An exploration into children's experiences of long term and recurring hospitalisation

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Abstract:

This thesis reports on a qualitative study concerned with the experiences of long term or regularly hospitalised children and young people. The study involved the recruitment of six participants to explore the research question: what we can learn from the stories that people choose to share about their experiences of hospitalisation. While much has been improved in relation to children's hospitals and the care that children receive, there is significant concern in literature and policy alike for children aged between 11-16 years old. This thesis attends to some of these concerns. Several disciplines have contributed to the understanding of children in hospital, including psychology, sociology, childhood studies, disabled children's childhood studies, critical disability studies, nursing, and medicine. This thesis partially outlines each discipline's key contributions. The thesis grounds itself in disabled children's childhood studies (Curran *et al.* 2013) and utilises poststructuralist thought and concepts of spatiality to explore the multi-modal data. Developing a cross methodological approach, the study develops and employs a narrative-autoethnographic approach to research methodology. It exploits the richness of different modes of storytelling to situate the researcher's stories alongside those of participants in the study. The study found that young people in the hospital had an idea of the way that they were perceived by others, which they found limiting and oppressive. A strong theme which emerged from the data was that of not feeling heard or being misunderstood whilst in hospital; this theme is explored in this thesis in relation to power. The theme of fear came through more subtly and highlights a need to better understand children and young people's fears, as well as how important the mundane was for young people. This thesis identifies a need to continuously problematise notions of normalcy, especially in terms of children's communication. It identifies an urgent need to develop ways of multi-modal listening to young people in hospital, and thus has implications for policy, practice, research and theory, respectively. The thesis calls for a more nuanced understanding of non-verbal communication employed by many young people, whilst also reflecting on how we can better hear young people's communication.

Chapter 1: Introduction

This chapter explains the focus, justification and purpose of this research, noting the methodological direction of this thesis. It highlights the timeliness of this project and offers a brief background of the history of children's hospitals before contextualising historical understandings with current knowledge and literature in the area of children's hospitalisation. An important and consistent theme in the understanding of children's hospitalisation was child participation and thus, the chapter outlines influential concepts of child participation as well as legislative texts guidelines and policies that influence how we think about child participation and act upon children and young people's expressed wishes. The chapter moves on to outline the theoretical backdrop of this research before summarising and offering the thesis' indicative content

1.1 Focus and justification of the research

The thesis focuses on the experiences of children and young people who have had reoccurring and or long-term hospitalisation. It utilises qualitative methodological approaches and draws on both narrative and autoethnographic methods in order to include the voices and stories of six participants, aged between 9 and 31 years old, including my own teenage voice that was taken from historical diaries that I wrote as a young person in hospital. In this thesis, the participants and I become the tellers of our stories as we reflect on and story our experiences and understandings of hospitalisation. Our narrations offer a new perspective and question the helpfulness of dominant narratives within society. Ricoeur (1990) highlights how people's lives and identities are entangled through acts of storytelling, arguing that stories connect people's experiences and how they story their understandings connect them to the worlds in which their experiences take place.

This research took an open method approach where participants were given no boundaries on what stories to tell or how to share their stories. I think that this encouraged participants to express their experiences in a variety of ways. Some participants choose creative ways to tell elements of their story. As a result, multi-modal data was collected which aided an understanding of the multiple ways young people told their stories that were important to them. The reason to collect data in this way and the purpose of this research was to create a safe space for stories of hospitalisation to reside. Children's experiences of hospitalisation have, so far, been explored by researchers across different disciplines, including Medical Studies, Sociology, Medical Sociology, Geography, Health and Social Care, Education Studies, Disability Studies and Nursing Studies. Much of this literature frames hospitalised children and young people using a medical understanding of illness and disability (see for example, Dewhurst *et al.,* 2015; Popp *et al*. 2014; Rodenburg *et al*. 2011; Roberts, 2010; Ekinci *et al.* 2009; Forsner *et al.* 2009; Roter *et al.* 2005; Carter, 2002). This research however frames hospitalised children and young people as autonomous social actors in their own right. Their knowledge, competence, understandings and experiences are valued.

The events of 2020, where the nation entered lockdown highlighted the continued necessity and timeliness of research valuing social justice, amplifying the priority that this must take. Since Covid swept the UK population over 197,000 people have died as a result of the pandemic. Two thirds of these deaths have been sick and disabled people (Liddiard, 2022). This demonstrates the relevance of this research, two thirds of Covid fatalities relate to people with long term illnesses, yet those voices and hospital experiences are rarely prioritised. This thesis begins to create a space for sick and disabled young people's voices to be amplified and pushed into the realms of sociological and academic debate and consideration. As we will discover through the thesis, sick and disabled children and young people's voices are seldom heard and understood. The thesis then, is only a start, a stepping stone to ensure that the voices in this research are no longer misplaced. The thesis commits to the voices here being heard, understood and valued. The voices and stories of sick and disabled children and young people are relocated to their rightful home within the sphere of critical disability and disabled children's childhood studies in order to work towards social justice and ethical knowledge production in research (Liddiard, 2022). Furthermore, by centering disabled children's voices, it respects their knowledge and contribution on an equal level to their non-disabled counterparts, aligning with disabled children's childhood studies (Curran *et al*., 2013).

1.2 Background and Context

Prior to 19th century hospital reforms, the wellbeing of children was viewed by general society to be a matter of maternal responsibility. As such, there were no institutions, such as hospitals, set up for ill children. There were, however, orphanages which were focused on offering care to abandoned children in the hope that they would reach adulthood (Pugh, 2011). In 1739, Thomas Coram established a successful Foundling Hospital, an institution whose goal was to rehabilitate sick infants, nurse them back to health, and teach them a trade so that they could be productive members of society (Pugh, 2011). Coram's Foundling Hospital was, at the time, revolutionary as it was the first children's charity to be established in the UK, and it still remains the primary organisation for children in or out of care. Representing sick and abandoned children within a charity model was crucial at this time, as it was made successful by its many donations from wealthy members of society. This Foundling Hospital was the earliest form of what would later become a children's hospital (Pugh, 2011).

By the mid 19th century, infant mortality had begun to decline. However, there was growing concern about the health and well-being of children living in poor conditions. Children's hospitals resembled middle-class homes. British children's hospitals created strict rules that children and their families were expected to adhere to. However, children under two were rarely admitted to hospital, as they were deemed too costly and too time consuming to the staff who worked there (Pugh, 2011). The first formally recognised children's hospital opened in Paris in 1802. 50 years later, in 1852, The Great Ormond Street Hospital opened in London. By the early 20th century, children's health became increasingly tied to the physician and hospitals. New fields of medicine, mainly the study of children's medicine, was being introduced across the country. In 1959, the Platt Report, formally known as the Welfare of Sick Children in Hospital, detailed how children's hospitals were miserable places for children to stay. The report noted that children had to obey strict ward routines and were not allowed to play, and that under no circumstances were parents permitted to visit children out of pre-established visiting times (Platt, 1959). The Platt Report recommended that children should have unlimited access to their parents while in hospital (Platt, 1959). The recommendations of the Platt Report were slow to be implemented. In 1988, the Convention on the Rights of the Child formalised the Platt Report, and by 1993 a report by the Audit Commission, called Children First, showed that further improvements had been made. However, they reported that the Platt Report (1959) had not been implemented for young people aged between 11-16 years old as successfully as it had been for younger children (Dodd, 1993).

During the first two decades of the twenty-first century, the UN Convention has driven a child-centred approach to run alongside a family-centred approach. The child-centred approach insisted that children ought to be recognised as active and equal members in the care partnership (Carter *et al.,* 2014). That said, many studies done with hospitalised children, in recent times, have highlighted the welfare of children in hospital, many highlighting concerns for the needs of children from the ages of 11-16 whilst in hospital. Furthermore, many of these studies (e.g. Hemmingway *et al.* 2011; Bricher, 2000; Curtis, 2004), explored in the following chapters, highlight that children are still not being viewed as an equal in their care and that more can and should be done to make children's hospitalisation a better experience. My study responds to this by forefronting children and young people's own voices, detailing what they perceive to be important, as well as how they feel about their care in hospital. This study highlights what young people perceive as the problems within hospitals and offers new ways to understand communication. The research utilises and develops narrative and autoethnographic ways of conducting research, and exploits the richness of multi-modal story telling. It asks a key question: What can we learn from the stories that people choose to share about hospitalisation?

1.3 Child participation and voice

Children's voices have been identified as important in the background and context of children's hospitalisation (above in 1.2) as well as being identified as lacking within literature focussed on improving services for sick and disabled young people (see chapter 2-4). It is important to note how children's voices are considered more widely. Alignment with disabled children's childhood studies, that centres the voices of disabled children and celebrates all childhoods equally (Runswick-Cole *et al.* 2013), it is important to understand how children's voices are currently understood in culture.

One of the recurring themes throughout previous studies is that of child participation. Many academics who write about child participation advocate the importance of listening to and taking seriously the voices of children and young people (Livesley *et al.,* 2013; Wood, 2013; Forsner *et al.,* 2009; Kellet, 2009; Coyne 2008; Mast, 2007; Shier, 2001). This section identifies and critically explores three major contributors to the understandings of children's participation and voice. Firstly, the United Nation Convention on the Rights of the Child (UNCRC, 2010) is widely drawn upon when discussing how adults listen to children and is outlined first, in relation to children's voice in hospital settings. Secondly, originating from the Judicial system I outline Gillick competence alongside the Fraser Guidelines before moving on to finally consider both Hart and Shier's 'ladder of participation' which provides a more conceptual understanding of participation but has been influential in framing and understanding children's participation more widely. I then discuss child participation in relation to hospitalisation and offer a broader discussion of the literature.

1.3.1 The United Nations Convention on the Rights of the Child

The United Nations Convention on the Rights of the Child (UNCRC, 2010) establishes the rights of the child across the United Nations. Article 12 of the UNCRC (2010) notes that children's opinions should be sought especially at times when people are making decisions that impact them (such as decisions about their bodies during hospitalisation). It notes that their opinions, worries or concerns should not be dismissed. It also notes that children and young people should not have to seek their own information and it is the responsibility of an adult to provide children with good quality information on the things that affect them so that children are able to make informed decisions. In essence, the convention asserts that all children have the right to be heard in all matters which affect them. It also highlights that the child has the right to voice their concerns in either verbal or non-verbal means of communication. Interestingly, while Article 12 of the UNCRC notes that children should be listened to and taken seriously, regardless of their age, article 13 makes the recommendation that the age and maturity of the child should be taken into consideration when children are involved in decision making (UNCRC, 2010).

This policy fails to give a framework of how practitioners should assess the ability of a child to make decisions about their healthcare. Warming (2011) highlights that the child's right to be heard is almost always withdrawn because the UNCRC fails to clarify how maturity should be assessed. Warming (2011) critically argues that assertions such as these depict children and young people as vulnerable 'becomings' who are in need of adults' protection instead of framing children as competent social actors and decision makers in their own right. She suggests that these depictions silence the voices of children and young people (Warming, 2011). This is a viewpoint which is shared by scholars such as Polvere (2014) and Bricher (2000), whose studies argue that children's voices are silenced by unequal power relations amongst children who are in the hospital and their doctors.

1.3.2 Gillick competence and Fraser guidelines

Gillick competence is a measure of young people's competence to make decisions about their health. Typically, it allows medical professionals to assess whether a child is mature enough to make medical decisions about treatment options. The Fraser Guidelines accompany Gillick competence and are used by medical professionals to assess whether a child can be considered as Gillick competent. These guidelines are intended to help medical professionals balance the need to listen to children with their responsibility for ensuring the child's safety. Here, child safety is produced as an opposition to listening to young voices and thus, listening to the expressed wishes of a child during hospitalisation is framed as a privilege and luxury instead of a human right.

Both Gillick competence and the Fraser Guidelines derive from a legal case in the 1980s which investigated whether doctors ought to be able to advise and treat children aged 16 years old on sexual health without parental permission. These guidelines continue to apply, in law, for advising and treatment in relation to sexual health; however, they have been utilised more widely in the medical profession to assess and establish whether a child can be considered as competent enough to make decisions on their care and treatment in hospital.

In law, Gillick competence was not passed as an Act until 1991 where it now runs parallel to the Children's Act (2004) focusing on the importance of recognising the status of children as a person in their own right. Dickenson *et al.* (1995) identify, however, that there are some loopholes in the act which makes it possible for courts to override the act by suggesting the child's wishes are not their 'true wishes' and thus does not serve the child's 'best interest'. This paternalistic side of the act has been highlighted in case law where 'best interest' has been utilised to dismiss the child's wishes, especially if the child's wishes did not align with their doctors' or parents' wishes. This is reiterated in Devereux *et al's*. (1993) study when they suggest that a child or young person whose competence is in doubt will be found competent if they accept the proposal of treatment but incompetent if they refuse. Within the parameters of this understanding, the concept of competence does not assume fluidity or scope for negotiation for young people. Instead it is assumed that competence is acquired (usually) with age. The idea of 'best interest' and 'true wishes' is therefore used to actively silence a young person's expression because as long as someone with parental responsibility consents treatment, the child or young person has no right to refuse, whether or not they are judged as Gillick competent. Dickenson *et al.* (1995) observes how this creates a harsh boundary between adults and children, with adults presumed competent to make medical decisions about their bodies and given more choice and opportunities to meaningfully contribute to medical decision making than their younger counterparts.

A key element of deciding what is in someone else's best interest is the value that a person places on the risk of the decision. Risk assessment is arguably subjective rather than 'objective'; therefore, it is likely that the risk of a procedure or medical treatment is assessed differently for different people. With this in mind Dickinson *et al.*

(1995) argue that working in the ‘best interest’ of the young patient requires deep knowledge of the patient’s values and to act/decide in relation to these values rather than the own good sense and values of the doctor making the decisions.

Dickinson *et al*. (1995) suggest that individual values are fused to identity, marking us out as individuals and impacting how we operate in society. On the other hand, identity is a philosophical position towards determining the ‘true wishes’ of a child receiving medical care and treatment. The nature of personal identity, however, like that of rationality, has been understood in widely differing philosophical frameworks. This leads the authors to question whether the relevant distinction between adults and children is the perception of a fully formed identity. They note that adults have had a longer time to secure their identity. Dickenson *et al.* (1995) highlights the presumption that the value structure, linked to identity, that young people draw upon to make decisions is less stable than the value structure of adults, again noting the sharp contrast between children and adults.

Drawing on Erikson’s (1968) assertion that the whole essence of adolescence is the attempt to secure an identity and establish a self that can be seen as continuous and unified, Dickenson *et al.* (1995) point out that such definitions make it possible for courts to impose paternalistic values. They argue that this provides a loophole that permits judges, courts and welfare officers to assume that their values, reflections and conclusions are more thorough, rational and thus more ‘true’ than the young person’s values. To an existentialist, there is no outsider source of identity or values beyond that which is deliberated through the very process of making choices. Dickenson *et al.* (1995) suggest it is ‘bad faith’ to believe or to consider the choices that the doctors or young people make to come from anywhere other than within the person making the choice. They argue that in order for identities to develop people need to be permitted to make choices including the ability to make mistakes. Identity, then, like rationality, fails to provide grounds for UK courts to recognise children’s choices as valid and meaningful decisions. This is because it is possible to argue that children’s expressed wishes are not their true wishes.

Dickenson *et al.* (1995) detail an interesting case where a young woman who identified as a Jehovah’s witness refused a blood transfusion; however, the young woman (age

20) was given a blood transfusion as doctors deemed that it was in her best interest. Doctors were able to justify this by arguing that her expressed wishes were not her own as she was too much under the influence of her mother and thus, her expressed wishes were the ones that fit within her mother's identity and value system rather than the young woman's. Noting this example, then, it is possible to argue that what the young woman lacked was neither identity or rationality, but instead, autonomy. Dickenson *et al.* (1995) highlights that this example then leads to a third possible interpretation as to why courts (and indeed adults in general) can view a child's wishes as untrue; because they view children as less autonomous as adults. Smetana *et al*. (1991) suggested that children develop notions of fairness and rights from a very early age. A paternalistically-inclined court may then argue that children's sense of themselves as autonomous and possessing rights does not necessarily mean that they are autonomous, nor does it give them rights. However, autonomy, like rationality, is a moral 'ought' rather than a factual 'is'. Dickenson *et al.* (1995) suggest that courts are more readily accepting that autonomy can and should be separated from rationality when adults are admitted to hospital but they question why this is not willingly accepted for children. The presumption that the autonomy of adults should not be infringed mirrors the presumption of competence in adults. Similarly, the presumption of competence in children is twinned with an apparent judicial assumption that children are not fully autonomous. Dickenson *et al.* (1995) argue that this reflects an essential and devastating confusion in our societal view on children. They argue that autonomy is the same for everyone and is not an outlandish concept that can be measured but instead it is a norm of how we treat each other. Autonomy therefore implies that we [should] treat others as an equal counterpart. Aligning with the values of disabled children's childhood studies, it is possible to argue that the autonomy of children and young people deserves equal respect to that of adults (Runswick-Cole *et al.,* 2013) because, as Dickenson *et al*. (1995) suggest, all too often the 'best interest' of the young person gets confused with the self-interest of the more powerful party.

Dickenson *et al.* (1995) are eager to note that they do not argue that any expression, made by a child, is an expression of a 'true wish'. Instead they argue that children's competence to express their 'true wishes' are more complex than current theories of competence and are deserving of more attention and thought. Dickenson *et al.* (1995) argue that competence in children (and indeed adults) fluctuates and is fluid depending on other aspects of the child's life. They acknowledge that some critics may argue that this is giving children too much autonomy which could, in medical settings, have potentially fatal consequences. However, they believe that children's own good sense (despite their age), as well as doctors' thorough and nuanced examination of competence, will ensure that this would not be the case. Dickenson *et al.* (1995) drew on Alderson's (1993) study which asked 120 children who were undergoing orthopaedic surgery what age they thought that children were able to consent or refuse such operations. These children set a mean age of 14 years old. Dickenson *et al.* (1995) argue therefore that if practitioners were to listen to the voices of children and young people they will find that children are very aware of their limitations and recognise their possible irrationality. It is noteworthy to add here that giving children the option to consent and participate in medical decisions also provides an option to waiver their rights and allocate another person, such as their parent, the right to consent on their behalf. Dickenson *et al.* (1995) therefore argue that all children, despite their age, should be given a real opportunity to be an equal partner in making medical decisions about their body.

1.3.3 Hart and Shier's concepts of child participation and voice

Lundy (2007) suggests that children and young people's rights solely depend on the cooperation of adults who may not be committed to giving them a voice. Lundy (2007) proposes that adult concerns around the reliability of children's voices are due to: (i) scepticism about children and young people's capacity to be 'rational'; (ii) a worry that sharing control and authority will undermine adult authority; or (iii) a concern that time, cost and effort to comply with policy (such as the UNCRC affirmation to hear children and young people or the compliance with Fraser guidelines in understanding children and young people's expression of their 'true' wishes, outlined above) would be better spent elsewhere. Despite the opposing stances, children and young peoples' participation has been measured and categorised using Hart's ladder (1997) and, later built upon, by Shier's ladder (2001). This project does not have the scope to explore all rungs and steps in depth, however I will give an overview of both ladders here before building upon these in relation to the participation of hospitalised children and young people.

Hart (1997) developed a ‘hierarchy of participation’ and created a metaphorical ladder to illustrate the levels of participation children and young people can have when working on projects with adults (See Appendix 12 for Hart's Ladder and appendix 13 for Shier’s pathway). The ladder consists of eight rungs, the first three are 1) manipulation; 2) decoration and 3) tokenism. These bottom three rungs are what Hart (1997) describes as non-participatory practices and are therefore unacceptable (Hart, 1997). The top five rungs all signify differing levels of participation 4) Assigned but not informed; 5) consulted and informed; 6) adult initiated, shared decisions with children; 7) child initiated and directed; and 8) child initiated, shared decisions with adults. According to Hart (1997) the top five rungs of the ladder are acceptable. Shier (2001) built on Hart's (1997) concepts of participation by offering a pathway of participation. Shier notes 5 steps to participation, each step has the same three elements of openings, opportunities and obligations. All three elements needed to be met before the next step to participation could take place. Shier’s (2001) steps are 1) children are listened to; 2) children are supported in expressing their views, and 3) children’s views are taken into account. Shier (2001) argues that these first three steps are the minimum requirement to meet the obligations of the UNCRC in relation to child participation. The next two steps are levels of participation that go beyond what the UNCRC (2010) requires. These are 4) children are involved in the decision-making process and 5) children share power and responsibility for decision making. Unlike Hart (1997), Shier (2001) does not list non-participatory or unacceptable practices and instead lists levels of participation. Interestingly, Shier (2001) does note where the UNCRC (2010) fits within his steps, highlighting that any level under 3 is not fulfilling the needs of the UNCRC (2010). It is important to keep this framework in mind as we move through the thesis as it provides a framework to understand the levels of participation children are describing and their perceived challenges to participation in medical settings.

Sinclair (2004) suggests how the term participation has passive connotations in contrast to viewing participation as active and presuming empowerment to those involved in the process. Thus, highlighting the way one views participation as either:

passive (listening to and consulting young people) or active (empowering young people, sharing power and authority, disturbing social constructs).

Lundy (2007) and Murris (2013) highlight that most 'voice' systems are tokenistic due to the way society constructs young people, consequently adults miss out on important information that children and young people can provide us with. Alderson (2000) suggests that tokenistic practices within institutional systems concerned with children’s voice can have a negative impact. They suggest that it is not enough to simply start to listen to children adding that, if adults refuse to act on or take seriously the meaning and wishes of what children express then they are not honouring children’s voice as anything more than tokenism. Lundy (2007) argues that employing a tokenistic voice system is a violation of the UNCRC. Academics (Alderson, 2000; Sinclair 2004; Murris 2013) recommend that to achieve a successful and meaningful 'voice' system, other aspects within set institutions, such as hospitals or schools, should also be changed in order to foster democracy. Whilst the fostering of Democracy in institutions is important, scholars and theorists such as Fielding, (2011) and Brown-Easton (2005) tend to utilise schooling institutions as an example. I would suggest that their ideas can be more widely implemented to all institutions that involve young people, including children’s hospitals.

Literature contributing towards participation is shaped by various factors, for example, constructs of child, youth and adult and understandings of the UNCRC. This in turn makes the current debate around participatory practices complex and intricate. The notion of participation is inherently interdisciplinary and participatory practices cross disciplines.

Polvere (2014) argues that the reason children and young people feel uninvolved in their care plans is because doctors view age as an ‘impairment’. She argues that doctors view young people as ‘severely’ incapable of making decisions. Goodley *et al.* (2013) suggest that the non-participation of disabled children is a result of disability becoming wrapped up in the psychological and social responses of the non-disabled. They describe this as a phenomenon of ableist cultures.

The Journal of Paediatric Nursing and *The Journal of Adolescent Health* take a medical approach when studying how doctors and children engage in shared decision making. They illuminate the child's voice within medical research, highlighting that children do not feel involved in discussions or decisions about their medical treatment (see for example: Butz *et al.,* 2007; Beresford *et al.,* 2003). Although studies conducted within the medical sphere acknowledge that there needs to be a change so that children's voices are heard, they scarcely offer practical guidance which medical practitioners can use to involve children and young people in the decision making process. When practical solutions are attempted, such as in the work of Butz *et al.* (2007) and Hemmingway *et al.* (2011), explored in more detail in chapters 2 and 3, it is drastically problematic, again resulting in tokenistic practices. Thomas (2007) highlights that, whilst having good intentions in their researchers, medical sociologists such as Butz *et al.* (2007) and Hemingway *et al.* (2011), can inadvertently contribute to ill and disabled peoples' oppression and powerlessness.

Kellett (2009) and Azzapardi (2013) offer alternative ideas when thinking about child participation, highlighting the multiple ways children communicate and including children's silences as a form of communication. Kitchin (1998) adds to the discussion and argues that a combination of perspectives is needed to gain a more nuanced understanding of the experiences of children and young people in hospital. he supports the ideas of Kellett (2009) and Azzapardi (2013) that the silences are important to acknowledge, and suggests that a spatial understanding of the hospital is important in order to understand this silence. Kitchin (1998) explains that space is socially produced to exclude and oppress disabled people and suggests that if we understand the space we can understand its structure in silencing young voices. Kitchin (1998) suggests using a spatial perspective alongside Critical Disability Studies (CDS) (which will also be discussed in more detail later) to gain a better understanding of participation.

1.4 Theoretical underpinnings and motivation for this study.

The social model separated impairment and disability which was a radical step in disability politics, giving disabled people a tool to shift the 'problem' of disability from bodily difference to disabling societal barriers (Oliver, 1990). The gains made by disabled activists from separating disability and impairment should be celebrated and not underestimated however, despite the social model's critique of the Medical Model, it still concedes the body to medicine and understands the body through medical discourses. Furthermore, the social model of disability has been regularly accused, especially by early disability feminist scholars, of somatophobia (Morris, 1999; Goodley *et al*., 2013). Whilst shifting the discourse of the body away from disability was an important strategy in early Disability Politics, it lacked an understanding of illness. Despite this, approaches to discuss the body had started to evolved within disability studies with some taking a Critical Realist perspective (Shakespeare, 2006; Shakespeare *et al.* 2001). Residing in a 'Nordic Relational Model' perspective (Tossebro, 2004), Critical Realists assume a body that is not constructed through culture and impairment as wholly a biological limitation. Critical Realists perceive disability to be a relational concept between impaired bodies and socio-cultural environments. This perspective allowed the body to enter the discussion on disability, however it maintains the impaired body as a 'fact', removing it from both cultures and discourses (Goodley *et al.* 2012). Goodley *et al*. (2013) note how both the social model and the critical realist perspective create dualities between disabled and non-disabled. However, as Koch (2008) notes, this still aligns the disabled body within medicine and rehabilitation

To understand the ill and disabled body, some drew on Poststructuralist thought, questioning the meanings we give to things, the power of discourse and the impact this has on what we think and consequently behave like. Hughes *et al.* (1997) called for a 'Sociology of Impairment' arguing the importance of considering impairment and the body more generally as part of socio-cultural discourses. The pairing of poststructuralism with critical disability studies opens up a space to question what it means to be young as well as disabled within the culture of the hospital. Critical disability studies (CDS) is an interdisciplinary endeavour which aims to capture and interpret the lived realities of disability. At the same time, it aims to trouble ableist discourses and disturb traditional concepts of difference and Dis/ability more widely (Campbell *et al.* 2009). As Goodley (2011: 157) writes 'while Critical Disability Studies may start with Disability, they never end with it'. Campbell, (2009) advises that there is a need to step back and redirect our scholarly gaze to theorise the construction of ability rather than disability. Taking Campbell *et al.* (2009) advice, in this research, I was sensitive to the routine perception of young people being commonly constructed as less able than adults. I have remained vigilant to ableism (both overt and covert) throughout this research especially when thinking about young people's ability to contribute to research as well as their care plans. I utilise Campbell's (2009, p. 44) definition of ableism as:

> A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human.

Several feminist scholars are utilised in CDS. Feminist scholars such as Morris (1999), Ghai (2002) and Butler (2004) have made connections between the personal and the political. Similarly, Foucault, a key figure in poststructuralist theory (1977; 1981, as translated by Lynch 2011), developed ideas around the personal politics of power. Ahmed (2006) reminds us that how we experience the world through our bodies is political. Harrison *et al*. (2001) work resonated with me as they explain that feminists are drawn to disciplines and topics that are important, not only to women but other groups of people whose identities sit within the margins. Reflecting on Ahmed (2006) and Harrison *et al.* (2001) work I revisit a letter I wrote at the beginning of my PhD. The letter captures how my own identity as a sick and disabled young person sat with the margins and notes my motivation and initial hopes for this study.
Dear reader,

> As I embark upon PhD research I wanted to tell you how I got here. It's quite incredible really as the biggest obstacle I've faced in getting to this point in education was the assumptions made about my body, mind and capabilities. I have been met with pity, admiration, sympathy and even disbelief. Generally, people are shocked that someone like me, who missed so much schooling, received no GSCE's or A-levels, who spent more time in hospital than at home could 'make it' to this level of education. I often wonder why and how I am still here. For me, a disabled PhD student I have encountered many frustrating

> educational obstacles that have had to be navigated with patience and many stereotypical assumptions. I think about all the frustrations I have experienced along the way and question why I chose to continue and board the PhD train. The answer is simple. I have a story to tell and I suspect others do too. I have a strong sense that there are people, with stories similar to my own. Stories that were misunderstood and misplaced. Remembering my own childhood experiences, I recall the hundreds of other children I met on the wards of the hospital during my many admissions, children who shared similar experiences to mine, who could recall similar encounters to me. At present, I only see these kinds of stories in nursing and medical journals and I wonder if this could be one of the reasons why experiences like mine are largely untold. I perceive these stories as important and my reason for persevering with the PhD train was the sense of injustice that these stories were mis located and misunderstood, even silenced or unknown of. It is an injustice to stories like mine to perceive them through the lens of medicalisation and pathology. Stories like mine need a different theoretical understanding and deserve to be located in a sphere which values them.

Aligning myself with feminist politics where the personal is political, the reason for not quitting then was a desire for social justice. This thesis was envisaged to be a safe place for stories like my own. The hope was that these stories would sit in research that strived to develop approaches which celebrated the complexities of people's lives and did not work to dehumanise stories like mine. This research aligns itself with the values of disabled children's childhood studies where all childhoods are celebrated and are considered equally important (Runswick-Cole *et al*. 2013).

Theoretically underpinning this research are ideas from Poststructuralism, Critical Disability Studies, Childhood Studies, Children's Geographies, as well as ideas from influential scholars within the social sciences such as Foucault and Butler. Drawing together these ideas to explore stories of hospitalisation will yield new insights and offer a nuanced understanding of children's everyday experiences of hospitalisation. This project will utilise CDS to challenge and problematise stereotypes and stigma surrounding hospitalised children and their ability to credibly contribute to decision-making. These theories will be drawn upon in this thesis to enable me to politicise the personal and subjective experiences of being hospitalised, whilst also offering an alternative sociological insight to that of the dominant charity and medical framings of hospitalised children and young people. Furthermore, the research aligns itself with critical disability studies and disabled children's childhood studies to rightfully re-locate the stories of hospitalised childhoods.

1.5 Chapter conclusion

By this point the chapter should have achieved its goals in that it makes clear the Focus, Justification and purpose of the research whilst highlighting the timeliness of research that has a focus on young people's experiences of hospitalisation while maintaining their voices as front and centre of research. The chapter has given a brief background and context of children's hospitalisation in order to place current knowledges and begin to think about moving forward to a more equal negotiation of knowledges around children's hospitalisation. The debates and difficulties in understanding concepts of children's voice and participation was highlighted and three major contributors to understanding children's voice and participation in hospital settings were identified; therefore, a brief overview of policies, guidelines and legislative texts that underpin current concepts and understandings of young people's participatory practices in medical settings were outlined. After, I outlined Hart (1997) and Shier's (2001) concepts of child participation as these were influential concepts in legislation and helps us to understand child participation more widely. This chapter builds a clear picture of where children's hospitalisation started, where it has been, what it has done, what has improved, what needs more work and the obligations that are set in legislation aimed at improving the experiences of young people in the hospital. Highlighting how my research responds to this and yields new understandings of children's hospitalisation, I outline the direction I took in research as well as the theoretical underpinnings that this research relies upon. Below I offer a brief outline of the indicative content of the thesis.

1.6 Thesis outline:

Chapter 1:

This provides a brief background and historical context to the understanding of children's hospitalisation. Further to this, it provides an overview and justification of the research and highlights important concepts and legislative texts that direct current ways of thinking. It notes the indicative content of the thesis.

Chapter 2

This chapter details how I have drawn on multi-disciplinary theories. Here I outline the different theories and concepts drawn on in this thesis, including critical disability studies and disabled children's childhood studies, as well as spatiality and poststructuralist concepts.

Chapter 3

This chapter highlights and reviews literature from psychological and sociological perspectives of childhood hospitalisation, outlines what understandings these perspectives offer us, and explores their contribution to the study of childhood hospitalisation.

Chapter 4

This chapter focuses on medical and nursing perspectives of hospitalisation, critically reflecting on what understanding this perspective offers to the study of children's hospitalisation, before shifting focus to an approach that works towards a critical disability studies understanding of childhood hospitalisation.

Chapter 5

This chapter sets out my research question and methodology. It discusses how my positionality, ontology and epistemology are entwined not just with each other but also with the research topic itself. Here I highlight both narrative and autoethnographic approaches that underpin this research. I outline the multi-modal methods used to collect data, as well as the participant recruitment and the approach taken to thematically analyse the data. This section ends with a pen portrait of each participant, before offering some concluding thoughts in relation to method and methodology.

Chapter 6

This chapter outlines the importance of ethics in practice, and highlights how ethical considerations have been woven into all aspects of this research. I discuss some ethically interesting moments that arose in this research and detail how these were sensitively navigated during fieldwork. Finally, I critically reflect on notions of vulnerability.

Chapter 7

This chapter engages with and interprets the multi-modal data gathered in this research in relation to gaze, normativity and resistance through the mundane. The chapter is divided into 5 sections: labelling and stigma; othering and oppression; dehumanisation and gaze, and the importance of the mundane, before offering some concluding thoughts.

Chapter 8

This chapter engages with and explores the multi-modal data in relation to communication and trust, it is divided into four parts which explore participants’ stories in relation to relationship and trust, modes of expression, and participation and agency in hospitals, before offering some concluding thoughts.

Chapter 9

This chapter highlights the theoretical application of the data gathered in this research, pulling the threads of the research together in a discussion.

Chapter 10

This chapter offers concluding thoughts in relation to the research findings. It makes recommendations for future research, as well as thoughts on its theoretical, practical and political applications. Finally, it offers a critical reflection.

Bibliography

A bibliography is provided.

Appendix

An appendix is provided.

Chapter 2: Employing a multi-disciplinary theoretical backdrop

2.1 Introduction

This chapter aims to outline discussions around how spatiality and poststructuralist thought offer new insights when thinking about disabled children's childhoods through a critical disability studies (CDS) lens. Key theories are discussed in turn, and I highlight here how they have been utilised in both this study and similar studies within the literature, respectively. This review gives an overview of theories used within this study and is therefore summative and partial. It is not intended to be a comprehensive, in-depth discussion and analysis of different theories and concepts. This chapter begins with an overview of the British social model of disability and how it came about in response to and in opposition to oppressive medical model understandings of disability. The section moves on to discuss intersectionality and how the employment of a critical disability studies (CDS) perspective allows the uptake of cross- and trans-disciplinary perspectives which reflects the complexity of this research. Moving on, I outline how childhood studies perceives childhood as 'a complex social phenomenon' (James *et al.* 2008, p. 19) and frames childhood, like disability, as a social construction. Moving on, I highlight how disabled children's childhood studies (DCCS) came about as a response to certain childhoods, mainly disabled childhoods, not being valued and being generally overlooked, and indeed, some would argue ignored (Liddiard *et al.,* 2018). I discuss poststructuralist concepts and highlight how Poststructuralist thought has been adopted within this research, before finally discussing spatial approaches. Here, I discuss concepts of space and place and how they are conceptualised as a socially constructed phenomenon. I explain how a spatial approach, alongside poststructuralist thought, yields new understandings and interpretations of the power dynamics of children in the hospital. Utilising Kitchin's (1998) work, I discuss how space and power have a complex interaction in the lives of disabled people, to 'keep disabled people in their place'.

2.2 Social model of disability and the formation of disability studies

The social model as a concept emerged within disability studies as an academic discipline in 1976, when The Union for the Physically Impaired Against Segregation (UPIAS) formed and threw light on capitalist structures in society that led to the marginalisation of disabled people (Oliver, 1990; 2009; Barnes *et al*., 2003). UPIAS was an early disability rights organisation in the UK which made a distinction between impairment and disability. Prior to this, the medical and charity models of disability dominated culture, serving as the only perspective through which to understand disability (Burke, 2008). According to Barnes *et al*. (2003) the medical profession produced (and reproduced) its power in order to name illnesses and diseases, as well as to heal, cure and fix people who are ill, broken, or just do not conform to the social norm. The World Health Organisation (WHO, 1980, p. 27) provides a medical definition of impairment as ‘Any loss or abnormality of psychological, physiological or anatomical structure or function’; whereas disability is defined as ‘any restriction or lack (resulting from an impairment) of an ability to perform an activity in the manner or within the range considered normal for a human being’ (WHO, 1980: 28). Social model thinkers such as Oliver (2004, 2009) and Barnes *et al.* (2003) argued that disability is inherently social, while impairment is biological. Mallett *et al.* (2011) suggest that the medical model of disability defines disability in terms of a tragic problem for unfortunate individuals, and wrongly concentrates on what the individual cannot do.

Davis (2010) argues that the idea of normalcy was socially constructed in the 19th century and was influenced by eugenic science and discursive structures which constructed, and indeed promoted, the concept of an ‘average’ person. Johnstone (2001) goes on to note that such ideas shape perceptions around disabled people. In a challenge to the perceptions which had been fuelled by eugenics, UPIAS aimed to cut the causal link between impaired bodies and social discrimination (Shakespeare, 2006; Oliver, 2009; Barnes *et al.,* 2003). Social model theory also drew attention to the definitions of impairment and disability (outlined above). Tregaskis (2002) suggests that disability, and indeed the prejudice around disability, disablism, can be defined as:

> The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from mainstream of social activities.
> (Tregaskis, 2002, pp. 459).

Theorising disability through this materialist lens was necessary at the time, in order to effect change and throw disability into the political and sociological spotlight. The British social model was however viewed by some as totalising, dismissing anyone who deviated from it (Goodley, 2011; Oliver, 2009; Shakespeare, 2006, 2010).

2.3 The problems with the social model, and moving beyond it towards a critical disability perspective

Many disabled feminists (Wendall, 2013; Morris, 1999; Crow, 1996, amongst others) have noted several problems with the early social model of disability, as set out by UPIAS. The work of these disabled feminist scholars and activists has been vital to the emerging newer concepts of disability and the consequent movement of disability politics past the social model of disability.

Wendall (2013) noted that because disability activism had worked so hard to resist medicalisation and promote the social model of disability, activists had to sometimes downplay the fluctuating effects of their impairments and the consequences of their illnesses and medical conditions. Whilst Wendall made a distinction between the healthy and unhealthy disabled in 2001, in 2013 she published her work again to emphasise caution with such categories, urging that thinking should move away from categorisation of (healthy/unhealthy) bodies to an understanding of experience through bodies. In Wendall's (2013) article she argues that further understanding is required on what is valuable about illness and impairment, but also what is troubling about it, on a bodily level rather than medical (such as pain or tiredness). For Goering (2015), the main difference between 'healthy' and 'unhealthy' disability has to do with psychological suffering that cannot be remedied by social change. Like Wilcox (2020), Goering (2015) argues that the social model of disability deserves more recognition and uptake in the field of medicine. However, Goering (2015) notes that we have made little progress in recognising chronic illness as a potentially valuable difference and experience, especially in relation to other impairments which are more concrete in the social model of disability.

Similarly, Morris (1999), argued that UPIAS excludes the experiences of disabled women. Her feelings and frustrations were shared by Crow (1996) who, when critiquing the social model of disability stated that:

> ‘Impairment is safer not mentioned at all. This silence prevents us from dealing effectively with the difficult aspects of impairment. Many of us remain frustrated and disheartened.’
> (Crow, 1996, p.209)

Here, Crow (1996) implies that there should be a focus on both disability and impairment in order to develop approaches to thinking about impairment not only in biomedical terms, but also in terms of how we experience our bodies in a given place, space or circumstance.

The social model of disability has generated many discussions and debates. Mallett *et al.* (2011) highlight how the social model devalues medicine, and they argue that removing barriers from the lives of disabled people will not stop discrimination. Mallett *et al.* (2011) added that removing barriers alone is not sufficient to challenge the cultural norms and values in society which position impaired people as inferior (Mallett *et al.* 2011). Further criticisms have also suggested that some social model thinkers do not consider ‘the body’, and as such, overlook the importance of bodily experiences (Sheldon, 2004). However, Oliver (2004, p. 85) states that ‘The social model is not about the personal experience of impairment but the collective experience of disablement.’

Theories of ‘social oppression’, along with the disability movement, have challenged attitudes to disabled people and the use of discriminatory and exclusionary language to refer to them. Abberly (1987) highlights how society assumes that able bodiedness is the only natural experience of the body, and anything that deviates from able is unnatural and not worth experiencing. Morris (1989) has similar ideas and suggests that disabled people's lives are devalued and their human rights are undermined.

Influential social model thinkers, such as Oliver, emphasises the materialists' perspective. Whilst this position was important for the formation of the social model, Oliver's position is now seen by some as out of date (Goodley, 2011). Goodley argues that a more holistic understanding of disability/impairment is needed, and suggests that CDS perspectives offer this. Shakespeare (2006, 2010) argues that the social model has been a great tool for disabled people to reshape the way they think of themselves, but it has gone too far and cannot deny the dominance of the medical model in British society. This means that whilst institutions such as schools, hospitals, and workplaces are saying, and perhaps even believing, that they are practising the social model of disability, they still view both disability and impairment through the dominance of the medical model.

In British disability studies, the materialist approach is suggested to be the most dominant approach. Materialism refers to the material exclusions and social (instead of psychological) marginalisation which people can experience as a direct consequence of the physical world (Meekosha 2004; Goodley 2011). It is perhaps noteworthy here that the social model has been critiqued for being deeply masculinist – designed and 'promoted' by physically impaired, middle class white men, and it is this characteristic that served to exclude a multitude of disabled people and give prominent focus to disability rather than impairment and the body (Thomas *et al.,* 2002). However, British disabled feminists have tried to broaden the social model through drawing in experiences of their own bodies and intimate oppressions. Crow (1996) observes that arthritis, in which the symptoms manifest as pain, is the main cause of impairment and illness among women in the UK. To ignore impairment, she argues, is to ignore women and this consequently reduces the relevance of the social model.

Olkin (2002, p. 136) asked when disability would be able 'to board the diversity train' which led to the growth of CDS, which 'placed' disability as a social identity along with other identity groups whilst paying attention to impairment effects and intersectionality

(Goodley, 2001; Thomas, 2007). Thomas (2012, 2007) argues that disability sudies views illness and disability in terms of social oppression, rather than as a pathological ‘problem’. Thomas (2012, 2007) argues that the social model does not fully acknowledge the complexities and disabling factors of medical conditions in the same way that it does for physical, learning, psychological and sensory impairments. My study mirrors Thomas’s (2012, 2007) concerns and draws on DCCS (discussed in more detail later in this chapter) to add that the social model also fails to represent the lives of ill children. This study builds on Thomas’s (2012, 2007) work and aims to detail and discuss the complexities of regularly and long term hospitalised children’s lifeworlds.

2.4 Critical disability studies and intersectionality

Unlike disability studies, critical disability studies (CDS) employs a variety of theoretical approaches to explore the effects of socially constructed disability in relation to society, individuals, psychology, discourse, culture and education (Goodley, 2001). This study utilises CDS, which acknowledges that the struggle for social justice continues, and understands that this struggle is complex and multi-layered.

> ‘Use of CDS signifies an implicit understanding that the terms of engagement in disability studies have changed; that the struggle for social justice and diversity continues but on another plane of development – one that is not simply social, economic and political, but also psychological, cultural, discursive and carnal.’
> (Meekosha and Shuttleworth 2009, p. 50)

Liddiard (2018) also reminds us that it is important to stay mindful of issues of intersectionality and the context of oppression regarding sexuality, gender, and ethnicity. Intersectionality is a product of the scholarship of critical race theory, brought into the scholarly gaze by women of colour such as Kimberlé Crenshaw. Whilst intersectionality does not emerge from CDS, it is an example of a way in which CDS draws on critical race theory. Crenshaw (1991) welcomes the broad use of the concept, writing ‘intersectionality might be more broadly useful as a way of mediating the tension between assertions of multiple identity and the ongoing necessity of group politics.’ (Crenshaw, 1991, p.1297)

Crenshaw’s works on intersectionality, then, can be used to facilitate a deeper understanding of young people’s hospital experiences, what identities are presented, and the tensions in-between identities that are both given to and chosen by young people in hospital. Liddiard (2018) argues that disabled children and young people are often infantilised or de-gendered by others, and notes that their intimate lives and selves are often erased.

> intersectionality, then, can help us to understand that processes of categorization (through gender, class, sexuality, dis/ability, age and so on) are not just descriptive markers which produce different experiences but are in fact co-constructing of one another
> (Slater *et al.,* 2018, pp.339)

Here, Slater (2018) is highlighting the purpose and importance of intersectionality when attempting to gain an understanding of someone’s life or identity; they highlight that identities are not descriptive markers but are instead co-constructed through each other and are in constant play, depending on context and situation.

CDS considers how the understanding of being ‘othered’ may intersect and overlap with different oppressed and ‘othered’ identity groups, such as child, woman, or Black. (Goodley 2011a, 2011b). Understanding the trajectory of being or becoming ‘other’ is a key issue in CDS, as it allows parallels to be drawn with other minority groups, which leads to a deeper understanding of intersectional identities and how these operate in society in relation to power and prejudice (Goodley, 2011). Othering can be defined as:

> A discursive process by which powerful groups who may or may not make up a numerical majority, define subordinate groups into existence in a reductionist way which ascribe problematic and/or inferior characteristics to these subordinate groups.

> (Jensen, 2011, p.65)

Like Crenshaw (1991), Jensen (2011) argues that the discursive practices that result in othering contribute to the affirmation of superiority of the powerful, and thus condition an inferior identity to the subordinate group. Jensen's (2011) definition alludes to how othered identity groups intersect and interact in terms of power relations.

Exploring the process of othering in the context of the lives of hospitalised children allows for the exploration of the way in which age intersects with other identity groups. Jensen (2010) challenges dominant developmentalist discourses about children and young people's ability to credibly contribute to decision-making, suggesting that othering discourses that surround hospitalised children perpetuate a developmentalist understanding. Furthermore, it purposely situates illness narratives alongside those of disability, highlighting othering discourses which contribute to the oppression of young people in hospital.

> A body or mind that is disabled is also one that is raced, gendered, trans/nationally sited, aged, sexualised and classed. Disability is imbricated with other categories of difference, experience of marginality and forms of political activism.
>
> (Goggin, as cited in Goodley 2011, p. 33).

Goodley (2011) highlights the intersectionality of disability whilst also noting the complex problems which arise when considering disability in isolation from other identity groups.

Critical disability studies scholars tentatively and sensitively build on the social model of disability set out by UPIAS and draw similarities between disability politics and the politics of other minority groups. In doing so, they claim that marginalisation is both a relational and psychological concept (Goodley, 2011).

Mitchell *et al.* (2006) argued that disabled people's experiences were 'dis-located' by charitable, medical, and socio-cultural understandings of disability, suggesting that common understandings of disability as 'tragic' did not represent the experiences of disabled people's lives. Similarly, according to Crenshaw (1991):

> 'the descriptive content of those categories and the narratives on which they are based have privileged some experiences and excluded others.'
>
> (Crenshaw, 1991, p. 1298).

Crenshaw aims to unpick the processes of subordination, highlighting how privilege and oppression are experienced as a result. She argues that the categorization of people is not necessarily the problem, instead it is the meanings, narratives and values which are attached to these categories that create hierarchies and oppression.

CDS underpins my research because of its grounding in intersectionality and its ability to be cross- and trans-disciplinary. It is also critical in nature, allowing space within the field to employ a variety of different concepts and theories in order to explore how the socially constructed notions and perspectives of hospitalised children and young people are perceived in relation to society, individuals, psychological discourse, and education. The underpinning of this work by CDS means that I employ its fundamental knowledge and belief that the struggle for social justice has yet to be won, but continues on a social, economic, political, cultural, discursive and bodily terrain.

This section has explored the role of intersectional work in CDS in understanding young people's experiences of hospitalisation. It highlights the early work done by critical race theorists such as Crenshaw as an example of how CDS scholarship draws on critical race theory to better understand subordinate and othered groups. Drawing on Slater's (2018) example, it offers insights as to why thinking about intersectionality and age is important when considering children's experiences of hospitalisation.

2.5 Childhood studies

Childhood studies is a multidisciplinary field of study. Its aim is to understand childhoods as they are experienced by children, historically and contemporarily. Childhood studies views childhood as 'a complex social phenomenon' (James *et al.,* 2008, p. 19). Hackett *et al*. (2015) argue that children's subjective interpretations of events often differ significantly from those of adults, yet Livesley *et al.* (2013) assert that the voices of children and young people, and their respective knowledge and unique perspectives (especially regarding hospital care), remain relatively unexplored. As a field of inquiry, childhood studies draws on the social sciences, the humanities and behavioural sciences in order to understand childhood as socially constructed. James *et al.* (2008) identify that the concept of childhood differs around the world, and as such they argue that a universal understanding of childhood does not exist (James *et al.,* 2008). Rudduck *et al.* (2000) emphasise that the false dichotomy and constructs of ‘child’ and ‘adult’ limit children and young people in political decision making. Oakley (1994) makes similar observations, and adds that these constructs (of child/adult) form a barrier to children who want to contribute to decisions about their health care. In agreement, Prout (2003) adds that many studies have rendered children and young people as objects, brought into the ‘adult’ (medical) ‘professional’ gaze to be surveilled, disciplined, shaped and moulded, in order to ‘fit’ society (Prout, 2003). Burman (2008) notes that developmentalist ideas influence day-to-day living to become what is now termed ‘common-sense’ knowledge.

Slater (2013) takes an interdisciplinary approach to understanding youth, reminding us that the developmentalist understanding of 'youth' is often framed as a transitional stage when one leaves childhood and enters adulthood. Slater (2013) argues that ‘youth’ is a socially constructed concept used in order to dismiss certain voices at certain times and in certain places, which is inherently produced and reproduced through power struggles. This is in accordance with Azzapardi (2013) and Foucault, 1981). Slater (2013) alludes to the power structures that may be at play to make it difficult for young people to be heard and taken seriously. Furthermore, Slater (2015) argues that the concept of ‘correctness’ is an adult construction of normalcy, and explains how it is developed through medical and psychological schools of thought which operate in society and prescribe what constitutes ‘correct’ or otherwise.

Slater (2013) highlights the ‘common-sense knowledge’ of the unacceptability of young people to be ‘active’ without adult rationality; linking youth to ableism, they assert that an adult perspective is an ableist one and in doing so they problematise the adult perspective of the child’s body. My research builds on Slater's earlier work by centralising children’s own voices and highlighting how children observe, interpret, and often resist adults' perceptions of their bodies and minds. Interestingly, Murris (2013) also illuminates how ableism is linked to ageism; using the idea of 'common-sense-knowledge' she asserts that adults view their own knowledge to be 'real', and thus if a child understands something in a different way to that of the adult, the child is automatically thought to be incorrect. Contrary to this notion of 'common-sense-knowledge', writers including Rudduck *et al*. (2000), Sinclair (2004) and Mack (2012) have asserted that adults have a lot to gain from listening to and understanding the perspectives of children and young people. Murris (2013, p. 246) summarises this assertion when suggesting that adults put 'metaphorical sticks in their ears' when listening to children and young people. Their age is often viewed as a disadvantage to the extent or value of their contribution to knowledge (Murris 2013).

These studies are relevant because my work allows an understanding of how childhood is conceptualised and constructed, and in doing so points to a perceived normative childhood. It also notes how normative child development is frequently drawn upon in the literature around hospitalised children's capabilities, which is important to understand in order for me to begin to challenge normative assertions about childhood. Consequently, it highlights a gap in which I am able to then situate the childhoods of disabled children as both normative and worthwhile (Slater, 2013; Azzapardi, 2013; Haraldsdottir, 2013; Curran, 2013; Runswick-Cole, 2013). These theories will be drawn upon in this research to enable me to politicise the personal and subjective experiences of being hospitalised, whilst also offering an alternative, cross-disciplinary insight which contrasts with those of the dominant charity and medical framings of hospitalised children and young people.

2.6 Disabled Children's Childhood Studies (DCCS)

Runswick-Cole (2011) identifies that disabled children very rarely appear in childhood studies, and when they do it is in the context of an unhelpful comparison to non-disabled children. Further to this, within disability studies, disabled children appear predominantly in relation to discussions around inclusion in education and schooling. As Runswick-Cole (2011) and Curran *et al.* (2014) point out, this denies the everyday experiences and understandings of disabled children, their families and their allies, and frames their childhoods as ‘unfortunate’ or ‘abnormal’. DCCS argues that the experiences of disabled children are, and should be, just as valued as the experiences of children who do not identify as disabled. It draws on both disability studies and the sociology of childhood to ‘bring disabled children out of the shadows of normativity’ (Curran *et al*., 2014):

> ‘Disabled children’s childhood studies is different because it always begins with the concerns of disabled children, young people their families and allies; this means that it takes the voices of disabled children and young people very seriously; it does not compare disabled children’s childhoods with ‘normal’ childhoods but values all childhoods equally.’
> (Curran *et al.* 2014, p.1617).

As Curran *et al.* (2014) allude, disabled children’s childhood studies contests and criticises concepts around normative childhoods and the ‘standard child’. Further to this, DCCS draws on critical disability studies (CDS) to critique the medical and individualised discourses and the scope of medical, and I would add adult authority on disabled children’s bodies and minds. Scholars such as Runswick-Cole (2011), Curran *et al*. (2014), and Overbore (2004) emphasise the importance of moving discussions away from the historic accounts which frame disabled children within a charity and medical depiction of ‘suffering and deprivation’, which often focuses on ‘impairment talk’, inequality, and even abuse. They argue that such discussions fail to address the experiences of disabled children and depict disabled children’s childhoods as ‘tragic’. Instead, they suggest placing the disabled child’s voice, which, as Runswick-Cole (2011) argues, is so often silenced in research, at the centre of any research design, in order to provide a space for disabled children’s childhoods to be valued.

Drawing on CDS, which problematises notions of normalcy, DCCS rejects any mythical concepts of normal childhood or normal child development, such as those set out in pychological theories by writers including Piaget (1936) who claimed to have identified the trajectory of normal child development. Runswick-Cole (2011) argues that DCCS should work to promote a better and wider understanding of disabled children’s intersectional identities, by emphasising that (1) disabled children do have ordinary and productive childhoods that are experienced both positively and negatively, and (2) disabled children do experience inequality and prejudice, and these experiences should be valued like any other experience.

The use of DCCS allows me to situate this research in a sphere where children’s lives and hospital experiences will be valued. This sphere also offers principles and an ethos that I align with, allowing me to contribute to the understanding of disabled children’s lives that resist normative notions of both childhood and ability. In addition, DCCS enables me to draw attention to children’s own interpretations of their experiences, bodies and lives, contributing to theories around childhoods. It demands a re-conceptualisation of childhood, and provides a catalyst for thinking positively and productively about disabled children and young people’s llives. It allows me to highlight, centre, and increase the volume of the voice, knowledge and agency of disabled children and young people who experience hospitalisation; something that is seldom done in other studies which focus on children in hospital.

2.7 Poststructuralism

Structuralists focus on a universal knowledge and universal facts, believing that meaning is made in the same way, via the same cognitive systems, to end at the same result irrespective of culture or experience (Wellington, 2000). Piaget’s work and developmentalist perspectives) are an example of structuralism. Poststructuralists challenge this, suggesting that universal facts, if they exist, are unknowable, and that culture affects the meanings we give to things. The focus then is on how malleable we are as humans. Poststructuralists examine what meanings are made from a particular system of knowledge, and how they influence and impact society and act to include some and exclude others (Kitchin, 1998). Poststructuralism recognises that meanings are given to people through dominant systems of thought. For example, the charity and medical model tells us that children suffer in hospitals due to their impaired bodies (Rose *et al.,* 2010). The model proposes that sick children are ‘in need’ of a cure, without which they will live restricted lives (Barnes *et al.,* 2003; Curran, 2013). This is in contrast to the way in which DCCS affirms the childhoods of disabled children. However, as the medical and charity model holds authority in society, it becomes a common-sense understanding (Lynch, 2011). Poststructuralism notices how other, less dominant systems are silenced (Tremain, 2017).

Poststructuralists examine the interconnection between power and knowledge and notice how the hospital buildings and the illnesses are accused of causing oppression, but the medical profession and the stigma and stereotypes which operate in society are less likely to be accused (Curran, 2013; Tremain, 2017). Goffman's (1963) famous work on Stigma explored the idea of labels and stereotypes becoming culturally embodied, which in turn created a stigma. Goffman's (1963) observation was that the stigma of a lable produced more damaging consequences on an individual's life than the diagnostic label itself and become so ingrained within culture that they are embodied by individuals and felt deeply. He suggests that a stigma derives from aspects that are considered to deviate from the norm and reiterates how the concept of norm derived from medical understandings thus arguing that stigma originates from medical underpinnings.

A poststructuralist lens offers to illuminate the whispered voices and connections between power and knowledge that are not as visible (Tremain, 2005). This is unlike structuralism or medical thought, which would consider voices that contradict the dominant narrative as an anomaly, single them out and work to silence them, which in turn works to uphold its own authority, (Barnes and Mercer, 2003). Poststructuralism is unconcerned with the volume of a voice; is a philosophical position which places value and indeed volume onto the voices that are seldom heard, and the knowledge and experiences that are often unvalued (Curran, 2013; Tremain, 2005).

Poststructuralist thought helps me to situate children's own voices and knowledge within the centre of my research and to offer new insights into childhood hospitalisation. My interpretation of poststructuralism is that it does not claim truth or superiority but instead explores possibility. It is inquisitive and open ended. It is unconcerned with discovering a grand truth or universal experience, but explores the structures of truth, how it is born and how it is upheld. It is critical, and questions any fixed truth and notes the vulnerability and evolution of truth.

Drawing on this philosophy allows me to problematize adult able-bodied ‘correctness’, as explored above. It is exciting as it gives hope for change, explaining that when society begins to understand the non-dominant narratives, possibilities arise for children’s knowledge to be heard. It helps me to challenge how charities use discourse to serve and maintain the powerful, and how these discourses can shape understandings (such as children in need) but observes power to exist not only within the dominant narrative, but also as a result of the frictions caused by smaller narratives (Lynch, 2011; Tremain, 2005; 2017). Poststructuralism observes how no singular truth can exist without resistance, and this resistance causes frictions. These frictions cause erosion, which creates space for new knowledges to leak into the gaps (Tremain, 2017).

These ideas relate to my study as it challenges dominant narratives about hospitalisation and the exclusion and oppression of disabled children's voices. It challenges psychological narratives of children being less competent or able to make meaningful contributions to research. It problematizes medicine’s assumptions of a disabled body being inferior. My study embeds poststructuralist thought and spatiality through a Foucauldian, and thus poststructuralist, lens. Poststructuralist thought is not new to critical disability studies or disabled children’s childhood studies, and has been utilised by other academics in the field in order to make connections between knowledge, power and subjectivity, as well as the possibilities for change (Hall, 2001; Curran, 2013, Rose and Miller 2010; Tremain, 2005, Tremain, 2017).

Knowledge-power strategies are related to the management of time and space, including going to school, attending hospitals, entering libraries, and all other areas of everyday life. Curran (2013) claims that our subjective experiences are created through this management which limit us and generate our preferences, options and choices.

The work of Foucault’s (2003) is influential as it helps us to understand medicine as an institution of power which manufactures discourses that categorise individuals based on developmental or biological measurements (Tremain, 2017). This medical gaze exercises power over its cultural subjects as a system of social control.

Impairment categories thus exist due to the political, economic and social need for them (Curran, 2013; Goodley, 2014). A Foucauldian lens therefore is an important tool to help question the power imbalances within a hospital institution (Kitchin, 1998). Whilst poststructuralism can be viewed as offering the most radical interpretation of disability and impairment, poststructuralist thought also does an important job in that it creates oppositional discourses. Oppositional discourses are important to illness and disability, in that they allow us to identify issues, think critically, and challenge dominant understandings. This provides leverage to raise the volume of young people's own voices and to further the knowledge about their experiences of hospitalisation. The philosophy of poststructuralism is vital to this study as it centres children's subjugated disqualified knowledges and places these knowledges and voices at the forefront of my research. In doing so, this philosophy allows us to see past common depictions of sick children living limited lives, to embrace the possibility of a more affirmative understanding of hospitalised childhoods that sit within the sphere of DCCS (Liddiard *et al.,* 2018).

2.8 Spatial approaches through a poststructuralist lens

The co-constitutive relationship between people and place is defined by Pink as emplacement (2009). To be emplaced 'attends to the question of experience by accounting for the relationships between bodies, minds and the materiality and sensoriality of the environment' (Pink 2009, p. 25). Pink calls for researchers to 'acknowledge their own emplacement as individuals in and as part of specific research contexts' (2009, p. 25) in order to engage with other people's emplaced experiences.
This research draws on understandings of emplacement (Pink, 2009) to consider how children's experiences of hospitalisation are situated within the social, cultural, economic and political place of hospital itself; in doing so it centralises experience. Furthermore, it considers the lines and threads that connect children and young people's experience in hospital to their experiences in other places and spaces, such as home or school. The study draws on the concept of intersectionality (Crenshaw, 1991) to develop understandings of how place and space can influence identity. Likewise, how identity can influence experiences in certain spaces. Cresswell (1996)

argue that places are ascribed meanings that signify when our bodies or behaviours are 'out of place'; that is when we are operating outside of what is expected and accepted by society. Kitchin (2010), builds on the earlier work by Cresswell (1996) and suggests that 'spaces are social texts that convey to disabled people that they are 'out of place' (Kitchin, 2010, p. 345). In this way, hospital spaces can be understood as social texts that characterise children in particular ways. Chapter 2 explores these ideas in relation to hospitalisation in more depth.

Lefebvre (1991), Soja (1996) and Massey (2005) argue that space is socially constructed, dynamic and political. Kitchin (1998) highlights that, in order to understand stories of illness and disability, a spatial understanding is necessary. Taking Kitchin's advice, this study will incorporate a spatial lens to yield new understandings of children's hospital experiences. Keith *et al.* (1993) suggest that societal practices overlap and are interwoven with those of the spatial and thus we must understand the spatial as well as the social to gain a robust understanding of cultural or institutional practices. Hackett *et al.* (2015), highlight the subjective experiences of spatiality, stressing the important role of the imagination in how children may experience space:

> 'Children's way of knowing goes beyond spoken or written to include what is remembered or imagined by the body or mind and thus is unshareable and unknowable to some extent.'
> (Hackett *et al*. 2015, p. 5)

Furthermore, Procter (2015) highlights the role of emotion, suggesting that emotions are enforced or oppressed through various spatial environments. Enforcing or restraining certain emotions within specific spaces, Procter (2015) argues
es, influences the formation of identity. This is important to consider, as spatial theory will help to explore emotion, illuminating how societal stereotypes around hospitalisation are reinforced.

Kitchin (1998) highlights how space is produced to exclude disabled people in two ways: firstly, through its social texts that convey to disabled people that they are 'out of place' and unwelcome; and, secondly, spaces that are purposely organized to keep disabled people 'in their place'. The spaces given to children are either political or ideological and, as Hackett *et al*. (2015) note, adults restrain and restrict children's freedom in space, thus children's interactions and experiences of space are also restricted. Others, such as Davidson *et al*. (2005), Pile (1991) and Kraftl (2013), explore emotion and its role in constructing experience. Such scholars believe emotion is located in both bodies and places. Hackett *et al.* (2015) argue that by examining the interconnections between space, place and emotion, researchers can understand children's lived experiences in new ways. Kitchin (1998) argues that the 'geographies of resistance' have so far neglected to consider disablist practices, which this study aims to address.

De Certeau (2011) draws on Foucault to highlight that socially constructed structures, such as buildings or roads (strategies), attempt to control movement and dictate how we use space. However, this is not always successful and cannot control how space is used by people (tactics). For example, the hospital is a structure designed for a particular purpose: beds to rest in, chairs to sit in, curtains for privacy and machines for monitoring. All of these are part of the hospital landscape. The strategy is that patients rest in bed whilst being monitored until they are deemed 'un-sick' enough to return home. However, the children lie on the floor, play with the machines, wrap themselves in the curtains and follow the nurses around the ward (tactics). All of these actions from children are resisting the culturally accepted use of the hospital landscape. By resisting these historic spatial 'scriptures' of what a hospital space is, it could be argued that the children are reconstructing the landscape of the hospital.
Using a spatial and emotional lens to explore the emotions of hospitalised children offers to problematize popular understandings of emotion in illness, such as those set out in Dewhurst *et al.*'s (2015) study. Furthermore, it asks what sort of space reinforces an illness identity and how, offering to bring fresh understandings of disability to the sphere of children's emotional geographies.

2.9 Concluding thoughts on the theoretical backdrop

The study has its foundations firmly within the sphere of critical disability studies and disabled children's childhood studies. Bringing ideas from disability studies, and poststructuralism as well as the spatial, helps to form understandings of how socio-spatial scriptures are developed and maintained. Using a spatial and emotional lens to explore the experiences of hospitalised children within this project challenges popular understandings of emotion in relation to illness, such as those set out by Dewhurst *et al.* (2015). Furthermore, a spatial understanding of childhood hospitalisation requires exploration of what sort of space reinforces an illness identity and how such identities are reinforced. By utilising these lenses, this project offers to align itself with the work by Runswick-Cole (2018; 2011) on disabled children's childhoods, contributing to new understandings in the sphere of children's spatiality. This is in contrast to a medical understanding of disabled childhoods that is more readily applied to the study of children's spatiality in the literature to date (for example, by Hemmingway *et al.,* 2011; Dewhurst *et al.,* 2015; and Curtis, 2004).

Foucault's ideas around power and knowledge, in conjunction with the use of multiple theories and concepts in critical disability studies offer a way to study experiences of illness and hospitalisation which centres upon power instead of bodily difference or disability (Kitchin, 1998). Recognising bio-power through a spatial lens, alongside childhood studies and disabled children's childhood studies, allows us to develop new perspectives of how children and young people are constructed through the practices of the hospital and how they resist, transgress and re-construct themselves and their identities through time and space (Curtis, 2015; Kitchin, 1998; Procter, 2015). This allows for a new and different construction of hospitalised children's childhoods. Furthermore, by utilising spatiality alongside CDS, DCCS, and poststructuralist thought, the project highlights how children and young people are unrepresented and oppressed through dominant social narratives and how they resist such conceptions, both verbally and non-verbally, in order to change the socio-spatial and political landscapes and accepted narratives of what it means to be a hospitalised child.

Chapter 3: Psychological and medical sociological studies of childhood and medicine

3.1 Introduction

Psychological and sociological research on children in hospitals use a variety of methodological tools. Qualitative and quantitative methodologies are used, and methods vary, including interviews, questionnaires, case studies, literature reviews, observation, and experiments. This chapter attempts to give an overview of how sociological and psychological studies approach the phenomenon of hospitalised children and is thus partial and summative. It is not intended to be a comprehensive and in-depth analysis of psychological and sociological perspectives.

Psychological perspectives on the phenomenon of hospitalised children highlight that children often have different and complex needs. They highlight the importance of attachment and of parents being present in hospitals with their children. Psychological studies emphasise the pain and trauma experienced by children during hospitalisation, whereas sociology offers more of a focus on interactions between child and medical professionals, and the barriers families face when a child is hospitalised. However, both disciplines offer a developmentalist and cognitivist understanding of the phenomenon of children in hospital. While psychological perspectives have done much to improve the experiences of children in hospital, by highlighting the importance of attachment to parents, sociological perspectives offer improvements to the experience of hospitalisation by focusing on networks of support for families, and new understandings of interaction. Research in both spheres very seldom centres the child’s voice and understanding’s. My study takes a different direction, by challenging the psychopathological tone that dominates these studies and offers an emphasis on children’s own voices.

3.2 Children’s emotional needs and psychological impact of hospitalisation

Working within psychology, Robertson *et al.* (1971) conducted research into young children’s responses to being left without their parents. Although dated, their study is considered pivotal in effecting change to the experiences of hospitalisation, as it highlighted the trauma of parent and child separation. Their work was thought to be one of the main catalysts for improving policy for children in hospitals and influenced many other studies on childhood hospitalisation that followed.

Importantly, Robertson *et al.* (1971) observe how separation had long lasting effects on the child and that altered behaviours were still observed four years after separation. They note that institutionalisation causes more trauma to children than foster care and called for major reform and better understanding of children’s emotional needs. Their findings contributed to hospital reforms that called for hospitalised children to have unlimited access to their parents.

Van Der Horse *et al.* (2009) note that hospital reform was long overdue. They observe that in the past, medical professionals, were never able to take a child’s view, and they suggest that this has now changed. However, as I will explore in this chapter, many researchers disagree and are still trying to develop ways in which adults can understand children, with some (Hackett, 2015; Procter, 2015; Azzapardi, 2013) claiming that adults can never fully understand the world through a child’s perspective. My study does not claim to fully represent a child’s perspective but provides insights to allow adults to think differently about sick and disabled children’s lifeworld’s.

Despite the improvements made to children’s hospitalisation as a result of the Platt report (1959), psychology researchers were still concerned with the trauma children experienced during hospitalisation. Roskies *et al.* (1975) noted their surprise to find that the trauma experienced from an emergency admission was only slightly greater than that experienced by children who had planned admissions. Although dated, the work of Roskies *et al*., (1975) was one of the first studies to highlight adult-child communication (or lack of) as a contributing factor to trauma. It is important to note their observation on communication, as it is a point that researchers are still making today and indeed an issue that this research reports upon. Roskies *et al*. (1975) asserted that it was a shame that the opportunities for communication and indeed preparation for hospitalisation were not taken by adults, and they reiterated that more can and must be done to effectively communicate with children in the hospital. They argued that better communication was a simple step that adults could take to drastically reduce trauma (Roskies *et al*. 1975). Concurring with Roskies *et al.* (1975), Rennick *et al.* (2002) argued that hospitalisation can be particularly traumatic for younger children, noting that Post Traumatic Stress Disorder (PTSD) was a common effect of childhood hospitalisation, with as many as 14% of children having PTSD symptoms six months after hospitalisation. They reiterate points made in the earlier work by Roskies *et al.* (1975) and call for better communication, adding that a better understanding is needed of the trauma children experience in hospital. Building on this, Rokach (2016) claims that the severity of emotional and psychological pain is the same for children of all ages, and for those who have either short and long-term hospitalisation. They also suggest that there is no variation to emotional and psychological upset for different scenarios of hospitalisation (planned/emergency). They concur with the work of Robertson *et al.* (1971) by highlighting that the psychological harm to children is greater when their parents are not present in hospital or are not able to respond to them calmly. They concur with developmentalist perspectives, outlined above, arguing that children have cognitive and emotional limitations which hinder their ability to adapt appropriately to hospitalisation. In common with earlier studies, they note the long term psychological effects of hospitalisation, arguing that communication with children, in an age appropriate way, is vital to reduce trauma. This is noteworthy, as Rokach's (2016) work came 57 years after the Platt report (1959) and mirrored the concerns raised 41 years ago by other researchers (Roskies *et al.* 1975) in the same field, demonstrating a lack of progression. My research does not discuss trauma in the same way as psychology research; however, it does note similar issues, such as distress, highlighting the urgency of developing better communication between hospitalised children and the adults involved in their care.

Hägglöf (1999), also working within the field of psychology, sought a wider understanding of hospital trauma. They argue that one age category does not report more needs (emotional, psychological, or communicative) than others *per se*, just different needs. For example, 7-12 year old children seemed to require more information on play times and accessible activities, whereas 13-16 year olds seemed to require information on visiting hours and social activities. Häglöff (1999) claims that children who spend a lot of time in hospital experience more stress and thus have a higher risk of psychological ‘harm’. This is worth keeping in mind, because one criterion for participation in my research was that participants had to consider themselves to have experienced reoccurring or long-term hospital admissions. Häglöff (1999) lists the expressions of unhappiness for each age group, for example wetting the bed, unruly behaviours, and crying, arguing that these ‘symptoms’ [*sic*] may indicate poorer mental health due to hospitalisation. They further suggest that having poorer mental health in hospital also hinders the child from coping well with hospital treatment and that those who spend a lot of time in hospital are at higher risk. This is important to note for my study as, although Häglöff (1999) refers to bed wetting and crying as ‘symptoms’, framing such behaviours within a psychopathological understanding, he is indirectly listing non-verbal communication. Perhaps it is more accurate to note that Häglöff (1999) has identified some of the non-verbal cues that children use to signify unhappiness. Like other researchers in his field, Häglöff (1999) made recommendations for better communication with children. My study picks up on some of these ideas, but differs in that it is centred around the children’s own voices. In framing children’s hospital experiences within a DCCS and CDS perspective, my study also challenges psychopathological discourses around children’s behaviours, experiences and communication.

3.3 Developmentalist approach to children’s understanding of illness

Nargy (1951) notes that when considering communication with children about illness it is important to consider how children themselves perceive illness. Whilst outdated now, Nargy (1951) recognised that children understood the world around them differently to adults. She was the first author to systematically view children’s conceptualisations of health and illness. Whilst the Piagetian framework which Nargy (1951) drew on and suggests that children pass through linear stages of development and understanding has been critiqued, for example Slater (2013). Nargy (1951) was one of the first to place a focus on practitioner education, and started a conversation on developing better ways of communicating with children of different age groups. Later, Bibace *et al*. (1980), conducted similar research, also highlighting Piaget's theory of cognitive developmental stages. They were among the first to apply cognitive developmental psychology to the specific understanding of illnesses and hospitalisation, and although dated, their work still informs practice in hospitals. Nargy (1951) and Bibace *et al.* (1980) concur that physicians require an understanding of children's 'stages' in order to pitch medical information at an age-appropriate level. They anticipated that when medical staff are able to reassure and educate children (by understanding their stages of development) then hospital trauma would reduce. Eiser *et al.* (1984) concurred and built positively on this by suggesting that research needs to focus on a child's concern. Several studies, (such as Hemmingway *et al* 2011, Bricher 2000 see next chapter) have called for better training, as physicians report not feeling confident at pitching health information in an age-appropriate way. However, the work of Bibace *et al*. (1980) and Nargy (1951) not only recognised these 7 decades ago but also proposes a means by which doctors can learn to talk to children; understanding and identifying the child's 'stage' of development. Work since then has seldom aimed to develop medical training in communication with young people in the hospital. Whilst I acknowledge work by Nargy (1951) and Bibace *at el*. (1980) respectively, in that it positioned the problem of communication within the medical practitioner's education, my study differs. My study does not do this in a cognitive developmentalist framework, which would use discourse and notions of children lacking an ability (to communicate/understand etc). Instead, it focuses on children's ability and frames children as politically active and able to both communicate and understand. By exploring communication in this research, I redirect the 'problem' of communication and investigate the possibilities of developing new, multi-modal ways of communication.

3.4 Working towards a medical sociology approach to understand hospital cultures

Cockerham's (1981) article provides a thorough discussion of the evolution of medical sociology. He claims that since the 1960s, medical sociology has emerged as one of the largest subfields of sociology. The growth of medical sociology has been rapid, and to use his term, 'phenomenal'. Cockerham (1981) observed that 'modern' sociology, and thus, the birth of the subfield medical/health sociology, has been largely influenced by Emile Durkheim, whose work in explaining human behaviour stood in opposition to biological theories. Cockerham (1981) noted Durkheim's argument that in order to understand human behaviour, one needs to search through social processes embodied in environments, culture, and human thought processes. Thus, behaviour can only be explained through the perspective of norms, values, status, and the social components that make up the basis of socially and humanly 'being'.

Cockerham (1981) concludes that good health is perceptual and based upon the delicate relationship between mind, body, and social and physical environments. He argues that the contribution of sociology, more specifically medical sociology, to medical knowledge is significant and has the potential to improve life and treatments in the medical sphere. Nevertheless many research questions and health related sociological questions have yet to be answered. Cockerham (1981) predicted that the partnership between medical sociologists and medicine will grow stronger and continue to improve the lives of those seeking medical assistance.

Jutel (2009), working within the field of medical sociology, builds on Cockerhams's (1981) discussions, noting that there was a call for a sociology of diagnosis almost forty years before her own work; but that unfortunately there has been no clear or consistent uptake of this notion. Jutel (2009) suggests that diagnosis is a powerful social tool with unique impacts on social life, which deserve its own specific analysis. Diagnosis, as the classification of individuals within the sciences, is pivotal to the way medicine exerts its role and authority in society. Jutel (2009) first focuses on the history of diagnosis in terms of a) how the names of diseases came to be a part of Western society, and b) the specifics of how individual diseases emerge. They then explore and debate how diagnostic labels both reinforce and sometimes contest the authority of medicine in Western society. Jutel (2009) observes that medicine is becoming viewed more and more as goods to be consumed, and that a sociology of diagnosis is long overdue. She argues that the sociology of diagnosis, as a subfield, is contemporary and is immediately relevant to both health care outcomes and practices, as well as health policy.

3.5 Sociological understandings of hospitalisation and illnesses impact on life course transitions

Ogilvie *et al*. (2019), publishing in medical sociology, took a different direction and set out to look at the correlation between psychiatric disorders and school engagement. They argue that it is important to address mental health issues in childhood so that a successful transition to adulthood is achieved. Ogilvie *et al*. (2019) urge both educators and medical professionals to pay more attention the reasons which may cause young people to avoid school, and to work on resolving this issue for young people with mental health difficulties. They call for better understanding of young people's perspective and worries when transitioning back to school post-discharge.

Building on the work of Ogilvie *et al*. (2019), McBride *et al* (2022) employed questionnaires and surveys to examine how socially connected young people feel, prior to discharge from a psychiatric hospital. McBride *et al*. (2022) found that young people leaving psychiatric care felt disconnected with the outside world and reported difficulties with friendship groups, social isolation, and loneliness. Young people in McBride *et al*.'s (2022) often had a negative perception of themselves. The researchers report that young people who have experienced mental health difficulties find it challenging to expand their social networks and quality of friendships. McBride *et al*. (2022) advise that clinical follow-ups post discharge have some focus on social relationships, and aim to ensure that the young person is being fully supported. However, Lim *et al*. (2019) found that young people did not feel that the social interventions put in place for them by schools and communities were helpful to them. McBride *et al*. (2022) note that much more research is needed in this area to ensure that resources to support young people's transition are being used efficiently, and to test the effectiveness of different interventions. The work of Ogilvie *et al*. (2019) and McBride *et al*. (2022) are pertinent studies as two participants in my my own research are narrating their experiences and challenges in and after admission to a children's mental health unit.

3.6 Children and young people's social network and its impact on hospitalised children and their families

The work of Haspel *et al*. (2021) had a focus on parental perception of illness in terms of coping with and adjusting to a new diagnosis. The study showed that parental perception and adjustment to acquired disability determined how children felt about their body and their new diagnosis. Here it is noteworthy that, like many sociological studies that focus on childhood hospitalisation, parental experiences and voices were sought and forefronted. My research takes a different approach and centralises the child's voice and experiences.

Like Haspel *et al*. (2021), Gage's (2013) work highlights the needs of the family of a hospitalised child, highlighting how complex interpersonal and social dynamics impact social support networks. Connecting with wider literature, they suggest that parents who have good social support networks are better able to cope with paediatric hospitalisation and treatment, and have better psycho-emotional wellbeing then those without secure social support networks (Gage, 2013). Furthermore, Gage (2013) draws on literature to argue that parents with good social support are able to emotionally recover from their experiences more quickly. Gage (2013) believes a focus on multiple individuals in a network of support would provide a valuable insight into the intricacies through which social support is perceived, received, experienced, and negotiated. Gage (2013) ponders the prospect of developing programmes that counsel parents to identify their needs as well as potential sources of support so that they are able to better communicate their support needs and mobilise an approach to more sustained support. This study is important, as we know that children experience less trauma when they have unlimited access to their parents (Robertson *et al*., 1971) However, its primary focus was on parental support and developing better communication for parents to articulate the support they required, rather than, as my study emphasises, children's perspectives and what support they feel is needed.

3.7 The impact of space on the experiences of hospitalised children and young people

Moving on from the impact of social networks for hospitalised children and their families, James *et al*. (2012) observe that studies around hospitalised children and young people to date have foregrounded the child's 'sickness' status. They argue that although hospitalised children and young people engage with and share the same hospital spaces, their experiences of these spaces are often quite different. James *et al*. (2012) report that children in their study suggested that the hospital felt familiar.
James *et al*. (2012) suggest that this was because of the bright decor and material things like toys and games that were available to children when they were in hospital. They also note that the routines and rules of the hospital mirrored school and home rules. James *et al*. (2012) noted how children drew on their experiences of school in order to adapt and make sense of hospital spaces. However, the young people aged 11-16 years in the study noted how specific rules were uncomfortable for them, describing the rules as making them feel they were being treated like a baby. James *et al*. (2012) noted that 11-16 year-olds sought autonomy and privacy within hospital spaces. They felt that having parental caregivers stay with them overnight was an invasion of their privacy. In contrast, James *et al*. (2012) observed how children younger than age 10 felt comforted by familiar rules and by their parents' presence and closeness during overnight hospital admission (James *et al*., 2012):

> 'Feelings of social isolation from their peer group were often compounded by the very public display of parenting that took place at their bedside […] young people have developed a strong sense of personal identity and independence that, when in hospital, can feel threatened.'
> (James *et al*. 2012, p. 768).

One young person in their study suggested that the hospital have a separate wing for parents where they are close enough should they need them during the night, but are not sharing their space and being watched over throughout the night. They report that a constant parental presence felt degrading and alien to young people age 11-16, and that it could be experienced as a potential threat to personal identity, leading to an 'enforced' identity of 'being sick', in turn resulting in young people subtly resisting medical treatments (James *et al*. 2012). This is interesting because it opposes other studies, such as that done by Roberts (2010), who argues that it is a basic right to have parental presence while in hospital, as discussed in more detail at the beginning of this chapter. Nevertheless, they are among the few studies that do incorporate how hospitalised children feel about their care.

Brady *et al*. (2015) observed that much research in this area to date focused on promoting health, detecting illness and investigating the consequences of illness on the lives of children and their families. While these are important, they argued that now there is a need for research to move towards researching with children and young people, from the child's perspective, in order to better understand the consequences, impact and meanings of health and illness in the lives of children. However, Brady *et al*. (2015) warn that there is a risk of homogenising and decontextualising both children themselves and the context of research on children's lives. Brady *et al*. (2015) urge any research that builds on this to find a way to place children's voices, autonomy, and experiences at the centre of research and knowledge production, which my study attempts to respond to. When commenting on children's health and illness narratives, Brady *et al*. state:

> 'the narratives told by the children themselves reveal a complex picture of illness stories, resistance to being defined as ill, and […] protest talk – where children strive to come to terms with the ambiguities of being regarded as sick while feeling and looking well.'
> (Brady *et al*. 2015, p.180)

Brady *et al*. (2015) suggest that childhoods are subjective experiences, and from exploring the lifeworlds of a range of children it can be concluded that there is very little that signifies any universal characteristics of what it means to be a child. They noted that now, more than ever, research should refer to a variety of childhoods instead of uncritically adopting Western values around what childhood is in both research and global health policy. Brady *et al*. (2015) concluded by acknowledging that neighbouring fields, such as childhood geographies, child disability studies, and studies of children's play, were not included in their discussions, and they urged future research to consider colligating literature from these fields to help build and promote the social study of child health. Brady *et al*. (2015) hope that their paper encourages a positive and productive debate amongst a range of professionals, policy makers, and academics alike.

A study by Monaghan *et al*. (2015) aligned itself with that of Brady *et al*. (2015). Monaghan *et al*. (2015) aimed to explore the value of ‘biographical contingency’, which they note is a concept referring to the construction of chronic illness, particularly its ‘visibility’ to onlookers, and is referred to in the paper as an ‘only sometimes’ problem to a person’s daily life. They note that much of sociology’s work around health has sought to hear adult’s voices; however, there is a growing effort to hear children’s own voices in research now, and their study, like mine, aims to contribute to the growing literature that forefronts children’s perspectives of their own health. Monaghan *et al*. (2015) observe that biographies were still often disrupted by problems that included, but also went beyond, asthma. During interviews, discussion around illness was often overshadowed by other topics that the children felt had more value, such as fashion or relationships, thus demonstrating that experiences of illness does not exist in a vacuum and therefore cannot be understood in isolation and should be given social context (Monaghan *et al*., 2015). This is a noteworthy observation, as my study observes similar patterns of discussion with the young participants. Monaghan *et al*. (2015) call for more research that interrogates the underlying social and structural realities that influence both the embodied and lived experiences of chronic illness in day to day living, and its broader maldistribution in divided societies.

3.8 Children’s agency, power and voice in hospital spaces and cultures

Mayall (1998), writing from a health sociology perspective, observes that there is a neglect of children’s perspectives, voices and experiences within the sphere of medical sociology. She (1998) observes that, in comparison to other minority groups, children have very little power, and notes that the mental and physical aspects of being a child, as well as the child’s ascribed vulnerability, for example on account of their age and stage of development, are called into question when children actively participate in health care decisions. Mayall (1998) draws on the work of Foucault to understand how power acts on bodies to make them docile, and how power and discipline can work its way into the minutiae of institutional settings to emphasise normalcy and enable power. Mayall (1998) also draws on feminist work to help critique the idea of the 'natural body' as a basis for social inequality. She argues that the natural body of a child has been widely regarded as inferior, both physically and socially. While Mayall's (1998) focus is on health rather than illness, their paper aims to open up discussions that can help to sculpt the construction of a sociology of child health; and by default, illness. They state that

> 'the concept of generation allows us to study the extent to which and the ways in which children's lives are structured through their relationships with adults and through adults' understanding of what children are, and how their childhoods should be lived.'
> (Mayall, 1998, p. 274).

Their point is that children's childhoods and experiences of health decisions should be studied through the perspectives of the child, rather than the partial view of childhood that adults offer. Mayall's (1998) perspective resonates with me as my research also values the child's voice and perspective. Additionally, Mayall (1998) utilised poststructuralist thought which is also drawn upon, in conjunction with DCCS and spatiality, in my study. Mayall (1998) goes on to suggest that adults' views of children and childhood are skewed by culture and society, and are an unfair representation of children's perspectives and the lived and embodied realities of their childhoods. They observe that children's positioning within medical encounters are heavily dependent upon the behaviour, attitudes and perceptions of a child, as well as on the behaviour of parents and medical staff, and the goals and policies of the health services. Mayall (1998) concludes by suggesting that the rethinking of children as competent health care actors in their own right will need to encompass not only medical and health sociology but larger frameworks of sociology in general; something that my research aims to contribute towards.

3.9 Incorporating notions of emancipation and empowerment

Liddiard *et al*. (2018) take another direction by highlighting emancipatory and participatory research processes within sociology, urging future researchers focusing on children’s health and hospitalisation to follow similar principles of empowerment. They detail their own research processes in order to encourage other researchers, particularly those within disability studies, to adopt and embrace virtual environments as a tool of research, especially when researching the lives of disabled young people. Liddiard *et al*. (2018) detail the challenges of co-producing research with disabled young people, and describe some of the solutions they found to these challenges. Methodologically, their work offers a new way to ‘do’ research by highlighting common dilemmas in research ethics, and power relations in the research and write up process when researching with disabled young people. Resonating with my study, the work of Liddiard *et al*. (2018) is positioned within disabled children’s childhood studies, where an ethics of collaboration is central. It highlights ethical and institutional challenges highlighting that research is inherently both ableist and ageist. Liddiard *et al*. (2018) call for a consideration of how intersectional lives and identities of potential co-researchers can impact participation, inclusion and involvement in co-produced research. They contribute to the theoretical understanding of the phenomenon of hospitalised children and offer new ways of doing and thinking about research which involves young disabled people.

Similarly, Mladenov *et al*. (2022) add to theoretical understandings and observe similarities between medical sociology and disability studies, suggesting that they have realised that disability and illness need to be studied from the perspective of personal experience, but that it should not be detached from the structures of oppression and power that surround people’s histories. Mladenov *et al*. (2022) state that their paper seeks to further advance these efforts to reconcile disability studies and medical sociology by suggesting that disability and illness are studied from a perspective of injustice. They argue that doing so could help to explain the workings of power and mechanisms of oppression between service users and professionals. Mladenov *et al*. (2022) argue that epistemic injustice are characteristics of modern healthcare. They explain that the patient as a ‘knower’ of disability through their own experience is difficult to transform into a more empowered presence in any clinical space, due to the subtle displacement of the patient's voices. They note that, in terms of studying disabled children’s lives and experiences, parents are both allies and oppressors, as they embody and transmit ableism whilst also observing the discrimination and oppression that their disabled children face. Mladenov *et al*. (2022), suggest that a focus on parental voice, which is so often the case in researching childhood hospitalisation, as exemplified earlier in this chapter, further risks increasing the marginalisation disabled people face daily. However, they suggest that it is through parental advocacy that the rights of disabled children have been kept in the public domain, and that their epistemic struggles have been pivotal for both disability studies and medical sociology alike. Thus, they argue, parental voices deserve respect. In common with the paper by Liddiard *et al*. (2018), Mladenov *et al*. (2022) conclude by urging medical sociologists and disability studies scholars to work together.

Building on their previous work in 2018, Liddiard *et al*. (2019) encourage researchers within the field to explore different approaches when researching the lives and families of sick and disabled children and young people. Liddiard *et al*. (2019) suggest that their work in this area builds upon the assumption that the generation of theory and contributions to knowledge can be constructed through a meaningful engagement with young disabled people as co-researchers. Liddiard *et al*. (2019) note that the young disabled colleagues in research would not necessarily identify themselves as part of academic discourse or even claim to be theoretical thinkers in any way, but throught their work as activists they offer a different approach to theory and new perspectives for thinking about the world we occupy. The researchers engage in narrative and arts to seek new understandings of the experiences of young people with life limiting and life-threatening illnesses.

3.10 Concluding thoughts on psychological and sociological perspectives on children and young people in hospital

Psychological perspectives in research around children's hospitalisation have two main foci; first trauma, and how the experience of hospitalisation might psychologically affect children. It is generally agreed that hospitalisation is emotionally traumatic for children and young people, and that children are less traumatised and recover more quickly if a close and consistent caregiver is present at all times. Its second focus is competence, in terms of how much children are able to understand about hospitalisation. Such research discusses how children understand treatment options and procedures, as well as their understanding of their own bodies at different ages and developmental stages. Generally, it is agreed that very young children do not have the same sort of sophisticated understanding as older children. In discussing children’s ability to understand, and their competence and ability to make healthcare decisions, it is generally agreed that older children are more capable to make decisions about their health care than younger children.

Alternately, sociological research around children’s hospitalisation has generally agreed that health services could be improved for younger patients, and that we need better understanding of how to include children and young people in health care decision making, and to include them in more meaningful ways in research. Furthermore, it is generally agreed that we need more research on and a better understanding of, the lasting effects of hospitalisation and illness in the everyday lives of children and their families. Cockerham (1981) predicted a strong partnership between medical sociology and medicine in 1981. While there have been clear attempts to build this partnership, the work of Liddiard *et al*. (2019) takes us in a different direction. They call for researchers to experiment through different lenses, which my research responds to as it explores children's hospital experiences through poststructuralist and spatial lenses whilst upholding the values of DCCS. Furthermore, the research is firmly centred within the sphere of critical disability studies, which demands a multidisciplinary approach.

Chapter 4: Medical and nursing approaches, and working towards disabled children's childhoods approach

4.1 Introduction

Research into children's experiences of hospitalisation has largely been conducted with a desire to improve services for the young people hospitals serve. Literature concerning children in the hospital from the medical and nursing fields often focus on the management of patients and their illness, the severity of illness, the ability to administer medicines, and patient outcomes and prognoses after treatments. Equally, many studies in this field focus on very specific illnesses (such as cancer) and report the chance of survival after certain treatments (such as chemotherapy). Literature like this has therefore been omitted from this chapter, as the purpose of this section of the literature review is to discuss hospitalisation more broadly and give an overview of the contributions of medical and nursing studies to the phenomenon of hospitalised children. In this chapter, I use the terms 'service users' and 'patients' interchangeably. The use of the term 'patients' denotes the terminology used in the literature that I will draw upon in the chapter, rather than my personal preference, 'service users'. This field focuses on mainly quantitative research; however, I have limited space to discuss research from nursing studies. To be clear then, any study in this area that does not focus on lived experiences has been omitted. The literature that does focus on experiences has two main foci: firstly, on medical procedures, often discussing how to encourage compliance in children who resist procedures; and/or secondly fear, with respect to how to avoid fear or comfort fearful children. However, both foci contain an overarching theme of communication. In this chapter I first explore how hospitalised children's voices are represented and the improvements that can be made to the hospital protocols which support the relationships that children develop with their medical team. Here I discuss ways in which research has proposed to increase child participation and communication within the medical setting, before problematising current depictions and representations of hospitalised children (and their communication) using a CDS perspective.

It is generally agreed that it is important to improve communication between young service users and health care professionals. It is regarded as important to listen to the opinions of children and young people and their views of hospitalisation, which are vital for patient satisfaction and improvement of services. Academics in this area generally agree that young people need to be listened to more ,and that adults could better support the participation of children and young people in medical consultation and decision making. Further to this, it is agreed that assembling children’s opinions and views is often complex and multi-layered. Consequently, professionals require training, support and/or simple strategies to elicit children’s opinions and increase levels of participation in consultations.

4.2 The representation of children’s voices in medical and nursing literature

Hudson *et al*. (2013) conducted a review of nursing literature to examine how hospital readmissions had been assessed and perceived in the past. They identified gaps within literature and detailed the implications these gaps had for medical practitioners. The study was motivated by the proposed changes in healthcare environments which caused concern for children who have complex medical needs. Hudson *et al*. (2013) suggests that children with very complex medical needs are a subpopulation that is often overlooked, and who are affected greatly by ‘cost cutting’ practices. Whilst hospitals were the most common setting in which to conduct research in this field, Hudson *et al*. (2013) argue that more research needs to take place in the community, to observe what preventative measures are being encouraged. Further to this, they suggested that rural communities had less available health care, so they predicted that levels of re-hospitalisation would be higher in those areas. Hudson *et al*. (2013) suggest that research needs to take place to better understand the healthcare needs of rural settings. They observed that the literature in the area was seriously lacking the perspective of young service users and/or their primary caregivers. Furthermore, they note the overwhelming number of quantitative studies in the area. Hudson *et al*. (2013)

note that they were unsuccessful in identifying any study which had a primary focus on service users with complex medical needs; rather, those with complex needs were portrayed as being at the top end of a spectrum and were characterised as the most costly children. In their view, this argument is made in the literature without any real understanding of other variables that could contribute to rehospitalisation, such as age, race, and geographical location. Hudson *et al*. (2013) urge nurses to be aware of the implications for children with complex needs, while suggesting that nurses should be active in implementing interventions and tailored plans to reduce risk of re-hospitalisation.

Taking a different route to explore children's experiences of hospitalisation, Carney *et al*. (2003) suggest that it is essential to identify children's own views and perspectives of hospitalisation, and gain an understanding of how children experience the process of hospitalisation. The aim of their work was to investigate a broad range of experiences in a general paediatric population, as opposed to a specific focus on age, complexity of needs, the department in which they were admitted; furthermore, they aimed to determine the most effective method to obtain children's perspectives of their hospital experiences. Carney *et al*. (2003) aimed to conduct research which did not limit responses, and 'allowed' [*sic*] young people to speak freely.

The researchers found that the physical environment was more important for older children, especially boys, whereas for younger children, having continuity with their caregivers was most important. The children in Carney *et al*.'s (2003) study were also twice as likely to report on positive experiences in hospital than negative ones, and nearly half the participants mentioned having positive relationships with staff during their time in hospital. The researchers also noted that only 16.9% of participants reported feeling anxious about being in hospital. The researchers urge medical professionals to acknowledge the difference in the values of younger and older patients in hospitals, and to acknowledge that different age groups find different things important. Carney *et al*. (2003) suggest that any future research should include follow up studies post discharge, in order to identify the things of which children have lasting memories, and which aspects became irrelevant. Picking up on Carney *et al*.'s (2003) call to identify what children have lasting memories of, my study included some participants who are narrating their stories retrospectively; thus they report on the things that have a lasting impact. My study also aims to highlight what aspects of hospitalisation mattered the most to young people in hospital.

4.3 Improvements in hospital spaces, protocol and relationships

Building on the work of Carney *et al*.'s (2003), Angström-Brännström's (2008) study narrows down the exploration into how children experience hospitals and, in her work, draws light on the importance of comfort. The study accepted that children will feel negative emotions in hospital, and instead of focusing on these emotions it highlighted the importance of understanding ways in which adults can help children to 'cope' with their chronic illness. The children who took part in their study emphasised that their family, particularly their mother, was their main source of comfort. Angström-Brännström's (2008) suggests that nurses can and should acknowledge their role in providing comfort to children in the hospital. They advise that nurses use gentle touch, hold hands, read books and play with children, in order to comfort them in difficult times. They acknowledge that nurses are usually there when children experience scary or painful procedures, but suggest that nurses can build trusting relationships with children. They suggest that nurses talk to children in order to comfort them during medical procedures so that children are able to comply for longer, until they have had their procedure. Angström-Brännström's (2008) is keen to point out that in her study, children's views about being in hospital were not invariably negative, and that the hospital was a unique environment that could be fun as well as threatening. It could be perceived that Angström-Brännström's (2008) study was responding to the call to have more detailed strategies for medical personnel to engage with and comfort children. However, suggesting that nurses hold hands and read books to children oversimplifies the complexities of relationships, whilst failing to acknowledge or address the reasons why children are fearful in hospitals. My study differs in that it highlights children's relationships with medical professionals from a child's perspective. My study utilises a CDS and a poststructuralist perspective to highlight the practices and protocol that often had an adverse effect on children's relationships with medical professionals.

Unlike Angström-Brännström's (2008), Ekra *et al*.'s. (2012) study utilised retrospective voices to illuminate the importance of comfort to young service users. Ekra *et* *al*. (2012) highlighted progression in the treatment of hospitalised children. In common with some aspects of my research, Ekra *et al*.'s. (2012) work highlighted the social and psychological impact of childhood hospitalisation by illuminating the retrospective voices of adults reflecting on childhood hospitalisation. Their rationale for focusing on retrospective experiences is that it provides academics with a better understanding of the past, in order to comprehend current practices. They note that until the 1970s it was common for parents of hospitalised children to leave their child in hospital, only visiting them for very short and strictly kept visiting times. Ekra *et al*.'s. (2012) study aimed to explore and better understand how the hospital environment influenced the lived experiences of children in hospital. The participants in their study all experienced hospitalisation where they were left by their parents, and described strong feelings of being abandoned by their parents, feeling scared, and being in an uncomfortable and unfamiliar environment. Ekra *et al*. (2012) describes how their participants highlighted that their stay in hospital was disempowering because the buildings were not designed with children in mind, and they described the environment as sterile and not child friendly, detailing structural barriers such as door handles or light switches being positioned in a place that was too high for them to reach, doors being too heavy for children to move freely, and beds that were too big and made them feel small, powerless, inadequate, and vulnerable. My study explores the issues of spatiality and children's accessibility in hospital spaces, and challenges ideas that issues such as access to parents and feeling anxious or scared, have now been addressed. My study shares similarities with Ekra *et al*.'s (2012) study in that it focuses on the lived experiences of the child in hospital.

In common with Ekra *et al*. (2012), Roberts (2010) highlights the improvements that have been made to support children's social and psychological health in hospitals, and frames children being accompanied by parents as a basic need of the child that should be met. Her research looks at the unaccompanied hospitalised child from three perspectives: the child, the nurse and the parents. She argues that even with families present, hospitalisation is still stressful for children, and notes that nurses have two stances on the unaccompanied child in hospital, with some believing that the child whose parents do not stay impact the nurse's role, as the child takes more of the nurse's time since the nurse has to act as parent and comforter for that child. However, some nurses feel that parents can have high levels of anxiety about their children's health, which also causes extra workload as the parent's anxiety can affect the child. The nurses who felt like this described anxious parents as 'secondary patients' who demanded the nurses' time. Parents on the other hand report a desire to be with their hospitalised child, but report feeling stressed and anxious about their extra caring responsibilities, and unequipped to care for an ill child (Roberts, 2010). Whilst arguing that having a parent present in the hospital with the child is better for the wellbeing of the child and their family, Roberts, 2010 also acknowledge that this is not possible for all families. This could be due to external factors such as not being able to have time off of work, or the hospitalised child may have siblings that the parents must give equal attention to. They also highlight internal factors that might hinder a parent from staying with their hospitalised child, such as extreme anxiety about caring for their child in hospital. For this reason, Roberts (2010) claims, there are several occasions where children may not be accompanied by a parent to hospital, in which case the child is at higher risk of psychological distress within the hospital.

4.4 The influence of hospitalisation on the child, and parents' perception of the self

Aligning with Roberts' (2010) study, Popp *et al*.'s (2014) study assessed the hospital experiences and illness narratives of parents whose children had spent time in hospital and had received a diagnosis of chronic illness. They collected the narratives of children, as well as their parents, to explore whether children's narratives mirrored parental narratives. They observed that while the child's narrative of hospitalisation had similarities with those of their parents, children's narratives were more pragmatic than their parents. Parents emphasised the potential problems and emotional labour of hospitalisation, whereas children's narratives focused more on the practicalities of hospitalisation (Popp *et al*. 2014). However, they do report that children are aware of the continuing danger of their medical conditions, but would often represent emotion through their parents (i.e. 'my mum would not like that' or 'my dad says he worries about that'). My research builds on this, further exploring how children communicate their emotions, and some of the barriers they experience in doing so. Popp *et al*. (2014) assert that the shock and upset of a diagnosis is felt for a longer period of time by parents. While children narrate similar emotions, they seem to feel differently about illness over time. Popp *et al*. (2014) report parents' observations that a diagnosis of chronic illness affects the family overall, and some parents detailed the negative effects it had on communication and relationships. Popp *et al*. (2014) observe that children's narratives match these, although children highlight themselves as the cause of broken relationships and family conflict. Popp *et al*. (2014) highlight the need to target interventions at parents coping strategies, in order to provide holistic care for hospitalised children. They argue that such interventions would help to improve and even avoid family conflicts which result in self-blame for young people. My research takes a different approach, in that it does not seek to compare narratives of illness or children's and their parent's narratives. My research differs in that it centres the child's voice and does not set out to give a focus to family dynamics and coping strategies.

Like Popp *et al*. (2014) and Roberts (2010), Rempel *et al*. (2012) also focused her study on parents. However, Rempel *et al*. (2012) focuses on parents who have had babies born with illnesses. All parents reported that they felt they had struggled to bond with their child. Some parents attributed this struggle to the machines, tubes and wires that were required to monitor their baby's health, whilst others reported that one barrier to bonding with their baby was fear. The parents were worried about losing their child, so they emotionally withdrew. They all reported feeling increasingly anxious as they began to bond more closely with their baby. Further to this, Rempel *et al*.'s (2012) study did not report parental sorrow or grief for their child on diagnosis in the same way that other studies (such as Popp, *et al*, 2014) emphasise. While Rempel *et al*. (2012) focus on parental stress and anxiety when parenting a child in hospital, they contradict Popp *et al*.'s (2014) study by reporting that parents do adjust to their child's illness and cope better with a diagnosis as they adjust their expectations over time. Whilst forefronting children's voices, my study will challenge the idea that parents and children feel less connected or able to bond during hospitalisation.

4.5 Increasing child participation and improving communication in health care settings

Moving the focus from parents to children, Hemmingway *et al*. (2011) identified the need to increase the level of participation by children and young people in hospital, especially their involvement in decision making and health care plans. Whilst they identified the importance of children's involvement, they also articulated concerns held by many medical professionals who felt ill equipped to seek a child's involvement, and they described how doctors struggle to identify whether a child was competent enough to understand information about their medical needs, and found it difficult to pitch information in an appropriate way for children to understand. Further to this, doctors were worried about telling children too much, in case the child worried. Hemmingway *et al*. (2011) articulate a belief that a child's parents are useful and valuable allies to hospitalised children and they therefore developed a 'checklist' to enable parents to prepare their children to participate in discussions about their healthcare while still at home. With this checklist, parents would be able to help their child communicate in consultations with their health care professional. They proposed that this was a simple way to involve the parents in making and creating health care plans, giving them an active role in facilitating good relationships between their child and their health care professional. With this idea of a checklist, Hemmingway *et al*. (2011) attempted to create a simple solution, or maybe more accurately, a change in the focus of medical interaction and dialogue. The change they highlighted involved creating a patient-parent-practitioner interaction, rather than a parent-practitioner interaction. Hemmingway *et al*.'s (2011) attempt at a practical solution to include young people highlighted the need for a three-way interaction as well as offering a practical solution for medical professionals who feel ill equipped when trying to involve young people in medical decision making. Whilst highlighting the need for a three-way interaction was necessary, Hemmingway *et al*.'s (2011) checklist oversimplifies communication, and although responding to the need for medical professionals to feel more confident to interact with children, their study does not recognise the non-verbal ways in which children communicate, nor does it consider what we are teaching children when asking them to communicate via a (pre-prescribed) checklist. My study directly challenges the notion of adult communication, and utilising CDS and DCCS, questions what normative communication looks like in hospital settings.

Like Hemmingway *et al*. (2011), Bricher (2000) similarly focused on the perceptions of children. Like me, Bricher (2000) noted that children's voices in the hospital setting were consistently missed within research aiming to improve services for children and young people. Instead they observe how the voices of nurses and parents were more readily sought in research. Bricher (2000) highlighted the unequal power relations between adults and children in a hospital environment, and argued that the principle of 'in the child's best interest' is part of a dangerous discourse that can deny children an appropriate way to be involved in health care decisions. Bricher (2000) further observed that, in their own study around the voices of hospitalised children, when children were asked about their healthcare plans, this happened in a tokenistic way. In other words, it was done in order to formally tick a box that the child was consulted and heard, but in reality, the child's voice was not taken into consideration prior to the formation of any treatment and support plans. Bricher (2000) concluded this through his observation that children were heard if they agreed with the healthcare plans and were compliant with the practitioner's perspective; however when children disagreed and resisted treatment, their concerns were ignored (Bricher, 2000).

Building on Bricher's (2000) work focusing on the child's voice, Beresford *et al*. (2003) aimed to explore experiences of communication between young service users and their health care team, which included the doctors, nurses and social workers involved in looking after them. In their study they highlighted that young people felt more comfortable raising concerns and contributing to their care plans with professionals that they were familiar with. Young people in their study stated that communicating with professionals who they had never met before was more difficult and posed a barrier to their willingness to communicate in hospital settings. In Beresford *et al*.'s (2003) study, young people highlighted that communication was usually between the doctors and their parents and that doctors rarely aimed their questions at the young people specifically. On the other hand, healthcare professionals in the study felt that young people were not always aware of their condition, and were thus unable to give adequate or detailed descriptions of their health and illness. Beresford *et al*. (2003) study highlights a need for more research with young service users, and urges future studies in this area to forefront the voices of children and young people in hospital. My study responds to this call in that it centralises young people's voices and challenges the idea that children are often unaware of their condition or may be unable to contribute to medical understanding in a meaningful way. My study uses poststructuralist CDS ideas in order to 'switch' the focus on communication. With a focus on ability, it explores how children and young people can communicate, and problematizes notions of normativity in communication. It places an emphasis on a child's right to speak and be heard in all matters affecting them, and asks if children's voices are heard yet.

Like Beresford *et al*. (2003), Butz *et al*. (2007) also focused on communication in a hospital setting in order to improve services for young people in the hospital. Their focus was on children with asthma, and they argued that engaging in shared decision making with children was essential if services were to be improved. They argued however that children do not have the same competencies as adults. Butz *et al*.'s (2007) study aimed to offer a practical solution to aid medical professionals to involve young service users in consultation. With professionals questioning how to engage children, and how much information to share with them, Butz *et al*. (2007) suggested that the health care professional should assess the child's competence in order to establish how involved a child should be. Butz *et al*. (2007) advise that this can be done by asking the child to count to 100 or spell words. They suggest that the ability to count or spell words is an accurate assessment of the child's potential ability to make decisions about their health, and would indicate to the medical professional how competent a child was in terms of being included in discussions and decisions about their health care plans. It is worth stating here how desperately problematic this is, and whilst Butz *et al*. (2007) were aiming to provide a practical solution to issues around communication, they do so in a way which discriminates against all but the most literate and numerate young people.

Despite the 11-year-long attempt by researchers such as Bricher (2000), Beresford *et al*. (2003), Butz *et al*. (2007) and Hemmingway *et al*. (2011) to improve communication with young people in hospital settings, researchers continue to identify communication as an issue. In 2019 Loureiro observed that children and young people were still dissatisfied with certain aspects of nursing care. Loureiro (2019) conducted a search for empirical studies which involved children's experiences of hospitalisation, with the aim of synthesising current knowledge on school aged children's satisfaction with nursing care in acute care settings. This topic was selected for study because Loureiro (2019) observed that in many studies children were identifying aspects of nursing care that they felt were important but which were not especially valued by their parents or caring professionals. Within healthcare, patient satisfaction is a complex, multi-dimensional concept, and is considered a critical aspect in care settings such as hospitals. Good patient satisfaction is a concept that concerns nurses worldwide and is considered the 'gold standard' of care. The author observes that nursing care is consistently found to be a major influence in patient satisfaction. Patient satisfaction scores are one of the ways that health care settings can integrate the service user's voice and opinions and improve and reflect on services. The authors argue that this is particularly relevant for vulnerable groups such as children, who are often seen as silent consumers of healthcare. They argue that children's views have often been poorly explored or are clouded by their parent's views, and parents' overall satisfaction in their child's care. However, they note that previous studies have established that children often do not share the same views as their parents in terms of satisfaction with health care, and often children identify aspects of nursing care that their parents value less. Children expected nurses to be caring, kind, helpful, to have a sense of humour, to be friendly, smile, and be approachable. They noted that within the studies they reviewed, children suggested that nurses should have respect for children and should have the ability to connect and relate to them, as well as to stand up for them, advocate for them, and be good listeners. It seems that for children, humanity and trustworthiness were the most valued characteristics. The children also felt that the nurses who provided entertainment such as televisions or video games understood their needs more, and such entertainment was described as being one of the best aspects of staying in hospital. Children reported that some of the worst parts of staying in hospitals were when professionals failed to talk to them or consult them, having to have procedures done against their will, when nurses were controlling in the space and wouldn't let them move around, were not available (physically and emotionally) for them, when they poorly communicated with children, and when they lost the children's trust by lying; for example, saying that a procedure will not hurt when it does. The major source of dissatisfaction was long waits for procedures. Loureiro (2019) highlights that children have expressed a need for more information about their illness so that they are better able to make decisions about their healthcare and feel more confident, involved, and prepared for their treatments or procedures. The author calls for follow up studies as well as more longitudinal studies in the area of children's satisfaction with their health care. Further to this, Loureiro (2019) suggests that valid and more reliable tools are required to both understand and continuously measure satisfaction with nursing care. My study recognises the importance of the issues that Loureiro (2019) observes. It supports the concept of children being heard and given the opportunity to meaningfully contribute to their health care, and concurs that children's satisfaction with their healthcare should be prioritised over parental satisfaction.

4.6 Researching with social model ideas to challenge and problematise current representations of children in hospital

Johnson (2010) conducted a study exploring how Canadian mental health service users critique or appraise their doctors. Johnson (2010) reports that service users felt that they were perceived as an inconvenience when their doctors did not listen or make careful attempts to learn about their life beyond the clinical symptoms; more so, if doctors failed to give service users a sense of autonomy in their care plans. Johnson (2010) claims that counter narratives that challenge dominant perspectives and attitudes to disability and disablism have had some media attention, and as such, have given (some) people a voice in debates that they would typically have been excluded from. Johnston (2010) finds this valuable because he believes that the studies carried out from the perspective of the mental health service user, as opposed to the clinician, productively challenge dominant perspectives about mental health and the mental health system. Johnson (2010) recognises a way of knowing that takes into account the lived reality of service users; recognising the power imbalances that are present in many clinical establishments. Johnson (2010) uses a feminist standpoint on epistemology, privileging situated and experiential knowledge, and challenging the notion of universal and value-free knowledge consumption. She argues that care improves when good relationships between the service user and clinician are formed along with a praxis of ‘mad studies’ with the aim of re-inscribing psychiatric narratives within the sociological and political forces that initiated unhelpful master narratives. Johnson (2010) concluded that more engagement is needed between service users and their doctors, and that mad studies should continue to mobilise the voices of service users in order to identify ways in which the mental health system can improve. She also urges future research to engage with service users and work out ways to sustain healthy relationships between service users and their psychiatric health care team, who are often reportedly distant from the lived reality and personal experiences of their patients. Johnson (2010) urges future researchers to explore both the positive and negative experiences of psychiatric care and relationships with psychiatric clinicians. My research responds to Johnson's (2010) work, exploring aspects of good practices when developing professional relationships with young people in hospital. It is worth noting here that two of the participants in this study are narrating their time in a children’s mental health hospital.

Like Johnson (2010), Savage (2018) notes that academic work is often distanced from personal experiences; however, like many others, Savage (2018) notes that her work does not do this. Her work draws on her personal experiences and employs methodologies that are based on her personal subjective experiences of liver disease. Savage (2018) therefore produces an academic autobiography using memories and storytelling from her family, her own memories, and her medical notes, which allows insight into the emotional landscape. Savage’s (2018) work was insightful and informed my own work, as my study also draws on my own personal and subjective experiences of hospitalisation. Furthermore, in common with Savage’s (2018) work, my study highlights young people’s understanding and interpretations of master narratives in order to challenge them. Like Savage (2018), McElwee *et al*. (2018) also write from a personal experience perspective; they question what it means to participate, whilst also arguing that service users have a set of knowledge about their bodies and lives that should not be ignored by medical professionals. McElwee *et al*.’s (2018) perspective serves as a tool for disabled young people to challenge any system-held beliefs. McElwee *et al*. (2018) emphasise young people as the ‘think tank’ behind their work, and presents a strong argument for better participation and, more collaboration and mutual respect between young people, their families and allies, as well as medical practitioners.

Similarly, Dowling *et al*. (2018) report that the young people in their study described having altered friendships after experiencing an acquired brain injury, and all young people in their study constructed information about themselves based on the altered friendships. Young people interpreted their changes in friendships as a result of their injuries, and as such internalised their isolation as their fault (Dowling *et al*., 2018). These changes in friendships were perceived by young people as negative, and young people reported lower self-esteem and confidence as a result. As identity was formed through, often unhelpful, interactions with others, it was difficult for participants to form a positive sense of self (Dowling *et al*., 2018). They call for better resources in helping explain the social implications of an acquired illness/injury to a wider population, suggesting that information booklets and teacher training would be ideal. My research builds on this, as it explores relationships in general, noting the importance of developing and maintaining good relationships with both adults and peers.

Runswick-Cole *et al*. (2018) question common models of resilience, or notions of children being able to ‘bounce back’ and ‘succeed against the odds’, which are built on concepts of normative individual development or progression in spite of threat, hardship or adversity. Families in their study highlighted that when they were deprived of material resources such as wheelchairs, hoists, or communication devices, not only was the families’ resilience reduced but so was their confidence and self-esteem (Runswick-Cole *et al*., 2018). Families also noted that they felt less resilient when they had recurring hospital appointments, operations, or rehabilitation. Disabled children in their studies were also very aware of their own bodies and how their bodies might be perceived. Runswick-Cole *et al*. (2018) observed that children were often aware that their body was an (often unwanted) site for medical and psychological understanding. The children in Runswick-Cole *et al*.’s (2018) study noted their absence from any medical decision making, and found it difficult to access good quality information. Runswick-Cole *et al*. (2018) felt that information sharing with children was also a key contributor to building resilience. The researchers argue that all the adults in a child’s life; family, teachers, medical professionals and others, all have a role to play in enabling or stifling disabled children’s resilience (Runswick-Cole *et al*., 2018). They conclude by noting that the children and young people in their study as well as their family members, consider that the ability to access a range of resources involves resilience. Runswick-Cole *et al*. (2018) problematise the idea of resilience as an internal bodily structure that is developed through hardship. Instead they place resilience within the environment. They note that children’s own understandings of their bodies are shaped by other people’s reactions and relationships with them, and that these relationships are always embedded in culture, power relations, control and communication. Building on Runswick-Cole *et al*. (2018), my study explores how children understand other people’s perceptions of their bodies. Further to this, my study highlights what informal ‘lessons’ are being taught to hospitalised children through mainstream protocols and cultural practices. Additionally, my study highlights the pressing issue of communication, offering a new way to perceive communication.

Approaching the phenomenon of hospitalised children from a different angle, Wilcox (2020) reflects on her own day-to-day work with children in hospital. Wilcox (2020) defines herself as an artist who works, in a multidisciplinary way, in a hospital. Whilst applying a disability studies perspective to her practice, Wilcox (2020) highlights the importance of listening to non-verbal communication. This is important to acknowledge, as communication has been identified as an issue through all disciplines and their respective studies around hospitalised children's lives. That said, Wilcox (2020) is one of very few who detail the nuances of including non-verbal children in her work. In doing so, she draws on what is being said without words, which resonates with my own study, which builds on Wilcox's (2020) work by broadening how we think of non-verbal communication, and exploring what hospitalised children tell us and how we can listen to them.

4.7 Concluding thoughts on medical and nursing perspectives and working towards a critical disability studies understanding

The medical and nursing literature that does focus on children's experiences highlights communication as a key area for improvement. Literature in this field has two main foci; firstly encouraging compliance in children that resist procedures, and secondly, how to avoid fear or comfort fearful children. It is agreed that communication can be improved; however, it is acknowledged that children, their parents/allies and medical professionals all need support in doing this. My study aims to build on this by focusing on young people's perceptions of communication and discussing what was and was not helpful in their experiences. It will build on this by employing a CDS and poststructuralist lens, and will foreground children and young people's own voices and perspectives of their lived experiences of hospitalisation.

It is generally argued that more uptake of the social model of disability is needed for children in hospital. My study aims to add to the body of knowledge of hospitalised children through a CDS lens whilst also centralising the voices of young people in hospital. Critical disability studies (CDS) and disabled children's childhood studies (DCCS) offer a different understanding of hospitalised young people, in that these approaches politicise their personal experiences and seeks equality and social justice. DCCS is a valuable field in which to base future discussion, as it emphasises the often silenced voices of hospitalised children to re-think the problem of communication in ways which other disciplines have struggled to master. Furthermore, DCCS is better equipped to appreciate and explore the complexities and challenges that children in hospital and their allies face, and to better represent children's worries and the things that are important to them. CDS and DCCS perspectives help to challenge dominant narratives about hospitalised children's lives, and appreciate all childhoods equally. Whilst there is much literature on hospitalised children from other fields, there is very little from CDS and DCCS; something which my study addresses and contributes to.

Chapter 5 – Method/ology

5.1 Introduction

Methodology is the study of methods, research design and procedures used in research, and is the framework of the research (Hammond *et al*. 2013). In this chapter I will highlight the benefits of having one broad research question before discussing how my positionality, ontology, epistemology and therefore methodology, overlap and are entwined with one another. I make the case for engaging in narrative research which utilises Critical Disability Studies (CDS) and Disabled Children's Childhood Studies (DCCS) to forefront children and young people's embodied accounts of hospitalisation. I move on to make a case to include my own diary entries, written by my younger self in 2001, to enrich the data and to add transparency. Moving on, the chapter outlines how participants were able to shape this research through my application of multi-modal storytelling and how this led to a multi-modal collection of data. After briefly discussing the research schedule, I detail how analysis was thematically conducted, and outline the development of a theme in this research. The chapter then moves on to provide a pen portrait that participants helped to create. The chapter ends with a brief summary and some concluding thoughts.

5.2 Research Questions

The purpose of this research was to create a space in which stories of hospitalisation and medicalisation can be explored, and the individuals' experiences can be fully acknowledged. This study was, therefore, designed in a way that was flexible and thus had one broad research question instead of many:

What can we learn from the stories that people choose to share about being in hospital?

Having one broad research question allows the exploration of themes which may have been overlooked if more than one research question was used. I am aware, as Wellington (2000) suggests, that the purpose of research questions is to give the researcher focus; however, I did not want it to be my sole focus. This design allowed the participants to forefront topics that were important to them without their ideas being devalued, considered un-interesting, unimportant or irrelevant to the study. Creating a space for participants to talk about what is important to them is, as Ellis (2004) suggests, one of the nuances of ‘doing’ ethical research. Ensuring enough flexibility to enable participants to shape some of the project by openly talking about what was important to them allowed for a wide range of topics to be discussed.

5.3 Positionality, Ontology and Epistemology

Bartlett *et al*. (2007) argue that it is important for researchers to define their ontological and epistemological stance within their research in order for readers to properly understand their writing. Whilst my positionality, ontology and epistemology are evident throughout this thesis, I will aim to highlight them here for the purposes of this chapter. Providing insight into the rationale of this project, I discuss how the research was not just affected but was nurtured by my own experiences of childhood hospitalisation. I also highlight my epistemological and ontological understandings which contribute to the shaping of this research.

I am a social scientist based in the field of education. I became interested in social modelist ideas whilst engaged in Disability Studies. Social modelists distinguish between impairment and disability. Current research does not always accurately represent the very specific struggles of hospitalised children, nor does it explore the ‘lessons’ hospitalised children are informally learning through their hospital experiences (as explored in more detail in the literature review).

I position myself as a Critical Disability Studies (CDS) academic, drawing on a multidisciplinary approach and grounding my research within the sphere of Disabled Children’s Childhood Studies (DCCS). I view my positionality as unfixed (Tinker *et al*.

2008); instead, it is constructed in the moment, and is thus relational and fluid dependent on the context and the related dynamic and performative elements. In my epistemological stance, knowledge arises from experience. For me, experience cannot be so simple that it is untouched by culture, power or discourse. Instead, it is defined in space and place through the discourses available at the time. Reports of experiences then (i.e. stories) are treated as socially conditioned and interpretive in the time, place and space that they were created. Taking a constructionist approach to ontology, reality is constructed through interaction and through language (Andrews, 2012). The idea that cognitive processes form a reality is itself constructed. In the same way that identities can be multiple and intersect, there is the possibility that multiple realities exist. Ontology then is fluid and unfixed and is relational in the same way positionality is. Like epistemology, it is also interpretive and works in relation to time, place, space and discourse.

5.4 Narrative Research

In this section, I define what I mean by narratives. Then, I discuss how this research uses narratives to validate and facilitate children and young people's expression of embodied accounts of hospitalisation, whilst also highlighting issues around representation of hospitalised children and young people. Moving on, I discuss a central focus on performance and expression within narratives, and acknowledge how narratives detailing hospitalisation can, be perceived by some as 'illness narratives'. I make the case for shifting narratives about illness and hospitalisation away from common systems of knowledge, which are mainly medical and charity model depictions. I frame narratives within this research as *narratives about illness and hospitalisation*, instead of the *illness narratives*. I note my use of CDS and DCCS to honour embodied accounts of illness and to forefront participants' subjugated knowledge's.

The term 'narrative' is open to a range of interpretations. In this research it is used in the broadest possible way, meaning a story that someone shares. Within narrative research, researchers are looking at the ways in which participants make meaning from the stories that they tell (Wellington, 2000). Narrative researchers are just as concerned with the type of narration as with the content of the story itself (Chase, 2011). The act of storytelling is considered as a form of performance or a kind of discourse in and of itself (Hammond *et al*. 2013). The purpose of narratives in this study is both emic and etic, that is both facilitating participants to give voice to experiences that are somewhat unreported in academia, as well as addressing concerns around representation of children's hospitalisation. Narrative researchers have been known to use a wide range of methods and most, like this research, report a multi-modal approach (Bryman, 2007). Like myself, narrative researchers often state an explicit intention to work closely and in collaboration with research participants. This approach to research has been used to illuminate aspects of professional practice and lends itself to a cross disciplinary approach. Hammond *et al*. (2013) remind us that narrative researchers can face criticisms about trustworthiness or reliability of their data. However, this research does not aim to uncover any hidden truths, and thus it is unconcerned with how reliable and trustworthy participants' stories are. Instead, it places a focus on the performance and expressions of the story, and on the stories' content. Bury (2001) suggests that narratives that depict illness are illness narratives. They describe three types of illness narratives: contingent narratives, moral narratives and core narratives. Grouping illness narratives in this way surrenders the body to medicine. It provides a structure and discourse of how to speak and write about the ill and disabled body that forefront medical underpinnings, rather than embodied accounts and disqualified knowledge of illness (Be, 2019). In CDS and DCCS, storytelling is honoured and aims to legitimise the subjugated knowledge gained from first-hand accounts of disability and illness. Throughout this thesis I will use the term 'stories about illness' rather than the more common term 'illness narratives', for several reasons. Firstly, it denotes a person's first discourse, prioritising the participants' voice and story over illness. Secondly, it moves the narratives away from the specific aims and structures of illness narratives that forefront medical understandings of illness.

Aiming to move narratives about experiences of illness away from medical and charity framings, I make no attempt to 'fit' participants' narratives within the three categories as outlined by Bury (2001). I find these categories limiting and over-simplistic. In line with my ontology and epistemology (outlined above), stories are constructed and reconstructed through their interactions with social and environmental aspects and are thus more complex and intricate (Bochner, 2002; Coffey, 1999; Hammond *et al*., 2013).

CDS and DCCS scholars work to foreground embodied accounts of disability and illness (Liddiard *et al*. 2019; Goodley 2011). Narrative researchers view themselves as ‘listeners’ and the participants as ‘narrators’, focusing on the relationships and meanings of narratives. This work employs narrative research with the participants in the study. As a researcher, I listen to participants’ accounts and focus on the modes of expression that participants choose, as well as how they tell and make meaning of their stories. My own stories, narrated by my 14-year-old self in 2001, are situated in the data set. Autoethnography was thus employed in order to analyse the accounts of illness and hospitalisation in my former years. I therefore employ narrative enquiry with participants and carry out autoethnography on myself.

5.5 The Autoethnographic Elements of this Research:

Here, I justify the use of my own diaries and argue that they add a greater transparency to this research. I discuss the benefits of autoethnographic research, before claiming that autoethnography in this research offers a sharing of experiences between researcher and participants (Bochner, 2001).

In common with narrative research, autoethnography works closely with individuals and their stories. However, emphasis is placed upon the dialogue and discussions the researcher and participants have (Chase, 2011). This emphasis on the interaction helps to explain how stories are both re-constructed and co-constructed (Chase, 2011). An autoethnographic approach to research allows me to be subjective, and to draw on my own hospital experiences as participants tell of theirs. It allows, to some degree, a shared experience of hurt, rather than hurting in isolation, and allows me to openly empathise with participants during their narration. Analysis of my diaries was done in the same way as participants’ accounts, however autoethnography allows an additional layer of reflexivity and transparency. By interpreting my own experiences, I am able to gain a much deeper understanding of how and why I have come to interpret participants’ stories. The idea of a sharing of experiences has been used and unpicked by disabled feminist scholars (e.g. Morris, 1999; Crow, 2010; Wendall, 2001, 2013; Ghai, 2002, 2006) who discuss how women share experiences of being isolated from the social model of disability and also excluded from feminism (as explored in more detail in the literature review).

Chase (2011) reminds us that narrative researchers analyse other people's stories, both reflecting on their interpretations of the participant's story and analysing their relationship with the story teller. Autoethnography makes space for my own narrations about illness and interpretations to sit alongside those of the participants in the study. This is in agreement with Bochner's (2001) claim that autoethnography can aid the balancing of disembodied and embodied knowledge. The robustness of autoethnography has been challenged by some social science researchers (Delamont, 2009; Mykhalovskiy, 1996; Atkinson, 2006) who claim it is too artistic to be science and too scientific to be art. Others however, such as Ellis *et al*. (2011), Bochner (1997), Coffey (1999) and Anderson (2006) have identified its benefits.

Ellis *et al*. (2011) claim that one of the benefits of autoethnography is that it can be more inclusive to a wider audience and is a useful tool to accommodate multiple and fluid ontological positions in research. Bochner (2001) further suggests that given its nature, reflecting on subjective emotions, autoethnography draws on everyday occurrences to politicise the personal, subjugated knowledges, yielding new insights into the experiences of hospitalisation. Whilst it understands knowledge to be constructed in a space, place and at a specific time, it provides an opportunity for greater reflection. This holds the researcher accountable for the knowledge produced in the process of research, rather than the participants (Spry, 2011).

Miles *et al*. (1994) highlight that social research is not a rigid adherence to methodological rules; instead, it is a craft. They suggest that every study requires the researcher to adjust the methodology to the particularities of the setting, arguing that no one way of *doing* research is superior to another.

This study adopts a narrative approach which incorporates elements of autoethnography. I argue that doing research in this way allows for greater flexibility, choice and transparency. The two methodologies, for me, weave together intuitively. This partly enables the collection of multi-modal data, as participants were able to choose how and where to share their stories of hospitalisation. Furthermore, it also facilitated participants’ ability to shape the research design and offered the freedom to describe the things that were most important to them.

5.6 Methods

In this section, I detail the multi-modal methods used in this research. As methods were not selected prior to fieldwork, a justification of each method is not given; instead the section justifies the benefits of creating a space for participants to shape this element of the research through their own personal preferences and selection of methods. It details each participant’s mode of storytelling, and if applicable where participants choose to meet. I move on to explain why unstructured interviews were utilised, exemplifying the types of questions asked during interviews. I explain the parameters of data collection, specifically in relation to diaries and blogs. Finally, I reflect on the learning journey I have taken, and argue that the diversity of storytelling within this project enriches the data set overall.

I gave participants a choice of which method they would like to use to tell me their story. Four participants chose to be interviewed, three of whom wished to be interviewed in person and one chose an email interview. I started each interview with the question ‘So tell me about your experiences.’ The participants knew that the study was about children in hospital, so they naturally started with a story about being in hospital. All interviewed participants started by detailing why they were admitted to hospital and the events directly before hospital admission. The interviews were unstructured, so different questions were asked to different participants. Unstructured interviews were selected because I wanted participants to discuss the stories that mattered to them rather than answering questions that were led by me, the researcher. An advantage of an unstructured interview is that it offers more flexibility in the research and allows the research focus to change and shift in line with the data collected (Bryman, 2007). In terms of the interview questions, I asked participants to elaborate on something that they had mentioned, or asked how that experience had made them feel. Each participant also chose where they would like to be interviewed. This was because I was aware that some stories could be sensitive and I wanted participants to feel comfortable in their interview. Participants provided an array of artefacts including drawings, poetry, letters, music transcripts, photographs and diary entries. Participants were able to shape this research through their use of multi-modal storytelling, which in turn encouraged me, as a researcher, to engage in multi-modal research and data analysis.

One participant, Jazz, chose to meet on the university campus, where I had scheduled a private room for us to meet. Our discussions lasted for 90 minutes. Jazz initially expressed a desire to chat to me again but later withdrew to focus on her own study, although she agreed that I could still use the data that she had given me in the first interview. Another participant, William, also chose to meet at the university campus, and again I scheduled a room for us to meet in. William's interview lasted 80 minutes. At the first meeting, he provided me with both verbal stories about being in hospital, as well as transcripts of music that he had composed himself. Like Jazz, he expressed a desire to meet again with me. Given my lack of expertise in music, I asked William if we could use some of the second interview to discuss his music; he agreed and chose his home as a venue for this interview. He explained that he had computer software at home which would help me to see and listen to his music. Discussing his music, I asked him what it meant, why he created it and what stories it told. At this time, William had also prepared a (hypothetical) letter to his doctor and a poem, which are used as part of the data set. William's second interview was three hours long, which could be a result of him being at home and feeling more comfortable in his surroundings.

Joe wanted to be interviewed too and chose to meet at a popular fast food restaurant. Joe chose to include his father in the interview, and we agreed this in advance. Joe's interview lasted for 90 minutes. When discussing whether he wanted to meet with me again, he explained that he thought that he had told me everything he wanted to tell me, but if I had any questions I could ask him. He chose for us to communicate via texting or calling his father's mobile phone; his father agreed to facilitate this. In Joe's interview, I often asked 'what does that mean?' and 'how did you feel when that happened?' and 'why do you think they did that?'.

Unlike other participants, Rachel chose to participate in email interviews. I started by asking her to tell me a story about when she went to hospital. I asked her questions, based on the story she shared, for example: ‘how did you feel when that happened?’. Our communication was initially several times a week but she became slower at responding to my emails, and eventually stopped responding altogether (discussed in more detail in the ethics chapter).

Ella was excited about participating in the research. After explaining to Ella that she could tell me her stories in any way that she wanted, she asked me to use her already existing blogs. She sent me a link to her blogs and told me to email her should I have any questions. Ella and I agreed that the blogs that she would write after data collection had ended (those that were written after 2017) should not be included. A few times, I emailed asking her to elaborate on the experiences or ideas that she had written about in her blog, or why she chose to write about a certain topic. Email communication was slow, often taking weeks to obtain a response. Ella often asked me if I liked her blogs and if they were helping me with my research. She expressed how grateful she was to be included in the project and was happy that I liked her stories. In common with my own diaries, Ella’s blogs were not written for the purposes of research and were created prior to research. The topics she chose to discuss are not influenced by what she thinks is useful for this research, but are topics of importance to her.

With respect to my own diaries, I kept diaries throughout my teenage years, and stored them in a box at home. I chose a diary at random because I wanted to see what was important to me as a teenager at a specific time, rather than seeing all diaries as an adult researcher and choosing what entries were important to me now. I chose a diary from 2001. On reading the diary, I excluded some entries that were made in between hospital admissions, as they were not relevant to the research. Some of the stories which detail hospitalisation were also omitted because I felt uncomfortable sharing and analysing them. Initially I grappled with whether this was acceptable. I was reminded by my supervisors to exercise the same ethical framework for myself; Just as participants are offered the chance to omit aspects of their data, I allowed myself the same privilege.

Researchers who use narratives note that the contents of the diaries kept by their participants have been specifically constructed for the research project. Therefore, there remains uncertainty as to whether the participants are presenting a complete representation of the feelings they experienced, or whether they are writing what they perceive the researcher wants to hear (Bartlett *et al*, 2007). My diaries were utilised as part of a therapeutic tool to deal with emotions I felt as a teenager, and it was never envisaged that they would contribute to research. Similarly, Ella's blogs were not written with this research in mind, so the topics she chose to discuss are the ones that are important to her, rather than being led by research motives or a perception of how useful the topic is to research. Ellis (2004) highlights that journals and diaries provide crucial in-depth emotional insight, which is fundamental to any qualitative research. I argue that Ella's blogs and the diaries I created are a good representation of what we felt was important at the time of writing, and are a rich source of data. Using data not written for the purpose of research enables me, to capture the nuances in the everyday lives of both Ella and my fourteen-year-old self, in ways which may not have been possible for other studies. Similarly, William's music was created before this research, although his discussions of the music were prompted by this research. As discussed later on this section, there were commonalities in the themes that participants chose to discuss.

On reflection, the multimodal data collected for this study catapulted me onto a path that I had not envisaged, and into spaces of vulnerability that I had not initially anticipated. The diversity of storytelling that this research engages with exemplifies possible modes of expression and storytelling that are not common in social science research, and therefore offers new ways to engage with people's stories.

5.7 Recruitment and Research Schedule

To help with participant recruitment, I approached charity organisations that supported children and families during hospitalisation. The only organisations that responded were Magnolia House and Treetop House, who advertised my research and contact details via an email that they circulated to their service users. However, no participants were recruited from this. I therefore broadened my search beyond charities to Facebook groups concerned with supporting families with children in hospital. Of the Facebook groups I approached, Young Epilepsy and CPteens responded and allowed me to advertise my project on their page. Here, I was able to recruit 2 participants. One participant heard about my research from his father and approached me. In an attempt to recruit more participants, I approached the University of Sheffield's Disability and Dyslexia Support Service (DDSS) service who advertised my project to individuals who they thought could be interested, and I gained another participant from this process. A further participant attended a conference where I spoke about my-then-proposed research. He was interested in my research and offered to help. The final participant was myself. From the start of this research, I intended to utilise my own diaries written whilst in hospital in 2001.

Inclusion criteria included participants considering themselves to have had long term or recurring hospital admissions as a child. The terms 'long lasting' and 'recurring' were not definitively outlined in the literature or by the National Health Service (NHS). However, the Organization for Economic Cooperation and Development (OECD, 2011) suggests that an average stay in hospital is 7.7 days, and thus, in this study, anything over 7.7 days is considered long lasting. 'Recur' is defined as anything more than two (Dictionary.com, 2016) so without a definition in literature, this study defines 'recurring hospitalisation' to mean anything more than two admissions to hospital. Uniquely, this project breaks the parameters of who defines 'long' or 'recurring' by encouraging participants to decide for themselves whether they have had long stays in hospitals, or recurring hospitalisation. For example, Joe was in hospital for 4 years, whereas Rachel was admitted for just over a week. Rachel had a shorter stay in hospital, yet she was required to attend follow-up appointments (therefore not necessarily admission) for a long period after her admission. All participants who came forward met the inclusion criteria, and thus were all recruited.

Once the participants were recruited, data collection started in April 2017 and finished in July 2017. Transcribing did not take place immediately, as I took a year for parental leave. I transcribed on my return, between August and November 2018. All transcripts were given back to the participants to check and to offer an opportunity to omit any data that they had not meant to give. All participants responded and no data were omitted at this time. I began analysis in January 2019 and identified codes (see thematic analysis in next section) by February 2019. I completed coding by April 2019 and then began writing the data chapter. A first draft version of the data analysis chapter was finished by July 2019 and was sent to participants by August 2019. Only one participant responded to this and was interested in how I understood his story. On reflection, I believe that taking such a long period of time away from the study had regrettably created distance between myself and the participants. Whilst participants were fully engaged and excited about the project during data collection, they were less interested in how they were written about and understood (see chapter 6 on ethics).

5.8 Approach to Thematic Analysis

In this section, I note the complexity of analysing qualitative data, before arguing that a thematic analysis was ideal in this study due to its flexibility in analysing the multimodal data set that this project collected. I move on to discuss the benefits of thematic analysis before briefly addressing what is meant by the terms ‘code’ and ‘theme’. I highlight how widely Braun *et al*. 's. (2006) steps to thematic analysis are utilised in qualitative research. Using this framework, developed by Braun *et al*. (2006) and Clarke *et al*. (2017), I describe the analytical steps taken in this research. I note the expansion of the second step, open coding, and describe three elements that I took in relation to this step. I then exemplify one theme from this research and describe how this theme evolved from raw data to codes and eventually the theme: ‘the importance of the mundane’. Finally, I reflect on my choices and thought process at this time, and note how this theme is perhaps the most important in this work. This is because it demands to be understood and included in order to make sense of, and yield new insights from, the narratives shared by participants in this work.

Torne (2000) describes qualitative data analysis as mysterious, suggesting it is the most complex phase in qualitative research, yet is one of the phases that has received less attention or detail in its discussion. Kiger, *et al*. (2020) note that thematic analysis is a powerful tool, and suggest that it is one of the more flexible methods of analysing data. Thematic analysis is ideal for those who, like me, seek an understanding of experiences, thoughts and or behaviours across a data set (Wellington, 2013). Kiger *et al*. (2020) urge researchers to remember that themes within research do not emerge but are actively constructed patterns or meanings and cannot be presented as mere summaries.

Thematic analysis is widely used, and because it is so flexible it is vital for researchers to be transparent. Braun *et al*. (2006) remind researchers to avoid the pitfall of not clearly stating their ontological, epistemological and paradigmatic positions in research; something which this thesis details at the beginning of this chapter. Braun *et al*. (2006) argue that stating these elements clearly provides transparency, and trustworthy findings and interpretation. Thematic analysis was adopted in this research for its flexibility and its ability to search for common and shared meanings within the data. Braun *et al*. (2006:82) define a theme as 'a patterned response or meaning'. Often positioned in opposition to a category which describes and organises aspects of the data, a theme is more abstract and requires greater interpretation (Nowell *et al*., 2017) the identification of a theme and its importance and centrality in the research is not always reflective of how frequently the theme occurs in the data set (Braun and Clarke, 2006; Nowell *et al*., 2017). Thematic analysis as outlined by Braun *et al*. (2006) has become the most widely adopted method of thematic analysis (Kiger *et al*., 2020) Braun *et al*.'s. (2006) steps of analysis were followed in this research. It is worth noting here that Clarke *et al*.'s (2017) method of thematic analysis was designed to be understood as a recursive process, rather than linear one, which was indeed the case in this study, although the steps I carried out are outlined in a linear way for the purposes of this thesis.

1: Immersion in data, listening to data, transcribing data, and reading transcripts while listening to data; here I was not looking for themes *per se*, I was more focused on gaining clarity on the story and familiarity with it This ensured that I was clear of the context of each element of the story, what participants choose to talk about, and I also focussed on what participants choose to share before and after the story to give the story context.

2a: Open coding (every sentence or so I wrote a word on a mind map, i.e., 'needle' 'emergency': see appendix 12 for mind map). These were words that participants said which resonated with me, or was the topic of conversation, or which I associated with what was being said; for example, when Joe discusses Doctors not letting him home when they had said they would, and how he thinks that Doctors lie, was given the code 'trust in medical professional'.

2b: Overlapping and repeating topics across data were identified (e.g., the data of Rachel, Jazz, Joe, and myself had the code ‘needle’).

2c. Comparison of topics, and some collapsing or expanding of codes (i.e., medical procedure and hospital procedure were collapsed into ‘procedure’, whilst cooperation and participation was separated).

3. The words/topics were grouped together to make a theme (i.e. emergency, trauma, needles, procedures), and each theme was given an initial name which summarised and encompassed the codes within it (i.e., ‘biomedical’) and was colour coded (e.g. highlighted yellow).

4. Review all data from that theme and remove from it data that did not tightly sit within it. Content that was relevant to more than one theme was placed in both themes.

5. All non-coded data were put in their own theme, initially titled ‘miscellaneous’ and these data were reviewed to see if they fitted with any other themes. I observed that this theme was discussing the ethics and design of the project and getting verbal consent or talking about the mundane, and therefore this theme was re-named ‘the mundane’.

6. Writing the report - It is worth noting that the ‘mundane’ theme was not apparent to me, straight away. It was only when I had started my findings that I felt uneasy. I reflected on this moment in my researcher’s reflective diary, where I noted that Ella’s story lacked Ella’s personality. With the research question in mind, I argue that we are not able to learn from the participants’ stories if we do not have enough of the participants in the research data. In addition, we cannot comprehensively learn from the stories that they choose to share if we do not utilise and analyse all the stories that they offer to the research.

In search of data that highlighted some personality, I was led back to the un-highlighted sections of my data set. The mundane experiences portrayed an identity within which participants wanted to be seen. The identity that participants portrayed appeared to juxtapose the identity that they believed was given to them by medical practitioners and society in general. Further to this, young people’s chosen identities are often missed out of research due to intense focus on research questions. By discussing their everyday mundane, participants can be seen to have been asserting their chosen identity. Bourdieu (2003) suggests that mundane topics or explorations that the participants experience seem to stand before our eyes, not in need of understanding; however, I argue that incorporating participants' everyday mundane into this project allows greater depth and insight into their experiences of hospitalisation.

In this section I have that the approach of Braun *et al*. (2006) and Clarke *et al*. (2017) to thematic analysis was followed. I argue that thematic analysis is appropriate for the data set in this study due to its recursive nature and ability to be flexible. I outline the above approach to analysis, and specifically break down step 2, pen coding, into 3 sub-steps in order to provide clarity on the data coding that this study engaged with. Reflecting on the choices made in this research, I map out the evolution of one theme to exemplify how coding was crucial in identifying and developing themes for this research.

5.9 Pen Portraits of The Participants

This section introduces the participants of this project. Each pen portrait was written with the participant, and describes what the participants' main message to the research was. It also details what method(s) each participant chose, and indicates the level of involvement and participation each participant had in the project.

5.9.1 Ella:

Ella is a fifteen-year-old girl with a diagnosis of cerebral palsy and epilepsy. She presents herself as an activist who 'spreads awareness'. She presented me with and gave me access to her existing blogs. She blogs about what is important to her, including her medical conditions, hospital appointments, school life, and friendship groups. Through her blogs she opposes societal stereotypes and assumptions placed upon her, presenting herself as 'just another teenager'. She strives for a day where her impairments are considered as ‘just another normal’. Ella enjoys audiobooks, photography and socialising with her friends and family. Whilst I have communicated my initial thoughts to her, she has explicitly not wanted an input on how she is represented in my research. Despite this, Ella would like me to let her know when I have finished my project and to inform her if and when I publish any work that comes out of the research.

5.9.2 William:

William is 31 years old with a somewhat disputed diagnosis of bipolar, reflecting the many years he spent in a mental health hospital for young adults. He wanted to perform his data and choose two songs that he composed himself, as he believes that this music captures what it feels like to be in hospital. William also contributed two extensive unstructured interviews, a poem, and a letter he wrote to a doctor. He presents himself as a very creative, capable and accomplished young man. He enjoys fashion, crafts, creating music, and learning new skills. He feels a strong sense of injustice that he was diagnosed, and believes he did not belong in hospital and should not have been sent there. He details a childhood of abuse (discussed in more detail in chapter 6: ethics), and suggests that the behaviour he was ‘showing’ was due to the abuse he had experienced and not mental health problems. He highlighted the flaws in the mental health system and the importance of relationships with practitioners whilst in hospital. He presented his story in the form of music, letters and discussions in which he details the emotional and psychological struggle of being in the mental health system. William was keen to be part of this research and, as such, has impacted how he is represented in my writing throughout. He is in regular communication, and has contributed to this research at every stage.

5.9.3 Jazz:

Jazz, a 23 year old woman, reflects on her time on a neurological ward after she had a brain tumour removed. She wanted to stress the importance of schools and friendship groups, and aimed to focus on the positives of being in hospital, such as spending more time with her mum and the special visitors she had whilst in hospital, as well as being bought special presents. She notes how doctors can be patronising when performing procedures like fitting children with cannulas, suggesting that things like numbing cream increased anxiety around needles rather than decreasing it. She reflects on feeling angry with a doctor for making assumptions about her and offers some insights into how she became familiar with processes involving needles. She withdrew from the research after the first interview to pursue her own academic career but has participated in the creation of this pen portrait and given permission to use the interview she provided me with. She is not interested in having an input on the way she is presented in the research, nor does she wish to be notified when the project is complete, but has expressed the hope that the research does well and reaches the 'right people'.

5.9.4 Joe:

Joe is a 14-year-old boy with a diagnosis of anorexia. He was very explicit with the message that 'boys get anorexia too'. He suggested that mental health hospitals are not 'kitted out' to help boys with anorexia, and he details the stigma he feels having been diagnosed with anorexia, as well as the struggles he faces making friends and continuing his education. He suggests that because anorexia is seen as an illness that mostly affects girls, he faces further stigma and assumptions. He draws on notions of belonging, highlighting his confusion when he was sectioned under the Mental Health Act. He articulated that he felt that he did not belong to his parents anymore. He was the only participant who expressed a desire to have a parent with him in the interview, and wished to have his dad as a partial advocate, contributing to the interview itself. Joe comments on the 'cracks' and inconsistencies in the mental health system which result in a loss of trust, such as practitioners making false promises of going home. He also details the threats that doctors made to force feed him, and the issues he had with being restrained. The interview with Joe and his dad is interesting and, in my opinion, quite beautiful because it allowed me the privilege to glimpse the relationship they have together as they made jokes between each other. Joe presents himself as a 'typical teenager' who enjoys shopping at Topman and teasing his dad and sister. In terms of engagement with the research, Joe was involved in writing his pen portrait, but whilst he articulates a keen interest in the research and is passionate about his stories being heard to inform medical practice, he doesn’t always choose to impact on how he is represented in the research. Responses to communication are very sporadic, but his desire for his story to be included has remained consistent.

5.9.5 Rachel:

Rachel is a 29-year-old woman reflecting on a hospital admission due to meningitis when she was 7. She talks about the importance of ‘normality in hospital’, and details her experiences of being visited by the tooth fairy whilst in hospital, and watching a television programme called The Crystal Maze. She recalls that she enjoyed playing with the heart monitor machine as she could ‘trick the nurses’ by making it beep. She highlights the effects of medications on her physical and mental state, as well as her dependency on her mum due to her limited mobility. She highlights the struggles she had in relation to the accessibility of the toilet and washing facilities whilst in hospital. She also details the panic she felt when a doctor placed a handful of needles on her bed. Rachel was the only participant who chose to be interviewed via email, which she explained was for convenience. After she contributed to the writing of this pen portrait, she stopped responding to my emails, which I have interpreted as a withdrawal from research. As she was happy to contribute, and has offered me her story and contributed to the pen portrait, I have decided to still use her story to inform this research (discussed in more detail later in this chapter).

5.9.6 Holly (me):

I am a 35-year-old woman with a diagnosis of epilepsy. I provide excerpts from my personal diaries from when I was 15 years old. I detailed what I called ‘doctor’s threats’ in relation to taking medications. I referred to my diaries as ‘talking to paper’, believing it was safer to talk to paper than people. My diaries consist of both written and drawn text and can be seen as a challenge to the medical practitioners’ power. I provide poems and letters to doctors which can be seen as transgressing and opposing power. In the diaries, my 15-year-old-self highlighted the stigma and oppression that I felt, as well as the implications of my medical condition and the medication I had to take in relation to school, friendship groups, and leisure activities. My diaries illuminate how important friendship groups were to me, and I presented myself as a ‘normally abnormal’ teenager who liked to socialise and go swimming with my friends. I detail problems with my treatment in hospitals and at school, and still feel the pain of this as an adult. I draw on images I produced, age 14, that depict how I struggled to be perceived as ‘normal’, and the challenges I had to have my voice heard. My hope is that highlighting these problems, as well as those outlined by participants, and offering alternatives, allows educational and medical practitioners an opportunity to reflect on their own assumptions and practices.

5.10 Concluding Thoughts

In this chapter I outlined my singular research question ‘What can we learn from the stories people chose to share about being in hospital?’ and argued that having one broad research question allowed a flexibility that may not have been possible if more than one question was used. I discussed how this contributed to a making of space which facilitated participants’ discussion of what was most important to them. I moved on to make a case for qualitative, subjective narrative research which is rooted in constructionism and draws upon poststructuralist thought, CDS, and DCCS, to yield new understandings and interpretations of children’s hospital experiences. I proceeded to define what narrative meant for this study, and highlighted the dynamic and discursive power of storytelling. Here I made an argument that stories about illness should be moved away from common systems of knowledge which retell the body through medical framings. Focusing on subjugated disqualified knowledge, I make explicit efforts to shift stories about illness in research away from the common ‘*illness narratives*’ to ‘*narratives about illness*’. Using person first discourse prioritises the participant’s own voice in the telling of their story, and places the person before the illness. I moved on to outline the autoethnographic elements of this research, claiming that, in this study, it makes sense to weave narrative and autoethnography together. I argued that autoethnography provides a greater level of transparency and reflexivity within this research and allows for a sharing of experiences. I moved on to discuss the methods that participants selected in this research, and reflect on the challenges and benefits of multi-modal data collection and analysis to a novice researcher. After briefly detailing the research schedule I then discuss my approach to analysis, arguing that Braun *et al* (2006) and Clarke *et al*’s (2017) steps to thematic analysis offered a flexibility that this study demanded. Lastly, but by no means least, the chapter introduced the participants of this project by offering pen portraits that each participant co-created. Each portrait set out their main messages to this study as well as their chosen method(s).

Chapter 6 - Ethics

6.1 Introduction

Throughout this chapter, I discuss the ethics in general before explaining which approval procedures were taken in this study. I reflect on my discomfort during the ethical application procedure, due to the classification and assumptions it makes of young and disabled participants as vulnerable, and their chosen topics of conversation as ‘high risk’. I move on to how this research aims to neutralise this by not restricting any topics of discussion, even if these topics were considered as ‘risky’. I explain how this facilitated participants to speak openly and freely about their lived experiences and about what mattered to them. I explore relational ethics, and note how this project was conducted within what Ellis (2007) refers to as an ethics of care. I highlight how the study was designed in a purposefully incomplete way, so that participants were able to assume control over some of its design, structure and direction. Moving on, I discuss informed consent and anonymity, detailing how voluntary informed consent was gained. I pay particular attention to the participants under the age of 18 at the time of fieldwork, before discussing the parameters of ethical data collection. I move on to discuss leaving the field and doing no harm, drawing on examples from fieldwork to exemplify how I dealt with difficult, hard to hear conversations with participants. I reflect on the dilemma and difficulty of researcher vulnerability and how this was mitigated and managed. I detail the emotional and psychological labour of this research and how I managed the ‘emotional hangover’ (McGarrol, 2017:240) experienced in this study. I draw on the work of McGarrol (2017), Sikes *et al*. (2019), Hubbard *et al*. (2001), Hammond *et al*, (2013), among others, to argue that there is a great need in social research to properly and fully engage with the emotional impacts of research, before ending with a summary and concluding thoughts.

6.2 Procedural ethics

Ethics is woven throughout every chapter of this project. Whilst ethics is set out as a separate chapter for the purposes of this thesis, it should be seen and understood in conjunction with and an extension of the methodology chapter above. Ethics in social research is defined as:

> ‘The moral principles guiding conduct, which are held by a group or even a profession; in social research, ethical questions often concern respect shown to others, the purpose of the research, who the research benefits and how it is reported’
>
> (Hammond *et al*., 2013, p.167)

Hammond *et al*. (2013) emphasise that ethics are shaped by moral principles which underpin the research process at every step, whilst highlighting that good ethical practice can be dependent on the profession, and the ontological and epistemological framings of the researcher.

Before fieldwork began, I had to obtain approval from my university, which decided that my research was ethically sound, or, simply put, that it met the ethical standards set by the institution, which in my case was the University of Sheffield, through its Ethical Research Code of Conduct (2017). Ethical regulations focus on procedural ethics, guided by research ethics committees such as the British Educational Research Association, (BERA) (2011) and the university's ethical research code of conduct, to ensure researchers conform to basic ethical standards. These include: informed consent, confidentiality, right to privacy, avoiding deception, and protecting human subjects from harm. Often social researchers reflect on ‘situational ethics’, or ‘ethics in practice’, which deals with the unpredictable, subtle and often ethically important moments that arise in the research field, forcing researchers to make decisions which are often unguided by ethics committees (Ellis, 2004; Ellis, 2007; Coffey, 1999).

My ethics application was complex because my research was considered to be ‘high risk’. It was considered in this way because it sought to explore the experiences of young disabled people. Being young and being disabled classified participants as ‘vulnerable’. It was also considered ‘high risk’ because the interviews had the potential to discuss a topic that the ethics institutions list and describe as ‘sensitive’, which are discussions that trigger distress or discomfort to participants. Therefore, I had to ensure that ethical sensitivity was of paramount importance throughout the research process, as well as explaining in more detail how I would negotiate and mitigate these dilemmas with people who are classified as disabled and (potentially) young (it is worth noting here that not all participants were young people; some were adults reflecting on their time in hospital as a young person).

Despite my ethical application being approved, I reflected on my discomfort during this process, specifically in relation with the categorisation and homogenisation of large groups of people who were stereotyped, by ethics boards, as being vulnerable. Furthermore, ethics boards consider whole topics of conversations as ‘risky’, for example, abuse, or bullying. They justify this risk by claiming that these topics are likely to evoke negative emotion. *Vulner* derives from the Latin word *vulnerare*, meaning damage or wound. Vulnerable therefore means ‘damageable’. When thought of in this sense, it seems that certain groups of people were perceived as more fragile than other groups. Despite being contested, the concept of ‘vulnerability’, is often regarded as interchangeable with the notion of lacking competence (Carter, 2009). This has the potential to overlook disabled children’s abilities to contribute to research in meaningful ways, as well as their participatory rights. Positioning children, especially disabled children, as ‘fragile’ in this way can have consequences for their involvement in decision making in both research and their care plans. My discomfort around homogenising all disabled children as vulnerable was shared by Liddiard *et al*. (2019), who notes that this classification contributes to the othering of disabled children, whilst also working to silence them in research. For Clark *et al*. (2015), this othering highlights how power laden and discursive the concepts of ‘child’ and ‘disability’ are. Despite the ethical complexity of potentially discussing ‘risky’ topics with ‘vulnerable’ participants, one of the main objectives of this research was that the stories of how young people experienced hospitalisation were told and heard, rather than being silenced or misunderstood.

Before fieldwork commenced, I was aware that ‘sensitive topics’ could emerge during discussions with participants. Hyden (2013) argued that sensitive topics are relational, and depend not only on the narrator and listener but also on the context, time, place and space of narration. Ellis and Bochner (2005), supported by Hyden (2013) argue that making space in research for so-called sensitive issues to emerge is vital to a holistic understanding. Making space (both physical and discursive) for participants to tell their stories was important both to the participants and to me as a researcher. I noticed that often a ‘sensitive’ topic such as bullying or suicide was brought into discussion by the participants without any prompting. I noted how the participants did not appear to be uncomfortable, nor did they avoid these topics or stop speaking about them. Ellis (2007) argues that facilitating discussions around ‘sensitive’ topics during research is part of an ethics of care, and advises that we sit with the discomfort of stories in order to reflect and learn from them. Bochner (2001; 2002) notes that quite often it is more uncomfortable to the listener and reader of the story than the teller themselves.

6.3 Relational Ethics

In this research, I have applied what Ellis (2007) calls an ‘ethics of care’, which is closely related to what she terms ‘relational ethics’, and it has thus been at the forefront of this project and central to its design and conduction. Relational ethics operates in the relationship you have with others (participants, readers, etc.). Simply put, it is about managing and maintaining good, caring and truthful relationships with others involved in or impacted by the research. Ellis (2007:4) asserts that ‘relational ethics is doing what is necessary to be true to one’s character and responsible for one’s actions and their consequences on others.’ For example, when Ella was angry at the statistics she found which suggested that able bodied people perceive disabled people as undateable and would never consider dating someone who is disabled, I shared her feelings of anger and frustration. Similarly, Joe explained the powerlessness he felt when he was restrained by medical practitioners and force fed against his will. I could not and did not appear unaffected by their stories. The relationships that we forged and the care that I have for participants meant that I naturally showed my emotion and concern, empathising with them as they were telling me their stories. Kiyimba *et al*. (2016) discuss witnessing stories, and suggest that researchers experience vicarious traumatisation. Pearlman *et al*. (1995) explain that this is a result of the researcher empathetically engaging with participants’ trauma narratives, arguing that witnessing the stories participants tell about their pain, fear and helplessness creates an ‘emotional residue of exposure' for the researcher (Kiyimba *et al*. 2016:471).

Ellis (2007) article warns that utilising stories in research will confront researchers with the most complicated ethical issues of their research career. Adding to existing discussions around ethics, Ellis (2007) describes 'relational ethics' as closely related to an ethics of care. According to Hill (2020), relational ethics requires researchers to act with their hearts and minds, acknowledging their intimate and interpersonal bonds with other people. Brooks (2006) recognises that mutual respect, dignity and contentedness between researcher and participants is required in relational ethics.

Parr (2010) also recommended 'allowing'*[sic]* the participants to take control of the research and make important decisions about it. She suggests that her own research was successful because the child participants involved in the study had power and autonomy to make decisions. She explains that this minimises the power relations between adult and child. Furthermore, the adult researcher's knowledge was not prioritised over the children's knowledge (*ibid*). Whilst Parr (2010) has some useful ideas, I think it is important to be sensitive to the notion of adult researchers 'allowing' children to have power, as this, yet again, positions the adult researcher in a more privileged position. Parr (2010) identifies her position of power as an adult and a researcher, and chooses to limit her control in the research. Whilst her effort and intention to minimise power relations is clear, it could be argued that she still reinforces her power as an adult researcher by stating that she 'allowed' *[sic]* child participants to have 'power', highlighting that it was within her power to 'give' (and therefore take away). This research draws on Parr's (2010) work as it has similar intentions to my own in terms of attempting to minimise the power relation between researcher and participant; however, it uses Parr's (2010) work as an example of why relational ethics should be maintained even after the research has concluded. This study refrains from using power laden language such as 'allowing'. It takes the position that, instead of giving or allowing young participants, it invites young people or helps to facilitate them. I do not restrain them or refrain from any topics of discussion with them. I assume their input to the design and direction of the project. Relational ethics therefore does not end when you leave the field, but must be maintained through the write-up and any future publications of the research. I am therefore careful in the discourse used not to present participants as less authoritative or powerful that myself.

I felt it was important to keep in mind ethical advice from other, more experienced, researchers whilst carrying out this research (Liddiard, *et al*., 2018; Ellis, 2007; Bochner, 2001; Wellington, 2000; Hammond *et al*., 2013; Coffey, 1999). Furthermore, this research also planned to have participants involved in the analysis and writing up of the project, specifically their approval as to how I framed them within theory. However, instead of inputting, some participants preferred not to see how I had written about them, giving me full responsibility. Whist at first glance this may appear to be less complicated and easier, for me, this was a complicated and uncomfortable space. I found this uncomfortable because everything I had read around ethics informed me to disseminate my findings, not just in publishing my work but by 'giving back' to the research participants (Wellington, 2000), which I sometimes could not do as participants were disinterested in what I had written. Further to this, it is perceived in the social sciences, and in qualitative research in particular, that this ongoing dialogue with participants is a good way to validate the interpretation of the data (Wellington 2000; Liddiard *et al*., 2018)

6.4 Informed Consent and Anonymity

My ethics application was approved by the university and my conduct during research was guided by its regulations (see appendix 5 for letter of approval). For example, information sheets and consent forms were provided to all participants in two forms (text form, and easy read form). These explained that the research was voluntary and explained that participants could withdraw at any time. The participants were asked to sign the consent form if they agreed to the research. Two of the participants were under the age of 16, and while they signed consent, it was compulsory that their parents/guardian also gave voluntary informed consent. In both cases, the young people gave consent prior to their parents/guardian. I wanted to ensure that the young people's decision to be part of the research was their own and not based on their parent's/guardian's decision (Skelton, 2008). For Joe, his father was present in his interview with me, and for Ella, her mother had already given me permission to use Ella's blogs, explaining that she reads all of Ella's blogs before she makes them public. Anonymity was compulsory for participants, because of the danger of narrative foreclosure (Freeman, 2011). I thought it was ethically sound to anonymise their stories in case the way that they represented themselves now differs in the future. I had a conversation with all participants in which I explained that while I would do everything in my power to maintain confidentiality it could not be guaranteed, as some had published their stories on other platforms already (Shakespeare *et al*., 2010). Whilst trying to have good relational ethics with the young people in her study, Parr (2010) 'allowed' *[sic]* children to be primary decision makers, enabling them to decide whether they would like to participate before approaching their 'significant adult' for consent. BERA (2011) suggests that a parent or care giver's consent is 'informed consent'. However, most social science researchers will seek to gain ethical informed consent from children or young people, in addition to parental consent. Mortari *et al*. (2012) discuss the nuances of gaining consent from children and their parents, and warns researchers to be aware of 'adult gatekeepers'. Adding to the debate, Cree *et al*. (2001) suggest that the 'gatekeepers' are usually parents or carers who judge whether their child has the 'capacity' to inform researchers. Whilst this is likely to be a factor in social research, I think most parents would be worried about potential harm to their child.

Within this project only two participants, Joe and Ella were considered 'children', for whom parental consent was sought at the beginning in addition to participant consent (see examples of both consent and information sheets in appendix 1,2,3,4). As with all participants, Joe and Ella's consent was sought as an ongoing process. Joe was the first person who showed interest in being part of the study, and was very upfront in wanting to be involved; however, his parents worried that talking about his medical condition, anorexia, whilst still trying to recover from it, might prove too much and his recovery progress would suffer. At this point I took the difficult decision to leave him out. However, one month into data collection I was approached by Joe's father who asked me if I was still doing the project and if Joe could be part of it. After speaking with my supervisors I agreed that, despite his parents' initial concern, Joe would be included, given that they were now willing to give parental consent. While BERA (2011) suggests that this could be contrary to 'doing no harm', psychological or otherwise, this is a really interesting ethical moment that makes me question who is able to make assumptions around what will and will not cause psychological harm. Joe was very eager to be involved and was persistent in wanting to take part in the project from the start, to the extent that he persuaded his parents to allow him to be included.

Ella on the other hand was part of an online support group. She came to my attention through her online blogs about living with her impairments. After explaining my project to her she was excited to help and her parents were willing to give informed consent. Her consent was given at the beginning and she asked me to use the blogs she had already written as data. She offered to answer any questions I had about her blogs and suggested I email her if I had any questions. Her mother was happy for me to use her blogs as data as they were already public. It is worth noting that Ella continued to blog about her experiences after data collection was complete. Therefore, as part of this research, only blogs between 27th Feb 2014 -25th March 2017 have been included in data analysis.

I have taken Cree *et al*. 's (2001) advice; that researchers should move away from 'informed consent' and towards a practice of 'provisional consent', which was sought at every step in the research process. Similarly, Ellis (2007) encourages autoethnographers to practise 'process consent', checking at every stage of the research to ensure that the participants still want to be a part of the project. Despite the difference in terminology, both Ellis (2007) and Cree *et al*. (2001) illustrate the difficulties of consent when adhering to formal guidelines. During the research, two participants withdrew; Rachel informally withdrew by not responding to any contact that I attempted to make. The data she provided before her withdrawal is still used in this research as she has not asked me not to use it. Jazz withdrew formally, explaining that she wished she could help me more but felt she needed to focus on her own studies. She gave consent to use the data I had already collected. Whilst their withdrawal, at the time, was frustrating, I believe it is a good indication that participants felt able to and knew how to withdraw. For me this indicates informed consent at the onset because they knew and understood that their participation was optional.

6.5 Doing No Harm and Leaving the Field

In order to ensure that the research process is not distressing, researchers are required to adhere to BERA's (2011) ethical guidelines, which assert that any potential harm should be addressed and spoken about before embarking upon research. BERA notes that harm can include both physical and psychological distress (2011). Hammond *et al*. (2013) note that researchers should be open and honest with the participants, explaining the research process to them at every stage. Hammond *et al*. (2013) further suggest that keeping details from participants about the process of research could potentially cause them anxiety. BERA (2011) deems anxiety as psychological harm, which should be avoided.

While I continued to remind the participants about what was coming next in the research process, this study was purposely designed in a way which facilitated participants having some control over the planning of the project. Arguably, allowing for a flexible research design provides greater transparency and thus reduces the potential of doing harm.

Wellington (2000) highlights that sometimes research topics are difficult to talk about. He illustrated the need, on these occasions, for researchers to have a heightened sensitivity to their participant's needs, warning researchers that this might result in psychological harm. Ellis (2007) similarly explains that when a researcher asks participants to recall their past, it can evoke emotions from the past. She explains that the autoethnographic researcher should be aware that when asking participants to recall their past, one is also asking them to re-experience their emotions from the past. This was something I spoke to participants about prior to any other communication. During data collection whilst talking to William, there was a pause at one point and William said 'oh this is getting personal', but after I asked if he was alright he continued with his story. He did not seem distressed or emotional at the time, although his story was very evocative and whilst he did not get emotional I felt a deep sadness for him as he explained the physical, mental and sexual abuse he experienced as a young person. The next day, I still felt this sadness and I thought about and reflected on what he had told me. I felt it necessary to contact him again to check on his wellbeing and again, once I had transcribed the interview, I asked if he would like to change or omit anything that he had said. However, he chose not to change anything in the transcript.

Ellis (2007) suggests that the wisest researchers understand that any research can be considered as unethical, and it is naïve to think that research is harmless. However, she advises to be wise but not cynical, and states that:

> ‘[t]he wisest know that the best they can do … is not good enough.’
> Ellis (2007:23)

With ‘doing no harm’ in mind it is important to consider how and when to leave the field. In autoethnography, researchers are advised to stay in touch with the people who took part in the study (Ellis, 2007, 2004). Whilst I considered this, and perhaps naively, planned to stay in contact with participants, I found that participants naturally ‘drifted away’ during the write up stage of the research, preferring not to be involved and choosing to have distance. As this was their decision, I interpreted this to mean that they had participated as much as they wanted to. Subsequently, I did not push participants for a continued relationship.

6.6 Researcher Vulnerability

Feeling emotional for participants’ stories was not something I initially envisaged, nor is it something that ethics committees such as BERA (2011) give guidance on; however, throughout this study I was be supervised and guided by experienced researchers in this field as well as researcher colleagues, who helped me navigate some emotional and evocative ethical dilemmas. Widdowfield (2000) suggested that not only does the researcher affect the research process, but they are also affected by the process. McGarrol (2017) argues that it is therefore vital that researchers reflect upon their own emotions during the research process in order to be transparent in the meanings they are making in research; a perspective shared by many such as Coffey (1999) and Hammond *et al*. (2013). Elder *et al*. (2003) propose that fieldwork cannot be separated from the researcher’s life course and it is indeed undesirable to separate the two; instead the researcher’s life course events and emotional work should be presented as inter-linked. Hubbard *et al*. (2001) suggest that work that involves one’s own feelings, especially strong and intense feelings, can be described as emotional labour. Carroll (2013) highlights that the researcher’s job includes acts of emotional labour and there are specific risks to the researcher when researching sensitive topics, such as illness. Whilst these risks may affect researchers in different ways and at different times of their life, there is a lack of attention to and acknowledgement of emotional labour in fieldwork, that both Sampson *et al*. (2008) and Woodby *et al*. (2011) suggest will catch the novice researcher off guard. At the start of this process, and having engaged in autoethnographic work prior to this thesis, I thought of myself as prepared for the emotional labour of research. However, as Sampson *et al*. (2008) and Woodby *et al*. (2011) anticipated, I did still find myself feeling intense emotion. I felt angry and frustrated for the participants who took part in the study. I felt saddened, reading my 14-year-old voice, remembering how helpless I felt at times. I remember the feelings of fear and being scared and unsure, and felt these emotions resurface while immersing myself in the data.

One of my ethical dilemmas was whether I include aspects of one participant’s story where they disclose a childhood of abuse and sexual assault. The participant was clear that this influenced their feelings and perceptions of hospitalisation, and that this element of their story was important. However, this research restricts these details. As a researcher I want to justify my decision to do this. However, if I was to justify this there would be risk of harm to another person, not a participant but linked to the research in another way.

I experienced strong emotion listening to the participant’s story, and also conflicted and sad that my research was not going to offer a space for a detailed discussion of this aspect of their story. I felt torn, and struggled to balance the responsibility I had to not only accurately represent participants’ stories and protect participants and myself as a researcher from harm, but also who are attached to the research by proxy. Further to this, I reflected on who might read the research and how these details may affect potential readers. I realised that I was not experienced enough to negotiate this dilemma alone, so turned to my supervisors for guidance.

The participant in question, William, was an adult at the time of data collection and was not in any danger. Their abuser was serving a sentence in prison and this issue had already been dealt with by the appropriate authorities. There was no formal safeguarding that I needed to act upon, except to ensure that the participant was not giving me details that they may later regret, and to ensure that I was doing everything that I could to ensure that they were comfortable with me. Therefore, my supervisors were satisfied that the participant did not need me to take any further action, and concurred that omitting these finer details of the participant's story was the best course of action.

After establishing that the participant was safe, my supervisors turned their attention to my emotional wellbeing, offering more regular supervisions or just general chats, as they imagined the emotional labour of the researcher on hearing such harrowing stories. The work of Sikes *et al*. (2019) helped me to understand how this story had affected me. Their article discusses the complications to listening to stories that are 'too close for comfort'. They question whether researchers can ever build an emotional resilience and argue that they cannot; instead they become more experienced and better prepared in dealing with their own emotions during research. Whilst difficult at the time, I reflected that 'the day that stories like this stop affecting me is the day I should stop doing research.' What I meant by this was that my emotions taught me how deeply I cared, which is important. The point at which I am not emotionally affected by hard-to-hear stories would be a signal that I have become desensitised to such accounts and should not do research.

Throughout this thesis I have kept a researcher's reflexive diary where I have reflected at specific points in the research journey, as advised by Hammond *et al*. (2013). This researcher's diary has in some ways worked in a similar way to the diaries I kept as a teenager (as used in chapters 7 and 8). Sometimes it was to air my frustrations, other times it has helped me to understand and make sense of why I have felt a certain way. Often it has been a space where I can be honest about my anxieties and insecurities without fear of judgement. As emotions, and specifically the reflections of such emotions, help to make meaning, these reflections are scattered through this thesis. On reflection, the interrelated aspects of producing the thesis and my social life became blurred, and worrying about the future, running out of time, financial concerns, and childcare concerns, as well as the emotional toll of fieldwork, revisiting stories, and writing up my thesis, was what McGarrol (2017:240) refers to as an 'emotional hangover' which persisted with psychological feelings of unease and disquiet. I was emotionally affected by many of the accounts shared with me around hospitalisation, and often felt sad, angry, upset, powerless, or exhausted but mainly lonely, even long after interviews had concluded. McGarrol (2017, p.440) sums up how I felt when she states

> ‘By the time fieldwork was concluded […], the accounts from the wounded story tellers (Frank, 1995) had resulted in a wounded researcher.’
> (McGarrol, 2017, p.440)

Social researchers have not been silent about the continuing lack of attention to the researcher’s emotional labour and psychological wellbeing within academia (Ellis., 2007; Bochner, 2002; Coffey, 1999; Hammond *et al*. 2013; Sikes *et al*., 2019; Hubbard *et al*., 2001; McGarrol, 2017). However, at the same time emotions are considered key to many aspects of research, including fieldwork. Hubbard *et al*. (2001) argue that the emotion in research and thus the risks to researchers should no longer be omitted, hidden or undervalued, and suggests that researchers make their emotional work explicit.

My reflections echo this. In September 2019, I wrote:
‘It feels like a massive injustice to educational researchers that there is nothing outside of supervision that offers psychological support to researchers. I know that student nurses have their own counselling service that they can access, as well as 1:1 tutors, if they have witnessed something traumatic like a death or child abuse. I’ve spoken to more experienced researchers within education and sociology, in conferences, who exercise a buddy type system which provides a space to emotionally ‘offload’ to a trusted colleague. However, for the novice PhD researcher who is just trying to find their feet in research, there is nothing available other than standard supervisions and the student mental health services.’
Reflecting back, it is not that there is a need for counselling, but instead there is a need to properly engage with the psychological impacts and emotional labour of social research in general.

6.7 Chapter conclusion

Concurring with Liddiard *et al*. (2019) and Clark *et al*. (2015) I argued that the classification of young disabled people in research as vulnerable, and certain topics of discussion as risky in ethics procedures can create a potential barrier to young disabled people taking part in research, and results in their voices and stories being misunderstood, and their experiences and knowledges being devalued and even silenced. Moving on, I utilised Parr’s (2010) work as an example of why relational ethics must be maintained, even after the research has ended, especially during publication of research. I explored ‘doing no harm’ and leaving the field, and discussed how informed consent was sought in this study. I argued that consent should be perceived in social research as an ongoing process, before reflecting on how relational ethics encompassed ‘doing-no-harm’ in this study. I gave examples of my conduct when participants indicated a sensitivity to topics of discussion. Lastly, I discussed researcher vulnerability and noted how little guidance there was from ethics boards to navigate researcher discomfort and vulnerability. I reflected on this discomfort and highlighted its value in social research, before arguing that there is a greater need for social researchers to fully and properly engage with the psychological and emotional impacts of doing research.

Chapter 7 – Gaze, Normativity and Resistance Through the Mundane.

7.1 Introduction

This chapter explores the theme of normativity. Here, elements of different theories are applied to the data in order to interpret and understand the data from different angles. This section offers accounts to illustrate how young people felt they were perceived as non-normative in everyday encounters in the world, both in and outside the hospital. The chapter discusses how hospitalisation constructed normativity, whilst also problematising studies that provide a theoretical grounding, albeit perhaps not intentionally, to ignore the humanity of hospitalised children and young people. The chapter explores the process of Othering and details this process through the perspectives of the participants in this study. This chapter illuminated parts of participants' stories that shifted the bio-medical gaze onto their practitioner and where participants reiterated their preferred identity. In this section we see how participants have made explicit links to unhelpful media portrayals of hospitalisation as well as their desire to problematise such portrayals. This chapter is about young people's identity struggles within the hospital, how they believe they are perceived and how they come to perceive themselves.

7.2 – Labelling and Stigma

Whilst labelling and stigma is a common theme in other research (Barnes *et al*, 2003) which includes disabled people (Curran, 2013), my data highlighted how important the topic was for hospitalised young people. Participants in my research demonstrate a detailed understanding of how labelling and stigma affected their experiences

> *'Even though 1 in 500 babies are born with Cerebral Palsy, the majority of people probably don't really know what the condition entails. It is our job to raise*

> *as much awareness as possible therefore people will become more educated and less afraid of becoming friends with someone with CP like me'*
> (Ella)

Here Ella notes how common her condition is and concludes that people are afraid to become her friend. She perceives this as a lack of education about disability and perceives it to be her responsibility to raise awareness and provide education. Here she is trying to be proactive in her desire to obtain more friendships. She feels othered by her peers who she suggests 'don't want to be seen with the disabled girl' and longs for acceptance. Ella's feelings here align with the findings of other researchers who suggest that disabled children are denied the understandings of normative childhood, framing them and their childhood as unfortunate and abnormal. (Runswick-Cole, 2011; Curran *et al*, 2014)

When discussing her labels, how they affect her and what they mean to her. She wrote a blog demonstrating how the stigma of the labels she lives with causes her deep sadness

> *'I have been having a very up and down couple of months and I do get really frustrated sometimes. I don't understand why I have been given this particular life, why I have brain damage and why I can't just be like everyone else […] at the moment I am not able to do some of the things that I would love to be doing because of poor seizure control. I am not able to explore our world how I would like to […] in a few months I hope I'll be able to achieve small goals that mean so much to me such as going to school full time, going out with friends independently and to be able to go swimming! These may not seem that important or critical for happiness but for me this is all I want to do. I just want to get some of my life back!'*
> (Ella)

Here Ella is referring to the struggles of living with her medical labels and how ill health affects her freedom in life. The effects of illness are never experienced in a vacuum and instead are experienced and perceived through power and culture (Morris, 1999). I interpret Ella's post to be a friction of her prescribed identity (being Cerebral Palsy and having Epilepsy) - and her chosen identities (that is school student, sociable friend and swimmer) which draw parallels with Crenshaw's (1991) notion of intersectionality. This draws attention to the intersectional complex of disability and childhood. As Ella has become ill due to poor seizure control, her most prominent identities to her are those of her prescribed identity while her chosen identities are less prominent in illness. Ella is explaining how her chosen identity and prescribed identity do not align. This is noted by other scholars (Slater, 2013; Crenshaw, 1991; Goodley, 2011) who refer to these tensions as intersectionality. Intersectionality is a concept deriving from the work of Crenshaw in Critical race theory but utilised often by disability studies scholars.

Crenshaw (1991, p,1297) herself notes how the concept is valuable for a wide range of disciplines, asserting that it is useful as 'a way of mediating the tension between assertions of multiple identity and the ongoing necessity of group politics'. Slater (2018) and Liddiard (2018) emphasise the importance of the concept to researchers hoping to gain a deeper understanding of disabled children and young people's experiences. Later on, Ella dedicated a whole blog to directly address common myths and stereotypes about disability. Justifying her decision to do this, Ella writes:

> *'the reason I have decided to write about this topic is because many of the stereotypes surrounding disabilities are pure myths and have no truth to them at all therefore I would like [to] help people understand what it is really like being a disabled person instead of just going on our stereotype which are mainly very untruthful and old-fashioned […] common stereotypes surrounding disability include the inability to have a good quality of life, incapability and being introverted'*
> (Ella)

Ella writes a long blog about common stereotypes so it is paraphrased here. Ella explains and argues that many disabled people have fulfilling lives, that not all disabled people are shy and that many disabled people are very capable. Stereotypes and societal stigma was a topic Ella addressed frequently in her posts showing how much it mattered to her. The negative effects of stereotypes around disability have long been discussed by disability studies academics. Davis (2010) notes that stereotypes and normalcy were influenced by eugenic structures in the 19th century. Whilst the above data shows a very matter-of-fact, diplomatic approach to the discussion of stereotypes, other posts capture Ella's emotion.

> *'I love how I never used to feel different, disabled or less able than others. People used to accept me just the way I was and didn't care about the way I looked. But now people are so judgemental about disability. People are worried what their friends will say if they spend time with the 'disabled girl'. People do not want to be seen with me. Everyone has imperfections, I just think that people should get over what's on the outside and be friends with the person within the body instead of just going on looks […] what a lot of people don't realise is [that] my cerebral palsy effects everything I do from walking to writing and eating to sleeping. My disability effects my hands as well as my legs, this is why you will see my hands in fists when I'm tired. I've had to learn to accept that I'll always be disabled and that there is no cure or treatment which will change that. I am happy with who I am so why can't you be? I'm in pain 24/7, I fall a lot which is really scary for me because I can't stop it. It takes so much effort for me to walk even 10 steps. I've had to cope with all this and I don't want to have to endure people being horrible as well. Please can you be more considerate and see the person instead of the disability'*
> (Ella)

Here Ella is addressing the effects that her cerebral palsy has on her body. She describes the effort it takes and the pain she feels before stating that people are worried about being seen with her. She notes that she is accepting of her disability, despite the pain and obstacles she faces and wonders why other people cannot be as accepting as she is. She notes that she has enough obstacles to navigate and wishes that she did not have to navigate 'people being horrible' as well. Her post here indicates that she has experienced an unpleasant social situation where she felt stigmatised. She feels the need to explain her struggles as a way to justify why other people shouldn't make her 'endure' more difficulties. Reeve (2014) discusses experiences such as what Ella is describing as a form of psycho-emotional disablism.

In relation to stigma and stereotypes of disabled children Curran (2013) notes how the illness itself or hospital buildings are perceived by many, including the general public and disabled children and their families, respectfully, as the primary sources of oppression.

This was noted by Joe when discussing the space, he was allocated in hospital he noted

> *'I just put some posters up really. We couldn't do much to make it more personal. I used to just phone my mum every night […] I'd ring her every night it's all I could do really'*
> (Joe)

Joe is noting how the space he was in was not personal to him he felt dislocated in the hospital and called his mum in order to feel connected. Similarly, William notes the hospital space

> *'there was a corridor and off this corridor there was dormitory type spaces and, in each dormitory, there were 8-10 beds. And it was blue linen and horrible, like the old teaky looking furniture, blue curtains that stank and windows that had bars on them so you couldn't get out, fire exits had erm, what do you call them? erm, tie wraps around the security bits so that you don't run away'*
> *(William)*

However, Curran (2013) also note how, despite its contribution to stigma and stereotypes, within wider societal discourse, the medical profession are far less likely to be accused of causing oppression and upholding unhelpful stereotypes and stigma around disabilities, (an observation also noted by Tremain, (2017) and Kitchin (1998). As such, it is important to consider how medicine and specialist professions might contribute to stigmatising theories of disability (explored more in sections 7.2 and 7.3). While discussing the consequences of her impairment Ella can be understood to be addressing the consequences of societal stereotypes and stigma. In another post she writes:

> *‘In this post I will basically be going on about how society sees disability.*
> *I recently read that just 5% of all people over the age of 18 have EVER considered dating or had a relationship with a disabled person. This seriously needs to change, we are just like anyone else, why is it such a big deal to date a disabled person?! It's not like we only date disabled people so why should able bodied people only date other able bodied people?! This is a topic that I am really passionate about, maybe this is because I have never had a long term relationship and the reason they all have ended it is because they don't want to be seen with the 'disabled' girl.*
> *I would like to send a message to those idiots: Get over it, I'm disabled I always have been I deal with it so you can too! Get over yourself!*
> *Anyway, it isn't just this that really annoys me, it's how grown adults don't even address disability right. For example, a few years ago my old SENCO (special needs person at school) said to me and my mother how privileged she was to finally work with a SPASTIC! Yes, you read it right she called me a spastic and she was supposed to be a specialist in special needs, this made me so angry and upset, but also caused me to lose complete faith in there ever being equality for disabled people.*
> *So you get the point. Please, if you are able bodied reading this blog and never see a disabled person on there own, go over there, be nice and treat them like anyone else.’*
> (Ella)

Ella is evidently angry in this post where she addresses how stereotypes around dating someone with a disability impact her own life. Liddiard, (2018) notes that dating is more complex for disabled people due to the impact of societal stigma and stereotypes. Ella’s post draws parallels to Goffman (1963) when he explored the idea of labels becoming embodied by culture creating a stigma that has more serious consequences on an individual’s life than the diagnostic label itself. He suggests that disabled children eventually embody and internalise the stereotypes that have been constructed for them (ie, anorexic, vulnerable, child ‘in need’) by their cultural understandings of difference, noting how the concept of ‘normal’ derived from medical understandings. Ella is addressing these ideas in her blog. Her voice seems to speak directly to non-disabled people and she instructs the non-disabled reader that if they see a disabled person alone then to ‘go over there, be nice and treat them like anyone else’

Noting Goffman’s (1963) observation that disabled people eventually embody and internalise the labels that they are given and the meanings, created by culture, that are given to such labels, also draws parallel to William’s accounts.

> *‘like I am a person detached and disengaged with what perhaps is the essence of my being. So I know it has shaped me into becoming the person who I am and that experience particularly did because you know well I was branded a delinquent and, well you know however you wish to term it but that’s how I felt but I was given the label of bi-polar so for me, it is the essence of my being and that’s what shaped me’*
> (William, 2)

William notes how he felt judged by the adults around him stating:

> *‘In the terms of how they were categorising me and putting me in that unit was really detrimental in that respect because it judged me prior to me being who I am or even allowed to become who I am.’*
> (William)

This suggests that, whilst William has a complex and perceptive understanding of stigma and his reflections demonstrate his awareness of how others were defining him at the time of hospitalisation, he felt that he did not know himself. William notes that the experience of hospitalisation as well as the societal stereotypes and stigma which surrounded him, has made him into the person he is today. Here William is refuting, or finding strategies to refute being defined and stigmatised in the way he felt he was as a young person. This links to discussions around identity (as discussed by Goffman, 1963 and Butler, 2004). Whilst William is very aware of how social stigma and stereotypes operate around him now, it is important to remember that William is reflecting on his earlier, childhood experiences of hospitalisation and expresses that as a child, he did not have as comprehensive or complex understanding as he does now. It is worth noting that William expresses sadness while reflecting on his hospital experiences as a child. Many studies discuss the identity struggles of young people in terms of age and development (Wyn *et al* 1997; Berk, 2010) which would fit this data here; however, it is important to recognise the ageist approach taken in such studies, also highlighted by Slater, (2013) and Azzapardi, (2013). Similar to other participants, aged 14, I wrote:

> *'epilepsy, epilepsy, epilepsy. That's all they [adult/medical] care about. They want to make me normal again. They don't care about me, just my epilepsy.'*
> (Holly's Diary)

From the above quote I seem to have a concept of normal and suggest that the doctors are neglecting me through their focus on treating my seizures. I note the use of the word 'again' suggests that I had felt that I had moved from a category of 'normal' to 'abnormal' during the process of hospitalisation. Goffman (1963) also identifies that the concept of 'normal' stemmed from a medical perspective. Which highlights how I felt that the doctors' medical perspective perceived my body and seizures to be abnormal which successful treatment would, in essence, 'make me normal again'. Similar to Goffman, Butler (2004:25) uses the example of sex and gender, stating:

> 'Being 'in' and 'beyond' the body, but in the move from the natural to the articulated body. That one is not born, but rather becomes […] this 'becoming' traverses a path from disembodied freedom to cultural embodiment. Indeed, one is one's body from the start […] a sculpting of the original body into cultural form […] to 'exist' one's body in culturally concrete terms means, at least partially, to become one's gender expectations'.
> (Butler, 2004:25)

Applying a Critical Disability Studies (CDS) lens to Butler's (2004) ideas, it could be argued that bodily difference is inscribed with certain societal expectations.

The quotation above highlights how identities or labels which are given to individuals and assumed to be biologically fixed, can be embodied, enacted and performed by the individual, which Butler (2004) argues, is a circulation of cultural norms and assumptions which associate a different body with certain stereotypes. These are reinforced and enacted through socio-historical and cultural expectations of what it means to be young and disabled. In other words, to 'exist' in one's impaired, ill or disabled body, in culturally concrete terms means, at least partially, to become one's stereotype (Butler, 2004). Moreover, it could also be argued that the spaces which hospitalised children occupy begin to reinforce performances which circulate stereotypes within culture, including performances from children which demonstrate their understanding of adults' perceptions.

William also suggested that hospitalisation hindered him from discovering who he was:

> *'When dealing with the issues, the practical issues that were home, that were school which was my entire existence and my acceptance of who I am as a person. The abuse, the homosexuality and instead of looking at those which were difficult instead they looked at my mother, she was bi-polar and she was being treated for bi-polar and she had been sectioned, in and out, in and out, in and out of units and so they looked at that and kind of said, oh well he must have an element of it and instantly just carbon copied me, carbon copied her, on me and put an element of her on me which I thought was very unfair'.*
> (William)

As discussed above, William noted how his, often rebellious, behaviour brought him to the attention of professionals. In the above data, William notes how his behaviours were perceived as a symptom of bipolar. He feels upset and let down that the other difficult things in his life such as his home environment, abuse and trying to understand his sexuality was disregarded in the understanding of his behaviour. He feels that these were overlooked because his mother had a mental health condition and he was not helped in the way that he should have been as a young person. He felt that this was because it was easier to diagnose him with the same mental health problems as his mother. Interestingly, William uses the term 'carbon copied' which, I think, is quite powerful because it suggests that William felt that doctors had imposed the image of his mother onto him. Rather than being recognised as an individual, he is de-humanised and seen as an extension of his mother. The dehumanisation of disabled people is well documented by social modelist scholars such as Goodley, (2011);

Barnes *et al*, (2003); Oliver, (2009) Morris, (1999), Davis, (2010) amongst others and is not a new concept. William's accounts, I would argue, further support the work done by these scholars by highlighting that despite progress in law and social understanding of disability (Equality Act 2011 and DDA 1995; Oliver, 2009 Davis 2010, Goodley 2011), many disabled and ill people still feel dehumanised through the process of diagnosis and medicalisation (Shakespeare, 1999; Davis, 2010, Goodley, 2011).

Drawing on the notion of intersectionality, in the quote above, William raises the issue of his sexuality and how, when combined with a label of disabled, it was not permissible (as also explored by McRuer, 2006 and Barounis 2009). William further emphasises his environment and recalls how he felt at the time.

> *William: 'My perspective was, I wasn't happy at home, I was being bullied at school. I had parents that really couldn't give two monkeys about what I did or what my life was all about. I suppose in a way, you could say it might have been attention seeking but it wasn't attention seeking in a way, erm, it wasn't attention seeking with all the bad connotations that come with or come from attention seeking. Erm yeah it was just, I attempted suicide and that wasn't attention seeking that was just like with the intention of not to be here [laughs]*
> *Me: when did that happen? How old were you then?*
> *William: That was partly what put me into that unit.*
> *Me: oh ok, so that wasn't on the unit when you did that?*
> *William: no, no, no. I attempted suicide whilst I was erm, I was abused as a child and so it all came out when I was about 14 and erm, I didn't get on with my stepdad he was erm, I came out all at once at 14 as being gay, I came out with the abuse story and nobody believed me. No one was even prepared to even sit down and listen. [they asked] Why are you making these stories up, are you just attention seeking?*
> *Me: how did that make you feel when you got that response?*
> *William: I was absolutely dumbfounded, I was, I felt like I was lying. I was made to feel like I wasn't telling the truth and anything I said I had to really think about it and you were doubting everything you said. You were doubting your own beliefs at some points. Particularly, you know because you think am I? am I not? Is it just a phase? Is it the abuse that's caused this? Did I make this whole*

> *story up? But I hadn't imagined it because the man was eventually locked up but at that time when the whole thing was happening, I was made to feel that I had conjured the whole story up, that I'd fabricated it from nothing. They thought it was because I felt some kind of gay tendency and that it was going to be a phase which I would eventually grow out of. Yeah, that all kind of compelled my mum and my step dad, my mum was kind of more interested in my stepdad, I was more of an inconvenience to my mum. She didn't want me in the house, she didn't want me when I came back'*
> (William's interview)

On interpretation, this data could suggest that, when we become ill, the biological (which is the concerns of doctors) disrupts the lived reality, which was William's experiences: sexuality, a childhood of abuse and his home and school life, which he felt to be important. Ekra *et al*'s (2012:402) study collected adult memories of being a hospitalised child, which highlighted the significance of the emotional effects of 'becoming ill' stating:

> 'When we become suddenly ill, the harmony between the biological and the lived body is disrupted and the malfunctioning body part appears in our consciousness'.
> (Ekra *et al*, 2012, p. 402)

This resonated with William's words highlighting the disharmony between what William thought was the problem and what the doctors constructed as the problem resulting in viewing William's body (rather than his environment) as 'malfunctioning'. Disability studies scholars such as Goodley, (2011); Barnes *et al*, (2003) Morris, (1996; 1999); Oliver, (2009) and Davis, (2010) argue that disability is always situated in the environment rather than in individual bodies. It can be viewed here that William holds a social model understanding of disability and is situating his 'problem' with his environment and the attitudes and preconceived ideas of the doctors. William perceives the doctors, on the other hand, to hold a medical model view of disability and are situating his 'problem' within his body, constructing it as a malfunctioning genetic trait (Davis, 2010; Goodley, 2011; Barnes *et al*, 2003).

Interestingly, despite Ella's perception that stigma often stemmed from the label itself (as discussed more widely here) Ella hoped for a definitive label. She perceived that this label would move her further down the road to recovery and be an end to the multiple medical tests that she is expected to endure. She writes:

> *'I had one seizure during the test so hopefully now they have captured that, they will be able to give my family and I more information and a firm diagnosis […] if they don't get all the information they need from this test, I will be admitted for 5 days and they will try and capture more and different seizures'*
> (Ella)

Whilst participants often felt compelled to acquire a label it was framed as a means to an end. The label was perceived as an end point to the medical testing and hospital admissions. When discussing William's composition of 'The Last Flight of the Dragon'. Interestingly, he notes that a diagnostic label itself is 'the sad ending'.

> *'William: well that was just one episode, I mean there's no resolve here. You know this, it will just keep repeating this, every episode, it's the same pattern of they put me in the unit and I keep trying to get away, they give me a label and I'm defiant, they add another label and I tease them, they bring me back and I keep going. Its tiring. But it's like your diary. You have to take the medication, I have to be bi-polar. That's the sad ending!*
> *Me: oh ok, yeah*
> *William: so you see where I'm coming from like here, you can see here [points to music transcript], I'm labelled, there's no getting away from it, that's it! But see [points to music transcript]. From that note I can either spin on that note or I can move onto something else. And that note there's not really anywhere else to go but up, to fly, you get what I'm saying?'*
> (William, 2)

I interpret that the assertion of the label being 'the sad ending' in William's music is a note to feeling disappointed in the realisation that acquiring a label is not the end of medical testing and admissions. He highlights it as a low point [pointing to the transcript] whilst also stating that he can 'spin around on that note or move to something else' noting how he felt his options were limited. William goes on explaining:

> *'Me: So when you wrote this then, which event were you thinking of? Was it a specific event or admission that made you feel like this?*
> *William no its more general. It's about it as a whole. It's about how it makes you feel and how the music makes you (me as listener) feel. Like I said, I didn't have entry points into it and this was the entry point I was familiar with but its general and not representing a specific event as such. It's about the consequences it had. What the consequences of that hurt, that pain, that mistreatment, that label and what consequences that had on me and yes, it has helped me to become who I am now but instead of outwardly expressing my emotions I tend to [short pause] well I go to music.'*
> (William, 2)

William notes how his music is intended to be a tool to evoke emotion in his listener and highlights how it encompasses the consequences of feeling hurt, pain and mistreatment. He acknowledges how it has shaped the person he is today in that he struggles to outwardly express his emotions and how music is a tool for him to release certain emotions, including revisiting past emotions by using his music as a 'entry point'. Similarly, Magee (2002) notes how music is an important and useful therapeutic tool. While her research focuses on disabled adults, it is applicable and draws parallels to William's descriptions of what his music is and what his music intends to do. Magee (2002) notes that music is a tool that has an ability to surpass the barriers of spoken word. Magee (2002) notes how important music is to individuals in hospital, especially those who feel that verbal communication is challenging or not possible. William describes his music as an entry point, not just to being understood but also to be able to discuss his experiences verbally.

William illuminated how he had to discover what the doctors thought were normal in order to act as they wished:

> *‘when we all got our medication, so we'd all line up like cattle to go ‘arrrgg’ [opens his mouth and tilts head back and makes noise] and then they had to check. Urr, urr [opens his mouth and moves tongue from left to right and up and down, imitating what he had to do to prove he had swallowed his medication]. This is children. I was 14/15 years old.’*
> (William)

> *‘The communal area, oh communal area, this is so funny, those other kids would sit like this [sits in a rigid position, stiff, hunched over looking at the floor and rubbing his fingernails up and down the tops of his legs] they would scratch their legs like this. Some would rock and as soon as the nurses went they’d stop and get up and make themselves a cup of tea […] when you did what they expected you to do then you were more likely to be left alone.’*
> (William)

This demonstrates a performative aspect of his behaviours in a similar way to that of which Butler (2004) discusses above. It highlights how he, and others around him were interpreting expectations of them and performing them in a way which they believed was expected of the specific label as also highlighted by Morris (1999). Interestingly, he notes that this became a useful tool in order to be ‘left alone’. Here William is demonstrating an awareness of not only the implications and expectations of his own label, but also the labels of those around him. This understanding of his own and other peoples labels contradicts some interpretations in literature about children’s ability to understand their own bodies, minds and labels.

Beresford *et al* (2003) described young people with medical conditions as having superficial and incomplete knowledge about the management of their body in relation to their medical condition. Beresford *et al* (2003:173) state:

> ‘Among children and adolescents with chronic conditions, their knowledge about their condition and its management is often superficial’.

With this in mind, I have to wonder who, and by what measurement, in Beresford *et al*’s (2003) study distinguishes ‘superficial knowledge’. These ideas could, potentially, have negative consequences to the wellbeing of children and young people. Such ideas make it possible to overlook William's embodied 'knowledge' and the explanation of his behaviours as a direct result of a disturbed home and school life, a childhood of abuse as well as trying to understand his feeling towards his sexuality whilst dealing with the societal stigma that is associated with being gay (McRuer, 2006). William's awareness of the other patients' patterns of behaviours go some way to contradict Beresford *et al*'s (2003) claim.

Ekra *et al* (2012) argue that framing hospitalised children and young people's knowledge as incomplete or superficial 'others' them and further reinforces the unequal distribution of power which exists between children and adults, especially in a hospital setting (Bricher, 2000; Snyder *et al*, 2001; Davis, 2010).

Noting the effects of othering. Ella finds an article that suggests that only 5% of adults over 18 have dated or considered dating a disabled person and blogs her reaction to this. She writes:

> *'This seriously needs to change, we are just like anyone else, why is it such a big deal to date a disabled person?! It's not like we only date disabled people so why should able bodied people only date other able-bodied people?! This is a topic that I am really passionate about, maybe this is because I have never had a long-term relationship and the reason they all have ended it is because they don't want to be seen with the 'disabled' girl.*
>
> *I would like to send a message to those idiots: Get over it, I'm disabled I always have been I deal with it so you can too! Get over yourself!'*
> (Ella)

Here, we can observe Ella's frustration and how she feels that disabled people don't limit their dating to only other disabled people and that she feels it is unfair that abled bodied people do. She alludes to the stigma of being disabled and how non-disabled people can feel this stigma too when dating the 'disabled girl' and suggests the stigma of being disabled limits able bodied peoples' dating options (also discussed by Liddiard 2018 and Barnes *et al*. 2003). Addressing this directly in a voice that seems to speak to abled bodied people, she suggests that if she can deal with her disability then any potential partners should ‘get over it’. She highlights the ableist norms around dating and is seen to challenge these norms in her frustrations. She feels Othered by being discounted and dismissed as a potential partner. She is challenging the assumption in society that abled bodied people should not date disabled people and says ‘this seriously needs to change’.

Joe identifies that Othering does not only occur with a disabled identity but also emerges with gendered identities.

> *‘I just wanted to help you [with research] so that you knew that boys get anorexia too and I think it’s really important that you know that and it isn’t girly that it’s important that you can tell people’*
> (Joe)

It can be interpreted that Joe feels there is disharmony between his chosen identity as male and his prescribed identity of someone with anorexia, again highlighting intersectionality. When people’s chosen identities are dismissed or devalued it can lead to feelings of oppression as the chosen identity is othered (Richards, 2008). Joe is referring to the stigma of anorexia being a female illness and feels conflicted between the two identity groups. I interpret that Joe feels othered within his impairment group (a person with anorexia) due to his identity as a male. This is also discussed by Deal (2003) who highlights a hierarchy of impairment and discusses how mental illnesses are considered low on the hierarchy and when the presented identity. In Joe’s case, male, this contradicts the assumptions and stereotypes of the impairment itself, such as anorexia being an illness that affects women. As such, further othering occurs in that the individual does not comply with either an anorexic identity nor a male one.

This section has discussed how the young people in this study were aware of how they were perceived as non-normative, as well as how hospitalisation restricts normative behaviours (Kitchin, 1998). It details contradictions between the perspective of the young person and that of their medical team in terms of their identity and the causes of illness. I discuss Beresford *et al*’s (2003) claim here that children and young people have superficial and incomplete knowledge about their bodies and minds. This study challenges Beresford *et al*’s (2003) claims as the young participants in this study demonstrated a strong understanding of their body and mind as well as their behaviours or ‘symptoms’ of illness. Participants did not only demonstrate a strong understanding of their own bodily performativity but also that of those around them. This section argues that Beresford *et al*’s (2003) claim is not helpful to young people in hospital and could potentially have damaging consequences as it minimises children and young people’s understandings and disempowers their lived reality, whilst also working to further silence their voices. Through the process of othering, the dehumanisation of ill and disabled children and young people bodies and minds can occur (Davis, 2010; Barnes *et al*, 2003) Beresford’s (2003) study therefore, is providing a theoretical grounding or basis to justify ignoring young people’s humanity which this study seeks to challenge.

7.3 – The Oppressive Nature of Hospitals

This section draws on participants' stories where they recall and describe feeling oppressed and Othered. Participants use a variety of methods to communicate these feelings including interviews, music and poetry. Furthermore, participants make direct links to unhelpful stereotypes in the media and suggest that these contribute to their feelings of oppression and Otherness.

Within William’s interviews, he depicted his behaviours as a side effect of the environment he was in. He suggests that his behaviours mimic his mother’s behaviours and he was struggling to deal with a childhood of sexual abuse, his mother’s medical condition, home life and school life as well as his sexuality.

> *‘it just kind of escalated, oh yeah, school, I changed my name and the reason being was, was the school I went to I was picked on, I was called a [racial slur], and 3 lads trapped my wrist in a door and they crushed my wrist and broke my hand in 3 places […] yep, and this was, well now were talking about age 12 at secondary school, erm, and I always stank of smoke, of stale cigarette smoke and home life wasn’t nice, school life wasn’t nice and then one day I just flipped.*

> *I didn’t want to know anybody, I just did my thing and I rebelled, I was on report at school, I was, I was just a rebel.’.*
> (William)

William describes his behaviours as rebellious and details rolling a large manhole cover down a building site, building and crashing go-karts, running down a motorway and getting into trouble at school which ultimately lead to police involvement. These behaviours, he believes, led to police, teachers and his mum becoming suspicious of his mental health, ultimately viewing him as acting in a way that deviated from his ‘normal’ behaviour. William’s behaviour was extreme in the sense that he put both his own life and the life of others in danger through his actions before he came to the attention of the police. Slater (2012; 2016) argues that young people, particularly those who are considered disabled, are deemed as criminals in their political activism, rather than a group of people who feel let down and frustrated with the current system. Therefore, disabled young people, such as William, might have their resistance understood as criminal. Due to William’s ’rebellion’, it was viewed that his behaviour needed to be medically explained, observed, pathologized and regulated through the use of medical interventions (Davis, 1995; Deal, 2003). Therefore, even the notion of rebellion and resistance are socially contained to include, exclude, measure and surveil what acts are deemed to be too different or too rebellious (surveil being a transitive verb with negative connotations).

Due to the association of mental illness which his mother had, and he was now suspected to have, his voice was not being heard, and therefore, his mother’s voice, as adult, and doctor’s voice (as able adult specialist) appeared to hold more authority than William’s. This notion is supported by Wood *et al* (2013) and Bricher (2000) who note that children are presumed incompetent to make decisions about their health care due to their immaturity and lack of comprehension.

The idea of children being incompetent decision makers is also noted in my own diaries:

> *‘I don’t want to take Keppra [a specific medication]. I don’t understand why they [doctors] are so obsessed with it. Why can’t they just get a different tablet for me that isn’t Keppra?’*
> (Holly’s diary)

The above extract highlights my confusion and frustration when the decisions I had made about my medication were not valued or respected by the professionals around me at the time. I feel that this again highlights a deep developmentalist understanding that I was not able to make informed decisions about my healthcare due to my age, as also highlighted in Slater’s (2013) work. This is a topic that is explored in more detail in chapter 8.3 but is used here to highlight how my age contributed to me being excluded from medical decision making. It is worth noting that taking or not taking this medication is an ongoing theme within the diary entries and often I portray a feeling of oppression in terms of being overpowered during these entries.

William portrayed his feelings of oppression in the music he had composed and shared with me (see appendix). In the piece ‘The Last Flight of the Dragon’ he depicts himself as a dragon, wounded by his past but still wanting to fly away, his attempts to be heard and helped further injure him. I interpret his musical story to portray oppression, hopelessness and confusion as well as hope and resilience as the dragon emerges, each time with a new scar, making it more difficult to fly, exhausted from the pain but needing to survive. The dragon eventually rests, leaving his audience to imagine what will happen to the dragon next. William is therefore leaving his listener in a state of uncertainty. For me, William’s music is powerful as it allows his listener to imagine his feelings during the time of writing. He is trying to show his listener rather than tell his listener what it felt like. Through this music, William’s listener is never told anything, instead they are taken through a figurative journey with him to experience what he experienced (or at least that is what I think William is attempting to do). William offers more insights into his music during an interview with him:

> *‘William: there was but then he [the dragon] was injured a lot as well, I’ve given you hope just before an abrupt ending*
> *Me: well what happened to the dragon then?*
> *William: What do you think happened to the dragon?*

> *Me: I don't know, did he die?*
> *William: well that's for you to interpret but i'd definitely say that at least a piece of him did. A piece of him has gone!'*
> (William, interview 2)

William's intention to create unease in his music highlights his desire to communicate uncertainty and disruption within his hospital experiences. When pondering what could have happened to the dragon he claims that 'definitely […] at least a piece of him died' noting what I interpret as a signifier of permanent change.

Richards (2008) supports the view of permanent change to oneself after long term or recurred hospital admissions and explains how her psycho-emotional wellbeing is compromised as an adult due to her childhood experience of hospitalisation. She explains that, 'any unexplained symptom takes on a dreadful significance of impending doom', (Richards 2008:1721), highlighting how she embodies and performs societal expectations and understanding of '*being*' unwell.

Also noting the disruption of hospitalisation to everyday life is Jazz, who describes going into hospital:

> '*It isolates you and takes you away from what your normal day-to-day life is and just by being there you begin to feel isolated and not normal in a way.*'
> (Jazz)

From the above statement, it can be argued that, like William, Jazz is rendered abnormal which she feels deeply when admitted to hospital. If we utilise Kitchin's (1998) work here to look at how place and space disable individuals by letting disabled people know if they are 'out of place', we can see and interpret Jazz's own feelings to the hospital environment. By feeling like she needed to be in hospital makes her feel abnormal. This also is reflected in a poem I wrote whilst in hospital as a young person; I describe how I felt abnormal and trapped. Here, I described myself as 'like a snail with two shells' as I was under medical surveillance. In the poem, I pleaded to 'let me be normal' showing how, like Jazz and William I felt deeply oppressed and judged as abnormal. I wrote:

Poem 1:

‘Bored,
Bored of what people might say, think or do.
My body feels alien to me.
It’s not me, I’m not this, I am better. I can do better.
But it’s easier said than done.
If you take away the epilepsy and all my problems, I will prove it to you.
Please let me show you.
You have never seen the real me.
The normal, confident, Holly’
(Holly’s diary - poem)

I interpret this to mean that I was not happy with the expectation they had of me as a disabled young person. I was frustrated that they didn’t see past my label and alluded to medical professionals as being able to take away my label. This suggests I was aware that they had given me the label of epilepsy, and thus was aware that they had some power over how I was perceived. I see my voice in this poem to be directed at the medical profession as I plead with them to be perceived as more than epilepsy. Similar to William, I alluded to being viewed through the prism of medicalisation. I describe this perspective as ‘boring’ and suggest that other aspects of my life are more interesting and note-worthy. The expression of boredom could also be interpreted as a resistance to the oppressive nature of the hospital. William and I both create a distance between ourselves and the medical professionals, William does this by switching the gaze to the professionals whereas I do this by minimising their gaze on my illness.

Street *et al*. (2012) depict hospitals as being a separate island far away from mainstream society. The idea of hospitals being far removed from the mainstream also establishes hospitals to be not normal. Further to this, Jazz notes that popular media contributes to the Othering, isolating and de-humanizing of children and their experiences of hospital and reinforces the dominant narrative, which is a discursive narrative of dysfunction where children are depicted within societal stereotypes as brave or in need Barnes *et al*. (2003) highlight how popular culture and media portrails are unhelpful as they suggest evil or depravity. They argue that this is damaging to disabled people, an observation also noted by Shakespeare (2006). Jazz uses the example of the 'BBC's Children in Need' as well as *Casualty* which depicts hospitalised children as having a different life to 'normal children' (BBC Children in Need, 2018) and thus render hospitalised children as different to children that are not in hospital, (different being depicted as abnormal). This sense of isolation from the mainstream was felt when Jazz was admitted to hospital.

> *'when you're young there's always that, erm, knowing that you don't really know what is wrong with them and you do see programmes on television like Casualty and Children in Need and stuff that makes you think it's terrible, like and you know people die in hospital and stuff, basically you have a very grim picture before you go in and I suppose that is what makes it kind of intimidation but when you're there you don't think that. It's a bit confusing when you first go into hospital like, errm, I mean you have an expectation of what it will be like from watching tele and stuff and you brace yourself but it wasn't like that for me.'*
> (Jazz)

I argue here that such media representations contributed to Jazz's feelings of her being or becoming (culturally) abnormal (Barnes *et al*, 2003; Butler, 2004; Davis, 2010). The media depictions of ill children being 'in need' or as 'brave' (seen in such programmes like Children in Need), I argue, only serve to further isolate the embodied experience of hospitalised children. Slater (2013; 2016) makes an interesting observation arguing that young people who are politically active (actively showing disapproval with the system) are seen as not 'living up' to their depiction of 'in need' and 'vulnerable'. When young people actively show disapproval with the system, the depiction of dangerous youth and unruly bodies instead are projected onto the young person as troublesome. With Slater's (2013; 2016) observation in mind, and in contrast to William's self-confessed 'rebellion' which challenged media's dominant and dysfunctional narrative of hospitalised children, we can perhaps interpret Jazz as experiencing oppression as she has no other option than to 'live up' to such depictions of being 'brave' and 'in need' as to avoid the more negative depictions of being troublesome to society as discussed in Slater's (2013; 2016) work. I argue that William challenged the depiction of being brave and in need and resisted ‘living up’ to societal expectation. He demonstrated his politically active voice through his rebellion. His behaviour was seen as troublesome and was further medicalised whereas Jazz avoided further medicalisation of her behaviour by choosing to ‘live up’ to the expectation of being ‘in need’ and ‘brave’. The idea of depicting hospitalised children as brave is interesting and here Jazz reflects on how being brave was often contradictory to how she felt in hospital.

> ‘*I still have to have those cannulas now but in all honesty it’s just like, like a real superficial brave sort of thing and I’ll just go in there and just sort of sit there and you know, well as long as I’m not looking while its done and then that’s it but [laughs] that is not the honest me because on the inside I’m like this is horrible. It’s in me, get it out, quick and get it done with [laughs] but I don’t know, I suppose that’s just that one of those things that you try and be brave if you like. You’re always told to be brave all the time and when you’re in hospital you’re told that you are brave so you kind of feel that it’s important to be brave at that time, yeah, like especially with needles or other procedures’.*
> (Jazz)

Circulating the narrative of ‘brave children in the hospital’ within popular culture allows for only a dysfunctional narrative. Deviating from this pre-approved social narrative of brave not just renders a child as abnormal but instead, dangerously abnormal (Slater, 2016), as seen in William’s case where his resistance was further medicalised. Media portrayals therefore silence the embodied reality and frustration of hospitalised children whilst also systematically silencing their voices, rendering it further abnormal to be anything other than brave (Barton, 2005). This governmentality of children’s bodies and minds links back to Britcher’s (2000) work around hospitalised children not being considered mature enough to make healthcare choices. However, noting Jazz’s statement above, it seems that she was not viewed as competent enough to know how to feel either and instead was told how to feel. In feeling conflicted (not feeling brave but told she was brave) arguably meant that her experience of hospitalisation was disembodied through society’s pre-approved narrative for hospitalised children. I interpret that Jazz is told what her experience was (i.e. she was brave, she is thankful to the Dr’s etc.) This is a favourable narrative which is often reflected within media representations of hospitalised children. However, her actual experience (not feeling brave) did not align with this narrative and was therefore devalued. I question therefore, to what purposes do we subscribe to societal expectations of hospitalisation, (that is the expectation that children in the hospital are brave and patiently await the prescribed treatment of the heroic doctors that fix and cure their impairments, restoring normality in their lives that have been disrupted by illness.) Furthermore, I question whether this single and accepted narrative of children in the hospital can be viewed as simply a way to get children to comply, or as Slater, (2013; 2016) Azzapardi (2013) and Hart (1997) would argue, a way of silencing young people's political voices. It is worth noting here that I am not arguing that individual doctors premeditate the silencing of children's voices, instead it is a consequence of their training, teachings, values and expectations of them to apply medicine as prescribed.

Jazz goes as far as to explicitly list the media sources (Casualty and Children in Need) which portray hospitals as an awful place to go. She shows an association of death with hospitals highlighting the intimidating and scary messages children receive from culture about hospitalisation. This depiction of hospitalisation is, so far, largely unchallenged, see for example Dewhurst *et al*. (2015) leaving young people like Jazz to learn about hospitalisation via sensationalised versions such as Casualty and Children in Need.

Slightly differing from Jazz, Ella blogs about her experiences of attending a hospital appointment:

> *'We did pretty much what we always do when I have an appointment in the city, of course we went to IKEA! I had a hotdog and a milkshake so life was pretty good.'*
> (Ella)

Ella, like myself and William, is creating distance from medicalised perceptions of illness and hospitalisation. She does this by diverting her audience's attention to the positive aspect of going to hospital. Like William who framed his own behaviours as normative, Ella frames her hospital experiences within the culturally accepted notions of normal, like visiting IKEA and eating food (Barnes *et al*, 2003; Davis, 2010). By framing hospital appointments in this way, ‘life was pretty good’, it can be interpreted as a way of challenging the depictions in the media of hospitals being unpleasant. Here, Ella is transgressing the notion of a hospital being anything other than normal (Mallett *et al*. 2014). Azzopardi (2013) argues that, ‘young people are the protagonists in this discourse of resistance and seem to be aware of the struggle for public space, ‘fighting’ to reclaim ‘legroom’ that will contribute to helping them access society.’ I would add, in Ella’s case, she is using her embodied experiential knowledge to help portray a more holistic depiction of hospitalised young people through her blog writing. Ella writes a blog ‘oh the Joys of hospital appointments’ where she details an appointment. In this blog, she foregrounds her teenage identity by highlighting what she perceives as notions of normative teenage identity. She writes ‘Imagine, 5 days in one room with NO WIFI! How will I survive?!’ she reinforces her normativity with a selfie which she adds to the blog.

In her selfie, Ella can be seen with electrodes attached to her head whilst having an EEG (electroencephalogram). She is taking a selfie whilst pouting her lips and making a peace sign with her hand (middle and index fingers make a V-shape whilst the palm of the hand is facing outwards). Here, Ella is posing with the electrodes as an accessory. This is not unlike Ella’s blogs and in others she photographs her splints and ponders which colour splints to wear and what shoes might go well with them, again framing her splints as an accessory. Through this, Ella can be seen to be challenging societal and cultural stereotypes around ill and disabled children. Foregrounding her teenage identity, and interests in fashion and photography she can be seen to encourage her readers to see beyond the dominant narratives of hospitalised young people. Runswick-Cole (2018) and Goodley (2011) offers similar observations of disabled children who they argue, respectively, are the perfect protagonists and catalysts for social change.

Whilst Jazz and Ella demonstrate a lack of fear of hospitals and procedures, Rachel goes further in not only situating hospitals as familiar but also framing hospital procedures as an enjoyable activity.

> *‘I was used to going to the hospital so I wasn’t scared […]. I remember enjoying myself when they put the heart monitor on my finger because it beeped if I moved my finger.’*
> (Rachel)

The hospital narrative that Rachel, Ella and Jazz give, of hospitals not being scary and even fun isn’t portrayed in ‘Children in Need’ or ‘Casualty’ as suggested by Jazz. I have to argue then that given the stories of the participants in this study that media portrayals do not represent the embodied experiences of hospitalised children and young people's lives. Instead, the media portrays a dominant narrative of vulnerable, upset children in hospitals who bravely face the treatment from heroic and charitable doctors who restore the value to their young lives (Barnes *et al*. 2003). This narrative does not acknowledge the lived experiences or voices of young people. This dominant and dysfunctional narrative then contributes to their stigma, othering and feelings of oppression and isolation (Azzapardi, 2013; Slater, 2013; Barnes *et al*, 2003).

Jazz highlights how the hospital environment is isolating which can act as a catalyst to feeling abnormal.

> *‘when some of the people, including school staff actually came to visit me in the hospital which was really special and I remember feeling special at that time and I just think that that was really nice of them. One thing about being in hospital is that kind of, even though it’s for your own good it’s that kind of, slight isolation I suppose from the things that you are normally doing. You know like I mentioned I was in school, I was in year 4 or whatever and I was kind of ‘the norm’ whereas when you are in hospital you are relying on those people to come to you. You rely on those people to normalise your time in there*
> *Me: what do you mean by that?*
> *Jazz: well, it [hospitalisation] isolates you and takes you away from what your normal day to day life is and you start to feel isolated and not normal in a way but if your normal day to day life comes to you it makes you feel less isolated and erm well I suppose it makes you feel a bit more normal again.*
> *Me: oh ok I think I understand now*
> *Jazz: that is something that I do remember the feeling of, the feeling of joy when I was seeing people when they would come to you, yeah. It makes you feel*

> *supported in a way and remember your normal self but equally, you're kind of relying on them to come just so you can feel, errm, yeah like when they come you kind of feel a bit normal again.*
>
> (Jazz)

Jazz is suggesting that the hospital environment itself isolated her and contributed to her feeling abnormal. She highlights how when her family, friends and school staff visited her in the hospital it made her feel normal again but she also highlights the dependency on them to visit her. Here, Jazz is subscribing to Street *et al*'s (2012) depiction of hospitals as a lonely island separate from the mainstream society, an Othered island where Othered people stay. Goffman (1963), through his famous work on stigma was eager to emphasise that the concept of 'normal' and 'abnormal' originated from a medical perspective of disability. He argues that children eventually embody the societal stereotypes that have been constructed and placed upon them.

Scholars such as Procter, (2015) and Kitchin (1998) add another dimension, arguing that identity and society are also situated, contextualised and reproduced through space. It could be argued that the hospital spaces which children occupy position them into stereotypical performances of what it means to be a hospitalised child. Jazz for example is offered a stereotype of hospitalised children as 'in need', 'brave' or 'heroic'. Using Kitchin's (1998) ideas, it could be argued that, like Jazz, these stereotypes are embodied by children in hospitals. This, in turn, reinforces these stereotypes within society, in an ongoing cycle.

William's reflections of being in hospital he takes a philosophical stance to understand his experiences. Here he draws on a spatial element in his reflection of how to be a being in a hospital space.

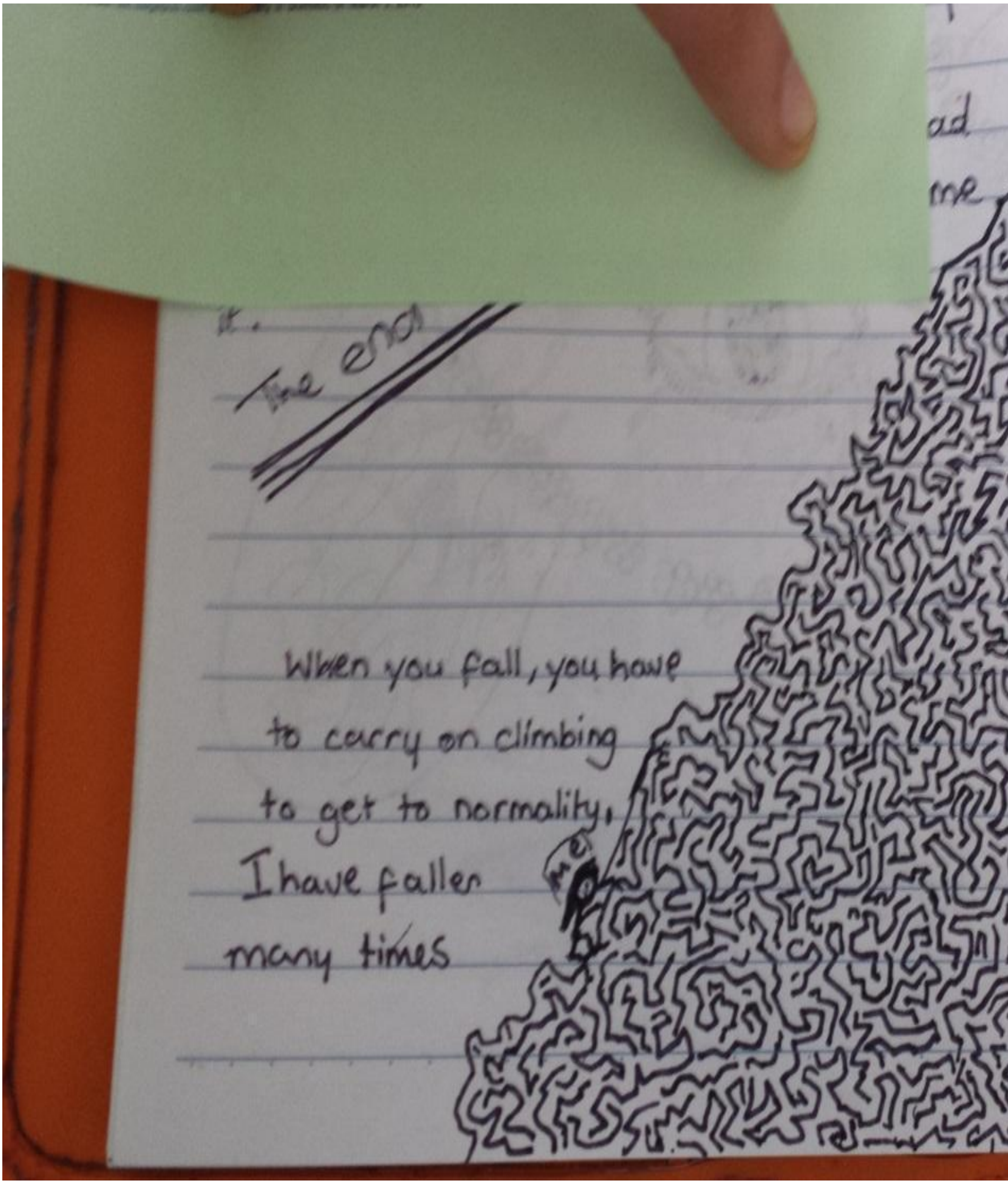
> *'William: I guess being in hospital is literally being in hospital, it is how you be, how you live in hospital, how you learn how to live in hospital. being in hospital is more complex than going to hospital. which is more transient, it's a passing, it's a one-off occurrence. Being in hospital is more complex than going to hospital […] so yeah it's about learning to be you in hospital. its understanding*

> *wider things like what's expected of you and it is about the struggle to resist them, it's the dragons struggle to resist it and be ok in the end despite it.*
> *Me: ok*
> *William: so, my point is that being in hospital is learning to be one's label or at least act as one's label? Do you know what I mean? This isn't making sense is it?*
> *me: yes! It is, I just want to make sure it makes just as much sense later when I revisit this conversation. You're saying that in hospital you have to learn what it means to be bi-polar or epileptic, what's expected of someone with that label then how to survive both in and out of hospital with thus label*
> *William: yes, 'being' is a human being, who is simply being human in a hospital that doesn't always treat you with the humanity and dignity you require as a fellow human being*
> *me: yes! I understand and I agree with you. Its more complex*
> *William: yeah, going to hospital simplifies it as a journey of a sort. Journeys have endings, they reach a destination. Being in hospital is consistent?*
> *Me: so what's the significance of being then?*
> *William: well, how I see it is that being in hospital is consistent trauma and still learning how to be a being through it. It doesn't stop at the hospital doors, not when you've had that level of trauma in there. It does something to you. It changes you. Your learning about yourself takes on a whole new scary level where your forced to defend yourself too, defend your worth, you have been forced to develop resilience which in some ways is good because it teaches you how to get through tough situations but then the actual teaching is hard to take, you know?'*
> (William, interview 2)

With this in mind, we can begin to understand the structure and societal framings of hospitals that encouraged Jazz and myself to feel dislocated and William to embody his label when we had to go to hospital. I argue that it is not the label that creates a permanent change or an 'impending sense of doom'; instead it is the experience of being and learning how to be in hospital that results in a permanent change.

Kitchin (1998) argues that spaces have cultural scriptures which dictate to people, specifically disabled people (and I will also add here, ill people) when they are ‘out of place’. Here, the hospital acted as a reminder to Jazz, William and myself that we were not free to be normal, not free to leave the hospital until we were back to ‘normal’, until we also internalised and conformed to the expectations of normality. Having to reject our purported flaws, which in turn denied a part of our individual identities, or as William depicts ‘the piece of the dragon that dies’.

Supporting this is an image I created as a young person. I depict an image of myself on a mountain referring to this as ‘the epilepsy rocky mountain’. The figure has a caption which says ‘*when you fall, you have to carry on climbing to get to normality, I have fallen many times*.’ The top of the mountain is horizontal and is labelled ‘normality’, illustrating that I felt I was put on an uphill struggle to achieve what doctors perceived to be normal. I have positioned myself on the mountain towards the bottom of the image.



This picture depicts how I understood myself as not normal as-well as how I perceived I was framed by the adults in my life, in that I believed they considered me as being far removed from ‘normality’. My feelings here align with many other disabled people who feel they are removed from normalcy. (Morris, 1999; Barnes *et al*. 2003; Davis, 2010; Goodley, 2011).

Interestingly, Ella seems to suggest that one can enter in and out of ‘normal life’. Ella also suggests that ‘normal life’ can cause illness (which is a theme picked up later on in this chapter.

> ‘*If you rush back into normal, busy everyday life then you will probably end up pushing yourself too hard which will result in an increase in seizures, then you'll be back to square one’*.
> (Ella)

Interestingly, Ella is suggesting that one person can enter and/or exit ‘normal life’ despite having an illness that is constant. Again supporting William’s philosophical reflections that it is the being in hospital rather than the label that is creating an Otherness and denying a piece of our identity. If we draw on critical disability studies (CDS) we can begin to make sense of the entering or exiting illness identity. Goodley (2011) argues that disability is a temporal state and everyone is only ever temporarily able bodied (TAB). I interpret that, similar to myself, Jazz and William, Ella feels more disabled when in hospital as her disabled identity is the main focus within the hospital space, giving less room to understand her other identities

Returning to Foucault’s (1975) concepts, we can begin to theorise bio-power and disentangle the ideas of self-surveillance, which is the surveillance of the self to ensure that the self stays within the parameters of what is culturally considered to be ‘normal’. Foucault (as translated by Lynch, 2011) suggests that we surveil ourselves to ensure that we do not deviate from ‘normal’. Our deviant behaviours (e.g Joe’s refusal to eat or mine and Ella’s seizing bodies) were viewed as ‘abnormal’

Using Foucault’s (1975) ideas, the discourses of normality running through the narratives starts to unravel the complex dynamics of a surveilled relationship with regards to bio-power. For example, William can be seen to switch the gaze onto the medical practitioner’s performance rather than his own behaviours in his musical composition ‘Fellow delinquents like I’. This piece is interesting on several levels and despite his rejection of any mental health labels and his suggestion that he did not have a mental illness, he depicts himself as a delinquent in a way that resists mental health labels. His choice of words here are interesting and purposeful, and as he explained in an interview that he was hoping to transgress and re-signify the term as discussed in disability studies literature by Mallett *et al*. (2014). I interpret this piece as William's resistance to medicalisation and an attempt to switch the gaze from himself, onto the medical professionals

Snyder *et al* (2001) utilise Foucault's concepts to highlight that for disabled people, the body has become a site of power/knowledge under the surveillance of medical 'experts' who use the medical 'gaze' to identify deviance and establish 'the subject' as a patient who needs fixing. These ideas are also explored by Reeve (2002) and Siebers (2011).

However, using the interdisciplinarity of CDS social theorists (such as Davis, 2010, Oliver (2009); Barnes *et al*. (2003); Finkelstein (2003); Morris (1999), amongst others) identify how ideas around 'normal' have evolved through time and depend on socio-cultural and historical contexts. Ella's for example, directs the cultural gaze onto her normative teenage identity and like myself minimises her disabled identity. This works to oppose the medical model of disability that pathologizes and individualises difference and disability, locating the 'deficits' within the disabled subject, which in turn strengthens the cultural gaze upon difference and abnormality (Goodley, 2011; Johnstone, 2001).

To put it simply, the enactment of medically constructed categories such as illness or abnormality (Davis, 2010; Goffman, 1963) is both temporal and environmental, in the same way Goodley (2011) argues disability is. Medical constructions such as this perpetuates the bio-medical power to control and regulate bodies and in doing so adds to its disciplinary conviction. This power then recirculates through spaces (othered or not) to enforce and ensure that (ill and disabled) identities are upheld by certain individuals in a way which recirculates and contributes to its own power and prestige within society (Kitchin, 1998; Foucault as translated by Lynch, 2011).

Within this section, I explored notions of normativity and highlighted that, for ill and disabled young people, two notions of normativity are at play: 1) what it means to be a normal child; 2) what it means to be a normal child in hospital. This section again reiterates that children and young people are not only aware of their own bodies and minds but also those of other people around them. They are aware of how other people perceive them and receive messages from parents, doctors and media alike that informs them what is expected of them in order to be perceived as normal. Young people however, often challenge these perceptions as they are aware they are being perceived through the prism of medicalization and often work to reiterate other aspects of their identity such as their age. This section also depicts the mental pain and trauma children experience whilst resisting these perceptions and how sometimes they can start to perceive themselves as non-normative or ‘like a snail with two shells.’ The data in this section supports Slater’s (2013; 2016) work where they argue that young people with impairments feel they have to ‘live up’ to what is expected of them by society and when they do not, or resist, they risk being perceived as troublesome or risky. In this section, I demonstrate how media depictions of illness, such as BBC Children In Need and Casualty, can have negative consequences to children in the hospital as they do not feel that their experiences align with such sensationalised versions of hospitalisation. This in turn, I argue, works to further silence the voices of young people in the hospital and devalue their embodied realities and knowledge’s.

7.4 – Staring and Surveillance

This section draws on elements of participants' stories that detail being surveilled. It argues that staring and the biomedical gaze have different processes and highlights the psycho-emotional effects and dehumanisation of the biomedical gaze.

> *‘school is ok. Once you learn how to live with the endless stares and whispers’* (Ella)

Ella is noting the nature of staring, she also mentions people’s whispers which suggests that this is an oppressive experience for her. Ella is drawing on a topic, staring, that has long been noted by disability studies scholars. Garland-Thomson (2010) argues that the act of staring is a communicative gesture and can sometimes be a positive encounter rather than political. Ella notes that she had to learn to ‘live with' endless stares. I interpret this statement by Ella as aligning more to Sontag (2003) understanding of staring which is deemed as an 'unworthy desire', framing stares as a visual intrusion and a surrender to unconstrained voyeurism. Garland Thomson (2010) and Sontag (2003) both note that the intention and how someone stares is more important than if someone stares. They note that staring with a will to become empathetic is different and can be a positive encounter. Whilst in the above statement Ella doesn't seem to interpret the 'endless stares and whispers' as a positive or productive experience she does in other blogs encourage a type of staring and guides her reader to empathy within her writing. An example of this is when she writes

> *'so, there you go, all my medications! 23 pills a day plus painkillers if needed, everyone says I must rattle'*
> (Ella)

Here Ella is allowing insight and makes a light-hearted joke at the end to brush past the curiosity, allowing her reader to know that she is fine with the idea of so many pills. Moreover, she has an awareness that the general public/her readers may find this excessive but writes to appease curiosity whilst also drawing on humour to enable her reader to relate to her as a person and thus turn an ethical corner (Garland-Thomson, 2010). However, Ella also notes discomfort with medical staring/gaze when she writes:

> *'then I had to do what you always have to do before appointments, I have got quite bored of this by now, being weighed and measured. I didn't mind this so much when I was little but all teenagers have some level of self-consciousness, including me, therefore even though I shouldn't, I find this slightly awkward and embarrassing'*
> (Ella)

Here Ella is highlighting something more than a stare. She highlights a consistent measurement of her body over time. The continued measurement of certain aspects of her body are kept under medical surveillance. This consistent observation turns a stare into a medical gaze. Ella illuminates how her perception of the medical gaze over her body, during hospital appointments, makes her feel embarrassed, as also discussed by French (1993). She notes that this is perceived differently now as to when she was 'little' highlighting her growing awareness of medical gaze.

French (1993) talks of the phenomenon known as 'public stripping', describing this as a direct consequence of the clinical gaze which leaves the 'gazed at' feeling vulnerable, exposed and humiliated. Reeve (2002) explains that being made to feel vulnerable and exposed is a form of psycho-emotional disablism as well as institutional abuse. 'Gaze', or more specifically, the 'Bio-medical Gaze' is much more than being looked at, starred at or watched. It is not transient and temporary like starring. Instead, it involves the process of pathologization as I will attempt to unpack in the rest of this section. Ella sheds some light on this process when she details how a doctor ordered her to have more tests. It should be noted that Ella speaks a lot about having different tests and different appointments and feels frustrated and annoyed by the frequency and intensity of medical testing. She writes:

> *'the neurologist wants it to be done as soon as possible, I'll likely be admitted sometime over the next few weeks. Hopefully, once the results come back from this test , my condition will become clearer and the doctors should be able to give me and my family a more certain diagnosis and further advice, which would be great […] I realise that this post has been very medical but I hope it gives you an idea about what is going to happen to me over the next few weeks […] I'll try and write about something interesting while I'm in there and post it when I'm home and back to civilization, where there's wi-fi and a proper shower!'*
> (Ella)

It can be seen that Ella is not looking forward to her upcoming test. Knowing that it will take a few weeks to be admitted to hospital highlights her familiarity with this sort of medical testing and surveillance. The test which she is referring to is an EEG and requires, quite literally, to be watched and observed. During such tests a video camera is set up to further survey her in the hope of capturing a seizure on tape. This seizure is watched by many specialists who then agree on what diagnosis to give. Ella's writing here describes and exemplifies the process of pathologization. Interestingly the phrase 'what is going to happen to me' suggests that she has been informed of what will happen but not consented to it happening. This has feelings of powerlessness. Similar to Street *et al*. (2012) who describes hospitals as being perceived as a separate island far removed from society, Ella describes home as civilization and produces home as opposite to hospital, suggesting she feels hospitals are removed from civilization. Ella then details the effects of waiting for testing, she writes:

> *'we waited and as we waited the nerves grew and grew and grew until we were finally called by the doctor'*
> (Ella)

Here Ella is describing the psycho-emotional effects of waiting for unpleasant tests or procedures. Despite experiencing these tests before, she notes that she was nervous, suggesting she is expecting an unpleasant experience. I do not think Ella was relieved to have a call from the doctor, instead I believe that she was looking forward to the testing being over. Richards (2008) highlights that 'Othering' means turning a person into an object, such as a stereotype or an item of study which can be applied to Ella's accounts above. Additionally, Richards (2008) claims that health practitioners in particular do this often. The bio-medical gaze, where one is othered as an item of study can also be observed in Rachel's story where she describes how, when she was recovering from treatment in the hospital, she was visited by many medical professionals from different departments to 'study' her rare type of meningitis.

> *'While I was ill I was given my own room because my illness was rare and they [doctors] wanted to study it without disturbing other patients which is fine but as a kid, I didn't like it, I remember being scared of people coming in and there were a lot of people! I did get upset about it but thankfully I always had my mum there'.*
> *(Rachel)*

She suggests that this made her upset, self-conscious and fearful of the different people she encountered.

> *'I remember the doctors coming with the trainee doctors asking to look at my legs, it wasn't very nice. My mom told me that they had to see it so that they could help future people since it wasn't very common'*

> (Rachel)

This is a clear example of the bio-medical ‘gaze’. Supporting French’s (1993) ideas on ‘public stripping’ via the medical gaze, Rachel’s psycho-emotional wellbeing was affected as she felt fearful and upset. Moreover, this suggests that Rachel had not consented to being studied and instead her mother consented on her behalf as she encouraged Rachel’s tolerance of the bio-medical gaze.

Leach (1994) highlights that everything adults do to the bodies of children without that child’s permission is potentially disrespectful and asks how children and young people can differentiate between feeling upset and humiliated by adults, and assault. This can be seen in the story where I felt distressed when I could not go home unless I agreed to take a tablet. Additionally, other diary entries depict how I felt that the medical practitioners were invading my personal and bodily space:

> ‘*everyone is looking and laughing at me. The nurse won’t even let me pull my curtains around’*.
> (Holly’s diary)

Once again, this highlights the psycho-emotional effects of bio-medical surveillance and the bio-medical gaze, as discussed by Reeve (2002). I describe how I desired privacy whilst I was upset but this was not granted. I note that I was ‘looked at’ suggesting I knew that I was being observed. The desire to pull my curtain could be seen as me withdrawing my consent to be observed but I note that this was not allowed. I felt dehumanised and humiliated and perceived ‘everyone to be laughing at me’ which highlights how I felt embarrassed and disrespected. If we utilise Garland-Thomsons (2010) notions of ‘good’ and ‘bad’ staring here we can see that the medical observations I was subjected to here was not met with empathy or an understanding of why I wanted privacy, instead my emotional cries were noted in an unbiased, disconnected way. This for me was not a positive encounter and I perceived this at the time as unethical. Here, like in Ella’s blogs detailed earlier on in this section we can see how bio-medical gaze as a process of pathologization moves beyond staring and encompasses surveillance, power and control (Tremain, 2017; Lynch, 2011). Demonstrating the feelings of powerlessness William describes the hospital as a ‘prison’ when he writes a letter to his doctors, which he constructed as an adult, recalling his past, William writes

> *‘To add insult to injury, the child was incarcerated without further contact with the outside world, in a residential ward, a prison for children with mental health issues to be assessed by a gaggle of psychiatrists, psychologists and social workers. Subjected to countless tests.’*
> (William)

Here, William is drawing parallels of the bio-medical gaze, likening it to being injured. This is supported by Leach (1994) when he suggests that children cannot differentiate between unwanted medical treatments and abuse. William recalls how he felt insulted. He likened the hospital to ‘a prison’, demonstrating how he felt trapped and even punished. He describes the medical practitioners involved in his care as ‘a gaggle’ which, for me, was interesting. A ‘gaggle’ by definition, refers to a flock of geese (OED, 2018) His choice of words here can be interpreted as an act of resistance, William is dehumanising the medical practitioners around him by likening them to geese rather than people. Similarly, the term ‘gaggle’ is commonly used to refer to a disorderly group of people (OED, 2018). Here, William is suggesting that the perception of his anti-social behaviours and the behaviours of the medical practitioners within the hospital have a similarity, that is, they are both disorderly. Portraying medical professionals as disorderly draw similarities with Ella’s accounts above when she suggests hospitals are uncivilised. Further parallels can be drawn between Ella’s and William’s accounts when they both note how they were subjected to medical testing. William chooses to use the word ‘subjected’ which highlights again how he felt the tests were done to him without consent whereas Ella uses the phrase ‘going to happen to me’.

Whilst it appears that the young people in this study were relatively passive and compliant with the bio-medical gaze the next chapter will deepen this understanding by adding complexity to the bio-medical gaze (as discussed by Lynch, 2011). The next chapter highlights the, often subtle, acts of resistance to the labelling, stigma, othering, oppression and bio-medical gaze described above. This chapter notes children’s resistance through the everyday, mundane occurrence where young people re-assert their preferred identity and challenging medical understandings as well as media portrayals of what it means to be a hospitalised child.

This section has discussed the concept of staring as a communicative gesture (Garland-Thomson, 2010) and explored participants' feelings of discomfort when they experienced staring. This is juxtaposed with stories in which some participants have encouraged staring (of sorts) and appeased curiosity by detailing illnesses publicly. This difference in this type of staring seems to be that the disabled young person was in control of which parts of their life was in view and were able to guide the curiosity to a more sympathetic and sometimes educational conclusion. I move on to make a distinction from curiosity and staring to gazing, or more precisely, the bio-medical gaze. I demonstrate how the biomedical gaze is not accompanied by sympathy or even education and instead is power laden. I highlight that the biomedical gaze is part of the process of pathologization and is experienced more intensely by the young people in this project. Drawing on French’s (1993) ideas of ‘public stripping’ I illuminate the deep psycho-emotional injury, humiliation and oppression experienced. This section builds on the last (7.2) as it demonstrates the process of Othering.

7.5 – The Mundane acts of Resistance

This last theme to be analysed emerged unexpectedly and after other themes were identified (as explained in more detail in the methodology section). It illustrates the juxtaposition I experienced between the identity I held for myself and that which was given to me by the doctors. Although resistance has been part of this research from the beginning and it has been explored more directly in other sections, I had not expected resistance to emerge through my narratives of the everyday and mundane, as it did. However, after analysing the hospitalised experiences which I documented in my diary in 2001, I realised that the everyday experiences were as dominant as the discussions of medical experiences. This made me wonder about William, Rachel, Joe, Ella and Jazz’s stories and if they showed any similarities with my own resistance throughout the everyday and mundane stories, which they did.

The following narrative explores these ideas and demonstrates how familiar I was with the medical setting.

> *Hi Diary,*
> *This girl in the next bed to me, called Alice, has got a Gameboy colour and she let me have a go and you have to make the Mario brother jump onto walls and then collect coins. I don't know why she is in hospital but she has to go for a scan in a bit and she said I can play with her Gameboy when she goes. I ordered pizza and a cookie for tea. I hope it is nice - the other one was salty but I'll let you know. My doctor came and told me that I have had a good day today and if I am okay in the night and in the morning I can go home, which is good because I'm meeting Ellie and Sophie on Saturday at the cinema. My nannan brought me some new pyjamas earlier today; they are really comfy and they fit me and they smell really nice. It is a pink top with a cow on it and pale pink bottoms with spots on it. I think I will wear them tonight because me and Alice are going to watch Free Willy and we already asked the nurse and she said that she will try and get us a TV, so that should be good.*
> *From me.*
> *(Holly's Diary)*

The diary extract above shows how I resisted biomedical governance and gaze. Re-writing my teenage identity into the pages of the diary was, in itself, an act of resistance, as I was resisting an othered identity given to me by medical practitioners who focused mainly on the site of impairment. Diary entries like this went some way to juxtapose the entries that were more heavily focused on the medical.

My fourteen-year-old self was transgressing the dependent, charitable object of pity, whose quality of life was compromised due to having epilepsy as seen in and reinforced through literature and media alike (such as BBC Children in Need, Dewhurst *et al*. 2015; Hemmingway *et al*, 2011; Nordli, 2001, amongst others). Instead, through writing the mundane, which refers to the ordinary everyday occurrences within my life, I reinforced my identity as an independent, sociable teenager who enjoyed watching films, going out with friends, and (apparently) pink pyjamas.

Similarly, Joe speaks in detail about how he torments his younger sister and enjoys shopping, declaring his favourite shop is Topman.

> *'Joe: I'm always teasing her, I once tied some fishing wire around this plastic spider and I taped the line to her ceiling and put the spider on the top of her door and when she had a paddy and slammed her door the spider fell on her.*
> *Dad: you do tease her quite a lot*
> *Joe: I do but she teases me too. I'm just better at it than she is'*
> (Joe)

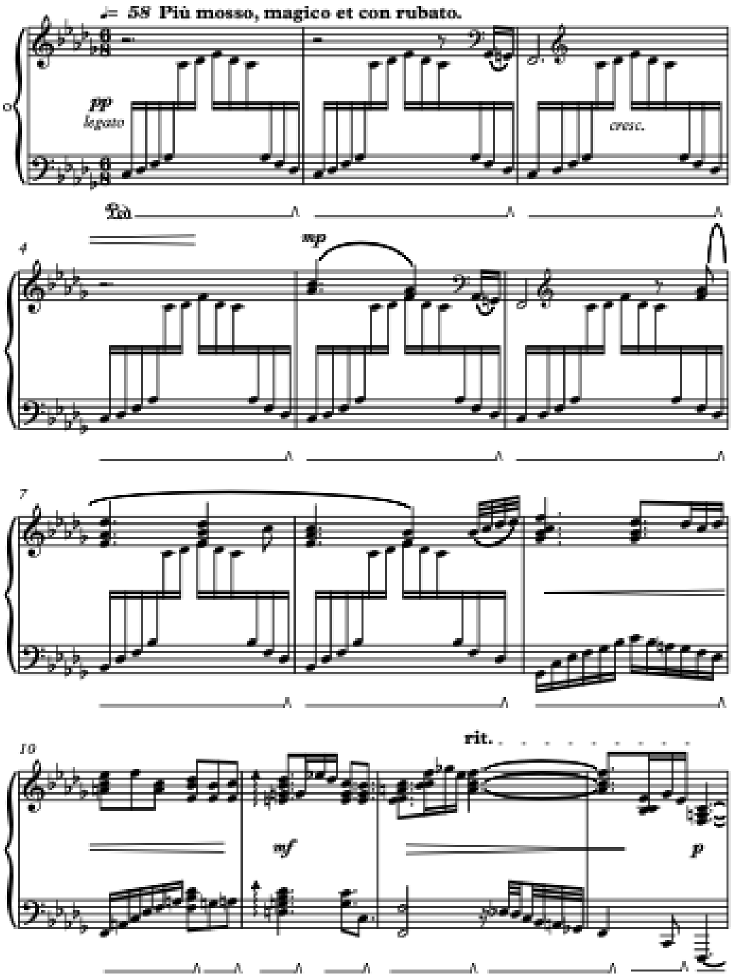
Here, Joe can be seen to assert the identity of 'older brother' making this identity more prominent than his hospital identity. Here he is projecting an image of a sibling rivalry type relationship with his sister and moving emphasis from his experiences of hospital and the medical to his personal and home life. Here, he is articulating aspects of his personality, rather than being perceived as a passive body to be acted upon he is presenting himself as 'more than' the label and even claims to be better than his sister at teasing. It is worth noting here that interviews were unstructured so Joe selected this to tell me, he is wanting me to understand him as belonging to a wider network of people, an active and potentially mischievous family member. He has the power and control to tell this aspect of his life as he claims agency over how I understand him.

Equally, Ella dedicates a whole blog entry to the mundane. She discusses her dislike for reading but love for audio books in a blog titled 'My obsession with audio books!' She talks about listening to books before bed and whilst getting ready in the morning.

> *'The only downside to audiobooks is they tend to be almost double the price of paperbacks even when it's just a download and not a CD […] It is quite annoying though because at the moment, I've been getting through them so fast. But anyway. I find audiobooks a great way to escape from everyday struggles and worries, just to be somewhere else in a different life for half an hour.'*
> (Ella)

It can be understood that through these writings, Ella is asserting her identity as a regular teenager and school student and therefore resisting a medicalised identity. This is also discussed by Evans (2017) who notes how disabled people, especially those with 'invisible impairments' *[sic]* can and often do choose to emphasise other aspects of their identity. Further to this, when the disabled identity is foregrounded, (i.e. due to illness), great effort is placed upon reminding onlookers of the other aspects of identity (Evans, 2017). It should be noted that the context of this blog for Ella the everyday struggles and worries she is referring to is that of school and exam stress. She notes how she finds this useful to relax and in a later blog lists audiobooks in her top 10 tips for getting a good rest on a school night. Again, she is redirecting attention away from her disabled identity and illuminating her teenage, school student identity (Evans, 2017). Similarly, Joe asserts his identity as an older brother and speaks of his relationship with his sister, both of whom draw attention from their medical conditions towards an identity which is more readily accepted as 'normal' by society.

William, does something similar; however, his resistance through the mundane is much more prominent in the study. When asked to share his stories, William initially produced music transcripts as data. I interpret this in itself as an act of resistance not only to the labels and diagnosis he was given as a young person but also to the power of 'professionals'. Here, I use the term 'professionals' very lightly, not just meaning medical professionals but also me, as a researcher. His choice to give music transcripts is a way of resisting any sort of power hierarchy (Foucault as transcribed by Lynch, 2011; Evans, 2017). Not only is he resisting, he is taking part in the project in a way which does not allow me access to his story in a way that I can understand, yet. Here, I interpret that William is (non-verbally) establishing his identity and constructing my understanding of him as a musician before I try to begin to understand any other aspects of his life.


♩= 58 Più mosso, magico et con rubato.
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Butler (1997) argues that the body is ‘docile’ only when the brain is ‘docile’, suggesting that disability is a mental state and by awakening the brain we awaken the body. The data utilised throughout this project, demonstrate that young people in the hospital were never ‘docile’. Young people used blogs, diaries, music, drawings and interviews as spaces to transgress dominant discourses and reassert their teenage identity, such as playing with Alice’s Gameboy and writing about my weekend plans to go to the cinema with friends, teasing younger siblings, shopping or audiobooks.

There were moments in each participant's story where their actions appeared to be bio-medically compliant, such as eventually taking the medicine (William and Holly) or asking for a feeding tube (Joe), agreeing to testing or observation (Ella, Rachel, Jazz) etc. However, I do not interpret these acts as a symbol of docility because participants choose to tell this story and thus, frame it in the way they wanted it to be framed (within a wider picture of identity). As such, we straddled different identities.

Interestingly, the mundane became prominent throughout all the data and were often narrated alongside and in conjunction with narrating more emotive or distressing events. Ella demonstrates how the mundane was weaved within stories of hospital and illness.

> *‘I've made my GSCE option choices and I'm now well into the courses. I chose Geography, History, ICT and Media and I'm enjoying all of them in one way or another although they are a lot of work! I have been having seizures and therefore been diagnosed with Epilepsy and taking so many anti-epileptic drugs that I'm out of it most of the time. Sadly, its been a bit of a bumpy road over the past few months with five hospital admissions, at least 22 pills per day and a whole load of seizures but hopefully over the next few months things will begin to settle down with the new drugs and I'll be less tired and out of it therefore be able to go back to go school full time which is literally all I want to do at the moment’*
>
> (Ella)

The act of talking about the mundane alongside the procedural/disability and impairment talk shows how Ella is framing herself as a normal school girl and also framing hospital appointments, medications and side effects within the mundane and ordinary. This demonstrates that the hospital experience was viewed by the children and young people in this project as another part of the mundane, everyday experience and not viewed as anything out of the ordinary. It was perceived as part of the mainstream and not perceived as far removed as Street *et al*. (2012).

This thesis provides us with a space to reinforce our identity as a ‘normal’ youth, challenging and rejecting the identity given to us through medical labelling and societal stereotypes and stigma associated with our respective labels as Evans (2017) highlights in her work. Through narrating hospital procedures alongside the narrative of the day’s other events, the young people in this study can be seen to be reclaiming their identity whilst challenging dominant stereotypes relating to what it means to be ‘normal’. Jazz recalls her cousin visiting her in hospital:

> *‘it was nice, we are a similar age and we just like sat around and chatted and played and she brought some dolls in and stuff so we played with them and did their hair and changed their dresses, yeah just like I say, a lot of one-on-one time chatting. It’s what we would have played with at home and stuff but she came to the hospital so we just played there’*
> (Jazz)

Here, Jazz is asserting her identity as a child as well as her right to play as a child. Her recollection of an event when her cousin visited her and she played with toys that she would have enjoyed at home, establishes an unchanged identity and in turn resists a medical identity or framings of her within the hospital. Her playing further resists the media portrayal of hospitals being unpleasant, dark, gloomy, distressing and not mainstream. Her choice to include this story within her narrative is an act of resistance in itself (Kraftl, 2013; Pile, 1991; Davidson *et al*. 2015). Later she says:

> *‘it’s like not a great memory about being in hospital specifically but it really is like to remember the after effects and the special moments which made being in hospital a special time which sounds strange because you wouldn’t necessarily think of hospital as a special or enjoyable place, place to be but I think because like, when you have to be [in hospital] its quite surprising that it can be special’*
> (Jazz)

Jazz is referring to the common-sense understanding and wider social perception of hospitals as not being a pleasant experience when suggesting ‘it sounds strange’ but asserts her embodied and experiential knowledge of hospitals by saying ‘it’s quite surprising because it can be special’. Jazz goes on to discuss how she is not supposed to think that hospitals can be pleasant but she does think that they are not dreadful. Again, we see a contradiction as to what society tells us to think about hospitals and the experience of hospitalisation and the embodied realities of children and young people who are hospitalised. This dominant and dysfunctional narrative within society acts to silence the narratives of Jazz, for example deeming her reality as minor or irrelevant. This is also exemplified in Rachel’s mundane accounts of when she was visited by the tooth fairy.

> *'While I was ill I lost my tooth, and my fondest memory is that I not only got 10p from the 'tooth fairy' but a double decker bar as well :) […] it might have seemed unimportant to everyone else at the time, you know, while they were busy saving my life and all but for me the tooth fairy was everything. It meant everything! Like she [tooth fairy] knew I was there and still visited me. It sounds kind of silly now but it meant a lot at the time. I mean, I was just a kid.'*
> *(Rachel)*

Rachel chooses to weave into her discussions around being in hospital, the event of losing her tooth, drawing attention to the ordinary and mundane aspects of her life at the time. By choosing to weave ordinary experiences into hospital experiences, disrupts the dominant narratives and directs the researchers attention towards this disruption. Here, I feel like she wanted me, the researcher, to know and include the mundane when telling her story of hospitalisation. Rachel goes on to further reassert her identity as a child by noting more ordinary and mundane occurrences:

> *'I spent most of my time either asleep or watching Crystal Maze (don't know if you remember that show) but it was on almost permanently on TV so I watched that and slept. I remember my mom mostly. She would get food for me (it was never very good. Hospital food is terrible :S)'*
> (Rachel)

The mundane, though unexpected, proved to be extremely important in understanding young people. This theme aided an understanding of resistance and why young people resisted the medical framings so strongly. Furthermore, young people narrate themselves as 'normal' which challenges the work of researchers' such as Valentine (2000), Hemingway *et al* (2011), Dewhurst *et al* (2015), Oostrom *et al* (2000), Bricher (2000), Rodenburg *et al* (2011) amongst plenty of others, who frame hospitalised children as separate from society, vulnerable, in need and abnormal, resulting in a recirculation of stereotypes and prejudices through society.

This section highlights the juxtaposition experienced by young people. Drawing on Intersectionality, I highlight how prescribed identities, that is those which are imposed on young people in hospital, often contradict the identities that young people hold for themselves. This section illustrates the additional labour for young people who often found a space and place to forefront their chosen identities and challenge their prescribed identities. On reflection, this sub-theme provided a richer understanding of resistance and the behaviours and strategies utilised by young people to resist. Through this research, young people were able to 'retell' their story therefore they were able to deconstruct and reconstruct their stories through narration (Hydén, 2013). I interpret this in itself as an act of resistance. Furthermore, I argue that through taking part in this project, participants are actually resisting through the everyday mundane experiences. Understanding this theme allowed me to challenge and problematize the framings of hospitalised children in pre-existing literature (Dewhurst *et al*. 2015; Curtis, 2015; Curtis, 2004; Coyne, 2008, Carter, 2002; Nordli, 2001, Hemmingway *et al*. 2011, to name a few). If the mundane was not included within this analysis, I would risk reinforcing and perpetuating research that frame hospitalised children within a charity and medical model depiction of disability. In contrast, this theme challenges perceived Othered identities and stereotypes of hospitalised children and instead depicts hospitalised children and young people in the way that they want to be perceived and understood. Building on the previous section, this is building a picture of the holistic self rather than the site of the impairment.

7.6 Chapter Conclusion

This chapter illuminated how hospitalisation impedes normative behaviours through the discursive, structural and physical spaces of the hospital (Kitchin, 1998). Drawing on Butler's (2004) work I have argued that the spaces which hospitalised children occupy encourage performances that contribute to upholding unhelpful stereotypes and stigma in culture and society. Concurring with Curran, (2013); Tremain, (2017) and Kitchin (1998) The chapter noted the importance of considering how medicine and specialist professions may work to recirculate unhelpful stereotypes and stigma. Drawing parallels with Crenshaw's (1991) work on intersectionality, the chapter highlighted the intersectional tensions of disability and childhood.

The chapter has challenged the helpfulness of Beresford *et al*'s (2003) work, noting its dismissal of children and young people's understandings. I have argued that this not only disempowers children and young people's lived reality, but also works to further silence their voices. Furthermore, I highlight the damaging consequences of providing a theoretical grounding to discounting young people's humanity, as Beresford's (2003) study offers.

I illuminated how young people framed acquiring a label as a means to an end and that despite progress in Law and understanding of disability (Equality act, 2011; DDA, 1995; Davis 2010), hospitalised children and young people continue to feel dehumanised through the process of diagnosis and medicalisation (Shakespeare, 1999; Goodley, 2011; Oliver, 2009).

This chapter identified two notions of normativity at play for ill and disabled children: 1) what it means to be a normal child; 2) what it means to be a normal child in hospital. I drew attention to how young people challenge perceptions of (ab)normality and work to reiterate other aspects of their identity that they perceive to be more important. This chapter considered how young people in hospital feel they have to 'live up' to what is expected of them by society and when they do not, or resist, they risk being perceived as troublesome or risky (Slater, 2013; 2016). I argued that it is not the diagnostic lable itself that causes lasting psycho-social pain; instead it is the obligation of being and learning how to be in hospital. I argued that sensationalised depictions of illness in media, such as BBC Children in Need and Casualty, do not align with children's lived experiences and demonstrated how such depictions have negative consequences to children in the hospital. I argued that this contributes to the devaluing of children's knowledge's and the silencing of their voices. In this chapter I have suggested that such sensationalised depictions of hospitalised children can be understood as another tool to exercise power and ensure compliance over young people's bodies and minds.

Moving on, this chapter highlighted different types of staring and noted the intense feelings of discomfort when unwanted staring is experienced as opposed to restrained staring when young people felt able to control which parts of their lives or bodies were in view (Garland- Thompson, 2010). I have argued that the biomedical gaze is experienced intensely by young people, which is power laden and an important part of the process of pathologization. Drawing on French (1993) and Reeve's (2002) work I argued that the biomedical gaze is not transient or temporary; instead, it is a form of public stripping and humiliation that continues to affect young people's psycho-emotional wellbeing, even outside of the hospital doors.

Highlighting the complex Intersectionality of hospitalised children's identities, in this chapter, I have argued that, while young people sought to find or make a place or space to forefront their chosen identities, this required additional labour that impacted their wellbeing and sense of self. I argued that understanding young people's chosen space and place to express their identity as well as their mode of expression was a key element to developing a deeper understanding of young people's strategies in resistance. The chapter argued that young people's participation in this research and re-telling and reframing their stories is in itself an example of a mundane act of resistance (Hyden, 2013). Furthermore, I argue that by excluding the mundane acts of resistance in research, recirculates unhelpful charity model depictions of young people in the hospital. I noted how including the mundane acts of resistance in research with hospitalised young people attends to the person more holistically rather than maintaining a focus on the site of impairment. Finally, I have argued that children and young people in the hospital seek to be understood more holistically.

Chapter 8 – Communication and Trust

8.1 Introduction

This chapter extends the discussion of normativity to communication. Firstly, it highlights the importance of accurate communication by the adults in a child's life, exploring the theme of misleading communication before addressing the claims young people made about not being listened to, exploring the theme of not being heard. Here, I demonstrate that young people in hospitals use multi-modal ways to communicate that adults often fail to acknowledge as a form of communication. I observe that young people's communication methods are complex and multi-layered and are often missed or misinterpreted by the adults around them. I note that when children feel misled or unheard causes relationships to be damaged and trust to be broken. The chapter notes how communication is addressed in other studies before using different theoretical lenses to gain understanding of the types of communication participants in this study reported. I argue that the misinterpretation of children's non-verbal communication as well as misleading communication from adults, contributes to children feeling unsafe in hospitals and demonstrates how young people are perceived as abnormal communicators. I suggest that the struggle to be heard contributes to young people being unequal partners in making care decisions. This section indicates a need to develop multimodal ways of listening.

8.2 Miscommunication Between Adults and Children

This section explores the data that details children's understandings and perceptions of adults. It draws on data where participants describe how or why adults behaved or said the thing that they report and highlights how children make meaning of adult's verbal and non-verbal communication. Arguably, often this was the communication that adults did not intend to have. The data here notes the frequent reports of children feeling misled by adults. Children in this study highlight that it is the barriers to clear information and being misled by adults that was a cause for them to feel unsafe and untrusting of the adults around them

William depicts his behaviour before diagnosis referring to himself as a ‘nice rebel’ detailing why he believes his behaviour was a direct result of his environment. He reports feeling unhappy when he lived with his mother and conflicted when living with his father whilst also trying to understand feelings around his sexuality and imaginings of what will happen when he ‘comes out’ as gay. He states that his behaviour should have been a clue to the adults in his life that he wasn’t happy. He feels failed by his mother who rejected him and by the doctors, nurses, social workers and teachers who did not hear his cries for help. He stories his experiences and explains how he understood the information he was given.

> *‘I ran away to my mums the first time and I got to door and she said, ’you’re not welcome here, you don’t belong here’ [...] so yeah, I went back home and my mum called the police’*
> (William)

William has understood his mother’s actions here to be communicating that she did not want to help. He recalls how his mother explained that he did not belong in her home and called the police to remove him from the property. William has understood this as his mother dis-owning him and a sign that he is alone. William’s choice to run to his mother suggests that he (initially) wanted to please her and felt that her home was a safer place than the hospital he was running away from. William feels a strong sense of rejection from his family

> *‘The truth came out that she just didn’t want any kids so she just left us and came to England. That is when it happened [abuse] and I attempted suicide, but my dad did not want anything to do with me after that he said I had brought shame on the family. My school phoned home so someone could take me to the hospital and my grandfather came to collect me and he said I had ruined my dad’s legacy as I was the oldest son. My grandfather sent me to England to live with my mum again, much to my mother’s dismay’*
> (William)

William experienced his father's unresponsiveness to his suicide attempt as a lack of care. He notes how he felt shame for attempting suicide. He recalls his grandfather's presence and response to the situation and recalls being told that he has ruined his father's legacy. He feels that he has let his family down but his own actions in attempting suicide depict desperation in dealing with feelings of abandoned by his mother and a series of sexual assaults shortly after his mother left. The act of attempting suicide is demonised by his family which his mother rejects and criminalised when she calls the police to remove him from her property. William is not believed about his experiences of assault and it is seen as a phase by his family, further demonising his communication. Runswick-Cole *et al* (2018) noted how children and young people struggled to acquire good quality and reliable information about going into hospital. When describing how and why he was admitted to hospital William recalled feeling confused,

> *'I wasn't expecting any of it, and my mother said to me 'you are going on holiday to assess your mindset' so I literally thought I was going on holiday. I couldn't make sense of it at all.'*
> (William)

In the extract above we can see why William felt misled by his mother in that he believed he was going on holiday. We could hypothesise why his mother said he was going on holiday as perhaps wanting his compliance. Maybe she didn't want him to worry or be afraid. Maybe she did not know how to explain it to him at the time. Whatever her reason, William interpreted this as a lie and a sign that his mother was untrustworthy.

William communicated his struggles and upset through his behaviours, running down a motorway, suicide attempts, rolling a man hole cover down a hill. This was non-verbal communication which he suggests were misunderstood by the adults around him.

> *'You'd have thought my behaviours would've been a clue to kind of say somethings happening. No one even asked me. When I told them, they didn't believe me.'*
> (William, interview 1)

Runswick-Cole *et al*. (2018) noted how all the adults in a child's life have a responsibility to share information with children and that withholding information, like William's mother did, could be potentially damaging to children's resilience. We see in William's quote above that his mother not only withheld information but purposefully misled him by telling him he was going on holiday. For William, hospitalisation was unexpected and felt jarring. He felt he was misled by his mother and was refused participation in his care and treatment plans, with all communication being between his mother and the hospital. As doctors communicated with his mother, who he now perceived to be untrustworthy, he started to perceive doctors as also untrustworthy. Hemmingway *et al* (2011) notes the negative effects two way communication can have on children and argues that a three way communication between doctor, parent and patient is required. Adults giving misleading information was also experienced by Rachel who recalls feeling terrified when a doctor placed a bunch of needles on a table next to her bed.

> *'my mum said that those needles weren't for me but yeah, she wasn't great at lying'*
> (Rachel)

She reports how her mother tried to comfort her by telling her that they were not for her but explains that she knew that this was not truthful information. Participants highlight that when adults provide misleading information to children in the hospital, it is interpreted by young people as a purposeful act. Participants, such as Rachel, Joe and myself feel that this often damages their relationship and trust in the adults and as such can cause more trauma. (Runswick-Cole *et al*, 2018). Later in the interview, Rachel suggests that she was lucky to have been seen by the doctors and treated so quickly so that her outcome was not worse. She articulates appreciation of the doctors despite her being scared yet still reports how terrified she was. We can see from Rachel's story that there was a desire, by the adults, to comfort her in an emergency however it is important to acknowledge that by giving misleading or untruthful information to children can cause more distress as they then perceive the adults as untrustworthy also noted in Beresford *et al*. (2011) study with young people in the hospital. William expands on this as he explains that not only are the adults in his life providing misleading information but also claims that they are producing untruthful information about him in a way that was self-fulfilling.

> *‘I didn’t need to go to hospital, if someone would have just listened to me and helped me then it would’ve been different. They knew about bipolar, they knew about my mother’s diagnosis. They don’t know how to help a kid through massive amounts of trauma. It was more simple for them to just work on diagnosing me. I did need help, like with the trauma of it all [sexual assault, disturbed home life] but not the sort of help they were giving me’*
> (William interview 1)

William perceived being admitted to hospital as the doctor’s choosing to privilege their own knowledge over his. Further to this, William felt further isolated as he perceived his mother as unable (and perhaps unwilling) to advocate for him, because she had a diagnosis of bipolar herself. William believes that his mother was unwilling to advocate for him because he was unwanted and it was easier for her to problematize him so as to absolve herself of the responsibility to amend her lifestyle and redirect her priorities to William. William understands the ignorance and lack of discussion around the sexual assaults he experienced as an indicator of not being believed. He perceives this as the doctor not possessing the capabilities to help him in a way that he needed. This could be a case of having knowledge that could not respond to the difficulties in William’s life; however, William perceives the lack of collaboration with him as a sign that the doctors do not think he is capable of making a meaningful contribution to his care and treatment plan.

The idea of the doctors privileging their own knowledge over his was something William returned to in his second interview. In his second interview he speaks more explicitly about control y*et al*lows some insight into his mental resistance during his time in hospital.

> *‘They put me in that unit because they wanted a diagnosis at the end of it and so they kept on prescribing me medications. I was out of it. I was comatosed off of it. I was zombified for most of the time. It was to keep me under control*

> *and that was an issue[…] They might have had control over me for that period of time but I knew ultimately that I would leave that place.'*
> *(William, interview 2)*

He describes his feelings whilst taking medications as being 'zombified', again his choice of words are interesting as they suggest he felt less than human. It is worth noting that William often describes his interpretation of his treatment at hospital as inhumane and here his choice of words are intentional. He notes his sadness and claims that he should not have been in the hospital but also describes a stubborn hope of what the future will bring. He is looking forward to the ordeal being over.

Beresford *et al*'s (2010) study with chronically ill young people highlighted that good patient-practitioner communication was vital in order to avoid passive involvement of young people during consultations. They observed that the parent-doctor interaction was more dominant than the patient-doctor interaction which William's accounts drew parallels to. Moreover, they noted that information giving was often between parent-doctors instead of being directed at the young person. William's story highlights similarities between his feelings of being unheard and the participants' experiences in Beresford *et al*'s (2003) study.

Like William, Joe was voluntarily sectioned, by his parents, under the mental health act. Unlike William's mother, Joe's father reported how he agonised over the decision to section him, noting how he felt that it was the only way he could secure appropriate treatment for his son. Joe details his understanding of adult's communication in his account of being moved from one hospital to another:

> *'Joe: I just kept thinking like I wasn't their [his parents] child anymore. They literally were not allowed to help me. I was alone. I felt like I wasn't theirs, I was someone else's. The doctors, they didn't care about me and that's why they were sending me away. It was like I was too ill and they gave up and got fed up of me so they sent me away to another place. They didn't want me to give up on trying to get better but they gave up on trying to make me better all the time. There was nothing he [dad] could've done and you know, I'd usually have to*

> *have parental consent and stuff but like, they didn't need it so they could just do whatever to me, they didn't even need to tell my parents […]*
> *Dad: [looks at Joe] that's what you said when you first went in you said 'I'm not yours anymore' that's what you said as soon as you were sectioned'*
> *(Joe)*

It is clear that Joe felt isolated and displaced during his time in the hospital but it is also interesting that he draws on his family in terms of ownership. The phrase 'I'm not yours anymore' can be perceived as Joe's understanding of where he belongs, where he feels most secure, that is, within his family and 'belonging to his parents'. Noting how he felt alone and isolated from his parents shows how vulnerable he felt. He notes that he perceived the hospital transition as a sign as adults 'giving up' on trying to make him better but also used the phrase 'they [doctors] didn't need it [parental consent] they could just do anything they wanted to me. They didn't even need to tell my parents' shows his understanding of the power the medical professionals hold over, not just him, but his parents as well. It can be seen here that Joe is very well aware of systemic and structural imbalances between himself and the medical setting.

Joe perceived his family sectioning him as them disowning him. That said, he understood how desperate his family was to help him and understood that he required medical help but simultaneously felt that he was 'given' away to medicine. Further to this, when it was decided to move him to another hospital, Joe perceived this as a result of his medical team 'giving up' on him. It is worth noting here that Joe does not mention any other reason as to why he moved hospital other than 'they gave up on him' making it reasonable to assume that he had no part in making this decision and that the reasonings as to why he had to move, was not explained to him. This failure to verbally communicate or include Joe in medical decisions meant that Joe had to fill in the gaps of knowledge himself. In doing so Joe concludes that their reason to move him was that they had given up on him. Joe discusses how his doctor treated him, and spoke to him, 'like a baby', and in doing so made Joe believed his doctors had made the assumption that he would not understand his treatment options or be able to make important decisions around his care.

It is worth noting that despite young people's understanding of adults perceptions of them and untrustworthiness, they still embraced the hope to be understood and continued to make efforts to build relationships with adults. William details how he used music to express himself often. Noting his desire to be heard, he gives an account of his experiences of playing his music to a trusted nurse.

> *‘well she was clock watching while she was listening, like I could tell even then that I was just so grateful for that moment, I knew she weren’t listening but I think on some levels I was trying or even hoping that I was being heard, that she would know what my music was about that she’d understand but I think it was something else to her. It was more procedural, like it had no purpose, but yeah, at the time I was hoping perhaps even in my delusional state believing she was hearing me. But yeah, it was hope, it was my only sort of glimmer of it so I latched onto it as much as possible.’*
> *(William, interview 2)*

The phrase ‘on some levels I was trying or even hoping that I was being heard, that she would know what my music was about’ explicitly notes how William had something to say, he wanted to be heard and he made explicit attempts to be heard. He also notes that although he knew she wasn’t listening, her agreeing to be there gave him hope. He notes how the nurse ‘clock watched’ and William understood this behaviour as a signal to mean that she was not listening. He understood his music, and in extension his voice and opinions, hopes, worries, as a chore to be heard.

One of the consequences of a breakdown in communication is that children are left to fill in the gaps of knowledge, that is the gaps between what is said or not (Beresford, *et al*. 2010; Butz *et al*. 2007; Procter, 2015). The interpretation and the filling in of these gaps can lead to fear, which is a result of failed communication (Butz *et al*. 2007). From the accounts above we can start to understand how children interpret adult’s words and behaviours to conclude that they are untrustworthy and unsympathetic. Returning to Reeve’s (2002) idea, we can understand how psycho emotional disablism can take the form that miscommunication can lead to feelings of traumas and fear.

In summary, while adults fail to understand children's non-verbal communication, they also fail to acknowledge their own non-verbal communication and how their actions or choices are understood and interpreted by the children. It is notable then, that non-verbal communication is complex and multi-layered (Slater, 2013; Curtis, 2004; Carter, 2002). From the stories shared in this chapter, I can conclude that active listening does need to be prioritised which has also been noted by academics such as Curtis (2004) and Carter (2002). I will add here that there is also a need to develop multi-modal forms of listening, a point explored through the next sections of this chapter. Finally, this section highlights a need to rethink how we reassure children in the hospital and think about the consequences of giving misleading information. As such, it makes a case for us to become reflective communicators. This requires us to turn the analytical lens in on ourselves to analyse what we, as adults, say to children and the possible interpretations children may have on both our verbal and non-verbal communication.

8.3 Attending to the Multi-modal communication of young people

Throughout all the data, participants detailed behaviours and expressions as a way to say something or they talked about what a behaviour meant. Not only did they discuss this when referring to their stories of hospitalisation but also, they choose to do this in research too. The multi-modal data collected for this research included spoken interviews, email interviews, blogs, photos, diary entries, paintings, drawings and music transcripts (discussed in more detail in chapter 5 – methods section). This section highlights the different modes of communication that children and young people engage with to exemplify the importance of noticing multi-modal forms of expression. This chapter draws on William, Joe, Rachael and my own accounts to exemplify young people's modes of expression as well as their attempts at communicating their thoughts and feelings.

William notes the importance of understanding multi-modal communication in that it allows an insight that words fail to capture

> *‘I see my music as a window into it. I mean all my music is inspired by my darker side, the side that finds words and language inadequate to explain things. My music are the aspects that I can’t touch. It's unfathomable but also unreachable […] It was darker and more disorganised than how I can give it to you. I don’t know what that means for you and the research but I just wanted to make it clear that my experience was more than what I can offer or describe or draw or anything I can give to you. That’s why I saying like words don’t tend to convey what my mind portrays.’*
> (William, 2)

William is eager to express to me that my understanding of his experiences through his music, words, letter and poem is inadequate to the true experience. He is making it clear that his experiences are so much more than what he is able to offer me and wants me to bear that in mind during the research.

William discusses his music during an interview and describes how his music helped him to find his way.

> *I found my way in music and so reflecting on it you can hear the sadness, like I shouldn’t have been there. You can hear the hope in it though because I knew it was just a phase. I knew it was going to end and I was literally going to control my destiny.*
> (William, 2)

It has been long established that children often use role play to enact different real life events or different scenarios in order to better understand their lived experiences (Proctor, 2015; Hackett, 2015). William was not able to ‘play’ with toys or people during his hospitalisation so instead he played the piano. Playing the piano and experimenting with different melodies allowed him to explore his feelings and experiences. He notes that music helped him to ‘find his way’ which suggests that it became a therapeutic tool for William. Often children’s communication is overlooked, misunderstood or even ignored (Liddiard, 2018). Runswick-Cole, (2018) highlights that research on childhoods grossly overlook the lived realities and voices of disabled children and young people. However, there is a growing emphasis to centralise

children and young people’s voices in research that concerns them. It is therefore essential that research explores and works in collaboration with young people to understand the modes of expressions they choose to use to communicate.
William sums up the importance of hearing multi-modal forms of expression:

> *‘If I was to use colour then mostly it would almost certainly be the darkest shade available in the most disorganised fashion to portray rebellion of being overruled but also all the immoral aspects of the so-called care of so-called caring professionals. If I was to use sound it would be a discord, a capacity of unbearable sounds but still neither would evoke the memories in a way which would engage with the experiences I had in any sort of true emotional state of how it was experienced. But it’s as close as you can get to it.’*
> (William, 2)

Here, William is highlighting the importance of understanding multi-modal expression (Hackett, 2015; Procter, 2015). He notes the impossibility of capturing the experience in any sort of true emotional state. He lists several expressions he could hypothetically use and claims that these would be the closest you could get to achieving an understanding of his experiences. It seems then, what William is telling us is that to even attempt to understand his experiences then we need to be ‘listening’ in a multi-sensory way. William’s words resonated with me. I understood his dilemma of not only being heard but also understood in any meaningful way, encouraging me to reflect on my own experiences and modes of expression. Below is an extract from my researcher reflexive diary

> *‘I started to try and write what poetry means to me, I’m 5 sheets of scribbled out paper into it and gained a whole load of frustration in the process. The task seems impossible, I could describe how ‘talking to paper’ seemed preferable to people, perhaps it’s because paper doesn’t have an ability to give unwanted and unqualified advice like ‘it’ll pass’ or ‘keep your head up’. Perhaps it was because paper could hold and enclose all the emotions I felt and be unaffected by it. I knew what to expect from paper and paper didn’t operate within accepted notions of communication. Maybe it was because no one would know if I swore or said any words which, as a child, were forbidden but were so often used to*

> *emphasise my emotion. Perhaps it was the conversations or responses to conversations I wish I had spoken. Maybe it was because it allowed a sense of control and freedom when I felt mine had been stolen. Perhaps it provided a type of therapy that was hidden from the medical gaze and avoided further pathologization. It helped me to make sense of what was happening around me. Perhaps it was all of the above and much more that words are unable to capture but William asserts 'but it's as close as you can get' to the experience.*
> *(Holly's reflexive researcher diary)*

However, there is a contradiction between wanting to be heard and wanting to stay private. In some ways, I think I wanted others to understand the impact of what I was dealing with but at the same time felt that they did not have the capacity to understand and thus, my diaries stayed private. Similarly, William expresses, repeatedly, that I cannot understand, yet still details his experiences for this research. It seems then that hospitalised young people are not expecting an understanding but instead are expecting to be heard.

Interestingly, writing and art-based texts such as photos, drawings and music composition were popular with other participants in this study leading me to believe that this is a coping strategy used by young people in the hospital as well as a valid and meaningful form of communication at a time where young people are seldom heard or understood. Deatrick *et al* (1991) discuss how drawings and writing are a language: a means of symbolically communicating feelings, thoughts and desires. William supports Deatrick *et al*'s (1991) assertions when he explicitly describes his music as not only a form of therapy but also a form of communication:

> *'I channelled it into music and it kind of became a therapy for me and it also became some way of communicating how I was feeling.'*
> (William, Interview 1)

Art based texts within this research highlight the most dominant theme to emerge from the data regarding voice.

Here we can see a page of William's music transcript, music that he composed and played in the hospital. William describes creating and playing music as a therapy and a tool to help him communicate. It is worth noting that William did not feel heard or believed when he spoke verbally and struggled to be understood. The music transcript above, to an untrained eye like mine, appears complicated. The notes appear to be on top of one another and are often layered. The music is busy. I interpret that William feels the same way his music appears. I think he has multiple feelings layered with each other and that felt simultaneously, his feelings are complicated and while they operate, they feel messy and disorganised. This was William's mode of expression, a mode he felt could best represent the impact of his emotions. In his words 'it's the closest you can get' to the experience.

In a similar creative fashion, I also found a useful mode of expression in my poetry. One of my poems which I wrote in 2001 whilst in hospital I illuminated the psycho-emotional effects of feeling like I am not being heard, through description of having a seizure, expression of my anxieties and feelings of oppression about a new drug. Whilst, William uses complicated notes and syncopation to layer his emotions and go off the beat, I sarcastically use different voices within the poem to provide insight into my own perceptions of the doctor (which were explored in more detail in section 8.1)

Poem 2

A Doctors Threat

1. ***M***isfiring synapses, my brain collapses,

Experience tells me to expect a moment of tranquillity
before the long and intense vulnerability.

0. ***I*** have something to say: 'I'm scared, I'm alone, I'm afraid, I'm in fear',

Words I know will be wasted on your ear.
Although you ignore,
I still try, because I have something I need you to hear.

0. ***T***he words choke me; they won't come out.

I yell, scream, shout but you do not hear my voice;
you do not care about my fears.
You cannot even see my tears.

0. ***I*** wander blindly through my mind.

For now I am undefined.

0. ***A***s I wake up here again,

my body limp and weak,
I hear the mumble of people speak.
I hear them speak but can’t speak back;
my words fly away, disappear, fall.
Some things I don’t try to say at all, so,
I cry the tears that I can no longer hold.

0. ***A***nother blow to the skull, another seizure, another scar;

I’m not shocked. It’s nothing new.
Am I dense or am I dumb, because my words still don’t come?
My brain deteriorates after every fit.
Your patronization is infuriating.
If I could speak I’d say ‘get a grip’, but,

0. ***F***or now my body is not mine –

for now it is theirs, theirs to own, to control,
to inject with anxiety, to prescribe fear,
and dish out despair, here and there.
0. Strapped down, locked in,

until I ‘open wide and swallow the medicine’.
My lips clench tight as I shake my head for ‘no’
but for you this is a sign that I’ve started a fight.

0. ***P***lease take your pills, you’ll get better,

Take them now and you’ll be home tomorrow.
Take your pills and lose control of your bladder -
don’t say no or I will be even madder.
Take your pills because I said so.
Take them now or never go home.

0. ***T***ake your pills, relax and chill, because it is the correct thing to do.

Take your pills and lose motor skills.
It’s very important, remember:
Epilepsy kills!

(Holly’s Diary)

Stanza two voices my frustrations that I do not feel that I am being heard and depicts how I feel my fears are unacknowledged or ignored by those around me. This is evident from the language utilised in the following excerpt: *‘words I know will be wasted on your ear.’* The experiences I report echo Beresford *et al*’s (2003) and Hemingway *et al*’s (2011) studies. Both studies draw attention to the communication barriers between patients and practitioners, identifying that only 6% of children who attempted to be heard were actually noticed (Hemingway *et al*, 2011).

Stanza three highlights how being unheard made me feel uncared for. Despite my attempts to communicate, I depict how I felt that medical practitioners were not interested in what I had to say: ‘*You cannot even see my tears’.* I feel that the display of my emotions was also an attempt to be heard and to make my distress known. Slater (2013) suggests that when resisting power, young people prefer to use non-verbal communication methods. My tears can be understood to fit in with notions of unorthodox communication, as outlined by Azzapardi (2013) in previous sections. Furthermore, by noting that the doctors were not able to ‘see’ my tears indicate that I wanted them to notice.

Stanza five illustrates that I felt that my words were not reaching the doctors: ‘*my words fly away, disappear, fall’*. Not being heard was a theme I expressed regularly through different modes as Deatrick *et al* (1991) suggested was common amongst young people in the hospital. One of these modes was a painting I created whilst in hospital (see image 2 below) which also depicts communication in speech bubbles. In the painting the communication line was broken between medical practitioners and myself)

Image 2

The poem illustrates how failing to verbally communicate resulted in the adoption of non-verbal communication methods. This highlights how my crying was a non-verbal cue of distress: ‘*I cry the tears that I can no longer hold*’. This theme emerged throughout the literature, predominantly in Forsner *et al* (2009) study and in Livesley *et al*. (2013) study. Forsner *et al* (2009) explain that children were not listened to when vocalising their fears, so would often use non-verbal means of communicating their distress such as crying. When doctors continued with a procedure the children often felt violated (Forsner *et al*. 2009). Returning to the literature, Livesley *et al*. (2013) and Hall *et al*. (1995) identified several more non-verbal cues which signify distress, such as pulling away from the medical practitioner, screaming, hiding and not speaking.

For me, I interpret this resistance as a way of communicating to adults. This communication is information about who I was and who I wanted to be. By challenging understandings of communication, I was informing the adults around me that I was not a cluster of symptoms to be gazed at and 'cured'. The idea of 'gaze' explored more in chapter 7.3 was also depicted in the painting I created (see image 2 above) where there are other faces in the picture that, are seemingly doing nothing. Despite their solid outline and their obvious presence, they still seem to fade into the background. I interpret these faces to represent being watched and pathologized. I believe the faces to be those of medical professionals.

Also, in an expression of resistance Ella takes photos of herself, sometimes with medical equipment or aids (photos are described here but not included for confidentiality purposes). One image she takes is of her leg splints and crutches as well as a few dresses. In the blog accompanying the images she is discussing what outfit will look the best with her splints. Whilst in another photo, Ella is posing for the camera while she is pouting her lips, making a peace sign with her fingers, her head is slightly tilted to one side in a pose common for teenagers at the time. What makes me interpret this as an expression of resistance is that Ella is attached to medical equipment in the photo and is therefore resisting notions of abnormality and difference due to her medical condition and disability. Again, Ella's photos provide clues as to who she is and how she wants to be perceived. Her images are purposeful and challenge common depictions of hospitalised childhoods (explored more throughout chapter 7)

Rachel reports an act of resistance via non-verbal communication in her accounts of being rushed to hospital during an emergency.

> *'I remember seeing the needles and just screaming. I was so loud but I was just terrified. I knew what I meant and I knew they were for me even though my mum was telling me not to look. I remember clinging to my mum so tight. She just held me until it was over. That's all she could've done. They were saving my life so there wasn't time to sit around and think about it'*
> (Rachel)

Rachel reports that she cried loudly and clung to her mother. It could be argued that Rachel's cry is communicating her fear, her worry about what will happen next. She holds onto her mother and reports feeling 'terrified' which could be interpreted as her way of communicating that she was uncomfortable with the doctor's presence. Rachel's story adds another layer to the analysis of non-verbal communication instigating a critical reflection as to whether emergency treatments such as what Rachel received, absolves the doctor's responsibility to hear the child and the child's right to be heard in all matters affecting them (UNCRC, 1990)

Therefore, themes of resistance and communication (or lack of) were extremely prominent in the data, especially my own diaries. The extracts taken from my diary entries below provide further insight and demonstrate that my resistance was also non-verbal:

> *I'm not talking to those doctors again. I hate them, they are so evil. I really want to scream really loudly but I can't even do that because I am in hospital and will get told off*
> (Holly's diary)

This extract demonstrates that I perceived that my attempts at communication were restricted. Researchers such as Livesley *et al*, (2013); Roter *et al*, (2005); Mast, (2007); Hall *et al* (1995), note that screaming is a non-verbal/'unorthodox' way to communicate distress and the extract provided above aligns with these ideas. Further supporting my non-verbal communication, I then go on to discuss a visit from my mum: *'My mum came but I didn't talk to her.'* Here, my choice to not speak was a communication method in itself, as discussed by Livesley *et al* (2013) and Roter *et al*

(2005). However, the subtle body movements such as nodding and shaking the head, although non-verbal, were acknowledged by adults; however, the distress of crying during this compliance seemed insignificant to the adults around me and my distress was not comforted as the nurse walked away, as seen in the next example:

> *They asked me, I nodded but was crying at the same time. The nurse gave me the tablet, I swallowed it and she walked off.*
> (Holly's diary)

Interestingly, it seems from this account that non-verbal consent (nodding) is noticed and utilised as a valid form of communicating compliance. However, nonverbal dissent (crying) was not noticed and was therefore not a valid form of communication. Furthermore, I had expressed verbally my concerns with this medication and resisted treatment with it which, despite being verbal, was still not considered as a withdrawal from using this specific medication as a treatment option for me. Bricher, (2000) and Hemmingway *et al*. (2011) and Murris, (2013) note similar finding within their studies suggesting that 'adults put metaphorical sticks in their ears' when listening to children and young people (Murris, 2013, p.246).

Building on Mast (2007) and Roter *et al* (2005) my diary entries provide clues for other non-verbal ways of communicating fear:

> *The nurse said I should go to sleep but I'm scared of that because they might give me Keppra whilst I am asleep and I won't know because they could give it to me in my cannula.*
> (Holly's diary)

The above extract was very interesting, as noted, fear was an undisputed theme in the literature however, there was no acknowledgement that not sleeping could be a non-verbal cue for fear. I interpret purposely staying awake, in the extract above, as a form of non-verbal communication to convey my fear. This extract demonstrates my perception of risk and my real concern that if I were to go to sleep my wishes to resist the medication would be violated. Pound *et al* (2004) place emphasis upon the choice not to communicate verbally, suggesting that it is important to acknowledge and understand new narratives, such as non-verbal communication. The extract above signifies that my communication of distress and fear were not acknowledged or understood. Further to this, non-verbal communication methods employed by young people, such as in the example above regarding sleep, might have been read by the adults around me as a form of non-compliance – thus, not acknowledging children's non-verbal communication as a mode of expression, not only lets young people's voices go unheard, but also misunderstood by the adults around them.

Within the theme of non-verbal communication, Joe tells the story of being restrained in a psychiatric ward for children and young people. He recalls being restrained many times before, however one particular time scared him more than any other and that is when the doctors threatened sedation. He discusses being restrained in order to be given a needle:

> *'yeah, it was right bad because they were all there and restraining me to sedate me and that was in a needle and I was shouting not to and they were just all there grabbing me when I didn't want it [the needle]'*
> (Joe)

The sedation was not given because another doctor highlighted that there was no authorisation to sedate him. Whilst it appears that Joe was heard and hence was not given the needle, had the authorisation been in place the doctors would have sedated Joe. The doctors were reacting to a procedural error rather than Joe's fearful and emotional cry (Murris, 2013). Joe's distress in this event was acknowledged by his father who Joe reports phoning in his distress. However, Joe's father does not give full credit to Joe's verbal and non-verbal communication of fear and lack of trust in medical practitioners and instead talks about his own emotions through the process:

> *'horrendous, absolutely horrendous feeling. Nobody, no parent should have to go through that'*
> (Joe's dad)

Here, Joe's dad is validating his own feelings about the event above. Joe's extract highlights an imbalance of power dynamics and a silencing of his voice and lived reality when he reasserted and revalidated his emotional experience by asserting:

> *'a child shouldn't have to go through that!'*
> (Joe)

Through this interaction I interpret that Joe's feelings were validated through how his father felt. Joe's father validates his son's feelings by noting his own feelings. Inadvertently however, choosing to highlight his own feelings to validate Joe's can be interpreted as a reinforcement of Joe's (child) feelings as inferior or lesser than his own (adult) feelings.

Finally, I will end on an observation made during an interview with William where he played his music 'The Last Flight of the Dragon' and he is explaining his music he uses phrases which demonstrate how multiple senses need to be engaged in order to listen. As we are listening to the music he states,

> *'William: there, there in the music, can you see it, listen how the tone changes, can you feel how it changes here?*
> *Me: yes it changes, why does it change?*
> *William: Listen, it will show you in a second […] there dum dum dum duuum. Did you see what happened?*
> *Me: I think so, I noticed it*
> *William: yes the sound of it changing there forces you to notice it. It's blunt and intense, it forces you to feel unease, you can see the injuries, the bruises to the dragon. You'll hear it again in a minute'*
> (William, Interview 2)

Here William is using the terms hear, listen, see and feel interchangeably. This is interesting because being heard and mode of expression was a prominent theme within the data. Here it seems that William is describing hearing, seeing and feeling as integral to being listened to.

This section highlights the importance of embracing multimodal expression, demonstrating a richness of multi-modal expressions and highlighting how these expressions are a valid and meaningful mode of communication (Proctor, 2015). Young people describe their expressions as ‘the closest you are going to get’ to understanding their experiences highlighting a need to become more familiar with different modes of expressions adopted by young people. Furthermore, the chapter highlights how creative modes of expression were popular amongst young people in the hospital and thus it is worth considering that this could be adopted as a coping mechanism for young people in the hospital. This section illuminated that when non-verbal modes of communication were adopted to conform to medical treatments and perspectives then they were recognised by adults as a valid form of communication yet when non-verbal was adopted to express opposition to the medical or treatments then it was not recognised. This chapter noted that young people identified seeing, hearing and feeling as fundamental to listening and argues that there is a need to consistently question and challenge notions of normative communication. Finally, this section evidences a need to urgently develop multi-modal, multi-sensory ways to listen.

8.4 Agency, Participation and The Right to Be and Feel Heard

This section will draw on participants’ accounts of participation in medical decision making. It highlights how young people in the hospital often felt in opposition to their care team, perceiving them as a threat. I note the data that highlights the perception of threat to bodily agency and voice, which is noted by participants as a primary reason for feeling fearful and oppressed in the hospital setting. I draw on the accounts of young people who describe feeling misunderstood by medical professionals or less able or mature to make a meaningful contribution to medical decision making. Furthermore, I highlight how bodily agency was continuously sought yet was a struggle to obtain. Finally, this section draws on accounts of where participation was offered and what sort of decisions the young people in the study reported they were entrusted with.

Joe discusses how having a CTO (community treatment order) and being allowed home was beneficial to him. Joe perceives that the doctors used it as a bargaining tool that they could give and take as they please. Joe states:

> *‘I [still] have to battle with anorexia but its only anorexia I have to battle and not other people and doctors and stuff’.*
>
> (Joe)

It is interesting that here, Joe places himself in opposition to the doctors. He frames his care team as a hindrance to him getting better rather than a help to him. He uses the word ‘battle’ which suggests he felt at war or unsafe in hospital. Feeling unsafe and unheard when receiving medical ‘care’, as Joe did, is a theme that has emerged in others’ work with children in the hospital (Forsner *et al*, 2009). Other accounts of children’s fears include: being hurt, having painful procedures, being abandoned by parents, needles, decreased independence and missing school, amongst others (Wilson *et al*, 2010; Butz *et al*, 2007; Oostrom *et al*, 2000; Ekra, 2015; Popp, 2014 and Ekinci *et al*, 2009). Ekra *et al* (2012) emphasise the importance of listening to children and young people during hospitalisation, claiming that there needs to be a collaborative decision-making process to minimise and avoid oppression and feelings of abandonment, which they claim children often feel whilst hospitalised. Joe suggests that medical practitioners ‘talk down to you’ highlighting his understanding of the position of power the doctors hold in relation to his own powerlessness as a child.

> *‘They talk to me as if I was a baby or something’*
>
> (Joe)

which asserts his perceived ability to understand in a more ‘mature’ way then what he was given credit for. He also refers to their communication with him

> *‘they just shout at you, and if you can’t do it or something then they just shout louder at you.’*
>
> *(Joe)*

Here, Joe is highlighting an element of intimidation used by medical practitioners in order to have their desired outcome (for Joe to follow their instructions). In addition to not hearing Joe's voice in hospital, it seems that at certain times the medical practitioners actively silence his voice,

> *'they said 'if you don't stop wailing we will take your phone off of you and then you will not be able to speak to your mum.'*
>
> (Joe)

Here, there is a direct threat to Joe's non-verbal communication of 'wailing' or crying. The medical practitioner views this as an annoyance and a behaviour that is not appropriate or 'not allowed' and thus needs to be punished with the confiscation of Joe's phone. In addition, to his non-verbal communication being ignored, his verbal communication to his mother over the telephone was threatened. Joe understood this interaction to mean that he had to communicate normatively, with spoken words, or his option to communicate at all would be taken away, further silencing his voice and adding another layer of threats and intimidation that Joe describes as part of his 'care'.

I interpret that because Joe was communicating unhappiness and dissatisfaction about his care and treatment to his mother in a verbal way the medical practitioners perceived this as a threat and an unfavourable view to have about their position of power over Joe's body and mind. The medical practitioner asserted disciplinary procedures over Joe's communication. Kellett (2009:402) notes that ''adult eyes' fail to see the type of communication favoured by some children and young people'. It is worth noting that, although dated, Robertson (1953) offers an explanation as to why adult medical practitioners fail to acknowledge children's unorthodox communication methods. Robertson (1953) argued that medical practitioners develop a decreased sensitivity to children's distress in order to protect their own emotions when trying to help young people. Bricher (2000) refers to this as developing a 'blind spot'[sic]. Applying Robertson's (1953) and Bricher's (2000) ideas to Joe's experiences, it could be perceived that medical practitioners were guarding their own emotions and had developed a 'blind spot'[sic] to Joe's distress.

Hemingway *et al* (2011) offers a further explanation of why the young people in this project report feeling unheard by medical professionals. They highlight that doctors feel uncomfortable communicating with young people due to lack of training, thus concluding that doctors feel unable to involve young people in consultation especially in emergencies.

> *‘be able to go back to school full time which is literally all I want to do at the moment. I know why they are saying it's best for me to be part time at the moment but I do wish I was back in school already. There’s not really much I can do about it until they decide I can try to be full time again.’*
> (Ella)

Here Ella is aware that she wants to do something different than what was recommended. She desires some agency. She notes how she understands why the adults in her life have suggested that part time schooling is best for her, demonstrating a mature understanding of the situation; however, she perceives that she has no control or agency over the decision and expresses that she can not do anything until the adults in her life decide otherwise. Jazz experiences similar emotions but demonstrates more active resistance at the time, stating:

> *‘Don’t get me wrong there was a lot of stubbornness involved too [laughs]. I mean this doctor that I saw was always just overpowering everything I said, he’s say stuff like ‘people like you’ can’t lose weight and made out that there was no point trying. I was just fed up with him telling me what I can and can’t do […] I wanted him to know it was my body and I knew it best.’*
> (Jazz)

Jazz, noted how she was ‘fed up’ with the lack of agency and participation over her care and her body and demonstrates oppressive language used by her doctor such as ‘people like you’, meaning people who took the same medications as Jazz. She indicates the need to be stubborn in order to resist being overpowered by the doctor, recognising the oppression that she experiences and noting how she actively worked to resist it.

Jazz recalls one event in which she was given an opportunity to participate.

> *‘I had an option of the sort of design for my injection device I think. […] don’t get me wrong it wasn’t very sophisticated, but yeah it was just a different colour sort of like what style caps I had on the top […] like do you want a purple one or a yellow one? you know, that sort of thing; or I could customise it with a little clip’*
> (Jazz)

Jazz is recalling how she was able to choose what colour her injection device was. She was also given the option to customise her device if she wished with a clip. Jazz states that it wasn’t ‘very sophisticated’ therefore she knew that she was given a very superficial, tokenistic ‘choice’. Arguably, the choice of colour made no difference to the medication or care and therefore Jazz’s choice was not an active participation in her care, rather it was a choice of style. Here we can see how Jazz was only trusted with decisions that had no consequences to her health, demonstrating how the doctors restrict choice to very low stakes/no stake decisions. Therefore, the doctors are not choosing to engage in any meaningful participation with Jazz

> *’I did have a choice about the type of injection device, so you can have one which sort of fires through your skin so it’s not effectively a needle, it just kind of shoots the fluid through but to me[it] just seems like too much impact. There’s the [needle] one that I’m still even using now which, I was using that right from when I started.’*
> (Jazz)

Here Jazz is implying that she had a choice of which device she used and thus her method of receiving the medication. This choice still seems superficial as she is still expected to take the medication that the doctors have decided for her but is given a choice on the method of administering the medication which is less tokenistic to the choice of colour. This finding aligns with Bricher (2000) observation that when children are given a choice it is often done in a tokenistic way.

> *‘There kind of were a certain type [of injection device] that they [doctors] implied was more for adults if you like so yeah there was a choice in that way. The other medication and stuff, I just didn’t have a choice about that […] it was just ‘you’ve got to take this’ sort of thing’*
> (Jazz)

Here Jazz demonstrates how despite her apparent choice of method, the doctors still implied that one method was for adults and steered her towards what they perceived were a more child friendly device. Jazz demonstrates that she knew that these were superficial and tokenistic choices when she asserts that she didn’t have a choice about her medication (Bricher, 2000). Whilst I do not think Jazz has any strong opposing feelings to the medication that her doctors prescribed. I think that her mentioning here that she did not have a choice of medication indicated that she would have liked to be more involved or informed about medication options.

Jazz discusses the dynamic of her relationship with the doctor

> *‘There's been a few things that I can say we’ve disagreed on, [laughs] me and the doctors like. I wouldn’t say I perceive him as an enemy or that I have majorly strong feelings against him but errm, we do disagree errm, quite often actually and errm it’s like I have to disagree […] or they’d just do whatever and change my medication, just for the sake of it and when you actually question it, in reality […] well there’s just no need for it.’*
> (Jazz)

Here Jazz is referring to the power dynamics in the consultation room and how she has to fight for agency when medical decisions need to be made. She feels she has to disagree with her doctors quite often and perceives that the changes that her doctor suggests are often unnecessary.

> *‘Jazz: yeah, I think what it is a lot of the time, what hospitals are very good at doing is thinking […] ‘if something needs doing let’s get it done’ sort of thing like procedurally wise of what have you, but what there not so good at doing is*

> *thinking about the other implications like what effects it has on patients like how it would make them feel or the long term, like what it's like to live with that, you know like medications or even how to live with the memories of what has happened in hospital sort of thing. I think they are very good at seeing things within the hospital door so to speak but they don't really think about things past those hospital doors'*
> *Me: yes it's interesting that you mention the doctors understanding of wider implications outside the hospital doors can you say more about what you mean?*
> *Jazz: sure, well I suppose it's like we know you are clever, we know you can think, we know that you have qualifications and certificates and as patients we mostly trust you but it's like they just need to have more thought into what they say or do. Errm, like they need to reflect, probably a little bit more than what they are doing'*
> (Jazz)

Jazz has expressed that she feels that the doctors are good at considering procedural logistics in hospital but rarely consider the implications of their decisions out of hospital. Similar to Bricher's (2000) findings, Jazz feels that the doctors do not consider her holistically and suggests that they should reflect on their practice with their patients so that they have more thought into what decisions they make or what impact their treatment has on patients when they leave the hospital.

Rachel also alludes to agency and participation in the hospital is Rachel. She expressed she has a preference as to where the doctors insert the cannulas that she needs,

> *'I preferred to have them [cannulas] in my hands rather than arms because you can bandage it up and not have to see it but I didn't have a choice. If they said they were putting it in my arm instead, then it was kind of 'tough luck'. I don't think they tried very much to do it in my hand when I asked. The nurse just looked and said 'no, let's see your arms'. I think my mum said later on that my hands were bruised from previous cannulas, so that's why it's best to go*

> *somewhere else. I think you can feel them more in your arms than in your hands.'*
>
> (Rachel)

Rachel notes her lack of choice and recalls that she has expressed her preferences which she felt were overlooked and ignored by the nurse. 'I don't think they tried very much' suggests that she perceives that there was a lack of effort from the medical professionals and doctors to include her or consider her preferences. She recalls that her mother later explained the reasons why this was overlooked which notes a lack of communication, discussion or explanation with her about it. Roskies *et al*. argued in 1975 that there was a lack of communication between doctors and their young patients suggesting this was a cause of trauma. We can see from Rachel's accounts that 40 years later, children are still reporting this lack of communication by doctors and medical professionals as a problem. Since Roskies *et al*. (1975), work by Rennick *et al*. (2002), Hemmingway (2011), and Bricher, (2000) also report poor communication as a contributing factor to trauma. The silence from the professional left Rachel feeling overpowered and unheard. Similarly, in my diaries I also detail when I felt ignored and overpowered.

> *'I don't see the point in him ever asking me about stuff. He says 'is it ok I tell your teachers? Is it ok if you tell your swimming instructor? is it ok if we change your medications:' I always answer no but then he goes on and on and on and I don't want to hear about it. I swear he's an idiot, he doesn't even know what no means, he shouldn't even be a doctor. He just does it anyway. I don't know why I have to go to my appointments. He might as well just do what he was going to do anyway. I'm fed up with talking to him, he is so stupid. He never listens anyway. I bet nothing would change if I just didn't talk to him and everything would be just as bad as it is now.'*
>
> (Holly)

Unlike Rachel, I point out that I was asked, however I felt that the doctors asking me these questions were procedural and a tokenistic gesture of participation and felt that my answers to their questions were never really heard or considered. I felt that I was not included in my appointments and observed how decisions were made about me and suggested that there was no need for me to attend the appointments. Again, this is an example of why I was feeling ignored and unheard and details my perceived lack of participation in decisions that involved me (Bricher, 2000). This example supports Jazz's claim that doctors are good at thinking about procedural elements but do not really consider how this makes their patients feel. I state 'he doesn't even know what 'no' means' highlighting how I was clear but felt ignored and thus silenced by their actions.

While the above extract from my diary was in relation to an outpatient appointment I also draw on similar issues whilst being admitted to hospital.

> *'I am so sad and people keep trying to make me take Keppra. Every single nurse has asked me to take it and they keep asking and asking and asking. I told them I didn't want to […] I think if they are so obsessed with me being on 2 tablets then they can find me a different one'*
> (Holly)

I note here how their disregard for my feelings in decisions makes me feel 'sad'. I describe feeling 'ganged up on' when every nurse and doctor ask me to take a medication that I had already expressed my opposition to and felt that I didn't have a choice in the matter. This was later depicted as I eventually, reluctantly, took the medication.

This section demonstrates how hospitalised children and young people often view themselves in opposition to their medical team describing and depicting this as a battle or a struggle. This section also highlighted, what young people perceived as, threats to young people's verbal and non-verbal communication. This was especially evident when young people were expressing opposition or dissatisfaction with medical decisions that were made or the medical team around them. Not only does this section highlight young people's lack of participation it also notes that when participation was offered to young people it was often tokenistic or procedural. Children were only permitted to make decisions on things that had no consequence (such as the colour of a medical device). This section demonstrated how children and young people showed a continued, but arguably wasted, effort to be heard, listened to, acknowledged and have their opinions and preferences considered in decisions in hospital. This section demonstrates how children’s voices are undermined and both their verbal and non-verbal communication is not just ignored but actively silenced by the professionals around them. This section supports the arguments made in the previous section (8.2) highlighting an urgency to develop better ways to include young people in medical decision making by inviting and respecting their participation.

8.5 Chapter Conclusion:

This chapter has extended the discussion of normativity to communication, highlighting the importance of accurate communication. In this chapter I noted that adults often failed to understand children’s non-verbal communication; moreover, they also failed to acknowledge how their own actions and choices could have been understood and interpreted. I have noted that non-verbal communication is complex and multi-layered (Slater, 2013; Curtis, 2004; Carter, 2002).

Concurring with Curtis (2004) and Carter (2002), I argue that active listening should be prioritised. Aligning with the work of Runswick-Cole *et al*. (2018), I highlighted how good quality and reliable information was not easily acquired by children in the hospital and argue that sharing information with children is the responsibility of adults (Runswick-Cole *et al*., 2018). This chapter notes the urgency to rethink how we reassure children in the hospital as well as the psychological and emotional consequences of offering misleading information. I argue that children in hospital often feel unsafe, threatened and insecure in the care of adults, especially when communication had broken down and relationships have been damaged (Butz *et al*. 2007). The chapter makes a case to turn the analytical lens in on our adult selves, in order to become more reflexive communicators.

This Chapter highlights the importance of embracing multimodal expression. I demonstrate how multimodal expressions provide rich information to develop understanding and argue that these communications should be considered as both valid and meaningful (Proctor, 2015). Moving on, I illuminated the need to become more familiar with different modes of expressions adopted by young people, especially creative modes of expression as these were popular amongst young people in the hospital. The analysis has highlighted that nonverbal communication which indicated compliance was acknowledged by adults; however, nonverbal communication that indicated resistance was often misunderstood. This chapter demonstrates the need to consistently question and challenge notions of normative communication and argues that there is a need to urgently develop multi-modal, multi-sensory forms of listening.

This chapter highlighted how children and you people in the hospital depict their relationships with medical professionals as a ‘battle’ because they perceive their medical team to work against them. This chapter draws attention to young people’s lack of meaningful participation during hospitalisation however note how children and young people show great and continued effort to be heard, acknowledged and participate in medical decision making. In this chapter I have argued that participants’ verbal and non-verbal communication were undermined and sometimes actively and purposely silenced by the professionals around them, supporting the urgency to develop multimodal, multisensory mode of communication so that young people’s participation in medical decision making can be properly acknowledged, respected and valued.

Chapter 9 – Discussion of the application of theory and legislation to the experiences of participants.

9.1 Introduction

This chapter explicitly mobilises the theoretical underpinnings of this research (as set out in chapter 2) to explore what new understandings can be gained. The chapter is structured in a way that explores each participant's story as an entry point into a discussion of a significant finding of the analysis. This structure fits within a biographical approach to research, and honours each participant's story and ‘main messages to the research’ through their storytelling. Furthermore, it permits a way of teasing out key themes, messages and recommendations for both research and practice. In structuring the chapter in this way, I am underscoring disabled children’s childhood studies (DCCS) by placing the voices of disabled children and young people at the front and centre of research. Aligning with feminist values, I revisit the stories from participants in light of the analysis, to make the personal experiences of hospitalisation political.

Throughout the discussion I address my research question: ‘What can we learn from the stories people choose to share about hospitalisation?’. This chapter will take each participant in turn and ask what we learn from each participant's story. This philosophy allows us to see past common depictions of sick children living limited lives, to embrace the possibility of a more affirmative understanding of hospitalised childhoods that sit within the sphere of DCCS (Liddiard *et al*., 2018). Whilst all participant’s stories touched on multiple themes, they often had a dominant theme in which they framed their stories. This is not to assume that participants embody one theme only, instead it is an entry point to the theme through each story.

9.2 Ella: Finding valued identities during medicalisation.

Ella’s narratives offer an entry point to discuss the theme of intersectional identity and resistance to unhelpful stereotypes. I understand that she felt oppressed by the dominant stereotypes around her. She provided data in the form of blogs and photographs. Through her blogs she works to oppose societal stereotypes and assumptions about her. Young people's stories around identity, as well as Crenshaw’s (1991) work on intersectionality, facilitate a more nuanced understanding of young people's hospital experiences and the types of tensions between their identities at certain times. Liddiard *et al*. (2018) note that young disabled people's intimate lives and selves are often erased, which echoes Ella's frustrations with the lack of identity recognition by medical professionals. Slater *et al*. (2018) assert that intersectionality can facilitate an understanding of categorisation, and Ella's narratives teach us that categorisation (disabled, young, female) does not in itself produce different experiences. Instead it is the frictions and intersections of these descriptive markers that produce a certain type of experience.

Throughout Ella’s blogs, she works to foreground her teenage identity; however, during hospitalisation she felt that doctors would foreground her disabled identity, which caused friction and was frustrating for Ella. Additionally, age was not perceived as an oppressive marker for Ella, and she often emphasised her age as a positive identity marker; however, when paired with a dominant disability identity during times of hospitalisation, her teenage identity held more negative connotations, which I unpack below.

Understanding young age during hospitalisation as a negative has also been noted by Wood *et al*. (2013) and Bricher (2000), who assert that children are presumed incompetent to make decisions about their health care due to their immaturity and lack of comprehension. They note how such perceptions of children derive from work in developmental and cognitive psychology, which suggest that young children are simply incapable of understanding the complexities of illness and the body, due to their limited cognitive development. Ella’s narratives support Wood *et al*. (2013) and Bricher’s (2000) claims that teenagers’ frustrations were not acknowledged, and her preferences were dismissed by the adults around her. Ella describes not being permitted to return to school full time (section 8.3).

> ‘I do wish I was back in school already. There’s not really much I can do about it until they decide I can try to be full time again.’
> (Ella)

Highlighting her powerlessness over the situation, she illuminates a lack of professional compromise. Moreover, Ella exemplifies the reach of medical control; one that extends from hospital to school. Not permitting Ella to be in school can be understood as maintaining and extending medicine's ability to control and have disciplinary power over other systems, such as education (Tremain, 2005, 2017).

Utilising Foucault’s concepts aids an unravelling of the complex dynamics of a surveilled relationship with regard to bio-power (explored more in section 2.9) and how this relationship is not contained only in medical environments but also, as Ella exemplifies, school. Ella often describes the effects of medicalisation on her home, school, and social life. In doing so she highlights the level of control medicine has on other aspects of her life, ensuring that her prescribed identity (ill, disabled) impacts on all aspects of her life. From a poststructuralist perspective, surveilled relationships are beneficial to medicine as they uphold and reinforce the power of medicine on culture and society (Tremain, 2015, 2017; Oliver, 2009; Barnes *et al*. 2003; Finkelstein, 2003; Morris, 1991). Ella’s work to forefront her chosen identity (young schoolgirl) was made more difficult due to medicine's potency to reach outside hospital spaces.

Revisiting the work of Crenshaw (1991), who notes how the foundational narratives of certain categories (age, disability etc) privilege some experiences and exclude others, and with the analysis of Ella’s narratives in mind, we can begin to unpick why Ella perceives her young identity as positive at home but as negative during hospitalisation. I argue that Ella experienced her age as oppressive in hospital spaces due to the foundational narratives that depict young people as being cognitively immature and incapable of meaningful contribution. When disability is the dominant identity then, younger age is not valued and, arguably, adds to the oppression. However, despite medicine’s power to surveil her outside of hospital spaces, Ella finds space to reinforce her chosen identity (young schoolgirl), her young identity being of higher value at home and school than in hospitals.

To further understand oppression in hospital spaces, I draw on the work of Tremain (2005, 2017) who utilises Foucauldian concepts to argue that medicine is an institution of power. She notes that this institution not only has the power to categorise individual bodies and minds, subjecting them to the medical gaze and judgement of normalcy, but also to create discourses of ab/normality. Tremain (2005) argues that the exercise of power and authority in medicine is a system of social control that works to uphold the authority of medicine. In other words, to be considered and perceived as ‘normal’ requires the oppositional discourse of ‘abnormal’; both categories rely on each other in order to culturally exist. From this perspective, it can be understood that any view that differs from the medical perspective is in opposition to it. That is, to understand Ella within her chosen identity (young schoolgirl) is to resist medicine’s power to construct her within a prescribed identity (ill, disabled). The fight to be understood within her chosen identity mattered a lot to Ella, and this is captured in the frequency with which she wrote about her frustrations with common stereotypes and stigma. Goffman (1963) observes how stigma is produced through medicine and is felt deeply by those who experience it. Goffman (1963) argues that medical labels and the stigma that comes with them can become institutionalised within society, and disabled children may well internalise these stereotypes and stigmatising identities.

Finding valued identities during the process of medicalisation highlights the importance of intersectionality, especially when attempting to understand individual lived realities. Further understanding of intersectionality can be gained from the vantage point of spatiality. Kitchin (1998) argues that space informs disabled people when they are out of place and encourages disabled people to ‘know their place’ (as discussed in sections 2.8 and 2.9). Utilising this concept then, we can understand school was an environment that was unwelcoming to Ella’s prescribed identity (ill, disabled). Kitchin (1998) highlights that, in order to understand stories of illness and disability, a spatial understanding is necessary.

Scholars who theorise and explore space, such as Kitchin (1998), Lefebvre (1991), Massey (2005), and Soja (1996) (as explored in chapter 2.8) argue that space is socially constructed, dynamic, and political. Kitchin (1998) describes space as possessing a sociological and political ‘scripture’, containing the unspoken rules and laws of a specific space (e.g. hospital, school). He argues that it is these scriptures that instruct children which of their identities are out of place.

Mobilising Ella’s narrative, we can begin to understand that her identity as a sociable, teenage, schoolgirl was unimportant in the hospital but valued in school. Instead, the only identity that belonged in the hospital environment was that of her ill and disabled identity. Hospitals are an institution whose focus is on (ill)health, rather than education and age-related identities. This frames hospital spaces as a distinct place separate from the mainstream (Street *et al*. 2012). However, for Ella and the other participants in this research, hospitals were very much ‘mainstream’, and discussions of hospitalisation were woven into the everyday mundane discussions of school life, hobbies and friendship groups. This oppositional understanding of the hospital - as a place of sociability - highlights frictions and tensions, allowing an understanding of medicine’s obligation to exercise control outside of hospital spaces in order to uphold its own power and authority in society (Tremain, 2017; Kitchin 1998). This interpretation draws parallels with the work of Mitchell *et al*. (2006) who argued that disabled people's experiences were ‘dis-located’ by the charity and medical interpretations of disability and illness as a tragedy. Mitchell *et al*.’s (2006) argument alongside Ella’s frustrations with stereotypes teaches us that sociological and cultural interpretations of illness are not always representative of sick and disabled children’s lives; a finding that echoes the work of scholars working within disabled children’s childhood studies (such as Runswick-Cole *et al*., 2013; Liddiard, 2022; Curran *et al*. 2013). The key analytical point here is that children’s experience of hospitalisation as part of the mainstream everyday mundane is in opposition to the power of medicine, the interests of which lies in upholding its prestige and authority, constructing itself as separate from the mainstream, and in so doing exercising power over children's bodies to exclude them from mainstream activities (such as school).

Building on the work of Kitchin (1998) and Massey (2005), Procter (2015) adds to the understanding of intersectional identities through spatiality by highlighting that emotions are enforced or oppressed through various spatial environments. She argues that enforcing or restraining certain emotions, within specific spaces, influences the formation of identity (Proctor, 2015). This is important to consider, as spatiality helps to yield new interpretations and understandings of the role and frictions of intersectionality within the unique space and culture of the hospital. Utilising Procter's (2015) work we can begin to understand Ella's prescribed identity (disabled) and prescribed emotions (sadness, fragile, afraid) as both reinforcing and challenging young people's experiences of hospitals. In turn, the role of space in Ella's narratives teaches us that young people not only find space in which to express their chosen identity but that in doing so, they also resist dominant socio-cultural stereotypes around what it means to be a child in a hospital.

To summarise, it is worth revisiting the research question; what can we learn from the stories that people choose to share? I note that Ella chooses to blog about her everyday experiences. Woven into these blogs is the centrality of hospitalisation. She chooses to explicitly address and challenge stereotypes. Ella's narratives offer an entry point into the theme of intersectional identity, noting how her usual emphasis on her age and gender identity is minimised when she blogs during times of hospitalisation, and her words and phrasing adopt a more negative and less autonomous tone: 'what will be happening to me'. She frequently blogs about her own frustrations with medicalisation.

Ella chooses to share in her blogs that the hospital, as a space, affects intersectional identity, making it more difficult to move between identities. Instead, a rigid identity (disabled, ill), along with its associated stereotypes (tragic, vulnerable) and emotions (sadness, fearful) are upheld by the socio-political scriptures of the hospital landscape which aid medicine in upholding its own power and control. The young people in this study, like Ella, are aware of these processes, and work to reassert their chosen identity (young, schoolgirl) with more positive stereotypes (sociable, fun) and associated emotions (happy, energetic, excited). However, this causes frustration because their chosen identity (young, schoolgirl) is understood to be less valued due to the presence and stereotypes of her prescribed identity (ill, disabled). The study notes the importance of not only finding (and maintaining) valued identities during times of hospitalisation but also recognising and valuing the identities that young people hold for themselves.

9.3 William: The importance of recognising children's multi-modal communications and expressions

William's narratives offer an entry point into the theme of communication. William contributed to data with two extensive unstructured interviews, two self-composed music transcripts, a poem, and a letter. William initially presented data in a way that he knew I could not access, ensuring I understood him firstly as a musician. The importance of communication was a major theme to emerge from the analysis, which found that children in this study communicated in multiple different ways. While many studies such as those by Beresford *et al*. (2003), Hemingway *et al*. (2000), Butz *et al*. (2007), Popp (2014), and Ekra *et al*. (2012) acknowledge communication to be important for children in hospital settings, this work tends to focus on encouraging children to verbally communicate with their doctors (Oostrom *et al*. 2000). Some literature, for example by Hemmingway *et al*. (2011) notes the importance of three-way communication with children, their parents and healthcare professionals, but much of the literature concerned with improving communication in hospitals does so with an aim to foster compliance (Nargy, 1951) or comfort fearful children (Bibace et el. 1980) (as discussed in section 4.5).

A significant finding of the analysis was that children report regular communication with their health care team, yet they describe this communication as largely unheard. Children's way of communicating was often non-verbal, as they chose to present their story in multiple and diverse ways. William was the most diverse in his methods of sharing stories, demonstrating a methodological necessity to rethink what we understand 'listening' to be in research.

Young people in this study reported regular use of multi-modal communication during hospitalisation. In light of the analysis and literature which seeks to improve and encourage children's voice in hospital settings, this research notes that children's voices are very present in hospital spaces. However, the ability to listen to the diversity of communication young people engage with is arguably absent. As such, I argue that increasing young voices during hospitalisation requires more than a tokenistic and ableist 'checklist' of suitable methods such as Hemmingway *et al*. (2000) set out. It requires more than encouragement of non/verbal communication (Carney *et al*. 2003). Instead, increasing the child voice in hospital settings (and beyond) requires a greater understanding of the complexities and nuances of young people's communication, requiring adult professionals to engage with and develop skills in multi-modal listening.

Despite detailing regular communication during hospitalisation, young people in this study report feeling ignored by the adults around them. William not only engaged with multi-modal communication on the wards of the hospital, but also in presenting his story for this study. James *et al*. (2008, p.19) describe childhood as a 'complex social phenomenon', while Hackett *et al*. (2015) acknowledge that children's interpretations of events often significantly differ from those of adults; however, the perspectives of hospitalised children are rarely sought and remain relatively unexplored (Livesley *et al*. 2013).

Despite the attempts by Bricher (2000), Beresford *et al*. (2003), Butz *et al*. (2007) and Hemmingway *et al*. (2011) to improve communication with young people in hospital settings, they fail to critique ableist and normative modes of communication or re-contextualize the way in which we understand children's communication in hospitals.

William's narratives draw parallels with Loureiro's (2019) study that demonstrates young people are still dissatisfied with their care in hospitals. William notes how he escaped and ran away from the hospital due to his dissatisfaction and discomfort with treatment, but was brought back to the hospital by his mother and the police. What William's narrative teaches us is that his mode of communicating his discomfort through his choice of actions were noted, but were also misunderstood by the adults around him, who understood his behaviour as rebellious and, as a result, incorporated extra security measures to contain him. I argue that the actions of medical professionals in ensuring William could no longer escape might be read as misunderstanding a very dramatic way of giving voice.

Neither the medical professionals involved in his care, the police officers who brought him back, nor his mother perceived his behaviour as a meaningful mode of communication, resulting in William's belief that his participation and opinions were not valued within the hospital. Within their work, Brooks (2013) and Slater (2013) problematize current notions of a ‘correct’ way for young people to voice their opinions or participate in discussions. They challenge the notion of (in)correct communication, arguing that young people are unheard not because they are communicating ‘incorrectly’, but because they are communicating in ways framed by adults as unorthodox. These assertions resonate with William’s narratives.

Foucault (1977) offers similar thoughts in his theorisation of the ‘mechanism of normalising judgement’ where control and power, over readily accepted modes of communication such as verbal, is re-established by managing and maintaining the ‘binary opposition of the permitted and the forbidden’ (Foucault 1977, p.183). William’s narratives (and indeed all of the narratives collected in this study) exemplify Brooks (2013) and Slater’s (2013) assertions, as young people regularly report being ignored, misunderstood and silenced in their communication attempts with adults. Some participants perceive that there were also punishments or consequences for practising unorthodox communication in hospital settings, fitting with Azzapardi’s (2013) assertions that young people's unorthodox communication methods are not only de-politicised but also demonised by adults.

Foucault offers an interpretation of the mechanisms of depoliticising communications with his discussions of bio-power, a byproduct of power. Foucault (1977) suggests that bio-power encompasses mechanisms for discipline and self-surveillance:

> ‘The central role of ‘bio-power’ in controlling the bodies and minds of subjects- but, in the process, the rules by which some people are produced as normal or healthy, and others are excluded, ensures that opposition and resistance are built-in effects.’

(Foucault 1977 as interpreted by Danaher *et al*., 2000:81)

The idea of bio-power is important to this study as it yields new interpretations of hospitalisation, framing narratives about illness within larger structures of power. We can understand how William’s communication method was understood by adults as abnormal. Foucault's concepts permit us to understand communication as constructed through the frictions of power relations, where medicine, as a powerful institution and school of thought, is permitted to define healthy and unhealthy modes of communication, and in doing so permits the silencing of communication that is seen to be unacceptable, simply because it does not fit within the notions of normalcy set out by medicine.

William’s multi-modal methods of communication teach us that children's communication does not fall into what is considered and constructed as normal, and that if children's experiences of hospitalisation are to be improved then there is a need to continuously problematise the notions of normalcy, especially in relation to communication. Johnson (2010) reports on the power imbalances that are present in many clinical establishments, arguing that care improves when good relationships between the service user and clinician are formed. William’s narratives teach us that in order for empowering relationships to be realised, a more nuanced understanding of children and young people's communication needs to not only be acknowledged but also valued as a meaningful method of communication.

Wilcox (2020), an artist working with children in the hospital, observes that the ableist framework of the medical model has taught generations of medical practitioners that atypical bodies and minds ought to be fixed or improved. It is thought that treatments are desired and should be sought. Wilcox (2020) suggests that hospital settings often undermine young disabled people's expressed needs, desires, choices and autonomy. Wilcox (2020) describes how her own non-verbal communication with young people in hospital helped her to build rapport and trusting relationships with children there.

Aligning with the values of disabled children’s childhood studies (outlined in section 2.6), Wilcox (2020) recognises her own responsibility as an adult in becoming methodologically accessible to the children’s needs rather than expecting children to meet adult needs. As such, she asserts that, in her own practices, she holds no expectations of children’s choice of communicative practices. Wilcox (2020), describes for example, the power of winking an eye in solidarity, noting how it helps children to feel comfortable to express their needs and worries through the art that they create with her.

Expression through art was employed by many participants in this study, and William not only used music but also wrote poetry and letters. William notes how he played music during hospitalisation and would ask a specific nurse, with whom he felt comfortable to hear his music. This echoes a finding in the study by Beresford *et al*. (2003) in that they highlighted that young people felt more comfortable expressing concerns with professionals with whom they were familiar as opposed to communicating with professionals that they had never met before. William used his music to demonstrate how he was feeling or how he wanted his listener to feel, and stated that his music was heard but not understood. With Wilcox's work in mind, William's methods highlight how children often access artistic modes of communication, and feel more able to express themselves through artistic mediums and with professionals that they are familiar with. I argue that this provides researchers and academics with a starting point in developing multimodal ways of listening.

William's narratives not only highlight difficulties in his modes of communication being heard and valued by adults, but also how adults around him often communicated in misleading ways. Beresford *et al*. (2003) noted that information-giving was often between parent-doctors instead of being directed at the young person. Health care professionals in Beresford *et al*. (2003) study felt that young people are not always aware of their condition, and had superficial knowledge of their illness and bodies.

Runswick-Cole *et al*. (2018) note that children's own, often complex, understandings of their bodies are shaped by other people's reactions and relationships with them, and that these relationships are always embedded in culture, power relations, control and communication. Like the children in Runswick-Cole *et al*.'s (2018) study, participants in this study complained that they were not asked for their opinions about things that happened in their lives. Also drawing similar conclusions to Runswick-Cole *et al*. (2018), young people felt frustrated that they were often excluded from healthcare practitioners' discussions and found it difficult to access good quality and truthful information.

William's narratives teach us that children not only feel excluded from communication and information sharing but also feel misled by adults, who, as exemplified by William's experience of being misled by being given false information about his vacation. He explained how he was told that he was ‘going on holiday’ by his mother, and how shocked and confused he was when he arrived at the unit. Butz *et al*. (2007) and Beresford *et al*. (2003) respectively identified that medical professionals and parents found it difficult to know how to pitch information to children about their health and treatments, and felt worried that children would not understand. They also noted that medical professionals found it difficult to know how much information to share with children, and worried that too much information would scare or confuse them.

Drawing on Slater's (2013) assertions that an adult perspective is a privileged one, I argue that adults’ worries about information sharing with children, identified in previous work (Beresford *et al*. 2003; Butz *et al*. 2007) are shaped by ableist assumptions deriving from theories in cognitive and developmental psychology, and underscore a narrative of sick and disabled children as tragic, incompetent, fragile beings in need of charity and protection. Children’s distress and upset in hospital therefore risks becoming ordinary.

Whilst charity model framings of hospitalised children in the times of Coram’s foundling hospitals (explored in chapter 1.2) had a useful function, in that they secured funds, these framings can be oppressive for young people in hospital. I argue that the social and historical origins of children's hospitals require critical examination, as it can be seen that children are still experiencing the stigma and prejudice of charity model depictions of illness.

William’s narratives, and indeed the narratives from all participants in this study, demonstrate that children want to be informed. William’s narratives also highlight that poor communication and misleading information were major contributors to feeling fearful. I argue that there is a need to produce more transparent ways of communicating with children and young people in medical settings, so that children are able to access good quality and truthful information about their hospital care, treatments, and admission.

The UNCRC (2010) articles 12 and 13 indicate that children have a right to be heard in all matters affecting them, and that this right should be upheld in accordance with the child’s age and maturity. The UNCRC (2010) also recognises children’s voices through artistic media such as drawings and art, recommending that this should be understood and accepted as a valuable mode of expression. These rights affect all children, including disabled and hospitalised children. With this in mind, I argue that William, and indeed the other participants in this study, had not heard about the things that affected him in his life. In failing to attend to multi-modal communication and develop multi-modal listening, adults not only silence children's voices but also deny them their rights.

To summarise, the narratives of young people in this study demonstrate the need to question what we understand about communication and listening, whilst problematizing ableist and normative notions of communication. The data have demonstrated that children and young people use a multitude of methods to communicate, and to achieve better communicative practices with young people in hospital settings requires a new understanding of listening. Furthermore, the narratives identify that the young people in this study found it difficult to obtain quality and useful information about their hospital admissions and illness, but were ready and willing to have better transparent communication with the adults and medical professionals caring for them.

9.4 Jazz: engaging with meaningful participation in medical decision making.

Jazz's narratives offer an entry point to discuss the theme of participation, specifically in relation to medical decision making. Jazz reflects on her time on a neurological ward after she had a brain tumour surgically removed. She chooses to narrate her struggle to be included within discussions and decisions about her. Her narrations demonstrate that she sought involvement in making decisions, and highlight her desire to gain meaningful participation in hospital. She describes feeling overpowered and oppressed by medical professionals, but also highlights that the types of choices that she was given during her hospital admission were tokenistic.

While participation broadly means to be involved and included, academics such as Shier (2001) and Hart (1997) describe differing levels of participation. Hart (1997) developed a metaphorical ladder to highlight the types of participation children can have when working with adults (discussed in section 1.3.3). Rung 3 of Hart's ladder details tokenistic participation, which Hart considers to be non-participatory practices. Tokenism is described by Hart (1997, p.41) as a 'particularly difficult issue to deal with'. Hart explains that tokenism is difficult because its practices are often carried out by well-intentioned adults who are concerned about the inclusion of young people. However, they only offer inclusion in choices that have no or little consequence. With Hart's (1997) concepts in mind, and Jazz's descriptions of her participation, Jazz's participation fitted with what Hart (1997) describes as non-participatory practices; thus highlighting a need to engage with children to facilitate more meaningful participation in medical decision-making.

Sinclair (2004) highlights how participation can be constructed as passive (listening to and consulting young people) or active (empowering young people, sharing power and authority, disturbing social constructs), and argues that active participation should be a priority to adults who work with children and young people. Jazz's narratives teach us that while her doctors were aware of her desire to be involved, they often overlooked her ability and thus were exercising passive participation. The assertion from McCluskey (2014) that adults' perception of child participation often silences the child's perspective resonated with Jazz's narratives, in that she believed that the medical professionals around her were under the impression that she felt involved with her care choices, despite Jazz seeking more meaningful participation.

Jazz believed that her limited opportunities to be involved in decisions were due to her age. Jazz's assumptions draw parallels with arguments made by Lundy (2007) and Murris (2013), who highlight that most child participation initiatives are tokenistic due to the way society constructs the capacities of young people. Jazz's narratives not only teach us that children are aware of how they are constructed by adults, but also that they feel the consequence of these constructions, especially in hospital settings. Jazz exemplifies how age might be considered as an exclusionary marker in hospitals, and used as a means to exclude her from meaningful participation.

Rudduck *et al*. (2000), Oakley (1994), and Prout (2003) amongst others have suggested that the social constructs of 'child' limit young people’s opportunities to participate. Thomson (2011) and Murris (2013) highlight the dominance of developmentalist understandings of young age, discussing how age is often viewed as a detriment to a person's understanding or rationale. These social constructs can often frame young people as too immature and underdeveloped to meaningfully contribute to society (Thomson, 2011; Murris, 2013). While challenging the notion of youth, Slater (2013) highlights dominant understandings by explaining that to be acknowledged as ‘adult’ or ‘grown-up’ is to have authority and respect. With this in mind, Jazz’s narratives teach us that she did not lack a good understanding of her situation, nor did she lack rationality. Drawing on Slater's (2013) assertion, I argue that what Jazz lacked was authority and respect in hospital.

Rudduck *et al*. (2000) point out that the perceptions of children and young people have been neglected, with adults suppressing the voices of young people, creating unequal power relations between the adult and child. Similarly, Leitch and Mitchell (2007) suggest that adults are often viewed as knowledgeable and therefore powerful (Gallagher, 2008). Sinclair (2004) adds that adults often do not share their power with young people. Jazz’s narratives teach us that she was aware of her power status in hospital, but she did not, however share the perception of her doctor in that she felt that, given the opportunity, she could have made a meaningful contribution. She was comfortable with the knowledge she had of her own body, framing her own knowledge as superior to the doctors: ‘it’s my body, I know it the best’. Furthermore, she highlights that she often did share her knowledge of her body, but her knowledge was perceived as superficial and was often ignored. Jazz notes how this caused her to feel frustrated at times.

Foucault (1977) offers an insight into the struggle to participate, in the way that Jazz describes, by highlighting bio-power and mechanisms of surveillance (discussed in more detail in sections 2.7 and 2.9). Foucault (1977) asserts that bio-power not only affects the perceived ‘powerless’, but rather that power is everywhere and arises from anywhere, and thus, the mechanisms of bio-power and self-surveillance also affect the perceived ‘powerful’, or in this case, medical professionals. Whilst it seems reasonable to understand medical professionals as oppressors, Foucault's (1977) concept of knowledge and power struggles offers complexity to this understanding, in that the nurses and doctors that Jazz refers to could be, like Jazz, suppressed by the social constructs of 'adult' and the concept of responsibility and rationale that is attached to being adult. Foucault (1977) offers a way to perceive medical professionals and adults in general to be the vehicles of governmental power (Mander,1997). Their education, understandings, ideals and beliefs are what they articulated in their practice. Failing to perform within the construct of reasonable, rational, responsible adults, or offering any more than passive participation, demonstrates adequate self-surveillance to uphold the power and prestige of medical knowledge (Gallagher, 2008). With this in mind we can understand Jazz’s desire for meaningful participation as a challenge to the medical institution. Jazz’s narratives disrupt the narratives that underpin charity model understandings of passive, tragic children. They also challenge developmentalist notions of children's understandings, demonstrating the very basic need for inclusion and equality have yet to be won for children who occupy hospital spaces.

Sinclair (2004, p.108), shifts the focus from adults’ perception of participation to children's rights as individual citizens, stating: ‘Children are citizens and service users and share the same fundamental rights to participate as others.’ Jazz’s narratives demonstrate her understanding of what she understands as her rights of equal citizenship. Jazz notes how she adapted to inequality by developing an ability to verbally resist and thus challenge institutional power. ‘I have to disagree […] or they’d just do whatever’. Jazz highlights that only when she disrupts the flow of power with a disagreement is she afforded more information and opportunities to be involved in consultation. This narrative emphasises that even during these disruptions, Jazz was not only able to obtain passive participation (to be consulted), but also contested the idea that child participation is a secondary consideration in medical settings.

Similar to the ladder proposed by Hart (1997), Shier (2001) developed a pathway to participation. Within this pathway he notes the minimum level of participation required in order to fulfil the requirements of the UNCRC (2010). Shier (2001) observes that in order to fulfil the requirements of the UNCRC (2010), adults are required to support children in expressing their views; their views would have been actively sought by adults, and those views would have been taken into consideration.

In light of the analysis, Jazz’s narratives teach us that children's views are not sought in hospital spaces, and adults do not support children in communicating their views. Children's perspectives were not valued in the hospital, and therefore Jazz was denied her right to participate. Jazz’s narratives demonstrate a need to better apply the UNCRC (2010) requirements to hospital spaces, to critically review what a successful application of the UNCRC (2010) would look like, and what it would mean to institutions of power, such as hospitals.

9.5 Joe: the importance of supporting and promoting autonomy

Joe is a 14-year-old boy with a diagnosis of anorexia who, through his narratives, strongly highlights the absence of autonomy and the psycho-emotional effects of hospitalisation. He details how he felt as if he was not his parent’s child anymore, highlighting notions of belonging, and describes how this made him feel unsafe.

> ‘There was nothing he [dad] could’ve done and you know, I’d usually have to have parent consent and stuff but like, they didn’t need it so they could just do whatever to me.’
> (Joe)

Joe’s narratives offer an entry point into the theme of autonomy. His narratives teach us that young people have a sense of autonomy which he perceived to be threatened during hospitalisation. He noted the exclusion of his parents in relation to the decisions made about him, in addition to his own voice being silenced: ‘I’m not supposed to say certain things, they [doctors/nurses] don’t listen anyway’. Joe’s narratives teach us that he felt not only oppressed but also unsafe in hospital.

Joe expresses an understanding that he was aware that some of the things that he did not wish to happen (e.g. for him to eat food), hindered his recovery. He explained a struggle in terms of him wanting to be well but also not knowing how to make himself feel more comfortable around food. Bricher (2000) argues that children have superficial knowledge of their bodies; however, Joe's narratives contradict Bricher's (2000) claims, as Joe seems to have a rich understanding of body and mind as well as their limitations during his hospital admission. Joe expressed that he was aware that some of his choices did not help him to get better and as such, he felt he could not always trust his own choices or judgements. Joe wished for his parents to make important decisions about his care on his behalf, but explained that his parents were not permitted to do this.

Joe often consulted his parents, seeking reassurance when he found something difficult, highlighting their role in comforting him. In light of the analysis, Joe's narratives underscore the importance of the Platt report (1959), which drew on Robertson *et al*.'s (1971) study (as outlined in section 3.2) to acknowledge the emotional and psychological stress and trauma children were subjected to in the absence of their parents, making it a right that children should have access to their parents at all times during hospitalisation. Joe's narratives, however, take the recommendations of the Platt Report (1959) further by highlighting that it was not enough to simply have access to his parents; he also needed his parents to maintain their right to parent him, which included having the right to make choices that were in his best interests. Joe argued that, during hospitalisation, he felt that he did not belong to his parents anymore, and as a result he felt they were unable to ensure his safety or protect him.

Joe's narrative teaches us that medical practice and protocol often contradict children's rights as set out in the UNCRC (2010). Joe's attempts to express himself in terms of his worries about proposed treatment plans were met with discipline, and even sedation, rather than reassurance and comfort. Joe makes it clear that he understood sedation as a threat or a punishment, and noted its consistency during his admission to hospital.

Counter to the Platt report's (1959) requirements, that children should have full access to their parents at all times during hospitalisation, Joe narrates the regularity of being reprimanded in hospital, as well as the threat to revoke the little communication he did have with his parents: 'they said 'if you don't stop wailing we will take your phone off of you and then you will not be able to speak to your mum.' (Joe) As such, they framed Joe's communication with his parents as a privilege and not a right. Joe's narrations and description of how fearful and unsafe he felt in hospital support the claims made by the Robertson *et al*. (1953) study which informed the Platt report (1959). Joe's narratives teach us that his experiences and perceptions are contrary to the recommendations of the Platt report (1959). I argue therefore that the Platt report (1959) is yet to be embedded in all hospital spaces that children occupy. Moreover, there is a need to assess how the UNCRC (2010) is implemented and upheld in children's hospitals.

Joe's claims underscore the Children First report, which noted that the Platt Report (1959) had not been implemented for 11-16 years olds as successfully as it had been for younger children (Dodd, 1993). Additionally, the UNCRC (2010) have driven a child centred approach that runs alongside a family centred approach, highlighting a focus on children as equal citizens and partners in care (Carter *et al*. 2014). As such, they recognise and shift the understanding of hospitalised children from passive consumers of care to active members of the care partnership. Furthermore, Joe's narratives underscore the many studies that have highlighted concerns about the welfare of children aged 11-16 years old in hospital (Hemmingway *et al*. 2011; Bricher, 2000; Curtis, 2004; Wilcox, 2020). Joe did not perceive his experience as either child centred or family centred. Instead Joe perceives his experience of care as occurring within a medical approach which stripped him and his family of any control or autonomy.

Joe's narrations exemplify the lack of autonomy he had in hospital:

> 'I was shouting not to and they were just all there grabbing me when I didn't want it [the needle]'
> (Joe)

Joe described how, on this occasion, he expressed his wishes by shouting. He makes it clear that he 'didn't want it' and explains how medical professionals grabbed him. Slater (2016) notes how young people with bodies or minds that are perceived to deviate from accepted notions of 'normal', such as Joe's, are afforded less autonomy.

Slater (2013, 2016) argues that when young disabled people do express a desire for, or perhaps their right to, autonomy, especially within hospital environments, their autonomy is also subjected to the bio-medical gaze, to be judged and monitored along with other symptoms of impairment. Thus, Slater (2013, 2016) argues that young people's resistance and verbal disapproval, like Joe's shouting, is considered as a problem in need of fixing, and Joe notes this was 'fixed' with the threat or use of sedation. Azzapardi (2013) concurs, and notes that often young people's expression of agency in institutional spaces, such as hospitals is perceived as deviant, as it constitutes activism in the space.

Lefebvre (1991), Soja (1996), and Massey (2005) argue that space is political as well as dynamic and socially constructed. Hackett *et al*. (2015) note that the spaces given to children are either political or ideological. Additionally, they suggest that adults restrain and restrict children's autonomy in space. Kitchin (1998) highlights how space is produced to exclude disabled people in two ways: firstly, through its social texts that convey to disabled people that they are 'out of place' and unwelcome; and, secondly, spaces are purposely organised to keep disabled people 'in their place', and are thus linked to the way disabled people feel in such spaces (i.e., frustrated, oppressed, etc.) However, Joe did not perceive himself to be out of place. He understood he was unwell and he wanted to recover. He also perceived hospital as an appropriate place for him to seek help, and thus he did not feel misplaced. Instead Joe's narrations challenge institutional organisation and hospital protocol that dictate where his place is in the hospital setting. The place Joe was afforded was a bed where he could rest whilst passively consuming his prescribed care. When Joe attempted to actively contribute to consume his care, he was met with disciplinary measures to ensure he was kept 'in his place' (Kitchin, 1998).

De Certeau (2011) draws on Foucault's concepts to illuminate how buildings, such as the hospital, attempt to control the autonomy and movement of individuals who occupy them, indicating how the hospital landscape ought to be used. For example, beds are to rest in whilst receiving care and treatment. However, Joe's narratives challenge the idea of children being passive consumers of care, and thus disrupts the socio-political scriptures and culturally accepted notions of children in hospital by assuming a right to autonomy. Joe's narratives teach us then that children and young people resist the accepted socio-spatial and cultural use of the hospital landscape, and in doing so they resist the attempt to control movement and autonomy in hospital spaces. Joe's narrative indicates that it is a reprimandable offence for young people to challenge their lack of autonomy in hospitals.

To summarise, Joe's narratives teach us that young people have more than a superficial knowledge of their bodies and minds. They are also aware of their limitations, and often identify a trusted adult to make decisions that they feel unable to make. Joe's narratives support the early work of Robertson *et al*. (1953) and highlight the necessity of the Platt report (1959) to improve hospitalisation for children and young people and minimise the trauma that can occur as a result of it (as discussed in sections 3.2 and 3.5). Joe's narratives indicate a need to assess the implementation of the Platt report and the UNCRC (2010) in hospital spaces that children occupy. Furthermore, Joe's narratives teach us that he had very little autonomy in hospital and that in assuming autonomy, he challenged institutional power and was reprimanded by medical professionals.

9.6 Rachel: the problem with hospitals as clinics

Rachel is a 29-year-old woman reflecting on a hospital admission due to meningitis when she was seven. Rachel's narratives offer an entry point to discuss the theme of dehumanisation. Her narratives support French's (1993) concept of 'public stripping' (explored in section 7.3), demonstrating how hospitalised children can feel exposed, humiliated and vulnerable to the medical gaze placed upon their bodies and minds.

Rachel's account of her powerlessness and vulnerability in hospital also draws parallels with Reeve's (2002) work, which argues that it is a form of psycho-emotional disablism and institutional abuse when adults make children feel vulnerable and exposed. Leach (1994) highlights that everything adults do to the bodies of children without that child's permission, such as observing and looking at them when consent has been withdrawn, can be experienced as objectifying and disrespectful.

Rachel's narratives teach us that there is a continuous need to question the necessity to observe children in hospital and a need for medical practitioners to acquire assent. Gaining assent is considered a key issue in ethical social research with children (Hackett *et al*. 2015), and requires researchers to continuously gain consent from children, rather than just once at the beginning of a study, in order to create opportunities for children to exercise their right to withdraw (either permanently or temporarily) from research. However, this ethical concern is not always practised when research is not formally undertaken, for example, in clinical observations in order to learn more about a person's body during hospitalisation. Rachel's narratives demonstrate that there is a need to be continuously reflexive in relation to the ethics of interactions that doctors have with their young patients.

Foucault (1963) noted that when medical professionals treat illness, such as Rachel's meningitis, the clinic, with both its intellectual and physical structures, creates a possibility for inspection, examination, and analysis of the human body. Therefore, when Rachel enters the hospital, which is within the medical sphere, she also enters the field of power that automatically has the authority to exercise a medical gaze over her. The medical gaze works to uphold its own power and prestige within culture and society through its assertion of 'superior' (medical) knowledge on bodies (Foucault, 1963).

Rachel's narratives teach us that when the clinic exercises its power to observe her, this is experienced as being against her wishes. Her narratives make it clear that the bio-medical gaze placed upon her was oppressive and was not in her best interest. Whilst she did not feel strongly about her emergency treatment in hospital, when the hospital established its right to impose intellectual 'epistemic' structures onto her body, using her body as a teaching tool, this was a problem. Furthermore, Rachel recalls the oppression from the age of seven years, demonstrating that even when her parents were present as the Platt report (1959) suggests, young children still experience the clinical gaze as oppressive. In light of the analysis, I argue that the clinical gaze is more than being observed, watched or stared at. Instead, it is part of the process of pathologization, which young people in this study feel deeply troubled by.

Rachel recalls how she became fearful of medical professionals as she felt embarrassed and self-conscious. Despite withdrawing from unnecessary observation, she noted how her compliance and tolerance were encouraged: ‘my mom told me that they had to see it so that they could help future people’. Ekra *et al*. (2012, p.402) asserted that:

> ‘When we become suddenly ill, the harmony between the biological and the lived body is disrupted and the malfunctioning body part appears in our consciousness’.

In this context, when Rachel became ill, the biological (the meningitis that concerned her doctors and her mum) disrupted her lived reality, which she felt was important. This resulted in an interpretation of Rachel’s body as ‘malfunctioning’ (Ekra *et al*. 2012). Silencing her wishes to withdraw from clinical gaze by encouraging her tolerance was a further apparatus of control (Lynch, 2011). Her mother assisted in upholding the power of medical knowledge by surveilling Rachel’s behaviours and expressed wishes (Lynch, 2011). Such mechanisms of power and control contribute to the reinforcement of an unequal distribution of power which exists between children and adults in hospital settings. Rachel’s narratives highlight the need to evaluate and problematise unequal power relations between children and adults in clinical environments, and Foucault's concepts of the knowledge/power relationship shed light on structures of power in institutions such as hospitals.

While Rachel had a good understanding of her emotions about medical students, her wishes did not align with the doctors’ wishes and thus, her mother was able to consent to assessment on her behalf. By continuing to invite medical students to visit Rachel, it could be understood that the doctors chose to privilege Rachel’s mum’s knowledge of her daughter's tolerance rather than Rachel’s expressed tolerance and wishes. Rachel’s narrations exemplify the negative effects of the bio-medical gaze, and again highlight how children's autonomy and voices in medical settings are overlooked by professionals.

Aligning with Dickenson *et al*.'s (1995) work, Rachel's narratives exemplify how children's wishes are overlooked and devalued if their parent's wishes are more favourable to the medical perspective, demonstrating the power of age in relation to being heard. This highlights the contrasting powerlessness of children in medical settings, especially when their wishes do not align with those of adults. The analysis illuminates how instrumental power relations are in devaluing the voices and undermining the emotions of young people in hospital. Furthermore, Rachel's narratives demonstrate that young people are key players and stakeholders in healthcare conversations and interactions. Foucault's concepts are a useful lens to employ in order to begin to understand the impact of power on hospitalised children's lives.

Hospitalised children's fear was a prominent topic of discussion within the literature. The majority of the literature describes children's fear as the fear of medical procedures; however, Rachel's narrations challenge work by Beresford *et al*. (2003) in that they challenge simplistic notions of children's fear and suggest that children are proactive participants in decision making. Rachel's narratives demonstrate that, despite her age, her experience of fear was more sophisticated and encompassed her lack of control and autonomy, and; the loss of privacy, highlighting how children's fear is both complex and multi-layered. Rachel's narratives not only align with Reeve's (2002) notions of psycho emotional disablism, but also Butler's (1997) assertion that doctors can cause mental pain and oppression.

Rachel describes how the doctors spoke more with her mother than her; she perceived this positively as it meant that she could avoid interacting with the medical professionals. However, she also notes how things were often done to her without prior warning. Rachel's narratives align with Beresford *et al*. (2003) work promoting a need to develop a better understanding of hospitalised children and young people's communication needs.

Rachel makes a comparison between the doctors she encountered in the emergency room, who needed to act quickly to protect her life, and the doctors on the ward who did not need to act as quickly. Whilst neither are described positively, Rachel is more troubled by the ward doctors. Rachel suggests that the ward doctors should have had different priorities, such as ensuring her comfort and participation during medical interactions. She reflects on her experiences and suggests that the emergency doctors' priority was to save her life, and the ward doctors' priority was to better her life. She was more troubled by the ward doctors because she perceived them to not be acting within their responsibility.

Rachel's narratives demonstrate that children in hospitals assume that different medical professionals hold different knowledge and employ different skill sets. For example, Rachel expected to be ignored in the emergency room when her illness was time sensitive, and despite the intensity of the experience, harboured no ill feelings towards the doctors there, who needed to urgently administer medication. However, Rachel does harbour ill feelings towards the ward professionals because she expected that when she was on the wards of the hospital, the pace of medical intervention would be more relaxed and allow her more autonomy. Rachel noted that she felt most oppressed in the ward. Rachel expected that the ward doctors would respect her autonomy, which she feels they failed to do.

Rachel's narratives teach us then that it is important to understand what children expect of their medical team, and to understand that these expectations can change depending on place (in the emergency room or on the wards). Supporting the assertions made by Kitchin (1998) and Procter (2015) in the area of spatiality, Rachel's narrative highlights a lack of understanding about what children expect of medical professionals and how place, space, and time affect these expectations. Additionally, it highlights that children require clear information about what to expect in certain spaces in the hospitals and by the various different medical professionals. Dickenson *et al*. (1995) argue that to act in someone else's best interest requires deep understanding of the individual's identity and values. As such it is vital that paediatric doctors find new ways to build rapport and a trusting relationship with their young patients quickly.

Rachel discusses how elated she was when she had a visit from the tooth fairy. The tooth fairy was meaningful and highly significant to her. She suggests that this made her 'feel normal again'. In light of the analysis then, we can again utilise the concepts of Foucault's who suggests that the clinical gaze refers to a way of thinking about health and illness that filters out irrelevant information. For Rachel, the tooth fairy was significant because it ‘proved’ her normalcy and gave her permission to act as a child. However, for the doctors, the tooth fairy was filtered out as irrelevant information, as it was not a symptom of her illness. Rachel's narratives teach us that it is not enough to note the environmental and social backdrop of patients. Additionally, they illustrate the importance of perceiving children and young people's lives, including their illnesses, more holistically. I argue that this requires a social and cultural gaze to be employed in medicine.

Rachel describes how she felt that no one shared her excitement about the tooth fairy, exemplifying how the clinical gaze creates a barrier for professionals in relating to and understanding children and young people. Rachel notes how she remembers feeling lonely and sad that no one comprehended her excitement, illuminating the psycho-emotional upset that can occur as a result of the clinical gaze.

To summarise, Rachel’s narratives teach us that when young people withdraw from medical observation in hospital settings, the clinical gaze makes it possible to overrule the withdrawal. I argue that the clinical gaze is more than being observed, watched or stared at; rather it is part of the process of pathologization. Rachel narratives support the idea that spaciality is important in the lives of children (Kitchin 1998; Procter, 2015; Hackett *et al*. 2015), demonstrating how children’s expectations of adults change in different spaces within the hospital. Foucault's (1963) theories around the power/knowledge relationship are useful to employ as they illuminate how instrumental power is in silencing the voices and wishes of children and young people. Furthermore, the clinical gaze, as a way of thinking about and understanding health and illness, can be counterproductive to professionals who are seeking to build rapport with children and young people in hospital, as the clinical gaze often filters out the elements of children's lives that are significant to children.

9.7 Holly (me): the importance of understanding children's lived reality

I am a 36-year-old woman with a diagnosis of epilepsy. I provided excerpts from my personal diaries that I kept when I was 14 - 15 years old. These excerpts were multi-modal in that they consisted of written diaries, poems, and drawings and paintings. I was hospitalised often as a young person and therefore the diaries contained many narratives that were written during hospitalisation.

My dairy narrations offer an entry point into the theme of emotion and embodiment which facilitates an insight into how I experienced hospitalisation and how I navigated medical understandings and restrictions imposed upon my body. I assert that my understandings and experiences of hospitalisation were shaped by the restrictions and consequences of 'incorrect' emotional displays within hospital spaces.

Proctor (2015) asserts that emotions are situated in space, whilst Hackett *et al*. (2015) and Soja (1996) note how space is both socially constructed and dynamic. As such it can be argued that adults restrain and restrict children's freedom in space, and thus children's interactions and experiences of space are also restricted. Kitchin (1998) highlights how space is produced to exclude disabled people through its social texts, conveying to disabled people that they are 'out of place', and that there are spaces that are purposely designed to keep disabled people 'in their place'. Hackett *et al*. (2015) argue that the spaces given to children are either political or ideological. Others, such as Davidson *et al*. (2005), Pile (1991), and Kraftl (2013), explore emotion and its role in constructing experience. Such scholars believe emotion is located in both bodies and places. Hackett *et al*. (2015) argue that by examining the interconnections between space, place and emotion, researchers can understand children's lived experiences in new ways.

In light of the analysis, I assert that the socio-spatial and cultural scriptures in hospitals also indicate which emotions, or maybe more accurately, which displays of emotions, are out of place: 'i'm scared, i'm alone, i'm afraid, i'm in fear, words i know will be wasted on your ear'. When displays of emotion are out of place they are pathologized, categorised, and controlled. We learn from the narratives of my younger self that restricting and redirecting emotions in hospital spaces also restricts and misplaces the experiences of children and young people in hospital.

I argue that children use emotional exchanges as an important means by which to sustain, contest or redefine their own and others' social positions in hospital spaces. Therefore, children's embodied emotions need to be analysed beyond the theoretical frameworks of cognitive and developmental psychology. A socio-spatial view of emotion is required in order to consider how emotions are integrated within the structuring processes through which people give value and meaning to their relationships, and indeed their experiences.

Children's experiences of hospitalisation have been widely documented as a negative emotional experience (see section 3.2). Many studies focusing on children's experiences of hospitalisation framed children's emotions as an obstacle to rational thought (see section 4.1), whilst others have noted trauma that children would experience in hospital settings, suggesting remedies such as ensuring parents are present in hospitals (highlighted in section 1.2), or offering extended discussions around how to comfort fearful children (explored in section 4.2). Most of these remedies had the aim of ensuring children's compliance with medical demands and were intended to minimise trauma (as explored in section 4.2 and 4.3). In light of the analysis, the narratives of my younger self demonstrate that while parents offer a level of comfort to hospitalised young people, they are not a mechanism to avoid trauma. Burman (2008, p.277) argues that:

> 'if we are really to become interested in children's emotional experiences, rather than in trying to manage them or make uncomfortable emotions disappear, then we have to engage with them, and with our own responses to them'.

In light of the analysis, I argue therefore that the Platt Report's (1959) recommendations to involve parents and maintain their presence in hospital is not as effective for young people aged 11-16 years old, as the Audit Commission: Children First (1993) suggests (explored in section 1.2), because young people require theirs and their parent's emotional presence to be not only acknowledged but also understood and for them to be involved in their care and treatment plans.

Within the literature, hospitalised children's emotions were understood to derive from uncertainty about their surroundings, or fear of medical procedures such as needles (Popp *et al*. 2014). Initiatives to ‘help children cope’, encourage children to manage their own emotions, and when this was not possible, for their parents or nurses to manage their emotions in the name of social and medical cohesion. However, the narratives of my younger self teach us that children's emotions in hospitals are more complex, and relate to the consequences of certain medicines and the social implications of illness: ‘I am scared they will give me [medication] in my cannula’. Furthermore, the narratives challenge literature that frames children's understandings of illness as superficial (Bricher, 2000), highlighting how children and young people’s emotions often derive from rational thought and understandings of consequence.

Additionally, the narratives of my younger self demonstrate that I had an awareness of the social consequence of displaying emotion ‘incorrectly’: ‘I want to scream really loudly but i can't even do that or i will get told off.'' When children display emotions that do not align with accepted charity model notions (for example, they are neither grateful to medicine nor brave), it makes it necessary and possible for adults to exercise control over expressions of emotions in order to maintain social order and compliance. Applying Slater’s (2015) assertions of ‘correctness’ being an adult conception of hospitalised children's emotional displays, it is possible to understand children's emotional displays as an adult construction of normalcy. Slater (2015) notes how this concept was developed through medical and psychological schools of thought which operate in society and prescribe what constitutes ‘correct’ or otherwise.

Slater (2013) highlights that society does not permit young people to be emotional without adult rationality. In linking youth to ableism and problematising adult perspectives of children, in this case children’s emotional responses, Slater (2013) asserts that an adult perspective is an ableist one. The narratives of my younger self demonstrate that I was aware of adult notions of stable emotions, and of which emotions were expected of me. Conveying what I perceived was a doctor's voice, I narrated ‘take your pill, relax and chill, because it is the correct thing to do’, highlighting how I believed that doctors were expecting me not to have strong worries about medications and suggesting that feeling relaxed was expected of me. While my narrations support the work of Slater (2015), who note that this perception challenges accepted ‘common-sense’ understandings of hospitalised children’s emotions being void of rationality and uncontrolled.

Barnes *et al*. (2003) highlights how sick and disabled people are expected to experience emotions which run parallel to a charity model depiction of hospitalised children, such as those depicted in media like *BBC Children in Need* which portray hospitalised children as ‘brave’. My narratives teach us that when emotional displays, such as crying, deviated from expected narratives of children in hospital, such as bravery, they were overlooked and unacknowledged: ‘you cannot even see my tears’. Furthermore, young people felt that unexpected displays of emotion were often misunderstood by medical practitioners as non-compliance: ‘for you this is a sign that I’ve started a fight’. The narratives of young people in this study highlight that when their publicly displayed emotions did not align with what was accepted or expected of them, they were often subjected to further surveillance and pathologization, and even denied privacy: ‘they won’t even let me pull my curtains around.’ I argue that this kind of response to children and young people’s unexpected and unwanted emotional reactions leads to their emotional feedback being dismissed as irrational and childish, rather than meaningfully explored.

Reeve (2002) and Siebers (2011) also observe how a poststructuralist perspective makes it possible to understand how the psycho-emotional can be affected by adults' dismissal of emotion. Unwanted emotional responses by children in hospital are often understood as deviating from medical expectations. Reeve (2002) and Siebers (2011) note that being perceived to deviate from medical perspectives and expectations makes it possible to place the blame for ill health, or indeed trauma, on the individual rather than on wider structures. This renders the individual, in this case me, as imperfect and inadequate, placing the blame of not only illness but also trauma with myself and not with society (Morris, 1991, Oliver, 2009; Siebers, 2011). My story echos this, especially when I narrated how the doctor had told me: ‘this will not do Holly’ after having a seizure, blaming the seizure on my decision not to comply with taking the new tablet.

Medical professionals' dismissal of my feelings taught me that the emotion I experienced was not welcome in the hospital space. The inadequate response by medical professionals to my emotions in hospital led me to feel embarrassed about my emotional display: ‘I feel like such a baby, but I can't stop it.’ Additionally, the confiscation of privacy could be understood as a mechanism of bio-power, aiming to teach me how to better self-surveil and self regulate. Their response ensured that I felt sufficiently humiliated to internalise shame: ‘I still can’t stop crying, I wish I didn’t exist’. This resituated the burden of concealing and regulating emotion onto me rather than making it their responsibility to understand. The narratives of my younger self teach us how the reactions, or perhaps more accurately, the non-reactions of medical professionals to young people's emotional distress is significantly harmful to their psycho-emotional wellbeing (Reeve, 2002).

Whilst my 14 year-old self’s narratives offer an entry point into emotion, it is also worth noting that my adult/researcher self chose to incorporate autoethnography into this thesis, again entering into the theme of emotion. Wendall (2013) argues that further understanding is required about what is valuable about illness and impairment, and also what is troubling about it, on a bodily rather than medical level. We learn then that whilst hospitalised children’s trauma is noted within medical and psychological spheres of thought, this acknowledgement does not capture or understand the injustice and long-term effects of the clinical gaze. Goering’s (2015),work resonates when she notes how some psychological suffering cannot be remedied by social change, and as I grapple with the nuances of writing myself and my younger emotions into this thesis, I continue to feel vulnerable around my data, knowing it will be read. I recall the memories of my younger self and again internalise the pain of not wanting to exist. This research was borne of anger, hurt and a sense of injustice that has been with me since I was fourteen. The same hurt and anger I was taught to conceal, regulate and internalise. bell hooks sums it up when she writes:

> ‘I came to theory desperate, wanting to comprehend - to grasp what was happening around and within me [...] i saw in theory then a location for healing.’
>
> (hooks, 1991, p.1)

I learned in theory then that the mechanisms of the clinical gaze reached far and wide; I was not alone, and I had a reason to feel a sense of injustice. I had internalised what was happening around me and my story sat within the same sphere as those who silenced me. As a young person, I did not have the power or authority to challenge unhelpful assumptions and hurtful perceptions. I see in theory then, not a location for healing but a location of change; a new sphere in disabled children's childhood studies, where my younger voice, emotion, trauma, and injustice can be heard, and my story and stories like mine can be fully appreciated. I see in theory a re-location of focus, and see in this re-location a potential to be heard. I perceive being heard and understood as a step towards healing; not healing me as a person, but healing a violent process of psycho-emotional disablism through a clinical gaze.

Aligning with Goodley’s (2011) argument that a more holistic understanding of illness and disability is needed, the autoethnographic narrative in this thesis teaches us that a critical disability studies approach is needed in order to comprehend that the struggle for social justice is not over. It continues, and CDS and DCCS understand that this struggle is complex and multi-layered. Meekosha *et al*. (2009, p.50) suggest that the use of critical disability studies:

> ‘signifies an implicit understanding that the terms of engagement in disability studies have changed; that the struggle for social justice and diversity continues but on another plane of development – one that is not simply social, economic and political, but also psychological, cultural, discursive and carnal.’

I surmise that the narratives of my younger self as well as the narratives of autoethnography offer an entry point to the theme of emotion and embodiment. These narratives teach us that medical and psychological framings of hospitalised children's emotions do not represent the complexities of children's emotion, especially in hospital spaces. The narratives demonstrate how the failure to acknowledge their public display of emotion caused significant psychological and emotional pain, and teaches children and young people to feel a sense of shame and to internalise their hurt.

9.8 Chapter conclusion

By now this chapter should have done its job in applying theoretical underpinnings and policy to the stories of participants. In discussing each theme and the main messages within each participant's stories, I highlight the sense of injustice and shared experiences of oppression through participants' stories. I have brought threads from the literature and theory to the narrations of participants in order to make their personal experiences of hospitalisation political. Within the chapter I have highlighted the desperate need for hospitalised children and young people’s rights to be upheld. I argued that children in hospitals require more agency and recognition of voice and competence. Young people in this study repeatedly narrate a struggle for agency, a desire to be heard, and to meaningfully participate in decisions made about them. I note that current understanding of young people's emotions in hospital is often oversimplified, and the role of emotion in experience deserves a fuller exploration. Finally, I argue that young people's strong emotions about their hospital encounters are experienced long term, noting how my own narratives began with a diary but evolved into a thesis which incorporates the emotional work required of autoethnography (Ellis, 2007). The following chapter will discuss this further in relation to the study's key findings and its implications for policy, practice, theory, and future research.

Chapter 10 – Concluding thoughts on key findings and wider implications.

10.1 Introduction

As the thesis is coming to a close, this chapter will summarise the key findings and contributions this research has made, before highlighting the implications this has for policy, practice, theory and research. The limitations of this research are noted and directions for future research are recommended. The chapter draws the thesis to its end with a reflection and a letter addressed to the 'well intentioned adult'. I chose to do this because, at the beginning of this study, in 2015, I was asked the question, '*Who are you writing to? Who is your audience?'* and this was not always clear at the start, but as the study progressed and narrative data were collected I realised that the audience was the adults who were often concerned with helping children, including doctors, nurses, healthcare workers, parents and hopefully allies. They are proactive in their learning and digest theory and concepts to help them to understand the lives of children, often considering themselves to be allies or protectors of children. However, quite often these adults embody docility (Foucault, 1981; Mayall, 1998), which works to maintain current power positions in society and recirculate adult, ableist practices. The letter directs my writings to these adults, urging them to reflect on their own practices. It offers a new perspective to understanding the lives and struggles of hospitalised children and young people.

10.2 Key findings and contributions:

This research had a single research question: *What can we learn from the stories that people choose to share about their hospital experiences?* The answer to this is complex and extensive; however, the following section will tease out the key findings of this research in relation to the research question.

Notions of normativity emerged from the data, highlighting that, for ill and disabled young people, there are two key notions of normativity: 1) what it means to be a normal child; and 2) what it means to be a normal child in hospital. Participants drew on and discussed normativity, demonstrating it was an element of their stories that they felt was important. Participants in this study were often not only aware of their own bodies and minds but also those around them, and as such they recognised how other people perceived them. From the stories participants chose to share, I learnt how children can reject the clinical gaze and often work to foreground other aspects of their identity such as their age. This finding aligns with Slater (2013; 2016) who argues that young people with impairments feel they have to 'live up' to what is expected of them by society, or risk being perceived as troublesome or risky (explored in chapter 7).

A second theme, which came through strongly in the data, was that children in hospital do not feel heard. Listening to children and young people should be a priority as set out in the UNCRC (2010). However, children and young people felt that their non-verbal communication was ignored and even misunderstood within hospital spaces. From the stories that young people chose to share in this research, we learnt how they employed communication as a form of resistance, aligning with the work of Livesley *et al*. (2013) and Roter *et al*. (2005), who highlighted that children and young people communicate in multiple ways, and yet their non-verbal communication is scarcely understood. Roter *et al*. (2005) suggested that children's non-verbal communication is a political choice. Unique to this study, I noted how the act of sleep refusal was a non-verbal cue for fear. Building on the work of Azzapardi, (2013), Brooks (2013), and Slater (2013), I learnt that young people were often not perceived as normal communicators, and that failing to acknowledge non-verbal and unorthodox communication methods, often employed by young people in hospital, not only allowed young people's voices to go unheard, but also misunderstood. As such, there is a need to continuously question and problematize notions of normalcy, especially in relation to communication, whilst also working to develop multi-modal and multisensory ways of listening to children and young people.

A third finding concerned the notion of emotion. Whilst hospitalised children's emotion is present in the literature, it was discussed mainly in relation to fear; predominantly in literature from psychology, medical sociology and nursing (explored in chapter 3).

Emotion, and more specifically fear, did emerge in my data and is woven through all narratives. In this study, emotion occurred in ways that challenged current understandings of hospitalised children’s emotional experiences and highlighted its complexity. Aligning with the work of Procter (2015), what I learnt about emotion from the participants' stories is that hospitalised children’s emotion is situated in both body and clinical space, and thus emotion requires a socio-spatial perspective which understands that space is both socially constructed and dynamic (Kitchin, 1998; Hackett *et al*. 2015). It seems reasonable to conclude that current understandings of hospitalised children’s emotions fail to acknowledge the complexity and depth of children’s emotional experiences. This research found that emotion, and in particular fear, was experienced intensely by young people when a clinical gaze was applied to their emotion. Young people describe how they were encouraged to conceal strong emotion to ‘be brave’, and that when they could not conceal, they felt humiliated and internalised feelings of shame. What I learned from engaging with this theme was that the emotional labour of being a hospitalised child deserves more attention, and that current frameworks to understand children's emotion, set out in psychology, are insufficient in exploring children’s emotion in hospital spaces.

Fourthly, I found that the relationships between young people and their medical teams were highly important in relation to children and young people’s experiences of hospitalisation. The data were overwhelmingly negative in relation to how the young people perceived their treatment, as they felt overpowered and oppressed by medical professionals. Despite the data around this theme appearing bleak, young people had a strong sense of hope for change. Analysis revealed that the perception of risk differed amongst children and medical professionals, and caused friction in the communication and relationships that these young people had with their medical teams. For this to be mitigated, young people suggested that healthcare workers need to take an interest in other aspects of their life, aligning with the work of Wilcox (2010), who argued that healthcare professionals needed to find ways to better relate to and understand hospitalised children and young people. I learnt that young people strongly desire that their bodies and minds should be considered more holistically by the adults around them, including a recognition of young people’s valued identities in hospital spaces (discussed in section 9.2). Additionally, I learnt that children and young people faced barriers to obtaining good quality information about going into hospital. The information they do receive is often misleading, causing them to feel sceptical about who can be trusted.

Finally, the mundane was found to be extremely important in the understanding of young people’s resistance to medical framings in hospitals. From the stories that participants chose to share, analysis showed that the mundane was vital to understanding young people's intersectional identities. I learnt that being young was perceived differently in and out of hospital spaces, and had differing connotations in different places. This research highlighted the juxtaposition experienced by young people in hospital in terms of how the identities imposed on them, such as being unable or tragic, often contradict the identities that young people hold for themselves. Thus, young people often found a space and place to forefront their chosen identities and challenge their prescribed identities. I discovered that, through young people’s tales of the mundane, they are able to de-construct, re-construct, re-tell, and reframe their stories in ways that challenge medicalised framings of hospitalised children's lives and childhoods, offering a way of understanding children’s resistance as a political engagement. I argue that ignoring stories of the mundane contributes to the reinforcement of research that wrongly frames hospitalised children and young people within a charity model of disability, and in doing so, reinforces a recirculation of unhelpful stereotypes.

The research question asked: ‘*What can we learn from the stories that children and young people choose to share?*’ To revisit the research question, firstly, the stories that young people chose to share challenge dominant narratives within society and culture that frame hospitalised children within a medical and charity model of disability. Instead, they highlight children and young people’s intersectional selves and lives. Young people’s narratives are engaged with themes of stigma, oppression, emotion, surveillance, and resistance. Choosing to engage with these themes not only highlights the failure to involve young people in medical decision making but also in research around their experiences of hospitalisation. The stories of young people in this research teach us that there is a consistent attempt and desire to participate, be heard and be recognised. Young people not only want their voices to be acknowledged, but also understood and valued. This research therefore calls for an urgent development of multimodal and multi-sensory ways of listening, especially in clinical spaces.

10.3 Implications for Policy

It is clear that the care of hospitalised children has made progress over the years with the implementation of the Platt Report (1959). Whilst children's hospitalisation is still not ideal, this study in no way wishes to undermine the progress that has been made thus far. That said, the literature review (section 1.2) identified that children aged between 11-16 were least impacted by the positive changes of the Platt Report (1959) (Dodd, 1993). This research mirrors the frustrations of young people represented in the report, as participants in my study detail similar frustrations with their hospital care. In chapter one of this thesis we can observe a gap where the positive impact of the Platt Report (1959) is neither applicable nor representative of the needs of hospitalised young people aged 11-16. This research therefore recommends that an amendment is made to the Platt Report, incorporated into the UNCRC, to better represent the challenges and needs of young people aged 11-16 in hospital. This should note that parental presence is not always enough for young people in hospitals who require information and autonomy. Furthermore, it should highlight how young people require their emotional and non-verbal presence to not only be permitted in clinical spaces but also heard, understood and valued.

Despite articles 12 and 13 of the United Nation Convention on the Rights of the Child (UNCRC, 1990; 2010) asserting that all children have a right to be heard in all matters affecting them, the participants in this study did not feel heard. The UNCRC (2010) asserts that children have a right to be heard through whatever medium of communication the child sees fit. However, the participants in this study felt that their medium of communication was unacknowledged, de-valued, misunderstood, and further subjected to the clinical gaze. The UNCRC (2010) suggests that children's voices should be given due weight in consideration with their age and maturity (UNCRC, 1990; 2010). However, the analysis at the centre of this thesis problematizes developmentalist perceptions of age and maturity, arguing that they are an adult and ableist construct. Therefore, if we are to listen to and take seriously the voices of hospitalised young people, their voices should be given due weight equally, despite their age and level of maturity. This research thus recommends that clinical institutions further reflect on the UNCRC (1990; 2010) and develop an urgent strategy to securely implement them into clinical spaces and practices for children and young people.

10.4 Implications for Practice

Children and young people in this study imply that the rigidity of general practices and procedures in hospitals contributes to their feelings of oppression and leaves little room for them to express their concerns and be heard, or to express other aspects of their identities that they perceive as important. This research evidences how literature concerned with paediatric nursing practice does have a focus on improving children's experiences, but that these studies focus on encouraging compliance and comforting distressed children (as seen in chapter 4). This research therefore highlights a need to perceive children's lives more holistically, and to understand their resistance and distress in hospitals in more depth. The young people in this study offered some recommendations for improvements, such as changing the nature of the discourse with which their lives are spoken about. A strong theme in this research was that of non-verbal communication, and how young people did not feel heard or understood in hospitals, as explored in chapter 8. This finding calls for immediate attention from medical and nursing practitioners to better understand and respond to the different ways young people choose to communicate, and for a development of multi-modal ways of listening. In chapters 7 and 8, participants highlighted aspects of their care during which they felt patronised, intimidated, humiliated and silenced by their care provider, which they felt created friction in their relationships. If medical practitioners are serious in their desires to improve services for the young people they serve, they need to critically reflect on and develop their own practices, especially their practice of listening, as well as being proactive in developing and maintaining good, trusting relationships with children and young people.

10.5 Implications for Theory

> ‘Theory should do some things in the social world: enhance our awareness of inequality and, wherever possible, permit new ways of thinking affirmatively about disability. Theory can shift our focus away from the perceived pathologies of disabled people on to the deficiencies of a disabling society and an ableist culture’
>
> (Goodley *et al*. 2012, p.4.)

This thesis has both utilised and built upon theories and concepts around children’s lives and spatiality, in order to explore how place and space may affect hospitalised children's experiences. In doing so, the data highlighted a connection to emotion in space which is underpinned the work of Procter (2015). This study not only highlighted how space played a role in constructing the experience of children in hospital but also how children understand, and challenge, the historical socio-spatial scriptures within space (as explored by Kitchin, 1998 and discussed further in sections 2.8, 7.2, 7.3 and 9.5). Building on Kitchin’s (1998) work, which also utilised both poststructuralist concepts and spatiality to understand the experiences of disabled people, I have done so in relation to hospitalised children's experiences. My findings were that children are aware that space is political; they understand that space restricts movement, whilst also understanding that space itself categorises them in a particular way. For example, being in hospital categorised them as sick, vulnerable, in need children. Uniquely, this research notes how hospitalised children and young people resist such categories. I found that within hospitals children and young people resisted through the mundane (explored in section 7.4), and more significantly, that young people were not only the consumers of space but were also the producers of a space which worked to resist the space to which they were assigned by adults. They did this through actions such as keeping a diary, playing the piano or writing blogs. This finding builds on the work of Kitchin’s (1998), who noted how disabled people occupied pre-constructed spaces which informed them, through its socio-spatial scriptures and power relations, when they were ‘out of place’. Building on this work, the participants’ in my study understood when they were ‘out of place’, and constructed safer spaces in which they could express themselves.

Whilst some areas of developmental and cognitive psychology claim to have identified a trajectory of cognitive development, the participants' narratives in this study support the work of disability studies scholars like Slater (2013), who challenge such assertions in mainstream psychology. This study found that children were denied agency due to their age (and thus presumed lack of cognitive development) or their diagnostic label, which supports Slater’s (2013) argument that an adult perspective is an ableist perspective. This study builds on this, as I found that children sought more positive relationships and more agency and involvement in the decisions and management of their care. Hospitalised children’s perspectives provide a vantage point from which to begin to develop a more inclusive model that allows for exploration of specific childhood experiences which challenge the bodily boundaries of the social model of disability. Additionally, Slater’s research (2015) highlights concepts of ‘correctness’ in young disabled people's communication, which this study expands on to argue that certain emotions, or more specifically, displays of emotions, are considered incorrect or otherwise.

10.6 Implications for Research

Wellington (2000) warned that researchers who are very close to the research can experience difficulties during qualitative data collection. During this research I experienced some of the challenges Wellington warns of in gaining detailed narratives. One example of this was when I was chatting to Jazz about her experiences of hospitalisation. She was describing medical practitioners' behaviours when the ward was busy, ending her description by stating: ‘*you know what it's like*’. Jazz was highlighting our shared experiences and drawing on how I could relate to her. Remembering Wellington’s (2000) warning, I responded, ‘I think I do but can you tell me more about what it was like for you?’ She went on to very briefly tell me about her frustrations with waiting for doctors. In this example, my experiences of hospitalisation provided an obstacle to fuller stories. It is important for researchers to be mindful of such barriers when conducting any future research in this area. Remembering Wellington’s (2000) caution can prepare new researchers to validate participants assumptions of the researcher, (‘I think I do’) and prompt participants for more details (‘can you tell me more about what it was like for you?’). However, I also found that being close to the research had advantages and aided more detailed description, aligning with the work of Sikes *et al*. (2019). An example of this was during an informal interview with William; I had gasped and demonstrated with my body language that I had an understanding of his anguish. This expression was not pre-planned and occurred instinctively. This very human interaction meant that William became visibly excited, and spoke more quickly, to share the details of why he felt the way he did, and explain how he understood other people's perceptions and understandings of the event. Contrary to Jazz, my own position in relation to the research gave William the space to draw on mutual understanding to emphasise sameness. This initiated the inclusion of more details within his narrations. The difference between Jazz and William’s examples of research above is that I not only sat and listened to William. My gasp provided him with an interaction and feedback on my understanding of his scenario. This is important for future research as it demonstrates that participants are not only expecting to be listened to in research; they are also expecting interaction, and it is within this interaction that participants feel they can openly speak and offer details and reasonings about what matters to them. Thinking about the research overall, I think that I was told such detailed stories because I was honest with participants about my own experiences and positionality in the project. This transparency helped participants to trust that I would not only accurately represent their stories but would do so with ethical intentions.

The benefits of incorporating an autoethnographic element to narrative research was that it allowed greater transparency of the research. As Ellis (2007) cautions, detailing my own experiences alongside those of participants has been interesting and at times difficult to balance. My intention behind incorporating autoethnography was that I would not be asking more of participants that I was willing to offer myself. This included treating the stories of participants with the same care and sensitivity as I had granted myself. Furthermore, autoethnography sits uncomfortably within established methodologies because of power imbalances and expectations of research and researched or listeners and narrators (Ellis, 2007; Bochner, 2002). Autoethnography is therefore an uncomfortable presence because it challenges power imbalances within research and blurs the lines of rigid research and methodological rules. Autoethnography contributes more than my marginal presence within the research and explicitly demonstrates my stories woven among those of participants.

Uncommonly, this research had one broad research question. I intended for my thesis to be a safe space where stories of hospitalisation could be shared and valued. Providing one broad research question allowed the scope for participants to highlight their own focus and messages to the research. This ensured that participants could discuss topics that were important to them without their ideas or contributions being devalued, overlooked or being deemed irrelevant to the research (Hammond *et al*. 2013). Ellis (2004) notes that creating space for participants to discuss what is important to them is part of the nuanced nature of doing ethical qualitative research. This flexibility in research design facilitated the discussion of a wide range of topics. This may be a helpful tool for future researchers to adopt when they intend to create an opportunity for participants to direct the focus of research.

Contrary to typical research design, I chose not to impose a specific data collection method on participants. Instead, I pre-planned an open approach to methods, designing my research so that participants could offer their stories in any way they chose, and in any medium. I felt this was especially important when engaging with children and young people. Upholding the UNCRC (2010), I decided that participants in my research would have a right to be heard by me and that they would be heard in whichever way they saw fit. This seemed especially important to my research, as participants would be sharing intimate and emotive stories and experiences, which I hoped they would do in ways that they felt comfortable with (Sikes *et al*. 2019). What manifested was a multitude of different types of data, indicating that this research required me to take a multimodal approach to data collection and analysis (Hammond *et al*. 2013; Bryman *et al.* 2019). The only method that I was positive would arise was that of diary entries, from my own personal diaries. Through its design, it was necessary for me to prepare for all potential methods that could be chosen by participants; however, I had overlooked the possibility of receiving music transcripts as a representation of ‘a story’ (Magee, 2002). For future research, an open method approach, that is the practice of not having pre-planned methods, has the potential to uphold a space for participants to shape the research design, and obliges the researcher to react to the needs of the research rather than only using methods that they are comfortable with (Bryman, 2007; Chase, 2011; Hammond *et al.* 2013). Importantly this research has found that children communicate in multi-modal ways, and therefore there is a need for future research with children and young people to be more flexible in adopting a multi-modal approach to data collection and analysis.

10.7 Recommendations for future research

This section of the thesis aims to suggest some directions for future research. Many of the suggestions derive from topics that were touched upon in this research, but were not developed further in this thesis as they were beyond the scope of this project. Other suggestions highlight the need for a continued and evolving understanding.

One such topic was that of gender and illness. One participant in this research, Joe, stated that ‘boys get anorexia too’ and discussed the challenges of acquiring relevant therapy and information for his illness. Whilst scholars in CDS (Goodley, 2012; Slater, 2013; Liddiard *et al.* 2019; Liddiard, 2022) highlight the continuing need to examine the intersections of disability and identity, it is important we begin to understand how gendered constructions of illness (Räisänen *et al*. 2014) are experienced by individuals whose gender identity does not align with that of the illness. For example, Joe discussed his worries about how his friends would perceive him should they discover that he had a diagnosis of anorexia, a label that is widely understood to mainly affect females (Räisänen *et al.* 2014). This highlights the importance of understanding how young people may understand and perform their gender after obtaining a highly gendered diagnostic label such as anorexia. There has been some research exploring gendered construction of illness (Räisänen *et al.* 2014), especially in relation to men. However, research seldom explores how children and young people understand and experience a gendered construction of illness and the effects this has on young people’s identities, lives, and on their families and allies. It is essential that this finding is explored further because boys experience a delay in recognising the symptoms of eating disorders, and thus experience a delay in appropriate treatments (Räisänen *et al.* 2014).

In this research, two participants narrated their time in a mental health hospital for children and young people. An observation I made in this study was the difference in accounts used by young people who experienced admission due to mental illness. I noted how the discourses they used had more violent connotations (forced, held down, lied to) which suggest that participants perceived medical professionals to hold negative intentions. They also describe a lack of empathy, and negative attitudes towards their illness by professionals caring for them (‘they don't care, they ignore, they just roll their eyes, they look at you like you're nothing’). Participants suggested that this had negative implications not only for their recovery but also their trust in their medical team. Whilst unhelpful attitudes to disability and ill health have long been established by academics across disciplines (Barnes *et al.* 2003; Goodley, 2011; Foucault, 1981; Lynch, 2011; Ghai, 2002; Butler, 2004; Goffman, 1963, for example), research scarcely unpicks children and young people's perceptions, understandings and encounters of negative attitudes from mental health professionals, nor does it explore how these attitudes affect young people's lives or trusting relationships. It is therefore vital that we not only better understand how medical professionals use non-verbal expression, but also how young people perceive the nonverbal expression of their medical team and examine the attitudes of adults working with children. In particular it is important to learn how this differs with professionals working within children's mental health institutions. This is important because my study observed that children who were admitted to a mental health hospital used discourses that held more violent connotations.

I observed that when the young people in this study were sectioned under the Mental Health Act (2007), their rights as a child, as well as the recommendations in the Platt Report (1959), seem to has been given less attention by the institution. The Platt report (1959) drew on the influential work of Robertson *et al.* (1953), who highlighted the negative and traumatic effects of hospitalisation for children, claiming that children’s hospitals were miserable and restrictive places for children and negatively affect children’s mental health and wellbeing. The Platt Report (1959) responded to this, recommending that children in hospital have unlimited access to their parents (explored more thoroughly in sections 1.3.1 and 3.2). The lack of rights or implemented recommendations in children's mental health units was also an observation made by Bradey (2001), who noted that less than half of children's hospitals and wards met the standards of the Platt Report (1959). It is vital that research explores the evolution of children's mental health units in relation to the Platt Report’s (1959) recommendations, in order to not only produce more research on children’s mental health units but also to identify the challenges that institutions encounter in implementing the recommendations, and to urgently develop solutions to improve these spaces for the children and young people who occupy them.

An additional topic that arose in this research but which I did not expand on was that of childhood abuse and mental health. Links between childhood abuse and mental illness have long been established (Aldinger *et al.* 2017; Garno *et al.* 2005; Daury-Filho *et al.* 2011, amongst others). One participant in this study, William, suggested that the treatment he required differed from the treatment he received as a child. William felt that treating his symptoms as bipolar disorder overlooked the environmental explanations for his symptoms and denied him relevant treatments that would have helped him to cope with the trauma that he had experienced. William described this denial as ‘detrimental’ to his development, growth and healing from trauma. This finding aligns with Aldinger *et al.* 's (2017) findings that treatments for bipolar disorder are less effective to those who acquire the illness through traumatic life events. Aldinger *et al.* (2017) asks clinicians to be mindful, cautious and thorough when diagnosing bipolar disorder. Whilst many scholars, such as Aldinger *et al.* (2017) and Gerno *et al.* (2005) draw links between adults diagnosed with bipolar and childhood trauma, less research explores children and young people's perceptions, understandings, and therapeutic needs after traumatic life events. William notes how he was not supported to deal with the effects of trauma, only medicated for symptoms of bipolar. It is necessary then that future research explores the helpfulness of treatments for bipolar disorder from young people's perspectives. It is also worth exploring whether children and their parents feel that trauma is effectively treated in mental health hospitals.

The young people admitted to a mental health hospital in this study discussed how their parents had to relinquish their parental responsibility in order for them to obtain the medical treatment that they needed, a finding that aligns with Hinshaw (2005) and Herbell *et al.* 's (2020) work. This made young people in this study feel extremely vulnerable, especially when they experienced a lack of agency. Bridge (1997) called for a better understanding of children and young people's autonomy, which has had infrequent and scarce consideration in relation to hospitalised children's autonomy. Bricher (2000) claims that healthcare professionals are often confused by their role in facilitating and maintaining children's autonomy during hospitalisation. It is important that future studies address this in order to work to better understand hospitalised children's autonomy, as well as the effects of relinquished parental responsibility for both parents and children who experience a childhood hospital admission. This is especially important for those who experience childhood admission to a mental health institution and relinquished parental authority.

Through this research I have identified that several areas need more exploration. Firstly, in terms of the social model theory, I think it is vital to cautiously and sensitively bring the body back into discussions around disability, impairment and illness. While the process of bringing the body back has already been set in motion by disability studies and feminist disability studies scholars (Morris, 1999; Crow, 1996; Wendall, 2013), this research recognises a need for a continued theoretical understanding in its application to children and young people's bodies, experiences and understandings. I urge researchers to maintain a critical disability studies (CDS) and disabled children's childhood studies (DCCS) framework when doing this, so as to use multiple theoretical vantage points, including the intersections of age and its interactions to the sick and disabled body.

Children’s modes of communication were an important aspect of this study that requires further exploration. While this study identifies that children do not feel heard or understood by the adults involved in their care, and details the damaging effects on a trusting relationship, the literature in this area (Beresford *et al.* 2003; Hemingway *et al.* 2011 amongst others) cannot be discarded. Bricher (2000) suggests that medical professionals remove themselves emotionally to guard their psycho-emotional wellbeing when working with sick and often distressed children. It is vital to continue exploring and developing understandings around how children perceive this selfprotective action that doctors proclaim to take, in order to work towards a compromise that works for both children and the professionals caring for them.

Children and young people in this study highlighted the need for improved communication, describing how they felt patronised or talked down to. This mirrors the findings in Bricher (2020) and Wilcox's (2020) work, which claims that doctors feel ill-equipped to communicate with young people and require support and training in both talking to and listening to young people in hospital. It is vital to continue developing an understanding of communication with children from a medical practitioner's perspective. This could potentially close some gaps in understanding the dynamic and complex relationship a doctor has with their young patients. Such work could aid the development of new multimodal ways of listening, and develop a shared and new understanding of communication for both young people in hospital and the adults involved in their care. Furthermore, it could lead to new training initiatives in communication that can help medical practitioners better support their young patients' autonomy and communication needs in hospital settings.

It is also important to reflect on what we, as a society, are informally teaching children about hospitalisation through media representations and common depictions of ill health, which are ingrained within cultural narratives of what it means to be a hospitalised child. Disability studies scholars (Barnes *et al*. 2003; Oliver, 1990; Shakespeare, 2006, 2001; Mallett *et al*. 2011, amongst others) have extensively noted the negative effects of charity model depictions of disability in culture and media, and this establishes a solid foundation for future research to explore the participants' claims that these representations are confusing for hospitalised children and young people, and that they cause psychological upset when representations of illness do not reflect their lived reality of illness and hospitalisation. Jazz felt ignored and isolated when her lived experience of hospitalisation contradicted the charity model depictions of suffering and bravery that are present in cultural representations of children's hospitalisation. It is therefore important for future research to revisit cultural depictions to understand both how hospitalised children understand these depictions and the effects they have on hospitalised children's experiences.

10.8 Reflection

My academic journey has not been easy; I have found academia both frustrating and, at times, limiting, but I also found it enlightening and transformative. I stumbled upon disability studies as an undergraduate student and landed there in my (happy) failure to become a biomedical scientist. This vital introduction to disability studies not only changed my perception of myself but also of society. As I reflect, I remember and will reiterate again here, the words of hooks:

> 'I came to theory desperate, wanting to comprehend – to grasp what was happening around and within me, most importantly I wanted to make the hurt go away. I saw in theory then a location for healing.'
> (hooks, 1991, p.1)

For me, these words were significant and resonated with me. I connected with them on a deeper level. For me, education was transformative, however unlike hooks, I saw in theory a location of restraint. I saw in academia, however, a location to loosen theory and make it more applicable to stories like my own. Applying theory to stories like my own became important to me. My stories of hurt were tucked away in a box of diaries that I kept in the attic. I did not want to forget my experiences, but equally did not want to be reminded of them either. I searched in academia for a place where stories like mine were represented and remembered, but was disappointed. I saw there was a gap and wondered if it was a diary-sized gap. This led to my research and an exploration of the stories of other children who had experienced long term or recurring hospitalisation. I am hopeful now that our stories can create change. I envisage this research as having the potential to inform the practice of medicine and etch its way into the consciousness of medical professionals, creating a culture of reflexive communicators.

By now this conclusion should have done what it is intended to do. That is to provide a summary of key findings, highlight the research's contribution to knowledge, answer the research question, to explore what we can learn from the stories that people choose to share about hospitalisation, and to discuss the wider implications of this research to policy, practice, theory, and research methodologies. I would like to finish this reflection with a letter. The letter is a hypothetical, imagined conversation highlighting multi-modal and multi-sensory listening that I have argued is needed. Further to this it highlights what we can learn from listening to young people's non-verbal communication. Within it I have used the terms 'hear' and 'hearing' to mean beyond the senses. I have used the term as emphasis and here, 'hearing' means 'to more than notice'.

Dear well-intentioned adult,

You cannot always hear us with your ears. You, our well-read, well-intentioned adults need a deeper ability to listen, not only to noise and voices and music and pictures but also to our silences, our tears, our sobs, our screams, sleepless nights and protests. Hear our redirection of attention and our tone. You needed to hear William's syncopation and contradiction within his music. Hearing this would have taught you about the confusion he had and the fear he felt in your care. You needed to hear where I (Holly) drew myself on a page. Here you would have learnt what you were teaching me about myself. You needed to hear Ella's EEG selfie. Hearing this would have taught you about who she really was and who she wanted to be recognised as. You needed to hear Jazz play with her cousin's Barbie doll. She would have taught you that she was not coping with being in hospital and needed more time to play. She needed your permission to play and perform 'child' again. You needed to hear the tooth fairy when she visited Rachel. If you had heard this, you would have learnt how dehumanising your biomedical gaze and surveillance made her feel. This was the first time she felt like a 'normal' child since being admitted to your ward. You needed to hear Joe's grip on his phone. It would have taught you how desperate he was to somehow be connected with the world outside of the hospital. How unsafe he felt when he did not have regular access to his parents. You need to hear the discourse we use when expressing ourselves, and hear the media and modes of expression we choose to use. This should have taught you that we felt unsafe to talk, we felt unheard in our attempts to communicate. You, our well-intentioned adult, need to be proactive to our distress rather than reactive to it. If you only take one thing from this research, let it be the act of listening, how listening means more than hearing, and noticing how in order to listen you need to become a reflexive communicator, striving to understand multimodal communication in order for us to participate in any meaningful way. Without participation, we cannot have agency, and without multi-modal listening, we are denied our right to be heard. To start, it might be worth reflecting on an appropriate way to respond to the voices you hear in this thesis.

Kind regards,
From Holly, Joe, William, Jazz, Rachel and Ella.

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Appendices:

Appendix 1: Information Sheet

Research Project Title:

Exploring Experiences of Hospitalisation, Medicalisation and Illness: A Narrative Inquiry Approach.

(This means that I am interested in your stories about being in hospital or receiving medical treatment.)

Invitation paragraph

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Feel free to ask me if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the project's purpose?

The purpose of the project is to create a space for the stories of hospitalisation, medicalisation and illness. This research is important because there is a lack of research which focuses on the experiences of hospitalised children and young people. This project could be used to help medical practitioners gain a better understanding of the needs of hospitalised children and young people and their family.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that the insights provided will be able to offer some new understandings to assist medical practitioners in understanding the needs of children and young people who are hospitalised.

What happens if the research study stops earlier than expected?

This is highly unlikely, but if this does happen you will be informed immediately and an explanation of this will be given.

What if something does not go to plan?

Sometimes, if there is something that makes a person unhappy, it can make them feel emotional when they talk about it. If you would like to raise a complaint you can speak to the researcher hntburkinshaw1@sheffield.ac.uk ,alternatively you can contact the Primary Supervisor of this project, Professor Daniel Goodley d.goodley@sheffield.ac.uk from the School of Education, University of Sheffield or the secondary supervisor, Kirsty Liddiard K.Liddiard@sheffield.ac.uk . If the complaint has not been handled to your satisfaction, you can contact the University of Sheffield's Registrar and Secretary, David Hyatt on D.Hyatt@sheffield.ac.uk .

Will my taking part in this project be kept confidential?

If you do not wish to be identified within the project the researcher will take all reasonable steps to ensure that you are not identified in accordance with The British Educational Research Association guidelines. If a participant leads the researcher to believe that they or another person whom the University of Sheffield defines as vulnerable (such as children or young people) is in danger, then the researcher will tell the relevant people to safeguard them from further harm.

What will happen to the results of the research project?

The stories will be included as part of a PhD thesis, the researcher may also write reports about the project and speak about the project at conferences.

Who is organising and funding the research?

This project is part of a PhD thesis and is funded by the researcher. The researcher will be receiving guidance by the University of Sheffield and will be supervised by an experienced researcher.

Who has ethically reviewed the project?

This project has been ethically approved via University of Sheffield Education Department’s ethics review process. The University’s Research Ethics Committee monitors the application and delivery of the University’s Ethics Review Procedure across the University and adheres to the British Educational Research Association Ethical Guidelines.

Contact for further information

For further information you can contact me, Holly Burkinshaw by emailing me at hntburkinshaw1@sheffield.ac.uk or call me on 07921800623. If you would prefer to speak to someone else you can contact Professor Daniel Goodley at d.goodley@sheffield.ac.uk

Appendix 2: Easy Read Information Sheet

Research Project Title:

Exploring Experiences of Hospitalisation, Medicalisation and Illness: A Narrative Inquiry Approach.

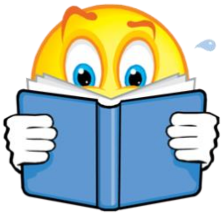
(This means that I am interested in your stories about being in hospital or receiving medical treatment.)

Invitation

You are being invited to take part in a research project.

Before you decide it is important that you understand why the research is being done and what you will be asked to do.

Please take time to read this information carefully.



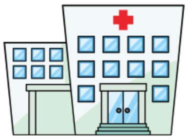
Discuss it with others if you wish.

And ask me if there is anything that is not clear.

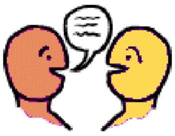
Take some time to decide whether or not you would like to take part. Thank you for reading this.

What is the project for?

I am doing a project to find out about what it is like to be in hospital.



I want you to tell me about what it is like to be in hospital.



I want to meet with you several times in the next year. I will ask questions such as:

1) What does it feel like to be in hospital?

2) Does being in hospital affect life outside hospital?

3) Can you tell me about your doctors and nurses?

4) How do people react when you have to go to hospital?

Why have I been chosen?

I am asking you because you have been in hospital and you or your parents/guardian are part of an online support group. I will ask three more people too.


Do I have to take part?

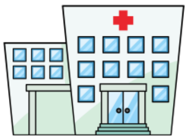
You can say ‘*yes*’  or ‘*no*’  or ‘*I don’t know*’ 

If you decide to take part I will give you this sheet to keep and I will ask you to sign a consent form.

BUT

You can change your mind at any time and you do not have to tell me why.

What will happen if I take part?

If you say yes  I will come to see you  several times to ask you about when you went to hospital. 

You can tell me about when you went to hospital in words, drawings, music or pictures if you want to. I will spend some time with you to find out what you think.

What are the bad things that might happen if I take part?

Sometimes, if there is something that makes a person unhappy, it can make them feel sad when they talk about it.

What are the good things that might happen if I take part?

I hope that your experiences will help other children who have to go to the hospital. Some people enjoy helping other people.

What happens if the research stops earlier than I thought?

I will tell you the reasons why.

Will you tell other people what I have said?

You can choose a pretend name if you want so nobody will know who you are.

I will not tell other people what your name is or what you have said.

UNLESS

If you tell me that you are in danger or that someone else is in danger than I WILL have to tell someone else BUT I will only tell the people who need to know.

Will I Be recorded, and how will the recordings be used?

If you say I can, I will record your voice using a voice recorder  I will use what you have said to write a big book called a PhD  I might use what you have said to write a report, an article or at a conference. But only I will be able to hear your voice.

I will keep the recordings on a computer which is password protected. At the end of the project I will destroy all of the recordings.

What will happen when the project finishes?

When the project finishes I will write a big book called a PhD I will also write an article and I will give you a copy of the article. I will show the book and the article to important people who look after children in the hospital.

What if something does not go to plan?

If something doesn't go to plan and it makes you feel unhappy you can contact:

Me (Holly)

✉ hntburkinshaw1@sheffield.ac.uk

☎ 07921800623

If you do not want to contact me you can contact:

Professor Dan Goodley (he supervises my research)

Professor Dan Goodley,
The School of Education,
The University of Sheffield,
388, Glossop Road,
Sheffield, S10 2JA

☎ (0114) 2228185

d.goodley@sheffield.ac.uk

Or


Dr Kirsty Liddiard (she also supervises my research)

Dr Kirsty Liddiard
The School of Education,
The University of Sheffield,
388, Glossop Road,
Sheffield, S10 2JA

(0114) 2228111

If you have a complaint you can also contact:


Dr David Hyatt (he is in charge of ethics)

Dr David Hyatt
The School of Education,
The University of Sheffield,
388, Glossop Road,
Sheffield, S10 2JA

☎ (0114) 2228126

Who has said that it is okay to do this project?

OK

The University of Sheffield has said that it is safe for me to do this research.

If you say ‘yes’ you would like to take part you will be given a copy of this information sheet and a signed consent form to keep. If you are under the age of 18 I will also ask one of your parents/guardian to sign the sheet.

Appendix 3: Consent Form

Title of Project: Exploring Experiences of Hospitalisation, Medicalisation and Illness: A Narrative Inquiry Approach.

Name of Researcher: Holly Burkinshaw

Participant Identification Number for this project:

Please initial each box

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

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason by contacting the researcher at hntburkinshaw1@sheffield.ac.uk or by calling 07921800623. Alternative you can contact the supervisor at d.goodley@sheffield.ac.uk ☐

I understand that all reasonable steps will be taken to protect my identi ☐

I give permission for members of the research team to use my stories. ☐

I give permission for the researcher to audio-record our conversations to ensure accurate transcription. ☐

I agree to take part in the above research project. ☐

__________________________ __________________

____

Name of Participant, Date & Signature

(*or legal representative*)

___________________________ __________________

____

Name of person taking consent, Date & Signature

(*if different from lead researcher*)

To be signed and dated in presence of the participant

Lead Researcher Date Signature

To be signed and dated in presence of the participant

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated
participant consent form, the letter/pre-written script/information sheet and any other written
information provided to the participants. A copy for the signed and dated consent form should be
placed in the project's main record (e.g. a site file), which must be kept in a secure location.

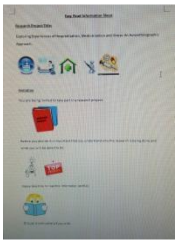
Appendix 4: East Read Participant Consent Form

Title of the project:

Exploring Experiences of Hospitalisation, Medicalisation and Illness: An Narrative Inquiry Approach.

Please tick

I confirm that I have read and understood the information sheet for the above pr and have had the opportunity to ask questions. ☐




I understand that I can say 'Yes'  or 'No'  to Holly  about being involved in the research. ☐

I understand that I can choose a pretend name if I want to and that other people can look at what I have to say once I have chosen a pretend name. ☐

I agree that Holly can record my voice with a voice recorder  ☐

I agree to take part in this research project  ☐

________________________________ _________________________

____

Name of Participant Date

Signature

______________________________ ____________________

____

Name of parent/carer (where applicable) Date

Signature

______________________________ ____________________

____

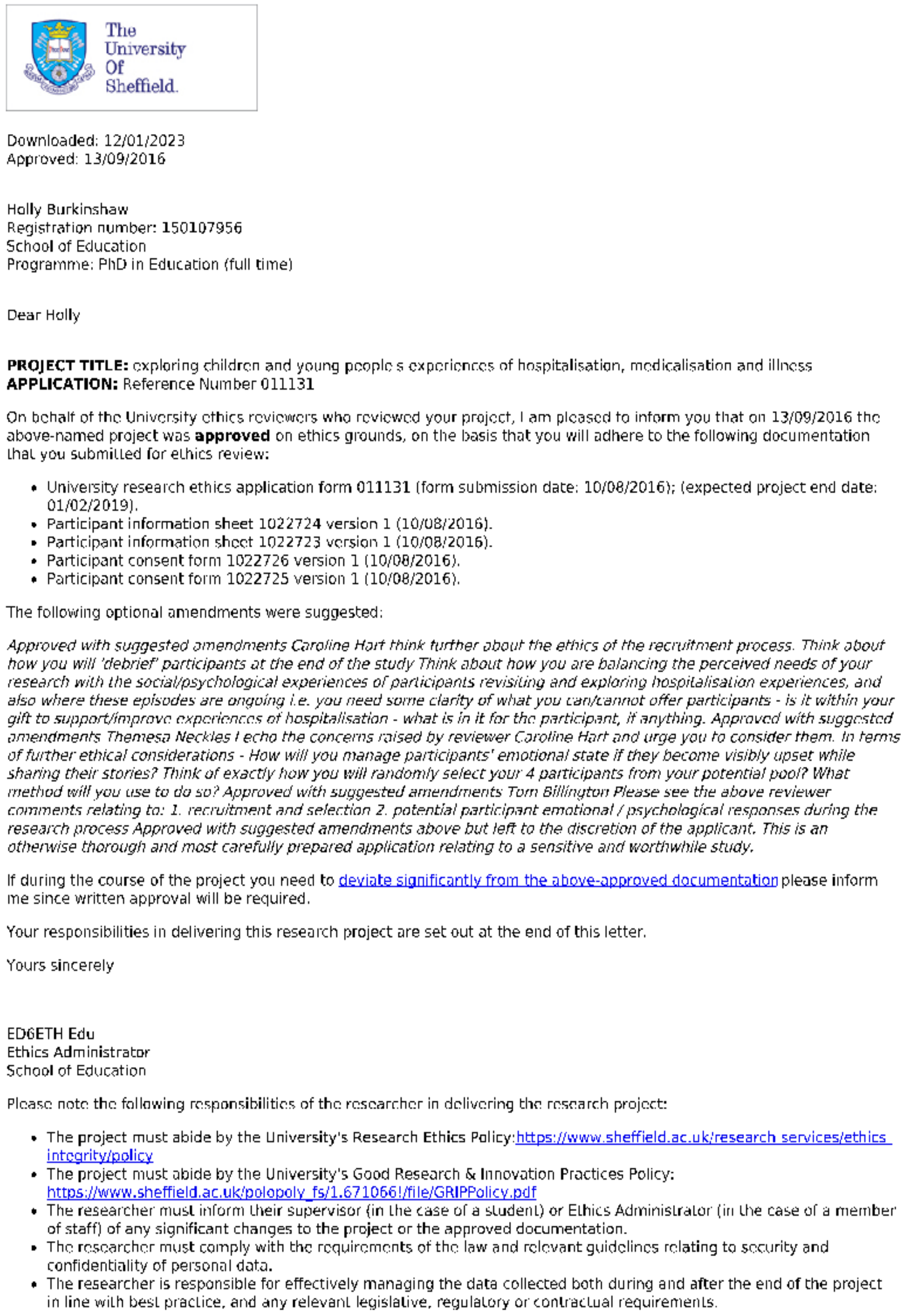
Name of researcher Date

Signature

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location

Appendix 5: Letter of Ethical Approval:



The University Of Sheffield.

Downloaded: 12/01/2023
Approved: 13/09/2016

Holly Burkinshaw
Registration number: 150107956
School of Education
Programme: PhD in Education (full time)

Dear Holly

PROJECT TITLE: exploring children and young people s experiences of hospitalisation, medicalisation and illness
APPLICATION: Reference Number 011131

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 13/09/2016 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 011131 (form submission date: 10/08/2016); (expected project end date: 01/02/2019).
- Participant information sheet 1022724 version 1 (10/08/2016).
- Participant information sheet 1022723 version 1 (10/08/2016).
- Participant consent form 1022726 version 1 (10/08/2016).
- Participant consent form 1022725 version 1 (10/08/2016).

The following optional amendments were suggested:

Approved with suggested amendments Caroline Hart think further about the ethics of the recruitment process. Think about how you will 'debrief' participants at the end of the study Think about how you are balancing the perceived needs of your research with the social/psychological experiences of participants revisiting and exploring hospitalisation experiences, and also where these episodes are ongoing i.e. you need some clarity of what you can/cannot offer participants - is it within your gift to support/improve experiences of hospitalisation - what is in it for the participant, if anything. Approved with suggested amendments Themesa Neckles I echo the concerns raised by reviewer Caroline Hart and urge you to consider them. In terms of further ethical considerations - How will you manage participants' emotional state if they become visibly upset while sharing their stories? Think of exactly how you will randomly select your 4 participants from your potential pool? What method will you use to do so? Approved with suggested amendments Tom Billington Please see the above reviewer comments relating to: 1. recruitment and selection 2. potential participant emotional / psychological responses during the research process Approved with suggested amendments above but left to the discretion of the applicant. This is an otherwise thorough and most carefully prepared application relating to a sensitive and worthwhile study.

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

ED6ETH Edu
Ethics Administrator
School of Education

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:https://www.sheffield.ac.uk/research services/ethics integrity/policy
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix 6: Example of (uncoded) transcribed interview:

Will: [laughs] no I’m alright they’re like, so what have you done this week. They’re so timid you just want to slap them and say like go and live, go and do some real work and then come back and try and sort my head out [laughs] sorry.

Me: You seem quite passionate about therapy.

Will: Urggh, they’re annoying, they’re actually annoying. They think they know it all and they think they erm supposed to not, that’s not their position; they are a sounding board they are supposed to be kind of a errm yeah. Someone to sound your anxieties and your fears to and all of that and to allay all of that. But they’ve got to be objective, they aren’t allowed to give their opinion and that frustrated the living daylights out of me. I would phrase my questions so that they would have to have some sort of bias and they have to give me some sort of erm [laughs] some kind of view point... [short pause]… ahhh, I used to analyse them [whispered], I used to sit there in my therapy and think oh, you’re doing this or saying this because of this. Alright so we’ll do this and [mumbles and laughter] oh its hilarious. Ok, so where were we? I’ve gone off on a tangent, I don’t know where we are.

Me: We were just ranting about therapy.

Will: Therapy, honestly. ‘How are you feeling?’ [shakes head] like it’s going to make a difference to you. You’re going to walk out of the room in a minute, have a cup of tea and pretend that I’ve had some sort of effect on your mental state. But let’s face it, you’ll go home and forg*et al*l about me.

Me: Do you think therapists would go home and forget about you?

Will: Oh of course they do, they have to leave their job at work. Don’t get me wrong, I know that there must be an element that will stay with them, particularly if they’ve had a harrowing… if they’ve dealt with a harrowing experience particularly with the youth or younger children more so than adults.

Me: Were you young?

Will: I was very young yeah, I think I was about 14/15 when I, I [slight stuttering]. I’m talking about the period that I was reflecting on. Erm yeah, I was 14, 15 something like that. So yeah I was sectioned. They were reluctant to diagnose me at that early stage so they put me in this ‘unit’ and this ‘unit’ [laughs at himself doing air quotes].

Me: Oh ‘unit’, somehow it sounds fancy!

Will: Cramwell unit

Me: What’s a cramwell unit?

Will: That’s what it was called. Cramwell unit. There were two, one for [taps table with fingers] children and it was literally, oh god I can describe it to the ‘t‘. You walked in up these horrible stairs and in front of you was where they dispensed the medication, to the left sorry, and erm, further on was the kitchen. And then there was a corridor and off of this corridor were like, dormitories and in each dormitory there were 8-10 beds. And so it was blue linen and horrible like old ‘teaky’ looking furniture, blue curtains that stank, and windows that had bars on them so you couldn’t get out. Fire exits that had erm, what do you call them, erm, tie wraps around the security bits so that you didn’t run away. It was for kids who, you know, were off the rails and stuff but it was to assess their.

Appendix 7: Example of uncoded poem

[this poem is presented verbatim]

A Doctors Threat

1. ***M***isfiring synapses, my brain collapses,

Experience tells me to expect a moment of tranquillity
before the long and intense vulnerability.

2. ***I*** have something to say: ‘I’m scared, I’m alone, I’m afraid, I’m in fear’,

Words I know will be wasted on your ear.
Although you ignore,
I still try, because I have something I need you to hear.

3. ***T***he words choke me; they won’t come out.

I yell, scream, shout but you do not hear my voice;
you do not care about my fears.
You cannot even see my tears.

4. ***I*** wander blindly through my mind.

For now I am undefined.

5. ***A***s I wake up here again,

my body limp and weak,
I hear the mumble of people speak.
I hear them speak but can’t speak back;
my words fly away, disappear, fall.
Some things I don’t try to say at all, so,
I cry the tears that I can no longer hold.

6. ***A***nother blow to the skull, another seizure, another scar;

I’m not shocked. It’s nothing new.
Am I dense or am I dumb, because my words still don’t come?

My brain deteriorates after every fit.
Your patronization is infuriating.
If I could speak I'd say 'get a grip', but,

7. ***F**or now my body is not mine –*

for now it is theirs, theirs to own, to control,
to inject with anxiety, to prescribe fear,
and dish out despair, here and there.
8. Strapped down, locked in,

until I 'open wide and swallow the medicine'.
My lips clench tight as I shake my head for 'no'
but for you this is a sign that I've started a fight.

9. ***P**lease take your pills, you'll get better,*

Take them now and you'll be home tomorrow.
Take your pills and lose control of your bladder -
don't say no or I will be even madder.
Take your pills because I said so.
Take them now or never go home.

10. ***T**ake your pills, relax and chill, because it is the correct thing to do.*

Take your pills and lose motor skills.
It's very important, remember:
Epilepsy kills!

Appendix 8: Example of diary entry

June 2001,
My mum came but I didn't talk to her. When she came I was lying down and she came in and kissed my head and rubbed my arm which was nice but made me cry even more. I know that she knows I am upset but I wanted to tell her I am really sad but I don't know how to make her understand. I needed to tell her that I feel sick and dizzy but I'm just so angry that when I try to tell people I feel fuzzy in my stomach and feel even more sicker. I still can't stop crying. I wish I didn't exist. I wish I would just die in here so they know how bad it is what they are doing. My mum said if I was not going to talk to her she would not come tomorrow but if she doesn't I will be even more sadder. I wish I talked to her or something because now I'm scared she won't come tomorrow and I'll be by myself.

Appendix 9: Example of Ella’s blog

(Ella’s words are presented verbatim)
Sunday, 5 February 2017

Ten top tips for a relaxing school night!

Hello,

I tend to start to wind down relatively early in order to have relaxed and stress free week day evening. Here are my top tips:

1. Lay your clothes/school uniform out the night before, this saves a lot of hassle in the morning, you won't have to go through your drawers and spend hours deciding what to wear!

2. Cleanse your face and brush your teeth early before you get too tired: this is especially important for people who get tired easily like my fellow Cerebral Palsy readers.

3. Tidy your room before you go to sleep, for me personally I find it nice to go to sleep in a tidy room. I also find the process of tidying very therapeutic.

4. Light a candle or listen to relaxing music, both of these are very calming.

5. Do mindfulness. Whether this is colouring, simple yoga or focusing on your breathing for a minute or two, this is a very good way just to relieve the stresses of the day and have a period of peace and reflection.

6. Turn off your phone for a while before you go to sleep, have a break from social media and just focus on you for a moment or two.

7. Don't stress about school or the homework you haven't done just try to let everything go and have a peaceful night sleep with no worries.

8. Read or listen to an audiobook before you go to sleep, this allows you to live another life even if it is just for half an hour, it allows you to forget any worries you

may have and just enjoy a story.

9. Don't go to bed too late, try and let your thoughts go and just close your eyes and drift off.

10. Sleep with one pillow and shift down in your bed so you are lying completing flat, I have found this so much more comfy and I feel I have better night rest when I do this.

So there you go, my ten top tips for a good nights rest and a relaxing weekday evening. I hope you have enjoyed reading this and if any of my advice has helped you please do let me know. As I keep saying, I would love some feedback about my posts and blog so don't be afraid to email, Facebook message or just fill in the contact form to your right, if you are using a mobile device scroll down to the bottom of the page and click view web version. Once again thank you for reading and I look forward to hopefully hearing from a few of you soon!

Appendix 10: Example of a coded poem.

William's Poem

Just look into my eyes,
you'll see that I'm not as strong as I appear to be

Behind that smile,
there hides a child,

misunderstood by all,
but still you let me fall,

I know tears can portray,
A picture that a thousand words could not convey.

But I won't cry,
To satisfy,

Your need to break me down,
In pain I'd rather slowly drown.

You told me pills could heal my pain,
Who stood to gain?
In branding me a stranger.
Forever a threat to a life endangered?

Your label's lasting legacy,
Of which you can't be proud,
Has held me back immensely,
Looming like the darkest cloud.

Appendix 11: Example of Coded Letter

William’s Letter

Dear Doctor,

Damn you for your crippling diagnosis. Thorough though it seemed at the time, your judgement was deluded; drastically confused! Can it be that a man of your calibre was misguided by a rebellious, relatively intelligent child of ten years goading your gullibility? Were you lacking in competence, experience or just moral conscience? Perhaps it was that you found pleasure in abusing your position of trust in a professional. Did you consider this an opportune, empirical case study to exercise your privilege’s as a doctor and advance your research on an unsuspecting minor, who could do little to protest?

There are several reasons, as I trust you’re aware, why a child might present with behavioural characteristics synonymous with the disorder of your speciality. If you’d bother to scratch the surface, you’d have easily established that the child was merely emulating his mother’s strange behaviours having seen the attention she derives when suffering severely from the disorder in question. You choose to diagnose the child, after a week-long observation in residence, as having the same illness without consultation or seeking a second opinion. On what logical grounds is this absurdity permissible? Heredity links are widely disputed, and the child had no previous history of mood instability, depressive or manic episodes.

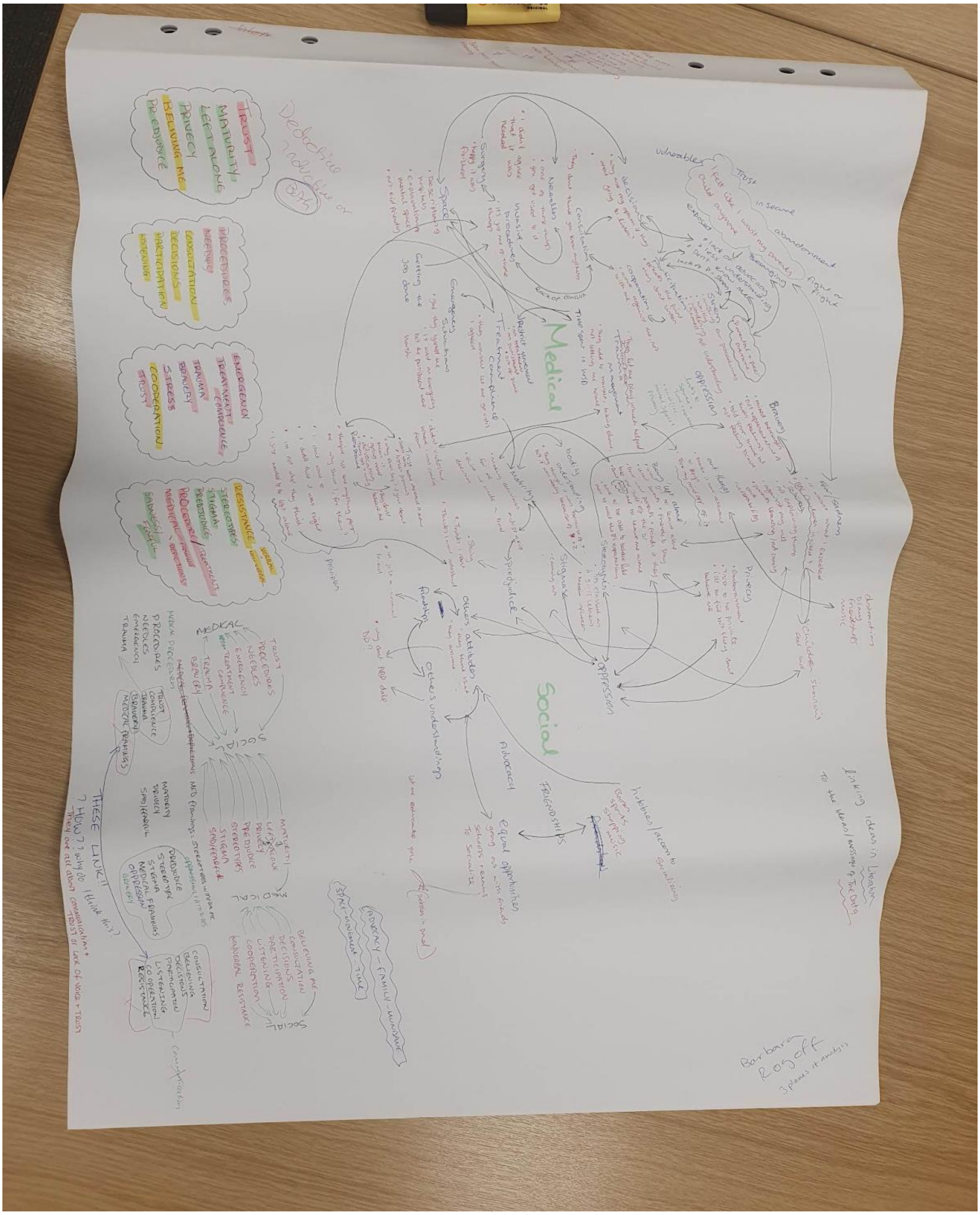
To add insult to injury, the child was incarcerated without further contact with the outside world, in a residential ward, a prison for children with mental health issues to be assessed by a gaggle of psychiatrists, psychologists and social workers. Subjected to countless tests, the only real entertainment was to resort to further acting. How could this be conductive to any kind of resolve for the underlying issues, the genuine pain and suffering you overlooked?

Sincerely,

Your victim – a true survivor

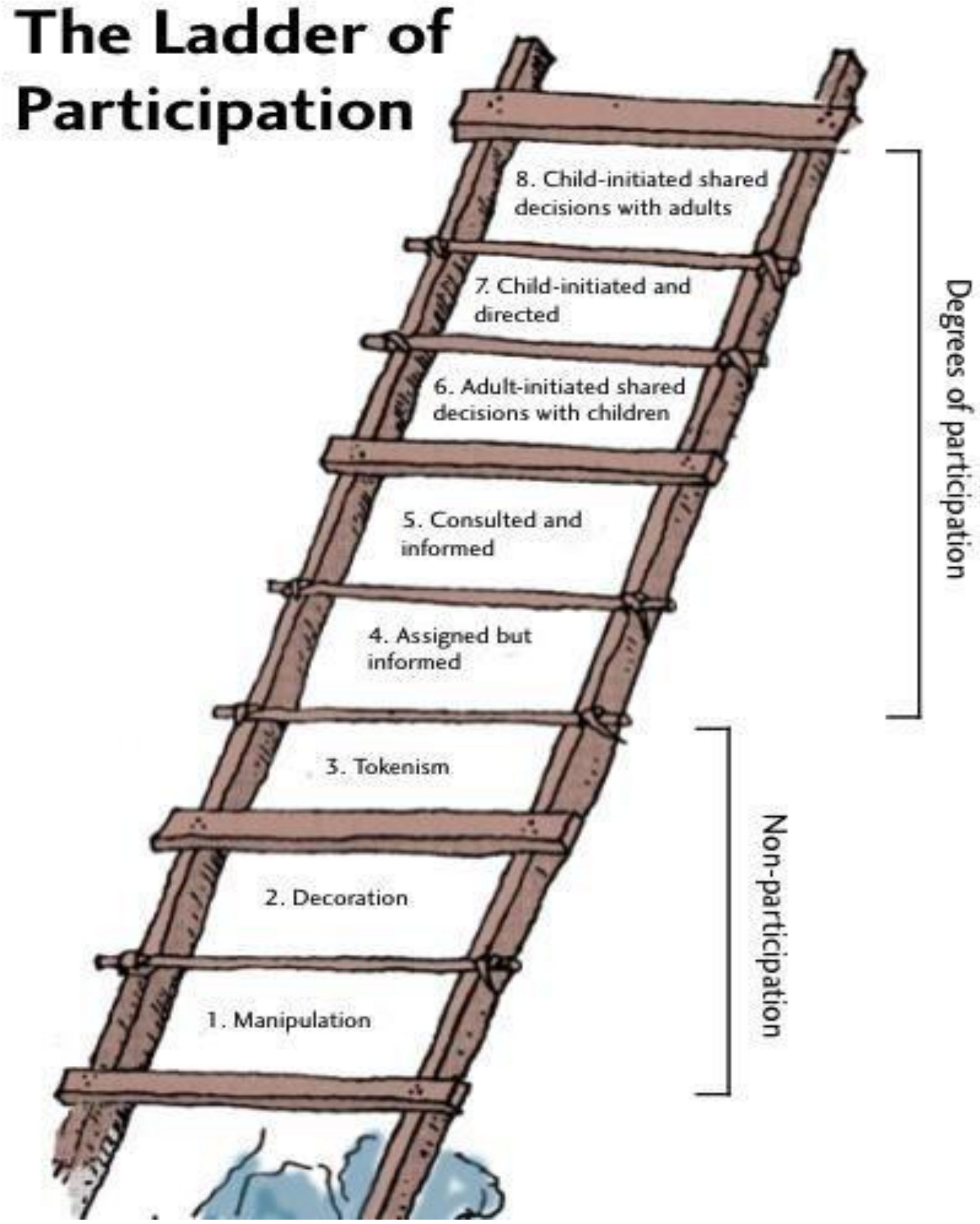
Appendix 12

Example of Braun *et al*.’s (2006) methods of open coding



Appendix 13 Hart's (1997) Ladder

Figure 1

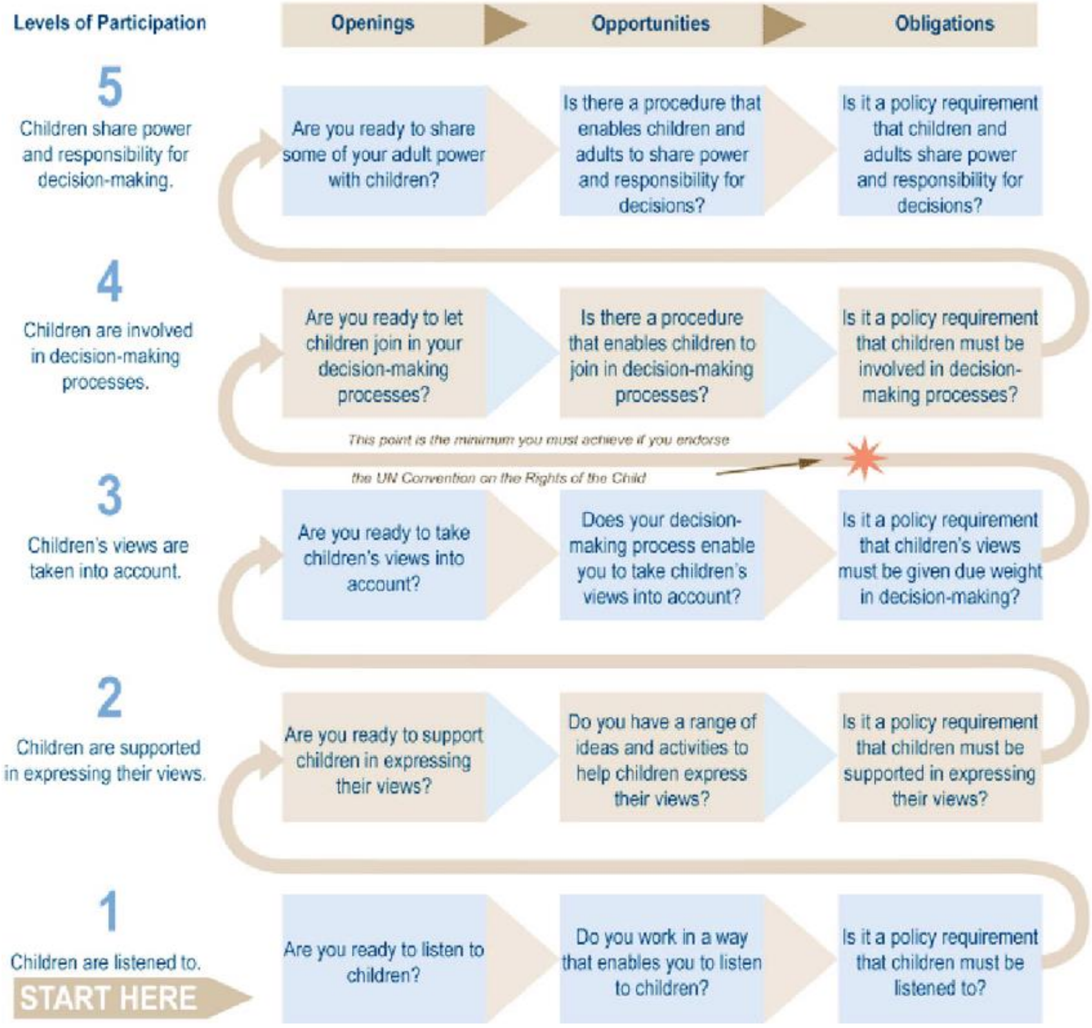


Roger Hart's original 1992 illustration of the Ladder of Children's Participation from *Children's Participation: From Tokenism to Citizenship*. Image can be found at:

https://www.google.co.uk/url?sa=i&url=https%3A%2F%2Fwww.kqed.org%2Fmindshift%2F33796%2Fare-we-taking-our-students-work-seriously-enough&psig=AOvVaw3Kt34ororJQZTy1IvRsqZT&ust=1718811467546000&source=images&cd=vfe&opi=89978449&ved=0CA8QjRxqFwoTCLi57_O95YYDFQAAAAAdAAAAABAE

Appendix 14: Shier’s (2001) Pathway

Figure 2



Levels of Participation	Openings	Opportunities	Obligations
5 Children share power and responsibility for decision-making.	Are you ready to share some of your adult power with children?	Is there a procedure that enables children and adults to share power and responsibility for decisions?	Is it a policy requirement that children and adults share power and responsibility for decisions?
4 Children are involved in decision-making processes.	Are you ready to let children join in your decision-making processes?	Is there a procedure that enables children to join in decision-making processes?	Is it a policy requirement that children must be involved in decision-making processes?
3 Children’s views are taken into account.	Are you ready to take children’s views into account?	Does your decision-making process enable you to take children’s views into account?	Is it a policy requirement that children’s views must be given due weight in decision-making?
2 Children are supported in expressing their views.	Are you ready to support children in expressing their views?	Do you have a range of ideas and activities to help children express their views?	Is it a policy requirement that children must be supported in expressing their views?
1 Children are listened to. START HERE	Are you ready to listen to children?	Do you work in a way that enables you to listen to children?	Is it a policy requirement that children must be listened to?

This point is the minimum you must achieve if you endorse the UN Convention on the Rights of the Child

Shier’s (2001) Pathway to participation illustration can be found:

https://www.google.co.uk/url?sa=i&url=https%3A%2F%2Fwww.researchgate.net%2Ffigure%2FShiers-Pathways-to-Participation_fig1_326949274&psig=AOvVaw2aZN83m2upQEha5oylptqE&ust=1718811766706000&source=images&cd=vfe&opi=89978449&ved=0CA8QjRxqFwoTCPjbjfi-5YYDFQAAAAAdAAAAABAE