> everybody says, oh, you know, you know, aren't they go lucky and with all the things they have.

Matt's extract is highly emotive, going beyond the written diagnosis, and has an effect that suggests a different, altered world view. Matt distinguishes between those who are disabled and those who are not, and the desire to simply fit in. This highlights the value and privilege of being able to do so and conform to societal expectations. "Our natural reaction is to smile" paints a picture of the management of the impact of CP, and a forced positivity which is interpreted by others as people with mild CP being relatively lucky. However Matt goes on to shed light on the reality of this…

> Matt: We play a survival game with that. without realising it. It's only when you get to a certain age, you certainly realise what you've achieved and how you've achieved it. Yeah. You know?

Conforming becomes something close to self-preservation, a subconscious need to achieve certain milestones in order to be accepted and to negotiate our place in an able-bodied world. This points to an alternative temporality and a trajectory that runs parallel to able bodied people, based on a conceptualisation of a binary of normalcy and difference (Spirtos and Gilligan, 2020). Polly summarised this as:

> Polly: it's about sometimes falling between two worlds a bit.

This confirms the idea that some people with mild CP manage feelings of liminality and in doing so become bodies on the margin. Belonging to a disabled and non-disabled group can produce different identities (Sandström, 2007).

This section has explored the ways in which people position themselves or are positioned by others to able bodied people or people with (mild) CP also. It has also pointed to how their feelings towards themselves, and their body can and do change depending on the social and physical space and begins to introduce the roles that normative positions such as motherhood can alter the way they perceive themselves. This raises questions around what the value of disabled bodies is considered to be, and also how this value is determined. Those I spoke to were aware of and in some cases internalised normative ideas around independence and successful social management of the body. This also needs to be considered however alongside the narratives of resistance that are beginning to emerge - these subjectivities are socially negotiated within normative environments which shape, and to varying degrees determine, the value placed on mild.

> Sue: Oh, my God. Yeah. I think to start with the thing that I resented the most was being and feeling so unable. You know, I

> remember learning how to get dressed. Now. I had no idea how my body was going to move. How I was gonna react. I have no guide, no book, I have no video saying, This is how you get dressed. When you're in a wheelchair. I have no clue. You know, I used to say to my parents, what do I do? And they're like, Well, I don't know because I'm not you and I'm not inside your body It was very trial and error. But it was a vicious cycle because I'm a perfectionist. I don't know if that's driven by my CP and by my feeling of, okay, well, I'm inadequate by design so I've got to be perfect in everything else. I don't know. But I am a perfectionist. So the idea of me trying something that I deem as simple as getting dressed, and failing is like, oh, and that feeling of, oh, I can't control my legs, or I can't control my foot. Why won't it go in this sock? Oh, it's so easy. Children get dressed why can't I?! You know, It was just this cyclical hatred of oh! And frustration and. Yeah, it was just I think I just resented feeling unable to be like, Oh, well, I can't go obviously, there's so much I can't do. You know, and I think feeling dependent gave me this ideology of Oh, you're like a baby…

Sue's recollection of learning how to get herself dressed independently (a reflection of the material reality of impairment too) whilst in a wheelchair gives insight into the work that often needs to occur after a diagnosis is given. This work, done by those living with CP, involves them becoming acquainted with their abilities, as well as how this can directly correlate with their sense of self and self-esteem. The material above speaks to the issue of a sense of lack of power over the body, a lack of control over how to move and use their own bodies. It is very interesting how they use the phrase "inadequate by design" which suggests an embodiment of disability and an acute awareness of ableist notions (Lola et al, 2013). Sue also explicitly recalls comparing her abilities as a teenager to those of a child, highlighting the tensions with growing up in a body with CP within a world which places such importance on physical independence (Moll, 2013). An able body held abilities that the participants either lost or never had, and their stories that led from this were often accounts in which the participants reflected on what they have now, how lucky they are compared to others, or conversely how this feeling has continued into adulthood. These stories seem connected through the idea of power. A power relationship not only between able and disabled, or patient and doctor (which are of great importance), but also of the power of mild CP held/does hold in both a mental and physical sense for them, especially when they feel they have to define their experience in relation to impairment. This is something that is difficult to escape from, but my examples of resistance contribute additional nuance to this.

Chapter summary

I have chosen to close my analysis with a discussion of liminality, as I feel that the discourse around liminality incorporates a recognition of societal boundaries (reflected in bodies) which are key to understanding the role and value of mild. Within this context, liminality brings medical and social boundaries around disability into discussion with each other. Someone with mild CP may be considered to be less impacted by their CP medically and yet face significant social disabling effects. It therefore has allowed me to highlight the often-overlooked impact of living with mild CP.

What has been learnt for people with mild CP?

- Ageing is not only a biological process, but it can also be hard to distinguish between secondary impacts of the CP and expected age-related changes. Having mild CP may make some people feel the need to push beyond their limits to 'keep up with' their able-bodied counterparts.
- The idea of mild may feel less applicable to describe their experiences as they age, hence there is a need for further support for people with mild CP to manage their bodies and balance any consequences of striving to 'fit in' with the able-bodied world.
- A trajectory of mild CP is not linear, and this is reflected in how their perception of the future may change according to their present body condition.

9. Summary of findings and overarching ideas

Hopefully the analytical threads presented here have demonstrated the importance of subjectivities, but also how these are socially negotiated and occur within a normative environment - an environment which still largely sees disability as a binary to able-bodiedness. Hence, there is a tension that arises for those with a mild disability - they are often bodies on the margin, and people articulate feelings of liminality. However, people are not simply powerless to this as demonstrated by the strategic use of mild and the narratives of resistance. Mild already held meaning to them (although this meaning is often fluid rather than static). This fluidity again is difficult to navigate in a world that is built around fixed normative assumptions and ideas surrounding impairment and disability. A mild diagnosis can therefore be enlightening or restricting (or both simultaneously). It lays out paths for people across their life course that have real consequences for how they are able to navigate the world (physically and socially), however these paths are negotiated. The key is permission to be a contradiction of the norms and to allow fluidity of experience that means people can be somewhere between able and disabled (this being socially and physically contextual) without being marginalised. Mild continues to have meaning beyond the interviews; why mild is important, the value of mild to individuals and an awareness of what forms and influences this value, for example the social context in which it is negotiated. It is also important to be aware of the restrictive norms that continue to form our ideas of disability/impairment and ability. A diagnosis is more than simply a biomedical categorisation, it is interpreted and lived by people in their everyday lives and drawn upon to make sense of their social as well as physical experiences as a disabled person. Mild is not something I am imposing on them; it is something which carries (different and fluid) meaning and value for them. Sociologically, it holds value in highlighting the thresholds of our societies' understanding of and response to impairment/disability - how and where and in what ways does someone become disabled or more able and how is this negotiated? There is a dynamic between disabled people and their social and physical world which can be explored through mild which hopefully allows for an understanding of this negotiation within prescriptive medical and social norms.

Main findings summary

- Mild CP is experienced within/through an embodied trajectory, which is set (negotiated) within normative environments which continue to marginalise disabled people.
- This leaves people with mild CP in a liminal position, negotiated or resisted through the management of the body and the engagement with (or rejection of) a mild discourse.
- The embodied element is key - there is a psycho-social element to impairment/the experience of disability that is not always acknowledged.
- Experienced on a trajectory - disability is not linear, nor a smooth transition (medically or socially) which is heightened by the CP.
- Disability is on an ever-changing continuum, albeit one that is dynamic and precarious.

Reflecting on these findings, I now need to introduce mild into discussions beyond this research.

10. Discussion points

Chapter introduction

Having now explored the key findings from my material, this chapter will apply these to the conceptual framework outlined earlier in the thesis. This is an important step to this research, as it will allow me to have a clearer understanding of where my research sits within current sociology/disability debates and highlight the concepts it brings to the forefront which hopefully make best use of both sides of the available literature. I will begin by locating my findings within the literature and concepts I highlighted earlier, with the goal to also highlight my findings' applicability to current sociological and disability studies, theoretical understandings of the body and lifelong conditions. However, given the invaluable role my participants have had in co-producing these findings, through the sharing of their personal narratives, I also wish to include a second discussion point; the applicability of my findings to them, in other words, seek to answer the question, what does my research mean for understanding the everyday lives of those with mild CP?

10.1. Discussion point 1: applicability to theory

This chapter will aim to return to the theoretical thought that has already contributed to this field to discuss this in relation to my empirical material. By bringing together scholars from Sociology, Disability Studies, Critical Disability debates, and the field of diagnostics, this shows the experience of impairment and disablement for people with lifelong conditions as complex and varied, and to a large extent temporal. The conclusion from this discussion will argue that it is more vital than ever to aim to understand how living with a lifelong health condition means experiencing both the disability *and* the impairment simultaneously, in order to better understand the everyday impact of mild CP. This is a conclusion that aims to build upon and move beyond the arguments that presume a linear association between an impairment and disability.

10.1.1. How does mild help to understand disability and impairment?

If it is immediately presumed that an impairment label does not at all times reflect the disablement experienced by an individual with a lifelong condition (Charmaz and Rosenfeld, 2016), (see discussion of disablement in chapter 2, section 2.6) then arguably the concepts of able and disabled also can no longer be assumed to be mutually exclusive states. Rather, as shown through the accounts of mild, there are temporal and environmental shifts which can determine how close an individual may feel to the able or disabled boundary. This suggestion is one that is being debated and discussed within the current academic literature, and where it can be helpful to draw across the work of disability studies (Thomas, 2004) and sociology (Douglas, 1970), as the social relational nature of disability shows how disability arises not only from the social environment that people may find themselves in, but also arises from the interactional mismatch between those with impairment and those without impairment (which is influenced to some extent by the visibility of the disability, (Thomas, 2002)). Disabled people are therefore marked as problematic compared to others.

This comparative practice is something which is identifiable through the participants' narratives. The physical body has influence on the social positioning of the body in society and in relation to others. These can be brought into discussion with foundational sociological scholars such as Durkheim and Mauss ([1903] 1963), Parsons (1951), to continue the discourse that is developing surrounding the reconceptualization of difference (see further discussion below). Again, this is a theoretical aim already somewhat established in the literature. The binary concept of the able and disabled body, and even the idea of disability, is built on an idea of difference. The aim is not to deny the presence of impairment, but rather to challenge the assumptions, on a societal and individual level, that can be attached to physical difference. This is also taken as a departure point for this research, as the focus on mild forms of CP provides an instant challenge to the binary notions of able and disabled. It incorporates the idea of severity and fluidity to presumed static diagnoses. Although the personal realities of living with mild CP have hopefully become clearer within my empirical material, this critical discussion of difference allows for a variety of experiences within the same diagnosis to be heard.

10.1.2. How mild helps to understand the relationship between impairment and disability?

In order to allow this space for the varied social impact and experience of a mild impairment to be told, disability could be thought of as being on a continuum rather than a singular and static experience. These theoretical ideas will be based in the literature of the sociology of diagnostics (Blaxter, 2009; Samuels, 2003) as well as once again Disability studies (Watson, 2002) to consider how disability is not only temporally contextual, but also contextual to the responses of others. Literature concerning concepts of the body and the social boundaries placed on them will also be discussed through the sociological literature of Shilling (1993), suggesting that the individual experience of disability cannot be understood entirely outside of the webs of societal assumptions and expectations encasing bodies more generally. Examining these ideas through the lens of 'the mild' and in adulthood, allows simultaneously the examination of both the disability and the diagnosis itself as having more fluidity and changeability than currently discussed. As the research will take a biographical approach to Cerebral Palsy, with a focus on adulthood, this also begins to challenge the idea that CP itself ceases to have impact beyond infancy and early childhood. Therefore, this chapter will conclude by drawing together theoretical conclusions, a potential focus for the research and the tangible impact of the research outside of academic literature. Centred around the idea of approaching the social and medical categorisation of CP with more awareness of its temporal aspects, and the weight of context when attempting to understand the everyday experiences of a mild diagnosis. This links back to the idea of disability being experienced as fluid and dynamic (Munger, 2011). There are temporal and environmental shifts that are experienced in parallel and therefore influence the experience of the disability (Shilling, 1993; Nettleton, 2013). Hence a diagnosis is not static and therefore neither can the disability be understood as being.

It is useful to return to the social model of disability, as this redefined the relationship between disabled people and their society. The model was a way in which to understand the interactions between an impairment and society and move away from the idea that the disability experienced by someone with an impairment, was the fault of that individual. The meaning of disability changed from being one of personal loss or inability, to one of social exclusion. In people's lives the change was seen through the removal of environmental and social barriers and a focus on civil rights for disabled people. Academic literature holds debates regarding the extent to which barrier-removal has been achieved in the reality of people's lives, and one which can be further revealed in empirical work. The focus for this section is the shifts and changes in theoretical thinking and academic discourse that occurred after the conceptualisation of this way of thinking through the model. Impairment and disability became two separate categories, distinguishable as physical abilities (impairment) and social exclusion (disability) (Shakespeare, 2016). Furthermore, disabled people become a distinct group from those without disabilities; the social model did significant work to highlight the oppression experienced by disabled people (ibid). An important consequence of this is how disability became the public presentation of people with illness and health conditions. A category of disabled and abled was still presented in society as a physical binary.

Categorisation was a key aspect of Durkheim and Mauss' ([1903] 1963) social theory and is an important theoretical springboard for this thesis. Durkheim and Mauss were primarily concerned with the origins of classifications and categories, and how classification is expressed culturally. Durkheim's work began with the assumption that humans are inherently social beings, and thus people maintain social and cultural categories, in this sense every group in society is distinct but relational in some way. This world view suggests how 'to be disabled' and therefore disability itself is a cultural category. Therefore, the social desire to understand how these two groups, disabled and able, relate to one another (how they are different) justifies their classification as such. When this is considered from the lens of a mild disability, this theory could be drawn upon to understand how the impairment itself is socially as well as medically classified. This research aimed to understand these social relationships further, by listening to the experiences of this socially organised system of able and disabled. Everyday responses to a mild presentation of CP may be expressive of, or at least someway relational to the cultural discourse of disability and impairment.

Thomas (2004) is a key scholar in the debates surrounding the meaning of impairment and disability. They also begin their work with an analysis of the social model, using it to highlight the way in which it moves the onus on the impairment to society as the cause of disability. Disabled people were recognised as an interactive member of society, for whom, similar to all people, the environment was not inconsequential. Importantly with Thomas, they also point to the need to consider the context of disability, and the variety in how disability and impairment can be in a given environment. Arguably, this environment can be both physical and interactional, and so it could be argued that disability can arise as much from interactional and societal discourse, as it can from physical objects in a given space. As discussed in the opening of this thesis, Thomas (2004) conceptualises this as disability being a socially relational concept. This idea was developed from the nature of the social model; it saw the world, and in turn the world's societies as being relational and thus so too was disability. It became socially universal rather than being individualised in people’s medical records and impairment diagnoses. Thus, this theory is vital to understanding how disability is surrounded and impacted on by social relationships between those considered ‘disabled’ and ‘non-disabled’. These relationships are, for Thomas (2004), the basis of exclusion and disadvantage in society. What can be taken further here is research into how the disabled people themselves feel about the notion of oppression, and how it may or may not manifest in their lives. Is the ‘mild’ aspect of their impairment a contextual or objective part of their identity, if it is considered part of their identity at all? This leads to discussions of the place impairment now has in people’s lives and in a modelled understanding of disability. Although a strong supporter of the social model, Shakespeare (2002), does highlight how the social model risks *assuming* oppression, rather than seeing disability as a *contributor* of oppression. Like gender or race, disability can instead be seen as a potential site for oppression, recognising that oppression is not simply arising from every non-disabled individual, rather it is an everyday experience written in the frameworks of society. Thus, it risks dismissing impairment effects (Thomas, 1999), that are the real limitations an impairment may place on an individual, implying impairment is not a problem (Crow, 1992; Shakespeare, 2006)

Whilst some participants rejected their impairment for the construction of their own identity, others celebrated their definitive space in the ‘disabled’ identity boundary. Of great theoretical importance to this research was Watson’s (2002) recognition of participants seeing their identity as a ‘reflexive process’ (Watson, 2002, p.516), one that was developed through their narrative. Thus, they did not necessarily sit within clear boundaries of disabled and non-disabled. Here there has not been an argument or expectation for a barrier-free society, but rather a society that aims to treat understanding as an everyday practice. To appreciate that acceptance goes beyond one lift, or one disability rights event, it is the awareness and willingness to accept the variety of impairment and the acknowledgement that the possible disablement that results from this is something that occurs within its own context and can therefore not be presumed to always be felt or experienced in the same way. This is not to argue for the absence of commonality or shared experiences, as these things are vital to understanding the social and cultural networks that surround disablement as well as the acceptance of impairment, but rather to acknowledge that disability is something connected to an ever-changing body and mind. As an individual moves through their lives so does their impairment. The impairment effects and disability can therefore be said to be embodied and socially situated. Mild can be seen to be an embodied practice, although it needs to be recognised how negation of a disabled identity can be limited by normative constraints (McLaughlin and Coleman-Foutain, 2018). In a society that is also ever changing, the everyday experience of disability (the barriers, exclusions, negative responses) must also change with it to aim to truly understand 'difference', and how this plays out in our normative world. Hence, this is continuing to challenge the assumption that disability is a linear experience and in doing so it challenges the way in which bodily boundaries and the binary of disability and able-bodiedness are reinforced. If this understanding of disability and impairment as having a dynamic and fluid relationship is taken forward, the question is raised regarding what happens to the diagnosis (which is presumed to be static) and how is this understood? Or in other words, how does mild help to understand the nature of diagnosis? This research could help to uncover the nature of the relationship between mildly disabled bodies, and other abled and disabled bodies, through personal narratives of embodied experiences. As demonstrated in the literature review, although diagnostic activity is a prescriptive process, there is a social element to diagnosis and as such the biomedical categorisations of bodily symptoms of CP can be seen as the product of the current medical classification of CP alongside the social understanding of the impact of disability (Blaxter, 1978). Although it may only be appropriate to identify this here, mild may also reframe the understanding of CP as a 'non-progressive' disability, as the participants'' narratives suggest that the trajectory of mild is intersected with changes in their feelings towards mild, which may challenge the static biomedical understandings of CP. If it is possible to challenge the notion of a linear diagnosis, it may be possible that we are overlooking aspects of the experience of living with mild CP, particularly as there are limited understandings in the current literature regarding how mild may carry through a lifelong disability. It may be, therefore, that the experience of living with a lifelong disability is possibly oversimplified or put another way may be creating a potential for misrepresentation of experience. My research may be relevant here to encourage a discourse around what language is needed when discussing a lifelong disability, and the choice to use or not use mild to describe their disability may enable people to articulate their experience to others. The discussion of liminality in the analysis chapters can be further drawn on here to expand on this idea, and to suggest that there is possibly an imperative to better understand the complexities of the experience of disability. Specifically linking back to the literature review, this should include how the expression of mild may involve a psycho-social-emotional element (Reeve, 2002). This element helps to explore how the psycho-social element may impact on the individual sense of security and there are clear links here back to the ways in which my participants expressed feelings towards liminality. In doing so, this further contributes to theoretical discussions regarding how this uncertainty is managed by those with CP in social interactions as well as internally in terms of their self-esteem and internalised oppression (Reeve, 2002; Charmaz and Rosenfeld, 2016).

10.1.3. How do people make sense of their own 'difference' (and how others may respond to this)?

At the centre of being able to understand how the experience of disability can change, is the ability to unpack and reconceptualise difference, made ever more important by the introduction of mild. This is not an entirely new concept in the academic literature, and thus relevant theorists will be discussed to determine how research concerning mild CP can help to contribute and develop these debates. In the context of disability, difference lies in the impairment and its move away from 'the normal'. Even where this may not be the case for disabled people (Watson, 2002) society, through its enforcement of bodily boundaries and expectations (Douglas, 1970), pathologise disability as abnormal (Thomas, 2012) thus assuming and maintaining the ideal of a 'normal'. There is arguably a further dynamic added through the lens of mild CP. Here the comparison of 'normal' is not simply between an able and disabled body, but rather a body classified as mildly disabled. Arguably, this label has value judgements attached to it by both the disabled person and the society in which they live. Furthermore, it raises questions as to where the boundaries lay for disabled and able, where does this mild identity fit in these distinctions? Is there a multiple comparison to both a body with CP and a body without? How will they consistently fit the 'sick role' often required of chronically disabled people to be legitimised by others (Parsons, 1951)? Scambler's and Goffman's work is a useful bridge between the diagnostics of a mild condition, and the potential societal and individual response to it. Scambler (2004)analyses Goffman's work on stigma, that provides sociological and anthropological theory to support the idea that a diagnostic label can lead to felt (presumed) stigma and enacted (actual) stigma. In Scambler's (2004) analysis, the fear of stigma is applied as justification for the concealment of impairment to 'pass as normal', and I would like to argue that mild becomes part of this process. This decision for non-disclosure, thus suggests how people are not simply passive to the disability they do, or may, face. Rather they may make decisions in the moment as to how they present their impairment. As discussed above, it is important to not merely dismiss the material actuality of impairments, and thus it could be argued that depending on the severity and manifestations of CP, the decision to conceal CP, and the extent to which this is possible, may vary. Therefore, focusing on mild CP brings nuance to these debates, as it is largely assumed that mild impairment can be more easily concealed (see immediately below for further discussion of ‘invisible’ or ‘hidden’ disabilities), and whilst this may be true in some contexts, it cannot be presumed that it will be the case for all spaces and times during the lifetime of a person with mild CP, hence the variability of visibility of mild CP can be explored through this research. This arguably situates the research within debates surrounding ‘hidden disabilities’.

Samuels (2003) makes connections between the language of ‘coming out’ in relation to sexual identity, and ‘coming out’ as being disabled where the impairment is ‘hidden’. Their work provides a critical analysis of the burden of proof (also referred to by Davis, 2005) placed on people with less immediately visible impairments (as the term ‘hidden disabilities’ would suggest that the disablement and disadvantage is hidden rather the impairment itself, this provides evidence for how disability and impairment can become conflated with one another). They must prove their legitimacy to be able to be contained with the able or disabled boundary in society. Therefore, disability is a discursive practice as much as it is, for example, the result of a physical barrier. The variability of mild conditions could mean that an individual with a mild form may have decisions to make as to whether to immediately reveal their impairment to those around them. The empirical data collected from my research will hope to better understand if and how the choices that are made by those with mild CP, such as how they frame their own impairment, have an impact on or are influenced by the disability they face. Those with a mild impairment could feel the need to reveal or to conceal their impairment to maintain continuity between the way they are deciding to present themselves and how their impairment fits into this or not. It is important to note here that to conceal an impairment does not mean to deny its existence or the existence of disability. What will be presented below is a suggestion for reimagining the ontological basis of disability, rather than to say disability can be there or not, it may be more helpful to understand disability as a fluid experience (Shilling, 1993). If it is to be caused by society it must change with it; it could be seen to be on a continuum. To close this introductory section to my discussion, where I have aimed to resituate key aspects of my findings within existing literature, I would like to develop initial thought surrounding the idea that empirical data on the life course of adults with a mild form of CP can contribute to the theorisation of disability as being on a continuum. Disability, as has hopefully begun to be shown above, is largely still considered to be a fixed state, the scale and nature of which can be presumed from knowing someone's diagnosis (Shilling, 1993; Brown, 1995). This arguably does not fully consider the contextual nature of disability, and the power relationships within society that shape relationships between the disabled person, their environment, medical settings, and people in their everyday life.

The idea that disability is on a continuum is not a completely new concept; there are foundational thoughts in the work of Thomas (2004) and Shakespeare (2016), but a focus on mild CP brings further light to this idea, as well as building on these theories. It has hopefully highlighted the more chaotic relationship between impairment and disability on a larger scale (a mild impairment does not presume a mild disability), and also in the smaller scale of people's everyday lives and encounters with their social and physical world. Specific spaces and other individuals may shape or impact on the disablement that is felt by the individual, although the impairment will remain the same. Blaxter's work on diagnosis is useful to draw upon, as their analysis points to the co-production of diagnosis; a diagnosis is the product of medical imagery, doctors interpretation of that, and the felt knowledge of the patient (Blaxter, 2009). Therefore, a question that could be asked of the empirical data may be, is the use of the phrase 'mild' sometimes a part of, or evidence for, the co-production of diagnosis? Could society also be brought into this idea of co-production? Do people's choices to present or note their impairment as mild, and people's responses to this, co- and reproduce norms and assumptions of the relationships between impairment and disability?

Taking this idea further can support the argument that disability is not a universal state, it is something that is temporally, socially, and individually influenced, meaning that it is both negotiated and contingent. Furthermore, it may demonstrate how the body becomes a site for the evidence of impairment and therefore disability. This is important when work such as Davis (2005) is considered, as they highlight the point that 'invisible' disability does not refer to something which is completely unseeable, rather it can be made invisible to certain people in certain circumstances. Given the variety of 'types' of CP which have been discussed in this thesis, visibility is something which some people might have a certain degree of selective discretion, while others may find it difficult or impossible to 'conceal' their impairment. This can arguably be applied to 'less-visible' impairment also; where impairment is not of a severity to be directly opposing the norms of an able body, they arguably remain in a space of liminality, a space which I hope to show as being a vital source of analysis regarding power relationships in medicine (Oliver, 1990), the categorisation of disability and illness within a diagnosis, and the fluidity of the everyday experience of disability and impairment (simultaneously or separately) for individuals with a mild condition.

Therefore, this section has aimed to bring together the key ideas from my findings and applied these to the existing conceptual ideas I began to outline in my conceptual chapter and literature reviews. It is important to know where my research will be able to build upon and hopefully contribute new ideas to sociological theory, as much of the foundational ideas around the relationship between impairment and disability will be helpful to bridge the understanding of the complex and sometimes on the surface seemingly contradictory experiences of mild CP. The following section will highlight a second key discussion point to further expand on this; the applicability of my research findings to everyday life. It has remained vital to me that I am able to share not only new concepts for theory but also be able to say what this may mean for the everyday lives of the people I spoke to. These interviews were for many the first time they were able to share their experiences and be listened to, where they may have been overlooked with less conforming presentations of impairment (Calder-Dawe et al, 2020), or even where they may have been overlooked in deeply personal experiences such as their experience of pregnancy and motherhood (Frederick, 2014; 2017).

Hence, the embodiment and self-management of the body, disability and risk contains a psycho-social element, which has a significant influence on the negotiation of managing a disabled body within normative environments. This points to an exchange of meaning between the body, the person and the environment.

10.1.4. Conclusion

There is a subjectivity of the interpretation of symptoms as ‘mild’, which problematizes the applicability of the term mild as a classificatory tool. This will be interesting to explore in relation to the purpose of classification when using the word mild. It can be asked, for example, what is the value of using mild given that it is so subjective? This subjectivity, however, could imply a more personal value, in which ‘mild’ is used to give meaning to experience. Here, I am introducing a sense of trajectory and an understanding that meaning is negotiated over the life course. This requires agency, realised in a social context that is also looking to define experience. This is perhaps where the tension of the use of mild occurs and is consistent with the idea that mild can hold multiple and possibly conflicting meanings. This contributes to the discourse around the (in)visibility of disability and the way in which this may be misunderstood or misrepresented (Calder-Dawe et al, 2020) in a way which does that align to how the individual with CP wished to present themselves, which could lead to their disability becoming further stigmatising or their identify challenged (Goffman, 1963).

My work here is attempting to lay the groundwork for a language in which people can express themselves in ways consistent with their experiences. This would suggest the importance of the word mild and helps to establish the value of mild as a conceptual device, to understand disabling experiences. There are positive aspects (it enables individuals to locate and give meaning to their experience in a way that is relevant to them) but also more negative ones, which enable the ‘dark side’ of care to emerge, in which mild can be used by others to define a person’s experiences in ways they did not intend. This is part of a creative dynamic, which requires negotiation, again pointing to trajectory and life course, along with fluidity, something which has not yet been explored in relation to mild CP, and therefore could be currently overlooking the value of mild, as a conceptual device, to understand disabling experiences.

What remains is a discussion of what this means for the everyday lives and social policy of those living with mild CP. Locating the empirical experience of those with mild CP amongst relevant conceptual understanding in (medical) sociology and disability studies helps to develop an understanding of disability, while offering a strategy to ensure narratives do not become the basis for discrimination but enable people to voice their experiences in ways relevant to them.

10.2. Discussion point 2: applicability to everyday life and social policy

This second discussion point will look at what my findings mean outside of academic discussion, and within the everyday lives of those living with mild CP. This will allow me to ensure that there is potential for my research to expand understanding of mild CP and create an acknowledgement of the barriers they may face whilst not undermining their achievements as individuals. I will close by briefly reflecting on social policy contributions and the implications for the care of adults ageing with CP.

10.2.1. Challenging the binary of able and disabled: what is the value of mild within a spectrum of disability?

The value of mild for those with CP and in social spheres also includes reflections on the value of understanding mild for clinicians and other stakeholders such as researchers. This is where it can derive different meanings. Clinically, mild helps to distinguish between the severity of CP, potentially for prioritising access to medical and social care as part of a diagnostic process. Outside of medicine, the use of mild is complex. It seems to be used as a point of comparison. It highlights identity politics and the vulnerability of the boundaries between able and disabled. Being a categorisation of experience, in certain spaces using mild takes away choices – it categorises advantageously and disadvantageously, depending on context. It can take away the choice or ability to discuss the effects of CP, as they are often already assumed to be known. Arguably, mild was not needed in the past as it is now. Those with mild CP, would possibly either remain undiagnosed or be treated in the same way as severe cases. This is no longer possible (or arguably desirable), and choices are made as to access to care and such like. However, mild can provide a way for people to articulate their experiences. Each person has their own story and therefore their own personal and bodily relationship with ‘mild’, and each person I spoke to told that story in their own way. The complexity of mild allows for contradictions to be embraced within and between each person’s narrative. Mild can also potentially be considered as a boundary for reflection. What mild means now can be compared to what mild may once have represented for people individually as well as socially (and the social and historical contexts that have influenced any changes).

Because mild is not at either end of the binary it is left open to interpretation. With no script, there is a wider opportunity for people to challenge, negotiate, and question (this can be both restrictive and empowering). Disability will not improve until people allow others to have good and bad days and allow them to speak to their own experience, including experiences which may seem contradictory when only considered in a biomedical sense. Therefore, mild and the use of the mild discourse adopts different meanings, messages and images throughout the life course.

10.2.2. Ageing with mild CP: the fluidity of impairment effects and the changing nature of a mild disability

There is a clear shift for most people ageing with CP as they tend to struggle more with age. It is important however to not oversimplify this connection between normative ageing and their CP. There can be shifting and competing temporalities as people age, which means that the physical and social impact of their impairment and how this may affect the disability their experience can change. The meaning they give to their experience may change too, as they reinterpret previous experiences. This brings up the question as to the ontology of ageing, specifically, what does it mean to age with mild CP? This is a question that is largely yet to be asked before this research. When working with individuals in care and medical settings it is important to acknowledge the subjectivity of ageing and allow them to reflect on their own experience and personal biography in relation to their CP to allow for a clear picture of current and possible future struggles. ‘Mild’ is the interaction of the social, medical, and biomedical; it is a crossroads through which to understand experiences from a varied and nuanced way. This includes allowing space for them to share potentially negative experiences of ageing with an impairment – negativity and positivity don’t have to be mutually exclusive. Mild conditions are not allowed to be disruptive, and this needs to be relooked at. Mild can enable an individual to give meaning to their impairment, in ways that makes their disability less disruptive but also enable broader discursive practices to make disability safe and less threatening. A key place to start with this is to listen to how those with CP speak of their lifelong experiences with CP. This journey is far from linear, and the impact of their impairment and the severity of their disability can often change over time and place. Therefore, the normative ideas of what it means to become and live as an able bodied or disabled adult may not fully encapsulate their experience.

10.2.3. Rewriting scripts (the adulthood experience of mild CP)

The path towards adulthood is mediated by personal, social and medical influences. For everyone, reaching adulthood is a negotiation of the self and social expectations, and negotiation is made ever clearer for a disabled person. It is commonly the case, that at the point of diagnosis, a prediction is made from the clinician as to what the individual will be able or unable to achieve across their lives. The usual social and physical milestones that are anticipated for able bodied people may be presented as different or altogether absent for those with CP. Therefore, the usual scripts for adulthood, along with their normative milestones, may need to be challenged or rewritten by those living with a disability. Hence this discussion point helps to highlight the normative milestones, whilst also seeing how achievements and experiences across the life course are often linked back to a diagnosis. Importantly, there are feelings attached to this, how they feel as a disabled person (and what this means for each individual). There is a moral element found in the choices made at the (retrospectively) transitional periods such as career and parenthood. Comparison is key here, and there is an opportunity to look at the future of those with mild CP, the expected future (from others), and possibly even more importantly how this is managed in relation to the future that they perceive for themselves.

Something which is highlighted through lived experience of early acquired lifelong conditions is how the future (or perception of it) often impacts the present, in a way that may not be seen for an able-bodied person. The boundaries between disability and age can become blurred, and changes or worsening of symptoms can be difficult to assign to biological ageing or the consequences of growing older with CP. So, it is important to acknowledge the real impacts that CP may have on the ageing body, whilst at the same time making claims that the scripts of adulthood will by default look so vastly different from those of able-bodied people. It is also important to think about the consequence of a late diagnosis of CP, potentially more of an occurrence where the disability or impairment presents as ‘mild’. I spoke to people who had a misdiagnosis or a mismanagement of a diagnosis, leading to a delayed understanding of their body. Understanding the potential future impacts of CP, whether physical or social, is arguably made harder to predict where normative clinical outlooks for CP are often based on more severe impairment. There is a lack of a medical and social script for mild CP, hence there is a complexity which highlights the common but problematic positioning of disabled people as binary to able bodied people. There is an assumption that what able people can do, disabled people cannot. This returns to the ways in which a mild diagnosis or identifying with/drawing on the mild discourse can be both limiting and empowering – it opens ways for people to be able to subvert the expectations for disabled people, and yet in doing so people carry a complexity which is often not well received within society.

Something important to reflect on is how medical and social complexity is often juxtaposed to the way in which CP becomes part of the 'norm' for those with CP. Whether created from a strategic rejection of able-bodied norms or not, new norms can be created. It is important to think critically about where these norms may become prescriptive, particularly where they are created in response to social or interactional experiences with others. The presentation of mild may be influenced by the way individuals feel they will be perceived by others. The lack of a script for how to navigate their own disability/body/identity may also be linked to the fairly common lack of interaction between those with mild CP. This suggests a value of shared experience between a group of people who, through the nature of 'mild', commonly do not interact with each other. Therefore, there is less opportunity for seeing how other people navigate a similar personal or medical trajectory to themselves.

Therefore, to summarise thus fat, to be disabled is still very much understood in relation to being able, rather than in its own right. Those with CP may resist assumptions of what it means to live with CP through the discourse of mild CP. Although, mild is not clearly categorised medically or socially, and therefore if people use mild, they may open themselves up to more confusion, questioning or challenging from others. Social scripts are an important element of social interaction, though not always tangible, the lack of a script can cause feelings of liminality for those with CP. A diagnosis is socially mediated, and can be of great personal significance, particularly in relation to the articulation of their experiences (whether they conform or reject the social assumptions and expectations attached to the diagnosis or not).

Reframing care in adulthood

The giving and receiving of care are often a site for this social mediation, being fraught with expectations of where care should or should not be needed for normative bodies. Consequently, exploring the space between individual subjectivities and the discussions that attempt to ascribe them can assist our understanding of the circumstances through which care is realised. Considering the ways in which those I spoke to were able to articulate their experiences of and feelings towards needing care across their lives, suggests that there is scope and indeed a need for a reframing of care from one based on dependence, to fluid interdependency. As a higher level of physical care, needs were not consistently related to a lack of personal independence, in the same way that independence was not automatically understood in its physical forms.

Chapter summary

It therefore is becoming clearer that a new set of language or set of understanding is required, which encompasses this mild discourse. This can help to challenge the epistemic injustice faced by those with CP, as they are continually dismissed or misunderstood and largely missing from academic literature (this again points to the importance of their narratives). It is increasingly questionable that the current means of classification alone are sensitive enough to more fully include these experiences of adulthood. Mild is a relative term, meaning it is often understood in terms of perceived higher severities of CP, and it is often used in a comparative manner, often guided by the moral compass and binary understandings of disability and able-bodiedness within our society. As such, the majority of my accounts included an element of systematic oppression, experienced throughout their lives and manifesting in various ways. Attempts to avoid this have contributed to the strategic use of mild, and adds a performative element to mild; there is an interdependency on their use of the term mild and the way in which they are able to ensure that that body behaves. Knowledge of the full extent of these complexities and intricacies of everyday life with mild CP are currently lost due to a lack of academic focus on this. The next and final chapter will conclude this thesis by reflecting further on the originality of the research, where the scope is to further exploration, and what I may have wished to have done differently.

11. Concluding chapter

This final chapter will be a space for me to both reflect back on my work and look forward to where the research may remain relevant for future dissemination opportunities. This chapter ensures that my research has maintained its originality, in line with my initial research aims. It will also highlight areas that were discussed unexpectedly. This chapter is something that can be used to reflect a final time on my role as a researcher and ways this has had an impact on the research.

11.1. Reiterating originality

This research contributes to debates surrounding ‘visibility’ of disability by drawing on theories associated with critical disability and the sociology of disability. It provides understanding of diagnoses as socially negotiated and embodied experiences, beyond clinical (and quantitative) categorisation. This research addresses an area of academic and medical importance, as by using participant voices, the research can reflect upon and critique social policy by exploring potential impacts on people living with lifelong, early acquired neurological conditions.

In its most basic form, the aim of this research was to explore the adulthood experiences of mild CP. This is an area of CP and disability more generally that is yet to be explored in any detail or specificity. Further originality of my work lies within my aim to locate this discussion sociologically and connect it to the life course. My focus was on speaking with adults with a diagnosis of 'mild' Cerebral Palsy (without an intellectual disability) through narrative/biographical interviews. These narratives were drawn upon to ask questions of the social and political positioning of mildly disabled bodies. To my knowledge, these questions are yet to be focussed upon, and for those I spoke to, the interviews were often the first opportunity they have had to share their experiences beyond their personal community. Theoretically, my research provides original thought to the following core tensions within the sociology of the body/disability. When discussing order and disorder, my research has shown how bodies can be changed and altered and socially influenced all within their own trajectory. In this way, my research has confirmed the centrality of the body to identity, but again in a way which allows for bodily change. There is plurality to the meaning and use of mild which is reflected in the instability of a mild identity; mild can carry multiple meanings in different environments, further suggesting that disability can also be placed on a continuum. Currently those that identify with the idea of mild are largely invisible bodies, in varying ways they can become on the margins of both able bodied and disabled people's worlds. The impact of this can be heard within the accounts I share, contributing original thought to negotiating a lifelong disability trajectory within a world still largely designed to accommodate able bodies.

My accounts also explored topic areas that I did not entirely anticipate would feature so significantly such as parenthood, or more specifically motherhood, and the way in which this role had a significant influence on the way in which women negotiated the world. Although there was not the scope to explore this in full detail during my analysis, I also wish to highlight the role of parents and family relationships in the way in which this was an ongoing influence on the ways in which people interpreted mild within themselves and the ways in which they responded to this. This is an area of the accounts which may become a useful area to explore where there would be more space to focus on this, within academic papers.

11.2. Co-authorship of the interviews and making sense of mild

There needs to be some recognition within the analysis chapters/sections of the co-authorship of interviews, especially as the interviews were based largely in conversation rather than ordinary questioning. As well as an openness regarding my own diagnosis, and the times in which participants drew on shared (or differing) experiences between them and me, They also used phrases such as “people like us”, “I don’t know about you, but”, and directly asked me about my ability to walk. My level of involvement differed in each interview depending on the needs of interaction, but I think it is necessary to recognise the subjectivity of the interviews, and thus the influences of feelings and opinions that will be valued and prioritised in the analysis. Recognising the multiplicity of mild is key to understanding what mild means to people living with CP and the way in which it is employed. The contradictions and confusions surrounding mild are to be expected and there is a layered complexity to a mild ‘diagnosis’ which recognises the way in which a diagnosis can have both a therapeutic purpose but at the same time can reinforce boundaries, making it ever more important to analyse the complexity in context.

11.2.1. A final reflexive reflection: emotion

I have reflected throughout this thesis on the potential emotions held within the interview, here I would like to briefly acknowledge the personal impact of hearing people articulate feelings and experiences that I have experienced versions of myself as the author. Participants' voices need to be prioritised, but it is also vital to give acknowledgment of the interactional environment of the interviews.

> Holly: if somebody came up to you in the street and caused the amount of pain that I’m in, you would have them for GBH. [I: mmm]. Erm and if that this amount of pain was metered out to prisoners from the moment, they woke up to the moment they went to sleep for twenty-six years we would call it torture and an abuse of human rights,
>
> Holly: Yeah-I only ever tell people who are going to understand [I: mmm] like my neurology, care advisor erm, that, ehh I wish I hadn’t been born I’m in so much pain [I: mmm] for so long that I wish I wish that when they had revived me that they hadn’t done it. [I: oh right]. And. I’d definitely be better off dead, but I don’t have the guts to do it myself-if I-I always say to mm counsellors and people that ask that ‘yes definitely I would be but don’t worry I’m not going to do anything [[slight laughter]] because if I’d have had the guts to do that I’d have done it when I was twenty [[slight laughter]]
>
> I: It’s understandable to endure [Holly: yeah] that amount of pain for so long [Holly: yeah] it’s not-it’s not a completely irrational-like it’s not irrational or illogical to come to that like that conclusion I don’t-I don’t think.

This interview and aspect of the interview in particular had a significant emotional impact on me. It felt as though a mirror was being held up to my future, particularly as chronic pain is something I currently live with. This reminded me of the value of narrative interviews, but also the impact they can have on the researcher as well as the participant. The insights that they produce, although extremely valuable, can carry an exchange of emotions, as well as knowledge, from the participant to the interviewer. I feel that having been guided through key moments in their narratives of mild, I hold a degree of accountability to advocate for those who have similar experiences. I therefore feel that it is important that I am able to contribute to lay community debates and not only debates in academia.

11.3. Dissemination opportunities

I anticipate clear dissemination opportunities from this research, namely papers focussing on the idea of mild and the role of the diagnosis in relation to more traditional classificatory terms, and how individuals perceive themselves. I also believe that there needs to be a focus on the way in which those with mild CP appear to be labelled by the medical and social systems and then lost within them, particularly once they have transitioned to adulthood.

I also believe that a paper on the meaning of mild and fluidity of this and CP more generally would hold academic and social value, to be able to challenge our notions of the reality of a non-progressive lifelong condition. Linked within this are the personal circumstances that may have significant influence on the way in which individuals experience the world, for example in examples of motherhood. This is a developing area of study for women’s health for women with CP, and I believe that the material I have presented in this thesis could contribute to this.

I believe that there is also scope for discussion of the role of parents in my dissemination material, with a focus on the application of care throughout childhood and adulthood (with both parents and romantic partners) and the relationship that may or may not have to feelings of (in)dependence. On a much larger scale, this topic would be particularly interesting as a comparative study of other countries, to really begin to understand the intersection of government, social care provision, the individual and their support network in determining the everyday care experiences of those with mild CP.

11.4. What would I have done differently?

The opportunity to speak to others who lived outside of the UK is something which had I had the scope to do so would have been very interested in pursuing, particularly as one of my participants was not a UK national, their international experiences could not be fully explored or compared as the focus of our conversation was not a comparative one.

With my remaining interviews I also reflect upon the benefit of follow up interviews, as I believe that these would have allowed me to focus in more detail on certain areas of people's accounts once they had been identified as one of the key running themes amongst the other interviews. In the interest of time and also as I had not outlined this as a possibility in my recruitment material I did not feel this was possible, despite several participants articulating a willingness to continue to discuss their experiences in more detail with me.

That is not to say that the conversations I had were not detailed. I have considered the idea of focussing on recruiting a lesser number of participants to be able to present their narratives as a whole in my analysis to allow me to consider each element of their experiences more closely, however, the space within this thesis did not allow for this.

I am however very grateful for those who took the time to speak with me, their insights have been invaluable. I was emotionally impacted upon by the interviews in a way that I had not fully anticipated, and my role as a researcher with CP played a much more significant part in their decision to take part in the interview than I had considered that it might. This highlights the importance of disabled researchers carrying out research *with* disabled people, as this helps to create a uniquely productive interview environment.

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Appendices

Appendix 1 - participant information sheet

THE UNIVERSITY of York

Provisional Study Title: "A narrative exploration of the embodied experiences of living with 'mild' Cerebral Palsy".

Participant Information Sheet

Hello,

My name is Emma Collins, I am a PhD student researcher in the Sociology Department at the University of York. I am researching experiences of living with *mild* Cerebral Palsy (CP) into adulthood.

I am looking to interview adults aged 18+ to explore their experiences of mild Cerebral Palsy. It could be that you have been given a medical diagnosis of mild CP, or you may feel that you have a milder form of CP.

I will outline below the key information you need to know before agreeing to volunteer to be interviewed for my research:

Previous research suggests that there is a lack of knowledge of the everyday experiences of adults with CP, and even less so on what it means to live and grow older with a milder form of CP. I have mild CP myself, which has led to my interest in this topic.

I aim to explore this further in my study. I am very interested in listening to your own experiences of your disability. The experiences you tell me about will be used in my PhD work, as well as in academic articles. I will **not** use your name in anything I write, even if I quote something you have told me.

If you agree to take part in my study, the interview will take place online using, for example, Zoom, Google Meet, or Microsoft Teams, depending on the video call software that works best for you. The interviews will last up to an hour long. I will be able to do follow-up interviews if you would like to tell me more after your first interview.

I will use an external recording device to record what you tell me. Devices will be secured and password protected, and information saved in a password protected file, seen only by me. The interview transcripts, as well as any information you give me, such as your name or contact details, will be kept securely according to the Data Protection Act 2018. This research has been approved by the University of York ethics committee. You are able to contact them regarding my study using the contact details in the box at the end of this document.

You can choose what you tell me and what we discuss, and you can withdraw from my study for **up to three months** after you have been interviewed. After I finish my PhD your data may be archived anonymously for **a minimum of ten years in a secure data archive**, according to University policy, if the interview transcripts are considered to have a long-term value.

Questions you may have:

What will I need to take part in the study?

You will need an internet connection and an electronic device to take part in the interview. You can choose where you do the interview, but a quiet and private space is recommended so that you are able to talk to me as openly as you feel comfortable and able to do so.

If you are using a desktop computer or a laptop, you usually do not need to have downloaded Zoom to your device, as you can access the interview through a private link using your web browser. However if you use a tablet, mobile, or other similar device you will usually need to download the Zoom app for free.

For Google Meet you will need a free Google Account to access Google Meet. You can access video calls through the Meet Mobile App, Gmail Mobile App, or a web browser if you are using a desktop laptop or computer.

Accessing video calls on Microsoft Teams will require the Teams Windows app for any device, but you do not have to have a Teams account.

I will be able to advise further if you need technical support with accessing the interview online.

What if I have accessibility needs?

As I have CP myself, I am anticipating the possibility of short breaks during the interview. I am also going to enable auto-generated captions (speech recognition technology will automatically create captions as we speak to one another) during the interview.

I am aware that I may not have anticipated all accessibility needs. **Please email me (emma.collins@york.ac.uk) with any concerns, or if there is anything I can do to help make your interview more accessible for you.**

What if I change my mind after the interview?

It is completely voluntary to take part in my study. If you wish to withdraw from the study, you are able to do so for up to three months after your interview.

What will happen to the results of the study?

The results of the study will be published in my PhD work. This work will be open to the public. Results from the study may also be published in articles, or other publications. You will also be offered a summary of the findings of the research. Your name will **never** be used in any publication of the results, and **no information will be used in a way that could reveal your identity or break confidentiality guidelines**:

What are the anonymity policies?

Your interview data will be anonymised. This means that none of your information or interview will be used in a way that could identify who you are. In order to achieve this, your name will be removed from the transcripts and replaced with a pseudonym. With your permission, I might include information, such as your age or gender identification, alongside extracts of your transcript in the final piece of work, to provide relevant context to what you say. Importantly however, this information will not be used if it could risk identifying you. Care will be taken when publishing material to ensure that none of your data can be used to identify who you are in any way.

What do I do now?

If you would like further information on the study, or wish to take part in the study, please email me using this email: emma.collins@york.ac.uk

Emailing me or asking questions does not mean that you have to take part in the study. Taking part in the study is completely voluntary.

If you have any further questions please see the contact details below for myself, the Head of the Sociology Department, and my academic supervisors:

My email address: emma.collins@york.ac.uk

Head of the Sociology Department, Professor Nik Brown:
nik.brown@york.ac.uk

My academic supervisors, Professor Karl Atkin: karl.atkin@york.ac.uk
Professor Nik Brown: nik.brown@york.ac.uk

Professor Tony Royle, the Chair of the Faculty Ethics Committee (the ethics committee accessing this study): tony.royle@york.ac.uk

Appendix 2 - further explanation of the self-defined nature of mild and my positioning as a researcher

Target audience for the research: what I am meaning when I use the term 'mild', and why 'mild' is being used as a self-defined term for this research

The research is interested in how people define 'mild' within the context of CP, by exploring their own definitions, as they move into and through adulthood. This explains why mild is being used as a self-defined term, as the experienced reality of mild CP may affect people in different ways.

Not having a concrete definition has also helped me be mindful that what mild CP means for me personally, (as I have mild CP myself), may not be the same for others. I am interested in people's own definitions and how their CP impacts on their day-to-day life, including in the past and possibly the future.

Providing that someone is over the age of 18, a UK resident, and either have previously been given a diagnosis of ‘mild’ CP and/or feel themselves that they have a mild form of CP, they would be the target audience.

I am reluctant to specify a GMFCS number, or give a set of criteria, as I understand the word ‘mild’ is subjective and the research’s aim is to understand the experiences of those with CP, rather than impose external definitions, which may not have a great deal of meaning for a person lives their life. Therefore the research will be drawing from what people say to define what mild is, and importantly for the research, what this means throughout people's lives.

The interviews will be led by the person with CP and explore how they feel CP impacts on their lives. This is deliberately broad as again I do not want to make assumptions about what is important to the person. I want to get a sense of person’s life by asking them to share their experiences. This could be social or emotional reflections or perhaps, a concern with the physical impact. This may also include changes to how CP is experienced throughout people’s lives. I am interested in the person’s story.

There is little research exploring adult’s experiences of CP, as much of the previous works focused on childhood. This explains why I am doing the research, and taking a narrative and more broad approach.

Appendix 3 - initial interview topic guide

Key focus: stories/experiences of life with mild CP.

Research Questions (RQ)

1. What are adulthood experiences of mild Cerebral Palsy?
2. How are ‘mild’ diagnoses constituted in medical, social and personal spheres?
3. To what extent are diagnoses of mild Cerebral Palsy contested?
4. How do people living with ‘mild’ Cerebral Palsy manage and negotiate their disability, body, and identity?

Key topic areas:

- RQ 1: adulthood (changes, past, future, socio-historical and personal context)
- RQ 2: how is the mild diagnosis understood (for the individual [and their network], medically [or medical interactions/settings, physical impairment and disabling impact], socially [discussion with others, the responses of others, the environment, buildings, as a disability]).
- RQ 3: How do understandings of ‘mild CP’ differ (between medical staff, those with CP, and the wider public), any changes to understandings.
- RQ 4: The day to day, everyday experience of mild CP. Where CP sits within their self-identity, and production of identity (past and present). The response to place, space, and other people around them (disability). Feelings towards their CP and potential or perceived changes to this.

Interview stages:

PART 1: introduction to the topic, focus for interview, interview admin

Introduce the key focus, explain in accessible language the purpose of the interview – to gather stories and learn about their own experiences of living with mild CP, with a focus on adulthood.

Explain the nature of the interview in accessible language - taking a narrative, meaning that I don't have a list of specific questions to ask, rather I'd like to hear your life stories. The interview will be recorded, and I may make notes, this is to remind me of key points and/or as a reminder to myself to return to something you may mention later in the interview.

Ethical practice: reiterate to the participant the ethical practices of the interview: they are leading the interview with what they feel comfortable talking to me about. I will suggest a break around halfway for the both of us. But they can stop or move onto a different conversation topic when they feel the need to.

Consent etc (record verbal consent).

PART 1a: 'warm-up questions'

What made them interested in taking part in the research? What are they hoping to get from the interview?

REMEMBER TO TAKE A BREAK

PART 2: eliciting the narratives

Initial questions:

In your own words, can you tell me what the phrase 'mild CP' means to you?

How do you feel this applies to you, and your experiences of CP?

- Have they always felt like that? Or has it changed over time? What made them feel differently?

Topic areas: (follow the direction of the participant, use prompts where needed, return to interview question ideas to keep on track)

How did you first become aware of having mild CP?

- What did they feel about this?
- Did they think about what this might mean for them?
- How did those who told you react/describe your CP to you? (Did it make sense to them? Does it make sense now?)

What does the term 'being disabled' mean to you?

- How does it fit with your own experiences of living with CP?

How would you describe to someone not in your shoes, how it feels living with CP?

- Have you always felt the same?
- Has there been a significant moment / person in their life to influence how they feel?
- Typical day in your life? ‘Bad days’ (how do they experience bad days?)
- Has there been any point in your life why you would have described how it feels differently?

When you were younger/a child, what did you imagine adulthood to be like?

- How does your current experience of adulthood compare to what you imagined?
- Was it ever suggested to you what adulthood might be like for you?

Thought exercise: can you describe to me what an accessible space is to you?

- What makes a space perfectly accessible?
- Can you recount spaces that have been inaccessible to you, and what made them inaccessible?

Do you have any standout memories of how others have responded your CP? (whether you chose to mention it to them or not)

- Do you recall times when you have made the decision to tell someone that you have CP?
- (connect to probe on disability – how disabled are you made to feel??)
- Why did you feel like you had to tell them?
- Can you tell me how this went?

(if not mentioned during the interview, ask them to recall any notable interactions with medical staff etc).

Part 3: follow up/clarification reminder

- Go back to notes, check understanding etc

Part 3a: reflection questions (future)

Reflecting back on your life experiences so far, what advice would you give to someone starting a similar journey to your own on living with mild CP?

- What would you want them to know?
- What have you learned?
- What would you want them to know now, that you knew then?

What is the one thing you wish people (I) would ask/consider or know about your CP?

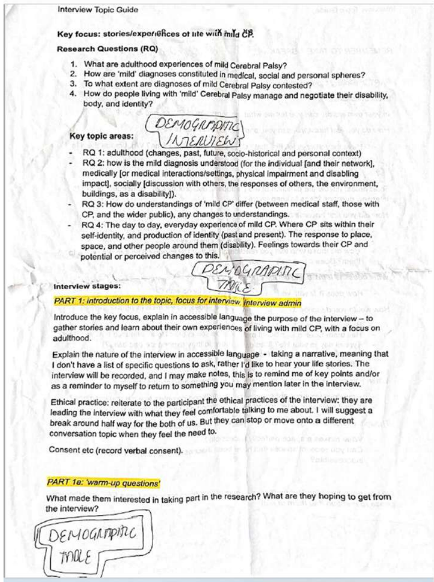
Demographic information (consent to use in analysis)?

- age, gender, rural/urban, CP type etc

Part 4: closing of the interview, reflections (self and of interview)

- Make notes after the interview
- Make notes on how I felt during and after the interview

Appendix 4 - adapted interview topic guide



Interview Topic Guide

Key focus: stories/experiences of life with mild CP.

Research Questions (RQ)

1. What are adulthood experiences of mild Cerebral Palsy?
2. How are 'mild' diagnoses constituted in medical, social and personal spheres?
3. To what extent are diagnoses of mild Cerebral Palsy contested?
4. How do people living with 'mild' Cerebral Palsy manage and negotiate their disability, body, and identity?

DEMOGRAPHIC INTERVIEW

Key topic areas:

- RQ 1: adulthood (changes, past, future, socio-historical and personal context)
- RQ 2: how is the mild diagnosis understood (for the individual [and their network], medically [or medical interactions/settings, physical impairment and disabling impact], socially [discussion with others, the responses of others, the environment, buildings, as a disability]).
- RQ 3: How do understandings of 'mild CP' differ (between medical staff, those with CP, and the wider public), any changes to understandings.
- RQ 4: The day to day, everyday experience of mild CP. Where CP sits within their self-identity, and production of identity (past and present). The response to place, space, and other people around them (disability). Feelings towards their CP and potential or perceived changes to this.

DEMOGRAPHIC TABLE

Interview stages:

PART 1: introduction to the topic, focus for interview, interview admin

Introduce the key focus, explain in accessible language the purpose of the interview – to gather stories and learn about their own experiences of living with mild CP, with a focus on adulthood.

Explain the nature of the interview in accessible language - taking a narrative, meaning that I don't have a list of specific questions to ask, rather I'd like to hear your life stories. The interview will be recorded, and I may make notes, this is to remind me of key points and/or as a reminder to myself to return to something you may mention later in the interview.

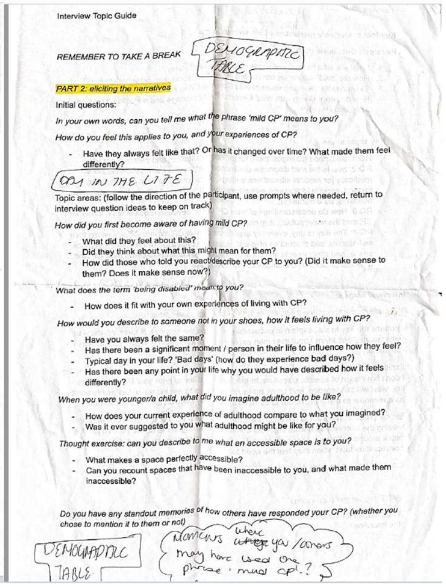
Ethical practice: reiterate to the participant the ethical practices of the interview: they are leading the interview with what they feel comfortable talking to me about. I will suggest a break around half way for the both of us. But they can stop or move onto a different conversation topic when they feel the need to.

Consent etc (record verbal consent).

PART 1a: 'warm-up questions'

What made them interested in taking part in the research? What are they hoping to get from the interview?

DEMOGRAPHIC TABLE



Interview Topic Guide

REMEMBER TO TAKE A BREAK

DEMOGRAPHIC TABLE

PART 2: eliciting the narratives

Initial questions:

In your own words, can you tell me what the phrase 'mild CP' means to you?

How do you feel this applies to you, and your experiences of CP?

- Have they always felt like that? Or has it changed over time? What made them feel differently?

DAY IN THE LIFE

Topic areas: (follow the direction of the participant, use prompts where needed, return to interview question ideas to keep on track)

How did you first become aware of having mild CP?

- What did they feel about this?
- Did they think about what this might mean for them?
- How did those who told you react/describe your CP to you? (Did it make sense to them? Does it make sense now?)

What does the term 'being disabled' mean to you?

- How does it fit with your own experiences of living with CP?

How would you describe to someone not in your shoes, how it feels living with CP?

- Have you always felt the same?
- Has there been a significant moment / person in their life to influence how they feel?
- Typical day in your life? 'Bad days' (how do they experience bad days?)
- Has there been any point in your life why you would have described how it feels differently?

When you were younger/a child, what did you imagine adulthood to be like?

- How does your current experience of adulthood compare to what you imagined?
- Was it ever suggested to you what adulthood might be like for you?

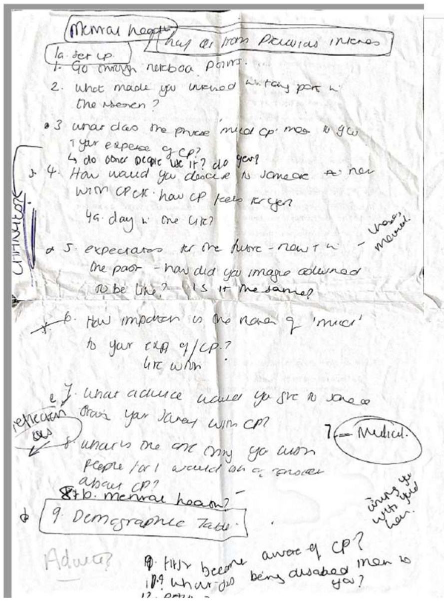
Thought exercise: can you describe to me what an accessible space is to you?

- What makes a space perfectly accessible?
- Can you recount spaces that have been inaccessible to you, and what made them inaccessible?

Do you have any standout memories of how others have responded your CP? (whether you chose to mention it to them or not)

DEMOGRAPHIC TABLE

Moments ~~where~~ where you / others may have used the phrase 'mild CP'?



Mental health

Key Qs from previous interviews

1a. set up.

1. Go through ethical points.

2. What made you interested in taking part in the research?

3. What does the phrase 'mild CP' mean to you / your experience of CP?
↳ do other people use it? do you?

4. How would you describe to someone not living with CP what how CP feels for you
4a. day in the life?

5. expectations for the future - now + in the past - how did you imagine adulthood to be like? Is it the same?

- views, married.

6. How important is the notion of 'mild' to your exp of CP?
life with

7. What advice would you give to someone starting your journey with CP?

reflection Qs

8. What is the one thing you wish people / or I would ask or consider about CP?

7 — Medical.

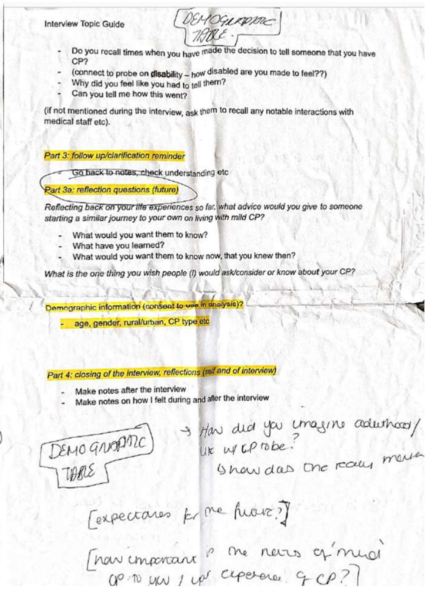
8+b. mental health?

9. Demographic Table.

things you wish you'd heard.

Advice?

9. First become aware of CP?
10. What does being disabled mean to you?



Interview Topic Guide

DEMOGRAPHIC TABLE.

- Do you recall times when you have made the decision to tell someone that you have CP?
- (connect to probe on disability – how disabled are you made to feel??)
- Why did you feel like you had to tell them?
- Can you tell me how this went?

(if not mentioned during the interview, ask them to recall any notable interactions with medical staff etc).

Part 3: follow up/clarification reminder

- ~~Go back to notes, check~~ understanding etc

Part 3a: reflection questions (future)

~~Reflecting back on your life experiences~~ so far, what advice would you give to someone starting a similar journey to your own on living with mild CP?

- What would you want them to know?
- What have you learned?
- What would you want them to know now, that you knew then?

What is the one thing you wish people (I) would ask/consider or know about your CP?

Demographic information (consent ~~to use~~ in analysis)?

- age, gender, rural/urban, CP type etc

Part 4: closing of the interview, reflections (self and of interview)

- Make notes after the interview
- Make notes on how I felt during and after the interview

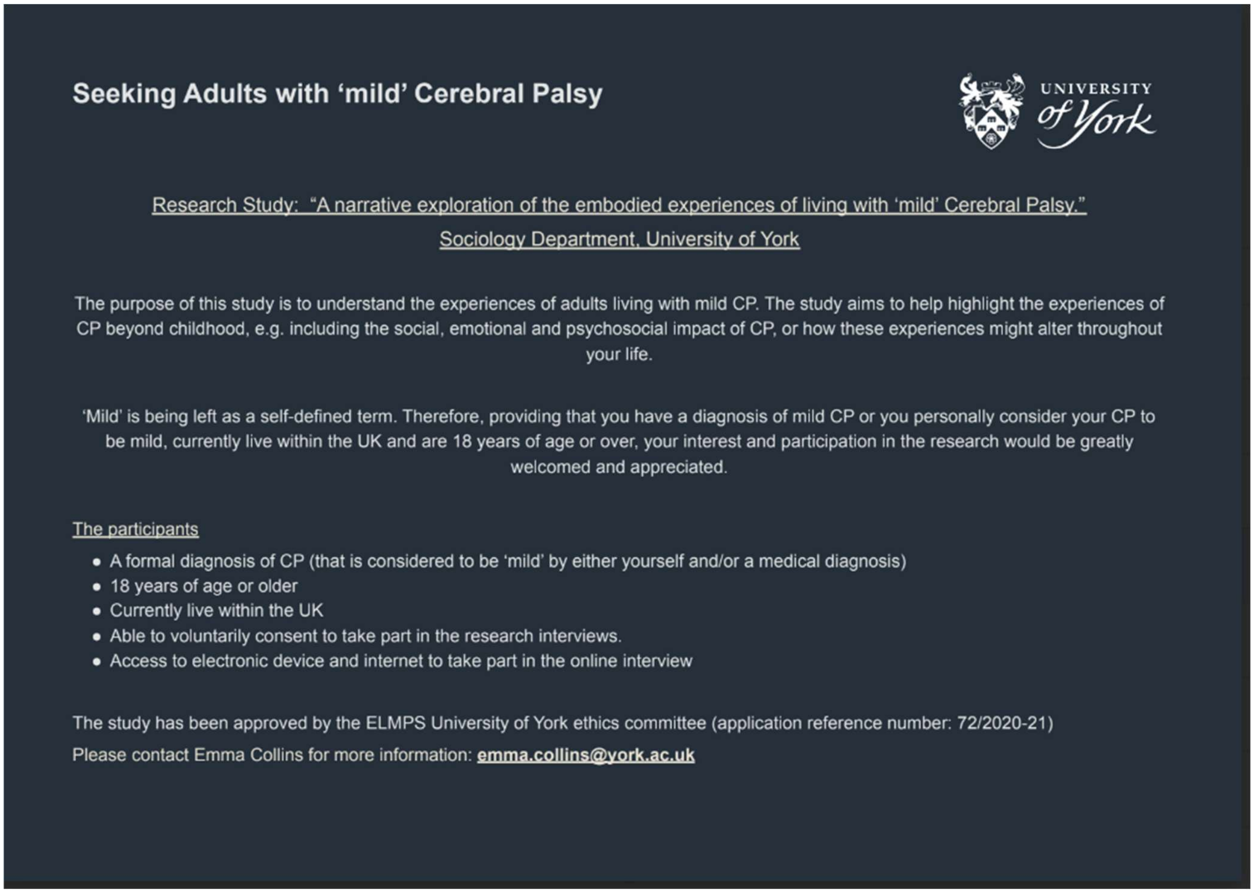
DEMOGRAPHIC TABLE

→ How did you imagine adulthood / life w/ CP to be?
↳ how does the reality match

[expectations for the future?]

[how important is the notion of 'mild' CP to you / your experience of CP?]

Appendix 5 - accessible advert



Seeking Adults with 'mild' Cerebral Palsy

UNIVERSITY of York

Research Study: "A narrative exploration of the embodied experiences of living with 'mild' Cerebral Palsy."

Sociology Department, University of York

The purpose of this study is to understand the experiences of adults living with mild CP. The study aims to help highlight the experiences of CP beyond childhood, e.g. including the social, emotional and psychosocial impact of CP, or how these experiences might alter throughout your life.

'Mild' is being left as a self-defined term. Therefore, providing that you have a diagnosis of mild CP or you personally consider your CP to be mild, currently live within the UK and are 18 years of age or over, your interest and participation in the research would be greatly welcomed and appreciated.

The participants

- A formal diagnosis of CP (that is considered to be 'mild' by either yourself and/or a medical diagnosis)
- 18 years of age or older
- Currently live within the UK
- Able to voluntarily consent to take part in the research interviews.
- Access to electronic device and internet to take part in the online interview

The study has been approved by the ELMPS University of York ethics committee (application reference number: 72/2020-21)

Please contact Emma Collins for more information: **emma.collins@york.ac.uk**

Appendix 6 - participant consent form

THE UNIVERSITY of York

Participant Consent form

Please initial each box if you have read and understood the sentence and are happy to take part: *(To initial electronically in Google Docs: click on the box, select 'edit', and in the pop up screen click in the centre of the box and type)*.

☐ 1. I have read the information sheet, and I understand what I will be asked to do for the interview.

☐ 2. I agree to talk to Emma about my experiences relating to my CP

☐ 3. I agree that Emma can audio record my interview

☐ 4. I have read and understood the information regarding the anonymisation of my data on the participant information sheet.

☐ 5. I understand that my name will be removed from interview transcripts, so that it cannot be used in the final piece of work.

☐ 6. I understand that no information from my interview will be included in the transcripts or used in the final piece of work that could risk me being identified.

7. I am happy for contextual information (information that provides helpful background to what I say in my interview e.g. my gender identification or age), to be included with extracts of my interview if they are used in the final piece of work. I understand that no contextual information will

☐ be used if there is a risk of breaking confidentiality or the anonymity policies outlined above and in the participant information sheet.

☐ 8. I understand that taking part in the study is voluntary, and that I can withdraw any or all of my interview answers **up to three months** after my interview.

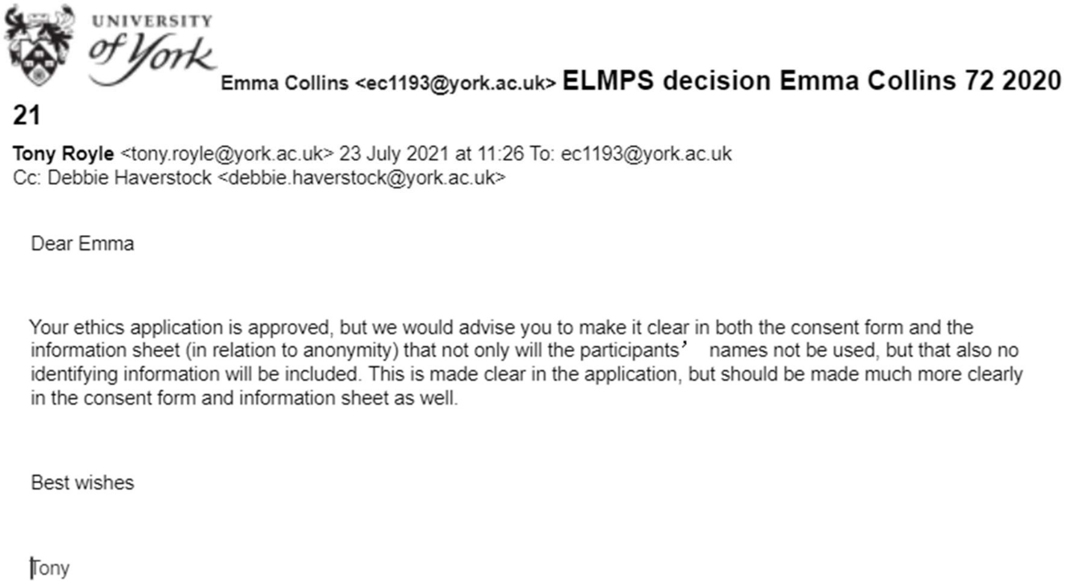
☐ 9. I agree to the transcript of my interview being stored. I agree to transcripts of my interview being stored securely and anonymously in a data archive **for a minimum of ten years** if they are considered to have a long term value for Emma and other researchers.

☐ 10. I understand that Emma and other researchers may use my words in publications, reports, and other research outputs, only if they agree to preserve my identity as outlined above.

☐ 11. I agree to assign the copyright I hold in any notes and recordings related to this project to Emma Collins.

Name of Participant	Date	Electronic Signature *(please hand sign, or type full name as an electronic signature)*
Name of Researcher	Date	Electronic signature

Appendix 7- ethical approval email



UNIVERSITY of York **Emma Collins <ec1193@york.ac.uk>** **ELMPS decision Emma Collins 72 2020 21**

Tony Royle <tony.royle@york.ac.uk> 23 July 2021 at 11:26 To: ec1193@york.ac.uk
Cc: Debbie Haverstock <debbie.haverstock@york.ac.uk>

Dear Emma

Your ethics application is approved, but we would advise you to make it clear in both the consent form and the information sheet (in relation to anonymity) that not only will the participants’ names not be used, but that also no identifying information will be included. This is made clear in the application, but should be made much more clearly in the consent form and information sheet as well.

Best wishes

Tony

Appendix 8 - participant demographic table

Name	Interview Code	Age	Gender Identity	Ethnicity	Living Situation	Marital Status (if discussed)	Sexual identity (if discussed)	Employment Status	Geography	Type of CP	GMFCS Level (if known)	Mobility	Secondary Health Conditions (if discussed)
‘Andrew’	CPM00I	31	Male	White irish	“cohabiting with long term partner”	Single	Chose not to disclose during the recorded elements of the interview	Permanent full time	Town/suburban	“mild/ moderate?”	Unknown	Walking sticks, occasionally self-propelled/manual wheelchair	Discussed autism
‘Lucy’	CPF002	43	Female	White/british	Husband and son	Married	Not discussed	Employed full-time	Town	Spastic hemiplegia	Not known	Aids in bathroom - stool, handrail	N/A
‘Christine’	CPF005	56	Female	White	Husband	“happily married”	Not discussed	Medically retired	Town	Right hemiplegia	N/A	Walk independently with heel rise and fes machine trialling since retirement	N/A
‘Holly’	CPF001	46	Female	White/british	Alone	Single	Not discussed	Part time - 12hrs/week	Small city	Spastic diplegia	Not known	Power chair and stick, manual chair	Non-verbal learning difficulty
‘Sue’	CPF007	23	Female	White british	Parents and dog	Single	Not discussed	Employed	Village	Spastic quadriplegia (affects legs more than arms)	Not known	Chair	Not discussed
‘Tina’	CPF003	39, nearly 40	She/her / female	White british	Husband, two children	Married	Not discussed	Employed	Village	Spastic diplegia	‘wouldn’t have a clue’	Manual chair and walk. Don’t use walking aids, clumsy	Not discussed
‘Amy’	CPF006	27 at time of interview (28 now)	Cis woman	White british	Not known	Not discussed	Not discussed	Discussed employment in interview	Not discussed	Mild athetoid cerebral palsy	Not known	Can walk, run, ride a bike unaided - cannot swim	Not discussed

‘Eve’	CPF004	40	Female	White british	Not known	Married	Not discussed	Stay at home mom	‘urban suburb?’	Spastic diplegia	Unknown/not discussed	Mostly mobile, occasional use of a cane	Not discussed
‘Ben’	CPM008	41	Male	White british	Not known	Married	Not discussed	Employed full time	Not asked	Mild right-side hemiplegia, spastic cerebral palsy	“i am too old to have got a classification formally but i'm confident that i am level 1 if you want to use that!”	“no mobility aids or assistive devices used currently”	Not discussed
‘John’	CPM009	52	Male	White, northern irish	Not discussed	Not discussed	Not discussed	Self employed	Not asked	Spastic diplegia	Not discussed	No - tried sticks	Not discussed
‘David’	CPM011	26	Male	White british	Mum and two sisters, mum’s partner and 9 cats	Not discussed	Not discussed	Full time employed /entrepreneur	Town	Spastic diplegic	Don’t know - level 2 we think	Crutches and a wheelchair	Mental health - anxiety and depression
‘Mary’	CPF010	37	Female	White british	Not known	Not discussed	Not discussed	Part time	Not asked	Right side spastic hemiplegia but it does affect all my body. Diagnosis at birth	Not known	Not discussed	N/A
‘Ruth’	CPF012	42	Female	Filipino	Lives alone	Widow	Not discussed	Unemployed	Village	Spastic diplegia	‘i don’t know. Just say spastic diplegia’	Manual wheelchair. When younger, zimmer frame/crutches. Now uses wheelchair for convenience	Not discussed
‘Matt’	CPM013	58	Male	Christian / white british	Not known	Divorced, but in a long	Not discussed	Retired	Not asked	From birth - spastic hemiplegia -	Not asked	At the moment using walking	Not discussed - did mention

						term relationship				down the right side		stick, but very rare	previous accident
‘Molly’	CPF014	43	‘straight female’	White british	Lives with 16 year old son	Divorced	Not discussed	Full time employed	Not asked	Dystonic spastic cerebral palsy	Not asked	I'm supposed to use a walking stick, but i don't (naughty i know)	Not discussed
‘Alice’	CPF015	25	Female	White british	Partner	Not married	Not discussed	Employed	Not asked	Right side hemiplegia	Not discussed	No chairs/walking stick	Dyslexia and ligamentous laxity
‘Luke’	CPM016	54	Male	White	Not known	Not asked	Not discussed	Employed	Not asked	Ataxia / ataxic cerebral palsy	Not discussed	No mobility aids	Not discussed
‘Charlotte’	CPF017	45	Heterosexual / female	Other mixed asian and white	Not asked	Cohabiting	Not discussed	Full time employment	Not asked	Left side hemi	No	No	Not discussed
‘Alex’	CPM018	56	Male	White scottish	Wife (and mice)	Married	Not discussed	Long term sick	Not asked	Spastic quadriplegic	Not asked	Wheelchair, elbow crutches, orthotic shoes, push/pull car hand controls.	Discussed depression and eating problems.
‘Polly’	CPF019	42	Female	White british	Husband and two boys	Married	Not discussed	Part-time	Not asked specifically	Spastic hemiplegic cp - left sided	Not a clue	No chair and stick, orthotics	Additional, unrelated abdominal related condition (not related to their cp)
‘Katie’	CPF020	32	Female	White	Husband and cat	Married very happily		Employed, full time	Town	Spastic diplegia	2	No	GAD
‘Adam’	CPM021	65	Male	White	Alone	Single		Unemployed	Not discussed	Athetoid	Not discussed	Not discussed	Currently wheelchair - previously able to walk and run unaided.

‘Daniel’	CPM022	33	Male	White british	Wife and kids	Married	Not discussed	Volunteer	Rural	Quadriplegic	Not known	Scooter	Mentioned down periods and being on a low dose of antidepressants
‘Jessica’	CPF023	31	Female	White	Not asked as not discussed in the interview	Not asked as not discussed in the interview	Not discussed so not asked	‘employee’	Participant specified a city name	Hemiplegia on right side.	1.5-2	Discussed not using any in the interview.	Not discussed so not asked