Disability Studies, Buber and Professional Practice: An Exploration into the Relationships Between Practitioners and People Described as Having Complex Needs

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Declaration: This thesis is an original work composed solely by the undersigned candidate in fulfilment of the requirements for the Doctor of Education degree at Liverpool Hope University and has not been submitted previously in support of any degree qualification or course. All sources of information therein have been specifically acknowledged, and the content of the thesis is legally allowable under copyright legislation.

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Abstract

This project explores the profound connections between Disability Studies practitioners and individuals described as having complex needs, uncovering the power of human relationships in fostering inclusive and respectful care. Drawing on the integration of Disability Studies and Buberian philosophy, the research examined person-centred practices, challenged stereotypes, promoted collaboration, and illuminated deeper dimensions of human identity. The research was coordinated by a committee that shaped the approach and captured data in two stages: first through a practitioner focus group, and then during an arts-based activity using wearable cameras. The collected data were analysed using Reflexive Thematic Analysis and was informed by Buber's philosophy of dialogue and Disability Studies. This research contributed to the field by introducing innovative methodologies and both theoretical and theological insights. Methodologically, it offered Action Research *with* Participation (ARwP) alongside a creative approach to data transcription for capturing alternative expressions of voice from individuals who do not use the standard language. Theoretically and theologically, it integrated Buber's philosophy of dialogue in caregiving to harness genuine human connections that extend transactional interactions. This approach presented the significance of 'Vulnerability', 'Practising', and 'Tangling' in such relationships, elevating mutual respect, friendship, and a compassionate approach. In challenging dominant perspectives of disability, this project endeavoured to present inclusive research methodologies for a more reflective and holistic understanding of caregiving relationships between disability practitioners and individuals described as having complex needs.

Dedication

Thank you…

To Ellie, Reuben and Seth, ILYWAMH.

To Mum, for proofreading and genuine interest.

To those who can’t be named.

To Claire, Owen and Laura.

To Jesus.

> *So if there is any encouragement in Christ, any comfort from love, any participation in the Spirit, any affection and sympathy, [2] complete my joy by being of the same mind, having the same love, being in full accord and of one mind. [3] Do nothing from selfish ambition or conceit, but in humility count others more significant than yourselves. [4] Let each of you look not only to his own interests, but also to the interests of others. [5] Have this mind among yourselves, which is yours in Christ Jesus, [6]who, though he was in the form of God, did not count equality with God a thing to be grasped, [7] but emptied himself, by taking the form of a servant, being born in the likeness of men. [8] And being found in human form, he humbled himself by becoming obedient to the point of death, even death on a cross.* ***Philippians 2:1-9***

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1. Introduction

This chapter will frame the project and set the foundation for all that follows. In this introduction, the reader will gain insights into the origins of this research, the motivations behind it, the theoretical underpinnings behind it and how I, the researcher, have arrived at the research question which this project sought to answer. This chapter is divided into four parts. The first section, vital to this study, introduces my personal background, academic journey and employment. The second section will introduce Disability Studies to the reader, a crucial theoretical foundation of this project. This will provide examples of how disability has been framed and its relevance to this project. Then, building on this second section, I will introduce some thinking around individuals described as having complex needs as the very people this research is about. The third section will introduce the Educational Philosopher Martin Buber, his background, philosophy of dialogue and his connection to this study. Finally, the fourth section will draw the sections together to share the central motivations behind the project, specifically to capture relationships between Disability Studies practitioners and individuals described as having complex needs. In this final section I will introduce the research question and sub questions that this project sought to answer before detailing what the reader can expect from each chapter that follows.

1.1 A decade, a poster, an organisation and a family

The origins of this project pre-dated the Educational Doctorate which I commenced in 2018. After many years working in the field of ‘Disability Sport’, I enrolled on an undergraduate degree in Education Studies and Special Educational Needs in 2012, believing my professional experiences had afforded some insight into the field. I entered university as a mature student to contribute to the field. My arrogance was soon disrupted. The undergraduate course, which was informed by Disability Studies, was eye-opening and challenged the way I perceived the world around me. In particular, the subject and exploration of inclusion were influential, and I felt a personal conviction about the passive role I had often played. In the final year of the undergraduate degree, our cohort was asked to culminate our theoretical positioning into an inclusive environment poster (Image 1). My project was the ‘Interdependent Community Hub’ (The Hub); a reconceptualisation of the purpose of education. It was informed by disability theory and the work of Educational Philosopher Martin Buber. The Hub reflected my own values as a student of Disability Studies with a mission to educate for a democratic society and belonging. Its curriculum, or ‘route’, was based on alternative ways of knowing and being in the world informed by disabled experiences. Its teachers who, informed by the philosophy of Martin Buber, I called ‘builders’, were all its attendees, those passionate about relationships and readers of power. The assignment scored well, but I believed that was the end of the matter as I moved into a Master’s degree.

Twelve months later, while undertaking a Masters degree in Disability Studies, I found myself in an interview before a Board of Trustees for a charity in the field of education. Although the job advertisement was somewhat vague, it was clear that they wanted a programme created to work alongside disabled young adults. I took the opportunity, and the interview consisted of my undergraduate poster, and the principle of making ‘The Hub’ a reality. The years that followed saw the creation of an organisation which replicated the Interdependent Community Hub. In this research project the organisation will not be named in order to respect the confidentiality of those who attend, specifically those who have contributed hugely to this research, but I cannot over emphasise the importance of this organisation in shaping this project and my personal identity. Based on the principles of the social model of disability, the organisation existed within a broken Health and Social Care system, but sought to make a difference within it. Its formal status is a structured day service- but in practice it is so much more than that. One key difference is how the organisation privileged relationships over activities and interventions. As it grew over many years, as Head of Service I was astounded by how much the relationships across the service meant to those involved. This was not just ‘The Hub’, it was not just an organisation - it was a family. The influence of Disability Studies on this family caused me to ponder how theory can be taken into practice, furthermore I wanted to celebrate, emphasise and explore what relationships between Disability Studies practitioners and individuals who might be described as having complex needs look like, and mean. For this, I needed to conduct a project alongside individuals from this family and within the setting itself who might be described as having complex needs, and those who shared my experiences within a Disability Studies informed undergraduate course. This is the origin of this research project.

Image 1

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MISSION

The Hub is a reconceptualisation of the purpose of education; who it is for and what it will lead to. It aims to create an inclusive, interdependent community which values human variation (Baglieri and Knopf, 2004). Individuals are more than physically present in this environment; everybody belongs (De Boer, Pijl, and Minnaert, 2011). The former neoliberal experiment which promoted competitive individualism and disabled generations (Slee, 2011) is now opposed to The Hub whose mantra is 'OTHERS'. For and by the community, The Hub is a picture of, and training for, a democratic society. This new society are encouraged to work together to become problem solvers within a democratic culture (Pearl and Knight, 1998) as belonging is everybody's business in The Hub. The mission is to change society, it is to show that education is not something that can be 'boxed up' or 'ticked off', or something that should be automatically assumed to be synonymous with cognition. In The Hub, the value of education is found in the value of others.

STRUCTURE

The Hub, as a heartbeat of the community, should be accessible for the builders at various times during the day opposing a traditional factory model of schooling with ringing bells and set class ages and times (Dudley-Marling and Dippo, 1995). A flexible timetable recognises that learning is an on-going life process and that restricting learning to one hour can place a detrimental pressure on the builders. This flexible timetable will compliment a non-compulsory ethic to lessons. Using the Summerhill Model (Neill, 1968), the builders are given the power to choose whether they attend certain courses or not. All who attend The Hub acknowledge that learning is always taking place, irrespective of where individuals are. Allan (2011) recognises that Summerhill is an example of how learners, despite having extreme degrees of freedom, do not fall into disorder. Therefore, The Hub places more emphasis on what is being learnt throughout an individuals life than what is being taught at certain times of the day.

ENVIRONMENT

Traditional segregated facilities signified place and politics (Armstrong, 2003), and for too long communities have been divided by separate locations. Those days are gone. The Hub is located in the heart of a community, accessible by public transportation and not in isolation from the people in which it serves. The facility is purpose-built, brought together by those who will use it. The architect values Universal Design as beneficial to all people (Ostroff and Hunter, 2003) and appreciates that those who will use the facility are the most obvious consultants and design team available (Mannion and I'Anson, 2004). The facility design differs greatly from that of traditional learning environments, as The Hub is a picture of colour, expression and freedom. The wide ranging facilities reflect a broad curriculum (route) enabling the builders to experience and enjoy variety in learning.

INTER DEPENDENT COMMUNITY HUB

ROUTE

The traditional route for learning lacked variety and avoided engagement with people's lives (Slee, 2011). Distracted by an economically determinist view of education, humanities and arts were often dismantled (Nussbaum, 2010) in favour of 'important' subjects. A myth prevailed that the train tracks of education were literacy and numeracy. However, learning is life long, and varied and subtle changes to a flawed system will not suffice. The old, narrow route segregated the nonconformist, and 'inclusionism' became merely a neoliberal gloss. An engagement in disability theory presents a new horizon (Baglieri et al, 2011). The Hub will recognise and value lived experiences as ways of knowing (Mitchell, Snyder, and Ware, 2014) and a history of inequality will inform practice and philosophy as communities strive towards interdependence rather than an individualistic performance model. Variety of routes mean that arts, sport and other formerly shunned courses are given equal value as a means for relationship building. Previously, friendships would be low on a national curriculum, in The Hub it is an outcome of paramount importance.

BUILDERS

A community that is learning to be interdependent will recognise and value the contribution of all those who attend its facility. The most important component of The Hub is its people; the builders. Unlike traditional learning environments, The Hub is not compliant to national standards or league tables; the attendees are valued rather than considered 'risky' (Slee, 1998). This will be a step towards abolishing the detrimental effect of positioning value on individuals via performance, and it will also highlight injustice that was so commonly distributed by those in positions of power (Dorling, 2010). Those who might previously be expected to submit to authority without question, (formerly students), are helped to become readers of power, and given the freedom to challenge inequality (Allan, 2011). Subject enthusiasts may facilitate lessons, but they must be willing to shift their relationship and potentially undermine their own expertise and authority in order to develop an environment in which those who attend courses might feel 'free' to learn.

Age related norms and year groups need not apply.

JOURNAL

The previous examination systems definition of achievement failed to recognise the talents of many. 'Success' was only for those who were literary competent, and able to perform in stressful conditions (Hart et al, 2004). The Hub does not conform to this narrow measurement of success. An interdependent community will measure success through relationships and by a personal journal which each individual takes ownership of as they journey through life. An individual's progress will be observed against their individual needs rather than comparing with age related norms or false national targets (Armstrong, 2012). Both the builders and subject enthusiasts recognise that all people are capable (Terzi, 2005), and are never, at any stage, 'behind' where they should be. Learning and relationships are life long, the journal approach, being fully owned by each person, helps individuals observe, (not measure), how they have changed and gained success in various areas of life. The journal should be a colourful expression of a broad route, filled with a variety of experiences unique to the owner of it.

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1.2 Theoretical foundations and models in Disability Studies: From academic discourse to practical implications

Disability Studies is a subject that crosses both Education and Humanities. Learning from civil rights, feminism and other freedom movements, Disability Studies is both a form of activism and a subject of academic excellence with international credibility (Driedger, 1989). It offers researchers a framework for critical reflection, motivation for social justice and the tools to deconstruct normative human behaviour as part of interdisciplinary approaches (Barnes and Mercer, 2003; Siebers, 2008). Disability Studies emerged as a distinct academic discipline over the past fifty years, gaining recognition in the 1980s and 1990s alongside broader human rights movements. Foundations since the mid-1970s have made the field principally about social and cultural causes on disablement through and influenced by the early activism of the Union of the Physically Impaired Against Segregation (UPIAS, 1976). That same group published a manifesto in 1982 surrounding a social model of disability, which later became foundational to the field. The field was strengthened by influential publications such as Oliver's 'Politics of Disablement' (1990) Davis' 'Disability Studies Reader' (1997), Shakespeare's 'Help' (2000), Garland-Thomson's 'Extraordinary Bodies' (1997) and McRuer's 'Crip Theory' (2006) to name a few. Alongside the writings of influential scholars, Disability Studies found its place within formal academic programmes in Higher Education in UK and US based institutions from the 1990s.

1.2a) Models of disability; social, medical and religious

At its core, Disability Studies is about how disability is framed (Oliver, 1990). This is often called modelling, and although the scope of Disability Studies has expanded to cover many areas it could be suggested that all such developments originate from models of disability. There are many models to view disability through yet for this project it is relevant that I introduce three; the medical model, the religious model and the social model.

The medical model, also known as the individual or tragedy model, is the most dominant understanding of disability within society. It constructs disability as something existing within an individual, and something that can be medically explained and finds no distinction between impairment and disability. Within this dominant perspective, individuals who cannot conform to a socially desirable 'sameness' are considered abnormal (Hunt, 1966; Davis, 1995 and Richardson, 2005). Using a medicalised lens means that so-called abnormalities are framed as a problem to be diagnosed and cured. This process of normalisation empowers the role of professionals in the lives of those subject to tragic stories who become passive and dependent (Finkelstein, 1980). In particular, the role of medical professionals is heightened as the process of diagnosing, or 'labelling' often becomes the starting point for care and support for individuals with impairments. This dominant model shapes society, asserting that there are preferable ways of experiencing the world, with impairment situated as undesirable (Oliver, 1990 and Gramsci, 1997). Within this project, I will seek to offer a perspective which challenges the medical model of disability while recognising its dominance within society.

Like the medical model, the religious model frames disability as a problem that resides within the individual. A problem which is a result of sin, a test of faith, or a landing point for miraculous healing. The religious model was used by disability scholars to frame disability throughout history, and from within religious movements. Barnes (1997) claims that religion has contributed to disablement since Ancient Greece and Rome, where gods exemplified able-bodied and masculine ideals. He argues that Judeo-Christian thought significantly influences perspectives on disability. Schuelka (2012) extends this by arguing that religion frames disability as a blemish on the human condition resulting from offending God, and a reason to seek mercy. This model portrays a God opposed to those with impairments. Scholars use Old Testament passages from Leviticus, which is principally about Priests and the Tabernacle (later the Temple), to show how disabled people are unclean (Barnes, 1997; Braddock and Parish, 2001). Additionally, Stiker (1999) suggests that the notion of spiritual uncleanness, is linked with disability, creating disabling barriers through religious texts. Furthermore, scholars such as Black (1996), Koosed and Schumm (2005) and Betcher (2006) use New Testament accounts to suggest that the healing narratives surrounding Jesus of Nazareth can be used to dehumanise disabled people who are rejected from the Temple. Shah (1999) would use this perspective to claim that such 'healing shows' are akin with modern day televangelists. Rose (1997, p. 398) summarises the religious model's perspective of Judeo-Christian framework by claiming that '*the Bible is clear in its message* *that perfection and beauty should surround things religious and that imperfection should be rejected*'.

The religious model of disability has faced critique from modern theologians. Swinton (2000) reframes suffering and disability as opportunities to encounter God's grace, while Amos Yong (2011) claims disability reveals God's presence rather than being linked to sin. Other theologians like Eiesland (1994) claim that God identifies with disabled persons experiences, as seen in Christ's crucifixion wounds while Betcher (2007) argues that framing disability as a test reinforces ableist hierarchies but in fact all embodiments as sacred. Finally, Reynolds (2008) calls for a theology of hospitality that celebrates diverse embodiments is contrary to exclusionary models of impurity. He argues that Jesus' inclusive ministry calls churches to dismantle exclusionary structures. It could be suggested that these perspectives dismantle punitive narratives, offering a theology rooted in grace and inclusion. Together, these arguments challenge the religious model's claims.

Although the primary purpose of this project is not to offer an opposing view to the religious model, my positionality, which will be explored in more detail within the Methodology chapter, allows me as a researcher to understand how disability scholars have created the religious model as a framework, while, like those in the theological community, wholeheartedly disagreeing with it. One inadvertent outcome of this project will present Disability Studies with an alternative perspective of Judeo-Christian understandings of God and disability, consistent with identified theologians.

Finally, in this section, arguably the foundation of Disability Studies itself is the social model of disability. It could be suggested that in fact all subsequent models are born out of the social model, which, as a tool for critical reflection has enabled an understanding of disablement and providing a foundation for other models. The social model highlights that rather than disability being something that resides within an individual, it is society which contributes to a process of disablement. The process of disablement is prevalent everywhere within society, from social and physical structures to public attitudes, languages, opportunities and technologies (Davis, 1995). A simple example is that everyone can enter a building if it has a ramped entrance, but an entrance with stairs reduces significantly the amount of people who can enter by this means. The social model exposes and recognises how individuals with perceived impairments are excluded from mainstream society. It offers a distinction between disablement and impairment: the former refers to social structures and experiences of the individual while the latter recognises the biological characteristics of the body and mind which is consistent with the diverse human experience (Barnes, 2012). The social model is not without its critics, but its influence is undisputed. Shakespeare (2010) for example, claims it cannot be thought of as a unified model, yet, with other models coming from the field, recognises how the social model plays a central role to the development of such ideologies throughout the field of Disability Studies.

This project is significantly influenced by this simple understanding of the social model. It is the desire that this project will not contribute to the disabling barriers experienced by people in our society but contribute to thinking consistent with others who subscribe to this model. There are individuals within this project who I may at times recognise as being disabled, this language makes specific reference to the barriers they have and do experience in a society which is still dominated by a medical model even though this project subscribes to social model principles.

1.2b) Terminology and perspectives surrounding individuals described as having complex needs

1.2bi) Terminology, labels and historical context

This project, and my personal experiences, have been significantly shaped by individuals who are described as having complex needs. This section will clarify choices surrounding terminology, explore how individuals described as having complex needs relate to this project and connect a brief history of such individuals with the medical and social models highlighted above.

This project adopts the phrase ‘individuals described as having complex needs’, but other terms have been used, including ‘Profound and Multiple Learning Difficulties’, ‘Profound and Multiple Learning Disabilities’, ‘Complex Needs’, ‘Complex Health Needs’ and ‘Severely Disabled’ which may be considered synonymous with the phrase and description used in this project. There has been a range of attempts to arrive at a ‘satisfactory definition’ for individuals who might be described with this range of labels (Imray, 2005, p.4). This researcher finds all such labels and titles extremely problematic. At no point throughout this research, nor in my professional experiences, have these titles been adopted by the individuals to whom they pertain. Instead, these titles have been imposed as a reductive summary of those individuals' experiences. Imposing a title on someone who has never claimed it is problematic. It becomes even more concerning when such titles become the primary identity marker in an individual's life, reducing diverse personalities to a single category. As the reader journeys through this project, the phrase *'described as having'* is repeated intentionally to cause both the reader and researcher alike to reflect on the terminology so often used and imposed within our society. Furthermore, it is used in a sincere desire not to speak on another's behalf. This project recognises that individuals described as having complex needs are a relatively new people group due to advancement in medical sciences, particularly for those individuals, like those who shape this project, who have reached adulthood. Newport (2021) summarises the literature surrounding individuals described as having complex needs by recitation shared experiences as being 'limited' normative communication; multiple medical or sensory impairments and dependent upon 'support' for everyday life.

1.2 bii) Models of understanding and critique

Such is the prevalence of medical professionals in the lives of individuals described as having complex needs that understandings of disability surrounding such persons are shaped by medical model perspectives. From this position, people described as having complex needs are considered to exist in a state of childhood, never reaching full humanity and are often the subject of euthanasia debates (Lyons and Cassebohm, 2012). Their place and meaning within society is under explored as their ability to shape reciprocal relationships is questioned (Whitehurst, 2007 and Hughes et al, 2011). Consequently, it has been questioned whether people described as having complex needs have their own perspective (Lewis and Porter, 2004; Ware, 2004; Williams, 2005).

For individuals described as having complex needs, the medical model's reliance on behavioural and educational psychology, particularly behaviourism and cognitivism, underscores its approach to understanding and supporting relationship formation (Simmons, 2020). Behaviourism, with its focus on operant conditioning, often employs technologies like micro-switches—'one-click' buttons that elicit programmed responses to stimuli—as a means of fostering communication and measuring engagement (Lancioni et al., 2005; Mellstrom et al., 2005; Tullis et al., 2011). Meanwhile, cognitivism interprets connections through observed reactions and movements, frequently through the lens of developmental norms (Zdyk, 2012). While these approaches aim to elicit communication from individuals who may not use standard language, they exemplify the limitations of a purely medicalised understanding of the body, potentially narrowing the scope of human connection. The lives of individuals described as having complex needs are routinely shaped by the presence of medical professionals and frequent interventions. On any given week, the individuals who participated within this project experience one-hour interventions of physiotherapy, hydrotherapy, rebound therapy, speech and language therapy, music therapy and occupational therapy. This engagement emphasises the dominance of a medicalised approach in the lives of individuals described as having complex needs. Simmons and Watson (2014) suggest that medical model perspectives which remain deficit-based reduce individuals to objects of intervention, lacking in volition and intention, unable to participate within society.

Another perspective is needed, one which celebrates the human experience as ‘multiple, dispersed, fragmented, complex and contradictory’ (Elliott, 2014, p.245). Individuals described as having complex needs challenge perceptions of personhood and call for a broader understanding of what it means to be human (Hogg, 2007). Social model perspectives enable such understandings. However, it has been suggested that the social model faces challenges if applied to individuals who might be described as having learning ‘difficulties’ or, those described as having complex needs. Thomas (2004) highlights that the effects of impairment significantly challenge a perception of disablement being purely a social construct. Shakespeare (2010) uses Thomas’ work to explore how the social model might be perceived as falling short when it relates to physical discomfort and pain. Furthermore, other scholars such as Mitchell and Snyder (2015) advocate for a deeper engagement with the body. The desire behind this project was not to ignore the influence of the body, nor to neglect a recognition of pain and discomfort faced by those who partook in the project, but to recognise that even outside of these effects, the disabling barriers these individuals face from society, influenced by a medical model, need questioning, and some need removing.

One way that this project will acknowledge the body is by seeking to capture relationships between individuals described as having complex needs and practitioners who have been shaped by Disability Studies. As the reader will find throughout this project, the experiences of the body are significant to everything which follows. As highlighted at the start of this chapter, my experiences have led me to believe that there is depth in the relationships which are under explored within the field of Disability Studies.

1.3 Martin Buber: Personal background and philosophy of dialogue

1.3a) Personal background and historical context

This section introduces the educational philosopher Martin Buber and the application of his philosophy to human relationships, a theme significant to this project. Born in the late part of the nineteenth century, Martin Buber, originally from Austria, worked as an academic in Germany before having to flee Nazism. From Jewish cultural heritage, this period of European history influenced Buber’s identity as a utopian socialist who sought human flourishing (Buber, 1958b and Fischoff, 1958). His educational philosophy is primarily associated with education for peace; he pursued peaceful dialogue between Jews and Arabs in Palestine, controversially calling for a bi-national state. His writings on peace earned him many awards throughout his life, until his death at the age of eighty-seven (Ravenscroft, 2017).

1.3b) Philosophy of dialogue and educational impact

Buber desired respect-filled relationships, an approach which he believed was fundamentally about dialogue. His understanding of dialogue transcends mere verbal communication; it is about how people connect relationally. *I* and *Thou* (Buber, 1958a), his most famous work is a philosophy of relationships and claims that people display two kinds of relationships: *I-Thou* or *I-It*. This philosophy of dialogue is fundamental within this research project. In ‘*I* and *Thou’*, *I* refers to an individual’s relationship to the other, with the

Thou or *it* indicating the nature of this relationship. '*Thou'*, in its most simplified explanations, refers to a living being, and '*it'* refers to an object without value and life. *I-Thou*, then, could be summarised as a meeting centred on dialogue, connection and mutuality between equals. Alternatively, *I-It* infers a relationship resulting in the objectification of the other. For Buber then, relationships are either about mutuality, or objectification. Despite a binary perspective, for Buber, these two are not fixed as he recognises that during human relationships, *I-Thou* has the capacity to merge into *I-It* and vice versa.

Buber believed that people exist for relationships. Such relationships, or understanding of dialogue, is for one another and for God; the eternal *Thou* (Buber, 1958a). He argues that our identity is truly found through relationships and mutuality. *I-Thou* respects the difference and uniqueness of two parties while harnessing a relationship of wholeness. His message is simple; meaningful relationships are what make us people, this is our most important experience (Buber, 1947). This philosophy privileges others more than ourselves which, in turn, connects us with something Divine.

Buber's writings are filled with terms such as 'students', 'teachers' and 'layers of curriculum', which reveal his practical philosophy. His goal for education focuses on democratic societal peace rather than modern experience of education which he describes as overly structured with too much emphasis on trade, skills and performance. He claimed that this approach reinforces *I-It* relationships (Buber, 1958a and Guilherme, 2014). He is not, however, a mere idealist. He is a pragmatist in recognising that *I-It* relationships are needed for social structures to function but cannot become the sole purpose of education, which he calls *Bildung,* which is character formation (Buber, 1947, 1999). He calls for living community, that is, human flourishing for all people, maintaining life and peace, upholding principles of equality, mutual stimulation and collaboration (Buber 1958a).

Buber does claim the need for individual roles within relationships of mutuality. He calls those with leading roles, akin to teachers, 'builders'. They offer direction and support in the efforts to privilege other's needs, interests and creativity (Morgan and Guilherme, 2014; Mendes-Flohr, 1976 and Avnon, 1993). Buber's desire for dialogue and the ontology that underpins it is vital during times of war, and in times of peace. As a philosophy it is fundamental to the nature of relationships between two individuals as the need to grow in mutual understanding is never completely fulfilled. As such, for every generation there will be those who fulfil builder roles; those who seek to nurture living communities. In this project, Buber's philosophy of dialogue will influence how the captured relationships between individuals described as having complex needs and disability practitioners are understood.

1.4 Bridging theory and practice in Disability Studies and Social Care

1.4a) Motivations and objectives

There are several motivations behind this project. Firstly, I am convinced there is much to be learned about the relationships between individuals described as having complex needs and disability practitioners, who, in this project, are graduates of Disability Studies occupying professional caregiving roles. This project will explore these unique relationships and highlight their value. Secondly, over the previous decade I have repeatedly encountered scepticism about the practical application of Disability Studies. Phrases like *"well that's all very good in theory, but we live in the real world"* are reoccurring when I discuss the social model with friends, family, and colleagues. This scepticism is experienced by those hearing of the social model for the first time, and those who have heard it all before, but are left discouraged after many years of fighting for social change.

As a practitioner working alongside men and women described as having complex needs, I am also motivated by the inaccessibility of Disability Studies for this group and the lack of contributions for those who might be described by this term. So, this project seeks to bridge that gap by collaborating with individuals who have something to share about building relationships that society can learn from. Through this, I aim to demonstrate that Disability Studies theory can indeed translate into practice. In combining Martin Buber's philosophy of dialogue with Disability Studies in this project, I hope to show how their ideas can both capture and shape interdependent relationships within Health and Social Care settings. This project then, is inherently tied to applying theory to practice and learning from those who experience the world differently from me, using Buber's dialogue to make sense of what these individuals want to teach me.

1.4b Research questions and project structure

To do that most effectively, I have sought to address the following research question and sub-questions and structured this project as follows:

Research question: What might Buberian philosophy bring to an appreciation of relationships between Disability Studies practitioners and people described as having complex needs?

Sub questions:

- What does Disability Studies bring to professional practice with people described as having complex needs?
- In what ways do practitioners enact Disability Studies theory?
- How do people described as having complex needs enrich professional practice?
- Do relationships with people described as having complex needs impact life outside of professional practice?

Chapter Summaries

The Literature Review will undertake a comprehensive analysis of what has been researched across several areas relevant to this project. It will explore the transition of theory to practice within the context of Special Educational Needs (SEN) and medicalised discourses. The chapter will then critically analyse the application of Martin Buber's philosophy of dialogue across different disciplines. Then it will synthesise current literature on the topics surrounding individuals described as having complex needs considering research collaboration and the scarcity of voice-informed research. The chapter closes with an exploration into the methodologies utilised to capture relationships involving individuals described as having complex needs, showcasing the tensions between inclusive education policies and neoliberal agendas.

The Methodology offers a systematic breakdown and rationale behind the project, ensuring it is rigorous and defensible. In this chapter my research positionality as a Critical Realist is identified alongside the paradigms the project will be operating from shaped by my belief system and experiences. The chapter reflects on the careful process employed when doing disability research and considers how and why this needs to be aligned with emancipatory principles. Action Research with Participation (ARwP) will be introduced to the reader as a unique methodological approach and explained alongside participatory methods which seek to capture relationships and the voice of those in this project. This chapter will offer a simple step by step guide to how the project was conducted, the methods chosen and an explanation of such; like the adoption of wearable cameras, participation in arts-based activity sessions and focus groups. It will also introduce how Reflexive Thematic Analysis is adopted to analyse and transcribe the data.

The Analysis will provide the reader with the steps taken to capture and transcribe the data. The reader will be given examples of how the data from both the arts-based activity sessions and focus groups was transcribed, coded and themed. The reader will be introduced to example extracts from the transcribed data as three themes are introduced and summarised. Finally, this section will apply Martin Buber's philosophy of dialogue to interpret the chapter's themes.

The Conclusion will highlight the findings of the project and consider what they mean. The chapter will combine what this project has found to answer the research question and sub questions. It will use the three themes generated by the data analysis in the project 'Vulnerability', 'Practising' and 'Tangling' to showcase contributions to the field of Disability Studies and Health and Social Care practice, both in policy and training. It will highlight the project limitations and consider further points for exploration going forward.

In summary, this project aims to bridge the gap between theory and practice in Disability Studies and Social Care, with a specific focus on capturing relationships between individuals described as having complex needs and disability practitioners. Through applying Buber's philosophy of dialogue, I have sought to understand the value of these relationships. What follows is a further exploration of the existing literature, a description and explanation of the systematic approach adopted, a presentation and analysis of the data, and conclusions with the implications of what this project found. It is hoped that as you read, those involved in this project will influence you as they have me, demonstrating the practical relevance of a philosophy of dialogue and the implications of Disability Studies in contributing to a more inclusive, vulnerable and interdependent society.

2. Literature Review

This chapter, the literature review, examines prior research relating to the experiences of people described as having complex needs and the application of Martin Buber's philosophy on Disability Studies and practice. It will delve into how Disability Studies theory applies to the support of people described as having complex needs. It will employ a problem-solving approach pertinent to this research topic and its broader context, rather than simply summarising existing literature. It is structured into four sections to enhance understanding of theory and practice in Disability Studies and their implications for individuals with complex needs.

1. The first section examines the transition from theory to practice amidst the prevailing SEN and medicalised discourses. It highlights successful integrations in Higher and Teacher Education, and Health and Social Care.

2. The second section explores and evaluates Buber's philosophy across various disciplines. It discusses the application of Buber's concepts in educational research, mental health nursing, and schooling, and is complemented by disability theorists' reflections on the relevance of his work.

3. The third section synthesises literature on complex needs and research collaboration, noting the lack of voice-informed research due to inclusion and language barriers. It advocates for breaking conventional frameworks and fostering more genuine, diversity-embracing research collaborations.

4. The fourth section explores various methods adopted for capturing relationships with those described as having complex needs, exploring the clash between inclusive education policies and neoliberal agendas, and highlighting caregiver experiences that promote joy, development, and interdependent relationships.

By the conclusion of this chapter, the reader will gain a deeper understanding of how Disability Studies theory informs practice across Education, Health and Social Care, and Research. The reader will see the impact of this on practice for people described as having complex needs alongside a review of the integration of philosophical perspectives, like Buber's, on the development of meaningful relationships.

2.1 Application of Disability Studies theory in the care and support of individuals described as having complex needs

2.1a) The dominance of SEN discourse and medicalised power over Disability Studies theory

Prior to highlighting how Disability Studies practitioners have applied theory to practice, I must first acknowledge the lack of literature in this area. That is, in comparison to the overwhelming array of practice-literature informed by a Special Educational Needs (SEN) and medicalised discourse. The medical model dominates the field of disability, leading most Google Scholar or online library searches to produce results that view disability as an individual condition to be diagnosed and, if possible, cured. In a culture where disability is framed as lack, such approaches are popularised by teachers, parents and Health and Social Care professionals who seek guidance in their practice. The dominance of this conceptualisation of disability contributes to the continuous struggle that Disability Studies has in its attempts to influence society, as outlined in foundational texts such as Oliver's (1990) 'Politics of Disablement', Barnes and Mercer's (2003) 'Disability', and Shakespeare's (2013) 'Disability Rights and Wrongs'. Even decades since these foundational texts, these scholars still maintain this critique of the wholly medicalised perspective of disability calling for cultural transformation within educational and care settings based on social model practices (Goodley, 2017; Oliver and Barnes, 2019). Good evidence-based examples of theory to practice from a social model perspective are available, as will be detailed below, however this is the exception, not the rule with foundational scholars acknowledging this concern. As such, bringing theory into practice is about changing a culture and the way disability itself is conceptualised.

2.1ai) Theory to practice

This section critically examines how Disability Studies theory has been applied in Higher and Teacher Education, as well as in Health and Social Care. In the first section Disability

Studies within Higher and Teacher Education critically examines and challenges the dominant perspectives and the social construction of disability. It emphasises the need to rethink views on Special Educational Needs and learning difficulties by advocating for a more critical and ethical framework. This framework aims to disrupt power dynamics and linguistic practices, recognising disability as a social construct. This also highlights how Disability Studies practitioners have sought to shape educational inclusion by challenging stereotypes and promoting person-centred practice. They do so out of a desire to create inclusive environments, which challenge a competitive, neoliberal education system. Finally, in this section theory to practice is explored within the field of Health and Social Care as scholars have advocated for an affirmative approach to disability services emphasising the importance of learning from disabled people. Scholars have argued that doing so fosters collaboration among professionals who operate with integrity.

2.1aii) Theory to practice: Higher and Teacher Education

Foundations

The literature suggests that the application of Disability Studies theory has had the greatest influence within Higher and Teacher Education. Theory has been put into practice through legislative compliance, inclusive teaching and learning practices, accessibility services and support, student engagement and representation, staff professional development, strategic policies, frameworks, and partnerships (Goodley, 2014 and Riddell et al 2005). Additionally, and arguably most crucially, as will be explored in this section, through research and scholarship. While Higher Education isn't always focused on the practical application of research, courses like Disability Studies, which offer new perspectives on societal inequalities, gain credibility not only from their content but also from their context within the perceived apex of the educational hierarchy. This positioning significantly shapes the practices of those who transition from Higher Education into the teaching workforce. The approaches taken within Disability Studies scholarship, rather than being concerned with minor matters of practice, seek to disrupt the ideologies which shape the practices (Baglieri and Shapiro, 2017). Nevertheless, Disability Studies continues to occupy a marginal position within the broader expanse of Higher and Teacher Education research. The task of Disability Studies scholarship is to both highlight and disrupt this discourse. Penketh and Waite (2015) do this by exploring how 'Special Educational Needs' within Higher Education, and more specifically Teacher Education, is a site for critical avoidance. They argue that by fulfilling Teacher Education criteria and the privileging of attainment, students are left without a critical and ethical framework which is the core function of academia to influence social responsibilities. They advocate for a resistance to the individualistic performance agenda that dominates Special Educational Needs discourse, challenging the perpetuation of a narrative that avoids critical engagement.

Disability Studies is employed in practice by applying a critical lens to dominant practices. Such approaches in Disability Studies have been influenced by the application of post-structuralist philosophers of the 20th century, such as Derrida, Foucault, and Deleuze, who each call for critical thinkers to look beyond and question the power of what are considered modern views on language, power, reason, and truth claims. Derrida (1967/1998) does this by seeking to deconstruct language which focuses on binary privileges. Foucault (1977) does it through exposing power and its influence on the creation of the subject. Finally, Deleuze (1993/1998) does it through showcasing how difference itself is what helps shape identity. These foundations are used by contemporary scholars to critique the process of disablement and promote more inclusive educational practices. Tremain (2017), for example examines how Foucault's ideas are applied within Disability Studies to critique power structures in education. Similarly, Campbell (2019) applies post-structuralist theory to review how disability is constructed across educational settings. The post-structuralist philosophers are embraced by Disability Studies scholars who believe that their philosophy offers a ‘theory of disability as opposition [that] recognises and, in the present context, emphasises the social origins of impairment’ (Abberley, 1987, in Barnes and Oliver, 1997: p176). It is therefore through processes of the application of critical thinking that Disability Studies theory is taken into practice in Higher and Teaching Education. It could be argued that this is just further theory, however this underlining principle is essential for all practical applications.

Early 2000’s

Disability scholars in the early 2000s endeavoured to shape inclusive educational practices and policies rooted in the same principles found in Disability Studies. Hehir (2005) advocated against ableist practices and for the development of inclusive strategies, significantly impacting national policies that shaped learner environments to affirm diversity. Ware (2004) called for a pedagogical flip which framed differences as strengths within school cultures as a move toward inclusivity. Artiles (2011) delving into the crossover between disability and cultural linguistic diversity, called for nuanced inclusive approaches that address inequities and result in educational settings characterised by responsiveness. Traditional segregation practices within SEN settings were reviewed through a critical lens by Danforth and Gabel (2006) who, like Titchkosky (2011) explored the cultural framing of disability, concluding that the disruption of a segregated status quo is essential for society to fully embrace diversity and difference. In 2008 Bentley extended the application of Disability Studies theory to practice to a group, often overlooked. Bentley (2008) claims that collaborating with those traditionally on the fringes, namely individuals who might be described as having complex needs, shapes inclusive practices and this is most evident in the natural pedagogical interactions among children with their peers, irrespective of their experience of the world. The call then was for an education system that privileges diverse capabilities and contributions of all students, particularly those described as having complex needs. Building on this, Baglieri and Shapiro (2012/17) applied Disability Studies' core principles for inclusive classrooms by ‘normalising difference’. Sharing the detrimental effects of competitive individualism within the education system, they proposed integrating Disability Studies into the curriculum to celebrate diversity, counter ableism and shape person-centred practices alongside the principles of universal design. Together, this scholarship can be synthesised as advocacy for changing educational paradigms, from exclusion to belonging. Together, their work calls for a reimagining and transforming of educational systems and teacher education with practical guidance to ensure barriers are removed for marginalised students.

Contemporary Applications

Both foundational scholarship and the work highlighted in the early 2000’s have been maintained by the original authors and paved the way for more contemporary scholars to apply such practices to their own projects working with individuals described as having complex needs. Newport (2021), a Disability Studies graduate employed within a Further

Education college, created PAGES; a person-centred assessment tool which offers a holistic approach to assessing people described as having Profound and Multiple Learning Disabilities (PMLD)[1]. PAGES, which stands for PMLD Assessment Guide for Education Settings, maximumises flexibility, in contrast to other assessment tools that are not person-centred and often make reductionistic conclusions, perpetuating a neoliberal assessment system. This development helps those in the field explore the lived experiences of individuals with the label of PMLD and their encounters within their classrooms. This development is to be used by practitioners who adopt an altered view of the purpose of education and a rejection of standardisation. Newport takes theory to practice in PAGES, supporting an ideological shift away from the medicalised understandings of PMLD.

Similarly, Maes, Penne, Vastmans and Arthur-Kelly (2020) sought to take theory into practice by developing an ecological framework for optimal learning environments for students who might be described as having complex needs. Their ambition was to create learning environments that reflect genuine belonging. Their framework considers context, input, process and outcome of an educational journey, not just the classroom influence. This big picture approach considers health, home and school life. Their framework gives individual recommendations for class level planning and an adapted curriculum, supporting the teacher’s role in gaining materials, delegating group work and harnessing a climate of care. This ecological framework can be adopted to consider wide ranging factors which influence a child’s development which are not limited to the classroom. The ecological framework uses methodologies which include measuring changes in behaviour in a range of settings; eye contact, pulse rate and even skin tone to have a more holistic range of connecting with someone who might not engage through formal assessments or offer verbal feedback. The influence of this framework is dependent on school policy, the leadership team along with parental partners reflecting the frameworks principles of collective belonging. Only in true adoption would theory be taken to practice through this ecological framework approach.

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[1] In the introduction chapter I highlighted how this project will adopt the phrase ‘described as having complex needs’, but that there might be occasions when terms such a PMLD and SLD might be used as it relates to specific works- this is one such example.

The limited examples used in this section highlight the dearth of literature in this research area, particularly in contemporary scholarship. Despite this Disability Studies application to practice has rendered significant progress. Nevertheless, several challenges and considerations persist. Although scholars such as Hehir (2005) and Ware (2004) successfully influenced policy and pedagogical theory surrounding ableism and inclusivity, bringing such ideals into practice continue to face resistance within a SEND discourse. A more thorough evaluation is needed regarding the effectiveness of these policies in bringing genuine change for educational settings. It remains to be seen whether educational settings have the willingness or capacity to address Artiles (2011) decade old challenge surrounding the intersection of disability and cultural diversity. Particularly while so-called specialist provisions are still widely adopted today despite Danforth and Gabel's (2006) critique of such segregated settings. Moreover, the challenge which Bentley (2008), Baglieri, and Shapiro (2012) propose; to normalise difference within classrooms through a Disability Studies curriculum, still faces the barriers of a system which is dominated by numeracy and literacy. In such an individualistic and performance-driven environment, even more contemporary initiatives like Newport's (2021) PAGES tool and the ecological framework proposed by Maes et al. (2020) will need to overcome the systemic barriers of cultural acceptance and financial backing from educational decision-makers. Especially when such approaches require careful consideration surrounding potential biases and limitations. The application of Disability Studies theory to practice within Higher and Teacher Education is a continuous challenge. Despite the challenges and dearth of contemporary literature compared to the dominant SEN and medicalised discourse, applying Disability Studies theory to practice in Higher and Teacher Education remains essential as a launching point for societal change.

2.1aiii) Theory to practice: Health and Social Care

This section considers and reviews how Disability Studies theory has been applied in practice within the field of Health and Social Care. What follows is a range of examples of how theory has shaped practice in relation to individual roles within the field. Parental perspective and the role of paid caregivers are reviewed within the literature before the work of medical professionals in the sector is considered through the foundational text *Disability* *on Equal Terms* by Swain and French (2008). This is particularly relevant to this project which was undertaken in a structured day service within a Health and Social Care setting alongside individuals described as having complex needs, their parents and paid caregivers, who were Disability Studies graduates

Parents

Vaughan and Super (2019) use personal narratives to connect Disability Studies with parenting disabled children. They conclude three things: first, being a parent of a disabled child influences their scholarship in Disability Studies. Second, they believe Disability Studies scholarship has the potential to shape parents' understandings of disability for good to the point of advocacy for their children. Third, parents who engage in scholarship have the opportunity and positionality to inform problem-solving research within the field. The authors acknowledge the substantial tension that exists between theory and practice within Disability Studies. They call for parents to engage deeply with broader concepts of personhood and to work together to improve the social environment for disabled children. It could be argued that while their parental influences on scholarship are insightful, an emphasis on personal experience could limit theoretical development and offers potential biases and unequal power dynamics within a dual role.

Paid caregivers

Robinson et al. (2021) explore paid support relationships between disabled people and their caregivers. Such relationships are said to lack authentic engagement due to restrictive organisational rules (Fisher and Byrne 2012). The authors argue that the relationship dynamic between paid caregiver and care recipient is under-researched despite the significance of the relationship for forming wider networks (Skar and Tam 2001; Mason et al. 2013 and Romer and Walker 2013). Robinson et al's principles are consistent with principles of Disability Studies and they employ 'recognition theory', which explores how justice and identity are configured through mutual respect and acknowledgment between people and networks. Doing so they aimed to identify possibilities for mutual recognition within the professional relationship. This desire for reciprocal understanding leads the authors to theorise identity development and interpersonal recognition. They find that the probability for mutuality within professional relationships is increased when the paid caregiver and person receiving support both invest in their interpersonal relationship. They find that this is achieved when each respects and values their unique contribution to the relationship and recognise their need for one another, and the centrality of inherent human rights. These findings are illuminating, yet the research might be strengthened from a more nuanced consideration of the practical challenges that influence these paid support relationships between disabled people and caregivers. It could be suggested that mutual recognition runs the risk of oversimplifying the complexities within these relationships.

The medical professionals; occupational therapists, speech and language therapists and nurses

Swain and French (2008) take Disability Studies theory and put it into practice by calling for a non-tragic approach to services and practice. They examine the work of service providers and explore disabled people’s advice to professionals who seek to adopt practices which do not reinforce inequality. Their approach is practical throughout encouraging practitioners to disrupt power relations so that the blueprint is one where disabled people control any policy, practice or provision which alters their lives. Contributing authors maintain a theme of challenging power imbalances in professional practice. Ballantyne and Muir (2008) call for rethinking occupational therapy in light of developments in disability theory. Calling for a recognition of the affirmative model of disability, they request that occupational therapists engage with Disability Studies and disabled individuals. In doing so they challenge professionals and their organisations to embrace the principles of partnership, even at policy-level. The authors claim this approach will affirm difference and challenge deficit-based service provision. They recognise the tension between addressing medical needs and advocating for the affirmation of disability within occupational therapy. Yet they argue that occupational therapy's philosophical foundations are compatible with the affirmative model allowing aspects of fluidity between affirmative and medical approaches.

Similarly, Pound (2008) advocates that speech and language therapists perceive communication impairments through an affirmative lens. This requires changing the narrative within service provisions and challenging hero and victim stories that frame impairment as a deficit. The author calls for strategies which embrace accessibility and celebrate difference. This means placing individuals with communication impairments in decision-making positions within organisations, showcasing diversity in practice. Far from token gestures, these roles are essential to service planning and delivery. Additionally, the authors reaffirm the importance of challenging the dominant narratives that link language to power dynamics. They demand alternative narratives which celebrate cultural differences in equal standing to so-called restitutive outcomes and approaches which reinforce accessible communication as the new norm. These paradigmatic shifts to speech and language therapy will empower disabled individuals to foster a more inclusive society. Further to this, Spain (2008) argues that disabled representation is a key factor in taking theory to practice. The author claims that there is a growing recognition that nurses with lived experience of impairment offer key insights to patient care due to personal experiences. This signals other key developments which challenge a narrative of lack to one of appreciation and affirmation, including suggesting improved patient care.

Collating the medical professional perspectives above, Swain and French (2008) offer the greatest example of theory to practice in the field of Health and Social Care concluding that the realisation of disability on equal terms fundamentally achieved through adopting the affirmative model. This model challenges individual and corporate assumptions about difference and recognises the diverse aspirations of disabled people. It calls for a move away from passive client-based approaches to a citizen-based approach which recognises the freedom of service users over their own care processes. Furthermore, they reaffirm the importance of service users challenging professional agendas to ensure that the services provided are appropriate to the needs and preferences of those who need it. Swain and French, and the contributors to Disability on Equal Terms demand inclusive practices in Health and Social Care, which are fuelled by an appreciation of diversity.

Although this work is sixteen years old, it is a classic text which remains relevant and informs contemporary scholarship. For example, Bigby et al. (2021) aligns with the affirmative model in discussing practical approaches to safeguarding quality service delivery. The author advocates for respectful and dignified practices which promote the freedom of disabled individual through practical approaches to inclusion and healthcare. Ocloo et al. (2021) use the affirmative model to review the barriers to public involvement in Health and Social Care emphasising the essential component of involving disabled people in the decisions that impact their lives. Finally, Macdonald and Deacon (2019) in combining disability theory with social work practice call for an integration of various models of disability to front line social work practices. Doing so aligns with affirmative model principles, privileging disabled persons contribution and affirms their rights and identity. This approach demands anti-discriminatory practices which is foundational to Swain and French's challenge to societal norms and prejudices. These three contemporary examples maintain Swain and French's ideas by applying affirmative principles in professional contexts.

This section questioned what the literature says about how Disability Studies Practitioners apply theory to practice, particularly for individuals described as having complex needs. The section noted that available literature was scarce compared to dominant Special Educational Needs (SEN) and medical perspectives. Nevertheless, within Higher and Teacher Education and Health and Social Care there are examples of how Disability Studies Practice is adopted. This is either through conceptual understanding, calls for inclusion, or an adoption of affirmative practices resulting in the disruption of power imbalances within the professional relationship. Such changes advocate for a cultural shift towards recognising and valuing difference. This section was relevant to this project as participants within this study, who formed the research committee, are made up of individuals who might be described as having complex needs and caregivers who are Disability Studies graduates. The next section considers the philosopher Martin Buber's relevance to this project by exploring how his dialogue has previously been applied.

2.2 Application of Martin Buber's philosophy to different fields

Martin Buber and his philosophy were presented in the previous chapter. His philosophy of dialogue is primarily about the transformative power of genuine, respectful relationships through *I-Thou* encounters. He claims that people can encounter one another through *I-Thou* and *I-it* relationships. *I-it* encounters, although necessary within society, lead to objectification of the other, whereas *I-Thou* encounters can offer mutual understanding and societal harmony.

2.2a) Applied examples of Buber’s philosophy

Veck and Hall (2020) use Buber’s philosophy of dialogue to critique reductive and specialist answers to the questions surrounding inclusion practices within educational research. Applying Buber’s philosophy, the authors seek research collaboration which is ‘with’ people rather than ‘on’ people. Scholars such as Barnes and Mercer (1997) and Oliver (1997) in the field of Disability Studies have shared this principle for emancipatory research for decades and emerging researchers are encouraged to adopt such approaches (Barton and Hayhoe, 2023). Veck and Hall (2020) suggest that applying a research approach which leaves those who contribute as submissive or voiceless is contrary to Buber's core convictions which are influenced by applied Hassidism (Mendes-Flohr, 2019). Hassidism does not draw a distinction between the world and the sacred. This is key for Buber as it means that God’s immanence is present in the universe, giving sacredness to even the most mundane of acts. He describes Hassidism in practice as the turning of self-obsessed monologue into a dialogue with those around him, the natural world and God.

The authors draw on Buber's concept of distance to illustrate that establishing separation can allow researchers to capture genuine experiences and create spaces where participants feel included. They suggest that for Buber this experience of dialogue fosters mutual respect and the unique identity of others. The authors claim this approach will cause researchers to reflect on social structures. Key then, is not what someone might ‘get’ from the moment in research, but what they bring and share. They argue this approach can awaken us to that which cannot be captured: to the uniqueness of the *Thou*. Confirming mutuality teaches researchers that persons labelled as having ‘complex’ needs are more than their identified ‘needs’ or ‘complexities’. Therefore their involvement in a project is not bound to the technicalities involved in eliciting voice or matching needs to methods. Therefore, using Buber’s dialogue of *I-Thou*, the authors conclude that the primary question for inclusive research is not one of method or measurement, but that of how researchers develop relationships with the persons they encounter and write about.

This resonates strongly with Veck’s (2013) previous critique of special education in the UK, where he used Buber’s concept of inclusion to highlight how educational practices can become exclusionary when they privilege technical mastery over relational trust. While Veck’s (2013) earlier work centres on education rather than research, the parallels are clear: both articles argue against the objectification of individuals, be they students or research participants, and call for a more inclusive and dialogical approach. However, a key difference emerges in their emphases; Veck (2013) focuses on the everyday, often unnoticed acts of inclusion that transform relationships, grounding these in educational practice, whereas Veck and Hall (2020) apply Buber's philosophy to research methodology, emphasising the ethical obligations of researchers to uphold the dignity and voices of those they engage with. Both perspectives, however, underscore the transformative potential of Buber's dialogical philosophy in fostering inclusion, whether in education or research. The task for the researcher is to embark on an essentially educative endeavour, adopting a patience that creates unexpected possibilities which could not have been anticipated within the confines of the research plan.

The next example of Buber's theory applied is found in Hanson and Taylor's (2000) application of Buber's philosophy to mental health nursing. The authors recognise the fluidity, necessity and complimentary nature of *I-Thou* and *I-It* relations in this profession. They seek to apply and modernise the terms as 'Being-with' and 'Doing-with'. They use 'Being-with' and 'Doing-with' as a model, in practice, of nurse–client relationships highlighting that both types of relationships are needed to be deployed to be effective practitioners. The authors summarise that by 'Being-with', they mean the situation in which the total being of the client is engaged in mutuality with the practitioner, and in 'Doing-With', the client is helped to assist them living in the world. This recognises Buber's argument that *I-it* and *I-Thou* are both needed for society to function. Nevertheless, it can be suggested that *I-Thou* relationships, or 'Being-with' relationships, represent person-centred care. Yet the authors in this article recognise the absolute necessity for 'Doing-with' approaches to health care. It is interesting to note that the authors do not use *I-Thou* and *I-It* in practice as they believe the term *Thou* is now more or less obsolete. Their use of 'Being-with' and 'Doing-with' is claimed to be relevant and user friendly. Yet, it should be noted that this is inconsistent with the emphasis Buber placed at the heart of his philosophy- the eternal '*Thou*' and the heart of his lived Hassidism (Mendes-Flohr, 2019). Yet, it is not Hanson and Taylor's directive to be bound up in philosophy or theology, rather to implement a relationship descriptive model. The significance of this will be examined later in the Analysis chapter.

Building on Buber's position that *I-Thou* connections transcend any awareness of time, Hanson and Taylor (2020) use this to propose that for nurses to truly connect with their patients, they must embody 'Being-with' by being fully present in the moment. They also recognise that ‘Being-with’ can only be compared to *I-Thou* if the whole being speaks, extending what might be considered normative communication methods. ‘Being-with’ therefore pushes past purely linguistic engagement for a holistic mutuality and is developed through reflection, supervision and self-awareness. The emphasis on holistic engagement beyond mere speech sets a framework for Hanson and Taylor's exploration of the practical dimensions of nursing care which the authors clearly recognise is essential to the role. ‘Doing-with’ relationships are reinforced for practice in the paper through the application of counselling, the investigation of disruption and the administration of medication. The *I- it* relationship is essential when a nursing intervention is required, and such practices are developed through training and continuous supervision. It is clear for this reader to see how the nature of relationships for practitioners in mental health nursing is fluid in this article, and why nurses will have to adopt both ‘Being-with’ and ‘Doing-with relations interchangeably. The authors conclude that mental health nurses then exist between experience and action, at the crucial point of human existence, as people need to be able to ‘do’ and to ‘be’. The interplay between being with and doing practice also features later in the Analysis chapter.

The final example is in Leach and Crisp’s (2016) paper examining the issues of emancipation and empowerment in schooling and exploring how Buber’s philosophy might create a more equal schooling system. The authors explore the impact of collaboration between student and teacher within a self-improving school system. The article examines the complexities of establishing *I-Thou* teacher– student relationships. Highlighting that a collaborative classroom is a place of democracy and mutual dialogue; both ’top-down’ teacher-led and ‘bottom-up’ student-informed. The authors argue that Buber rejects a binary either/or conceptualisation of approaches and recognises the need for both because good education is tied to authentic dialogue, mutual trust and respect. In such an environment, the views, needs, and interests of the teacher and the student are supported. This offers teachers a broader perspective without losing or compromising their ability to provide guidance and instruction (Guilherme and Morgan, 2014).

Leach and Crisp (2016) highlight that although this balance might be theoretically supported, in practice ‘top-down’ instruction prevails, especially in cases when schools are failing and the necessary response is to ‘turn the school around’ by the introduction of an expert. The prescribed *I-It* strategies, which characterise the ‘turnaround’ of schools, include the imposition of ‘proven’ managerial-led solutions which drive improvements in teaching and learning strategies that conceptualise the learner as purely a recipient. The authors call for educational practitioners to resist falling into mere *I-it* relationships but to demonstrate the balance which is needed to be displayed in the democratic classroom. This example from the field of Education has parallels with that from Health and Social Care and Hanson and Taylor’s (2020) critique of practitioner relationships. The issue at hand, which was not picked up within the article surrounding mental health nursing is the position of power the practitioner holds. Leach and Crisp’s approach to Buberian dialogue within the classroom setting seeks to disrupt the power imbalances between teacher and student leading to democratic outcomes. This example is relevant to this project as the challenging of power imbalances between practitioner and individual described as having complex needs is at the heart of the applied philosophy of *I-Thou*. Furthermore, it is consistent with the approach identified in section one of this chapter as outline by practitioners who seek to promote principles of the affirmative model in practice.

This section has used three examples of how Buber’s philosophy has been applied to practice- in emancipatory approaches, mental health nursing relationships and within democratic education. The literature claims that the application of his theory has encouraged more inclusive, respectful and mutual relationships with a focus on working together in a holistic manner. Achieving these ideals can be hindered due to unequal power dynamics and a practice culture which remains predominantly task-oriented. The next section will explore the relationship and engagement between Buber’s philosophy specifically to the field of Disability Studies.

2.2b) What is the relationship and engagement between Buber’s dialogue and Disability Studies?

Buber’s dialogue has been explored within the field of Disability Studies by Saur and Sidorkin (2018) and Haslam (2012). Saur and Sidorkin's (2018) critique of Buber's dialogue centres around how it is applied, pointing out the complexity of implementing an approach which fosters understanding and growth. They claim that Buber's ideals are aspirational but the practical challenges of embodying these principles in everyday practices perpetuate ableism. They argue that the understanding of dialogue should be separated from traditional Western expressions of Humanism which privileged white, able-bodied, middle class, heterosexual, western males and excluded individuals whose identity is outside these identifying markers including individuals who might be considered to have complex needs. Instead, their response is to offer a new interpretation of dialogue to align with a post-human era identified by Braidotti (2016 / 2019), which is a term surrounded by investigations and questions of what humanity is becoming through the possibilities afforded in the modern technological age. Unlike Hanson and Taylor's (2000) alternative interpretation of Buber's linguistics, these authors argue that Buber's concept of dialogue is limited to spoken language and reflects what could be seen as an identity centred on able-bodied norms. The authors therefore pose this is not the diverse experience of many bodies and so conclude that Buber's dialogue is only applied to a certain societal group, reinforcing disabling attitudes.

Saur and Sidorkin (2018) claim that Buber's dialogue is limited, narrowed to a specific normalised perspective. They prefer Braidotti's (2016) broader view of post-human theory which aligns with many Disability Studies scholars, claiming that being human is an open and contested field with a range of interactions which are available in a post-human age due to technological and barrier removing advances. Dan Goodley is one such prominent scholar from Disability Studies who has contributed to discussions about post-human theory by exploring the intersections of disability, activism, and critical theory by challenging the view of 'the human' as conforming to able-bodied, neurotypical, and Eurocentric norms. Within his scope of work in post-human theory he builds on Braidotti's work by advocating for broader and diverse forms of existence by critiquing human exceptionalism (Goodley, 2017) and celebrating how disability exemplifies the entanglement of bodies, environments, and technologies within an evolving world (Goodley, 2020). His work disrupts the myth of the autonomous, self-reliant individual

(Goodley et al. 2014), and shapes collective and ecological understandings of justice (Goodley, Liddiard, & Runswick-Cole, 2018).

Influenced by such scholars like Goodley and Braidotti, Saur and Sidorkin (2018) thus reject Buber’s theory of dialogue between two free individuals and instead favour post-human theories. These theories reimagine the self as deeply interconnected within a fluid space that blurs the lines between what might be classified as real and virtual, encompassing both places and experiences. Braidotti (2016) places this interconnectivity with an ontological mutuality inside post-human dialogue which is not bound by self-centred individualism and negative perceptions of diversity. Saur and Sidorkin (2018) use post-humanism to interpret the evolution of connections as a move away from traditional human-centric relationships to include a wider scope involving inanimate objects, abstract concepts and technology. This transition represents a significant shift in how individuals connect with the world, privileging new forms of interaction rather than the existing *I-Thou* framework described by Buber. Simply, the authors find Buber’s dialogue restricted and human centred. They claim humanity does not have a centre so only post-human dialogue can survive.

This philosophical interpretation clashes with a project influenced by Critical Realism (see Methodology chapter). It could be suggested that Saur and Sidorkin (2018) have missed the spirit of *I-Thou* in their analysis of the *process* of dialogue. Applying post-human theory to Buber’s dialogue, like Hanson and Taylor (2020), removes ‘*Thou*’ from *I* or *it*. The authors place too much emphasis on the mode of dialogue rather than the heart. *I-Thou* appears to be more about empathy than English, love than language, worship than words. Reducing Buber’s dialogue to spoken linguistics makes it about the mode, but their entire argument is undone by Buber’s insistence on the eternal *Thou* and Hassidic life philosophy. For Buber’s God (*Thou)* has no body and no tongue but is spirit (Exodus, 33:20 and Isaiah 40:25). Interpreting Buber’s dialogue as ableistic communication is inconsistent with his wider examples in practice and motivation.

Another perspective can be gained from Haslam (2012) who seeks to present a constructive theology of intellectual disability. Haslam calls for society, but in particular the Christian church, to recognise that human identity is tied to mutuality and response. She uses a theological framework to draw into question what it means to be human. The author recognises that within theological reflection little has been written or researched about profound intellectual disability. That which has been written places too much value on whether an individual has intellectual capacity to make choices while ignoring those who might be deemed to lack such capacities. Using her experiences as a physical therapist she argues for relationships which are built on participation and mutuality irrespective of the form of communication- such relationships would celebrate responsiveness which are non-symbolic in diverse bodies. In direct contrast to Saur and Sidorkin (2018), Haslam shows the broad perspective associated with Buber's philosophy. She claims that Buber's dialogue not only values individual identity but also increases the ethical component of supporting people described as having complex needs through fostering a deep, personal *I-Thou* relationship. Haslam shares Buber's perspectives of *Thou*. Although Haslam may not share Buber's Hassidic view on God's immanence in all things, she does offer her perspective on the Imago Dei, that is, what is known as people being created in the image of God (for more on the Imago Dei, see Methodology under sub-heading positionality). She argues that the Imago Dei means to respond to the world around and through relationship, and that this is achieved both bodily and symbolically. Such an interpretation, therefore, does not exclude people with intellectual disability being created in the image of God, or from theological conversations.

2.2c) How does Buber's dialogue relate to this project?

Martin Buber was not a Disability Studies scholar, yet this project is evidence that his philosophy of dialogue can be applied by Disability Studies practitioners in a range of fields, including Health and Social Care. His approach is consistent with the principles of this research as this project considers the nature of interdependence, the significance of *Thou* to human relationships and the notion of dialogue transcending linguistics. Buber's approach underpins this project's exploration of mutual joy and belonging in relationships, highlighting the transformative potential within Health and Social Care. Disability scholars have claimed that belonging truly exists within interdependent relationships (Richardson, 2005; Brown, 2012 and Slee, 2011). A Buberian perspective of dialogue applied to interdependent caregiving is consistent with the claims that people who might be described as having complex needs contribute to joy and are not merely ‘landing sites’ for care and support (Vorhaus, 2005, Kittay, 1999 and Shah, 2013). This mutuality and creation of joy demonstrates that belonging to a diverse collective, what Tuomela (2013) calls ‘we-mode’ membership, is not one way and is consistent with the spirit of *I-Thou*. Instead, Buber’s dialogue transcends solely linguistic methods and promotes interdependence as one genuinely opens up to others without imposing an pre-determined agenda (Gadamer, 1979). The literature would suggest that such dialogue, characterised by care, humility, and the readiness to change, can lead to transformation (Freire, 1995 and Kazepides, 2012). This is crucial when connecting with individuals described as having complex needs, for Belva et al (2012) and Vorhaus (2015) claim their voices are considered inconvenient and often overlooked. Despite challenges in traditional communication, dismissing their contribution to dialogue according to Nussbaum (2007) is an infringement on their human rights.

Buber’s dialogue is not constrained. For Buber, dialogue is lived. This project identifies parallels between Buber’s dialogue and the nature of connection for people described as having complex needs. Despite *I* and *Thou* being considered ‘messy and unconventional’, ‘suffering from suggestive but unclear language’, ’traditionally unsuitable’, ‘pulsating on the threshold of speech’, and ‘difficult for readers who do not think phenomenologically’ (Ravenscroft, 2017; Mendez-Flohr, 2002; Kaufman, 1970 and Friedman, 1991), in this project, the unbounded dialogue is enjoyed through relationships and reveals itself in interdependence. Buber’s philosophy has been applied to different contexts as this section has uncovered. This project has been influenced by his *I* and *Thou* which is used in the analysis chapter to reflect on the captured relationships between disability practitioners and individuals described as having complex needs. These principles advocate for genuine, respectful interactions which foster mutuality and promote inclusive and humane care. They generate a shift which celebrate the uniqueness of each person resulting in empathetic and effective support based on true connection and mutual respect. It is necessary then to next consider collaborating in research projects with individuals who might be described as having complex needs.

2.3 The challenges and opportunities in collaborating with individuals described as having complex needs

There are limited examples of research collaboration with people described as having complex needs framed from a lens which is critical of the dominant model. There is a clear lack of voice-led research due to inclusion challenges and, more specifically, linguistic barriers. Individuals who might be described as having complex needs do not speak what might be considered a standard language, and as research is presented in the conventional language there are barriers to presenting something which does not fit this model. Furthermore, there is a lack of exploratory research on what inclusion actually means for individuals described as having complex needs (Whitehurst, 2007). This is primarily because interpersonal relationships are questioned where individuals might struggle to display reciprocity (Hughes et al, 2011). Consequently, the perspectives of people described as having complex needs are questioned and presumed unknown (Lewis and Porter, 2004; Ware, 2004; Williams, 2005). For people described as having complex needs, the overwhelming narrative surrounding research and professional practice remains deficit-based, conceptualising individuals as those who lack volition and intention, unable to participate within society and contribute to research (Simmons and Watson, 2014).

Disability Studies calls for broader conceptions of personhood for individuals who may not readily offer self-determination (Hogg, 2007). Scholars such as Goodley and Rapley (2002) critically engage with the dominant discourses, particularly as it relates to 'learning difficulties' or ‘intellectual disability’. Their analysis deconstructs and reconceptualises social practices and language that contribute to the construction of such a phenomenon. Doing so highlights the challenges posed by linguistic and societal norms that reduce individuals with 'learning difficulties' as incompetent and constructs such social realities. The authors identify a pivotal issue, consistent with claims made by Sigelman et al. (1981a), surrounding acquiescence bias—where those with 'learning difficulties' may conform to the expectations of authority figures during interactions. Individuals labelled as having learning difficulties have experienced pressure to play a role and thus compromised the authenticity of their interactions. This is an example of power dynamics, where linguistic and social dominance can lead to the marginalisation of individuals with learning difficulties, or those described as having complex needs, thereby undermining their freedom to present themselves as they choose. Additionally, Goodley and Rapley's (2002) stance agrees with Erving Goffman's (1963) insights on stigma and identity, further expanded upon by Garland Thomson (1997). Both these works showcase how structures in society promote ableism and construct normative standards reducing diversity as deviance and exacerbating the challenges faced by individuals described as having complex needs. Despite these challenges, Goodley and Rapley's (2002) provides opportunities to advance inclusive and equitable collaborations. In acknowledging 'learning difficulties' as socially constructed the authors claim a more sensitive and dynamic understanding of society is available. This creates a shift towards practices that recognise the complexity of social engagement and interactions, advocating for approaches that embrace a holistic view of inclusion and collaboration with individuals described as having complex needs.

There are projects which seek to advocate for and celebrate the diverse contributions of people who are described as having complex needs, but whether this might be considered collaboration is open to interpretation. For example, Biggs and Snodgrass (2020) explore how non-disabled primary school-aged children experience friendship with their peers who might be described as having complex needs. They present evidence that all people, irrespective of needs and linguistic preferences can form meaningful, reciprocal friendships. The data findings showcased robust commonalities across the relationships investigated. They conclude that to promote friendships in schools a strengths-based perspective that deliberately facilitates opportunities for children to be together and value one another's common humanity and individual diversity is needed. One might argue, informed by critical reflection, that this project doesn't fully collaborate with people described as having complex needs despite their involvement. For example, there were sixteen children who participated in the semi-structured interviews offered by Biggs and Snodgrass (2020), and although four students described as having complex needs were identified as key to this study, none directly participated. The sixteen children involved were non-disabled, and the four children identified as having complex needs were involved by association. Although the authors argue their participation in this study was not necessary because they were concerned with broader friendships, one could argue that this does not represent the mutuality which friendships bring.

The phenomenological experience of people described as having complex needs is broad, but their embodied interactions are difficult to translate into normative framework (Merleau-Ponty, 1968 and 2002). Instead, phenomenology and dialogue need to be broad and experienced through our bodily interaction with the world (Guilherme and Freire, 2015). Researchers recognise this, but conceptualising this as collaboration is difficult. Clearly our world is experienced through our bodies so a broadening of our capacity for interpretation is needed if we are to share in embodied citizenship (O'Loughlin, 2006). The most evident example found in the literature of this are from the works of Waite (2018), Simmons and Watson (2014) Nind and Strnadova (2020) and Mercieca (2009, 2011 and 2013). These approaches are influential in demonstrating collaboration with individuals described as having complex needs.

Waite's (2018) first person critical action research *'Deterritorialising Moments: An Exploration into the Educational Experiences of Children said to have Profound and Multiple Learning Difficulties'* draws on exploratory stories about encounters with children with the label of PMLD. Drawing on teacher and personal experiences as a speech therapist, Waite employs a range of philosophical ideas including 'the rhizome' (Deleuze and Guattari, 1987/1994), 'the fold' (Deleuze, 1993/1998) and 'the body with/out organs' (Deleuze, 1969/1990) to express the nature and process of *becoming* in the lives of those with PMLD and the professionals who share them. She celebrates relationships of depth and meaning. Her story about "Karen", for example, gave evidence of empathy and connection during a period of personal grief. Yet, in her professional practice this deep encounter was not reflected in her professional framework as a speech therapist as there was no framework to adopt it. However, the encounter shaped her wider practice despite Karen not conforming to any linguistic norms.

Offering a similar perspective to Waite, Simmons and Watson (2014) present *'The PMLD Ambiguity'* which disrupts medicalised perspectives surrounding the label of PMLD. Offering a range of methodological and theoretical perspectives the authors highlight the problematic nature of trying to put individuals into a theoretical framework 'box', consistent with Waite's story of Karen. They claim the term PMLD is ambiguous. The authors share a story about "Sam" as an example of someone who experiences the world in non-normative ways which challenges concise definitions. It is concluded that limited and fixed definitions recycle a negative experience and can lead to dehumanising practices but instead, but recognising ambiguity creates the space for the development of new narratives and peer relationships in what is a diverse world.

Nind and Strnadova (2020) edit *'Belonging for people with profound intellectual and multiple disabilities: Pushing the boundaries of inclusion'* where multiple authors, consider inclusion in education, research and community. Multiple authors including Ben Simmons, Jill Goodwin, Debby Watson, Noelle McCormack, Catherine de Haas, Liz Tilley and Sue Ledger are tasked to think diversely about participatory involvement in individual research projects. Challenging the popular notion of inclusionism—which Mitchell and Snyder (2015) argue focuses on mere diverse presence rather than meaningful engagement and systemic change to address the root of segregation—Nind and Strnadová emphasise belonging rather than inclusion to underscore it as a basic human right. More vital than social inclusion, belonging is a form of agency, and the authors reflect on this as a relationship with other people, within one's own community and in a relation to a location. They conclude that belonging is a social construction. It is dependent on relational, multidimensional and dynamic influences including the wider political spectrum. The book is ultimately about trying to make belonging more than a tick-box exercise, it is about starting a dialogue with those on the margins of society with the label of profound intellectual and multiple disabilities.

Mercieca's (2009, 2011 and 2013) contribution emphasises the complexities associated with care and support of individuals describes as having PMLD. She highlights the need for individualised, holistic and collaborative approaches focusing on effective communication, quality of life and advocacy. Her work in 2009 focused on supportive structures for development including the key roles family members, support staff and individual education plans play in setting and achieving goals. Her focus in 2011 was surrounding communication strategies including alternative and augmentative communication and multi-sensory environments emphasising the importance of choice-making based on preferences. In 2013 her focus intensified surrounding quality of life as it relates to holistic care, advocacy and rights and community inclusion.

These examples within the literature make a combined contribution calling for change and collaboration. The positionality and methodology of those who conduct emancipatory research as highlighted in this literature assemblage are not ones that focus primarily on methods, but on relations. Yet, it is suggested that the prevalence of linguistic norms within higher education still makes collaboration within research projects challenging, and this is the case in this project. This very thesis conforms to such norms. Even for disabled researchers themselves, collaborating with individuals who might be described as having complex needs remains challenging, especially in conceptualising and translating their contributions into words. The challenge for the researcher is how to share their project and fairly represent the persons encountered who connect in such a broad embodied way (Veck and Hall, 2020). This project did that through working alongside a research committee (as will be explored in the next chapter) and capturing the relationships. The next section therefore draws on two examples of capturing relationships as it pertains to people who might be described as having complex needs.

2.4 Other examples of capturing relationships for people who might be described as having complex needs

Once again, there is a limited array of literature that addresses this issue and aligns with a Disability Studies perspective. Most of the available literature focuses on the effectiveness of practitioner interventions in care and support. However, there are two examples within the literature which are consistent with my approach and influence this project from Simmons (2020) and Kittay (1999).

Simmons (2020) unpicks so-called inclusive education highlighting the clear tension between international policy for inclusive education as a human right (UN, 2006), and what Tomlinson (2017) describes as the challenge of including diverse learners in the current neoliberal education system. Simmons describes the tension as a mismatch between the ideologies of schooling, which according to Greenstein (2016) aim to produce obedient citizens for the global market knowledge economy, and the needs of pupils with diverse learning experiences who cannot cognitively engage with the National Curriculum. In this tension, the author claims that the child always loses as they cause a problem within the system, calling for the inclusion debate to consider 'researching the social'. Simmons (2020) offers evidence from his doctoral research which investigated social inclusion of children with PMLD who experienced both special and mainstream educational opportunities. The research was about how different settings (mainstream and special) offer varying opportunities for social engagement, how children with PMLD respond to them, and their impact on social awareness and communication skills. He established trust and rapport with those involved in the project enabling him to capture relationships and hold informal discussion in real time. He noted that children labelled as having PMLD had minimal interactions with other children in special schools. However, there was a variety of interactions between these same children with PMLD and mainstream children. The children within the mainstream setting developed their own unique methods of connecting with the children in the project identified as having PMLD. The children created relationships, and this was captured during play. These moments caused the author to call for a reform of the education system which reflects the diverse learning needs of all children. He argues that society must begin with the principle that inclusion is beneficial for social cohesion, only then can we consider the conditions that lead to belonging, shared identity, and social cooperation. His research, consistent with this project, supports social model perspectives and is greatly influenced by the evidence captured through relationships.

Another example within the literature where relationships are captured are found in Kittay's (1999) *Love's Labour*. Using her own perspective as a parent of someone who might be described as having complex needs, she examines female caregivers, the significance of dependency work, influential liberal theory and public policy. She claims that policy and theory miss the importance of dependency in discussions about justice, resulting in their inadequacy. Instead, she calls for a vision of an equal society in which caregivers are part of a wider supportive community. Acknowledging dependency while calling for equality are the major principles of her book, desiring a society which accepts and responds to its social responsibility for the care of dependents and those who offer primary care. The reality experienced by Kittay is a burden of care, like many parents or primary caregivers she experiences the barriers of finding her place in an unequal society while maintaining care from a labour of love. This, a common experience for those in her position leads caregivers to be vulnerable to poverty, sickness and isolation.

Kittay's account of primary caregivers offers an insight into the tensions and experiences for those who play a vital part in the collaborative social identity experienced through relationships for people described as having complex needs. Her observation is that the stress to become as 'independent as possible' for people described as having complex needs subtly questions their full humanity. Kittay is able to challenge this perspective with every embrace with her daughter, reinforcing her determination to redefine 'fostering development'. She calls for a new perspective surrounding development—one that emphasises enabling individuals described as having complex needs to experience joy.

Love's Labor as a reflective piece is full of raw expression, it showcases the love, and at times pain which accompanies caregiving. This literature capturing Kittay's reflections of her daily experiences was helpful during the preparation for this project which is concerned with capturing relationships. In particular, her claim that there are days when we are not "inter" dependent was challenging and thought-provoking. Although those who hold to the social model might highlight how societal barriers maintain dependencies, it is fair to claim that even with the removal of socially constructed barriers, some individuals will remain dependent on caregivers. The removal of barriers is nonetheless necessary though, as her parental experiences bring to light the challenges associated with supporting a dependent person in a system where there is not a collective effort to care for those who need it, and their caregivers. Yet, one of her key points is to acknowledge the significant value and contributions that those who might ordinarily be considered dependent bring to relationships. For what caregivers receive from these relationships significantly surpasses what they contribute. Words cannot summarise the influence her daughter has on her life, Kittay claims that she is unable to read philosophy- she will never read or contribute to English communication, yet she is the tutor on every page of her book.

The literature in this chapter was chosen because, overall, it offers an alternative perspective to the dominant narrative surrounding the subject of disability practice, particularly as it relates to individuals described as having complex needs. The subject area is broad, and there are many areas I have been unable to cover or felt was unnecessary due to the specific consideration of this project. What has been offered from the literature as a common thread is the complexities which surround the implications of Disability Studies for practice. The chapter has in some detail also considered what has been said about complex needs and practiced through collaboration and considered what Martin Buber’s theory has to do with any of this. This chapter has offered some insight to the literature relevant to the field and following this the rest of this project will make a unique contribution and addition to the body of literature.

3. Methodology

The Methodology chapter outlines the approach used to capture relationships between disability practitioners and individuals described as having complex needs. It begins by discussing the theoretical foundations of the data gathering methods, divided into specific sections. Firstly, it examines positionality and Critical Realism, exploring how beliefs and experiences influenced the research approach. Secondly, it considers disability research, including power dynamics and ethics. Thirdly, it discusses the methodological approach, including emancipatory research and distinguishing between Participatory Action Research and Action Research *with* Participation. Fourthly, it describes how a research committee was formed and the research design and ethical considerations relevant to this project. Finally, it introduces the analytical framework to analyse and interpret the data.

3.1 Positionality and paradigms

3.1a) Positionality

I am the driving force behind this doctoral thesis, a Christian, a professional within the Health and Social Care sector, and a student of Disability Studies. This multifaceted background has, at times, been challenging, given the assumptions surrounding identity within each category. The discomfort arises from being perceived as aligned with the liberal socialist left, as a humanities student, and with the traditional conservative right due to the association with evangelicalism. The effort to reconcile potential clashes within this belief system often leave room for self-questioning. The influences on this study extend beyond personal experiences, encompassing perspectives posed from post structuralist philosophers as identified in the previous chapter, Deleuze, Derrida and Foucault. Equally significant are influences from thinkers such as Lewis, Buber, Bonhoeffer, and broader Judeo-Christian material, including the authority of biblical text considered to be of the highest significance.

In recognising the impact of researcher positionality on decision-making throughout the research process, this section aims to elucidate the factors that have shaped the researcher. Firstly, Christian values and interpretation of scripture form a foundational aspect, guided by a comprehensive summary of the entire Bible found in Matthew 22 verses 36-40, emphasising the directive to love God and love people. The belief in the equal creation, inherent value, and significance of all human beings as Imago Dei, that is; made in the image and likeness of God, is deeply ingrained. The concept of the Imago Dei has been central to Christian theology and the way it is interpreted deeply informed my positionality. Historically the Imago Dei was linked to rationality and intellectual capacity. Augustine of Hippo (354–430) and Thomas Aquinas (1225–1274) associated human reason, love, and free will with distinguishing humans from other creatures and affirming their divine origin. This perspective, outlined in De Trinitate (Augustine, as cited in MacIntyre, 2013) and Summa Theologica (Aquinas, as cited in Taylor, 2012), has historically contributed to a rationality-centric framework. This framework has marginalised disabled people, including those who might be described as having complex needs.

Contemporary theologians have reimagined the Imago Dei as rooted in relational and communal dimensions rather than intellectual ability. Vanier (2008) highlighted the sacredness of all human lives in their capacity for relationships and love. Swinton (2012) argued that the Imago Dei is expressed through vulnerability, dependence, and relationality. Similarly, Yong (2011) proposed an interpretation that emphasises that the Imago Dei reflects the capacity to embody the Spirit of God, regardless of ability. This shift toward a relational understanding reflects broader theological movements. Haslam (2012) and Tataryn and Truchan-Tataryn (2013) suggest that the Imago Dei aligns with the Trinitarian nature of God as an interdependent and inclusive community. They argue that humanity, created in this divine image, should embrace interdependence and celebrate diversity. Contemporary theology reframes disability not as a diminishment of the Imago Dei but as a profound reflection of it. My position on the matter aligns with Reynolds, who, in vulnerable communion succinctly frames it this way:

> *‘every human being has the image of God in common, even as it is expressed in variety and difference. Differentiation is part of God’s intention for humanity, so it does not indicate an inequality between some, but the equality of all. Here disability does not mark an incomplete humanity…. It models one way of being human as vulnerable yet creative, relational, and available. Notice the*

> *absence of terms like “reason”, “productivity” and “independence”’ (Reynolds, 2008, p.186).*

This personal conviction about the Imago Dei goes beyond a theoretical or philosophical understanding, representing a practical commitment to what being an image bearer means. Introduced in the previous chapter, Buber's *I-Thou* philosophy underpins this project, as such it is crucial to highlight how I share many of his views surrounding the Imago Dei and this has shaped this project influencing how data is collected and analysed. Secondly, I have been significantly influenced by professional experiences in Health and Social Care working alongside individuals described as having complex needs. Amidst the daily responsibilities, ranging from leadership and quality assurance, being a caregiver and collaborator was the most challenging but rewarding experience. At the time of conducting this study I was Head of Service for the organisation in question and I observed my experiences and responsibilities change as the organisation grew over many years. This shift in my professional role led to a heightened awareness of the potential impact my personal beliefs may have on the first-hand experiences of others within the organisation. The fear of ‘not caring’ has significantly shaped my positionality in this project as care and collaboration remain integral values stemming from my own professional experiences. The shaping of my perspective extends beyond personal experiences to encompass my belief system, professional practice, and educational journey.

As highlighted in the Introductory chapter, I am a student of Disability Studies who is informed by the social model of disability. The insight gained in both Undergraduate and Masters courses has inevitably shaped how I approach disability and how this project was conducted. The amalgamation of my spiritual, educational, and professional journeys has significantly shaped my worldview, consequently influencing the approach adopted in this project. The three dimensions of my life can be succinctly summarised: my spiritual journey shaping my character, my educational journey informing my convictions, and my professional journey moulding my competencies. The research choices in this project are rooted in my personal perspectives and emotions. They take a value-driven stance, politically motivated to challenge traditional assumptions about relationships between disability practitioners and individuals described as having complex needs calling for a socially-just society (Dowling and Brown, 2010; Shildrick, 2012).

3.1b) Positionality; Critical Realism and qualitative approaches

Given the preceding considerations, this project aligns with Critical Realism which stems from the belief in an objective reality and rejects the notion of everything being open to interpretation, while acknowledging the influence of dominant social structures on belief systems and prompting reflection and deconstruction of assumptions (Bhaskar, 2008 and Easton, 2010). It further contends that the world encompasses objects of necessity, with social observations influenced by abstract ideas derived from social practices. In essence, Critical Realists argue for the division of reality into the empirical (including human experiences and observations), the actual (comprising events) and the real (consisting of means and processes influencing the actual). The adoption of a Critical Realist approach strikes a balance between the rigid binary positions of positivism and interpretivism and maintains an appreciation of constructivism. For this researcher, adopting criticality as it relates to structures and language, permits a critical reflection towards the motives behind truth claims, while allowing a belief in an ascertainable truth. This epistemological stance recognises various interpretations of experiencing and understanding the world, acknowledging the influence of social construction on many facets of reality (Mertens, 2002).

In the landscape of educational research, ongoing debates surround the nature of truth and knowledge (Cohen, Manion, and Morrison, 2018). This project's assumptions about truth and knowledge, while not jeopardising its credibility, shape its trajectory in alignment with Critical Realism, which allows me to uphold scepticism towards concise definitions of personhood (Pratt, 2003; Creswell and Roth, 2017; Greenbank, 2003). It gives the freedom to embrace uncertainty. Such an approach profoundly impacted the project's outcomes. Therefore, the project lacks value-neutrality which might be associated with other research paradigms. The eagerness to explore the social world through a lens of doubt and scepticism about the nature of reality, as proposed by Garfinkel (1967), sets this project apart. Acknowledging this lack of value-neutrality may lead some to question the evidence-based nature and credibility of the findings, yet my positionality and experiences resist any other way forward. This leads me to recognise the limitations of my knowledge. This awareness significantly influenced the project’s approach to research paradigms, characterised by cautious scepticism towards truth claims and an appreciation of the social model of disability. Consequently, positivist paradigms and its assertions of absolute truth claims were unfitting with this project, such rationale has shaped the medical model employing reductionistic methods to justify assertions. Framed from a Critical Realist perspective then, this project employs qualitative methods to capture and understand human relationships within the research paradigm. This was deemed essential as the project was influenced by those who do not use, what might be described as the standard language. The research paradigm needed to allow for meaning-making. Qualitative approaches prioritise the meanings, social relations, and practices of the individuals involved, they aim to understand and describe social phenomena from the perspective of insiders by exploring their voices (Lapan et al., 2012). This perspective is reflective of the researcher's position within the study and the lives of those involved. Qualitative methods do not undermine the emotional connection within the project but, according to Denzin and Lincoln (2005), allow for a deep consideration of others. Employing Critical Realism with qualitative methods allowed me to explore participants' voices to uncover what shapes social phenomena. It meant that I could connect human experiences with actual events while remaining sceptical of the underlying structures which shape both.

As I am a non-disabled researcher, adopting a conversational approach was essential in this project in learning from disabled perspectives, which McRuer and Johnson (2016) claim will challenge ableist strongholds. Achieving this necessitates explorations and descriptions of experiences. Meaning-making in this project is not presented as absolute truth. It is an interpretation based on partial knowledge, acknowledging the inherent limits of this researcher's understanding. Adopting qualitative methods allows for the exploration of the fluidity, multiplicity, and vagueness of reality as identified by Law (2004, p.42). Central to the project is the emphasis on voice, and Critical Realist approaches were deemed suitable as they allow for meaning-making (Bhaskar, 2008). This approach allowed the participants to shape the project collaboratively, without being overly concerned with precise definitions of language. The alignment of Critical Realism with the researcher's values, coupled with qualitative methods, was considered to enhance the potential for wider participation within the project (Maes et al., 2020).

3.2 Doing disability research

As highlighted in the Literature Review chapter, there is plenty of research surrounding disability, but historically, projects have been deficit-based and only served to empower the researcher and subdue the researched. Disabled people have, in the past, been objectified in the name of research (Oliver, 1992). Certainly in the 20th century, difference was scrutinised in a bid to establish so-called desirability at the expense of those who were considered deviant (Barnes, 1997). Scientific revolutions and medical interventions were lauded as ‘breakthroughs’ seeking to overcome undesirability with a eugenic philosophy, and this still influences medical and educational practice today (Mitchell and Snyder, 2003). The research which did take place with disabled people, elevated the authorship status of powerful practitioners over the lives of those produced as ‘docile bodies’ (Foucault, 1977a and Bolt, 2014). Despite this power play, it was disabled people themselves who challenged the discourse and altered the picture by taking control of projects to offer new perspectives (Oliver, 1990 and Brechin, 1993). The problematic history of doing disability research caused this non-disabled researcher to adopt a careful approach ensuring that the project would be underpinned by Disability Studies, promoting what Shakespeare (2015) describes as inclusive forms of research with genuine, not tokenistic, collaboration. Throughout the project I remained mindful of the potential impact on participant co-researchers through the intricacies of data gathering and analysis (Guba and Lincoln, 1989). I adopted critical consciousness which Sakamoto and Pitner (2005) describe as the ability to recognise and interpret a range of inequalities present in a situation in order to take action against them. As a non-disabled researcher doing disability research adopting critical consciousness meant that in recognising historic and systemic issues at play, I was motivated to consider my approach in order not to recycle social injustices within disability research.

3.3 Adopting a suitable methodological approach

3.3a) Emancipatory research and participatory methods

With the dangers of doing disability research explored, it was necessary to remain consistent with Priestley's (1997) guide to emancipatory research which adopts the social model as foundational to practice. Doing so maintains a socially just and politically driven intent; removes disabling barriers; shares project control with disabled persons involved and adopts flexible methods of data collection as a response to the changing needs of those involved.

The heart of emancipatory research is its liberatory focus, pursued through participatory methods, adopted by this project, reflecting the wider trend towards inclusive methodologies. Participatory methods were deemed suitable as individuals described as having complex needs have previously been absent from self-advocacy movements, but inclusive and participatory methodologies rightly place disabled people as co-researchers, advisers, data gatherers and authors (Bigby, Frawley and Ramcharan 2014, Da Silva, Smith and Rocha, 2020 and Kid and Kral 2022). It was hoped that this approach would result in a project considered fair, diverse, insightful and of greater impact for those involved, shaping future projects that seek to collaborate alongside people described as having complex needs (Munn-Giddings and Cook, 2016). Participatory methods offered an array of possibilities and provided a stage for oppressed individuals to affirm their diverse identities. This was an exciting yet unnerving prospect, as it forced this researcher to be vulnerable and relinquish control. Participatory methods within disability research have developed alongside Dan Goodley's contribution to post-human theory, as introduced in the Literature Review. His contribution extends beyond theoretical discussions, he offers significant methodological and practical advancements in Disability Studies. His work has shaped research approaches which challenge human exceptionalism and recognise the diverse ways of being and knowing that disability exemplifies. This project, in critiquing traditional research methodological norms finds similarities to his work which, like this project promotes creative research methods, including arts-based approaches to reflect the interconnectedness of bodies, environments, and technologies (Goodley, 2020).

The unconventional approach to participatory methods, common in liberatory research (Cook, 1998; 2009), presented opportunities to connect and gain insight into different experiences and were felt to be enjoyable and suitable for the research context. Participatory methods alone, however, would not achieve emancipation; this research needed action. Research that initiates a difference, as highlighted above, is that which has outcomes in practice; problem-solving research. Therefore, the next section considers the methodological approach of Action Research, and its relation to Participatory Action Research.

3.3b) Action Research

Action Research (AR) is a term describing several methodological approaches that reflect on and improve professional practice (McNiff, 2017). It functions in cycles which interrelate; it is critically reflective throughout - both on the journey and the result; it requires participation and collaboration from all involved; it results in a change or enhancement of practice (Kemmis and McTaggart, 1992; Ebbutt, 1985). Usually, those who engage in AR within their own practice attempt to identify problems within their setting, and then undertake a series of actions and reflections to improve their practice. AR is about studying social situations in order to improve what is taking place within it (Elliott, 1991). It combines action and reflection, theory and practice, through participatory means to improve areas of concern, which, in this case, relate to human flourishing (Reason and Bradbury, 2013). AR could be considered a collaborative effort to address issues within professional practice and bring about positive change (Reason and Bradbury, 2013; McNiff, 2013; Stringer, 2013; Zeichner and Noffke, 2001). Kane and Chimwayange (2014) claim that the outcomes of AR contribute to improving practice and empowering those involved. It is believed that AR aligns with the positionality and social values of this researcher because of the importance placed on reflection, participation and change (Koshy, 2009).

3.3c) Participatory Action Research; truly an emancipatory approach

For this project it could be suggested that AR does not go far enough. It was the desire of the researcher to adopt Participatory Action Research (PAR), an approach which goes further than AR with an emphasis on collaboration in *all* areas of the project (McNiff, 2013). PAR equalises power, positioning the researcher as ally and fellow traveller with co-researchers rather than subjects (Carroll 2009; Atkinson and Hammersley, 1994 and Koshy, 2009). There is a distinction between AR and PAR. While AR is concerned with social change with those involved being considered imperative (Lewin, 1946), PAR, learning from the work of Friere (1970), goes further to blur the lines completely between the researcher and the researched for emancipation and social change. PAR is fundamentally tied to the principles and values of Disability Studies, as it promotes inclusion and emancipation throughout the research cycle. This is of primary importance as PAR seeks to take principles behind the social model and put it into practice (Stack and McDonald, 2014), providing true emancipatory research opportunities for disabled people to shape all stages of the project. PAR aligns with researcher values and would have reduced potential harm throughout this project as it does not allow authorial ownership over apparently docile bodies from the outset. Instead, it increases accountability because it is participatory from start to finish, embodying a social practice that is practical, collaborative, emancipatory, critical, reflexive and transformative (Kemmis and McTaggart, 2005). However, over the years working on this project it became clear that the use of PAR for a project, which was ultimately about achieving a professional doctorate, was going to be problematic.

3.3d) The EdD problem and a methodological innovation

For a project to truly adopt PAR, complete collaboration would have been essential from the outset, encompassing the formulation of research questions, consideration of project aims, and attainment of ethical approval (Barnes and Sheldon, 2007; Barton, 2005; Goodley and Moore, 2000). In this project, the researcher retained ownership and significant control over the direction, ensuring specificity, focus, achievability, originality, and relevance before involving co-researchers. Despite the desire to empower and benefit participants, claiming a full adoption of a PAR methodological approach in this doctoral research would be disingenuous.

This study, therefore, took a middle ground which I have called Action Research ***with*** Participation (ARwP). Handing over as much control as was feasible, as early as possible, was the intention. So, from the point of ethical approval onwards, I sought to redistribute power and control more equally between myself and those involved in the project. This was achieved by facilitating the co-researchers, who selected and shaped participatory methods for data collection and analysis, thus influencing the direction of the project. As with all AR approaches, this research was *with* people not *on* people and so I evidenced how my co-research committee actively shaped the project from the very first meeting, which outlined its purpose. Like Waite (2018) identifies in her AR project, the emancipatory principles within Disability Studies blended with AR create a more inclusive approach, therefore, ARwP was adopted in this project as a means of conducting inclusive research. ARwP is a novel approach, but the principle of inclusive research depends not on titles but on impact.

3.4 Complex needs and reflecting upon the nature of voice

3.4a) The co-researchers with voices to be heard

The co-researchers in this project formed a research committee. Within ARwP, the research committee did not just partake in the methods of data collection; they chose them. The committee included diverse disability experiences: Disability Studies graduates (professional caregivers on behalf of the organisation), parents, and those who might not have ever claimed the identity of having complex needs but had it attributed to them. Within the research committee, I was particularly keen to learn from those with the label of complex needs, as there was much to gain from their insights. Doing research alongside people with such a status attached to their identity brings controversy, as they are a substantially marginalised group and have rarely had a platform within Disability Studies (Barton, 2005 and Boxall and Ralph, 2010). It seems that calls for self-empowerment have created opportunities for some voices to be heard, but with great emphasis on speech or associated normative translations. There are other reasons for the absence of individuals described as having complex needs within wider research. Harding (2009) highlights that the nature of consent is complicated, particularly when there is debate as to what might be considered rational ‘views’ (Lewis 2004; Ware 2004 and Williams, 2005) and whether the right adaptations are available to both capture and interpret what might be understood by voice (Mitchell, 2010 and Beresford, 2012). There remains a lack of exploratory research on what inclusion means for individuals with this label, as the quality of interpersonal relationships are often belittled. Reciprocity is presented as absent yet necessary for friendships, with notable exceptions (Whitehurst, 2007; Hughes et al, 2011).

3.4b) Relationships, connection and struggling to translate

As highlighted in the introduction, the cultural context surrounding individuals described as having complex needs is shaped by behavioural and educational psychology, particularly influenced by behaviourism and cognitivism which tries to develop relationships, establish connections and capture voice through the use of one-click buttons and partaking in practices such as intensive interaction (Simmons, 2020). This project, however, advocates for broader conceptions of personhood than these methods use for those who may not readily offer self-determination (Hogg, 2007). There needs to be more scope for not-knowing. Although capturing data from those described as having complex needs presented a challenge, meaning-making from non-verbal connection and pre-established relationships, as shown in the analysis, will provide valuable insights for readers and clear learning points for professional practice (Mazzei, 2007).

3.4c) Bodies, voice and meaning-making

It is fair to suggest that all people experience the social world through their bodies. Researchers should therefore broaden their capacity for interpreting the way language is perceived. Communication being defined as ‘the imparting or exchanging of information by speaking, writing, or using some other medium’ (Oxford Dictionary, 2020) presumes that meaning is to be subject to translation. For many people in the world, this excludes their personal experience of language. Instead, non-normative approaches to communication provide rich variety (Biklen, 2005; Baggs, 2007; and Bogdashina, 2005).

This understanding of language, where all people experience an embodied citizenship (O’Loughlin, 2006), lies at the heart of this project. It aligns with the foundational principles behind the works of Mercieca (2009, 2011 and 2013), Nind and Strnadova (2020) and, those explored in the literature review (Waite, 2018 and Simmons and Watson 2014), which is why collaborating with a diverse group of co-researchers to offer creative ways of listening without privileging spoken words was felt to be essential. Instead, movement, reflections, produced artefacts were all considered forms of expression, broadening the definition of voice. Doing so privileged difference, which St. Pierre (1997) claims increases the boundaries of what is considered data.

3.5 Research design and plan

This next section outlines the project design and plan. At the start of the second phase of the EdD, I considered the research aims, plan and wider design within the project. I considered the main research question, sub questions and the ‘What, Why, Who and How’ of the project as displayed in Image 2.[2]

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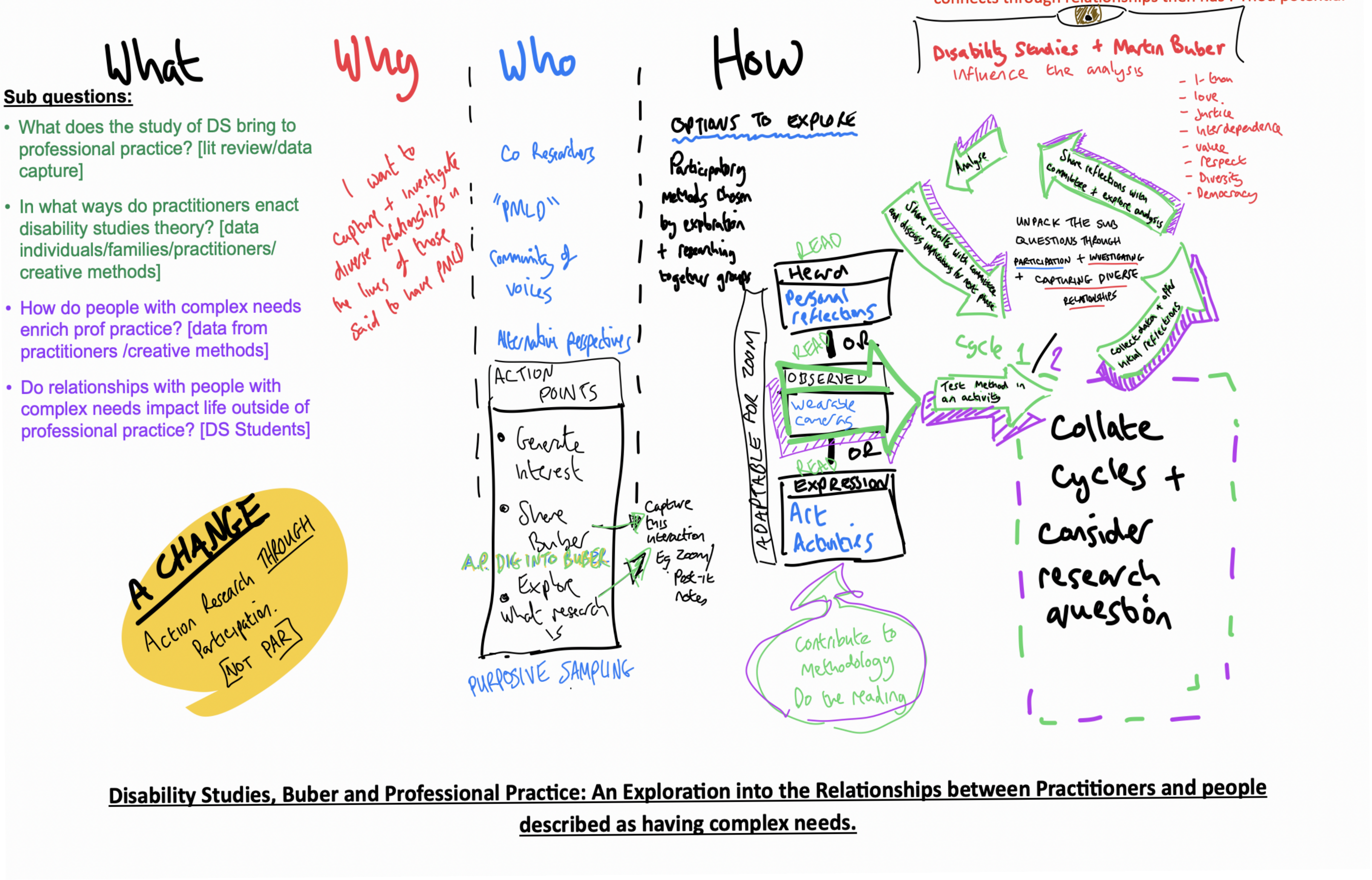
[2] The project has developed since this initial plan, including crucially refining the research question

Image 2



Sub questions:

- What does the study of DS bring to professional practice? [lit review/data capture]
- In what ways do practitioners enact disability studies theory? [data individuals/families/practitioners/ creative methods]
- How do people with complex needs enrich prof practice? [data from practitioners /creative methods]
- Do relationships with people with complex needs impact life outside of professional practice? [DS Students]

Disability Studies, Buber and Professional Practice: An Exploration into the Relationships between Practitioners and people described as having complex needs.

This exercise led to the following research question: **What might Buberian philosophy bring to an appreciation of relationships between Disability Studies practitioners and people described as having complex needs?**

The following sub questions were also adopted within this project:

- What does the study of Disability Studies bring to professional practice for individuals described as having complex needs?
- In what ways do practitioners enact Disability Studies theory?
- How do people with complex needs enrich professional practice?
- Do relationships with people with complex needs impact life outside of professional practice?

Although the research question and sub questions are primarily addressed within the Analysis chapter, these questions were considered throughout this project at all stages. To do so, the following research plan was followed, the specific details and points from this plan are covered in more detail in the remainder of this chapter:

1. At the time the project was conducted, I was the Head of Service for the organisation in which the research took place, therefore gatekeeper consent was sought and approved from the Chair of the Board.

2. Purposive sampling was adopted to draw together nine co-researchers to form a research committee. They included four caregiving practitioners who were graduates in Disability Studies, three young adults who might be described as having complex needs and two parents.

3. Consent forms, information sheets and an accessible information video were shared with all involved and consent was gained, while recognising its problematic nature in relation to some of the individuals that made up the purposive sample.

4. In the first meeting with the group, the aims of the project were shared and ARwP was explained in relation to their role. The research question and sub questions were shared along with some of the foundational principles of Martin Buber's *I-Thou* philosophy. I shared with the group a range of data collection methods and activities which might be suitable for capturing relationships and the group considered different approaches presented. They collectively decided to conduct two data collection exercises, the first would be an arts-based activity session, with all involved which would be captured via wearable cameras, and the second a practitioner focus group captured via audio recording. Having shared some initial thoughts on the process of analysis using 'something heard', 'something observed' and 'something expressed', the group expressed a desire to keep the meetings to three occasions including this initial meeting and adopt all three headings for how the data was to be captured and transcribed. A summary of decisions and outcomes were shared with the group in minuted format which was not verbatim.

5. The arts-based activity session, captured through wearable cameras, took place in July 2022. This was the first data collection cycle.

6. The practitioner focus group, which was audio recorded, also took place in July 2022 to gather further data. This was considered a second data collection cycle and built on the first session.

7. The data from the arts-based activity session captured through wearable cameras was then transcribed and arranged under three headings; 'something observed', 'something heard', and 'something expressed'. The data from the practitioner focus group was transcribed verbatim.

8. The data was coded, thematically grouped and themed, then analysed using a Buberian theoretical lens alongside Disability Studies theory.

9. The conclusions and implications for practice were gathered and shared with the research committee.

3.6 Ethical approval

3.6a) Approach and BERA

Like all research, ethical approval was obtained following the professional guidelines for Educational Research outlined by British Educational Research Association 2018 (BERA) before engaging with those who participated in this project. The ethical approval process considered various aspects: a) who would be involved, b) how they were approached, c) how consent was obtained, and d) how they were informed about the nature of their participation.

The project also outlined measures to reduce or eliminate any potential physical or psychological harm to those involved including myself. A comprehensive plan detailing the protection and anonymisation of data collected from those involved was provided. Pseudonyms were used to ensure confidentiality, and any personal details shared by individuals that could reveal their identity were anonymised in the analysis and transcript. The recorded data was securely stored in a password-protected folder until the project's completion, after which it will be deleted to uphold ethical standards and prevent reuse for other projects. Along with BERA (2018), adherence to Liverpool Hope University's 'Research Ethics Policy' was imperative, requiring a thorough review by a team of academics to assess risks to participants, the university, and the researcher.

3.6b) Recruiting the research committee: purposive sampling

As the project sought to examine relationships between people described as having complex needs and Disability Studies practitioners, both were essential for this project’s research committee. The research committee consisted of; three young adults who might be described as having complex needs (two of whom are siblings); two mothers of those involved in the project (both of whom had more than one child who might be described as having complex needs); and four staff members who were professional caregivers- all graduates in Disability Studies. For this project, purposive sampling was deemed the most suitable way to recruit those who would form the research committee. Approaching both Disability Studies graduate practitioners within the organisation and those known for the longest period of time, who might be described as having complex needs, provided the project with the maximum opportunity to address the research question through their experiences of extended time together because:

- This project would benefit from a small research committee who had shared experiences to reflect on.
- As the research question directly relates to Disability Studies, then Disability Studies graduates were needed to be extracted from the wider staffing team to contribute to the research committee.
- This research was open to researcher interpretation, knowing those involved meant that when capturing and analysing the data there was potential for more accurate and contextual interpretative insights into experiences gained or shared. This was of particular relevance to those who might be described as having complex needs whom I had known for a period of over five years at the time of capturing the data.

3.6bi) Names and roles

In the Analysis chapter, the captured data will highlight individuals within the research committee under the following pseudonyms: Mary, Courtney, Gabriella, Holly, Harvey, James and Blake. I have taken the decision in this project not to identify who out of the named individuals are Disability Studies graduate practitioners and who out of the named individuals might be described as having complex needs. I have taken this decision for several reasons. Firstly, as a reflexive researcher I am seeking to disrupt an unnecessary labelling process which can stigmatise or privilege certain individuals. Secondly, it is the belief of this researcher that the disregarding of classification of roles actually supports the analysis and the themes which are presented there.

3.6c) Problematic consent

Consent was considered through best interest and consistent with the principles behind the Mental Capacity Act (2005). For those partaking in the project described as having complex needs, interpreting their consent was problematic because they do not speak the standard language and translating would be problematic. They could not sign consent forms or verbally express their willingness to take part in this project in a language I could directly translate, and, vitally, I was never going to be able to confirm with any certainty that they were aware of the aims and objectives of the project, despite trying to make the information as accessible as possible. Moreover, it was challenging to know whether the individuals would discern a change in my role from caregiver to researcher in this project. This became even more complicated when the nature of vulnerability is considered; it is not known whether the men and women who participated in the project would consider themselves vulnerable. The Mental Capacity Act (2005) highlights the need to assume capacity and for incidents where capacity might be called into question (or in this case, hard to establish and translate a preference) a best interest decision is a suitable outcome rather than parental consent alone.

Based on the prior existing relationship with those involved, I believe the individuals who took part in the project were comfortable doing so alongside friends and family. Furthermore, as this research was directly connected to their experiences and aimed to capture relationships between Disability Studies graduate practitioners and individuals described as having complex needs, it was considered their right to be involved. That said, due to the complexity of the project, the views of parents remained essential to the project creating collective accountability to reduce any harm and always ensure we remained reflective of what we thought were the desires of those involved. Therefore, a video was created which sought to inform participants in the most accessible means possible about the research and it accompanied an additional information and primary caregiver consent form. This approach was deemed more accessible for participants who may struggle to interpret easy read / symbol communication, aligning with the researcher's aim to provide critical reflection, sensitivity, and respect.

3.6d) Risk considerations and clear boundaries

Vitally, all involved within the research committee were at minimal risk of physical harm. The project participants were approached and treated with care and sensitivity, without intrusion and maintaining the policies of the setting in which the project was conducted. Furthermore, all persons were aware and reminded of their right to withdraw at any point and to withdraw their data within one month after participating in the first data capture. All were reassured that data collected would be anonymised as would be their identity. It was deemed appropriate that the data capture should be carried out in locations that were physically accessible, safe and familiar. Although there was minimal anticipated psychological risk to those involved, all were reassured that if someone displayed any sign of psychological distress, the subject of discussion would be halted and a new approach adopted. For individuals who are described as having complex needs any visible signs of distress would be interpreted as a request to take a break or withdraw, although this did not happen to be the case within the project.

The risk considerations towards Disability Studies graduate practitioners (who were colleagues and may have brought their own preferences and prejudices to the project which could have challenged the rapport and trust during the process), were also considered. Prior to the project I reflected upon how my position as Head of Service could have influenced their engagement. It was therefore made clear in writing and verbal engagement with these members that participation was voluntary. Documentation from Liverpool Hope University such as ‘guidance for researchers’ emphasised this was an academic piece. Prior to the project start there was also consideration to the potential benefits of participation which included individuals being able to celebrate their story and showcase diverse experiences, develop a critical awareness of what relationships look like for people who might be described as having complex needs and Disability Studies graduate practitioners.

3.7 Methods

This section highlights the systematic steps and participatory methods I and the research committee used to capture relationships between disability practitioners and individuals described as having complex needs.

3.7a) The first meeting

The research committee first convened for a preliminary and introductory meeting in which the participation video and research information sheets were shared. This provided an explanation of the project aims, research question and introduced Martin Buber's philosophy and ARwP. The committee was asked to consider two cycles of data collection, one altogether which sought to capture relationships and a second specifically for disability practitioners to reflect on practice (image 3). Bloom et al (2020) offered a review of five of the most effective methods for eliciting voice in those with speech and communication barriers and concluded that there was a clear gap in the research in terms of suitably robust and transparent methods to elicit the voice of those with communication needs. Interpreting movement, vocalisations and behaviour is subjective. This project did not solely focus on methods to capture individual views, but methods which captured relationships, this is also open to subjectivity. Nevertheless, this project privileged relationships above methods, as such any artefact produced throughout the arts-based activity, was secondary to the connections made within the activity (Veck and Hall, 2020). Privileging this was in order that attention shifted away from deficit or dependence and to mutuality, dignity, capability, personhood and citizenship (Kittay, 1999 and Vorhaus, 2005).

3.7ai) Cycle one: The choices

For cycle one, the research committee was offered a choice of participatory methods (detailed below) to capture relationships under the following titles 'something observed', 'something heard', and 'something expressed'. I grouped the methods in this way to encourage the group to reflect upon a specific form or mode of communication. For 'something heard' I proposed storytelling as a method to capture auditory communication within the research committee because sharing photographs and objects could provoke shared experiences aligned with the research questions and disrupt normative approaches to verbal storytelling (Grove, 2014). For 'something expressed' I proposed making created artefacts as a method to capture expressive choices. This approach, inspired by studies like Williams and Hanke (2007), could strengthen group identity and that could have been effective for capturing relationships. Despite critiques, such as those by Prosser (1998) and

Atkinson and Delamont (2006), the combination of storytelling and art, as seen in storyboarding and graphic novels, offers multi-layered emotional impact and credible participant experiences (Galman, 2009 and Fischman, 2001).

For ‘something observed’, I proposed capturing the data through observation or the use of video. Observational research methods are common within educational research, specifically in settings-based analysis. Simmons and Watson (2014, 2015) used participatory and longitudinal observation to study an individual with the label of PMLD in special and mainstream settings to propose an appropriate setting. Observations allow for creative thinking about engagement, as demonstrated by Watson (2020) using realistic play in combination with observation methods and interviews. In the context of relationships, observational interpretation of group interaction may confirm assumptions through unstructured and participatory engagement, offering a less intrusive alternative to video methods (Watson, 2020).

There are examples of the benefits to using video for data capture; Buckingham (2009) and Rojas and Sanahuja (2012) are an example of projects where video can present a mode for capturing voice for people with learning difficulties. Of particular interest is Warwick’s (2020) use of wearable cameras which shifted the gaze and perspectives of life experiences for people described as having complex needs. Wearable cameras within research projects change the relational dynamic, they showcase participation, create an equitable and accessible platform to capture diverse experiences and relationships (Low et al, 2012 and Boxall and Ralph, 2010). In this project, the use of wearable cameras by individuals who might be described as having complex needs could offer a first-person lens adding an accessible layer to the data capture. It was acknowledged that wearing cameras might change the group dynamic because of an increased sense of surveillance and this might disrupt the very thing the project is trying to capture but the risk was felt to be worth taking.

The group decided that the wearable cameras would be a good way of capturing relationships, but they also believed this would be enriched by an art-based activity session. There was consensus this would not be invasive or make those within our research committee uncomfortable but would offer an alternative perspective. The group considered that wearable cameras would offer far more than observable data as the cameras would also pick up audio recording. Finally, the group considered that ‘something observed’ would be covered in the observational data picked up by the wearable cameras, ‘something heard’ would be picked up by the audio, and ‘something expressed’ could be an artefact produced in the session together. This unexpectedly shaped this researcher’s approach to the analysis.

3.7aii) Cycle two: The choices

Cycle two was about capturing Disability Studies practitioners reflections on practice. Following the decision that wearable cameras might best capture diverse relationships within an arts-based activity session, the next decision was between reflective practitioner diaries or through a focus group. It was suggested to the committee that the use of practitioner diaries might capture individual reflections without the risk of coercion which accompanies group dynamics. It was also suggested that in writing, practitioners might more readily crystallise their thoughts which I would be keen to consider. However, the drawback of practitioner diaries is that they are time consuming and that group reflections might more easily yield stories which address the research question. Alternatively, it was suggested that reflections in cycle two could be captured in a focus group. Focus groups are a form of group interview which places reliance on the collective rather than the individual (Morgan, 1996 and Nind et al, 2020). Krueger and Casey (2014) claim that working as a collective can reveal deeper understanding and nuances about complex relational issues which might not be picked up in individual surveys or interviews. Operating as a collective, enables the researcher to step back and not impose their agenda as the interactions between the group generates the data. For this reason, group dynamics are essential and, in general, are more successful when comprised of relative strangers, yet, within this project, which is primarily about capturing relationships, familiarity becomes an important criterion for the group. With this being the case, it was proposed that I would be a suitable moderator to enable the group to remain on task but without the controls that a semi-structured interview might hold.

There are some drawbacks to focus groups, they are typically an unnatural gathering and as such can make the discussion contrived (Cohen, Mannion and Morrison, 2018). A challenge in this instance would be ensuring individuals feel comfortable enough to speak out. For others their chance to speak out is reduced when there are particular dominant members (Krueger and Casey, 2014). Another drawback is if the group discussion is led by the collective then it might naturally go off topic and not address what the researcher seeks to learn. This can result in a facilitator getting overly involved and as such controlling the session. Yet, for this project and the nature of the topic it was proposed that this approach would offer a strong addition. Focus groups empower those involved to speak out as collective, which due to the nature of the research question is suitable for this project. Crucially, Cohen, Manion and Morrison (2018) highlight that focus groups are of particular use when gathering feedback from previous studies or to triangulate data from other forms of data capture, which, due to the timing of this study and its relation to cycle one, the arts-based activity session, would offer a substantial approach to tackling the research question. The Disability Studies practitioners chose to demonstrate their professional reflections through the form of a focus group rather than individual diaries as they described conversation, and the sharing of experience would enable them to better address the research questions. Furthermore, they decided that working together might stimulate more reflections and it would be more time effective to complete this in one meeting rather than reflective diaries over the course of one week.

Following the first meeting, two dates for the sessions were set within the same week: one for all to take part in a range of arts-based activities to capture relationships through wearable cameras, and another for practitioners to conduct a focus group capturing practitioner reflections.

IMAGE 3 (these are the slides from the first meeting)

DISABILITY STUDIES, BUBER AND PROFESSIONAL PRACTICE:
AN EXPLORATION INTO THE RELATIONSHIPS BETWEEN PRACTITIONERS AND PEOPLE DESCRIBED AS HAVING COMPLEX NEEDS

SESSION 1: AN INTRODUCTION

05001491@HOPE.AC.UK

MY ROLE IN THIS PROJECT IS AS STUDENT RESEARCHER - ALTHOUGH I HAVE GATE-KEEPER APPROVAL FOR THIS PROJECT IT IS NOT RELATED TO MY ROLE AT RUSHTON FUTURES

SESSION AIMS

1. BACKGROUND TO THIS RESEARCH:
A) DISABILITY STUDIES
B) BUBER
C) RELATIONSHIPS WITH PEOPLE DESCRIBED AS HAVING COMPLEX NEEDS

2. THE METHODOLOGY:
A) ACTION RESEARCH WITH PARTICIPATION
B) THE RESEARCH COMMITTEE

3.HOW DO YOU WANT TO CAPTURE RELATIONSHIPS?
A) PROFESSIONAL REFLECTIONS
B) CAPTURING MOMENTS: SEEN, HEARD, EXPRESSED

1A) DISABILITY STUDIES

WHAT IS IT?
- ACADEMIC SUBJECT, ACTIVISM, AND A WAY OF SEEING THINGS

WHAT ARE SOME IMPORTANT ASPECTS OF DISABILITY STUDIES?
- MODELS OF DISABILITY

WHAT IS ITS RELEVANCE TO THIS PROJECT?
- A PERSONAL BACKGROUND, THE EXPERIENCE OF SOME HERE, A WAY OF INTERPRETING DATA

1B) BUBER

WHO IS HE?
EDUCATIONAL PHILOSOPHER FOR PEACE EDUCATION

WHAT ARE SOME IMPORTANT ASPECTS OF HIS EDUCATIONAL PHILOSOPHY?
I-THOU AND I-IT / DIALOGUE

WHAT IS THE RELEVANCE TO THIS PROJECT?
A THEORETICAL LENS FOR CAPTURING RELATIONSHIPS

1C) RELATIONSHIPS WITH PEOPLE DESCRIBED AS HAVING COMPLEX NEEDS

WHAT DO WE MEAN BY 'DESCRIBED AS HAVING COMPLEX NEEDS'?
THE PROBLEM WITH FIXED CATEGORIES

WHY ARE DIVERSE RELATIONSHIPS SO IMPORTANT?
HOW DOMINANCE HAS SHAPED KNOWLEDGE

WHAT IS THE HUNCH THAT I HOLD AS A RESEARCHER?
WHERE WE LEARN AND THE WAY WE THINK ABOUT LANGUAGE

2A) ACTION RESEARCH WITH PARTICIPATION

2B) THE RESEARCH COMMITTEE

YOU!

3A) PROFESSIONAL REFLECTIONS

FOCUS GROUPS?

DIARIES?

KAREN'S STORY

3B) CAPTURING MOMENTS: SEEN, HEARD, EXPRESSED

ACTIVITY GROUPS:

WHAT ACTIVITIES GO WELL; ARTS, MAKING PAPER?

CAPTURING IT:

SEEN - WEARABLE CAMERAS

HEARD - STORYTELLING

EXPRESSED - COMIC BOOKS

3.7b) Cycle one: An arts-based activity session captured through wearable cameras.

Due to the nature of this project, the activities in which the data would be captured needed to facilitate relationships and be guided towards answering the research question. The activities did not have to be complicated, but needed to involve interaction, touch and mutual engagement. This would facilitate non-conventional storytelling, like McCormack's (2017; 2020) ethnographic approach, which interprets diverse communication patterns and social interactions through spending time with participants and analysing movement and objects rather than relying on auditory storytelling. Creative, fun and participatory activities would showcase these relationships in practice offering insight to a diverse experience of life which could potentially offer a catalyst for change (Abma and Banks et al, 2019 and Munn-Giddings and Cook, 2016). Furthermore, unlike a formal interview or 1:1 engagement which can leave people feeling exposed and elevate the researcher's power, group working offers real collaboration which will afford emancipatory gains (Bloom et al, 2020).

Three wearable cameras were purchased and, using a body harness, were worn by three members of the research committee who might be described as having complex needs. I believed three cameras would offer enough viewpoints to capture how the activities took place across the room. It would capture observable data; it would capture audio data and it would capture any artefacts produced within the session. While wearing these cameras, all within the research committee participated in the three following activities in one large room:

i) **Deconstructing paper to make paper.** Completing this task created something expressed. Those within the group collaborated to tear up different coloured paper and place it in a blender which was attached to an accessible switch. The paper was then blended into small pieces by using a switch, then placed into a large box of water to turn it into mulch. Using a paper making mould frame the group worked together to take out some mulch and drain it within the frame. They then added different decorative items to the drying paper before it was left over night. This is a messy activity which requires some hand over hand activity along with the use of an accessible switch.

The images below are Mary and Courtney's deconstructing paper to make paper and James and Gabriella's deconstructing paper to make paper.

ii) **Balloon Volleyball**. Those within the group worked together to keep several balloons from hitting the floor for the longest period of time by the use of an accessible switch and a hair dryer for as long as possible. It was considered that this activity would generate a sense of competition, and one which might result in those involved having fun and enjoying working together. This activity needed the use of some hand over hand working and the use of an accessible switch. In practice this activity was not as successful, as the wire length of the hair dryer restricted the area covered.

iii) **Recreate canvas challenge**. Completing this task created something expressed. Those within the group chose to collaborate to recreate one of three pieces of scenery art. There were no set instructions on how to recreate these scenes, but there was a range of options for those involved from which to choose from including, balloons filled with paint which needed to be burst, water guns filled with paint, brushes, scrapers and individual paint pots. Using a range of methods to recreate the scenery the group needed to work together. This activity would need some hand over hand, some reaction-based responses and some use of an accessible switch.

The images below are Harvey and Holly’s recreated canvas challenge (a waterfall) and James and Blake’s recreate canvas challenge (trees).

3.7c) Cycle two: The focus group

Following this the Disability Studies graduate practitioners met together to reflect on the activity, the nature of their practice and the relationships they hold in a focus group. Focus groups have been effective for emancipation and liberation of voices through storytelling of those often not heard (Madriz, 2000). Focus groups offer participatory gains as group deliberation and mutual learning among participants is stimulated (Abma and Banks et al, 2019). This principle of the collective is stronger than the agenda of the researcher as the attraction of synergy offers a problem-solving approach to research questions (Cohen, Manion and Morrison, 2018). Focus groups are a particularly effective method for investigating positionality and individual values (Morgan, 1988).

The group met after a work shift and were asked a range of questions to generate discussion. Firstly, the group reflected on the research questions and sub questions with their individual perspectives. The group took turns responding and there was little need for the researcher to offer prompts. The group also reflected on the activities within cycle one highlighting what areas they felt might best capture relationships. The focus group was audio recorded and lasted 23 minutes.

3.8 Analytical method

3.8a) *I-Thou* as a lens

As highlighted in the Literature Review, there are few projects which use Buber's *I-Thou* philosophy for a theoretical lens to analyse data, even fewer within Disability Studies. Yet in this project it was adopted along with Disability Studies theory to make sense of the data. The process of ARwP and the analysis which fits within the cycles did not have to produce neat tales with a meaning. The stories which follow do not have to be policed as this is about genuine experience in a real world of difference (Riessman, 2008). For this reason, I find Buber's *I-Thou* useful as a tool for interpretation. Interpretive research offers numerous valid interpretations of reality as does this project (Riessman, 1993; Riessman, 1997 and Biggam, 2015) and so it is the desire of this researcher that a Buberian framework to understanding the data, will affirm difference and the beauty of human relationships, and in so doing will oppose hegemonic inequality (Ewick and Silbey, 1995). It is hoped that the stories in the project will have counter-hegemonic potential (Ewick and Silbey, 1995).

3.8b) Reflexive Thematic Analysis

Throughout this project I have made a conscious decision to consider the impact of my approach. A reflexive researcher is connected to those in their project and sensitive of their own actions while recognising a need to offer a contribution. The lens by which the data would be understood was Buberian, but the method to understand the data in this project was through Reflexive Thematic Analysis (RTA). RTA, outlined by Braun and Clarke (2019) is fluid and recursive, recognising the researchers personality, reflections and instinct within the project. Typically, RTA has six stages as outlined by Braun and Clarke (2006, 2012, 2013, 2014, 2019):

1. Familiarisation with data

2. Production of initial codes

3. Creation of themes

4. Review potential themes

5. Define, and name themes

6. Produce the report.

Although these steps appear structured and linear, it is typical for researchers to move back and forward within the data as RTA is considered an evolving and time-consuming process as different interpretations come to the surface that require further iterations of previous phases (Byrne, 2021). As such the process above was considered as a set of guidelines rather than rules. RTA allows for decisions about themes to be based on personal reflections of the data. Clearly there is subjectivity in this approach, but this could be argued for all approaches. The researcher is not passive in this project, and neither are the themes which emerge from the data; they are not hidden 'in' the data which are stumbled across, they are shaped through critical reflection.

3.8c) Transcribing the data

The focus group was transcribed verbatim. Transcribing the videos was more complicated. Firstly, the amount of possible data available made the task challenging; there were over seventy-one minutes of footage split between nine individual video clips captured from three perspectives. When writing up the data I adopted the following approach:

Tables were created for each individual video to transcribe the data specific to that recording. Each video was thoroughly reviewed, first in its entirety, then on mute, and finally with the screen hidden. Every time pauses were made when there was noteworthy content capturing something diverse about relationships or in relation to the research question. When transcribing, detailed notes were taken regarding the video's time, the recording individual, and relevant data. As suggested by the research committee in our first meeting, the recorded data was transcribed under one of three titles: 'Something Observed' for observational data, 'Something Heard' for auditory data, and 'Something Expressed' for instances when the camera captured a produced artefact or work in progress. The below table provides a summary of the amount of data gathered:

Data Capture	Content Length	Transcribed data
Arts-based activity session captured through wearable cameras	9 videos with a combined length of 72 minutes 43 seconds of content.	4,005 words
Disability Studies practitioner focus group	22 minutes 37 seconds of content	2,834 words

In the upcoming chapter, The Analysis will provide more substance to the process of collecting and interpreting the data within this project. The analysis used established methods of Reflective Thematic Analysis; it involved watching, listening, and reflecting on the captured data, grouped into themes related to Disability Studies and Buberian philosophy, thereby addressing the research question.

4. Analysis

This chapter will present a rigorous analysis of the data gathered in this project. It is organised into three sections. The first section describes the method of analysis. The second section presents the data, highlighting themes and explaining the rationale behind them. Finally, the third section uses insights from the data to address the research question: "What might Buberian philosophy bring to an appreciation of relationships between Disability Studies practitioners and people described as having complex needs?”. Throughout, a critical reflection on Martin Buber’s *I-Thou* and *I-It* philosophy is undertaken, highlighting its strengths and weaknesses for understanding relationships between Disability Studies graduate practitioners and individuals who might be described as having complex needs.

4.1 Method of analysis

As emphasised in the previous chapter, the research committee opted for two methods to capture relationships. The first method was an arts-based activity session, using hand-over-hand and accessible switch technology and captured through wearable cameras. The second was a practitioners’ focus group. The data was analysed via Reflexive Thematic Analysis which builds on Thematic Analysis as it privileges researcher subjectivity, organic and recursive coding approaches and a deep reflection with the data (Braun and Clarke, 2019). The steps in my Reflexive Thematic Analysis were:

1. The data was captured through a session with wearable cameras (video and audio) and a focus group (audio). The wearable camera session included three arts-based activities over a 25 minute period, utilising three wearable cameras that captured nine individual pieces of footage with 72 minutes of total audio and video footage. The focus group was audio recorded and was 23 minutes in length.

2. The focus group was transcribed by listening to the audio and transcribing verbatim the content. The content captured was 2834 words.

3. A table was formulated for the transcription of data extracted from wearable camera recordings. It centred on the categories 'something observed’, 'something heard’, and

'something expressed' (the latter denoting collaborative outcomes such as the artefacts produced). The wearable camera sessions underwent transcription by identifying salient points. The criteria for what was considered salient was gathered under the headings of 'something observed', 'something heard' and 'something expressed'. I did not knowingly disregard any movement captured by any person on video or knowingly disregard any captured audio content by any person. To ensure this, the videos were viewed three times, each time with a distinct focus. Initially, the complete videos were observed, and relevant information pertaining to the research question and literature review was documented. A second viewing involved muting the audio to prevent oversight of content under the 'something observed' category. For the third viewing, only the audio content was accessed, with visual content obscured to prevent oversight of material categorised under 'something heard.' The systematic approach to data capture aimed to eliminate conscious omissions or oversight, recognising the challenge of transcribing broader actions within video data.

Video title / participant (Example from H3)	
	What is captured
What drew my attention and when? (Describe what is observed, heard, expressed)	Harvey3. **Observed**: First 45 seconds of the video mum is recording Harvey on her phone, she is smiling. At the end she shares the photo on her phone with carer and Holly. H3. Mum turns to Mary 1m08 and touches her on the shoulder and leans in for an embrace, Mary responds with a smile. Harvey covers the camera with his hand. 1m 19 captures Courtney and Mary holding hands moving hands around one another’s hand. Courtney then leans in closer and Mary puts her hand around Courtney and feels her hair. H3. She then pulls it! H3. **Heard**: 5sec Holly “no paps! you have to keep this cool mysterious guy that never smiles” mum says “go on Harvey”. HG. 30 seconds mum says “he can’t see the camera but he knows it there”… Harvey responds with “waaaaaaaaa”. 2m04 Harvey says “aaaaaaarrrr” and Holly says “do you want to help, is that why you’re whining?” H3. **Expressed**: Harvey tries to throw the piece of art created 2m27 and mum, Courtney, Holly and carer laugh. 2m31 the camera shows the piece of art Harvey created- a waterfall canvas.
How does this relate to the focus group?	
How does this relate to the research question?	

4. The video data was reviewed, and individual codes related to disability theory and Buberian philosophy were generated. From this, 48 codes emerged.

Video Session Codes
Assumptions around objection, carer power, captured collaboration, authors, choices, assumptions, decision makers, reactive sense-making, gently keeping informed, sharing, anticipation brings calm, personal spaces, sharing spaces, affection and pride, requesting to gently help, change when spoken to, intimacy and mutuality, pride, gentleness, normalised culture, assumptions of consciousness, fun, chaos, capturing moments, closeness and touch, pride in gaining, affection, verbal engagement less during engagement, focused, concentration, silently forgotten, metaphorical pictures of chaos, a narrative of questions, a narrative of touch, priorities, ability shapes engagement, facing people, perspectives, intimacy, chaos and disruption, mischief, working the environment, multitasking, the use of we, dictating practice, coughing counts, attention doesn't mean looking that way, moments of connection.

5. Next, the focus group transcript underwent a similar process; the audio was listened to again along with the transcript and the data was merged into three categories, analogous to the video categories. The table looked like this:

What was said	What it means	Interpretation (how it relates to theory)

6. Analysis of the focus group generated 11 further codes which are listed below:

Focus group additional codes
being unsure, mutual vulnerability, ideology and practice, caring feels good, being part of something, people rather than tasks, task and relationships, anxiety and uncertainty, person -lead, affection more than tasks, pride and demands of care

7. Codes from both transcripts were compared, and data from the focus group incorporated into the video data table under a new row - 'how does this relate to the focus group?' This was so that consistencies and inconsistencies between the focus group data and

video data could be identified, aiding the creation of themes across the project and consider their relationship.

4. All codes were listed and then were grouped by patterns of meaning (Braun and Clarke, 2019) and then assigned a colour along with the relevant data.

5. Grouping codes rendered seven initial themes which would help summarise, organise and tell the story which has been constructed from the data, they were: Assumptions / Choices, Collaboration / Sharing, Uncertainty, Chaos / Fun, Joy / Pride, Task, Closeness / Touch.

6. Part of continuous reflections within the coding process and the titles of the initial themes provoked me to re-watch the videos, focusing on moments of physical touch, whispers and questions posed to some individuals. A table was created, quantifying these moments:

Moments of Touch (any person)								**Questions asked**	
Video	Total time	Touching of hands		Embrace		Whisper			
H1 (8m34)	19m 46	1	**13**		**7**		**7**	7	**42**
H2 (8m37)		10		4		5		21	
H3 (2m35)		2		3		2		14	
J1 (13m06)	25m15	3	**10**	1	**2**		**1**	15	**65**
J2 (12m09)		7		1		1		**50**	
M1 (8m34)	27m42	10	**37**	8	**15**	4	**20**	14	**45**
M2 8m36)		18		3		1		18	
M3 (8m37)		16		7		12		12	
M4 (1m55)		3		5		3		1	

Initial reflections: These interactions appear intense and intimate. Such close physical proximity and questioning, beyond immediate family, seems unusual. Despite this, interactions appeared comfortable and natural, even upon initial viewing. Mary predominantly initiated moments of closeness and touch with Courtney, who seemed to enjoy these interactions. In contrast, James was compliant as a dialogue dominated by questions was directed at him by Gabriella.

11. Following this I made some reflexive considerations of potential explanations and counter-explanations for these observed incidents. The relational context I hold with those involved in the project contributed to this reflexivity. I decided to apply the 60 captured moments of hand over hand to the theme Collaboration/Sharing. 152 moments were added to the themes Vulnerable/Uncertain and Task as this was the number of questions asked toward an individual taking part during the activity. 24 captured embraces or hugs, 28 whispers and 60 moments of hand over hand were added to the theme Closeness/Touch.

7. Consistent with Braun and Clarke's (2019) approach to RTA, I continually reflected on my own thought process during the coding process, questioning the assumptions I was making, whilst interpreting and coding the data. The intention to adopt reflexivity resulted in a decision to further group coding and, consequently, themes. The seven initial themes became sub-themes of three major themes. I combined Closeness/Touch, Collaboration/Sharing, and Joy/Pride as sub-themes of 'Tangling'. Chaos/Fun and Uncertainty became sub-themes of 'Vulnerability'. Assumptions/Choices and Task became sub-themes of 'Practising'. These titles, consistent with the coding process, intimate something of Buberian philosophy and disability theory.

4.2 Presenting the themes

This next section will present and define the themes. Data from the relevant sub-themes is then presented, and then the construction of the major themes from the sub-themes elucidated.

Theme	Occurances	Sub-themes

Vulnerability	Evident in two sub-themes and 12 codes. 152 questions asked (this data applies to both Vulnerability and Practising)	Chaos / Fun Uncertainty
Practising	Least prevalent. Evident in two sub-themes and 16 codes 152 questions asked (this data applies to both Vulnerability and Practising)	Assumptions / Choices Task
Tangling	Most prevalent. Evident in three themes and 20 codes. 24 embrace / hug 28 whispers 60 occasions of hand over hand	Collaboration / Sharing Joy / Pride Closeness / Touch

4.2 a) Forming 'Vulnerability'

'Vulnerability' is about embracing risks, uncertainty, and complexity while humbly remaining open to new possibilities. This theme combines two sub-themes which are Chaos/Fun and Uncertainty.

The sub-theme of **"Chaos/Fun"** encapsulates instances and depictions of amusement, laughter, and the tumultuous or disorderly facets inherent in intricate relationships on display in the data. This sub-theme presents the unpredictable nature of the human experience within complex social dynamics. Within the coding process, eight distinct codes emerged as integral components of this sub-theme, collectively constituting 30 instances within the dataset. The prevalence of these codes underscores the significance of chaos and fun within the activity sessions, shedding light on the nuanced and often paradoxical interplay of joy and disorder within the fabric of interpersonal connections of all involved.

Extracts:

Sub-theme: Chaos / Fun	
Data selection from the arts-based video session	**Transcript selection from the focus group**
Mary1. **Observed**: 5seconds Mary using left hand to tap and knock and shake the camera. Mary1. Heard 7m05 Courtney laughing saying "Mary keeps blocking the camera its like she's says 'no paps - no paparazzi today guys". Harvey3. **Heard**: 5sec Holly "no paps! you have to keep this cool mysterious guy that never smiles" mum says "go on Harvey". Harvey tries to throw the piece of art created 2m27 and mum, Courtney, Holly and carer laugh. Mary2 4m55 Mary can be seen grabbing Courtney's staff badge. 5m16 Mary can be seen knocking the switch over and over. Mary2 6m33 Mary tried to grab Courtney's pony tail and Courtney turns and smiles. 6m57 Courtney can be seen adjusting the table height so Mary can move closer to the activity. As Mary moves closer to the activity she immediately reaches for the bucket of water. Mary2. 4m55 as Mary grabs Courtney, Courtney laughs and says "aaaaaaah no, Mary". 7m47 Courtney says as Mary tries to grab the water "ooooh Mary I can see your eyes!" Harvey3 1m 19 captures Courtney and Mary holding hands moving hands around one another's hand. Courtney then leans in closer and Mary puts her hand around Courtney and feels her hair. Harvey3. She then pulls it!	*FG. Courtney: … She (Mary) was like trying to knock everything off anyway* FG. Gabriella: Its like I'm here, this is me, a bit like that probably.

In this selection, the data captures the fun but chaotic experiences of collaborating to complete a task. The first extract highlights both Mary and Harvey's reaction to having items on their person. Mary pushes away the camera and continues to turn it off and on through the session, whereas Harvey pushes the art piece away which makes those around him laugh. This sub-theme captures a relationship between Courtney and Mary. Courtney and Mary have a playful encounter as Courtney, somewhat unsuccessfully tries to encourage

Mary to join in the paper making exercise. Mary does not co-operate and is far more interested in making a game of the task. As Courtney seeks to engage in the playful exchange, she also tries to maintain a level of order. Mary seeks in one moment to gently embrace Courtney and then playfully pulls her hair. Courtney laughs and appears to enjoy Mary's disruptive efforts even when she seeks to grab a bucket of water on a nearby table. Although it is Courtney's voice throughout the exchange it is Mary who is calling the shots. Courtney's dialogue in response to Mary is playful, the tone feels like Courtney is egging her on. In the focus group, Courtney remembers this encounter as something which might be of note referencing Mary's desire to knock everything off the table.

This extract clearly emphasised how in this encounter, the task was secondary, and the relationship was primary. This exchange was beautiful. Both Courtney and Mary appeared to enjoy one another's company and enjoyed the chaotic engagement. These moments contradict a societal discourse that associates the experiences of those described as having complex needs as inherently tragic. In contrast, Mary and Courtney's moment was an affirmation of disorder. A celebration of non-normativity which is consistent with my own experiences of working alongside people who might be described as having complex needs- filled with happy memories; not sad, filled with chaos; not order.

The sub-theme of "**Uncertainty**" pertains to instances captured which evidence a lack of clarity within the task at hand. This uncertainty is discerned in the disability practitioner's (or indeed parents) delicate navigation of choices, introspective questioning of their approach, and the earnest exploration of potential solutions. In the scenarios presented there are questions which are posed without immediate answers, highlighting a vulnerability in the disability practitioner's engagement, often expressed through a tender touch, alongside explorative questions. Five distinct codes contributed to this sub-theme, encapsulating 13 illustrative examples that underscore the pervasive nature of uncertainty within the landscape of relationships between practitioners and individuals described as having complex needs. This data evidence the nuanced intricacies inherent in the practitioner's encounter with uncertainty, emphasising the depth of inquiry and the quest for understanding amid ambiguous circumstances.

Extracts:

Sub - theme: Uncertainty
Data selection from the arts-based video session
Mary1. **Heard**: Mary grinding her teeth 1m10. 1m14 Mary heard saying “gal gal gal gal go” mum responds with “what are you telling us?”. 5m20 Courtney can be heard saying to Mary “what do you think we should do?” Mary3. **Observed**: From 1 minute MB comes into shot leaning over Mary, Holly, who is supporting Harvey turns to look at Mary and taps her nose indicating to Courtney, next to Holly stands mum and private carer who along with Holly stop to look at Mary, they stare for 10 seconds, then smile and turn away. Mary3. **Heard**: MB approaches Mary and says “what do we think Mary?” Holly shouts over to MB at 1 minute “MB tap her nose” MB can be heard saying “are you here with me Mary, I gotta go I gotta go” The room which fell quieter for a few seconds then continues on with sound.

In the two extracts there is evidence of uncertainty. Mary’s mum responds to her noises with questions about what she is trying to express, Courtney seeks clarity with mum about what activity to do first. The other example of uncertainty is when Mary appears to have a moment of absence, all captured when the group turn and look towards Mary, and Holly asks MB to touch her nose, mum and carergivers stare watching on for Mary’s response. Once she responds and the moment of absence ceases those in picture carry on with their tasks. The extracts showcase questions without answers, the questions are explorative and reveal a sense of vulnerability and uncertainty within these relationships.

Chaos / Fun + Uncertainty = ‘Vulnerability’

The convergence of the sub-themes "Chaos/Fun" and "Uncertainty" within the broader theme of ‘Vulnerability’ underscores the nature of genuine human connection. "Chaos/Fun" injects a vibrant and unpredictable energy into the relationships between practitioners and individuals with complex needs. Amusement, juxtaposed with the disorderly nature of interactions, create an environment where spontaneity and unpredictability thrive. This chaotic yet fun dynamic becomes a catalyst for breaking down barriers, fostering a sense of shared experience, and ultimately laying the foundation for ‘Vulnerability’. Simultaneously, the sub-theme of "Uncertainty" introduces a layer of delicacy and introspection to the narrative. The examples here showcase disability practitioners navigating ambiguity, questioning their approaches, and earnestly seeking solutions without immediate answers. This ‘Vulnerability’ is most evident in the tender touches and explorative questions that permeate the diverse interactions on display. The uncertainty powerfully promotes humility as practitioners resist the temptation to rely on fixed judgments and instead embrace the unknown. The theme of ‘Vulnerability’, therefore, emerges as a combination of chaos and uncertainty, where the willingness to navigate the messiness of human connections becomes a celebration of humility, exploration, and the richness found in embracing ambiguity. Vulnerability therefore becomes the prerequisite for authentic connections, embodying a profound acceptance of the unpredictable nature inherent in complex social dynamics.

4.2 b) Forming ‘Practising’

‘Practising’ is about making assumptions and doing practice. The theme is made up of the sub-themes Assumptions/Choices and Task.

"Assumptions/Choices" unveils instances where practitioners or family members make pivotal assumptions or decisions on behalf of individuals described as having complex needs. This sub-theme showcases the nuanced landscape adopted by caregivers in making decisions for those in their care. It considers the weighty responsibility they bear in interpreting the wishes of individuals who communicate differently from what might be described as the standard language. There are 12 distinct codes which contributed to this sub-theme with 10 illustrative examples in the data. The prevalence of this sub-theme underscores the inherent challenges and ethical considerations associated with decision-making in the environment of complex care.

Extracts:

Sub-theme: Assumptions / Choices	
Data selection from the arts-based video session	**Transcript selection from the focus group**

Observed:Harvey1 5m40 pushes the camera facing towards his stomach. Carer lifts the camera back to the upright position and says “he wants to film his feet” Harvey1 **Heard**: 1m35 “aaaaaaaarrrrrrrr” during the story accompanied by a “sh sh sh sh sh and a whisper do you not like the story” **HEARD** James1. 11m40 mum says “he’s actually really interested in the balloons over there” 12m40 James changes position so he is facing other activities and mum says “is that better you can see a bit more now”. James1. **Expressed**: 9m10 Blake, Holly and Mum discuss which piece of art to try and express and decide to go for one related to trees because James likes trees	**FG** Blake: …*I was in another care job and the lad I looked after was described as non-verbal and we’d be making a lot of his decisions for him because there was that assumption that he didn’t have a voice*

In the examples, we see how decisions can be made on behalf of another quickly with a degree of assumption. For both Harvey and James there is a discussion of likes and dislikes by carergivers and family. It is assumed that Harvey wants to film his feet because the camera is moved. For James, the caregivers and family make a choice to move his chair based on an assumption that he wants to watch the balloon game, similarly the carergivers decide to paint a piece of art including trees based on James’ fondness of trees. These examples evidence the tension between assumptions and decision-making processes for people described as having complex needs. This is picked up in the focus group when Blake described in a previous care role having to make decisions on behalf of someone who might be considered to not have a voice because they are described as ‘non-verbal’.

These extracts evidence that the assumptions and decisions made were based on some level of relationship and prior knowledge. This context is important, because those involved in this project would not verbally explain why they might look a certain way, what their preferences are, or why they might knock a camera. Nevertheless, this does not make their movements meaningless, the meaning is open to interpretation, and this interpretation is strengthened in the context of relationships. These examples show the complexity of making decisions in practice for people who might not verbally correct another if their assumption is wrong- but it would be naive to think that any person might have the confidence to correct another following a misplaced but well-meaning assumption.

The sub-theme of "**Task**" refers to moments centred around task-oriented practices, examining the delicate balance between meeting routine care needs and fostering flexibility within relationships. This sub-theme captures the inherent tension between the structured nature of caregiving tasks and the adaptability required to navigate the dynamic nuances of interpersonal relationships. Ten codes were integral to this sub-theme featuring seven instances in the data. This sub-theme provides valuable insights into the intricate interplay between task-oriented responsibilities and the relational aspects inherent in caregiving practices.

Extracts:

Sub-theme: Task	
Data selection from the arts-based video session	**Transcript selection from the focus group**
James2. Blake keeps James involved in the outcome of the paper making 9m40, Turning to him and offering a chance to feel what has been made. James2. **Heard**: Gabriella describes that "What do you reckon? I think that is fab" showing J the art piece he has created. Gabriella asks James "shall we rip some paper up what do you reckon?". 2m55 Gabriella says "do you want to rip it, here would you like to listen to it?".	*FG Gabriella: before I started working here and before I did the Disability Studies I was doing supported living, and it was very regimental and to be honest I'd just go about it and go along with it because I didn't really know what else to go by.* *FG. Blake: one of the things I've found though which will be different from when you started was that because there are a lot of people here who have done Disability Studies we're all on the same page if that makes sense when it comes to outlooks and perspectives and when you get new staff in, our ideologies sort of go onto the new staff.*

This sub-theme picks up examples of task orientated practice. The focus group identified how practitioners in previous employment would be task orientated and routine driven. This is positioned as a negative experience and contrary to Disability Studies ideology. This is not explicit; it appears the focus group are seeking to make a reference that having a regimented approach to care is opposed to person-centred practice. Blake highlights how group experiences can shape a workplace culture. In the session, the data picks up the interactions between Blake, Gabriella and James. Blake and Gabriella seek to involve James in the activity, working together to rip the paper. But overall, James seems uninterested, he often turns away but the staff maintain the practice. The questions asked to James are all task based around James ripping the paper, for which he appears uninterested. It is interesting to note that the same staff who highlight regimental approaches within the focus group persist with the activity in this encounter.

The combination of the encounter and the focus group offer a point for reflection on a misconception that a task driven approach is not person centred. There are some tasks which if they are not done mean that an individual is left at risk of harm. This was a difficult tension to interpret but evidenced the power of the professional within the relationship of an individual who might be described as having complex needs.

Assumptions / Choices + Task = Practising

The theme of ‘Practising’ emerges as a nuanced exploration between assumptions, choices, and task-oriented practices in the realm of caregiving for individuals who are described as having complex needs. Building on the sub-theme "Assumptions/Choices," we are reminded of the weighty decisions made by practitioners and family members on behalf of those they support. The theme of ‘Practising’ showcases the challenges and ethical considerations inherent in assuming responsibility for individuals who express language in less conventional ways, even those described as having complex needs. The examples reinforce the gravity of decision-making in the complex care environment, emphasising the pivotal role assumptions and choices play in shaping the caregiving narrative.

Simultaneously, the sub-theme of "Task" introduces the dimension of routine care needs and the delicate balance when infusing flexibility into caregiving relationships. As ‘Practising’ unfolds, the tension between the structured nature of caregiving tasks and the adaptability demanded by dynamic interpersonal relationships becomes evident. The fusion of "Assumptions/Choices" and "Task" cements the overarching theme of ‘Practising’. The theme encapsulates both the challenges and the necessity of making assumptions and engaging in practices when providing support for individuals described as having complex needs. It recognises the dual nature of the term 'Practice,' encompassing both the noun and the verb, highlighting the essential role of both concrete actions and ongoing learning in the caregiving process. This synthesis is further evidenced by the 152 questions directed towards individuals during the activity session, emphasising the active engagement and continuous inquiry inherent in the practice of providing care and support. ‘Practising’ emerges as a theme that acknowledges the dynamic and evolving nature of caregiving, where assumptions, choices, and task-oriented practices meet within processes of learning.

4.2 c) Forming ‘Tangling’

‘Tangling’ is the profound intertwining of lives, emotions, and tactile connections that form a beautifully intricate tangling in the caregiving relationship. It is made up of sub-themes Collaboration/Sharing, Joy/Pride, Closeness/Touch.

The sub-theme of "**Collaboration/Sharing**" refers to occasions where two or more individuals engage in collaborative efforts or shared experiences. It demonstrates the significance of working together within the caregiving context, emphasising the interpersonal dynamics that contribute to effective collaboration. Seven distinct codes, comprising 23 instances within the data, illuminate the diverse ways in which individuals come together to share responsibilities, experiences and tasks. It demonstrates the importance of collaborative approaches within caregiving scenarios and the building of friendships and trust.

Extracts:

Sub-theme: Collaboration / Sharing

Data selection from the arts-based video session	**Transcript selection from the focus group**
Observed Mary2. 1m28 Courtney offers Mary a new choice of colours, she explains the colours and touches each hand with the colour to encourage Mary to make a choice, Mary chooses the white. Mary2. 3m58 C places the paper in the blender and encourages Mary to use the switch, Mary reaches out and touches the switch which starts the blender. Mary takes the switch out of Courtney's hand. Courtney has a big smile while Mary is taking the switch out of her hand and encouraging her to join in. Mary2. **Heard**:4m Courtney encourages Mary and says 'woooo' when Mary takes the switch out of her hand. "You got it" "can you hear it? Yes Mary! Yes Mary!". Mary3. 1m21 Courtney is **heard** saying "Mary, I don't think we've done this right". Mary grinds her teeth. 2m 25 Mary coughs. 2m29 Courtney can be heard saying "** Cough cough** , is that my cough, has Blake got my cough" Mary can be heard giggling.	FG. Courtney: I'd say a massive one is language, I think like defo you don't need to use words to get across what you want to get across. Like the people in this project use language in a much different way than me and maybe these two here but also from everyone else who's doing the research, I'd go as far as saying it'd even change depending on the relationships you have with each person. Like I'd say that James would relate differently with Blake than he would with me because of the depth of relationship. I'd defo say I'd learnt that from people we support that its not as simple as a want/needs or request relationship. There's loads of ways of doing it.

The second example in the table is between Mary and Courtney. Courtney asks Mary to choose a colour of paper which Mary takes from Courtney and then immediately throws on the floor. They then work together to complete tasks where Mary presses a switch to start the blender, Courtney reinforces the sharing by celebrating what Mary is doing. As the task nears completion Courtney and Mary share in a moment of diverse communication, Courtney fears they have completed the task incorrectly, but the dialogue between the two is shared back and forth, they share coughs, laughter and the grinding of teeth. The task is shared, and the way they interact was an exercise in collaboration. In the focus group, practitioners emphasised the value of collaboration, citing the relationships formed and the diversity in language as significant benefits. Their understanding of voice fuelled their practice as seen in the gentle requests and the back-and-forth playfulness in expressing themselves in the project.

This sub theme highlighted the crucial role of practitioners in the lives of those described as having complex needs and showed that engaging in collaboration offers mutual, often greater, benefits. In the focus group Blake described how collaboration has broadened his understanding of voice, and he uses the phrases ‘richness’ to emphasise the benefit of this diverse expression, an experience only available through sharing and collaboration.

The sub-theme of "**Joy/Pride**" encapsulates moments where disability practitioners or family members highlight happiness in their relational experience. Whether articulated through; discussions about individuals, their role, or the happiness derived from providing care, there is evidence of the positive emotional dimensions inherent in caregiving practices. 11 codes were identified with the data containing 23 instances that showcase the sense of enjoyment and esteem experienced by practitioners in their roles, as well as the reciprocal joy evident in the individuals receiving care.

Extracts:

Sub-theme: Joy / Pride	
Data selection from the arts-based video session	**Transcript selection from the focus group**

Harvey2 **Observed**: 30seconds …Mum watching James face with a smile, Gabriella sitting alongside and Blake supporting with an art piece hand over hand. James focus on Gabriella rather than the art. 59 seconds Harvey captures Blake rub James' head saying "well in mate" Harvey2 2m15 mum appears in shot and looks at Harvey with a smile Harvey2 8m08 Holly and carer support Harvey with the art piece when mum leans into observed shot with a smile on her face. Her expression seems to be in reaction to Harvey first. Mum smiling captures photo of Harvey taking part Harvey3. **Observed**: 45 seconds of the video mum is recording Harvey on her phone, she is smiling. At the end she shares the photo on her phone with carer and Holly	*FG. Gabriella:… I've given or helped facilitate the best day possible and that's a good feeling when I leave here.* *FG. Courtney: like I feel like when you're able to support someone to do something that maybe might be unable to do at home or unwilling to do with other people and they connect with you in that way you're so satisfied going home. …* *FG. Gabriella: yeah and when you've been part of that you feel good about yourself. Gabriella: its the best feeling ever* *FG. Courtney: I don't think its too far to say we love the people here no because when I'm home I love sitting down telling my friends and if I get home from work I love talking over dinner about what I did that day*

The extracts above clearly emphasise the importance of relationships. There is joy and pride on display in the sessions captured in parental expression and in reflection in the focus group as the practitioners reflect on their experiences. Mothers take pride in their adult children in these extracts, the camera captures them staring with a smile, taking photographs and sharing them with staff and encouraging their adult children with reassuring words. They appear happy to be present and proud of their adult children.

The staff express joy and pride in their focus group reflections by describing how they feel after spending a day in the same context. They talk about their friends who attend the day service with other friends and family expressing sadness at the thought of not being in their company. In both extracts the joy and pride does not appear to come from the task that they are involved in, but rather the enjoyment of the relationship. Clearly in these extracts it is the staff and the parents who appear to be the recipients of good care, they appear to be benefitting from the enjoyment of their relationship. These relationships are not one way, a burden or over-consuming. It would be hard to imagine in this moment a call to change the experience of these individuals considering the joy they bring to their friends and family.

The sub-theme of "**Closeness/Touch**" explores moments and descriptions that emphasise the significance of physical closeness and touch in the lives of individuals described as having complex needs. This sub-theme is an example of the nuanced ways in which tactile interactions contribute to the well-being and experiences of those receiving care. Eight distinctive codes, encompassing 27 instances in the data, shed light on the multifaceted role of closeness and touch. This emphasises the significance of touch within the caregiving context, particularly for individuals who do not conform to linguistic norms.

Extracts:

Sub-theme: Closeness / Touch	
Data selection from the arts-based video session	**Transcript selection from the focus group**
Mary1 Observed Courtney seen holding Mary's hand throughout. Mum out of shot holds Mary's other hand. 1m30 Mary once again knocks the camera but it focuses in on the intimacy of the hand holding with Courtney. 2m12 Harvey's carer can be seen whispering in on Harvey's ear, her right hand touching his face. 2m40 Courtney and Mary hand holding showing affection. James turns and looks at his mum who rubs his shoulder and leans in on him. She rubs his arm and whispers in his ear. 2m55 Mary tapping the camera. The camera captures affection for Mary with Courtney, James with mum and Harvey with carer- all touch, all close, all without words. James constantly looking at his mum. 3m50 Blake and James are looking at each other, Blake is on his knees.	*FG. Courtney: its funny like there's things people might say or vocalise here which I feel like I understand in this context, like I'm going home saying 'peno music' or 'inside out' and it makes no sense outside of the context of relationships but here in relationships it doesn't make sense and there's a degree of comfort to that. Like the words and sounds here I do take elsewhere and its like I think in that language sometimes like I don't even say piano anymore*

The data in this extract highlights the importance of touch in the lives of individuals who are described as having complex needs. The data displays great intimacy for all involved, it is comforting and a sign of connection. In a space of just over one minute there are examples of closeness and touch for all involved in the project and at one point the camera is knocked by Mary and has only her and Courtney's hand in the frame- it is the hand holding of friends. Courtney talks in her reflections with fondness about the significance of repeated phrases spoken by those in her care which she repeats to family and friends outside the setting. The embodied experiences of individuals described as having complex needs appears to be shared through touch as a form of language.

Collaboration / Sharing + Joy / Pride + Closeness / Touch = Tangling

In the theme 'Tangling', the sub-themes of "Collaboration/Sharing," "Joy/Pride," and "Closeness/Touch" converge to celebrate the profound and interconnected bond between individuals engaged in caregiving relationships. The sub-theme of "Collaboration/Sharing" lays the groundwork by emphasising the importance of working together within the caregiving context. The interpersonal dynamics highlighted here form the foundation for the 'Tangling' theme, showcasing how collaboration is more than a functional necessity—it is a weaving of lives and experiences. Building on this, the sub-theme of "Joy/Pride" injects a positive emotional dimension into the theme of 'Tangling' capturing moments of happiness and fulfilment experienced by disability practitioners and family members. The reciprocal joy evident in individuals receiving care adds layers of emotional depth to the tangled connection formed through caregiving. It highlights that the intertwining of lives is not only about functional performativity but also emotionally enriching, resulting in happiness and esteem. Further still, the sub-theme of "Closeness/Touch" brings a tactile and intimate layer to the theme of 'Tangling' emphasising the significance of physical closeness and touch in the lives of individuals described as having complex needs and those around them. The theme of 'Tangling' is thus deepened by the inclusion of the nuanced ways in which closeness and touch become integral components of the interconnected relationship.

In the culmination of these three sub-themes, 'Tangling' emerges as a celebration of the deep and rich connection between two friends in caregiving relationships. This theme transcends physical touch, encompassing collaborative efforts, shared joy, and the significance of intimate closeness. The quantification of physical interactions within the arts-based activity session, including 24 occasions of hugs or embraces, 28 instances of whispered conversations, and 60 occasions of hand-over-hand contact, further highlights the depth and complexity of the ‘Tangling’ theme. It showcases that the true essence of caregiving lies not just in functional aspects but in the profound intertwining of lives, emotions, and tactile connections that form a tangling.

4.3 Addressing the research question

In this section, I will make sense of the data and address the research question ***‘What might Buberian philosophy bring to an appreciation of relationships between Disability Studies practitioners and people described as having complex needs.’*** Drawing upon insights extracted from the literature review on the influence of Disability Studies on professional practice, the themes of 'Vulnerability,' 'Practising', and 'Tangling' will be investigated within a Buberian framework. This will explore how practitioners apply Disability Studies theory, the contributions of individuals described as having complex needs to professional practice, and the wider impact of such relationships beyond the professional realm.

The structure of this section will consist of three parts, each dedicated to one of the highlighted themes, and will provide examples from the data provided to illustrate key points. Employing a Buberian lens and anchoring the analysis in disability theory, critical reflection on Buber's *I* and *Thou* will be undertaken, utilising it as a framework to question and engage with the findings. The intention is to reflect on claims of a dual nature of human engagement, as emphasised by Buber, advocating for profound and authentic relationships that transcend utilitarian considerations.

Buber's *I and Thou* revolves around the concept of the dual manner in which people interact with the world, emphasising the importance of fostering open, genuine relationships devoid of instrumental thinking. In the twenty-first century, Buber's ideas continue to present challenges to prevalent perspectives that often assume a detached and asocial view of humanity across diverse disciplines. Such viewpoints may neglect the relational dimension of human existence that Buber aimed to illuminate in his work (Ravenscroft 2017). As the themes and insights from the data are explored through the Buberian lens, each section will conclude by contemplating the broader significance of these findings.

4.3a) 'Vulnerability'

'Vulnerability' emerges as a combination of chaos and uncertainty. It involves a readiness to navigate the complexities of human connections, demonstrating humility by embracing and exploring ambiguity. Vulnerability therefore becomes the prerequisite for authentic connections, embodying a profound acceptance of the unpredictable nature inherent in complex social dynamics. In this section, further examples from the data which evidence 'Vulnerability' will be offered and a case offered how this relates to Buberian philosophy.

Vulnerability	
Data selection from the arts-based video session	**Transcript selection from the focus group**
M2. **Observed**: Mary throws some paper on the floor at which Courtney smiles but with a look of shock playfully as if Mary is putting her out. Mary2. 1m28 Courtney offers Mary a new choice of colours, she explains the colours and touches each hand with the colour to encourage Mary to make a choice, Mary chooses the white. Mary2. She chooses it and immediately throws it on the floor.	FG: Courtney:…I'd defo say I'd learnt that from people we support. That its not as simple as a want/needs or request relationship. There's loads of ways of doing it. Blake / Gabriella: yeah agree Blake: I've learnt to communicate in different ways and there's a richness to that. Gabriella: you can communicate in a variety of ways. Courtney: I think like both people mutually getting something - like I benefit as much as the person I'm connecting with. Like I'm learning things. Courtney: Like you can tell when there's certain people in a room there's excitement when you see them, like I dunno like I don't even know if he would be excited to see me but if I know there's people here I'm genuinely excited to see

	but I think people are excited to see me so I do think its a relationship balance.

Here are two extracts which sum up this ‘Vulnerability’ theme: a connection within tasks and the reflection of practitioner friends. The first picture displays the vulnerability of working together. In the example, Courtney is trying to encourage Mary to make choices, and Mary in return is turning it into a game; Courtney’s desire to support active participation for Mary ends up with Mary teasing Courtney- she makes a selection and then seems to back out of it. It is a playful moment, but Courtney must be willing to play the game, otherwise she will be left frustrated as she is powerless to make Mary comply with the rules in the paper making exercise.

The second example is taken from the focus group. Blake, Courtney and Gabriella in these examples express their approach to learning; where, who from and how they learn. They express the benefits they experience in their relationships as practitioners, they feel recipients of care not just givers of it as they express excitement in caring for friends. Their experiences demonstrate how they have relinquished barriers and opened themselves up to emotional connections in the workplace and as such are experiencing the benefits of this.

4.3 ai) Exploring vulnerability in human connections

It can be suggested that people frequently conceal their vulnerability to sidestep societal stigma, a concept Goffman (1963) explored in depth. The act of limiting what is revealed of our true selves, treating social interactions as if they are a continuous job interview underscores the pervasive challenge of embracing vulnerability in human connections. Disability Studies scholars have sought to identify and deconstruct socially constructed norms within society that privilege sameness and stigmatises difference and those situated as vulnerable (Murray and Herrnstein, 1996; Davis, 1995; Dudley-Marling and Gurn, 2010 and Richardson, 2005). This desire to conform, termed normative positivism (Bolt, 2015), marginalises those who deviate, perpetuating oppression. Challenging this is essential, celebrating difference and deconstructing a belief that only certain people are vulnerable (Macartney, 2010; Baglieri and Knopf, 2004). Memmi (1984) and Montgomery (2001) claim that all people are mutually dependent and vulnerable. Others claim that all display infant like dependency needing care, affection, food and drink, protection and shelter and disregarding this basic human fact damages collective identity and personhood (Kittay, 1999 and Rasmussen, 1993). Instead, human prosperity and meaning is found through relationships; people need one another; what Reynolds (2008) describes as vulnerable communion. Thus, all people display mutual vulnerability by design. Vulnerability needs to be embraced in the steps towards interdependence as relationships are essential for human prosperity.

Adopting Buber’s (1958a) framework, this project celebrates the universality of vulnerability in forging deep human connections. While Buber does not explicitly reference vulnerability, his distinction between *I-Thou* and *I-It* encounters, inherently advocates for an open and mutual vulnerable foundation to be adopted for authentic relationships. Embracing vulnerability is consistent with his principles for a dialogue of difference. His desire for reciprocal relationships and openness in *I-Thou* relations underscore his view of vulnerability. By removing confining barriers, openness and vulnerability become somewhat synonymous. Vulnerability is not on display or needed when an *I* encounters an *it*. The *I-it* connection pertains to a relationship between the self and an object. In this interaction, the object is perceived as known and fixed, shaped by each individual's preconceptions of the other. Within that connection, there is a degree of predictability and cause and effect surrounding actions and reactions. On the other hand, when *I* relates to *Thou*, the person is not entirely known and so the possibilities increase. This creates a vulnerability or an openness, because the one who is unknown will never be known, unless they become connected, listened to and experienced in presence. For Buber, this requires personal risk but is essential to receive a full life, he says that *"All real living is meeting"* (1958a, pp.17). Therefore, an *I-Thou* connection requires removing the barriers that protect us and open up to become vulnerable to meet and live with possibilities. This may be frightening, but worth it, as Buber claims "*What is manifold is often frightening because it is not neat and simple. Men prefer to forget how many possibilities are open to them"* (1958a, pp.9).

In capturing relationships, this project embraces vulnerability as doing so is essential for the transition to meaningful relationships, moving to *I-Thou*. Two scenes within the data vividly illustrate this. It is the disability practitioners within the relationship who might be considered to adhere to the normal ideal. In the scene between Courtney and Mary, it first appears that Mary is helpless in completing the task without Courtney's aid. Mary could be positioned as abnormal, dependent and vulnerable. Yet the sessions and the focus group tell a different story, one which celebrates diverse connection and friendships. This celebration is influenced not only by Disability Studies theory but also by practical experiences. In both discussions and activities, practitioners demonstrate limited control, highlighting mutual vulnerability. Within the tasks, Courtney is helpless to make Mary perform the task. Courtney is the care leader in this relationship, responsible for supporting Mary. Yet in this instance she is not able to support her. Far from this being a problem, Courtney's reaction shows she enjoys Mary's playfulness. Her reaction recognises her helplessness to impose her will on another. The interaction between Mary and Courtney during the arts-based activity further exemplifies the principles of vulnerability in the *I-Thou* relationship. Mary's playful act of paper throwing, met with Courtney's smile and a look of shock, illustrates the spontaneity and unpredictability inherent in genuine connections. Courtney's patient guidance and tactile support for Mary's choices illustrate their commitment to mutual understanding. Mary's seemingly unconventional choice to throw the selected colour on the floor reflects her agency and autonomy in the interaction. This scenario demonstrates vulnerability for both—

Courtney relinquishing control and embracing Mary's choices, and Mary expressing herself unconventionally. Choosing colours becomes a symbolic dialogue, surpassing conventional communication methods.

The focus group is also of particular interest. The experience of the caregiving practitioners in this project position themselves as recipients of care. They evidence that practice is one where they learn new languages and learn about diverse relationships, and benefit from the joy of relationships. Courtney's reflections in the focus group highlight a shift in her understanding of relationships from a mere "want/needs or request" dynamic to a more nuanced, reciprocal interaction. Her acknowledgment that there are "loads of ways of doing it" implies an openness to diverse forms of communication and connection, aligning with Buber's emphasis on removing barriers for genuine encounters. Blake and Gabriella's agreement further supports the idea that communication is not limited to conventional forms but can take various shapes, emphasising the richness of diverse modes of expression. Courtney's mention of mutual benefit and learning reinforces the reciprocity inherent in *I-Thou* relationships, where both parties contribute to each other's growth. Courtney's excitement about certain individuals in the room reflects the emotional depth of these connections. This excitement goes beyond a transactional relationship, suggesting a genuine, emotional investment in the well-being of the other person. This resonates with Buber's concept that "All real living is meeting," emphasising the significance of authentic encounters in a person's life.

4.3 aii) Vulnerability in care: a catalyst for mutual growth

This project expands the premise that effective care fundamentally requires embracing vulnerability, not as a weakness but as a cornerstone for building mutual, growth-oriented relationships. Cipolla (2018) among others in Disability Studies, has similarly underscored vulnerability's vital role in nurturing deep interpersonal connections. Scholars such as Knight (2014), Shildrick (2019), and Snipstad (2020) reconceptualise vulnerability as a foundational element for authentic connections, rejecting notions of purely inherent limitation but societal implication. Utilising the concept of precarity, which is the prospect of uncertainty due to a range of socio-economic factors, they explore the multifaceted nature of disabled experiences within broader societal, economic, and political contexts. Precarity becomes a lens through which disability is scrutinised in relation to economic instability, limited social support networks, legal protections and intersectionality. Applying frameworks like Crip Theory (McRuer 2015), an approach which strips back ableist assumptions, results in vulnerability being exposed for what it is, an experience for all people, but exacerbated for a few due to socio-economic barriers. Another scholar, Leach Scully (2014), claims is inherent to all people and reinforces claims that dependencies and the resulting vulnerabilities are socially constructed and should be viewed as a normative aspect of human existence rather than as exceptional. Knight (2014) broadens this discussion, advocating for inclusive politics to address vulnerability as a common human concern essential for public welfare. Similarly, Shildrick (2019) challenges scholars to explore broader perspectives beyond identity-based rights, harbouring closeness and new ideas among feminist and disability scholars, while Snipstad (2020) emphasises the complexity of vulnerability, particularly for individuals with learning disabilities, highlighting its link to social experiences and the distinction between inherent and situational vulnerability.

This project captured practitioners acknowledging their own experiences of vulnerability, not brought to light through precarity, but experienced through human connection. The focus group and the arts-based activity sessions evidenced that care is not unilateral; effective collaboration emerges when individuals open themselves to connecting and learning from others. This dynamic foster the acquisition of new languages through a dialogue of difference. Vulnerability is present within every human connection. Through *I-it* relationships the objectification of the *other* imposes negative perceptions of vulnerability without a recognition of its presence in self, but *I-Thou* relationships, which acknowledges mutual vulnerability, does not objectify, but builds up. The importance of vulnerability to Buber's philosophy of dialogue is undeniable as we are not subjects or objects but living beings. For Buber then, all life is a vulnerable encounter, as an *I* requires a *Thou* to become; and in becoming *I*, *I* says *Thou* (Buber, 1958).

Revisiting the data, the presented extracts challenge normative perceptions of communication and relationships. This challenge is particularly evident in the focus on diverse ways of communicating, aligning with the rejection of a one-size-fits-all approach in understanding the experiences of individuals described as having complex needs. It challenges ableist norms and embraces different forms of expression. Moreover, the observation that the relationship is mutually beneficial challenges the traditional power dynamic often associated with caregiving. It underscores the reciprocal nature of relationships between caregivers and individuals receiving care, debunking the notion of vulnerability as a one-sided experience. This approach, as highlighted in the Literature Review, is consistent with Robinson et al’s (2021) project with paid caregivers. Overall, the extracts in this theme exemplify the intersectionality of Buber's *I-Thou* philosophy and Disability Studies, emphasising the transformative power of genuine, reciprocal encounters and challenging societal norms that marginalise individuals based on their abilities or modes of communication. The vulnerability observed in the data extends beyond immediate interactions to shape the broader philosophy of care and support. This reflects a paradigm shift within Disability Studies, recognising vulnerability not as a negative but as a genuine human experience for all and a prerequisite for meaningful connections while some, due to socio-economic factors face increased precarity. When embracing diversity and vulnerability, practitioners move away from a deficit-based approach and affirm difference where everyone’s modes of expression and embodiment contribute to the richness of the relationship. In recognising the limitations of their knowledge, the experiences have shaped the practitioners to learn new languages and create the space for *I-Thou* encounters.

The next section will explore the complex power dynamics in professional relationships that often hinder the open expression of vulnerability. Building on the foundations set from this section, such exploration is crucial for understanding how to foster environments where authentic connections thrive, challenging and transforming traditional notions of care and support. Yet for now, this theme, ‘Vulnerability’, serves as a crucial backdrop for understanding the transformative potential embedded in the intersectionality of Buber's philosophy and Disability Studies. This celebration of vulnerability signifies a departure from conventional perspectives that perceive vulnerability as existing in a greater extent in those who are recipients of care, and not those who give it. This theme claims that embracing vulnerability becomes a catalyst for creating inclusive and authentic connections.

4.3b) ‘Practising’

‘Practising’ encapsulates the challenges of and necessity to make assumptions while engaging in routine practice when providing support for individuals described as having complex needs. It emerges as a theme that acknowledges the dynamic and evolving nature of caregiving, where assumptions, choices, and task-oriented practices meet. This section explores examples from the data evidencing ‘Practising’ and its relationship to Buberian philosophy.

‘Practising’
Data selection from the arts-based video session
Harvey1 8m19 mum and carer explaining to Harvey what the game they are about to play is. Harvey responds with “ayaaa” at which mum responds “are you not in the mood for this matey” ….. Mum says “hehehe is this good fun”. Mary3. Gabriella can be seen in the background with James who has appeared in shot, Gabriella is trying to place the paper into James’ hand for him to grip and rip- unsuccessfully, James turns away. Carer distracts Gabriella who turns away from James, James suddenly looks at Gabriella while facing the other way.

Here two relationships are captured. Both examples have tasks associated to them and both result in assumptions. In the first picture Harvey is supported by his mum and a private family caregiver, who are about to play a balloon game using a switch. Harvey’s “ayaaa” is perceived by his mum as a reluctance to play. Discerning whether this reaction from mum is consistent with his wishes is challenging, she comes to such judgements as someone who knows him best. They still join in the activity; mum appears to enjoy participating and works alongside Harvey to play. Similarly, in the second example, Gabriella supports James in ripping paper, he appears disinterested in the task, turning away. Only when Gabriella is distracted by another caregiver does James show attention towards her.

In both examples Harvey and James are taking part in activities which they are not leading, or do not appear to show an interest in. The caregivers are doing the task and Harvey and James are docile bodies who play their part. They stand in contrast to Mary in the last scene who appeared to lead the interaction her way despite Courtney's initial efforts. In this scene however, it appears that a parent and disability practitioners are those that lead practice; they are playing their role in supporting Harvey and James, but in their task face a dilemma of whether or not to conduct practice. These pictures are everyday occurrences in the life of those providing care - those who are subject to outcomes, schedules and competency assessments; tasks are inevitable in the lives of caregivers. This theme recalls the tension which exists between being with and doing with as posed by Hanson and Taylor (2000) highlighted in the Literature Review. Due to the motivation behind this project, the data which connects are the moments where two individuals can simply 'be' together, enjoying each other's company, not subject to a task. This is why Courtney and Mary's relationship is so revealing, the task is insignificant in light of their affection, which is mutual, it is *I-Thou*. Yet, the reality for individuals who work as caregivers is that there is a necessity in the relationships to 'do', to offer tasks, deliver interventions and the practicalities of care activities. The practitioners in this project have a duty of care to deliver practice through tasks. They operate with power and have a necessity to maintain an *I-it* relationship as evidenced in this scene.

4.3bi) Understanding 'Practising': Navigating assumptions and practices in caregiving

Buber, as a peace educator, called for the education of character through dialogue, emphasising the mutual respect and understanding inherent in *I-Thou* relationships while acknowledging the unique roles and responsibilities each individual holds. His view was that educators were builders in the lives of those under their care, shaping peace and mutuality through clarity of roles and a dialogue of difference. Buber (1926) claims that in the quest for mutuality, one cannot avoid doing tasks or using power to affect the world, but this should be done with caution and with a desire to showcase power in love. In practice, finding this balance is challenging with *I-it* relationships being present in caregiving encounters. Individuals who are described as having complex needs will have a range of professionals in their lives. While the diversity of professionals, from neurologists to caregivers, underscores the importance of collaborative working, the prevailing individualised discourse surrounding disability amplifies professional power, presenting a significant challenge to equitable caregiving. This is problematic as experiencing only *I-it* relationships, as Buber (1958) notes, will lead to 'nothingness'. It is inevitable that those who work alongside individuals described as having complex needs will exercise power, they will need to operate in *I-it* in order to care through interventions, not doing so would be harmful.

The intricate relationship between power and professional practice is pivotal in the field of disability. Disability Studies scholars identify how diagnoses and professional surveillance can perpetuate power imbalances. One such scholar, Garland-Thomson (1997), uses a Foucauldian perspective surrounding the creation of the subject to explain the relationship between a disabled person and a non-disabled person who occupies a position of power (the normate) at the expense of the other. This normate status maintains societal hierarchy as the cultural deviant is belittled (Shakespeare, 1997). This relationship sounds aggressive, and it is, but is exercised in practice by well-meaning professionals who seek to help. Applying a Buberian approach to professional caregiving would be sympathetic of intervention-focused engagement while recognising that relying solely on them, without fostering personal connections fails to recognise the full humanity of those involved. For Buber (1958) claims people cannot live without '*It*', but the one who lives with '*It*' alone is not a person.

It could be suggested that the issue at hand is the way disability is framed; an individualised model of disability frames the practitioner as saviour. This ideology is reinforced by the status of the one who practises on one perceived to be in need. White coats, qualifications, and experience alter the way practitioners think about, sit with, talk to, and touch individuals described as having complex needs. This exemplifies how practitioners can sometimes act reflexively—without the intent to do harm—yet without also the necessary reflection on the wider implications of their actions. The example in this story includes a mother with a son, and it is placed in this theme as it emphasises that doing happens and is not to be associated with a lack of love, but sometimes is habit or a response to not knowing how to act or what to do. Clearly, there is a place to *do*; human rights demand that there is a place to *do* rather than just *be*. Yet, this theme, and the data that accompanies it, acknowledge that in the lives of individuals described as having complex needs, those around them can offer seemingly unopposed (or hard to interpret opposed) practice. Family members will have power, neurologists will have power, dieticians will have power, social workers will have power, front-line caregivers will have power.

Disability Studies practitioners within Health and Social Care might find the inherent power dynamics in caregiving uncomfortable as they recognise the importance of 'being' over ‘doing'. As was picked up in the Literature review chapter from Hanson and Taylor’s (2020) reflections in mental health nursing there is a need for practice. However, this project acknowledges that the necessity of action ('doing') alongside critical reflection forms the foundation for more informed and compassionate care. It is personal accountability, applying the values associated by Disability Studies, and a reflection on personal values that will challenge such professional dominance while maintaining the need for practice (French and Swain, 2001).

4.3bii) Significance of ‘Practising’: Balancing power and connection in the lives of individuals who might be described as having complex needs

Caregivers are accountable for meeting care needs, and work with individuals and the wrap around teams who shape the lives of individuals described as having complex needs. In this project, Disability Studies practitioners play a crucial role as caregivers. However, certain actions can occur without critical reflection, as observed in this scene. The data in this context illustrates instances of practitioners operating within an *I-it* framework, navigating their roles to foster engagement while grappling with inherent power imbalances and the instinct to 'do.' As practitioners work within this framework for the well-being of others, striking a balance between doing practice while also striving for genuine human connection is an ongoing challenge. The tasks in this scene are not considered interventions, and, unlike Courtney's approach (which was actually led by Mary), they could be disregarded. In the scene above, James and Harvey are not as visibly expressive as Mary in the previous scene, and as such can be perceived as docile. Consequently, it could be suggested that those in positions of power may engage in actions out of routine without challenge.

Buber (1958a) emphasises the importance of understanding in dealing with difference. However, understanding is distinct from explanation. In this scenario, the experience of difference is not met with understanding due to the lack of reflection time. Practitioners must cultivate critical consciousness in their practice to navigate the balance between doing and being (Sakamoto and Pinter, 2005). This is a self-reflection which is informed by the convictions that one holds. Convictions about human rights, about disability and about the type of practitioner one wants to be. Practitioners must acknowledge their power, embrace the necessity of *I-it* practices, and strive for a delicate and nuanced balance that meets the practical physical tasks of care while fostering genuine human connection. Buber's call for understanding, not just explanation, resonates, emphasising the need for practitioners to cultivate critical consciousness and a space for reflection amid the demands of routine tasks. In this complex dance, the challenge lies in balancing the practicalities of doing with the pursuit of meaningful connection in caregiving for individuals with complex needs. Embrace the nuance.

4.3c) 'Tangling'

'Tangling' emerges as a celebration of the deep and rich connection between two friends in caregiving relationships. This theme transcends physical touch, encompassing collaborative efforts, shared joy, and the significance of intimate closeness. It showcases that the true essence of caregiving lies not just in the functional aspects but in the profound intertwining of lives, emotions, and tactile connections that form a beautifully intricate tangling. In this section, 'Tangling' will be evidenced using further examples from the data and this will be explored alongside Buberian philosophy.

Tangling	
Data selection from the arts-based video session	**Transcript selection from the focus group**

Harvey2. **Heard**: 2m13 Holly says to Harvey "lets start with the blue and then you can blend it then. you hold that for me and we'll start with the blue"… "are you ready, can we hold hands and you do this with me". Harvey2. 2m50 Holly says to Harvey "I think this is a great start, but can you help me a little bit more… are you ready, can I borrow your hand". Harvey3 1m 19 captures Courtney and Mary holding hands moving hands around one another's hand. Courtney then leans in closer and Mary puts her hand around Courtney and feels her hair. She then pulls	FG. Courtney: I think the one thing I'll always remember even if I move on to another job is the friendships and relationships oh I'm going to cry Blake: I know yeah

These three scenarios relate while each telling their own story. Gentleness and social dignity are on display in the first story; this is about respecting permission, sincere encouragement and touch. The request for touch is not overbearing or forceful, it is gentle and based on completing a task together- not on behalf of someone else. Holly collaborates gently with Harvey; making a choice with colours, but then offers an inviting call to work together. She requests to hold hands, then the collaboration is truly displayed in the humble phrasing "can you help me?". This emphasises the true picture of collaboration; it is two way. In the previous scene highlighting 'Practising', an *I-it* example, actions and decisions were made on behalf of another in order to assist or help. This happens in this scene too, yet, the language used by Holly and her approach adopts the vulnerability needed for an *I-Thou* relationship, as displayed in the first theme, as she relinquishes her power status, and she is helped by Harvey. This simple, gentle request is at the heart of a caregiving friendship.

The second picture, an extract from the focus group, further explores caregiving friendships; the emotional connection that the practitioners have established through relationship is explored. This exemplifies the *I-Thou* relationship within Courtney's caregiving role. She expresses a deep emotional connection with her friends, emphasising the value she places on relationships in her professional capacity. Her vulnerability, as indicated by the prospect of tears, reveals an authentic and personal engagement beyond the confines of a caregiver to care recipient professional dynamic. This connection also goes beyond duties, becoming a source of joy and a defining aspect of Courtney's identity. In contrast to an *I-it* relationship, where the focus would be solely on performing the caregiving tasks, Courtney's emphasis on the emotional bonds highlights a departure from a purely transactional approach. This contrast underscores the significance of the *I-Thou* relations, emphasising genuine, mutual connection and recognising the humanity of the individuals in her care.

The third picture captures an intimate moment between Courtney and Mary, revealing a profound connection between the two friends. The camera skilfully documents their hands holding, engaging in a playful dance of deliberate movements that expresses close connection. Notably, Mary is not distressed, or in need of comfort, nor does she require hand holding as part of an activity. There is no clear need for hand holding. The act seems to be an expression of shared enjoyment in their connection, their hands intricately tangling and untangling. As the interaction progresses, Courtney is gently pulled towards Mary, who then runs her hands through Courtney's hair. This seemingly spontaneous and natural touch further intensifies the intimacy between them. Importantly, this interaction does not fit the description of a ‘Practising’ or *I-it* moment, where actions are task-oriented and lack the depth of personal connection. Instead, it beautifully exemplifies the *I-Thou* relationship, emphasising genuine, reciprocal engagement and a shared pleasure in the connection for its intrinsic value rather than as a means to an end.

There is nothing abusive or harmful about these three interactions; they are deeply personal and shared. These stories demonstrate that both physical and emotional connections occur as two individuals are intertwined. Such connections, though rare in society, may not be uncommon in the lives of those described as having complex needs. It is a dialogue that is taught to all who recognise their own vulnerability, move beyond solitary practice, and seek to intertwine.

4.3 ci) Embodied diversity in theological Tangling

In the moments identified in ‘Tangling’, it is evident that the collective relationship is more significant than the individual contributions. Acts such as seeking permission, gentle hand movements, and expressions of affection encapsulate genuine humanity. This experience resonates with *I-Thou* relationships, as connections unfold in diverse and interdependent bodies, creating an embodied moment. This project's investigation into embodied experiences draws from the dynamic field of affect studies, as explored by Blackman and Venn (2010) which emphasises the profound impact of non-verbal and, what might be described as, non-conscious dimensions on human connection. In the context of affect studies, the intertwining of bodies in 'Tangling' confronts traditional notions of human interaction, promoting a deeper understanding of connection that transcends normative cognition.

The interplay of diverse bodies in 'Tangling' epitomises a form of non-normative positivism which Bolt (2015) highlights as a challenge to the dominant ways of thinking about societal norms by advocating for the inclusion and validation of diverse perspectives. Here, it is showcasing the myriad of ways bodies interact and communicate beyond conventional boundaries. This aligns with Latour's (2004) proposition to shift focus from "What is a body?" to "What can a body do?". The tangling and emotional touch, led by Mary, becomes a form of non-normative affirmation, highlighting the complex and varied ways in which bodies can engage and connect. Siebers' (2013) emphasis on disability creating theories of embodiment, more complex than the ideology of ability allows, resonates with the shared embodied experiences, reflecting human variation. Capturing a multidirectional tangling, challenges traditional hierarchies, offering a snapshot of shared closeness. The rhizomatic nature of tangling aligns with Deleuze and Guattari's (1987) concept, proposing a space for diverse ways of being. Embodied experiences contribute to the exploration of affect studies, challenging ableist norms. Multidirectional tangling reflects human complexity, aligning with nuanced discussions initiated by Blackman and Venn (2010). This embodied experience is rhizomatic – interdependent, messy, and a unique way of experiencing the world through meeting; it is not easily comprehensible but is embraceable, as by authentic connection, completeness is achieved (Buber, 1958a).

According to Martin Buber's philosophy, *I-Thou* relationships unfold when individuals connect with the eternal *Thou* through their mutual engagement. It differs from *I-it* relationships when individuals are objectified. Buber's claim (1958) of the necessity of *I-it* relations for society to grow and remain orderly emphasises that not all relationships in all circumstances can operate in an *I-Thou* moment. Yet *I-Thou* is about something deeper and more meaningful than what one *gets* from a connection. *I-Thou* is being present in the moment with mutuality; it is empathetic and inclusive, not ordered or hierarchical. Through the lens of Buber, 'Tangling' is an expression of the *I-Thou* relationship, characterised by interdependence and relational depth, offering a profound experience of connection. This is a deep and meaningful experience. At this point it is essential to remind the reader, that Buber's *I-Thou* is lost without an understanding of his *eternal Thou*. The Methodology chapter highlighted a positionality shaped by Critical Realism which acknowledges a reality out there to be known, a truth to be known. For Buber, his theological framework, or reality out there to be known, is the God of Judaism. A Hassidic Jew, Martin Buber's spirituality was heightened through relationships in the natural world rather than limited to religious buildings (Mendes Flohr, 2019). His view of God, or his *eternal Thou*, shaped his *I-Thou* philosophy. In the Literature Review chapter, Hanson and Taylor's (2020) approach to Buber's dialogue claimed that "being with" was a more appropriate term because *Thou* is obsolete. This project more closely aligns with the work of Haslam (2012), also cited in the literature review as *Thou* is not obsolete, Thou is essential.

The belief system of those involved in this project, whether they consider themselves as having a belief in a God or anything related to the spiritual world, remains unknown. It was not deemed appropriate to ask them. Yet, as this project employs Reflexive Thematic Analysis, this researcher's connection with those involved, understanding of Disability Studies, and theological framework do influence the interpretation and are appropriate to be considered. Consequently, the researcher's experience of the *I-Thou* moment, themed within 'Tangling', is perceived within the context of an objective reality to be known. In the interpretation of this moment, the 'Tangling' of the individuals led to a spiritual reflection. Like Buber's recognition of an *eternal Thou* in an *I-Thou* relationship, two diverse individuals connecting and tangling, sharing dignity and love, were observed.

In *I* and *Thou*, Buber (1958a) claims that when two individuals engage with each other genuinely and in a human manner, it is God, the *eternal Thou* which flows between them, akin to the surging of electricity. The spiritual reflection called to mind Genesis 1 verse 27a *'So God created people in his own image, in the image of God he created them…'.* The spiritual reflection for this researcher was that here were two people, that, according to my own theological framework (and shared by Buber), were made in the image of God. From this interpretation, two insights emerge; one which reveals something about people, and another offers an insight about God, Buber's *eternal Thou*. It firstly speaks about people, that being made in the image of God, they own a dignity which cannot be removed (Welz, 2016). Observations, during the study of Disability Studies, have exposed instances where abuse and practices contributing to unequal lives have disadvantaged individuals. The professional's authority, at times, can overshadow another's life, stealing one's dignity. Hence this is why disabled voices have called for the acknowledgment of social dignity (Frazee, 2014). These convincing demands influence how I, as a non-disabled person, seek to adopt critical consciousness. Despite acknowledging these dynamics, the belief persists that irrespective of whether an individual loses their voice, their freedom or their rights; as image bearers they were made and own a dignity which can never be removed and as such it is not socially constructed. A relationship which is *I-Thou* must therefore recognise this, and respond accordingly, which is why the encounter between Holly and Harvey, and Courtney and Mary offer moments of tangling between people who own a dignity which cannot be removed. Secondly, individual reflection says something about God. It claims that if people are image bearers, then God loves diversity. In the captured relationships, individual uniqueness is evidenced. Martin Buber's desire for *I-Thou* peace dialogue between Israeli and Palestinian people showcases that he shares this theological framework. Yet, his framework differs to this researcher in the very nature of who God is; a trinitarian God, three persons but one God. In this it could be suggested that a trinitarian theology offers more insight to this tangling as it speaks about a diversity loving God. If God is trinity, then the image and likeness of God is something fundamentally relational as explored by Haslam, (2012). Tataryn and Truchan-Tataryn (2013) claim that trinitarian understanding of God highlights that in very nature this makes God an inclusive community. A trinitarian understanding of God; Father, Son and Spirit should cause a reflection for humanity about the importance of diverse interdependence.

4.3 cii) Tangling as a lived experience: Unveiling the sacred in *I-Thou* relationships

Delving into ‘Tangling’ moments between individuals with complex needs and Disability Studies practitioners reveals the depth of Martin Buber's philosophical and theological insights on *I-Thou* relationships, where each connection hints at the sacred. Through the lens of Buberian philosophy, these moments emerge as manifestations of the *I-Thou* relationship, where the *eternal Thou* is, in some small way, reflected in each encounter.

Buber, in his quest to unveil the relational dimension of human existence, points to a reality that often goes unnoticed. This ‘Tangling’, characterised by diversity and a dignity that cannot be removed, evidences an *I-Thou* relationship. It transcends the immediate context and touches upon something timeless and sacred. Buber’s declaration *that "Love is between I and Thou"* (1958a pp.28) resonates deeply within these ‘Tangling’ moments. It encapsulates the essence of the connections formed, not merely as functional interactions but as expressions of love. In the interplay between those labeled as having complex needs and the practitioners, love becomes the undercurrent, weaving a tapestry of genuine connection and mutual respect. A philosophy of difference is evident within the arts-based video sessions. The unity that emerges is not a conformity but a celebration of diverse ways of knowing and being, embodying the heart of *I-Thou* relationships. Buber claims that *"In each Thou, we address the eternal Thou"* (1958a pp.19) and this is echoed throughout these interactions as moments of ‘Tangling’ offer a profound acknowledgment of something eternal; a recognition that goes beyond the immediate circumstances. It is a testament to the sacredness embedded in the reciprocal engagement between individuals, where the reflections of *eternal Thou* is present in the addressing of each *Thou*.

While one might argue that these reflections delve into philosophical and theological realms, it is essential to note that these moments unfolded not in theoretical spaces or religious institutions. They took place, however, in a Health and Social Care setting, one informed by Disability Studies. The focus group concluded that their undergraduate education in Disability Studies offered a solid foundation, that encouraged them to build a culture that challenges power imbalances and fosters genuine connections. The genuine connections of this project, the ‘Tanglings’, are a call to consider *I-Thou* in practice where ‘Practising’ alone is problematised and ‘Vulnerability’ is celebrated. This is not merely a theoretical proposition; it is a lived experience that privileges complex embodied experiences and underscores the interdependence inherent in our existence. In essence, these ‘Tanglings’ within the Disability Studies framework become a transformative force, influencing language, and offering a profound shift toward genuine connection, humility and love. They represent the heart of Health and Social Care, challenging the status quo and paving the way for a more inclusive, respectful and interconnected approach to caregiving.

Analysis Summary

This chapter has offered a meticulous approach to answering the research question and analysing the data collected through focus group and arts-based activity session captured with wearable cameras. Informed by an understanding of Buberian philosophy and Disability Studies, Reflexive Thematic Analysis was adopted to group and theme the data, the same philosophy which supported the grouping of themes also helped to unpack their meaning. The chapter's start laid the groundwork by systematically describing the process of gathering the data and the subsequent overarching themes. It detailed the derivation of 58 codes and their subsequent grouping into seven sub-themes, ultimately consolidating into three overarching themes— ‘Vulnerability’, ‘Practising’, and ‘Tangling’. Next, the findings were presented as the three main themes— ‘Vulnerability’, ‘Practising’, and ‘Tangling’ — and were introduced and dissected into their respective sub-themes. Examples drawn from the data illuminated the meaning and creation of each theme.

This chapter also sought to address the research sub-questions by demonstrating:

- The way practitioners embody Disability Studies theory was encapsulated in the exploration of ‘Vulnerability’, highlighting how embracing vulnerability can foster human connection and mutual growth.

- The manner in which individuals described as having complex needs contribute to professional practice in all themes and found expression in ‘Practising’, revealing the tension in professional practice and the necessity for a delicate balance between doing and being in caregiving relationships.

- The broader implications of diverse relationships that extend beyond the professional domain were most evident in ‘Tangling’, showcasing relationships embodying mutual vulnerability and extending beyond conventional understandings of practice.

The final section used Buberian philosophy and Disability Studies theory to make sense of the data. The exploration of ‘Vulnerability’, ‘Practising’, and ‘Tangling’ responded to the main research question regarding the contribution of Buberian philosophy to relationships in the context of disability practitioners and individuals with complex needs. As this chapter draws to a close, it sets the stage for the upcoming conclusion, where practical implications for professional practice will be synthesised. It is hoped this impact will provide cross disciplinary learning points from the Social Sciences, Education, Health and Social Care practice, and Disability Studies, underscoring the profound understanding gleaned from the interplay between theory and practice.

5. Conclusion

This project used the amalgamation of Disability Studies and Buberian philosophy to reflect and shape person-centred practices, challenge stereotypes, foster collaboration and recognise something deeper in human identity in order to deliver inclusive and respectful care. This final chapter will bring together the full insights gleaned from the research. It will address the research question, and the accompanying sub-questions, outlining the themes produced from the gathered data. This summary of the findings will inform an understanding of the relationships between disability practitioners and individuals described as having complex needs. Subsequently, this chapter will consider the wider implications of such findings, considering the impact for practical application as well as contributions to theoretical frameworks. It will suggest how the insights gained through the project can inform and improve approaches in a range of practice-based settings including Higher Education and the Social Care sector. Next, the chapter will acknowledge the limitations of the project. This study is not without flaws and has experienced constraints and challenges during the research process. As such, a critical evaluation is necessary for the credibility of the project. A transparent approach can inform future research opportunities which may develop from this research with similar goals but one that can be informed by this project's constraints. Finally, the chapter and thesis as a whole will conclude by looking forward, considering future pathways for research and practice. In particular, this includes proposing a Buberian-informed, critical reflection training which could support building relationships between disability practitioners and individuals described as having complex needs. By doing so, this thesis aims to contribute to the ongoing dialogue and development of Disability Studies in theory and practice, contributing to the call to remove barriers which contribute to unequal lives.

5.1 What might Buberian philosophy bring to an appreciation of relationships between Disability Studies practitioners and people described as having complex needs?

This project concludes that Buberian philosophy can significantly enrich the practice and principles of relationships between disability practitioners and individuals described as having complex needs, by emphasising the depth and authenticity of human connections as framed in his distinction between *I-Thou* and *I-It* relationships. This philosophy can impact the way practitioners consider other persons as well as their own practice. They will do this firstly, by having a renewed consideration of what it means to be vulnerable in practice, understanding how this approach humbles those in professional caring roles, challenging preconceived judgements. Secondly, Buberian philosophy brings critical reflection to situations where practice might otherwise continue without clear reflection. Finally, an understanding and reflection of humanity and the tangled relationships between individuals will cause practitioners to recognise the embodied experiences of people described as having complex needs, their valued identity and their vital contribution to what it means to be human.

5.1a) The contribution of ‘Vulnerability’

The theme of ‘Vulnerability’ strongly resonates with Buber’s perspective on human relationships. His philosophy of dialogue highlights the importance of embracing vulnerability as a cornerstone for genuine connection. For disability practitioners, this means identifying and appreciating the inherent vulnerability in all of us, including those who give care. When vulnerability is not considered as a drawback but essential for building deep, mutual relationships, then disability practitioners may foster more supportive and genuine environments. By this they will challenge societal norms which often ignore the inherent vulnerability in all people but marginalise and stigmatise the few - those considered vulnerable because of the label of complex needs. Instead, a Buberian appreciation celebrates mutual vulnerability, emphasises encounters which are characterised by sincerity and openness, removing disabling barriers, celebrating diversity and unleashing the transformative power of humility.

5.1ai) Enhancing authentic interactions which build supportive cultures and removes barriers

Acknowledging ‘Vulnerability’ has the potential to enhance authentic interactions which build supportive cultures and removes barriers. Buber's *I-Thou* dialogue is foundational in fostering authentic interactions where two people are seen as whole beings, transcending transactional relationships that may be deemed inauthentic for the ways they speak to ideas of humanness. In the field of Health and Social Care, particularly with individuals described as having complex needs, this approach encourages practitioners and individuals to form connections which are deeper and more meaningful than typical caregiver and care-recipient roles. In the project, this relationship was most evident in the connection between Courtney and Mary, who demonstrated playful and unpredictable roles, which at times disregarded the task at hand. In their play, they enhanced mutual understanding and connection of each other. Their play demonstrated mutual vulnerability and acceptance of their true authentic selves, not being restrained by a desire to maintain inhibitions.

Buber’s philosophy shaped this finding, as true connection came to the fore only when individuals stripped back the barriers, or inhibitions, which hid their true authentic-vulnerable-self. This project claims that the stripping back of the illusion of invulnerability, particularly on the part of professional practitioners, is the catalyst for fostering authentic relationships. This principle is crucial when working alongside individuals who are described as having complex needs and are subject to holding all the (vulnerability) cards within the relationship. The project finds that embracing vulnerability not only assists practitioners to acknowledge their authentic selves as part of their professional identities, it also encourages good care as one moves beyond a transactional approach with preconceived notions of ability and disability. Doing this will foster an environment of openness where all forms of communication and expression are valued. This was evident within the arts-based sessions and in the focus group as practitioners acknowledge they are recipients of care to those they care for, this underscores how embracing vulnerability contributes to the reciprocal nature of caregiving relationships. This is claimed because Buberian philosophy can be applied to celebrate vulnerability as a universal inherent characteristic of all people essential to interdependent and authentic relationships.

This project contributes to shifting the perspective within Disability Studies which framed vulnerability negatively. The *I-Thou* connection emphasises the transformative power of truly seeing the other in the relationship. In practice, this means recognising individuals described as having complex needs not just as vulnerable recipients of care but as full partners in the vulnerable relational dynamic. This philosophical reflection can maintain and create adaptive and responsive care practices which respect the individuality and preferences of each person who are contributors to mutual caregiving, not merely passive recipients. This transformative recognition is crucial for shaping working cultures that are characterised by mutual respect. A working culture across practitioner teams which adopts inherent vulnerability challenges a perspective that practitioners have all the answers. Embracing vulnerability in practice will result in staff members who recognise that in caring for individuals described as having complex needs there is more unknown by the practitioner than known. The approach and culture of a vulnerable team is one of caution with a readiness to learn from one another. Furthermore, vulnerable working cultures resist being the powerful figures in the lives of those for whom they care because power can crush a vulnerable spirit. Recognising one’s own vulnerability and limitations is approached with sensitivity. It can be claimed that a reluctance to relinquish inhibitions or acknowledge one’s own vulnerability is surrounded in self-preservation. As such, practitioner teams which do acknowledge this self-reflection do so with gentleness and kindness. Gentleness and kindness are fundamental values of good care, as such a working culture which embraces vulnerability is good for all within the environment.

5.1b) The contribution of ‘Practising’

The project presented the theme of ‘Practising’ to demonstrate how Buberian philosophy contributes to practice by identifying, respecting and disrupting task-based approaches in disability care. While favouring *I-Thou* over *I-It* relationships which encourages practitioners to see the individuals they support as partners in the caregiving process, this theme also recognised the delicate tension and need to practise caregiving. While Buber advocates for authenticity and presence through his dialogue, he claims *I-it* relationships are, at times, inevitable. As such, the challenge from this project is for practitioners to integrate genuine human contact within the routine and inevitable interventions essential to their roles. The challenge is to recreate the mundane tasks and *I-it* moments into opportunities for deep, *I-Thou* connections.

5.1 bi) Encouraging critical reflection on the tension and need to practise

Integrating Buberian philosophy into Social Care settings which support individuals who might be described as having complex needs profoundly enriches practice by encouraging disability practitioners to balance 'being' and 'doing'. Due to the nature of caregiving roles, practitioners can become engrossed in interventions associated with only meeting the immediate practical needs of individuals, which inadvertently reduces interactions to transactional encounters. Although Buber’s philosophy accepts the inevitability of transactional processes (or *I-it* relationships), his main aim for dialogue is a recognition of the whole being (*I-Thou* relationships) and this approach applied to caregiving transcends mere task completion. Practitioners who adopt this guidance are critically reflective of their actions and this enables them to find moments of genuine connection even within routine tasks creating more meaningful interactions for both parties. This is consistent with a higher purpose within caregiving, enhancing the quality of life within human connections, not merely meeting practical care needs by interventions. In adopting Buber’s principles, disability practitioners can navigate the complexities of their roles, recognising the need to practise but within a more compassionate, respectful, and reciprocal framework.

Like the previous theme, key to this framework is a critical reflection which conceptualises those who might previously have been considered as care-recipients, as partners in the mutually vulnerable relationship. For the practitioner then, critical reflection on practice enables a shift from doing something "to" an individual to partnering "with" them. Buber's acknowledgment of *I-it* relationships as necessary for humanity does not undermine his desire to see genuine *I-Thou* connections. Caregiving does need to be practised, but with applied critical reflection, practitioners can facilitate routine interventions that amplify the nature of partnership within these tasks. To do this, critical reflection involves practitioners embracing their own vulnerability and reflecting on the assumptions and actions they hold when they practise. When practitioners examine their actions and intentions, they can identify any objectifying tendencies present within their desire to ‘do’ and engage more deeply in partnering. This thoughtful reflection fosters a more holistic approach to caregiving. Such critical reflection may present disability practitioners with a heavy burden of responsibility; but it could be argued that this is present irrespective of whether one seeks to acknowledge it. Critical reflection does not undermine the necessity to intervene in the lives of those who require care and support. Disability practitioners need not fear intervening, in fact Buberian philosophy brings an appreciation of the *I-it* and the need to do yet, it recognises this is not the heart of the relationship.

For organisations within the care sector, this maintains a high expectation of quality interventions. Good interventions are as much about fundamental human rights as they are about pride in one’s role. Yet, thinking more holistically with an *I-Thou* lens moves beyond the transactional to a partnering perspective. This is essential when thinking about the recruitment of caregivers since caregivers who are critically reflective about their practice are more likely to partner. It is individuals like this who are best suited to caregiving roles. Clearly interventions and wider practice of care and support can be learned and evidenced as ‘care experience’ when recruiting disability practitioners. For some employers, experience in the field of disability might contribute to the confidence placed in a new recruit who is familiar with practising the interventions associated with caregiving. This project can be used to show how values held by practitioners are more essential than their experience of professional caregiving. Buberian philosophy brings an appreciation to practising as one constantly learns and practises critical reflection. This is a value-based approach which has an ongoing impact to the nature of the caregiving relationship. An appreciation of relationships between disability practitioners and individuals described as having complex needs is one which encourages critical reflection on the tension and need to practise.

5.1c) The contribution of ‘Tangling’

Through ‘Tangling’, Buber's philosophy showcases the depth of connection that can exist when disability practitioners and individuals described as having complex needs engage in *I-Thou* dialogue. It celebrates the intricate, intimate moments that transcend physical touch to include emotional and spiritual intertwining. These deep connections demonstrate the potential for caregiving relationships to move beyond professional boundaries and become profound, life-affirming engagements. The *I-Thou* dialogue not only offers a profound lens for an appreciation of the relationships between disability practitioners and people described as having complex needs, it offers practical challenges. ‘Tangling’, as the intermingling of lives and emotions, resonates strongly with Buber's perspective on the transformative power of sacred human connections.

5.1 ci) Tangling in caregiving: Fostering authentic relationships and recognising sacred moments

In the relationship between disability practitioners and individuals described as having complex needs, the application of *I-Thou* dialogue shifts the focus from transactional practice to transformative interactions. In this specific context, this ‘Tangling’ privileges relationships which are authentic, in the moment and mutually engaged. This tangled partnership is vulnerable and mutual. The experience challenges practitioners to move beyond the function of their role to facilitate moments of shared connection and joy where every interaction has the potential to be meaningful and enriching.

Essential to the practise of ‘Tangling’ is the recognition of the full humanity between partners. Buber’s dialogue in ‘Tangling’ causes practitioners to relinquish status and boundaries to see their partner in their entirety; respecting their complexity and responding to them beyond utilitarian means. ‘Tangling’ as an exercise means that those in caregiving roles see their partner as they see themselves- they are intertwined. Furthermore, ‘Tangling’ necessitates an understanding of the sacred as every *I-Thou* encounter reveals something of the divine. Using this perspective, practitioners can move from mundane connections to something of greater significance as ‘Tangling’ recognises that people are made with a dignity than cannot be removed and a diversity to be celebrated. Practitioners who embrace vulnerability and connect with such ‘Tangling’ perspectives can reflect on this spiritually and emotionally uplifting experience.

The practical application and significance of ‘Tangling’ presents a challenge to the current context of care and support, particularly to the relationship between disability practitioners and individuals described as having complex needs. It could be suggested that the field of Health and Social Care, particularly disability practice, is subject to professional boundaries, or assumptions of such, which in a perfect world need not exist, yet do so for the protection of individuals who have been subject to abuse. This professional understanding of boundaries often instils a fear of touch, connection, and opening oneself up to love. Such areas can become taboo for caregivers who seek to exist somewhere between their professionalism and willingness to truly express how their relationship transcends professional boundaries. To be clear, ‘Tangling’ is not advocating for the removal of professional boundaries which seek to limit the abuse and emotional manipulation towards individuals in receipt of care and support. Such boundaries are essential. It is however challenging pre-conceived perceptions of professional boundaries which replace accountability with unnecessary and assumed formalities and learned behaviours. It is these which can inhibit the formation of these profound ‘Tangling’ relationships.

Disability practitioners often develop deep affection for those they support. They frequently need to touch and maintain physical contact with those they assist, fostering strong emotional connections. Through their care, disability practitioners can also form spiritual connections with the individuals they support. Talking about all of this in our roles need not be a taboo but should be wrapped up in accountability. ‘Tangling’ in practice celebrates a oneness and in adopting this approach, those who work alongside and care for individuals described as having complex needs not only challenge societal norms and embrace diversity but also create environments where vulnerability is not a professional risk but a prerequisite for authentic ‘Tangling’ and mutual respect.

Finally, ‘Tangling’, that is the embodied oneness which connects bodies, emotions and spiritual perspectives reminds practitioners who do so that individuals with the label of complex needs have a valued identity, made in the image and likeness of God and with a vital contribution to what it means to be a person. For practitioners like myself who are Christian, this positionality fundamentally shapes the approach to caregiving. It upholds the personal convictions and character values which shape competent practice, as highlighted in the Methodology chapter. As such, Buber’s *I-Thou* offers those influenced by a Judeo-Christian worldview, such as myself, the freedom to embrace ‘Vulnerability’, engage in ‘Practice’ and ‘Tangle’ with those who are described as having complex needs with the perspective that their doing so is not only a kind and respectful thing to do, but it also is an act of spiritual worship. This is no menial task; it encompasses the instruction of the whole bible - to love God and love other people.

Buber’s philosophy of dialogue has significant potential to enhance relationships between disability practitioners and individuals described as having complex needs as it demands mutual respect, recognising individual human worth. This project has consistently shown how Buberian perspectives challenge the conventional, transactional nature of caregiving, favouring an approach that welcomes unpredictable and complex experiences. *I-Thou* fosters mutual growth and genuine connection. By adopting this in practice, caregiving has to be a collaborative effort which results in an enriching experience as practitioners not only improve the quality of care but also partner in a community rooted in love. Buberian dialogue combined with Disability Studies provides professional practice in this field, a perspective that challenges deficit-based views of disability. Disability Studies has long been understood to advocate for a perspective of disability as a dynamic interplay of social, cultural, and political factors. This remains a social justice movement which emphasises empowerment and a rights-based approach, calling on professionals to remove systemic barriers and to celebrate difference. This project has shown how working alongside individuals described as having complex needs enriches the lives of those that partner with them. It has captured relationships which demonstrated mutuality, empathy, problem-solving skills and mischief. Buberian Philosophy alongside Disability Studies has influenced the discovery of such engagement. Applied to practice, relationships which demonstrate these outcomes can cultivate a societal ethos that values all people for their inherent worth, with dignity which cannot be removed, and a collaborative potential.

5.2 The broader significance and contribution to Disability Studies

Effective research, it could be argued, is one which highlights a need and meets it. This project has attempted to do just that. As highlighted in the Literature Review, the overwhelming contribution to knowledge as it pertains to individuals described as having complex needs, originates from a dominant medically informed understanding of disability. The field of Disability Studies has certainly contributed to knowledge, yet, due to a wide range of barriers to inclusion, there have been minimal contributions from individuals described as having complex needs even within emancipatory approaches to research. While the previous section highlighted several contributions and points to consider for disability practitioners, this section will consider the modest contribution to Disability Studies as an interdisciplinary field of research.

5.2a) Contribution to Disability Studies

The significance of the project is found in its methodological and theoretical contributions to Disability Studies. This project aimed to build on current work and capture relationships, as a positive discourse surrounding people participating in the project; their contributions enrich this project. In addition, Martin Buber's philosophy of dialogue represents a theoretical and theological contribution to the field of Disability Studies, particularly in light of minimal previous contributions that have involved individuals with complex needs.

5.2ai) Methodological contribution

This project offers two methodological contributions, firstly in its subtle but innovative methodological approach, using Action Research *with* Participation (ARwP) and secondly in the method adopted in transcribing the video data under the headings 'Something Observed', 'Something Heard' and 'Something Expressed'. As highlighted in the Methodology chapter, it was the desire of this researcher to deliver a project with emancipatory gains consistent with the work of other Disability Studies scholars. I had desired to deliver a project in partnership with the individuals who made up my research committee from start to finish, including the very inception of the project which would be consistent with a Participatory Action Research (PAR) methodological approach. I considered this impossible due to limitations in the processes for ethical clearance.

ARwP does offer a wider significance for those who seek to share research projects in the future. It could be suggested that ARwP, initially conceived as a middle ground between Action Research and PAR for doctoral students needing to own their projects and complete ethical approval before engaging with participants, has the potential to contribute to research beyond doctoral work. This approach will give researchers a broader understanding of methods, and for those who seek to research alongside individuals described as having complex needs, this broader understanding will provoke researcher reflexivity and reflections about the individuals who participate.

The second methodological contribution was in the recognition of a range of different types of contributions from participants. A position held by this researcher is that all people have voices to be heard. In this project, individuals described as having complex needs have voices to be heard which are different from what might be considered the standard language. As a researcher who is shaped by dominant understandings of expressive and receptive language, particularly spoken and written English, I was challenged by how I might fairly capture voice from individuals who use their bodies, make expressions and vocalisations in different ways to myself, and often in ways I find challenging to interpret. Although other multi-modal and multi-sensory approaches to data analysis do exist, such as Pink's (2009) approach to sensory ethnography. This project sought to capture voice through a means which might be considered collaborative. As researcher interpretation was significant, I resisted a restrictive approach by adopting the approaches suggested by the research committee which acknowledges what might be considered more diverse and broader means of expression.

Initially when speaking to the research committee in the first meeting when deciding what methods we might use to capture the data, I had suggested that I could capture the data under one of three categories; 'Something Observed' - which was about observational approaches, 'Something Heard' - which was about auditory recordings and 'Something Expressed' which was about interpreting produced artefacts. I am grateful to the research committee who pointed out that due to the multi-sensory experiences and tendencies of all people it might be worth adopting an approach which considered capturing and transcribing the data using all three. I adopted this approach because it aligned with a ARwP and it was a holistic approach which would help both the capture of and transcribing of data. So, *we* designed activities and transcribed the data which represented all three areas. This is a modest contribution, but it did offer a framework and a strategy which made me more reflective of how the body moves, and how to capture what was recorded on the videos, and it was consistent with ARwP. Each time I reviewed the video, I had a framework which guided when to pause, reflect and transcribe what had been captured. This framework had methodological rigour, as I firstly reviewed the video in full, then on mute, then with the screen covered, then finally by considering the produced artefacts. As I transcribed the data, I used this framework and transcribed under the appropriate headings.

The significance of this approach to transcribing the data has implications to those who do not use conventional speech. It causes researchers to think more broadly about how we move, to think more broadly about sensory engagement and to offer a framework to reflect on how voice might be expressed. Although the two highlighted methodological contributions are not limited to doing research alongside individuals described as having complex needs, they are the outcome of thinking about a project which captures relationships with individuals described in this way. As such, these methodological approaches can be adopted for future projects as gathering voice from individuals who do not use speech will continue to be a collaborative process.

5.2ai) Theoretical and theological contribution

This project also builds on contributions to the field of Disability Studies with its engagement with Martin Buber's philosophy of dialogue. The use of *I-Thou* and *I-it* rather than Hanson and Taylor's 'being with' and 'doing with' to make sense of the relationships between disability practitioners and individuals described as having complex needs in a Health and Social Care setting is a unique contribution. The framing of dialogue being beyond what is spoken and transactional, to include the emotional, physical and spiritual is consistent with our human experience yet often missed in the relationship between professional caregiver and individuals who receive care. An example can be found in the parallels with Buber's peace education. He used this philosophy of dialogue in areas of conflict to encourage opposing sides to recognise the humanity in one another. There are alignments here between the relationship of individuals described as having complex needs and practitioners. It could be suggested that the incessant desire to *practise* therapeutic interventions in the lives of individuals described as having complex needs creates a conflict between two individuals - even when this is unbeknown to professional caregivers. The significance of this project can be found in its celebration of *I-Thou* moments which offer peace between practitioner and the individual subject to *I-it* moments of transactional or intervention-based care for vast periods of their life. Practitioners who approach this project can, at least, be reminded of the need to reflect on practice and consider the nature of their relationship with those they partner.

Another contribution gained from using Buber's dialogue is rendered through a willingness to engage with the theological implications of his philosophy. The Literature Review chapter highlighted how other scholars have used Buber before but, in some cases, missed the deeper point of dialogue. This, it could be suggested, is due to not engaging with the theological significance of Buber's *Thou*. This project sought to explore an approach to dialogue consistent with Buber's Judeo-Christian framework and understand *I-Thou* relations consistent with the original author's intent. The implications of such are that this project, informed by Disability Studies, ventures into theological pathways which are not necessarily aligned with standard representation of the connection between Disability and Judeo-Christian writings often considered by Disability Studies theorists' 'religious model'. This project uses a theological framework to affirm difference and celebrate identity, an alternative perspective to that offered by the religious model of disability which frames religious representation of disability to be a result of judgement of wrong-doing or for the purposes of healing.

I must acknowledge that my contribution to this area builds on the foundation laid by Haslam's *A Constructive Theology of Intellectual Disability* (2012), as referenced in the Literature Review. My work aligns closely with hers in several key respects. Haslam challenges traditional theological frameworks by advocating for a reimagined understanding of human value and the divine image (Imago Dei) that emphasises relationality, vulnerability, and interdependence rather than cognitive ability or autonomy. Like my project, she draws on Martin Buber's philosophy of dialogue. However, while both projects utilise Buber's *I-Thou* framework, our purposes differ.

Haslam applies Buber's *I-Thou* dialogue to critique the ableist underpinnings of theology, which historically equated human worth and the Imago Dei with intellectual capacities. In contrast, my work focuses on how *I-Thou* dialogue can deepen understanding of the relationships between disability practitioners and individuals with complex needs, aiming to enhance professional practice with more empathetic approaches. Where Haslam's scope extends to church and society, I concentrate on its application in the field of professional caregiving, particularly within Health and Social Care.

Moreover, unlike Haslam, I do not engage in debates about the Imago Dei and rationality. Instead, I align with recent theological perspectives that affirm *humanity* as the marker of the Imago Dei, rather than rationality. My research assumes that individuals inherently display image bearer status without seeking to argue for it. While Haslam uses the *I-Thou* relationship of mutuality to address the rationality debate, my focus lies elsewhere. My contribution draws on Buberian philosophy to affirm two central claims: first, that God reveals Himself (in-part) through relationships; and second, that dignity is inherent to all human beings irrespective of external factors; a stance that challenges certain disability theorists who frame dignity as social – with the potential of stripping one's dignity by abusive practice. My point is not to justify the stripping of dignity- far from it- but to emphasise that, as created human beings, we possess an inherent dignity that cannot be removed, as it stems from a creator God. This point highlights another distinction from Haslam's proposal and my own: she suggests that all of the created order, including animals, might bear the Imago Dei. I do not share this post-human theory perspective stemming from concerns about human-exceptionalism. For the purposes of this project, particularly in relation to my co-researchers, I cannot follow that line, I take a different position. Grounded in my interpretation of Genesis 1:27, I affirm that the Imago Dei is unique to human beings.

Nonetheless, Haslam and I agree that humanity most fully expressed in mutual, responsive relationships characterised by immediacy and care. Buber's concept of mutuality deeply informs both our works, emphasising the importance of non-symbolic, bodily interactions as expressions of human connection. Haslam argues that such relationships affirm the dignity and full humanity of individuals with intellectual disabilities, challenging exclusionary practices and fostering inclusive theological and ethical frameworks. While our applications differ, we share a commitment to reorienting perspectives toward the value of relationality and community in understanding humanity and God, and use Martin Buber to achieve that end.

The innovations highlighted in this section demonstrate a commitment to inclusive and comprehensive data analysis. Furthermore, this section shapes the path for future projects which seek to collaborate alongside individuals described as having complex needs. The next section will consider the limitations of the project, yet for now, it is important to recognise that the strength and integrity of the adopted approaches lay the groundwork for future research practices in the field of Disability Studies.

5.3 Project limitations

As with all research, it could be suggested that this project has limitations. Specifically, these limitations could include limited sample-size, the uniqueness of the context and the subsequent generalisation the project has adopted in interpretation of data because of both factors. As highlighted in the literature review, historic relational context was deemed important within this project, and this influenced how participants in the project were approached via purposive sampling. Although this approach enabled the project to address the research question, the drawbacks to doing so meant that sample size was limited. The study which sought to capture relationships worked on a sample size of 9 individuals, and due to the layout of the arts-based activity session this number was further reduced to smaller groups as the wearable cameras captured three groups of relationships. These included Mary and Courtney, Harvey and Holly, and finally Blake, Gabriella and James. Although one could argue that the quality of captured data is more important than quantity in an investigation of this kind, it might be suggested that a small sample size limits the impact of the project. With only nine participants, and capturing three examples of engagement, the data is representative of this group but can still offer ways of working through particularity.

It might be suggested that another limitation is in relation to the research project being conducted in a specific setting. The Health and Social Care setting in which the project was conducted inevitably shaped the behaviours, responses, and interactions observed. Although a project like this can never take place in a laboratory setting, a neutral environment might significantly alter the behaviours of those involved. As highlighted in the Methodology chapter, this project took place in a setting where individuals involved received care and support and the practitioners are employed. At the time of conducting the study I was occupying the Head of Service role, and this influenced my relationship with all involved and inevitably influenced their actions. All of this means the results are highly context-dependent, therefore the conclusions drawn are valid only under this project at this time.

However, the approach might encourage others to consider the specifics of their context and to consider how this might inform them in practising ‘Tangling’. A further note, which is highly relevant to this project, was the influence of Disability Studies to the setting. Unlike other Health and Social Care settings across the United Kingdom which are significantly influenced by a dominant medical understanding of disability, this setting was established and shaped by Disability Studies. As such, a social model philosophy shaped all aspects of the programmes delivery model, from recruitment, to activities, to staff supervision and training. Furthermore, the influence of this organisation being shaped by Disability Studies meant that there was at the time, and historically, a high proportion of Disability Studies graduates employed within the organisation. This inevitably shaped both the culture within the setting and how the relationships played out in practice, which were captured in the data. The result of this is that the uniqueness of the setting and the limited sample size could make the claims found in this project open to criticism.

While the conclusions derived from this study can provide valuable insights and inform hypotheses for future projects, they should not be seen as conclusive evidence about all relationships between disability practitioners and individuals described as having complex needs. One recommendation following this project would be to replicate a similar study in different settings which are not informed by Disability Studies. Replication, it could be hypothesised with confidence, would render different findings. The methodological approach of this study was appropriate and most importantly ethical. Within the Methodology chapter I acknowledged how my positionality influenced the project. Even so, acknowledging the limitations here is vital as I consider this project's impact and scope. Doing so means that future researchers can be guided when applying the approaches within this project to broader contexts. Future studies can address these limitations by conducting a project in another location with different people. This will test the relevance of the claims of this study as the areas covered in this project are an under -researched area within the field of Disability Studies.

5.4 Future recommendations

This final section will consider possible areas that could be influenced as a result of the project's findings. Firstly, as this project has adopted a reflexive approach throughout, it is suitable to reflect on the impact to myself in my professional pathway. Next, this section will consider what the project could mean within Social Care settings, specifically as it relates to policy and training. Finally, this section, and the thesis, will close with specific reflections for the host setting in which this project played out.

5.4a) Future recommendations for personal practice and research

During the course of writing the Analysis and Conclusion chapters I moved organisations after seven years in post. I left a role in an organisation I had helped launch, to take up a role for another Health and Social Care company in a different location. The previous six months in the new role have generated reflections not only over the period of this research but the preceding seven years within the organisation in which it took place. There is an inevitable comparison between settings and practice, and I have considered how the research project is a little snapshot of everyday life in that previous setting. It could be suggested that the intimacy of the relationships in the previous setting could have been taken for granted and are not easily replicated. As will be seen in the section which relates to training and policy, there are learning points from this study which can be taken into this new role. The personal insights gained through establishing the previous setting combined with those gathered in this project significantly impact my conduct in the new setting, in particular in how I connect with and support caregivers. Primarily, this project challenges the way relationships between practitioners and individuals described as having complex needs can be considered. The impact therefore needs to be evidenced firstly through myself; I need to recognise how and when I showcase *I-it* dialogue, both with colleagues and those we support. Adopting personal vulnerability and demonstrating *I-Thou* is a starting point, one in which I hope to be an example to other caregivers around me.

Then, as I am keen to develop this research area and share the findings of the study which applies *I-Thou* in disability care beyond my current context, I will need to expand the project's scope. For example, future research could explore the longitudinal impact of relationships informed by *I-Thou* dialogue on the wellbeing of practitioners and individuals described as having complex needs. Such studies could consider the barriers or opportunities which come with implementing these philosophical principles across a wider range of Health and Social Care settings. For now, this starts with presenting this research within my new role, building the relationships with new colleagues, then taking such approaches and applying them to policies and training.

5.4b) Next steps in policy and training

One of the challenges encountered within this project has been adequately describing, and replicating what *I-Thou* relationships look like. One might question *'what does 'Vulnerability' look like? And, how does this impact 'Practising' empathetic and relational care? And, what does it mean to 'Tangle'?'.* Similarly, taking the outcomes from this project and offering an impact to policies and training for Disability Practitioners is equally challenging. However, in an attempt to do so, this project can be used as a point of reflection for those seeking to foster deeper, more empathetic relationships with those they support. The project could be used to emphasise relational skills and reflective practice within the field of Health and Social Care. Using Buberian philosophy, training which recognises the importance of seeing the '*Thou*' in each individual can develop an empathetic approach which privileges listening, allowing the cultivation of spaces and work cultures where embracing personal vulnerability is a starting point of person-centred care. Describing relationships in practice is challenging, instructing relationships is even more difficult, but in an attempt to simply frame an *I-Thou* dialogue in practice I have grouped the learning in three areas which can shape policy and practice between disability practitioners and individuals who are described as having complex needs. The three areas are 'how we sit with', 'how we touch', and 'how we talk to or talk about'.

5.4bi) How we sit with

One thing that working alongside people described as having complex needs has taught me is that I, as a 6ft male am very often the highest point in the room. My professional experience is such that many of my colleagues, who happen to be female are shorter than me, and the majority of people I support spend their days in moulded chairs, or, essentially, lying on the floor as part of posture support. How we sit with people is essential for relationship building. The way we sit with people has the potential to encourage vulnerability and presence. Challenging practitioners through policy and training to encourage vulnerability and presence in how they sit invites mutual openness and authenticity. This can be reflected from seating arrangements or the encouragement to staff to lie next to those they support minimising physical barriers and levelling the playing field symbolising mutuality and facilitating deeper connection. Mindful sitting can significantly alter the relationships within a space, and so standard expectations of Health and Social Care settings where individuals with care and support sit on the parameter of a room while caregivers stand or sit elsewhere should be disrupted. Mindful sitting in policy and training considers the dynamics of rooms and spaces to create critical reflection and attentiveness so that genuine encounters are more likely to occur. Furthermore, doing this encourages a shift in the unspoken power dynamic at play as those practitioners who adopt vulnerability in presence will actively resist inequality through their body language. They will seek to sit besides, or lie beside as doing so communicates respect and mutual vulnerability. 'How we sit with’ is ultimately about building *I-Thou* because avoiding any posture that appears domineering or disinterested will influence the trust and quality of the engagement.

5.4bii) How we touch

Closely related to the point made above is the need to develop *I-Thou* through how practitioners engage in touch. Touch is essential in professional caregiving, but it can also signify a willingness to be close and connect with, or Tangle with individuals who are only touched during an intervention. Touching individuals described as having complex needs is, as was the case in this project, as much about communication as it is about anything else. Therefore, training about ‘how we touch’ should be implemented acknowledging the need to explore and interpret consent. Policies and training should emphasise touch outside of interventions and should be responsive to bodily signals that may indicate willingness or unwillingness for physical contact. Practitioners should then be guided in how touch can build trust and connection as an extension of the relationship, not merely via a task. How we touch, or our willingness to do so, despite the risks of spillages, smells, or as was the case in this project - hair pulling, tells another individual that you as a practitioner are prepared to be vulnerable and connect with another, enjoying their presence. Training and policies in individual settings need therefore be person-centred and not generic. This is not a one-size-fits-all solution despite the inevitability of touch. The call for practitioners is to open the dialogue about individuals in each organisation and create policies and training which will equip staff to engage in ‘Tangling’ as appropriate to the wishes of individuals in their care.

5.4biii) How we talk to or talk about

The previous two points may be about the direct connection in sitting with and touching individuals who might be considered to have complex needs ‘how we talk to or about’ recognises the influence of our practise even when the individual we may offer care and support for is not in the room. Words can build up or to knock down, language in practice can shape working cultures. As such, policies and training as it relates to ‘how we talk to or talk about’ is centred on empowerment, sensitivity, reflection and disruption.

Policies and training which emphasises empowerment, recognises the full humanity of those in receipt of care and support and provides cultural reflections on how language, such as discussion of neurological age or development disempowers individuals. Similarly, practitioners should be encouraged to recognise when *not to talk but listen*. Gathering footage from wearable cameras like in this project is a good exercise to see how often practitioners do talk. In listening, practitioners are challenged to be more reflective and sensitive to the needs of individuals. Furthermore, through listening, non-disabled practitioners can be influenced by the voice of disabled individuals who can share how disabling language can uphold barriers in lives of those who do not use the standard language. Policies and training should privilege disabled voices and critical reflection about what is assumed knowledge surrounding care and support of individuals described as having complex needs. This project can influence how other professional caregivers talk about individuals who might be described as having complex needs because the evidence in this project is that caregiving is not one-way, the practitioners evidence a receipt of care in a relationship of mutuality. Sharing this means that the space for reflective conversations and challenging of assumed knowledge is disrupted.

By integrating *I-Thou* dialogue to Health and Social Care practices, both in policy formation and continuous professional development, transformation can occur fostering deeper, more meaningful connections. Such connections, grounded in vulnerability and mutual respect can significantly enhance quality of care and community wellbeing.

5.4c) Closing comments

A final word to the implications for the context in which this project took place. What was captured in this project was consistent to the personal experiences I had witnessed over seven years. There was an honesty and integrity in the relationships presented. The space is one where those individuals are listened to, vulnerability is adopted, and Disability Studies has a presence. It could be suggested that to maintain this culture the voices of those who so often are silenced need to remain at the forefront of future decisions including strategic direction, policy formation and staff development. To do this, I would argue that the significance of maintaining a relationship with Disability Studies in Higher Education is essential, as is being informed by disabled representation in practice. This organisation benefits from a relationship with Liverpool Hope University Disability Studies course, as such, year on year employs graduate caregivers to roles which nationally are not occupied by graduates. The critical reflection posed by Disability Studies challenges disability practitioners to take theory into practice. This project is an example of captured relationships as Disability Studies comes out of the lecture theatre, passed the corridors of Health and Social Care settings, and into the lives of individuals like those named in this project. The exploration into the application of Buberian philosophy to the relationships between disability practitioners and individuals described as having complex needs has not only highlighted the profound potential for transformative relationships but poses a challenge to reimagine the essence of care itself. It is a call to embrace vulnerability, love the people and rekindle the sacred element at the heart of human relationships. It is a challenge to nurture spaces where every individual is truly valued as having a dignity which cannot be removed.

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Appendix 1

Ethical Approval

Liverpool Hope University **Ethical Approval Request for research involving human participants including children or vulnerable adults** For research projects involving human participants who are NOT children (under 18) or vulnerable adults there is a different form which should be used.	
SECTION 1 [TO BE COMPLETED BY THE RESEARCHER]	
1.1 Researcher **For staff: Name:** **(For joint research conducted by staff, the names of all the researchers should be given with the Principal Researcher's name given in bold.)** **For students: Name, student ID, name of supervisor:**	Mark Bygroves 05001491 Owen Barden Claire Penketh Laura Waite
1.2 Title of Proposed Project:	I-Thou in practice: Exploring the Educational philosophy of Martin Buber in a community care setting alongside adults described as having PMLD
1.3 For students only: Programme Title and Level of Study (e.g. MA Education; Philosophy and Ethics Level H).	EdD

1.4 For staff only: Position held at Hope (e.g. Lecturer).	
1.5 Faculty and Department or equivalent : *(for research involving two Faculties or Departments, please state both. The name first given should be that of the Faculty and Department whose sub-committee is being asked to approve.)*	School of Education
1.6 Start date of proposed research (note: this must be later than the date at which approval may be given)	1st June 2021 (The project will not commence until ethical approval is granted)
End date of proposed research	1st December 2022
1.7 Professional guidelines referenced	British Education Research Association (BERA) (2018), Ethical Guidelines for Educational Research. Fourth Edition [Internet] Available from: https://www.bera.ac.uk/wp-content/uploads/2018/06/BERA-Ethical-Guidelines-for-Educational-Research_4thEdn_2018.pdf?noredirect=1 [Accessed 12/12/20]. Liverpool's Dignity in Care Charter Liverpool's Dignity in Care Charter.pdf

	RF Staff Code of Conduct and Values statement

SECTION 2

NOTES ON ALL RESEARCH INVOLVING HUMAN PARTICIPANTS

Approval will be given by

(a) The University Research Ethics Sub-committee for

- research that may involve deceptive or covert activity
- empirical research into illegal activities
- research that may be connected to any aspect of national security
- and/or research deemed to pose a significant risk to the University's reputation.

> The researcher should identify all such cases and refer them to their supervisor, who in turn will contact their Departmental Research Ethics Lead (DEL) for suggestions. The DEL will forward the application to the Faculty Research Ethics Sub-committee for consideration and, if necessary, for referral to the University Research Ethics Sub-committee

OR

(b) The Faculty Research Ethics Sub-committee for research involving children (under 18) or vulnerable adults and recommended by a Departmental Research Ethics Lead (DEL)

OR

(c) The DEL for research involving human participants but NOT children (under 18) or vulnerable adults.

OR

(d) An authorized staff who for good reason cannot refer the request to a supervisor

NOTE: There is separate request form for research not involving human participants. Likewise, there is another distinct request form for research involving human beings excluding children (under 18) and vulnerable people groups.

In all cases, initial scrutiny will be carried out by the supervisor or DEL, as appropriate.

Initial scrutiny consists of a careful reading of the request coupled with ensuring completion of the checklist given at the end of this form. This process may need to be iterative with the researcher*. When ALL responses are satisfactory, the initial scrutineer should complete the last section of the checklist and should send this form (and any associated documentation) on to the next stage of the process as explained at the end of the checklist.

*If ANY prompt cannot be given an acceptable response, the initial scrutineer should return the form to the researcher, clearly explaining the remedial action needed, and advising of a deadline for the form to be returned to the initial scrutineer. If, after this process has been rigorously followed, there is a ‘No’ in the checklist which the initial scrutineer regards as potentially valid, the form should be referred (via a DEL if the initial scrutineer is a supervisor) to the Research Ethics Sub-committee for ratification.

Section 3. INFORMATION ABOUT PROPOSED RESEARCH STUDY

Note: the checklist given at the end of this document should be completed by the researcher. The initial scrutineer may either add to it, or simply endorse it as agreed. A supervisor or DEL receiving a form without the checklist having been completed will return it to the supervisor (for student research) or the researcher (for staff research) for completion.

3.1 GENERAL

a) Full title of the research project:

I-Thou in practice: Exploring the Educational philosophy of Martin Buber in a community care setting alongside adults described as having PMLD

b) Aims and objectives:

The overall aim of the project is to capture and investigate diverse means of connection through relationships in the lives of those said to have Profound and Multiple Learning Difficulties (PMLD) and investigate the similarities between the nature of these relationships and the educational philosophy of Martin Buber.

This project seeks to capture how democracy is worked out through the relationships of people who experience the world and connect to each other in diverse ways. It will capture this through questioning how these relationships have shaped an adult day service focusing on how love, justice, interdependence, respect and diversity are fundamentally educational values which can outweigh notions of academic performance and progress.

c) Brief outline of the research study. Please ensure that you include details of the **design** (qualitative/quantitative, etc) as well as the **methods and procedures** (questionnaire, interviews, experimental trial, observation, etc).

Design:

This project will be a qualitative study which will draw data from a purposive sample of individuals with the label of PMLD, and parents, friends and carer staff of young adults with the label of PMLD from one community setting in South Liverpool. It will adopt an Participatory Action Research methodology (whilst acknowledging its potential pitfalls by calling this Action Research with Participation) because it is the desire of this researcher to relinquish some of the power within the project whilst being able to offer a facilitation of exploration. Using participatory methods which include handing over the selection of methods to the research committee we will seek to explore together what an adult day service in practice has in common with the educational philosophy of Martin Buber in Practice. Using action research cycles we will explore this question through data capture tasks which ask “who are the most influential ‘builders’ in the particular setting”, and “how do they build?” Following this they will explore what place I-thou and I-it relationships have in the lives of people described as having PMLD. Disability studies and Martin Buber’s educational philosophy will influence the analysis of the data as the data cycles are collated and main research question is considered.

Plan:

1. As I am the Head of Service for the organization in which the research is taking place, I will seek accountability and gatekeeper consent from the Chair of the Board of RF (the setting in which this research takes place). I have already contacted him for his consent and will share the ethical request form.

2. Approach a purposive sample of people I have worked alongside and with since 2017 since the start of our organization who I know well, feel would want to take part and could accurately support the research question in line with the organization timeline. This approach would mean that the purposive sample would be small and those who have joined the organization later would not feel excluded for this particular research. Share consent forms and research information sheets and research information **Video (watch by clicking link)**. Gain consent while recognising its problematic nature. Form research committee comprising self and participants.

3. Share the philosophy of Martin Buber and Explore ‘what is Action Research’ together through three group presentations and discussions (This data will be captured). I will seek to make this process informal, relevant and engaging for all as a context setting form of engagement through presentations and conversation.

4. Engage in Action Research through participation. Addressing research questions and sub questions through methods chosen by research committee to capture data. Methods to be explored by research committee may include but are not limited to: focus group ; observation through video data - such as wearable cameras and Zoom; or, multi-sensory activities - such as the creation of shared timeline projects. At this stage I seek ethical approval for a wide range of data collection methods in recognition that actual methods will emerge through dialogue with participants. This is an ethical move designed to help me relinquish power and not solely control the selection of methods.

5. Once the research committee have had some overview of types of methods which they might seek to explore, they will begin an Action research cycle by adopting one method and exploring a sub question through an activity. This researcher will then collect the data and offer initial reflections. These reflections will be shared with committee to explore initial thoughts on the process of collaborative analysis. Once I have adopted and implemented this analysis the results will be shared with the committee in order to consider the implications for the next phase. The cycle will be repeated offering a potential alternative data collection method chosen by the committee exploring the second sub question.

d) As mentioned under Section 2 (a), some types of research must be referred (by the Faculty Ethics Research Sub-Committee) to the University Research Ethics Sub-Committee. Therefore, please state here if your research involves or may involve deception, the use of covert methods, is into matters involving national security, is into illegal activity or might endanger the University's reputation. Please also highlight the key aspects which cause it to fall into one or more of these categories.

This research does not involve deception, nor use of covert methods. It does not involve matters of national security, illegal activity or activity that might endanger the university's reputation.

e) Where will the study take place and in what setting? If in a workplace, or if the participants are from a workplace (e.g. a school), identify what your connections are with that workplace.

Participants will be recruited from my workplace as this is where I have contact with participants. As a researcher I must acknowledge that I hold a position of power in this circumstance. I am the Head of this service in which the research will take place. This can influence all participants. I will seek to minimize this power imbalance by ensuring participants know that their participation is voluntary and data they provide will be anonymized, that they are free to decline partaking in the project, that they are free to shape the direction of data gathered and methods involved. Furthermore, it will be clear by any approach from myself as a researcher that this is a piece of work in my personal status as a university research student not as a service manager. Service user support/access to services will be in no way impacted by participation/non-participation in this research.

f) Give a brief description of your target sample (e.g. age, occupation, gender).

I will adopt purposive sampling as is suitable in a project of this nature.

I will seek to recruit up to six participants to be a research committee. This committee will include adults over the age of 20 years with a variety of experiences attached to the label of Profound and Multiple Learning Disabilities (PMLD). These experiences include paid carer staff members, family members and young adults who are described as having PMLD and friends. There are no specific characteristics being targeted within this research other than an involvement by choice and experiences of the label PMLD and an established group relationship. Purposive sampling is utilised as highlighted later in this document as it is deemed to be the most ethical means to justify consent.

g) Is the participation individual or as part of a group?

Participation will be as part of a group

Vulnerable groups: Special considerations

h) By use of this Form you are highlighting that some (possibly all) of your participants are in vulnerable groups (e.g. children under 18, or individuals with learning difficulties or mental illness). Please specify the nature of the vulnerability.

If you are in any doubt about whether adults whom you wish to research should be classed as vulnerable, please consult your supervisor or a DEL early in the process.

Yes. Some of the participants I will approach are described as having profound and multiple learning difficulties (PMLD) although I do not know whether they consider themselves vulnerable. People who are described as having PMLD have been described as some of the most vulnerable people in society due to needing direct care support with many aspects of their life (see Imray, 2005), this is furthermore complicated by the description of being "non-verbal" which so often is considered a synonym of "non-communicative". As a student of disability studies I personally reject blanket claims of vulnerability particular towards those who have not claimed to be vulnerable themselves. Clearly the nature of vulnerability is complex and the adults who are taking part in this project are adults. As a researcher I must be careful in my approach to the project in relation to power, yet it must be recognized that although people with the label of PMLD have been considered vulnerable previously does not mean that those in this project with this label would personally accept this status, or the very label which is attached to their experience of knowing and being in the world. This is delicate and I therefore will approach with caution and a sense of uncertainty and constant reflection surrounding this question of vulnerability.

Vulnerable groups: Special arrangements

i) Define the special arrangements which will be made to deal with issues of informed consent (e.g. is parental/guardian agreement to be obtained, and if so in what form?) and also of the participants' freedom to withdraw from the research at any time.

There will be some participation by individuals who are described as having PMLD. Gaining written or verbal consent is problematic for individuals who communicate in ways which could be described as non-normative. The nature of what consent means and relationships for people described as having PMLD is vital to this project. There have been previous attempts to gather and interpret voice for people described as having PMLD such as the government backed MENCAP 'Involve me' (2011) paper which adopts approaches such as peer advocacy, multimedia approaches and sensory games. This has been and continues to be problematic as practitioners, friends and carer staff continue to work in an element of uncertainty. However, at this point it must be emphasized that knowing anything with certainty is problematic, even if one uses verbal communication, I for example, might verbally say that I consent to something but this does not mean I mean or fully understand what I have said. The heart of this project is to try and capture that nature of relationships which is hard to do so when we reduce our interpretation of communication into what can be understood by written text (as Waite, 2018 would suggest), therefore like the question of vulnerability, the issue of consent and voice and exploration of such in relationships has complexities in this project. Therefore, I have considered the following:

a) The individuals described as having PMLD I have known and worked alongside daily for over four years. Although the organization of which I am the Head has grown considerably over the past few years into a large team and many attendees, at its conception four years ago there were only a very small number of people. Those who will be part of this project will have been together from 2017. Therefore no attendees or carer staff should feel excluded from the group taking part in this project. I and those taking part in the project have reflections to offer about our relationship and connection which celebrates their influence and are well positioned to collaborate as advocates. It is more appropriate to do so in one another's presence.

b) The nature of the study is investigating what relationships mean in the lives of individuals described as having PMLD, it is appropriate to have valued representation contributing to knowledge.

c) Purposive sampling will be adopted so that I can approach individuals I believe would feel comfortable in this project because I have known them for the longest period of time and who were at the organization at the start of the first year, I will seek to affirm this belief by also gaining parental consent to also take part. Consent can be considered a collaborative best interest's decision.

d) The research committee itself will be a close knit group who know and feel comfortable with one another and able to reflect on shared experiences.

e) This researcher will adopt a dynamic and reflective approach to consent, if I as a researcher or those who care for those who are described as having PMLD consider that there is a change of status of consent and willingness to be involved we will maintain a duty of care by withdrawing this individual.

f) It is the belief of this researcher that despite consent being problematic, the individuals who are taking part in this project have a voice to be heard and celebrated.

I wish to be a researcher who offers both critical reflection, within a context of sensitivity and respect, this is an ongoing line of reflection for emancipatory research.

Any individual can withdraw at any time during the Action Research sessions (this point is not in relation to the overall project but the group sessions themselves, points relating to the overall project withdrawal addressed later in this document), for those who display alternative or interpretative communication methods, any visible form of distress and frustration should be perceived as a reluctance to take part and withdrawal should be interpreted and accepted. For example, for participants who are unable to communicate in what might be considered structured language (speaking, signing, using socially understood norms of body language, writing or use of augmented communication devices) communicating by other means such as vocalising a sound of a scream, crying or pointing to the door are open to interpretation, although I cannot be sure that this is an objection to partake in the research, I also cannot be sure it is not. So I therefore should be sensitive to what I do not know. This is why the nature of the group and collective engagement is a form of advocacy. It is therefore suitable in this project to assume that such signs are a signal not to continue.

My own positionality as carer / researcher enables me to recognise signs of distress and discomfort for those I have a professional relationship with. The research project cannot take place in a period where basic human need is lacking – for example, support for person centred help, feeding and any medical interventions are needing to take place. Therefore, the activity groups will take place at a time after personal care, feeding or medical intervention has taken place, and the activity groups will also need to be responsive to need, so if an unexpected intervention is needed, the research process will be secondary to priority of person-centred support. It also may be necessary during the Covid-19 Pandemic for this research committee to meet virtually rather than in person. I must be a flexible researcher, and this must be a respectful research process.

j) How will participants be selected, approached and recruited?

Identify clearly and analyse fully any issues of power relations that might arise, and say what steps you will take to alleviate them. This applies particularly if the location of the research is a place of the researcher's own employment, or if they have other strong links with the participants.

I am a researcher in this project, but I am also the Head of a Service which this project will take place through. I have a duty of care to those under my care, individuals who could be described as service users, their parents and carer staff. I clearly have an influence and must be mindful of how I approach and recruit participants. I have sought gatekeeper approval of this project via the chair of the Board of RF (the setting in which this research takes place). Although what follows is a justification for why I have not chosen a certain route of recruiting participants, I believe it also clarifies my use of information sheets for parents and carer staff alongside an information **Video** **(watch by clicking the link)**.

For this project, I believe purposive sampling, working alongside those who I have known for the longest period of time and can address the research question through their experience of timeline, is suitable alongside an information video because:

- It is more accessible for the majority of potential participants who I am unable to interpret whether or not they are able to read or interpret easy read / symbol communication

- This project would benefit from a small research committee who have shared experiences to reflect on

- This research is open to researcher interpretation, it would be unsuitable to have a research committee which consisted of individuals I cannot offer an insight into experiences. Instead, this project will approach those who I have worked alongside and spoken to daily for the past 4 years. I set up the organization four years ago, I will approach those who have been with us from within the first year who can support the timeline of narrative in relation to sub research question B. There are some who were with us from the start who can no longer take part in this project. As interpreting consent for those who do not use standard communication can be complicated, working in partnership with those around an individual to make best interest decisions are consistent with the mental capacity act. If I and those around me are part of group best interest decisions I would suggest in this project length of time together is a key factor in having informed decisions. Therefore, although the organization is currently larger, it will be with those who were part of the project within the first year, who are available, that I will approach because I feel I can more accurately provide perspective on consent and they are more suitable at this point to journey through research sub-question b.

- As consent for individuals described as having PMLD is a delicate and collaborative discussion, I do not feel it would be appropriate to contribute to such best interests decisions for a project which will have a benefit to me (in gaining a qualification) unless I were confident about the nature of my connection with such individuals and have known them for an extended period of time.

Clearly as this project is concerned with capturing relationships for individuals described as having PMLD, relationships matter in this project. I will approach members who I have known since the first year of this organisation who also know that I have been enrolled on the EdD, who will not feel obliged or forced to take part, who will not be coerced, and have no threat in taking part. I am trusted by those taking part, I will approach these individuals 1:1, share my ideas of this project and its aims and objectives.

I will follow up initial contact with each participant via either email or letter, attaching an information sheet and information **Video** (watch by clicking link) about what it is I am doing and what their participation will involve (BERA, paragraph 11).

Regarding power relations, as the manager of a service this offers a problematic approach as carer staff involved will be my direct employees. It will be explicitly clear to all carer staff both verbally and in writing that participation or non-participation in this project will not impact on their employment or our working relationship. Furthermore, informed consent procedures are problematic for individuals who adopt a non-verbal language which is open to a wide degree of interpretation. I hope that by offering those who take part in the choosing of the methods in this project reduces the power I hold as a researcher to dictate direction or coerce discussion. Furthermore I will ensure the participants know that their participation is voluntary, that their contribution will be kept in confidence, that issues raised during the research process will not be repeated outside of the research context (unless something is said by a participant which could indicate either harm to themselves or another person, in which case safeguarding procedures would need to be followed). Participants have the right to withdraw their data within one month of participating in the first activity in which data is captured and for those who do not communicate verbally any signs of visible distress will be interpreted as a request to withdraw. The participants are individuals I am acquainted or in a position of power over, yet the approach/ request for participation will be informed by a professional and ethical approach from my personal status as a researcher and not a representative from the service they associate me with. This information will be stated in the information sheet given to willing participants. Any approach will utilise university letter head not that of the service we associate with, for any digital correspondence, my university email will be used, not my work or personal email address.

k) Is written consent to be obtained? Please delete as appropriate **YES**.

If **YES**, please complete the appropriate sections of the standard Consent Form(s) and the accompanying Research Information Sheet(s) that can be found at the end of this documentation.

If **NO**, please state *why*. As free and informed consent is essential, you need to give strong and convincing reasons for not obtaining informed consent.

Yes, written consent will be obtained from those taking part in the project or individuals parents and carer staff as outlined in section i) and j). Although the research information sheet and consent forms are available for parents and carer staff, as with the point surrounding recruiting participants through a poster, an individual consent form / information sheet is unsuitable for participants with the label of PMLD. Instead, the information will be shared in what may be considered the most accessible way, in this project a **Video**, and a group decision by those who know the person involved will be suitable- lead by parent or lead carer.

How will the participants' right to withdraw be ensured?

Participants right to withdraw from the research at any point and withdraw their data within one month after participating in the first activity in which data is captured will be communicated throughout the process. Participants can formally request withdrawal by email to 05001491@hope.ac.uk , they can also verbally withdraw and I will formalize this response in writing. On the part of individuals described as having PMLD where communication surrounding withdrawal is less clear, those around the individual including this researcher, family members and carer staff will inform a best interest decision to ensure voice is interpreted with sensitivity and accountability.

3.2 Risk & Ethical Procedures.

Please note: <u>all</u> studies with human participants have the potential to create a level of risk. “No risk” is thus not an acceptable answer, although “Minimal risk” is. You are fully responsible for the protection of both yourself and your research participants. Please try to anticipate the context and perspective of your participants when completing this section.

a) What potential risks are there of physical harm to participants? Please specify, and explain any steps you will take to address them.

There is minimal risk of physical harm to participants. The project with participants will be handled carefully, sensitively and without intrusion maintaining the policies of the setting in which it is conducted. Alongside, ensuring participants are aware of their right to withdraw from the research at any point and withdraw their data within one month after participating in the first activity in which data is captured, reassurance will be given that their responses will be anonymised alongside their identity. Any data capture will be carried out in locations that are physically accessible, safe and familiar to the participants.

b) What potential psychological risks are there to participants? In particular, how might participation in this research cause discomfort or distress to participants? Please specify, and explain any steps you will take to address these issues.

The potential risk of psychological harm to participants is anticipated as minimal as the action research cycles will be carried out in a sensitive and respectful manner seeking to explore areas and questions from which participants direct. It is anticipated that any data collection method or activity might capture and celebrate relationships. However, if a participant is displaying any signs of psychological distress the subject of discussion will be halted and a new approach will be adopted, for individuals who are described as having profound and multiple learning disabilities any visible signs of distress will be interpreted as a request to take a break or withdraw. Participants will be informed in the Participant Information Sheet that they have the right withdraw from the research at any point but will have one month after the first activity group has taken place to withdraw their data. There is a low level of risk of emotional harm to participants anticipated. However, discussions may naturally lend towards injustices and difficulties faced by the group for areas of funding, support, access and interpreting voice. Therefore, the action research cycles will be handled carefully, sensitively and without intrusion. I am acquainted with the participants, I am not a stranger to them and I have worked to establish positive relationships based on mutual trust and respect.

Another potential risk is that during the activity groups the individuals who take part may be reminded of what some might presume is inequality within society, this is in regard to presumed unwritten criteria which idealises certain bodies and the nature of perceived independence. Yet, it is good that participants have a space where they can talk about it with others who understand this area. However, this research will not take place at a time when other individuals on site might feel excluded from the project, this will be sensitive and at a suitable time after 3:15pm.

c) Are there any risks to you as the researcher (and / or your co-researchers, if you have any) in this project? If so, outline the steps you will take to minimise them.

YES - As a Head of a service this research could identify negative attitudes towards my own practice and challenge my position as a leader. Research offers a space for personal critical reflection. If I experience discomfort I will consult my research supervisors.

d) How might participants benefit from taking part in this research?

This is an opportunity for the participants to voice their story, to highlight the educational worth of diverse experiences and to showcase voice being not dependent on what might be considered normative means.

This project will value its participants and have their experiences acknowledged and shared

This project will develop a critical awareness of how people with the label of PMLD have shaped an adult day service. It will also offer opportunities for professional and personal reflection for all involved, including staff members.

e) Does any aspect of your research require that participants be naïve *(i.e. they are not given full or exact information about the aims of the research)*? Please explain why and give details of the debriefing procedures you would use when the need for the naiveté is over.

No

3.3 Data Security, Confidentiality, Anonymity and Destruction

a) Where and how do you intend to store any data collected from this research? Give details of steps you will take to ensure the **security** of any data you collect.

Note that data protection regulations stipulate that data must be stored securely and not be accessible or interpretable by individuals outside of the project. Hence, data should be stored in a password-protected file on a password-protected device such as a desktop or laptop, and not on easily movable devices such as USB keys or CD ROMs.

Data that is collected in video format will be transcribed into text in a typed document. The video recording will be password protected within a folder. The folder will be password protected and archived safely as it may be utilised for future projects. Any observable communication that takes place during the process by men and women who do not use standard means of communication will be captured as I will video the activity group. Video recording is a suitable means of data collection as it will evidence how participants engage in the activity in a more substantial way than audio collection alone. Any physical objects or created pictures will be photographed and added to the password protected folder until the project is complete, it will then be kept in a locked cupboard during the project that only I have access to with the possibility of being offered back to any individual or group members who created it after the project is complete. Additionally any handwritten consent and notes that are taken will be converted into a digital format and stored together with transcribed notes on a secure file on a computer drive that is password protected folder or password protected computer. All personal data will be stored and used in line with GDPR 2018. All data, once anonymised, will be accessible to the researcher, supervisor and examiners. In line with BERA paragraph 27, participants will have access to any personal data that is stored.

b) What steps will you take to safeguard the **anonymity and confidentiality** of personal records?

Data and personal records will be stored as stated in Section 3a. Pseudonyms, as agreed with both the researcher and the individual participant, will be given to all participants to maintain anonymity during and following the project. Identity revealing descriptions within this project are not necessary, it is not necessary for the data to use individuals real names, addresses or contact information. Pseudonyms will suffice. If during the interview any details are shared which could reveal their identity I will remove this from the data. No real names will be used during the write up, and no details which may reveal identification will be used. I will inform participants that I will not ask them about the matters discussed within the activity groups outside of the research setting unless safeguarding concerns arise.

If for any reason anything is revealed in the data which puts those within the project at risk, particularly around safeguarding or illegal activity, this information will be shared with the relevant authorities such as the police. I will highlight this prior to the project via the information sheet. Although personal details will be anonymised and identity remain confidential, the sharing of stories and the capture of relationships are part of the very project to be shared with those who read this Educational Doctorate.

c) Will this research require the use of any of the following (please delete as appropriate):

Video recordings YES

Audio recordings YES

Photos YES

Observation of participants YES

If you answered YES to any of the above, please provide a more detailed explanation of how you will ensure confidentiality and anonymity.

I will personally transcribe the recordings in private, using pseudonyms to protect identity. Once the data has been transcribed the recordings will securely stored in a password protected folder which only I as the researcher has access to. The data will be password protected and safely stored in the event I need to return to the raw data at a later date.

d) Please confirm that you will destroy all personal data and indicate at which point you will do so.

For students: A date should be provided. This should normally be no later than the end of their degree programme. Students should NOT make this point dependent on a successful outcome of their studies.

Any data gathered will be anonymized. I will not destroy all data when the project is complete but rather safely store with password protected folders which only I as a researcher can access. It could be that I utilise this data for many publications to come so it will be reasonable that I defer indefinitely. Personal data will not be required in this project, if for any reason any personal data is captured this will be destroyed after the research has been submitted for assessment. This date will include a date of re-submission.

For staff: A date should be provided. For certain types of research, it is acceptable for destruction of anonymised data to be indefinitely deferred. This must be clearly declared in the Research Information Sheet.

4 For students only: Supervisor's Comments

(Please note that applications that were submitted without your supervisor's comments will not be considered.)

Supervisor's name:

Date:

LIVERPOOL HOPE UNIVERSITY

RESEARCH CONSENT FORM – Disability Studies Carer Practitioners

Title of research project: Disability Studies, Buber and Professional Practice: An Exploration into the Relationships between Practitioners and people described as having complex needs.

Name of researcher: Mark Bygroves

1. I confirm that I have read and understand the information sheet / Video for the above research project and have had the opportunity to ask questions.

YES	NO

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

YES	NO

3. I agree to take part in this research project and for the anonymised data to be used as the researcher sees fit, including publication.

YES	NO

4. I consent to data collection method of video recording for this project.

YES	NO

5. I consent to data collection method of audio recording for this project.

YES	NO

6. I consent to data collection method of researcher observation for this project?

YES	NO

7. I consent to data collection of produced works for this project including both photographs of and collection of created art pieces.

YES	NO

8. Do my manager and Chair of Board of RF (gatekeeper) allow for my participation in this research?

YES	NO

Name of participant:

Signature:

Date:

05

LIVERPOOL HOPE UNIVERSITY

RESEARCH CONSENT FORM – Family Member

Title of research project: Disability Studies, Buber and Professional Practice: An Exploration into the Relationships between Practitioners and people described as having complex needs.

Name of researcher: Mark Bygroves

1. I confirm that I have read and understand the information sheet / Video for the above research project and have had the opportunity to ask questions.

YES	NO

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

YES	NO

3. I agree to take part in this research project and for the anonymised data to be used as the researcher sees fit, including publication.

YES	NO

4. I consent to data collection method of video recording for this project.

YES	NO

5. I consent to data collection method of audio recording for this project.

YES	NO

6. I consent to data collection method of researcher observation for this project?

YES	NO

7. I consent to data collection of produced works for this project including both photographs of and collection of created art pieces.

YES	NO

Name of participant:

Signature:

Date:

LIVERPOOL HOPE UNIVERSITY

RESEARCH CONSENT FORM – Parent/ Guardian on

Title of research project:Title of research project: Disability Studies, Buber and Professional Practice: An Exploration into the Relationships between Practitioners and people described as having complex needs.

Name of researcher: Mark Bygroves

1. I confirm that I have read and understand the information sheet for the above research project and have had the opportunity to ask questions. I have watched the information **Video** with the person in my care.

YES	NO

2. I understand that the person under my primary care participation is voluntary and that he or she is free to withdraw at any time, without giving any reason.

YES	NO

3. I agree that the person under my primary care may take part in this research project and for the anonymised data to be used as the researcher sees fit, including publication.

YES	NO

4. I consent to data collection method of video recording for this project for the person in my care.

YES	NO

5. I consent to data collection method of audio recording for this project for the person in my care.

YES	NO

6. I consent to data collection method of researcher observation for this project for the person in my care.

YES	NO

7. I consent to data collection of produced works for this project including both photographs of and collection of created art pieces for the person in my care.

YES	NO

Name of Parent/Guardian:

Name of person under parent / guardian primary care:

Signature of Parent/Guardian:

Date

LIVERPOOL HOPE UNIVERSITY

RESEARCH INFORMATION SHEET – Paid carer staff

Outline of the research

This project seeks to investigate and capture relationships between the lives of those said to have complex needs and practitioners influenced by the field of disability studies. Doing so, this project will seek to investigate the relationship between theory and practice using a philosophical lens of interpretation called 'i-thou' to consider how diverse relationships enrich lives.

Who is the researcher?

Name: Mark Bygroves

Institution: Liverpool Hope University

Researcher's University email address: 05001491@hope.ac.uk

What will my participation in the research involve?

I would like you to be part of a research committee which shapes the direction of my project. Initially I'd like to offer some introductions to my research. This won't be for more than an hour, but I may record this meeting.

After this I'd like you to help choose a method of collecting data that we as a research committee group will use to explore our relationships within an activity. This activity session won't be longer than an hour, you may find it fun. Once I gather the results and we can learn and analyse this together before trying to explore some more.

I do not anticipate meeting as a research committee (in person or online) on more than three occasions including the introductory information sharing meeting, but this depends how you are finding the process.

Why am I approaching you to be involved?

I think your contribution will be valuable. I am only approaching staff members who have a background in disability studies, that is either as a graduate or current student. It is hoped that your reflections on theory and practice would enrich this project.

How will the researcher gather their data in this project?

This project will engaging in something called action research with participation, this means that you will be part of a committee which shapes the directions and methods within the research. You can choose how we gather this data. However, I will share some ideas surrounding data collection methods and I have gained ethical approval to explore a range of data collection methods which include audio recording, video recording, observation and collected arts produced by those within the research which will include photographs of created pieces.

Will there be any benefits to me to taking part?

You will be able to share your experiences, feelings and values and have the chance to reflect upon these factors. It will give you the opportunity to shape the entire project in both methods, what the data is and how it is analysed. I am doing this project because I believe there is something extremely valuable that people can learn about the way we interact- you would be contributing to this and the understanding of voice for people described as having complex needs.

Will there be any risks to me in taking part?

There is anticipated to be very low level of risk for you as a participant. However, the research may address areas that could be sensitive to you as an individual. However, if you become distressed you have the right to leave the project and withdraw from the research process at any time.

What happens if I decide that I don't want to take part during the actual research study, or decide that the information given should not be used?

Please consider whether you want to take part in this study. If you do initially but then change your mind once you have begun you can withdraw from the research. If you decide you do not want your data to be used you have **one month** after first research activity session where data is captured to do so. Within this first month if you decide that you no longer wish to participate during the research study you can withdraw with immediate effect with no consequences and I will remove your data. You can contact me via my email address detailed above. If any participant decides they wish to withdraw after one month of the first activity session they will can do but their anonymized contributed data will still be part of the research

How will you ensure that my contribution is anonymous?

Every effort will be made to protect anonymity with no identifying details being published. Together we will agree on a pseudonym (a pretend name or reference) for you.

MY ROLE WITHIN THIS PROJECT IS AS STUDENT RESEARCHER. PARTICIPATION IN THIS PROJECT IS VOLUNTARY AND NOT PART OF YOUR ROLE AS A CARING PRACTITIONER. **Please note that your confidentiality and anonymity cannot be assured if, during the research, it comes to light that you are involved in illegal or harmful behaviours which I may need to disclose to the appropriate authorities.**

LIVERPOOL HOPE UNIVERSITY

RESEARCH INFORMATION SHEET – family members

Outline of the research

This project seeks to investigate and capture relationships between the lives of those said to have complex needs and practitioners influenced by the field of disability studies. Doing so, this project will seek to investigate the relationship between theory and practice using a philosophical lens of interpretation called 'i-thou' to consider how diverse relationships enrich lives.

Who is the researcher?

Name: Mark Bygroves

Institution: Liverpool Hope University

Researcher's University email address: 05001491@hope.ac.uk

What will my participation in the research involve?

I would like you to be part of a research committee which shapes the direction of my project. Initially I'd like to offer some introductions to my research. This won't be for more than an hour, but I may record this meeting.

After this I'd like you to help choose a method of collecting data that we as a research committee group will use to explore our relationships within an activity. This activity session won't be longer than an hour, you may find it fun. Once I gather the results and we can learn and analyse this together before trying to explore some more.

I do not anticipate meeting as a research committee (in person or online) on more than three occasions including the introductory information sharing meeting, but this depends how you are finding the process.

How will the researcher gather their data in this project?

This project will engaging in something called action research with participation, this means that you will be part of a committee which shapes the directions and methods within the research. You can choose how we gather this data. However, I will share some ideas surrounding data collection methods and I have gained ethical approval to explore a range of data collection methods which include audio recording, video recording, observation and collected arts produced by those within the research which will include photographs of created pieces.

Will there be any benefits to me to taking part?

You will be able to share your experiences, feelings and values and have the chance to reflect upon these factors. It will give you the opportunity to shape the entire project in both methods, what the data is and how it is analysed. I am doing this project because I believe there is something extremely valuable that people can learn about the way we interact- you would be contributing to this and the understanding of voice for people described as having complex needs.

Will there be any risks to me in taking part?

There is anticipated to be very low level of risk for you as a participant. However, the research may address areas that could be sensitive to you as an individual. However, if you become distressed you have the right to leave the project and withdraw from the research process at any time.

What happens if I decide that I don’t want to take part during the actual research study, or decide that the information given should not be used?

Please consider whether you want to take part in this study. If you do initially but then change your mind once you have begun you can withdraw from the research. If you decide you do not want your data to be used you have **one month** after first research activity session where data is captured to do so. Within this first month if you decide that you no longer wish to participate during the research study you can withdraw with immediate effect with no consequences and I will remove your data. You can contact me via my email address detailed above. If any participant decides they wish to withdraw after one month of the first activity session they will can do but their anonymized contributed data will still be part of the research

How will you ensure that my contribution is anonymous?

Every effort will be made to protect anonymity with no identifying details being published. Together we will agree on a pseudonym (a pretend name or reference) for you.

MY ROLE WITHIN THIS PROJECT IS AS STUDENT RESEARCHER. **Please note that your confidentiality and anonymity cannot be assured if, during the research, it comes to light that you are involved in illegal or harmful behaviours which I may need to disclose to the appropriate authorities.**

LIVERPOOL HOPE UNIVERSITY

RESEARCH INFORMATION SHEET – Parent/ Guardian and young adult described as having PMLD

SEE INFORMATION VIDEO WHICH ACCOMPANIES THIS SHEET

Click to see Video

Outline of the research

This project seeks to investigate and capture relationships between the lives of those said to have complex needs and practitioners influenced by the field of disability studies. Doing so, this project will seek to investigate the relationship between theory and practice using a philosophical lens of interpretation called 'i-thou' to consider how diverse relationships enrich lives.

Who is the researcher?

Name: Mark Bygroves

Institution: Liverpool Hope University

Researcher's University email address: 05001491@hope.ac.uk

What will my son or daughter's participation in the research involve?

I would like your son or daughter to be part of a research committee which shapes the direction of my project. Initially I'd like to offer some introductions to my research. This won't be for more than an hour, but I may record this meeting.

After this I'd like your son or daughter to help choose a method of collecting data that we as a research committee group will use to explore relationships within an activity. This activity session won't be longer than an hour, they may find it fun. Once I gather the results and we can learn and analyse this together before trying to explore some more.

I do not anticipate meeting as a research committee (in person or online) on more than three occasions including the introductory information sharing meeting, but this depends how they are finding the process.

Why am I approaching you / your son or daughter to be involved?

I think your son or daughters contribution will be valuable. I recognise that your son or daughter will not explicitly agree or disagree to be part of this project. I am approaching them because I have known them for over five years so have known them longer than other people who could possibly take part in this project, I hope this means I can make person-centred reflections more accurately. You don't have to, but I'd love it if you would join in with them in this project.

Where will this project take place?

Participation, where possible will be in-person. Participation will take place in a familiar environment, the day service that your son and daughter attends daily. The project is designed around a group of friends- so your son and daughter will be with those who are familiar to them.

If due to the impact of Covid-19 this cannot take place face to face. The activity sessions will be set up via a private, password protected zoom link and this researcher will ensure that this session is not interrupted by those not part of the project.

How will the researcher gather their data in this project?

This project will engaging in something called action research with participation, this means that the person within your primary care will be part of a committee which shapes the directions and methods within the research. They will be involved in helping choose how we gather this data. However, I will share some ideas surrounding data collection methods and I have gained ethical approval to explore a range of data collection methods which include audio recording, video recording, observation and collected arts produced by those within the research which will include photographs of created pieces.

Will there be any benefits to my son or daughter in taking part?

There will be no direct benefits for your son and daughter taking part. However, they will be able to contribute to have their voice captured in shaping an entire project. I am doing this project because I believe there is something extremely valuable that people can learn about the way we interact- your son or daughter’s contribution to this will shape the understanding of voice for people described as having complex needs and the community that surround them. It is hoped that it will be a fun process and improve the service they attend.

Will there be any risks to my son or daughter in taking part?

There is anticipated to be very low level of risk as the research or topics of discussion may address areas that could be sensitive to them as an individual. However, if there are any visible signs of frustration or distress this will be interpretation as their right to leave the activity group and withdraw from the research process. Similarly if a participant walks out of the room they will not be forced to remain or come back in.

What happens if my son or daughter or I decide that he or she doesn’t want to take part during the actual research study, or decide that the information given should not be used?

Please consider whether you want to take part in this study. If you do initially but then change your mind once you have begun you can withdraw from the research. If you decide you do not want your son or daughters data to be used you have **one month** after first research activity session where data is captured to do so. Within this first month if you decide that you no longer wish to participate during the research study you can withdraw with immediate effect with no consequences and I will remove your data. You can contact me via my email address detailed above. If any participant decides they wish to withdraw after one month of the first activity session they will can do but their anonymized contributed data will still be part of the research

How will you ensure that my son or daughters contribution is anonymous?

Every effort will be made to protect anonymity with no identifying details being published. All data will be collected and stored in a secure manner. Together we will agree on a pseudonym (a pretend name or reference) for your child.

What will happen if my son or daughter becomes distressed during the project?

On this occasion, we will interpret distress as a withdrawal request from the process. So to give me the best opportunity to interpret associated distress, I and those in the process will consider their individual care plan (as is suitable for the nature of pre-existing relationship), and conduct the sessions in a familiar place and at a suitable time. Doing so will ensure that someone's priority health needs are maintained as a priority over their participation in this project.

MY ROLE WITHIN THIS PROJECT IS AS STUDENT RESEARCHER. **Please note that the promised confidentiality and anonymity cannot be assured if, during the research,**

it comes to light that you are or your child is involved in illegal or harmful behaviours which I may need to disclose to the appropriate authorities.

CHECKLIST FOR RESEARCH ETHICS APPROVAL REQUESTS

(STAFF OR STUDENT)

Name of researcher: Mark Bygroves

Name of Supervisor : Owen Barden, Claire Penketh, Laura Waite

Date completed:

For use by staff or students to help improve the Ethics Approval request before submission

For use by supervisors before completing the Supervisor comments section of the form. If you cannot answer 'Yes' to every prompt, please discuss with, or return the form to, the student.

Checklist completed by:

Date: 16/02/2021

PROMPT	**See form:**	**Yes/no**
● 1 Start-date is after date of scrutiny	1.6	Y
● 2 Appropriate professional guidelines are identified	1.7	Y
● 3 Informed consent is being sought from ALL relevant parties and Consent Form(s) and Research Information Sheet(s) are included. *Note that the University encourages, as good practice, but does not insist on, asking children explicitly for their consent. Parental consent MUST be sought for all participants under 18.*	3.1 i–j End of document – Research Information sheets and Consent forms. Check that they match.	Y
● 4 Power relations are clearly defined and discussed and appropriate steps to address any issues are set out	3.1 e	Y
● 5 Risk to research subjects is adequately discussed and addressed. 'No risk' is not an acceptable response, although 'minimal' is. *Note that if questionnaires or interviews are involved, part of the assessment of risk is linked to the questions to be asked. It is therefore helpful if these can be attached, or at least if there can be as full information about them as possible.*	3.2 a	Y
● 6 Risk to the researcher is adequately discussed and addressed	3.2 d	Y

● 7 The right to withdraw is explicit and fully thought through in this Request Form. The Inform Consent Forms the Research Information Sheet(s) contain further information. It might be necessary for the researcher to give quite detailed information about HOW participants can withdraw and how possible psychological harm could be avoided.	3.1. i	Y
● 8 Anonymity is adequately dealt with in the Request Form and is confirmed in the Research Information Sheet(s)	3.3	Y
● 9 Confidentiality is adequately dealt with in the Request Form and is confirmed in the Research Information Sheet(s)	3.3 b	Y
● 10 Security of information is adequately dealt with in the Consent Form and is confirmed in the Research Information Sheet(s)	3.3 a	Y
● 11 Destruction of information is adequately dealt with in the Request Form and Research Information Sheet(s) Note: it must not be made dependent on **successful** completion of the research project; for students, an expression such as 'when my studies are complete' covers all eventualities. It is acceptable for staff research to have a 'never destroyed' statement, but this must be transparent in the Research Information Sheet(s) and Consent form(s).	33. d	Y
● 12 The research is NOT into illegal activities	2 a & 3.1. d	Y

	Likely to be buried in the narrative	
● 13 The research does NOT employ deceptive or covert methods, such as to negate or impede the ability of the participants to give informed consent.	2 a & 3.1. d Likely to be buried in the narrative	Y
● 14 The research HAS NO interaction with issues of national security	2 a & 3.1. d	Y

Appendix 2

Transcript Focus Group

Present:
Mark (researcher)

Gabriella

Blake

Courtney

Mark: So shall we start with this one, What has disability studies brought to what you do now?

Gabriella: for me its given me a different perspective on life, I feel like I look at people as individuals:

Blake: yeah I agree

Courtney: Its given me an understanding of what disability was, like from when I started the course I thought it was something else, like I'd had had a medical model view before I started uni and when I finished I was more towards the social model view which I think I've now brought into the workplace.

Gabriella: totally agree

Blake: I think before doing disability studies I was more medical model based and since doing the course I think it has impacted in a better way

Mark: You've touched on impacting in a better way there, and how you see things, I know this is hard but do you think you've acted differently because of it, not just like the way you think but the way you act and connect with people? If so how would you identify the difference between then and now?

Blake: For me, in my first year of doing disability studies I was in another care job and the lad I looked after was described as non-verbal and we'd be making a lot of his decisions for him because there was that assumption that he didn't have a voice but since doing the course and combining it with being here I think the opportunities are given because there's a understanding that the individual does have a voice.

Gabriella: I'd agree, before I started working here and before I did the disability studies I was doing the supported living, and it was very regimental and to be honest I'd just go about it and go along with it because I didnt really know what else to go by. But since I started the course I was like 'no' and I was challenging the staff members on what they were doing and I was like you know supporting them in a different way- an improved way a more positive way as individuals.

Mark: So you've used the term regimental and you've touched on decisions, do you think that disability studies has a connection with the term relationships itself or is that just unique to this field of care or this workplace per se?

Gabriella: I think it does have a connection to relationships because your connection to people is different to what it was before disability studies. As these two have said it was more medical model it was like 'aww' but now its like, its 'no', its 'this and its that' its positive.

Courtney: I feel like its like what Blake said about voice, like with relationships and friendships its like you want to be there to support that person with their voice, like we're all friends in this room and I feel like you'd all help me if I was trying to express something, like with disability studies and relationships that goes hand I hand. Like Disability studies taught me about people having voice and I think that goes hand in hand with the relationships.

Mark: Disability studies is a broad thing isn't it, a range of things, is there anything specific about disability studies that you've felt has been transferable to this working context here? Like either you've been able to take that into your own practice or seen, or not seen, others do something you feel has a connection to a specific area.

Gabriella: I think I'd say the affirmative model has been evident, like its like I'm here, this is me, a bit like that probably. I dunno, hard to get my words out.

Mark: I think when I first came here I found that I was proper determined to change everything and I was very strong in my views and I've found the slowness of that process hard because it almost dressed disability studies up in idealism almost, like society is that far away that theory and practice some times don't meet.

Blake: one of the things I've found though which will be different from when you started was that because there are a lot of people here who have done disability studies we're all on the same page if that makes sense when it comes to outlooks and perspectives and when you get new staff in, our ideologies sort of go onto the new staff.

Gabriella: yeah like the new staff who are coming in if they haven't done disability studies are coming in like everybody else and seeing disability as like individualised but obviously when they come to us we portray a different way really and I think that goes onto the new staff and I feel that's a positive way.

Mark: okay so we've sort of looked at theory to practice but I wonder if we can look at it the other way around, maybe practice to theory. How has sort of your practice and engagement here with people who might be described as having complex needs impacted your life thoughts and feelings outside of this context?

Gabriella: I do feel like when I've spent a day in this context I can go away feeling like I've given or helped facilitate the best day possible and that's a good feeling when I leave here.

Courtney: like I feel like when you're able to support someone to do something that maybe might be unable to do at home or unwilling to do with other people and they connect with you in that way you're so satisfied going home. Like even little things like someone coming into a different room can be a big thing for someone where as for other people that might be nothing.

Gabriella: yeah and when you've been part of that you feel good about yourself.

Blake: going back to relationships and stuff there's a good opportunity here if there's a connection with someone here you might support to help with maybe PA outside of the service. And for me I've done that for two people who I met here and I don't see that as a job or anything really I see that as I want to spend more time with that person because of the relationship I've got.

Mark: Obviously we support people who might be described as experiencing the world in a more diverse way, do you think doing a job or spending time with diverse experiences offers you more to learn about yourself or humanity or society from those specific connections?

Courtney: I'd say a massive one is language, I think like defo you don't need to use words to get across what you want to get across. Like the people in this project use language in a much different way than me and maybe these two here but also from everyone else who's doing the research, I'd go as far as saying it'd even change depending on the relationships you have with each person. Like I'd say that John would relate differently with Blake than he would with me because of the depth of relationship. I'd defo say I'd learnt that from people we support that its not as simple as a want/needs or request relationship. There's loads of ways of doing it.

Blake/ Gabriella: yeah agree

Blake: I've learnt to communicate in different ways and there's a richness to that.

Gabriella: you can communicate in a variety of ways.

Courtney: its funny like there's things people might say or vocalise here which I feel like I understand in this context, like I'm going home saying 'peno music' or 'inside out' and it makes no sense outside of the context of relationships but here in relationships it doesn't make sense and there's a degree of comfort to that. Like the words and sounds here I do take elsewhere and its like I think in that language sometimes like I don't even say piano anymore.

Mark: But you know when you do, is there like a genuine sense of affection, like would you say you're proud of what you do because of the relationships you have.

Blake: 100%

Gabriella / Courtney: yeah

Mark: What do you think of when you think of the term relationships?

Blake: friendships and empathy

Gabriella: understanding and appreciating

Courtney: I think like both people mutually getting something - like I benefit as much as the person I'm connecting with. Like I'm learning things.

Mark: So, all of you have worked with disabled people prior to coming to this role, so we've talked about your experiences outside this setting, like how you see yourselves and experience relationships, but would you say your practice has improved through the people you support here.

Gabriella: I'd say compared to my previous job its a lot different here, I'd say we work more as a team here, like I feel everyone wants to best outcome for the people who come. Its like a collaborative approach and I think that practice is a lot more beneficial for the people we support than what I was doing previous.

Blake: I'd agree, I'd say like in my last care job I almost felt like it was me against the rest of the team and I got so frustrated because I had this disability studies background and non of them did and so at the time I thought that was a problem but its not because at the end of the day we don't all do disability studies so I think over time I've come to be more patient when it comes to people who've got different care backgrounds and not a disability studies care background.

Mark: ok so that journey you described of a more teamed approach and not being so concerned about background and that, that journey, how has the people we support influenced that journey. Have they influenced that or is it just from your colleagues.

Gabriella: I feel here that everyone is very diverse, no-ones the same so its very apparent that you're trying to connect with many different people and working with different people.

Courtney: I think the positive energy and relationships we have as a team reflects on the diverse group of people we support and that reacts in a way that people are positive and happy which in turn then makes our jobs easier. Like I think if the work environment was a horrible place to work I reckon that would impact the service users whereas here its such a positive place its almost hard not to have a good day here. I think that helps our jobs as staff seeing the people we support having a good time.

Mark: I realise a big problem with this project is that I'm service manager and so that possibly influences your answers or the way you think about this place maybe in this process, but how about if we talk about the relationships you guys hold with the people we support outside of here, like I know you have all done some PA work with people outside of here- how does that influence your practice.

Courtney: I think its made me a bit more aware of peoples home lives. From supporting the guy I help in their home I see all that goes on that usually we wouldn't see. I think this had impacted my practice because I think more about what might be influencing the way he feels coming in, like if he comes in in like a different mood I can reflect more knowing about home and that. Like not that there's anything going on at home but like he's got a younger brother, his mum and dad both work its like a busy house and all that will affect him. Like that home life perspective has influenced me.

Blake: Yeah same for me and its made me realise like how important friendships and relationships are for people so I use Tim (pseudonym) as an example, he lived with his nan and grandad with no-one his age in the family so for him coming here or having his own PA has enhanced his own experienced because he had someone similar to his age if you know what I mean. And like what you said you see the bigger picture.

Courtney: yeah I think age is important like because Phil (pseudonym) has other PA's, not saying they're dead old or whatever but the impression I get is that he's really valued having people working alongside him who are like the same age and maybe similar interests like the other day we went for a pub lunch and he had such a good day and I think it was more about him being out doing things he maybe wants to do. Like that's what people want to do at the age of 20 like go the pub with your mates.

Mark: you can tell you've done disability studies because you're careful with your language like I feel like you're desperate to say 'normal stuff' but you're holding back a bit. It's funny how it does influence you. So I'm getting a bit philosophical now sorry. Do you think there is anything that you've experienced which you'll carry with you for the rest of your lives. So even for people who are no longer here but haven't gone away if you get me.

Blake: yeah, for me personally I'd never take for granted the friendships and relationships we have because we don't know how long we have those for.

Courtney: I think the one thing I'll always remember even if I move on to another job is the friendships and relationships oh I'm going to cry

Blake: I know yeah

Courtney: this is really bad (laughing) I'm actually going to cry literally when I said if I move somewhere else I started getting upset

Gabriella: I am myself

Courtney: Yeah I think I'll never take for granted the relationships here just simple things like what you said earlier knowing you're making a difference to someones day like its such a nice feeling

Gabriella: its the best feeling ever

Courtney: I don't think I'll forget the impact you make on someone's lives, in fact I'd say the biggest impact has been on my life.

Mark: Where do you think the balance is in that, like is it one way or another like do you think you're impacting folk more than they're impacting you or other way around or what?

Gabriella: I think its balanced in the middle to be honest

Blake: Like if you've got a good relationship with someone you see their face when you walk into a room.

Courtney: But you also have that reaction when they come into a room!

Blake and Gabriella: Yeah

Courtney: Like you can tell when there's certain people in a room there's excitement when you see them, like I dunno like I don't even know if he would be excited to see me but if I know there's people here I'm genuinely excited to see but I think people are excited to see me so I do think its a relationship balance.

Blake: and for certain people when you walk in a room you see them clocking you around the room waiting for you to go over and say hello and stuff.

Mark: is it going too far to say you love the people you work alongside

Blake: 100% yeah … oh no no no I don't mean its too far to say that but the other way around

Gabriella: yeah I don't think its too far to say that love it a lot

Courtney: I don't think its too far no because when I'm home I love sitting down telling my friends and if I get home from work I love talking over dinner about what I did that day like if its a really good day I could talk for hours about the people here that's why the instagram is great because I can put faces to stories, like I just love having the stories so yea I'd defo say that's the case

Mark: what would you say that I need to look out for in the videos

Courtney: I think the audio might be better than the video because during the first bit of the session like Mary had her back to the others so might not capture that range of interaction but the video might find that. She was like trying to knock everything off anyway

Blake and Gabriella: haha

Courtney: yeah so because she's facing the other way you might miss some key video so I think yeah going back and considering the audio might be important.

Blake: for me facial expressions are important

Courtney: yeah when Blake pops the balloon full of paint on himself I reckon that's probably important

Gabriella: that was funny that

THEME: FROM THE INSIDE OUT- IMPACTING VALUES MORE THAN PRACTICE BECAUSE PRACTICE ADJUSTMENT IS REGIMENTAL….. this relates to I-thou

Theme: Mutuality in positivity and complimentary approach

Theme: us and them?

Theme: see the bigger picture relationships matter more than DS

Theme: motivated by impact

Attach colours

Focus group		
Blake: …*I was in another care job and the lad I looked after was described as non-verbal and we'd be making a lot of his decisions for him because there was that assumption that he didn't have a voice* *Gabriella: before I started working here and before I did the disability studies I was doing supported living, and it was very regimental and to be honest I'd just go about it and go along with it because I didn't really know what else to go by.* *Courtney: yeah I think age is important like because Phil (pseudonym) has other PA's, not saying they're dead old or whatever but the impression I get is that he's really valued*	What it means Power Task focused	Interpretation (how it relates to theory)

having people working alongside him who are like the same age and maybe similar interests like the other day we went for a pub lunch and he had such a good day and I think it was more about him being out doing things he maybe wants to do. Like that's what people want to do at the age of 20 like go the pub with your mates…. <u>*Not sure if this paragraph should be in this section*</u>		
Courtney: ….Disability studies taught me about people having voice and I think that goes hand in hand with the relationships. *Blake: one of the things I've found though which will be different from when you started was that because there are a lot of people here who have done disability studies we're all on the same page if that makes sense when it comes to outlooks and perspectives and when you get new staff in, our ideologies sort of go onto the new staff.* *Gabriella: yeah like the new staff who are coming in if they haven't done disability studies are coming in like everybody else and seeing disability as like individualised but obviously when they come to us we portray a different way really and I think that goes onto the new staff and I feel that's a positive way.*	What it means Intimacy and mutuality - understanding, closeness and touch, Collaboration CULTURE CAN BE FORMED IF THERES ENOUGH OF YOU relationships matter more than DS	Interpretation (how it relates to theory)

Courtney: I think like both people mutually getting something - like I benefit as much as the person I'm connecting with. Like learning things. *Courtney: I think the positive energy and relationships we have as a team reflects on the diverse group of people we support and that reacts in a way that people are positive and happy which in turn then makes our jobs easier. Like I think if the work environment was a horrible place to work I reckon that would impact the service users whereas here its such a positive place its almost hard not to have a good day here. I think that helps our jobs as staff seeing the people we support having a good time.*	Voice	

Gabriella: I do feel like when I've spent a day in this context I can go away feeling like I've given or helped facilitate the best day possible and that's a good feeling when I leave here. *Courtney: like I feel like when you're able to support someone to do something that maybe might be unable to do at home or unwilling to do with other people and they connect with you in that way you're so satisfied going home. Like even little things like someone coming into a different room can be a big thing for someone where as for other people that might be nothing.* *Gabriella: yeah and when you've been part of that you feel good about yourself.* *Courtney: I think the one thing I'll always remember even if I move on to another job is the friendships and relationships oh I'm going to cry* *Blake: I know yeah* *Courtney: this is really bad (laughing) I'm actually going to cry literally when I said if I move somewhere else I started getting upset* *Gabriella: I am myself* *Courtney: Yeah I think I'll never take for granted the relationships here just simple things like what you said earlier knowing you're making a difference to someones day like its such a nice feeling* *Gabriella: its the best feeling ever* *Courtney: I don't think I'll forget the impact you make on*	What it means Pride - gaining something affection Caring for other people feels good	Interpretation (how it relates to theory)

someone's lives, in fact I'd say the biggest impact has been on my life. *Courtney: I don't think its too far to say we love the people here no because when I'm home I love sitting down telling my friends and if I get home from work I love talking over dinner about what I did that day like if its a really good day I could talk for hours about the people here that's why the instagram is great because I can put faces to stories, like I just love having the stories so yea I'd defo say that's the case*		

Gabriella: I think I'd say the affirmative model has been evident, like its like I'm here, this is me, a bit like that probably. *Courtney: I'd say a massive one is language, I think like defo you don't need to use words to get across what you want to get across. Like the people in this project use language in a much different way than me and maybe these two here but also from everyone else who's doing the research, I'd go as far as saying it'd even change depending on the relationships you have with each person. Like I'd say that John would relate differently with Blake than he would with me because of the depth of relationship. I'd defo say I'd learnt that from people we support that its not as simple as a want/needs or request relationship. There's loads of ways of doing it.* *Blake: I've learnt to communicate in different ways and there's a richness to that.* *Gabriella: you can communicate in a variety of ways.* *Courtney: its funny like there's things people might say or vocalise here which I feel like I understand in this context, like I'm going home saying 'peno music' or 'inside out' and it makes no sense outside of the context of relationships but here in relationships it doesn't make sense and there's a degree of comfort to that. Like the words and sounds here I do take elsewhere and its like I think in that language sometimes like I don't even say piano anymore.*	What it means Chaos, voice, mischief	Interpretation (how it relates to theory)

Courtney: I think the audio might be better than the video because during the first bit of the session like Mary had her back to the others so might not capture that range of interaction but the video might find that. She was like trying to knock everything off anyway		

Appendix 3

Transcript Arts-based activity session captured by wearable cameras

Capturing Reflexive Thematic Analysis in video sessions

H1 - supported by private PA		
	What is captured	What it means CODES
What drew my attention and when? (Describe what is observed, heard, expressed)	**Observed**: 36sec hand over camera at start of Karen's story. H1 5m40 pushes the camera facing towards his stomach. Carer lifts the camera back to the upright position and says "he wants to film his feet" H1 8m01 H captures M with carer- good eye contact and sharing in the wrapping of paper H1 **Heard**: 1m35 "aaaaaaaarrrrrrr" during the story accompanied by a "sh sh sh sh sh and a whisper do you not like the story" 2m48 mb reads "I gently press my chin against her forehead aaaaahhh" at which the response appears "aaaaaaaarrrr", the carer whispers "what's the matter". H1 8m19 mum and carer explaining to H what the game they are about to play is. H responds with "ayaaa" at which mum responds "are you not in the mood for this matey" ….. Mum says "hehehe is this good fun".	Assumptions around objection? Shows power of carer Moment captured with M showed collaboration. Authors Choices
How does this relate to the focus group?	POWER / TASK FOCUSED FG H1 Blake: *…I was in another care job and the lad I looked after was described as non-verbal and we'd be making a lot of his decisions for him because there was that assumption that he didn't have a voice* *FG H1 Gabriella: before I started working here and before I did the disability studies I was doing supported living, and it was very regimental and to be honest I'd just go about it and go along with it because I didn't really know what else to go by.*	

	FG H1 Courtney: yeah I think age is important like because Phil (pseudonym) has other PA's, not saying they're dead old or whatever but the impression I get is that he's really valued having people working alongside him who are like the same age and maybe similar interests like the other day we went for a pub lunch and he had such a good day and I think it was more about him being out doing things he maybe wants to do. Like that's what people want to do at the age of 20 like go the pub with your mates…. Not sure if this paragraph should be in this section	Assumptions Decision makers Reactively making sense Being unsure

H2		
	What is captured	What it means CODES
What drew my attention and when? (Describe what is observed, heard, expressed)	H2 **Observed**: 30seconds captures Jk and G supporting J with mum watching. Mum watching J face with a smile, G sitting alongside and Jk supporting with an art piece hand over hand. J focus on G rather than the art. 59 seconds H captures Jk rub J's head saying "well in mate" 1m12 Hy appears and instructs H carer to have some resources. 2m04 Hy places eysle on H lap ready for art piece, friend J now out of eyeline. H2 2m15 mum appears in shot and looks at H with a smile 4m05 carer comes over and shows Hy a cookie. H2 4m mum is captured telling MB a story about M and when she brought the family cheer after the death of a family member, she was in the next room and was clapping and shouting just moments after a death. Mum expressed "she knew" 4m49 and "that really helped me and Ian" 4m57 H2. 5m57 captures C looking at and smiling touching M side of face. 6m40 captures C leaning in and coughing in M ear, M responds with a smile. This is repeated and M offers C a hug. H2 8m08 Hy and carer support H with the art piece when mum leans into observed shot with a smile on	Gently keeping informed Sharing Anticipation brings calm Personal spaces

	her face. Her expression seems to be in reaction to H first. H2. 8m22 C acknowledges M been mentioned in joke with H and C makes head motion to M towards H. H2. Mum smiling captures photo of H taking part H2. **Heard**: 2m13 Hy says to H "lets start with the blue and then you can blend it then. you hold that for me and we'll start with the blue"… "are you ready, can we hold hands and you do this with me". H2. 2m50 carer says to H "I think this is a great start, but can you help me a little bit more… are you ready, can I borrow your hand" **Expresed**: 2m40 H and carer capture hand over hand art. Carer hand over H hand who holds the tissue with paint on. 4m54 Hy moves away from hand over hand rushes through it. H2. 6m58 MB says "get her M when she is offering C a hug". H2. 8m08 Hy "splodge splodge splodge" mum "is that good H?" "Are you pretending its M, H?"	Invading personal space is vulnerable for both Affection and pride Hy gentle in requests and uses an approach where H is helping her not the other way around.
How does this relate to the focus group?	*FG. H2 Courtney: ….Disability studies taught me about people having voice and I think that goes hand in hand with the relationships.* *FG. H2 Blake: one of the things I've found though which will be different from when you started was that because there are a lot of people here who have done disability studies we're all on the same page if that makes sense when it comes to outlooks and perspectives and when you get new staff in, our ideologies sort of go onto the new staff.* *FG. H2. Gabriella: yeah like the new staff who are coming in if they haven't done disability studies are coming in like everybody else and seeing disability as like individualised but obviously when they come to us we portray a different way really and I think that goes onto the new staff and I feel that's a positive way.* *FG. H2. Courtney: I think like both people mutually getting something - like I benefit as much as the person I'm connecting with. Like learning things.* *FG. H2. Courtney: I think the positive energy and relationships we have as a team reflects on the diverse group of people we support and that reacts in a way that people are positive and happy which in turn then makes our jobs easier. Like I think if the work environment was a horrible place to work I reckon*	Its noticeable during the moments when H is touched and talked to that his vocal expression is a lot quieter. M offering some mutually vulnerable moments. Intimacy and mutuality - understanding / Pride / Gentleness and

	that would impact the service users whereas here its such a positive place its almost hard not to have a good day here. I think that helps our jobs as staff seeing the people we support having a good time.	request, collaboration Ideology and practice Normalised culture
H3		
	What is captured	What it means CODES
What drew my attention and when? (Describe what is observed, heard, expressed)	H3. **Observed**: First 45 seconds of the video mum is recording H on her phone, she is smiling. At the end she shares the photo on her phone with carer and Hy. H3. Mum turns to M 1m08 and touches her on the shoulder and leans in for an embrace, M responds with a smile. H covers the camera with his hand. 1m 19 captures C and M holding hands moving hands around one another's hand. C then leans in closer and M puts her hand around C and feels her hair. H3. She then pulls it! H3. **Heard**: 5sec Hy “no paps! you have to keep this cool mysterious guy that never smiles” mum says “go on H”. HG. 30 seconds mum says “he can't see the camera but he knows it there”… H responds with “waaaaaaaaa”. 2m04 H says “aaaaaaarrrr” and Hy says “do you want to help, is that why you're whining?” H3. **Expressed**: H tries to throw the piece of art created 2m27 and mum, C, Hy and carer laugh. 2m31 the camera shows the piece of art H created- a waterfall canvas.	Assumptions of consciousness Fun and chaos

How does this relate to the focus group?	*FG. H3. Gabriella: I do feel like when I've spent a day in this context I can go away feeling like I've given or helped facilitate the best day possible and that's a good feeling when I leave here.* *FG. H3. Courtney: like I feel like when you're able to support someone to do something that maybe might be unable to do at home or unwilling to do with other people and they connect with you in that way you're so satisfied going home. Like even little things like someone coming into a different room can be a big thing for someone where as for other people that might be nothing.* *FG. H3. Gabriella: yeah and when you've been part of that you feel good about yourself.* *FG. H3. Courtney: I think the one thing I'll always remember even if I move on to another job is the friendships and relationships oh I'm going to cry* *Blake: I know yeah* *Courtney: this is really bad (laughing) I'm actually going to cry literally when I said if I move somewhere else I started getting upset* *Gabriella: I am myself* *Courtney: Yeah I think I'll never take for granted the relationships here just simple things like what you said earlier knowing you're making a difference to someones day like its such a nice feeling* *Gabriella: its the best feeling ever* *FG. H3. Courtney: I don't think I'll forget the impact you make on someone's lives, in fact I'd say the biggest impact has been on my life.* *FG. H3. Courtney: I don't think its too far to say we love the people here no because when I'm home I love sitting down telling my friends and if I get home from work I love talking over dinner about what I did that day like if its a really good day I could talk for hours about the people here that's why the instagram is great because I can put faces to stories, like I just love having the stories so yea I'd defo say that's the case*	M and C capture lovely moments. Closeness and touch Pride - gaining something affection Caring for other people feels good Being part of something

		People rather than tasks
J1		
	What is captured	What it means CODES
What drew my attention and when? (Describe what is observed, heard, expressed)	J1. **Observed**: 50seconds mum appears in sight line and J responds. 7m J is moved to take part in an art activity. 7m17 Jk smiles at J. J1. 7m28 Jk bursts a balloon filled with paint on himself, looks at mum and G laughing. Jk, mum and G look at each other and J while laughing about bursting the paint covered balloon. Mum leans in 8m05 to involve J further in the laughter, Jk and G share in the laughter looking at J. Camera says storage full from 10m30 but audio continues. J1. **Heard**: 5 seconds “J is now live” J responds with “mmmm mm”. 50 seconds J responds to mum in sight line “mmm mmm” quietly and then a third “mmmmmmmmmm” and mum returns. He then expresses a louder “mmmmm” when MB starts speaking. 7m mum says “what shall we do J would you want to feel this balloon?”…. “it’s got paint in it would you want to feel it? .. No?”. J1. 8m05 mum says “oh that was so funny J”… “hey what do you think do you want some paint on your face?”. 8m32 Jk says “J I’m covered in it”. J1. 11m40 mum says “he’s actually really interested in the balloons over there” 12m40 J changes position so he is facing other activities and mum says “is that better you can see a bit more now”. J1. **Expressed**: 9m10 Jk, Hy and Mum discuss which piece of art to try and express and decide to go for one related to trees because J likes trees	Interesting that J’s verbal engagement less prevalent during activities - task focused Concentration If you’re silent can you be forgotten Something metaphorical in the chaos and fun

		of the balloon bursting.
J2		
	What is captured	What it means CODES
What drew my attention and when? (Describe what is observed, heard, expressed)	J2. **Observed**: 5 seconds G sitting close to J, smiling. 27seconds carer leaning on H's head and arm rest meanwhile Hy notices that H's jejunostomy uncovered and she replaces H's top covering his stomach. 2m55 G helps J rip up the paper and then she takes some and holds it to his ear while ripping it. 3m40 C is helping M make paper in a stencil, its hand over hand, J2. M seems still and not looking at what is in her hand, C stops watching the activity and is watching M, she leans in and coughs in her ear.J2. M lifts her head and smiles. They share a laugh together. Jk doing lots of prep in and out of the room getting water. 5m50 Jk uses the flowers to offer J a smell. J2. Jk keeps J involved in the outcome of the paper making 9m40, Turning to him and offering a chance to feel what has been made. J2. 8m20 Hy can be seen doing hand over hand with H, leaning in and smiling and laughing, J2. **Heard**: G describes that "What do you reckon? I think that is fab" showing J the art piece he has created. G asks J "shall we rip some paper up what do you reckon?". 2m55 G says "do you want to rip it, here would you like to listen to it?". 4m06 G turns and says to H carer "is that them cookies.. unreal". J2. 5m45 Jk notices that there are dried out flowers next to the art and says "oh these are good you could have a smell of these J". G talks to J the whole way through the video but it is task focused. 7m J "mmmm" as Jk turns to grab the switch. **Expressed**: 45 second G shows J the art piece which is images of trees. 2m17 J connects with a session by ripping paper up and using a switch to turn on a blender to then put in a paper maker and make paper. 4m00 G creates opportunities for J to reach out and rip the paper with prompts. J2. 4m20 Gabriella shares in the ripping of paper. 7m20 J is offered the switch which he presses hand over hand with J and the paper spins in the blender. J2. Jk and G try to use the stencil to make the paper, and has difficulty, Jk turns to J and says 9m16 "J I think we've fucked it up"	A narrative of questions A narrative of touch G is very much on task, C is about relationship. Task is secondary to relationship. priorities Ability shapes engagement J only seems to make any noise

		when he's not faced.
M1		
	What is captured	What it means CODES
What drew my attention and when? (Describe what is observed, heard, expressed)	M1. **Observed**: M straight away using left hand to tap and knock and shake the camera. C seen holding M hand throughout. Mum out of shot holds M other hand. 1m18 M holding both C and mums hand. 1m30 M once again knocks the camera but it focuses in on the intimacy of the hand holding with C. 2m12 H carer can be seen whispering in on H ear, her right hand touching his face. 2m40 C and M hand holding showing affection. J turns and looks at his mum who rubs his shoulder and leans in on him. She rubs his arm and whispers in his ear. 2m55 M tapping the camera. Th camera captures affection for M with C, J with mum and H with carer- all touch, all close, all without words. J constantly looking at his mum. 3m50 Jk and J are looking at each other, Jk is on his knees. 7m30 C offers M some choices of colour paper and M grabs the pink colour. 7m52 C can be seen smiling as she rips the paper together with M. M1. **Heard**: M grinding her teeth 1m10. 1m14 M heard saying "gal gal gal gal go" mum responds with "what are you telling us?". 5m20 C can be heard saying to M "what do you think we should do?". M1. 7m05 C laughing saying "M keeps blocking the camera its like she's says 'no paps - no paperatsi today guys". All the ripping they do together. **Expressed**:	LOVE THIS! Perspectives - Challenging what can be heard assumptions in H video which seems to be about power. Perspectives! Intimacy Chaos and disruption

How does this relate to the focus group?	Perspectives / M will be seen and heard / Fun / chaos / voice / mischief *FG. M1. Gabriella: I think I'd say the affirmative model has been evident, like its like I'm here, this is me, a bit like that probably.* *FG. M1. Courtney: I'd say a massive one is language, I think like defo you don't need to use words to get across what you want to get across. Like the people in this project use language in a much different way than me and maybe these two here but also from everyone else who's doing the research, I'd go as far as saying it'd even change depending on the relationships you have with each person. Like I'd say that John would relate differently with Blake than he would with me because of the depth of relationship. I'd defo say I'd learnt that from people we support that its not as simple as a want/needs or request relationship. There's loads of ways of doing it.* *FG. M1. Blake: I've learnt to communicate in different ways and there's a richness to that.* *FG. M1. Gabriella: you can communicate in a variety of ways.* *FG. M1. Courtney: its funny like there's things people might say or vocalise here which I feel like I understand in this context, like I'm going home saying 'peno music' or 'inside out' and it makes no sense outside of the context of relationships but here in relationships it doesn't make sense and there's a degree of comfort to that. Like the words and sounds here I do take elsewhere and its like I think in that language sometimes like I don't even say piano anymore.* *FG. M1. Courtney: I think the audio might be better than the video because during the first bit of the session like Mary had her back to the others so might not capture that range of interaction but the video might find that. She was like trying to knock everything off anyway*	
M2		
	What is captured	What it means CODES

What drew my attention and when? (Describe what is observed, heard, expressed)	M2. **Observed**: M throws some paper on the floor at which C smiles but with a look of shock playfully as if M is putting her out. M2. 1m28 C offers M a new choice of colours, she explains the colours and touches each hand with the colour to encourage M to make a choice, M chooses the white. M2. She chooses it and immediately throws it on the floor. M2. 3m58 C places the paper in the blender and encourages M to use the switch, M reaches out and touches the switch which starts the blender. M takes the switch out of C's hand. C has a big smile while M is taking the switch out of her hand and encouraging her to join in. M2. 4m55 M can be seen grabbing C's staff badge. 5m16 M can be seen knocking the switch over and over. 5m42 C can be seen taking the blender to let M have a feel. 6m33 M tried to grab C's pony tale and C turns and smiles. 6m57 C can be seen adjusting the table height so M can move closer to the activity. As M moves closer to the activity she immediately reaches for the bucket of water. 7m55 C changing the environment around M. M2. **Heard**:4m C encourages M and says 'woooo' when M takes the switch out of her hand. "You got it" "can you hear it? Yes M! Yes M!". M2. 4m55 as M grabs C, C laughs and says "aaaaaaah no, M". 4m42 C asks M mum if it is ok if M has a feel. M2. 7m47 C says as M tries to grab the water "ooooh M I can see your eyes!" **Expressed**:	M is mischievous C works hard with and around M environment
M3		
	What is captured	What it means CODES

What drew my attention and when? (Describe what is observed, heard, expressed)	M3. **Observed**: 5 seconds At the very start of the video M is seen reaching out to pull the bucket of water off the table towards herself- C, while also trying to support M in the paper making task seeks to peel M's left hand off the bucket of water to avoid her being soaked. From 5 second M has a tight old of the bucket and with a strong grip is seeking to pull it off the table, C seeks to push down on the bucket and is seen seeking help as to not have M covered in the bucket of water and pink paper pulp. 15 seconds C is able to move the bucket of water further out of reach from M who then immediately reaches for the switch connection button which is plugged into the blending machine, she pulls this out and throws it over her shoulder. From 30 seconds, M is tapping the front of the camera with her left hand. C pats down the paper mulch in the stencil independently. M3. From 1 minute MB comes into shot leaning over M, Hy, who is supporting H turns to look at M and taps her nose indicating to C, next to Hy stands mum and private carer who along with Hy stop to look at M, they stare for 10 seconds, then smile and turn away. M3. 2m40 Jk appears in view approaching M, M reaches out and grabs the paper making stencil which has wet paper pulp on and pulls it toward Jk, C's hand appears grabbing the stencil, the stencil comes out of shot, Jk turns away and then suddenly having being splashed turns back. 3m55 C's hair appears in shot tied in a pony tale, M reaches out to pull it with her right hand and is holding C's hand in her left hand. M3. G can be seen in the background with J who has appeared in shot, G is trying to place the paper into J's hand for him to grip and rip- unsuccessfully, J turns away. Carer distracts G who turns away from J, J suddenly looks at G while facing the other way. M3. G turns back and catches J looking at her, G carries on with the paper ripping task but maintains eye contact with J for a three seconds. J turns away. M3. 5m55 M and C move to another activity and Hy, H and paid carer can be seen in view. Hy and C are seen in conversation and then Hy and C can be seen turning and smiling at M. M3. 6m40 C shows M a range of picture to choose an art activity, M reaches out towards the pictures, moves past them towards C's hand and squeezes it in view, C is pulled in for an embrace. 8m21 H can be seen with a huge smile while H bobs up and down while holding his hand to complete the art piece, mum appears in view seeking to get in H's line of sight to see him smile. M3. **Heard**: C says at 6 seconds "aaaaaaaaaahhhhh S help". She is heard at 16 seconds say "oooooops". 40 seconds "shall we pat this down". M3. MB approaches M and says "what do we think M?" Hy shouts over to MB at 1 minute "MB tap her nose" MB can be heard saying "are you here with me M, I gotta go I gotta go" The room which fell silent for a few seconds continues on with sound. M3. 1m21 C is heard saying "M, I don't think we've done this right". M grinds her teeth. 2m 25 M coughs. 2m29 C can be heard saying "** Cough cough** , is that my cough, has Jk got my cough" M can be heard giggling. M3. 2m40 C can be heard saying "Jk's covered in paint already M, oh Jk she's coming for you" "Jk says Oh M you better not, oooo….. splashed!" M3. 6m C asks M "I've not done this one before M have you?" M is heard saying "aaaa aaa goo ooouu" C and Hy laugh and say "you don't M". 6m40 C is heard saying "which of these do you think M, oh, oh thanks Mary *cough *cough cough*" MB is heard saying "get her M" C responds to MB "excuse me! You tell him M excuse me not a chance" **Expressed**: 3m46 M can be seen hand over hand with C pressing the paper mulch into the stencil.	Chaos, multitasking and fun We is used sometimes on behalf of people rather than what society might think together. Sometimes there are moments filled with anxiety and uncertainty. She is dictating what type of communication takes place by pulling in Coughing is communication - it doesn't need to mean anything to be funny. M is so much fun. Attention doesn't always mean

		looking at someone Affection is better than tasks.

M4

	What is captured	What it means CODES

What drew my attention and when? (Describe what is observed, heard, expressed)	M4. **Observed**: from the start H can be seen smiling with his mouth open, a piece of art is on his lap but his head is lifted high away from the piece of art and looking at Hy, M4. while Hy looks at him, mum and paid carer Also in shot smiling at H. 6 seconds mum can quickly be seen taking phone and accessing camera to capture H smile. C appears in shot and is seen watching H and Hy while mum, paid carer watch on taking photographs. Mum takes 1 minute taking photos and then turns the phone to Hy and shows her the image, they both smile and then mum turns the phone back looking at it on her own with a smile. M4. 1m35 C leans in towards M, and you can see the bottom of her face, she os smiling and talking to M, M4. She suddenly turns side on as M is seen pulling C's pony tale- C has a huge smile. M4. **Heard**: 1m21 Mum says to C "this one has us up this morning" "C said I've heard, I heard you've been awake all morning?" Mum says "you've been awake since 3am haven't you? Yes I know, I know, normally this is your time sat in front of the tele" 1m35 M Coughs and C says to M "well shall we just stop this then and chill then what d'you think?….. uhh I've lost my hair".	The moment between Hy and H had nothing to do with the task. Pride of parents and demands of care Moments of connection

Moments of Touch (any person)					**Questions asked**	
Video	Total time	Touching of hands	Embrace	Whisper		

H1 (8m34 length)	19m 46	1	**13**		**7**		**7**	7	**42**
H2 (8m37 length)		10		4		5		21	
H3 (2m35 length)		2		3		2		14	
J1 (13m06 length)	25m15	3	**10**	1	**2**		**1**	15	**65**
J2 (12m09 length)		7		1		1		**50**…. Might be worth counting how many times "Are you ready?"	
M1 (8m34 length)	27m42	10 1m30 is like she's showing me it.	**37**	8 She faces others in the first part of the video	**15**	4	**20**	14	**45**
M2 8m36 length)		18		3		1		18	
M3 (8m37 length)		16		7		12		12	
M4 (1m55 length)		3		5		3		1	

Some reflections

Is it worth counting how many questions are asked to individuals? Is there something in that? Rhetorical. Is there something about time and swiftness of response, is there something about normative timescales when we pre-empt a response. Count the number of times we see people whisper and the intimacy of this!

Where does it move into when I thou and when I it and sometimes how that is necessary. Add to theory rather than just I thou and I it.

Being too task focused doesn't always help relationships. Who's task focused who is relationship focused.

Key thing around intimacy.

Big things jumping out:

Task focused = power of the process, lack of voice, loads of questions without the intimacy. I-it, using the task as an ends.

Relationship focused = task is a mess, loads of touch and embrace, less questions. Being in the moment. I-thou.

Numbers, transcript and focused group aligning,

Both are important!

M dictates the type of communication. M is tactile and J and H are less so. J doesn't show emotive reactions on his face when speaking to him, perhaps the uncertainty staff face is reflected in the amount of Qs.

The amount of questions sometimes author the conversations

CODES	What is captured grouped	Grouped theme	Interpretation

Assumptions around objection? Shows power of carer Authors Choices Assumptions Decision makers Assumptions of consciousness Perspectives - Challenging what can be heard assumptions in H video which seems to be about power. Perspectives!	**Observed**:H1 5m40 pushes the camera facing towards his stomach. Carer lifts the camera back to the upright position and says "he wants to film his feet" H1 **Heard**: 1m35 "aaaaaaaarrrrrrrr" during the story accompanied by a "sh sh sh sh sh and a whisper do you not like the story" 2m48 mb reads "I gently press my chin against her forehead aaaaahhh" at which the response appears "aaaaaaaarrrr", the carer whispers "what's the matter". H1 8m19 mum and carer explaining to H what the game they are about to play is. H responds with "ayaaa" at which mum responds "are you not in the mood for this matey" ….. Mum says "hehehe is this good fun". FG H1 Blake: …*I was in another care job and the lad I looked after was described as non-verbal and we'd be making a lot of his decisions for him because there was that assumption that he didn't have a voice* HEARD J1. 11m40 mum says "he's actually really interested in the balloons over there" 12m40 J changes position so he is facing other activities and mum says "is that better you can see a bit more now". J1. **Expressed**: 9m10 Jk, Hy and Mum discuss which piece of art to try and express and decide to go for one related to trees because J likes trees H3. 30 seconds mum says "he can't see the camera but he knows it there"… H responds with "waaaaaaaaa". 2m04 H says "aaaaaaarrrr" and Hy says "do you want to help, is that why you're whining?" H3.	**Assumptions / choices**	Merge with uncertainty and task B G O

Moment captured with M showed collaboration. Sharing It's noticeable during the moments when H is touched and talked to that his vocal expression is a lot quieter. M offering some mutually vulnerable moments. M and C capture lovely moments. C works hard with and around M environment Moments of connection	Observed: H1 8m01 H captures M with carer- good eye contact and sharing in the wrapping of paper *FG. M1. Courtney: I'd say a massive one is language, I think like defo you don't need to use words to get across what you want to get across. Like the people in this project use language in a much different way than me and maybe these two here but also from everyone else who's doing the research, I'd go as far as saying it'd even change depending on the relationships you have with each person. Like I'd say that John would relate differently with Blake than he would with me because of the depth of relationship. I'd defo say I'd learnt that from people we support that its not as simple as a want/needs or request relationship. There's loads of ways of doing it.* *FG. M1. Blake: I've learnt to communicate in different ways and there's a richness to that.* *FG. M1. Gabriella: you can communicate in a variety of ways.* *H2. **Heard**: 2m13 Hy says to H "lets start with the blue and then you can blend it then. you hold that for me and we'll start with the blue"… "are you ready, can we hold hands and you do this with me". H2. 2m50 carer says to H "I think this is a great start, but can you help me a little bit more… are you ready, can I borrow your hand"* H2. Observed /Heard 8m08 Hy "splodge splodge splodge" mum "is that good H?" "Are you pretending its M, H?" FG. H2 *Courtney: ….Disability studies taught me about people having voice and I think that goes hand in hand with the relationships.* *FG. H2. Courtney: I think like both people mutually getting something - like I benefit as much as the person I'm connecting with. Like learning things.* J2. 5m45 Jk notices that there are dried out flowers next to the art and says "oh these are good you could have a smell of these J". **Expressed**: 4m20 Gabriella shares in the ripping of paper. 7m20 J is offered the switch which he presses hand over hand with J and the paper spins in the blender. Observed M2. 1m28 C offers M a new choice of colours, she explains the colours and touches each hand with the colour to encourage M to make a choice, M chooses the white. M2. She chooses it and immediately throws it on the floor. M2. M2 3m58 C places the paper in the blender and encourages M to use the switch, M reaches out and touches the switch which starts the blender. M takes the switch out of C's hand. C has a big smile while M is taking the switch out of her hand and encouraging her to join in. M2. M2. **Heard**:4m C encourages M and says 'woooo' when M takes the switch out of her hand. "You got it" "can you hear it? Yes M! Yes M!". M2 4m42 C asks M mum if it is ok if M has a feel. M2.	**Collaboration / sharing** **Quant data point: 60 points of holding or hand over hand**	Merge with closeness and touch

	FG. H3. Courtney: I don't think I'll forget the impact you make on someone's lives, in fact I'd say the biggest impact has been on my life. M3. 1m21 C is heard saying "M, I don't think we've done this right". M grinds her teeth. 2m 25 M coughs. 2m29 C can be heard saying "** Cough cough** , is that my cough, has Jk got my cough" M can be heard giggling. M3. M3. 6m C asks M "I've not done this one before M have you?" M is heard saying "aaaa aaa goo ooouu" C and Hy laugh and say "you don't M". 6m40 C is heard saying "which of these do you think M, oh, oh thanks Mary *cough *cough cough*" MB is heard saying "get her M" C responds to MB "excuse me! You tell him M excuse me not a chance" M4. **Heard**: 1m21 Mum says to C "this one has us up this morning" "C said I've heard, I heard you've been awake all morning?" Mum says "you've been awake since 3am haven't you? Yes I know, I know, normally this is your time sat in front of the tele" 1m35 M Coughs and C says to M "well shall we just stop this then and chill then what d'you think?….. uhh I've lost my hair".		

Being unsure Invading personal space is vulnerable for both Hy gentle in requests and uses an approach where H is helping her not the other way around. A narrative of questions Sometimes there are moments filled with anxiety and uncertainty.	*FG H1 Courtney: yeah I think age is important like because Phil (pseudonym) has other PA's, not saying they're dead old or whatever but the impression I get is that he's really valued having people working alongside him who are like the same age and maybe similar interests like the other day we went for a pub lunch and he had such a good day and I think it was more about him being out doing things he maybe wants to do. Like that's what people want to do at the age of 20 like go the pub with your mates…. Not sure if this paragraph should be in this section* J1. **Heard**: 5 seconds "J is now live" J responds with "mmmm mm". 50 seconds J responds to mum in sight line "mmm mmm" quietly and then a third "mmmmmmmmmm" and mum returns. He then expresses a louder "mmmmm" when MB starts speaking. 7m mum says "what shall we do J would you want to feel this balloon?"…. "it's got paint in it would you want to feel it? .. No?". M1. **Heard**: M grinding her teeth 1m10. 1m14 M heard saying "gal gal gal gal go" mum responds with "what are you telling us?". 5m20 C can be heard saying to M "what do you think we should do?" *FG. H2. Courtney: I think the positive energy and relationships we have as a team reflects on the diverse group of people we support and that reacts in a way that people are positive and happy which in turn then makes our jobs easier. Like I think if the work environment was a horrible place to work I reckon that would impact the service users whereas here its such a positive place its almost hard not to have a good day here. I think that helps our jobs as staff seeing the people we support having a good time.* J2. **Observed**: 27seconds carer leaning on H's head and arm rest meanwhile Hy notices that H's jejunostomy uncovered and she replaces H's top covering his stomach. J2. 2m55 M seems still and not looking at what is in her hand, C stops watching the activity and is watching M, she leans in and coughs in her ear.J2. M lifts her head and smiles. They share a laugh together. Expressed: J2. Jk and G try to use the stencil to make the paper, and has difficulty, Jk turns to J and says 9m16 "J I think we've fucked it up" M3. From 1 minute MB comes into shot leaning over M, Hy, who is supporting H turns to look at M and taps her nose indicating to C, next to Hy stands mum and private carer who along with Hy stop to look at M, they stare for 10 seconds, then smile and turn away. M3. MB approaches M and says "what do we think M?" Hy shouts over to MB at 1 minute "MB tap her nose" MB can be heard saying "are you here with me M, I gotta go I gotta go" The room which fell silent for a few seconds continues on with sound.	**Vulnerable / uncertain** **Quant data collect** **152 questions asked**	Merge with assumptions and choices and task

Fun and chaos Something metaphorical in the chaos and fun of the balloon bursting. LOVE THIS! Chaos and disruption M is mischievous Chaos, multitasking and fun M is so much fun.	M1. **Observed**: 5seconds M using left hand to tap and knock and shake the camera. OBSERVED J1. 7m28 Jk bursts a balloon filled with paint on himself, looks at mum and G laughing. Jk, mum and G look at each other and J while laughing about bursting the paint covered balloon. Mum leans in 8m05 to involve J further in the laughter, Jk and G share in the laughter looking at J. Camera says storage full from 10m30 but audio continues. M1. Heard 7m05 C laughing saying “M keeps blocking the camera its like she’s says ‘no paps - no paperatsi today guys”. All the ripping they do together. *FG. M1. Courtney: I think the audio might be better than the video because during the first bit of the session like Mary had her back to the others so might not capture that range of interaction but the video might find that. She was like trying to knock everything off anyway* HEARD J1. 8m05 mum says “oh that was so funny J”… “hey what do you think do you want some paint on your face?”. 8m32 Jk says “J I’m covered in it”. OBSERVED H2. 8m22 C acknowledges M been mentioned in joke with H and C makes head motion to M towards H. M2. **Observed**: M throws some paper on the floor at which C smiles but with a look of shock playfully as if M is putting her out. M2. 1m28 C offers M a new choice of colours, she explains the colours and touches each hand with the colour to encourage M to make a choice, M chooses the white. M2. She chooses it and immediately throws it on the floor. M2 4m55 M can be seen grabbing C’s staff badge. 5m16 M can be seen knocking the switch over and over. M2 6m33 M tried to grab C’s pony tale and C turns and smiles. 6m57 C can be seen adjusting the table height so M can move closer to the activity. As M moves closer to the activity she immediately reaches for the bucket of water. M2. 4m55 as M grabs C, C laughs and says “aaaaaaah no, M”. 7m47 C says as M tries to grab the water “ooooh M I can see your eyes!” H3 1m 19 captures C and M holding hands moving hands around one another’s hand. C then leans in closer and M puts her hand around C and feels her hair. H3. She then pulls it! H3. **Heard**: 5sec Hy “no paps! you have to keep this cool mysterious guy that never smiles” mum says “go on H”. **Expressed**: H tries to throw the piece of art created 2m27 and mum, C, Hy and carer laugh. 2m31 the camera shows the piece of art H created- a waterfall canvas. M3. **Observed**: 5 seconds At the very start of the video M is seen reaching out to pull the bucket of water off the table towards herself- C, while also trying to support M in the paper making task seeks to peel M’s left hand off the bucket of water to avoid her being soaked. From 5 second M has a tight old of the bucket and with a strong grip is seeking to pull it off the table, C seeks to push down on the bucket and is seen seeking help as to not have M covered in the bucket of water and pink paper pulp. 15 seconds C is able to move the bucket of water further out of reach from M who then immediately reaches for the switch	**Chaos/ fun**	Merge with joy pride

	connection button which is plugged into the blending machine, she pulls this out and throws it over her shoulder. From 30 seconds, M is tapping the front of the camera with her left hand. M3. 2m40 Jk appears in view approaching M, M reaches out and grabs the paper making stencil which has wet paper pulp on and pulls it toward Jk, C's hand appears grabbing the stencil, the stencil comes out of shot, Jk turns away and then suddenly having being splashed turns back. 3m55 C's hair appears in shot tied in a pony tale, M reaches out to pull it with her right hand and is holding C's hand in her left hand. M3. **Heard**: C says at 6 seconds "aaaaaaaaaahhhhh S help". She is heard at 16 seconds say "ooooops". 40 seconds "shall we pat this down". 2m40 C can be heard saying "Jk's covered in paint already M, oh Jk she's coming for you" "Jk says Oh M you better not, oooo….. splashed!"		

Intimacy and mutuality - understanding / Pride / Gentleness and request, collaboration Pride - gaining something affection Caring for other people feels good Being part of something Pride of parents and demands of care	FG. M1. Gabriella: I think I'd say the affirmative model has been evident, like its like I'm here, this is me, a bit like that probably. H2 **Observed**: 30seconds captures Jk and G supporting J with mum watching. Mum watching J face with a smile, G sitting alongside and Jk supporting with an art piece hand over hand. J focus on G rather than the art. 59 seconds H captures Jk rub J's head saying "well in mate" H2 2m15 mum appears in shot and looks at H with a smile H2 4m mum is captured telling MB a story about M and when she brought the family cheer after the death of a family member, she was in the next room and was clapping and shouting just moments after a death. Mum expressed "she knew" 4m49 and "that really helped me and Ian" 4m57 H2 8m08 Hy and carer support H with the art piece when mum leans into observed shot with a smile on her face. Her expression seems to be in reaction to H first. H2. Mum smiling captures photo of H taking part **Expresed**: 2m40 H and carer capture hand over hand art. Carer hand over H hand who holds the tissue with paint on. 4m54 Hy moves away from hand over hand rushes through it. H3. **Observed**: First 45 seconds of the video mum is recording H on her phone, she is smiling. At the end she shares the photo on her phone with carer and Hy *FG. H3. Gabriella: I do feel like when I've spent a day in this context I can go away feeling like I've given or helped facilitate the best day possible and that's a good feeling when I leave here.* *FG. H3. Courtney: like I feel like when you're able to support someone to do something that maybe might be unable to do at home or unwilling to do with other people and they connect with you in that way you're so satisfied going home. Like even little things like someone coming into a different room can be a big thing for someone where as for other people that might be nothing.* *FG. H3. Gabriella: yeah and when you've been part of that you feel good about yourself.* *FG. H3. Courtney: I think the one thing I'll always remember even if I move on to another job is the friendships and relationships oh I'm going to cry* *Blake: I know yeah* *Courtney: this is really bad (laughing) I'm actually going to cry literally when I said if I move somewhere else I started getting upset* *Gabriella: I am myself* *Courtney: Yeah I think I'll never take for granted the relationships here just simple things like what you*	**Joy / pride**	Merge with Chaos fun

	said earlier knowing you're making a difference to someones day like its such a nice feeling *Gabriella: its the best feeling ever* *FG. H3. Courtney: I don't think its too far to say we love the people here no because when I'm home I love sitting down telling my friends and if I get home from work I love talking over dinner about what I did that day like if its a really good day I could talk for hours about the people here that's why the instagram is great because I can put faces to stories, like I just love having the stories so yea I'd defo say that's the case* M3. 5m55 M and C move to another activity and Hy, H and paid carer can be seen in view. Hy and C are seen in conversation and then Hy and C can be seen turning and smiling at M.		

Ideology and practice People rather than tasks interesting that J's verbal engagement less prevalent during activities - task focused Concentration G is very much on task, C is about relationship. Task is secondary to relationship. Ability shapes engagement The moment between Hy and H had nothing to	DO WE USE SOME QUANT DATA HERE *FG H1 Gabriella: before I started working here and before I did the disability studies I was doing supported living, and it was very regimental and to be honest I'd just go about it and go along with it because I didn't really know what else to go by.* *FG. H2 Blake: one of the things I've found though which will be different from when you started was that because there are a lot of people here who have done disability studies we're all on the same page if that makes sense when it comes to outlooks and perspectives and when you get new staff in, our ideologies sort of go onto the new staff.* *FG. H2. Gabriella: yeah like the new staff who are coming in if they haven't done disability studies are coming in like everybody else and seeing disability as like individualised but obviously when they come to us we portray a different way really and I think that goes onto the new staff and I feel that's a positive way.* J2. Jk keeps J involved in the outcome of the paper making 9m40, Turning to him and offering a chance to feel what has been made. J2. **Heard**: G describes that "What do you reckon? I think that is fab" showing J the art piece he has created. G asks J "shall we rip some paper up what do you reckon?". 2m55 G says "do you want to rip it, here would you like to listen to it?". M3. G can be seen in the background with J who has appeared in shot, G is trying to place the paper into J's hand for him to grip and rip- unsuccessfully, J turns away. Carer distracts G who turns away from J, J suddenly looks at G while facing the other way. M3. G turns back and catches J looking at her, G carries on with the paper ripping task but maintains eye contact with J for a three seconds. J turns away.	**Task** **Quant data collect** **152 questions asked**	

do with the task.			

Personal spaces Closeness and touch A narrative of touch Intimacy She is dictating what type of communication takes place by pulling in. Coughing is communication - it doesn't need to mean anything to be funny. Affection is better than tasks.	J1. **Observed**: 50seconds mum appears in sight line and J responds. 7m J is moved to take part in an art activity. 7m17 Jk smiles at J. 1 Observed C seen holding M hand throughout. Mum out of shot holds M other hand. 1m18 M holding both C and mums hand. 1m30 M once again knocks the camera but it focuses in on the intimacy of the hand holding with C. 2m12 H carer can be seen whispering in on H ear, her right hand touching his face. 2m40 C and M hand holding showing affection. J turns and looks at his mum who rubs his shoulder and leans in on him. She rubs his arm and whispers in his ear. 2m55 M tapping the camera. Th camera captures affection for M with C, J with mum and H with carer- all touch, all close, all without words. J constantly looking at his mum. 3m50 Jk and J are looking at each other, Jk is on his knees. *FG. M1. Courtney: its funny like there's things people might say or vocalise here which I feel like I understand in this context, like I'm going home saying 'peno music' or 'inside out' and it makes no sense outside of the context of relationships but here in relationships it doesn't make sense and there's a degree of comfort to that. Like the words and sounds here I do take elsewhere and its like I think in that language sometimes like I don't even say piano anymore* H2. 5m57 captures C looking at and smiling touching M side of face. 6m40 captures C leaning in and coughing in M ear, M responds with a smile. This is repeated and M offers C a hug. Heard: H2. 6m58 MB says "get her M when she is offering C a hug". J2. 2m55 M seems still and not looking at what is in her hand, C stops watching the activity and is watching M, she leans in and coughs in her ear.J2. M lifts her head and smiles. They share a laugh together. J2. 8m20 Hy can be seen doing hand over hand with H, leaning in and smiling and laughing, . H3. Mum turns to M 1m08 and touches her on the shoulder and leans in for an embrace, M responds with a smile. H covers the camera with his hand. H3 1m 19 captures C and M holding hands moving hands around one another's hand. C then leans in closer and M puts her hand around C and feels her hair. H3. She then pulls it! M3. G can be seen in the background with J who has appeared in shot, G is trying to place the paper into J's hand for him to grip and rip- unsuccessfully, J turns away. Carer distracts G who turns away from J, J suddenly looks at G while facing the other way. M3. G turns back and catches J looking at her, G carries on with the paper ripping task but maintains eye contact with J for a three seconds. J turns away. M3. 6m40 C shows M a range of picture to choose an art activity, M reaches out towards the pictures, moves past them towards C's hand and squeezes it in view, C is pulled in for an embrace. 8m21 H can be seen with a huge smile while H bobs up and down while holding his hand to complete the art piece, mum appears in view seeking to get in H's line of sight to see him smile. M4. **Observed**: from the start H can be seen smiling with his mouth open, a piece of art is on his lap but his head is lifted high away from the piece of art and looking at Hy, M4. while Hy looks at him, mum and paid carer Also in shot smiling at H. 6 seconds mum can quickly be seen taking phone and accessing camera to capture H smile. C appears in shot and is seen watching H and Hy while mum, paid carer watch on taking photographs. Mum takes 1 minute taking photos and then turns the phone to Hy and shows her the image, they both smile and then mum turns the phone back looking at it on her own with a	**Closeness / touch** **Quant collection:** **24 points of embrace / hug** **28 whispers** **60 points of holding or hand over hand**	Could merge with collaboration and sharing Blue and Grey

	smile. M4. 1m35 C leans in towards M, and you can see the bottom of her face, she is smiling and talking to M, M4. She suddenly turns side on as M is seen pulling C's pony tale- C has a huge smile.		

	Merged		
Themes	Closeness / Touch Collaboration and Sharing Joy and pride	Chaos Fun Vulnerable and uncertain	Assumptions and choices Task
Codes	Personal spaces Closeness and touch A narrative of touch Intimacy She is dictating what type of communication takes place by pulling in. Coughing is communication - it doesn’t need to mean anything to be funny. Affection is better than tasks. Moment captured with M showed collaboration. Sharing	Fun and chaos Something metaphorical in the chaos and fun of the balloon bursting. LOVE THIS! Chaos and disruption M is mischievous Chaos, multitasking and fun M is so much fun. Being unsure Invading personal space is vulnerable for both Hy gentle in requests and uses an approach where H is helping her not the other way around. A narrative of questions	Assumptions around objection? Shows power of carer Authors Choices Assumptions Decision makers Assumptions of consciousness Perspectives - Challenging what can be heard assumptions in H video which seems to be about power. Perspectives!

	It’s noticeable during the moments when H is touched and talked to that his vocal expression is a lot quieter. M offering some mutually vulnerable moments. M and C capture lovely moments. C works hard with and around M environment Moments of connection Intimacy and mutuality - understanding / Pride / Gentleness and request, collaboration Pride - gaining something affection Caring for other people feels good Being part of something Pride of parents and demands of care	Sometimes there are moments filled with anxiety and uncertainty.	Ideology and practice People rather than tasks interesting that J’s verbal engagement less prevalent during activities - task focused Concentration G is very much on task, C is about relationship. Task is secondary to relationship. Ability shapes engagement The moment between Hy and H had nothing to do with the task.
New Theme	**Tangled**	**Exploring (need a better word)** Willing to take risks and embrace messiness, possibilities and ambiguity. Humbly Not coming to	**Doing (need a better word)** Making assumptions and doing practice.

	Working together forming one. Think about Rhizomes and I thou. Strongest one with most data. This is the story	fixed judgements without certainty. Considering difference.	
Stand out data	H2. **Heard**: 2m13 Hy says to H “lets start with the blue and then you can blend it then. you hold that for me and we’ll start with the blue”… “are you ready, can we hold hands and you do this with me”. H2. 2m50 carer says to H “I think this is a great start, but can you help me a little bit more… are you ready, can I borrow your hand”. *FG. H3. C: I think the one thing I’ll always remember even if I move on to another job is the friendships and relationships oh I’m going to cry* *J: I know yeah* *H3 1m 19 captures C and M holding hands moving hands around one another’s hand. C then leans in closer and M puts her hand around C and feels her hair. H3. She then pulls it!* **Quant collection:**	M2. **Observed**: M throws some paper on the floor at which C smiles but with a look of shock playfully as if M is putting her out. M2. 1m28 C offers M a new choice of colours, she explains the colours and touches each hand with the colour to encourage M to make a choice, M chooses the white. M2. She chooses it and immediately throws it on the floor. M1. **Heard**: M grinding her teeth 1m10. 1m14 M heard saying “gal gal gal gal go” mum responds with “what are you telling us?”. 5m20 C can be heard saying to M “what do you think we should do? **152 questions asked**	H1 8m19 mum and carer explaining to H what the game they are about to play is. H responds with “ayaaa” at which mum responds “are you not in the mood for this matey” ….. Mum says “hehehe is this good fun”. M3. G can be seen in the background with J who has appeared in shot, G is trying to place the paper into J’s hand for him to grip and rip- unsuccessfully, J turns away. Carer distracts G who turns away from J, J suddenly looks at G while facing the other way. **152 questions asked**

	24 points of embrace / hug **28 whispers** **60 points of holding or hand over hand**		

Tangled

Observed: H1 8m01 H captures M with carer- good eye contact and sharing in the wrapping of paper

FG. M1. Courtney: I'd say a massive one is language, I think like defo you don't need to use words to get across what you want to get across. Like the people in this project use language in a much different way than me and maybe these two here but also from everyone else who's doing the research, I'd go as far as saying it'd even change depending on the relationships you have with each person. Like I'd say that John would relate differently with Blake than he would with me because of the depth of relationship. I'd defo say I'd learnt that from people we support that its not as simple as a want/needs or request relationship. There's loads of ways of doing it.

FG. M1. Blake: I've learnt to communicate in different ways and there's a richness to that. FG. M1. Gabriella: you can communicate in a variety of ways.. H2. ***Heard****: 2m13 Hy says to H "lets start with the blue and then you can blend it then. you hold that for me and we'll start with the blue"… "are you ready, can we hold hands and you do this with me". H2. 2m50 carer says to H "I think this is a great start, but can you help me a little bit more… are you ready, can I borrow your hand"*

H2. Observed /Heard 8m08 Hy "splodge splodge splodge" mum "is that good H?" "Are you pretending its M, H?"

FG. H2 Courtney: ….Disability studies taught me about people having voice and I think that goes hand in hand with the relationships.

FG. H2. Courtney: I think like both people mutually getting something - like I benefit as much as the person I'm connecting with. Like learning things.

J2. 5m45 Jk notices that there are dried out flowers next to the art and says "oh these are good you could have a smell of these J".

Expressed: 4m20 Gabriella shares in the ripping of paper. 7m20 J is offered the switch which he presses hand over hand with J and the paper spins in the blender.

Observed M2. 1m28 C offers M a new choice of colours, she explains the colours and touches each hand with the colour to encourage M to make a choice, M chooses the white. M2. She chooses it and immediately throws it on the floor. M2.

M2 3m58 C places the paper in the blender and encourages M to use the switch, M reaches out and touches the switch which starts the blender. M takes the switch out of C's hand. C has a big smile while M is taking the switch out of her hand and encouraging her to join in. M2.
M2. **Heard**:4m C encourages M and says 'woooo' when M takes the switch out of her hand. "You got it" "can you hear it? Yes M! Yes M!".

M2 4m42 C asks M mum if it is ok if M has a feel. M2. . G. H3. Courtney: I don't think I'll forget the impact you make on someone's lives, in fact I'd say the biggest impact has been on my life.

M3. 1m21 C is heard saying "M, I don't think we've done this right". M grinds her teeth. 2m 25 M coughs. 2m29 C can be heard saying "** Cough cough** , is that my cough, has Jk got my cough" M can be heard giggling. M3.

M3. 6m C asks M "I've not done this one before M have you?" M is heard saying "aaaa aaa goo oooau" C and Hy laugh and say "you don't M". 6m40 C is heard saying "which of these do you think M, oh, oh thanks Mary *cough *cough cough*" MB is heard saying "get her M" C responds to MB "excuse me! You tell him M excuse me not a chance" M4. **Heard**: 1m21 Mum says to C "this one has us up this morning" "C said I've heard, I heard you've been awake all morning?" Mum says "you've been awake since 3am haven't you? Yes I know, I know, normally this is your time sat in front of the tele" 1m35 M Coughs and C says to M "well shall we just stop this then and chill then what d'you think?….. uhh I've lost my hair".

FG. M1. Gabriella: I think I'd say the affirmative model has been evident, like its like I'm here, this is me, a bit like that probably.

H2 **Observed**: 30seconds captures Jk and G supporting J with mum watching. Mum watching J face with a smile, G sitting alongside and Jk supporting with an art piece hand over hand. J focus on G rather than the art.

59 seconds H captures Jk rub J's head saying "well in mate" .H2 2m15 mum appears in shot and looks at H with a smile H2 4m mum is captured telling MB a story about M and when she brought the family cheer after the death of a family member, she was in the next room and was clapping and shouting just moments after a death. Mum expressed "she knew" 4m49 and "that really helped me and Ian" 4m57 H2 8m08 Hy and carer support H with the art piece when mum leans into observed shot with a smile on her face. Her expression seems to be in reaction to H first. H2. Mum smiling captures photo of H taking part

Expresed: 2m40 H and carer capture hand over hand art. Carer hand over H hand who holds the tissue with paint on. 4m54 Hy moves away from hand over hand rushes through it.

H3. **Observed**: First 45 seconds of the video mum is recording H on her phone, she is smiling. At the end she shares the photo on her phone with carer and Hy

FG. H3. Gabriella: I do feel like when I've spent a day in this context I can go away feeling like I've given or helped facilitate the best day possible and that's a good feeling when I leave here.

FG. H3. Courtney: like I feel like when you're able to support someone to do something that maybe might be unable to do at home or unwilling to do with other people and they connect with you in that way you're so satisfied going home. Like even little things like someone coming into a different room can be a big thing for someone where as for other people that might be nothing. FG. H3. Gabriella: yeah and when you've been part of that you feel good about yourself. FG. H3. Courtney: I think the one thing I'll always remember even if I move on to another job is the friendships and relationships oh I'm going to cry Blake: I know yeah Courtney: this is really bad (laughing) I'm actually going to cry literally when I said if I move somewhere else I started getting upset Gabriella: I am myselfCourtney: Yeah I think I'll never take for granted the relationships here just simple things like what you said earlier knowing you're making a difference to someones day like its such a nice feeling Gabriella: its the best feeling ever FG. H3. Courtney: I don't think its too far to say we love the people here no because when I'm home I love sitting down telling my friends and if I get home from work I love talking over dinner about what I did that day like if its a really good day I could talk for hours about the people here that's why the instagram is great because I can put faces to stories, like I just love having the stories so yea I'd defo say that's the case

M3. 5m55 M and C move to another activity and Hy, H and paid carer can be seen in view. Hy and C are seen in conversation and then Hy and C can be seen turning and smiling at M.

J1. **Observed**: 50seconds mum appears in sight line and J responds. 7m J is moved to take part in an art activity. 7m17 Jk smiles at J. 1 Observed C seen holding M hand throughout. Mum out of shot holds M other hand. 1m18 M holding both C and mums hand. 1m30 M once again knocks the camera but it focuses in on the intimacy of the hand holding with C. 2m12 H carer can be seen whispering in on H ear, her right hand touching his face. 2m40 C and M hand holding showing affection. J turns and looks at his mum who rubs his shoulder and leans in on him. She rubs his arm and whispers in his ear. 2m55 M tapping the camera. Th camera captures affection for M with C, J with mum and H with carer- all touch, all close, all without words. J constantly looking at his mum. 3m50 Jk and J are looking at each other, Jk is on his knees.

FG. M1. Courtney: its funny like there's things people might say or vocalise here which I feel like I understand in this context, like I'm going home saying 'peno music' or 'inside out' and it makes no sense outside of the context of relationships but here in relationships it doesn't make sense and there's a degree of comfort to that. Like the words and sounds here I do take elsewhere and its like I think in that language sometimes like I don't even say piano anymore H2. 5m57 captures C looking at and smiling touching M side of face. 6m40 captures C leaning in and coughing in M ear, M responds with a smile. This is repeated and M offers C a hug.

Heard: H2. 6m58 MB says "get her M when she is offering C a hug". J2. 2m55 M seems still and not looking at what is in her hand, C stops watching the activity and is watching M, she leans in and coughs in her ear.J2. M lifts her head and smiles. They share a laugh together. J2. 8m20 Hy can be seen doing hand over hand with H, leaning in and smiling and laughing, H3. Mum turns to M 1m08 and touches her on the shoulder and leans in for an embrace, M responds with a smile. H covers the camera with his hand. H3 1m 19 captures C and M holding hands moving hands around one another's hand. C then leans in closer and M puts her hand around C and feels her hair. H3. She then pulls it!

M3. G can be seen in the background with J who has appeared in shot, G is trying to place the paper into J's hand for him to grip and rip- unsuccessfully, J turns away. Carer distracts G who turns away from J, J suddenly looks at G while facing the other way. M3. G turns back and catches J looking at her, G carries on with the paper ripping task but maintains eye contact with J for a three seconds. J turns away.

M3. 6m40 C shows M a range of picture to choose an art activity, M reaches out towards the pictures, moves past them towards C's hand and squeezes it in view, C is pulled in for an embrace. 8m21 H can be seen with a huge smile while H bobs up and down while holding his hand to complete the art piece, mum appears in view seeking to get in H's line of sight to see him smile.

M4. **Observed**: from the start H can be seen smiling with his mouth open, a piece of art is on his lap but his head is lifted high away from the piece of art and looking at Hy, M4. while Hy looks at him, mum and paid carer Also in shot smiling at H. 6 seconds mum can quickly be seen taking phone and accessing camera to capture H smile. C appears in shot and is seen watching H and Hy while mum, paid carer watch on taking photographs. Mum takes 1 minute taking photos and then turns the phone to Hy and shows her the image, they both smile and then mum turns the phone back looking at it on her own with a smile. M4. 1m35 C leans in towards M, and you can see the bottom of her face, she is smiling and talking to M, M4. She suddenly turns side on as M is seen pulling C's pony tale- C has a huge smile.

Vulnerability

M1. **Observed**: 5seconds M using left hand to tap and knock and shake the camera. **OBSERVED** J1. 7m28 Jk bursts a balloon filled with paint on himself, looks at mum and G laughing. Jk, mum and G look at each other and J while laughing about bursting the paint covered balloon. Mum leans in 8m05 to involve J further in the laughter, Jk and G share in the laughter looking at J. Camera says storage full from 10m30 but audio continues.

M1. Heard 7m05 C laughing saying “M keeps blocking the camera its like she’s says ‘no paps - no paperatsi today guys”. All the ripping they do together.

FG. M1. Courtney: I think the audio might be better than the video because during the first bit of the session like Mary had her back to the others so might not capture that range of interaction but the video might find that. She was like trying to knock everything off anyway

HEARD J1. 8m05 mum says “oh that was so funny J”… “hey what do you think do you want some paint on your face?”. 8m32 Jk says “J I’m covered in it”.

OBSERVED H2. 8m22 C acknowledges M been mentioned in joke with H and C makes head motion to M towards H.

M2. **Observed**: M throws some paper on the floor at which C smiles but with a look of shock playfully as if M is putting her out. M2. 1m28 C offers M a new choice of colours, she explains the colours and touches each hand with the colour to encourage M to make a choice, M chooses the white. M2. She chooses it and immediately throws it on the floor.

M2 4m55 M can be seen grabbing C’s staff badge. 5m16 M can be seen knocking the switch over and over.

M2 6m33 M tried to grab C’s pony tale and C turns and smiles. 6m57 C can be seen adjusting the table height so M can move closer to the activity. As M moves closer to the activity she immediately reaches for the bucket of water. M2. 4m55 as M grabs C, C laughs and says “aaaaaaah no, M”.

7m47 C says as M tries to grab the water “ooooh M I can see your eyes!”

H3 1m 19 captures C and M holding hands moving hands around one another’s hand. C then leans in closer and M puts her hand around C and feels her hair. H3. She then pulls it!

H3. **Heard**: 5sec Hy “no paps! you have to keep this cool mysterious guy that never smiles” mum says “go on H”. **Expressed**: H tries to throw the piece of art created 2m27 and mum, C, Hy and carer laugh. 2m31 the camera shows the piece of art H created- a waterfall canvas. M3. **Observed**: 5 seconds At the very start of the video M is seen reaching out to pull the bucket of water off the table towards herself- C, while also trying to support M in the paper making task seeks to peel M’s left hand off the bucket of water to avoid her being soaked. From 5 second M has a tight old of the bucket and with a strong grip is seeking to pull it off the table, C seeks to push down on the bucket and is seen seeking help as to not have M covered in the bucket of water and pink paper pulp. 15 seconds C is able to move the bucket of water further out of reach from M who then immediately reaches for the switch connection button which is plugged into the blending machine, she pulls this out and throws it over her shoulder. From 30 seconds, M is tapping the front of the camera with her left hand. M3. 2m40 Jk appears in view approaching M, M reaches out and grabs the paper making stencil which has wet paper pulp on and pulls it toward Jk, C's hand appears grabbing the stencil, the stencil comes out of shot, Jk turns away and then suddenly having being splashed turns back. 3m55 C's hair appears in shot tied in a pony tale, M reaches out to pull it with her right hand and is holding C's hand in her left hand. M3. **Heard**: C says at 6 seconds "aaaaaaaaaahhhhh S help". She is heard at 16 seconds say "ooooops". 40 seconds "shall we pat this down". 2m40 C can be heard saying "Jk's covered in paint already M, oh Jk she's coming for you" "Jk says Oh M you better not, oooo….. splashed!"

FG H1 Courtney: yeah I think age is important like because Phil (pseudonym) has other PA's, not saying they're dead old or whatever but the impression I get is that he's really valued having people working alongside him who are like the same age and maybe similar interests like the other day we went for a pub lunch and he had such a good day and I think it was more about him being out doing things he maybe wants to do. Like that's what people want to do at the age of 20 like go the pub with your mates…. Not sure if this paragraph should be in this section

J1. **Heard**: 5 seconds "J is now live" J responds with "mmmm mm". 50 seconds J responds to mum in sight line "mmm mmm" quietly and then a third "mmmmmmmmmm" and mum returns. He then expresses a louder "mmmmm" when MB starts speaking. 7m mum says "what shall we do J would you want to feel this balloon?"…. "it's got paint in it would you want to feel it? .. No?". M1. **Heard**: M grinding her teeth 1m10. 1m14 M heard saying "gal gal gal gal go" mum responds with "what are you telling us?". 5m20 C can be heard saying to M "what do you think we should do?"

FG. H2. Courtney: I think the positive energy and relationships we have as a team reflects on the diverse group of people we support and that reacts in a way that people are positive and happy which in turn then makes our jobs easier. Like I think if the work environment was a horrible place to work I reckon that would impact the service users whereas here its such a positive place its almost hard not to have a good day here. I think that helps our jobs as staff seeing the people we support having a good time.

J2. **Observed**: 27seconds carer leaning on H's head and arm rest meanwhile Hy notices that H's jejunostomy uncovered and she replaces H's top covering his stomach.

J2. 2m55 M seems still and not looking at what is in her hand, C stops watching the activity and is watching M, she leans in and coughs in her ear.J2. M lifts her head and smiles. They share a laugh together.

Expressed: J2. Jk and G try to use the stencil to make the paper, and has difficulty, Jk turns to J and says 9m16 "J I think we've fucked it up"

M3. From 1 minute MB comes into shot leaning over M, Hy, who is supporting H turns to look at M and taps her nose indicating to C, next to Hy stands mum and private carer who along with Hy stop to look at M, they stare for 10 seconds, then smile and turn away.

M3. MB approaches M and says “what do we think M?” Hy shouts over to MB at 1 minute “MB tap her nose” MB can be heard saying “are you here with me M, I gotta go I gotta go” The room which fell silent for a few seconds continues on with sound.

FG: Gabriella: I’d agree, before I started working here and before I did the disability studies I was doing the supported living, and it was very regimental and to be honest I’d just go about it and go along with it because I didnt really know what else to go by. But since I started the course I was like ‘no’ and I was challenging the staff members on what they were doing and I was like you know supporting them in a different way- an improved way a more positive way as individuals.

Courtney: Like you can tell when there’s certain people in a room there’s excitement when you see them, like I dunno like I don’t even know if he would be excited to see me but if I know there’s people here I’m genuinely excited to see but I think people are excited to see me so I do think its a relationship balance.

Blake: and for certain people when you walk in a room you see them clocking you around the room waiting for you to go over and say hello and stuff.

Gabriella: I feel here that everyone is very diverse, no-ones the same so its very apparent that you’re trying to connect with many different people and working with different people.

Blake: yeah, for me personally I’d never take for granted the friendships and relationships we have because we don’t know how long we have those for.

Courtney: I’d say a massive one is language, I think like defo you don’t need to use words to get across what you want to get across. Like the people in this project use language in a much different way than me and maybe these two here but also from everyone else who’s doing the research, I’d go as far as saying it’d even change depending on the relationships you have with each person. Like I’d say that John would relate differently with Blake than he would with me because of the depth of relation Courtney: I think like both people mutually getting something - like I benefit as much as the person I’m connecting with. Like I’m learning things.

ship. I'd defo say I'd learnt that from people we support that its not as simple as a want/needs or request relationship. There's loads of ways of doing it.

Blake/ Gabriella: yeah agree

Blake: I've learnt to communicate in different ways and there's a richness to that.

Gabriella: you can communicate in a variety of ways.

Practicising

SMALLEST DATA

Observed:H1 5m40 pushes the camera facing towards his stomach. Carer lifts the camera back to the upright position and says "he wants to film his feet" H1 **Heard**: 1m35 "aaaaaaaarrrrrrrr" during the story accompanied by a "sh sh sh sh sh and a whisper do you not like the story" 2m48 mb reads "I gently press my chin against her forehead aaaaahhh" at which the response appears "aaaaaaaarrrr", the carer whispers "what's the matter". H1 8m19 mum and carer explaining to H what the game they are about to play is. H responds with "ayaaa" at which mum responds "are you not in the mood for this matey" ….. Mum says "hehehe is this good fun".

FG H1 Blake: …*I was in another care job and the lad I looked after was described as non-verbal and we'd be making a lot of his decisions for him because there was that assumption that he didn't have a voice*

HEARD J1. 11m40 mum says "he's actually really interested in the balloons over there" 12m40 J changes position so he is facing other activities and mum says "is that better you can see a bit more now".

J1. **Expressed**: 9m10 Jk, Hy and Mum discuss which piece of art to try and express and decide to go for one related to trees because J likes trees

H3. 30 seconds mum says "he can't see the camera but he knows it there"… H responds with "waaaaaaaaa". 2m04 H says "aaaaaaarrrr" and Hy says "do you want to help, is that why you're whining?" H3.

E *FG H1 Gabriella: before I started working here and before I did the disability studies I was doing supported living, and it was very regimental and to be honest I'd just go about it and go along with it because I didn't really know what else to go by.*

FG. H2 Blake: one of the things I've found though which will be different from when you started was that because there are a lot of people here who have done disability studies we're all on the same page if that makes sense when it comes to outlooks and perspectives and when you get new staff in, our ideologies sort of go onto the new staff.

FG. H2. Gabriella: yeah like the new staff who are coming in if they haven't done disability studies are coming in like everybody else and seeing disability as like individualised but obviously when they come to us we portray a different way really and I think that goes onto the new staff and I feel that's a positive way.

J2. Jk keeps J involved in the outcome of the paper making 9m40, Turning to him and offering a chance to feel what has been made.

J2. **Heard**: G describes that “What do you reckon? I think that is fab” showing J the art piece he has created. G asks J “shall we rip some paper up what do you reckon?”. 2m55 G says “do you want to rip it, here would you like to listen to it?”.

M3. G can be seen in the background with J who has appeared in shot, G is trying to place the paper into J’s hand for him to grip and rip- unsuccessfully, J turns away. Carer distracts G who turns away from J, J suddenly looks at G while facing the other way. M3. G turns back and catches J looking at her, G carries on with the paper ripping task but maintains eye contact with J for a three seconds. J turns away.