Parents, Power and Partnership; A Qualitative Study of Family Experiences of the Education, Health and Care Plan Process

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Glossary

DfE- Department for Education
DoH- Department of Health
EHCP- Education, Health and Care Plan
MoJ- Ministry of Justice
SEN- Special Educational Needs

Abstract

The Education, Health and Care Plan (EHCP) was introduced in the Special Educational Needs and Disability policy reforms of 2014/2015 in England to replace the Statement of Special Educational Needs. The EHCP process sees information on a child or young person's educational, healthcare and social care needs brought together, and aspirations and outcomes created for them, alongside a support plan. Designed to be a collaborative and co-produced document, the EHCP should outline exactly what support the child or young person needs to work towards their aspirations, who provides this support, and what form this support will take. Families should be supported by professionals and schools to play a key role in the process and be involved in the decision-making, with children and young people's voices central to the plan being created.

This research project used a qualitative case study methodology to explore the experiences of families in the process of creating the EHCP and how well they felt the plan represented their child and their views. Semi-structured interviews were carried out with 12 participants across England, 11 parents and 1 young person. An advisory group made up of parents and a young person with lived experience of the EHCP process co-produced the research to ensure the project focused on areas of importance, with discussions continuing around methodological elements, the findings and conclusions.

The findings showed that families have varying levels of involvement in the EHCP process, parents were more likely to be involved than children and young people, who were not found to have experienced meaningful engagement with the process. Families did not feel that their EHCP reflected their child appropriately at most stages of the process, with factual errors, deficit representations and a lack of clarity in the written outcomes. Families also reported difficulties with being listened to or included by professionals during the process.

A discussion of the findings using post-structural theories with elements of rights-based perspectives considered the power relations within the EHCP process, where families had experienced marginalising discourses, and how the EHCP process and plan operate as agents of surveillance and governmentality.

Recommendations for policy makers include focusing on meaningfully implementing the policy reforms, moving away from narratives of parent blame and providing appropriate, ring-fenced funding for local authorities to deliver the support outlined in EHCPs. Recommendations for local authorities and practitioners include focusing on creating true co-production and partnership with children, young people and their parents.

Key words: partnership, power, Education Health and Care Plan (EHCP), parents, children and young people

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This research is dedicated to the people whose views are still missing from the discourse.

Chapter 1- Introduction

Introduction

In this chapter I introduce the research topic, the research project, the theoretical context and framework, and I also discuss my interest in this topic. I also consider the language I use around disability and SEN (Special Educational Needs) through the thesis. These are important issues to consider at the outset of the thesis because the topic and the language surrounding it are contentious and have been the subject of debate for many years. When introducing and contextualising the research, researcher positionality is important to consider as this impacts the theoretical framework and therefore the discussion, outcomes and recommendations of the research.

The Topic

Education, Health and Care Plans (EHCP) were introduced in 2014 in England, under the Children and Families Act (DfE, 2014a) to replace the Statement of Special Educational Needs for children and young people with Special Educational Needs (SEN) who require support to access education, above what the school is able to provide. Children and young people are described as having SEN when they have a 'learning difficulty or disability' that makes it more challenging to learn or access facilities than others their own age (DfE and DoH, 2015, p.15). Schools and settings must make efforts to meet the needs of children with SEN before a needs assessment is requested for the purpose of accessing an EHCP, for example, making adjustments to teaching, providing one to one support with a teaching assistant, or group interventions (DfE and DoH, 2015). This additional contextualising information is provided by the SEND Code of Practice (DfE and DoH, 2015), the statutory guidance document accompanying the Children and Families Act (DfE, 2014a) and often referred to together as the SEND reforms, which I discuss in detail in the next chapter.

There are estimated to be 1.6 million pupils with SEN in England which accounts for approximately 17% of pupils (Long and Roberts, 2024). Around 4% of children and young people have an EHCP which makes up around 25% of children with SEN (DfE, 2023a). This equates to 575,963 EHCPs in the most recent figures, a number which has risen each year since the EHCP was introduced (DfE, 2024). Many of these children are both learning disabled and have physical impairments and can have complex health needs (EDCM, 2011). This means that there are many children in the England who, in addition to support in education, need to access health and social care services on a regular basis. There are challenges in providing definitive figures for disabled children, not least that local authorities categorise diagnoses differently, and eligibility for support (with or without an Education, Health and Care Plan) differs between local authorities. The most recent data suggests that 11% of children in the UK are disabled, up from 7% 10 years ago (DWP, 2024). Again, difficulties exist here in that though disability and SEN overlap, they differ in definition. Using disability definitions in the UK for example from the Equality Act, children with SEN may also meet the criteria, though again this compares people to an undefined norm; 'a physical or mental impairment' that has a 'substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities' (HMSO, 2010, 6.1, a and b). Disability figures are also collected at UK level (via census for example) rather than being specific to England which makes understanding how many disabled children and children with SEN live in England and my need an EHCP more complicated.

Returning to the specific documents governing the creation of the EHCP, it is a legal requirement to have regard in the EHCP to 'the views, wishes and feelings of the child or young person, and the child's parents' (DfE and DoH, 2015, p.19). The SEND Code of Practice also states that the child or young person's views must be sought for the EHCP, and this can be through alternative methods such as observing a child, or using alternative communication (DfE and DoH, 2015). EHCPs should be co-produced with the child or young person and their parents (DfE and DoH, 2015) though differing wording through the document, for example 'participation of children and young people and parents' (p.14), 'involved in discussions and decisions' (p.20), 'actively supported in contributing' (p.20), 'consulted about the content of the plan' (p.20) could create confusion about what this looks like. Parents are understood in the statutory guidance as those with legal parental responsibility for the child (DfE and DoH, 2015) and I use the term 'parents' in this thesis to refer to parents, carers, and those with primary parental responsibility for the child or young person. I use this as an inclusive term rather than to exclude those who may not be a biological parent to a child.

The Research

In this research project, I explore the roles and experiences of families on the process of creating the Education, Health and Care Plan, and consider how far their views are reflected in the final plan. Though research has been done in this area before, much of it focused on the experiences of Special Educational Needs Co-ordinators (SENCOs) in schools, so a small-scale, in-depth study will be important in understanding the roles and experiences of families in the processes and how this translates to representation within the plan. There are statutory guidelines that govern the way EHCPs are created (DfE and DoH, 2015) including the requirement that plans are co-produced with the child or young person and their parents, and within this research I explore whether this is the case; whether families feel that effort is made to get children and young people involved in formulating their EHCP, how this may be done, how parents are involved in the process and how far representation is seen in the plan itself. This represents two elements of what I see as a three-element whole; gathering evidence and deciding on outcomes- the process of creating the EHCP (process), the EHCP itself and its contents (plan), and the implementation of the provision in the plan (provision), as represented in figure 1 below. This research focuses on process and plan but not on the provision, since including provision moves the project away from the bounded case study area that keeps the study scope manageable and focuses on what is discussed in the policy and statutory guidance.

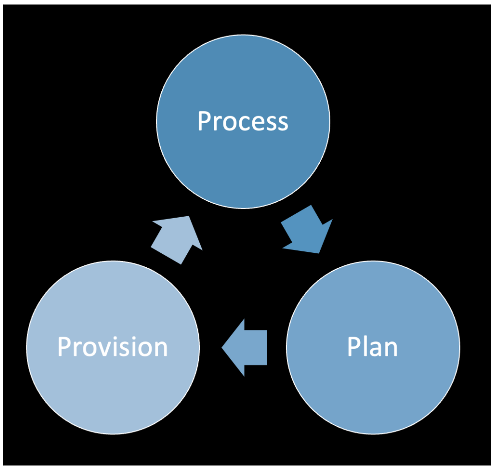

Figure 1: Map of the EHCP elements

The research I undertook explored and sought to understand the views and opinions of those with lived experience, in accordance with principles from the fields of Childhood Studies and Critical Disability Studies and using post-structural theory. I sought to move in an emancipatory direction in this research; it has been shaped by families themselves and seeks to address issues that are important to those with lived experience. I use the term 'family' in the research questions and through the thesis despite the majority of the participants being parents, as I also interviewed a young person and felt it was important to include their contribution and experiences.

The research I carried out links rights-based understandings of involvement and co-production with post-structural perspectives to consider the experiences of families. An aim of the research was to be able to publish cautiously representative (but not generalisable on a larger level) findings and make recommendations for improved practices. Shakespeare (2014) stated that more qualitative research would help support the findings of quantitative research already carried out in this area and would move away from creating data that is simply interesting to academics towards empirical research concerning the lived experience of disabled people.

There is a need for deeper understanding and study regarding lived experience; Curran and Runswick-Cole (2014) write about 'Disabled Children's Childhood Studies' as a distinct field of study (though inextricably linked with both Disability Studies and Childhood Studies) because of the damaging effects of medicalisation (viewing disability as a medical issue) and attempted normalisation of the disabled body. They advocate for change through listening to disabled children and young people and their families and allies to develop understanding and move towards action and contribute to wider theoretical debate, which was an aim for this research.

Research Questions

The research questions that I explored are:

What are the views of parents and young people on the Education, Health and Care Plan and process?

Sub-questions:

1. What are the views and experiences of families about their role and participation in the process of creating the Education, Health and Care Plan?
2. How well do families feel their Education, Health and Care Plan reflects the child or young person and their views?
3. What factors do families identify as important in how they experience the Education, Health and Care Plan process?

Disabled? Special Educational Needs?

I undertook research with children and young people who are considered disabled, or to have Special Educational Needs (SEN) and their parents. My position is that it is important to challenge disabling practices of research (Barton, 2005) and work towards emancipation in research. The first stage to creating research that can be considered moving in an emancipatory direction is to utilise the preferred terminology of disability movements and disabled persons themselves (Stone and Priestley, 1996); giving up personal notions or preferences in favour of terminology used by disabled people and disabled people's organisations. For this reason, I use language that situates the person as being disabled by society, in accordance with many disabled scholars, activists, disability charities and movements, which is 'disabled children'. The language around Special Educational Needs

(SEN) is more challenging because the language used in policy documents and guidance is considered outdated by many researchers and activists, but there is not a consensus on an alternative. Educational rights, suggested by Runswick-Cole and Hodge (2009) is where my preference lies, but this has not been adopted widely. Definitions of SEN along with diagnostic labels often converge around what children are not able to do, as in the official identifying definition (DfE and DoH, 2015) which suggests a deficit-focused pervading view, indeed, something which emerged in this research. This has historically contributed to a culture of low expectations for children and young people with SEN (Lamb, 2009) about what they may be able to achieve at school and in their future, as well as a lack of information, choice and support for their parents (DfE, 2011). Though disability and SEN are not interchangeable terms and have different definitions (as I go on to discuss in the next chapter) they are often used interchangeably or grouped together as 'SEND'. This is the case with the SEND Code of Practice (DfE and DoH, 2015) which uses 'SEND' to refer to groupings in policy but refers to 'children with SEN' separately from 'disabled children' (DfE and DoH, 2015, p. 15-16). Schools and parents, and children and young people themselves use SEN most often, as well as this being the language of current policy (DfE, 2014a; DfE and DoH, 2015) so I use this in my writing, in addition to my use of 'disabled children'. I discuss language and terminology and raising aspiration further in the next chapter.

Disabled children, those with SEN and their families have regularly been the subject of media scrutiny that creates questions about their entitlement to support, for example, 'Pupils lose out as £400m schools funding diverted to special needs' (Hurst, 2019) and from this year, '£5bn debt crisis of special educational needs, 'could bankrupt' English councils' (Butler, 2024). These headlines construct children with SEN as separate from their peers and blame them for financial shortfalls in education apparent in the articles. This is also the case for disabled adults who are being subjected to cuts in benefits and scrutinized through the use of, at times, harmful Fitness to Work assessments (Goodley, Lawthom and Runswick-Cole, 2014) and other forms of surveillance and control. This ongoing campaign means that carrying out sensitive research in this area is important at this time, and that it should be undertaken with a view to understanding the constructions of disability and children and young people with SEN. I discuss this next in the context of the theoretical framework for the project.

The Theoretical Framework

The theoretical framework for this project is drawn from multiple fields and forms an interconnected network of theory and research. I draw on sociological (post-structural) theory throughout in how it underpins newer theoretical perspectives. Fields I draw additionally from include Childhood Studies, Critical Disability Studies, ableism and Disabled Children's Childhood Studies, to understand the findings from both a post-structural and rights-based standpoint. My position is that these fields work together for a broader understanding of SEN and disability, and particularly, the experiences of families in accessing support in this area. The theorist I use to draw my discussion together is Michel Foucault. Foucault has been used to theorise disability previously (Tremain, 2018) and applied to research with children with SEN (Allan, 1996; McKay, 2014). This is particularly useful for disabled children and children with SEN in their experiences of the EHCP. Whilst Allan (1996) uses a slightly different 'box of tools' (Deleuze, 1972 cited in Foucault, 1977, p.208; Allan, 1996, p.219), from Foucault's work including medicine, madness and discipline, I shift away from more medicalised tools towards those that seek to understand power dynamics in relationships and discourse, as fits a piece of research not situated in a school or institution. Specifically, I use elements of Foucault's work; power/knowledge, surveillance, governmentality, discourse, and regimes of truth to theorise the findings and offer some explanation as to why families may experience the EHCP process in this way. I now go on to explore in more detail post-structuralism and relevant aspects of Foucault's work.

Post-structuralism and Foucault

Post-structuralism is appropriate for this project as it includes elements such as rejection of fixed narratives, generalisations and single truths, making implicit power relations explicit and showing how they hold up a set of truths (Hodgson and Standish, 2009). In this research, the focus was on family experiences of the EHCP process and plan, and power could be seen as a strong theme in the findings. This was a likely outcome, given that I was examining the enactment of an area of policy and statutory guidance, and issues of power are commonly seen in such examinations. I therefore decided to examine power relations and 'truths' in relation to SEN, disability, parenting and roles within the EHCP process at this particular time in history in the Discussion chapter. In creating a discussion using such a theoretical perspective, I carried out critical research to share authentic reflections from participants, applied appropriate theory, and sought to disrupt dominant discourses for social justice motives. To do this I used elements of the work of Foucault, who is considered an early proponent of post-structural theory, with his work looking beneath the surface of events and experiences (Krylova, 2024).

Crucial to Foucault's work are concepts of power. For Foucault, power is not static, it is not an object or something that can be possessed (Foucault, 1975) but an action or relationship, only visible when put into practice as a way of influencing the actions of another (Foucault, 1982). When Foucault discusses power, he describes it as inextricable from knowledge, knowledge is the exercise of power and power is a function of knowledge (Foucault, 1978). Use of power can lead to creation of knowledge (or privileging of knowledge) and where there is inequality and the powerful are providing knowledge (or regimes of truth), this can distort or ignore the experience of the recipients of knowledge, the powerless or subjected. When discussing disabled children and children with SEN, this can be linked to how children are categorised, labelled or diagnosed, and how 'truths' emerge from these labels (for example that children who do not communicate verbally are not able to participate in discussions around their future), from a more powerful party.

Linked to power and crucial in Foucault's work are his ideas of discourses and regimes of truth. Discourses create subjects of individuals, grouping them, dividing them, creating knowledge about them and attaching specific ways of characterising or talking about them (Foucault, 1969). Discourses rely on power, and creation of the other, usually for a purpose, for example, in controlling the actions of others (Foucault, 1975). Discourses are linked to governance too, as Foucault said;

> ‘Discourses are therefore structured in such a way that they can determine who the ‘subject’ is as well as defining, limiting and controlling the relation between how subjects perceive themselves in their relationship with the world’ (Foucault 1977, p.138).

The relationship between discourse and subject is problematic, and can be disempowering, especially when the power to define and control does not lie with the ‘subjects’ as in with disabled children and young people, or those with SEN. Cannella (1999, p.38) summarises Foucault’s (1969) governance of discourse in the following way;

> ‘most discourses are governed by rules and principles of exclusion that include prohibition, ritual, the privileged right to speak, the appeal to reason, and the will to truth.’

When a discourse is formed around disability or SEN, certain regimes of truth are created from that, controlling perspectives and understandings about its ‘subjects’. Regimes of truth are discourses or sets of discourses that society holds as true (Foucault, 1980); as Foucault goes on to state,

> ‘’Truth’ is to be understood as a system of ordered procedures for the production, regulation, distribution, circulation and operation of statements. ‘Truth’ is linked in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces, and which extend it- A ‘regime’ of ‘truth’ (Foucault, 1977b, p.133).

The link between power/knowledge, discourse and regimes of truth is also unentangleable, as discourses, regimes of truth and even knowledge itself are ways in which power is visible (Foucault, 1991). Though broadly, power/knowledge is diffused through the structures, with some knowledge privileged over others, and regimes of truth created and upheld by discourses, again created by the powerful. This research examines the power relations at different levels of family experiences with the process of creating their EHCP, and the resultant outcomes and aspirations in the plan, whilst being mindful that children and young people are active agents, with their own power.

Two additional core concepts of Foucault’s work that are important for this research project are governmentality and surveillance because these can be useful tools when considering enactment of policy or statutory guidance. When Foucault (1975) discusses governmentality, the term does not refer just to state level power (i.e. the Government), but how individuals and their behaviour are governed, by themselves and by others. Government of behaviour (and thinking and understanding) can emerge from discourses and associated regimes of truth around how an individual is supposed to behave, and can be achieved through technologies of discipline, including surveillance. Surveillance can take place through documentation to create knowledge about an individual; surveillance is not only at work in prison systems (i.e. for people who are constructed as ‘needing’ to be watched) but operated through schools and services and through documentation. The analogy used by Foucault (1975) to discuss surveillance is Bentham’s panopticon- a prison designed so that a single prison guard could monitor all prisoners because prisoners could be being watched at any time. If prisoners know they could be watched at any time, the theory is that they will regulate their own behaviour simply because of the threat of surveillance. This is a key tool of government, that citizens learn to govern themselves and their own behaviour so state intervention can appear minimal. I discuss how surveillance is visible in the EHCP process in relation to the findings, in the Discussion chapter.

Surveillance represents just one technology of the concept of discipline for Foucault (1975); the ability to behave according to an accepted norm or to use power to make one behave according to the norm. Other technologies, considered together are hierarchical observation, normalising judgement and the examination (Foucault, 1975, p.170-184). Hierarchical observation uses surveillance, control and checking, and constant observation to create truths about individuals. Power relationships are formed and sustained, and those tasked with supervising are themselves also observed. Normalising judgement uses knowledge of the individual to determine how well they measure up against (socially constructed) sets of norms or expectations, quantifying and assigning value, depending upon their distance from the norm. Hierarchical observation and normalising judgement are brought together for the examination, bringing knowledge of an individual under a qualifying, classifying gaze for the purpose of judging and controlling (Foucault, 1975), which

I discuss later in the thesis as reflecting the process of bringing professionals together for the purpose of creating an EHCP. This process also serves the purpose of governmentality, as above; ensuring people act as though they are surveilled at all times and regulating their own behaviour against the norm. Individuals who are judged to be too far from the norm can be punished or excluded. These technologies just discussed have been utilised in the field of SEN by other researchers, for example, Allan (1996) explored them in relation to pupils' experiences mainstreaming in SEN, identification of SEN, comparison to the 'norm' and formal assessment for a Statement of SEN. The Discussion chapter explores these technologies and applies them in a different way to other areas of the process of accessing support.

However, there are drawbacks to using post-structural theory and the work of Foucault in research that has disability or SEN as a focus. Firstly, by taking a static and linear view of a particular phenomenon, there is a chance that by seeking to identify and unpick power dynamics that these categories become further entrenched (Hodgson and Standen, 2009) or perpetuated through the work. This is especially apparent where the context of the research and findings is not clear. Post-structuralism can also focus too much on language or labels, ignoring people's realities which can be painful or unpleasant (Feely, 2016). This is also seen with the 'Manic Defence' (Craibb, 1997, cited in Shakespeare, 2013) of focusing on disability language and definitions because this can detract from the research that needs to be carried out around experiences of disabled people and the importance of this in transforming lives. Having a focus on language and the way it can be used to create alternative discourse can be a positive thing however, affecting the way that groups of people are seen and understood, and how they experience the world, especially where there is movement away from language that divides (Feely, 2016).

Using a highly theoretical framework like post-structuralism to discuss disability or SEN could be criticised for being excluding for those who it seeks to discuss, potentially undermining a 'nothing about us without us' position, as with learning disability (Cluley, Fyson and Pilnick, 2019). Similarly, it is important not to move Disability Studies away from the lives of disabled people and too far into abstract thinking (Shakespeare and Watson,

1996) as is the danger with using post-structural theory. This is problematic, however if researchers become overly concerned with ensuring that everything they write is accessible to all groups, then there is a risk of not engaging with the domain of theory and leaving it to those who are not concerned with inclusion (Walmsley, 2001) or social justice.

The use of Foucault's theoretical ideas as a model can limit the thinking outside these perspectives, which is against what Foucault intended (Hodgson and Standish, 2009) though I have tried to avoid being limited by the ideas as a model and instead considered them as tools to theorise the findings and explore what they could mean. For Foucault, the intention is not to understand a practice by studying the power/knowledge but to understand the conditions in which it emerges and is perpetuated (Hodgson and Standish, 2009). This again is what this thesis sets out to do in considering the forces at play in family roles in the EHCP. Foucault would posit that theory is not separate from practice and cannot be applied to practice, it *is* practice (Foucault, 1977) so rather than these being separate processes, or separate elements of the same process, they are one and the same.

Ultimately, my position is that post-structuralism is a useful theory with which to view policy development and resulting research on the EHCP because it represents a means by which to examine power relations at each level of creating the EHCP. It also has established theories and theorists, with Foucault being prominent among them, and can be combined with other appropriate theory. Post-structuralism and Foucault's work also provides an opposition to the functionalist perspectives often seen when discussing disability and SEN. Firstly, by moving the disabled body away from fixed deficit discourses to moveable and changeable constructions (Cluley, Fyson and Pilnick, 2019) and also by challenging the often dehumanising structures of understanding disability and SEN to recategorise what it means to be human (Feely, 2016). This is a linking theme between post-structuralism, Critical Disability studies and children's rights, expanding the definition of human, of worthiness and normality.

The benefits of using dimensions of Foucault's work in this doctoral research are to highlight power relations in a system of diagnosing, categorising, surveilling, governing and making assumptions about children and young people that impact their lives and outcomes, and how these processes have the potential to marginalise and exclude. These dimensions are distinct but linked and are all underpinned by concepts of power. As Foucault (1980) argues, “Power is not something that is acquired, seized, or shared, something that one holds on to or allows to slip away” (p.94) but instead a ‘multiplicity of force relations’ (p.92). In this sense, power is not tangible, uni-directional or easily explained, but part of complex, contextual relationships. In identifying where power relations exist and examining them using my chosen theoretical perspectives, I am effectively taking them out of context, and it is important to keep this in mind. This is because I am not asking parties on both sides of described interactions and experiences about how they perceive the relationship, for example, so links that I draw as the researcher should be viewed as tentative.

Disability and Children’s Rights

In this thesis I ground my findings not just in post-structural theory but also in rights-based models, specifically disability rights and children’s rights. It is crucial in this research to understand the development of the models of disability, and the way that disability is constructed within society as a starting point in research that concerns disabled children and young people, and those labelled as having special educational needs.

There has been a radical shift in how disability is perceived, from ‘divine punishment, karma or moral failing’ (Shakespeare, 2013, p.214) through charity models of disability based on pity (Longmore, 2013), the medical model perspective of personal tragedy and deficit (Best, 2005), to a social model perspective whereby society is the key disabling factor (Oliver, 1983). In the 1930s and 1940s, disabled children served as poster children for charities, to attract publicity and larger donations, having to ‘appear helpless but not too disabled’ (Longmore, 2013, p.37). Disproportionate numbers of children featured in telethons, even for conditions such as arthritis, which predominantly affects adults (Longmore, 2013). This exclusion and exploitation of disabled children for monetary gain, I would argue, served to deepen the divide between children and adults at the time, but also entrench the charity model of disability, constructing disabled people as victims and the object of pity.

In more recent history, the key perspective underpinning how disability was conceptualised was the medical model; disability results from physical impairments in an individual, occurring as a result of a disease or disorder (Johnston, 1996). The medical model of disability seeks a deficit in a person in the form of a condition that can be seen as ‘other’ to society’s ‘normal’, and advocates for change in the individual as part of the process of normalisation. Under the medical model of disability, the individual condition is why the person is seen to be disabled (not accounting for the disabling aspects of society) and this is considered as a ‘personal tragedy’ (Best, 2005, p.87). This model is derived from the understanding of disability as a medical or health issue, with interactions taking place between doctor and patient.

In the British context specifically, developments towards an alternative model of disability were fought for by disability rights groups in the 1970s, one of which was the Union of Physically Impaired Against Segregation (UPIAS), supported by the British Council of Organisations of Disabled People (Shakespeare, 2013). UPIAS, described as influenced by Marxism (Shakespeare, 2013) and the connotations of struggle and oppression, argued that disabled people should be considered an oppressed group (UPIAS, 1976), with society held responsible for excluding and disabling people. This new model of disability, the social model, distances disability from biology and emphasises the role of society in disabling individuals, rather than the individual’s condition (Oliver, 1983). Under the social model, disability is seen as socially constructed, rather than as the result of an individual’s impairment. ‘Nothing about us without us’ became the mantra of the disability rights movement with the development of the social model and represents a ‘demand for control’ (Charlton, 1998, p.3).

There needs to be a balance between recognising the effects of an impairment but not stigmatising or marginalising, or disrupting identity, as well as a balance between normalising and neglecting a person or body. This is why models have developed that combine elements of the medical and social models to try and show a more complete understanding of disability, but these can still take a biological versus social stance.

Examples of these models include the biopsychosocial model (Engel, 1977) a model suggested in developing biomedical practice, which takes account of what might be occurring physically for a person in terms of function in addition to their experience, as well as acknowledging the role society has in marginalising or excluding people based on their body functionality. This kind of integration, or more nuanced approach, is what is still being proposed and fought for by many today. In more recent years, disability rights movements have culminated in the development of both national policy developments, for example the Disability Discrimination Act (HMSO, 1995) and the subsequent Equality Act (HMSO, 2010) and international rights treaties, for example the United Nations Convention on the Rights of Persons with Disabilities (UN, 2007), repositioning disabled people as rights-bearers.

The focus of Disability Studies as a discipline is not about how to ‘care’ for disabled people, ‘rather it offers a distinct critical perspective on the mechanisms society has used to exclude disabled people and how these can be challenged’ (Cameron and Moore, 2014, p.37). Importantly this definition includes the idea of challenge, or resistance. Critical Disability Studies challenges the normative, ableist ideals, but advocates being careful not to ignore the importance of them in terms of health, well-being, or having a good life (Goodley and Runswick-Cole, 2014). There are measures by which society assesses if a life is good, or worth living, which are understood in terms of independence, satisfaction and proximity to normality, which I consider in more detail in chapters 2 and 3. It is important to balance what is considered as ‘normal’; whether an impairment is seen as exceptional or ‘an inevitable dimension of difference in the continuum of human experience’ (Arnold, 2014, p.106). What Arnold is claiming here will continue as a key theme through the Context and Literature Review chapters and indeed into the Discussion chapter; what it means to be normal, where the line is between normal and exceptional, since ‘making disabled peoples’ needs exceptional is part of the disabling process’ (Arnold, 2014, p.106).

The disabling process forms a key part of understandings of disability and ableism, and Campbell (2009) urges researchers to move from simply discussing Disability Studies to including ableism specifically, considering that much of what is researched or discussed about impairment or disability is actually about ableism; what bodies should look like or be able to do. Campbell also advocates for a development from Critical Disability Studies because without the central positioning of disabled people and their views and voices, accountability could be lost (Campbell, 2009) and this could also mean that power is again used by those without experience or personal narratives to guide the way disabled people are constructed. I reflect further on this point in the discussion of my findings.

Ableism creates the idea that there is a norm that all citizens should be aspiring to and working towards, and this norm is centred in the way society is understood and planned for. An issue with centring and privileging a perfect norm is that a species-typical individual does not exist (Campbell, 2009) and these are standards that people are not able to live up to (Goodley, 2014). By using terminology to create social divisions, some groups are set up as inferior, for example, use of 'Dis' in disability represents a lack of or deprivation, of power for example, with 'disabled' and 'human' too often set up as opposite (Goodley and Runswick-Cole, 2014). Goodley and Runswick-Cole (2016, p.3) have also suggested the focus should be on dis/ability studies which takes account of the "theoretical, practical and political work that takes place either side of the binary" - in this case the binary is represented by the '/' and splits the term disability to its component parts, with emphasis on the 'dis' in order to question what is understood or valued as human. There is also potential for resistance here, with power held and wielded on the opposite side, with Goodley and Runswick-Cole (2016, p.3) asking 'Is that all you've got: ability?' in a challenge to normative ideals. This examination of the 'dis' in disability has led to a broader discussion on what is viewed as human, named dishumanism, whereby the normative views on what it is to be human are disrupted by disability (Goodley and Runswick-Cole, 2016). As Goodley, Runswick-Cole and Liddiard show, disability has been constructed as opposite to human;

> "..the human has been constituted, particularly in the periods of modernity and the rise of capitalism, reliant upon the naming of disability as antithetical to all that counts as human" (Goodley, Runswick-Cole and Liddiard, 2016, p.770).

In order to broaden the definition of what it is to be human to include disabled people and more specifically disabled children, it must be recognised that disabled children have historically been constructed outside the norm, sometimes in extreme ways, for example, the 'monstrous other' (Goodley, Runswick-Cole and Liddiard, 2016, p.770). Though again it is important to remember that there is resistance; the authors also consider what disabled children contribute to the reframing and shifting of ideas and understandings on what it is to be human, alongside recognising their humanness (Goodley, Runswick-Cole and Liddiard, 2016), as I do in the discussion of my findings.

Similarly to the way Disability Studies has been constructed whereby it is not about how to care for disabled people (Cameron and Moore, 2014), Childhood Studies is not about how to care for children, but about how children have been constructed and understood in society, and how children have moved from objects to subjects with rights. Children have at various points throughout history been seen as incomplete beings, as less than adults, without agency or autonomy, though these depictions have fluctuated over the epochs (Prout and James, 1997). Qvortrup (2009) argues that children have been seen as human becomings rather than human beings in themselves, that they are seen as not yet fully human. Similarly to the discussion about ableism above, children are seen as 'other' to society's 'normal' whereby they are seen as having deficits, not living up to expectations to exhibit capability or rationality. This is important to understand in a project that focuses on disabled children, who can experience marginalisation for being disabled and also for being a child. In more recent years, children have been recognised as rights-bearers via international treaties like the UNCRC (UN, 1989), which I explore in more depth in chapter 2.

This chapter now moves on to discuss my interest in the topic and elements of how this has developed, giving some insight into my positionality.

The Researcher

My interest in this field has developed over many years of personal, familial, and later, academic and professional experience. I focus on the academic and professional here, to avoid sharing personal experiences that are interwoven with familial experiences and are therefore not entirely mine to share. After what I felt was a somewhat underwhelming performance at secondary school, and various burger flipping jobs, I began an undergraduate degree; joint honours in Early Childhood Studies (for my family, to show them I had intentions of getting a ‘proper job’ after university) and Sociology and Applied Social Sciences (for me, because I enjoyed learning about it). My focus throughout was representing children’s voices, and I created research projects at all three levels of study that did this, mainly on the topics of young children’s views of friendships and children’s experiences of unsupervised outdoor play opportunities. I was unpopular in my Early Childhood Studies classes in part because of my refusal to engage in an exercise where we had to share our social class; I felt I was engaging in a transformative experience in higher education, experiencing being in a liminal space and not defined by my parents’ class or income, so I refused to identify as either working class or middle class. I think again of Foucault here: ‘Do not ask who I am and do not ask me to remain the same’ (Foucault, 1969, p.19). This period of study led to me identifying as a sociologist in my thinking and study. For my master's degree, I undertook a Master of Science in Analysis and Intervention in Intellectual and Developmental Disabilities, with a focus on communication support and parents’ experiences. The themes that emerged from my master’s thesis inspired my further research, with parents reporting many wider societal issues of exclusion (Arnold, 2013) than just access to and engagement with communication support, which is what I had chosen to focus on. This represented a missing of the point on my part, focusing on areas I was interested in rather than considering areas that parents themselves felt were important. Many families felt that by focusing on communication support, I was missing out on bigger issues they experience with the system as a whole. I also undertook a clinical placement during this period of study, being placed in an office of clinical psychologists and labelled ‘the resident sociologist’.

Professionally, I have had several paid and volunteering roles with children and parents, including as a nanny, nursery worker, teaching assistant and support worker. I started working for a national children’s charity as a Disability Support Worker at age 19 and was able to support children to enjoy a range of indoor and outdoor leisure activities. During this period of employment, I was denied additional training for Makaton and non-verbal communication despite it being the primary method of communication for many of the children and young people but encouraged to attend training on physically restraining children. This contributed to my drive to further my understanding and research in the areas of communication, children's agency and social justice. I was able to form networks and relationships with families who were looking for personal assistants and undertook work with families on a one-to-one support basis as a personal assistant. The training I did receive as part of these roles includes safeguarding children, child protection, autism awareness, creative solutions in behaviour management, non-verbal communication (including eventually some Makaton sign language), manual handling and hoisting, and administration of liquids or medication via a tube feeding device. I consider myself an established communication partner to several young people who do not communicate verbally, and we remain friends now my paid role supporting them has come to an end. This may give some context as to the conditions and experiences of the children I have worked with, supported, and advocated for, without using identifying features, medical diagnoses or imposed or external labels.

I also spent some time living in Ethiopia and working as an intern for an African policy organisation, where I was involved in research regarding the status of child and disability-friendly policy in a variety of African countries. I was involved in the writing of final recommendations regarding inclusive policy and practice across Africa, contributing to reports and future publications, and preparing country summaries for distribution at a global level. This experience prompted further my querying of western, heteronormative constructs of children and childhood, and encouraged me to think more globally and in a more intersectional way. Working internationally also gave me a broader, more global understanding of the status of children (especially disabled children) and the urgency with which children need to be recognised as active agents and rights-bearers.

These elements of my history converge to create the position I take theoretically; I am interested in how western society constructs children, childhood, disability and 'Special Educational Needs', and the process of othering and comparisons to a normalised way of being. I am also interested in how society constructs and disempowers children and disabled people, how this can disproportionately impact disabled children and young people, and those considered to have SEN, and how this can be understood using post-structural theory.

I make reference in the thesis to the changes happening in society more broadly with the pandemic, neoliberal government and the cost-of-living crisis, but this has also been a period of immense personal change for me. Through ongoing health investigations, I have been diagnosed with several chronic and long-term health conditions which impact on my daily function, in addition to a neurodivergence. I have been told that under the Equality Act (2010) this defines me as disabled though I have had my own difficulties in claiming the label. I am in the process of questioning myself about whether this is due to my own internalised ableism or because of my feelings of guilt about associating myself with this label when others have experienced much greater exclusion and many more disabling barriers than myself. This paradoxically came up in my findings, with parents expressing guilt about the support they receive for their child. Much of the content of this thesis has, therefore, become personal in nature as these difficulties have presented themselves and I have got used to adapting my ways of working and thinking whilst managing my pain and fatigue.

My position is that it is important to do research that makes a difference to people’s lives, but without alienating the person from the research process, or taking ownership of somebody else’s experiences. Through this research, I consider the experiences of children, young people and parents, and represent them as authentically as I can, whilst considering why they might have had these experiences, and how English policy, education and social care systems and societal attitudes contribute to the construction and governance of child, young person or parent in a particular way. As a reflexive researcher, I must acknowledge and examine my positionality to use it to help me understand why I am making particular connections and conclusions, but also to work to reduce any bias, especially considering when starting the research I was considered a non-disabled researcher. To do this, I firstly engaged in reading and consideration of language and terminology, then I worked with families in an advisory group to co-design the research so that it addresses issues they have themselves and serves a purpose in removing disabling barriers in society and in research. I connected with my advisory group at key points through the process to stay aligned with the co-production aims of the research and to ensure I took inclusive approaches at each stage. Finally, I also kept a research journal, to record my own thinking and experiences in relation to the process of carrying out the research and to reflect on the connections I was making.

Outline of the Thesis

In chapter 1 I presented discussions on underpinning theory- post-structuralism, Critical Disability Studies and sociological understandings of children, childhood and disability. In chapter 2 I present the policy and legislation context nationally, with reference to global influences and neoliberal undercurrents, and in chapter 3 I critically review the research that has been carried out in this topic area already. In chapter 4 I move on to considering the methodological, ethical and practical considerations of carrying out research that moves in an emancipatory direction. I analysed the data inductively and thematically, and in chapter 5 I present themes constructed from participant contributions and relevant literature, policy and practice. In chapter 6 I consider these themes using post-structural, Foucauldian tools, grounded in rights-based theory. In chapter 7 I analyse the project and findings and make recommendations based on the research findings. Below is a visual outline of the thesis make up.

Chapter	Contents
1- Introduction	Introduces the research, the researcher and the topic
2-Context	Outlines the policy and theoretical context to the research
3-Literature Review	A critical review of the research carried out in the topic area
4-Methodology and Ethical Considerations	A critical account of the research process and the rationale around research decisions. A discussion of the ethical considerations made in the process of planning for and carrying out the research

5-Findings	Reports the key themes from the research, situating participant contributions in existing research
6-Discussion	A critical discussion bringing together the research findings with the theoretical context
7-Conclusion	Presents the conclusions of the research, alongside the recommendations, limitations, and summarises the original contribution to knowledge

Summary

This chapter explored the research, the topic area, the researcher and the theoretical framework underpinning the research project. I have also provided a chapter-by-chapter breakdown, detailing the contents and direction of each chapter. The next two chapters consider the policy and academic context before going on to explore research in the field.

Chapter 2- Context

Introduction

This chapter provides the contextual background for the research undertaken, including an account of the current policy and statutory guidance documents, core principles underpinning policy and guidance and relevant theoretical perspectives. Given that the focus of this research is the Education, Health and Care Plan (EHCP) which is a feature of English policy and statutory guidance, it is important to discuss the policy documents themselves, in addition to the key developments that took place at policy level in the pathway to EHCPs. I discuss the Children and Families Act (DfE, 2014a) and the SEND Code of Practice (DfE and DoH, 2015) which directly underpin the EHCP, as well as the key policy shifts from previous years that have led to them. I then go on to analyse the key principles upon which these documents have been based, including collaborative working, person-centred planning and co-production, and raising aspirations for children and young people.

Language and Labelling

It is important to define and discuss key terminology; to explore the connotations and implications surrounding current accepted or rejected terms and acknowledge debates and disagreements in these. Defining key terms and agreeing upon language and labels in a project related to disability is a difficult undertaking, since there is contention in the topic within academic work and disability rights groups and in terms of how disabled people self-identify (Barnes and Mercer, 2010). Generally, it is accepted that 'impairment' refers to the person's 'biophysical condition' (Barnes and Mercer, 2010, p.11) and 'disability' to the socially created barriers that impact upon the life of the person with an impairment (Shakespeare, 2014).

As discussed in chapter 1, in this thesis I use 'disabled people/children' rather than 'people/children with disabilities'. Person-first language (e.g. person with disability) is the preferred language structure in some countries and cultures, though disability rights groups and charities in the UK advocate against its use (Level Playing Field, 2016; Scope, 2017;

NICE, 2019). With this in mind, it is worth noting however that those who use the term ‘people with disabilities’ or ‘children with disabilities’ are usually adopting a ‘person first’ approach (Shakespeare, 2014) perhaps in an attempt to recognise shared humanity, rather than intending discrimination, and indeed, was my language of choice, before I carried out further reading into the preferences of disabled people themselves.

The term currently utilised in the education policy context in relation to children and young people who are seen to require additional support to access education is Special Educational Needs, or Special Educational Needs and Disability, often abbreviated to SEN or SEND (DfE, 2014a; DfE and DoH, 2015). This has developed from historical labels and categories; from ‘Children who require special educational treatment’ (MoE, 1944), ‘Handicapped Children’ (HMSO, 1970), to ‘Children with Special Educational Needs’ (DES, 1981; DfE, 2014a; DfE, 2017). The lack of development in language in policy between 1981 and present day (2024) is notable, especially when considering the drastically changing discourses in children’s rights, the rights of disabled people and other empowerment movements that I discuss later in the chapter.

Despite general government guidance on writing about disability appearing to have a preference for ‘disabled people’ (DWP and ODI, 2018) current policy (DfE, 2014a) (though due to be updated) uses person-first language, for example, ‘children with a disability’ and also uses the definition for disability outlined by the Equality Act 2010; having a physical or mental impairment which has a ‘substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities’ (HMSO, 2010, 6.1.a and b). Similarly, in language around ‘Special Educational Needs’ (SEN) there is still a focus on needs as opposed to rights, despite significant developments in SEN in the last 40 years (Hodkinson, 2019). The most recent government publication reviewing the ‘SEND’ system in 2022 uses a mix of terminology, including SEND- Special Educational Needs and/or Disabilities (HM Government, 2022).

To be eligible for the EHCP, children need to have already been identified as having SEN, with input provided in the classroom insufficient to successfully support them. Norwich

(2013, p.39) describes ‘SEN’ as a ‘poorly defined super-category' which leads to poor understanding of what the label is and how to apply it. This, crucially, does not give information about the support that the person can expect to receive (Norwich, 2013). Giving a label like this without due consideration to the context, teaching quality and the longer-term outcomes, in addition to the within-child factors (Riddick, 2012) risks applying an inappropriate label that does not lead to positive outcomes for the child. Often, labels in the form of SEN in general or more specific diagnoses are sought for children for the purpose of securing additional resources to support them in the classroom (Trussler and Robinson, 2015) as in the case of SEN and the EHCP. However, to secure this label and the support it can bring, practitioners have emphasised ‘children’s deficits rather than their capabilities’ (Trussler and Robinson, 2015, p.38). In addition to the reliance upon a deficit perspective, there is also the issue of the fixed view that a label can bring; the label positions the SEN or difficulty as intrinsic (Gross, 2009) and intrinsic difficulties are those that are inextricably linked to the individual and their identity. It has also been reported that having a label does not necessarily bring the additional support resourcing with it (Peer and Reid, 2012) which undermines support as an argument for labelling and leads to questions about how ethical it is to apply a label that will not ensure appropriate support.

The outcome is important; when children are labelled with SEN/D, this can force them into an education system that ‘sorts, categorises and segregates’ (Hodkinson and Burch, 2017, cited in Hodkinson, 2019, p.16) and have wider impacts in the life of the child into adulthood. These impacts can include further stigmatisation by the community (Riddick, 2012), the use of the label to control or exercise power over a person or over resources allocated to support (Barton and Tomlinson, 1984), and incorrect labels leading to inappropriate interventions (Riddick, 2012). Here, the purpose of labelling children with SEN/SEND comes into question; Allan and Youdell (2017) make the point that the SEND Code of Practice (DfE and DoH, 2015, p.86) states, ‘the purpose of identification is to work out what action the school needs to take, not to fit a pupil into a category’ but that children themselves are still subject to categorisation through this process, and are fitted into 4 delineated categories in addition to any other diagnosis of physical or mental health condition, developmental, social, behavioural, or learning condition they have received.

These 4 categories are Communication and Interaction, Cognition and Learning, Social, Emotional and Mental Health, Sensory and/or Physical, under the current Code of Practice (DfE and DoH, 2015). Crucially, if the label brings with it more negative impacts than positive impacts, the practice of labelling itself must be questioned. Riddick (2012) states that to move beyond the simplistic debate about whether or not to formally label children like this, it is more important to think about the quality of the label itself.

My position is though I understand the need for processes that identify where children and young people require support, where the system uses a label that further stigmatises them but still does not necessarily lead to additional support or resources, this is not an ethical way to operate. I use here the preferred language of disability rights groups, 'disabled children and young people' and also the terminology of current policy, 'SEN', though I use them together to acknowledge not all disabled children will identify with having SEN, and not all children with SEN will identify as disabled. I next discuss SEN and disability in English education policy and the emergence of the 2014-2015 reforms to the education system.

Origin of the SEND Reforms

Though there has been a long history within English education policy of changes in how disabled children and young people are educated, from the early education acts of the 1870s-1890s regarding 'defective and epileptic children' as well as 'deaf and blind children' (DoE, 1870; DoE, 1893; DoE, 1899), my focus will be on more contemporary educational reforms. Significant changes in how and where disabled children and young people access educational support took place in England in the 1970s and 1980s with The Warnock report; the resulting publication of the Warnock Committee (DES, 1978), which then informed the 1981 Education Act. Under the 1981 Education Act, if a child was seen to require more support to access the same learning opportunities as their peers, formal assessments were carried out, and if they indicated that the child had Special Educational Needs (SEN), then the Local Education Authority created a document called a 'Statement of Special Educational Needs'. This Statement of SEN, 'specifying the nature of the needs, how and where they should be met, and the resources that should be made available' (Galloway et al, 2013, p.8) contained the child or young person’s diagnosis in addition to the support required in education.

The 1978/1981 changes can also be viewed as a particularly significant development in shifting 'SEN' from a health domain back to an educational domain, with changes in language; abolishing the category of ‘handicapped’ and ‘maladjusted’ in favour of an all-encompassing ‘Special Educational Needs’ (DES, 1978). The significance of this shift relates to an increasing drive to view children with SEN as people with individual strengths, circumstances and requirements. Arguably this is movement towards a social model of disability, considering how environmental aspects impact upon the learning of the child, and how these can be addressed, rather than situating an issue inherently within the child. This reflects the disability activism of the time, as discussed in the Introduction chapter, whereby rejection of the medical model and early social model thinking was emerging. However, a perceived lack of consideration of social influences and lack of sociological expertise on the committee (Lewis and Vulliamy, 1991) means that some of the conclusions drawn and recommendations made in the Warnock Report rely on an exclusively psychological, medicalised view of disability and education. Additional changes brought by the 1978 and 1981 documents included stronger rights for parents to be considered as partners in their child’s education, and for children and young people, then given the new ‘SEN’ label to be educated together with their peers.

The next significant policy reform was to the Education Act in 1993. The 1993 Education Act (DfE, 1993) introduced a requirement to ensure children with SEN were able to access the national curriculum, and to issue a SEN Code of Practice. The accompanying 1994 SEN Code of Practice (DfE, 1994) provided schools and settings with more in-depth information about how to meet their statutory duties under the 1993 Education Act (DfE, 1993) but also crucially made it a duty for schools to appoint a Special Educational Needs Co-Ordinator (or, SENCO), who would organise and oversee provision for children with SEN in mainstream schools. This furthers the drive for the integration of children with SEN into mainstream education, with the beginnings of inclusion as a concept emerging. There were still however, deficit-based definitions of SEN:

> "156. (1) For the purpose of the Education Acts, a child has "special educational needs" if he has a learning difficulty which calls for special educational provision to be made for him.
>
> (2) For the purposes of this Act, subject to subsection (3) below, a child has a "learning difficulty" if-
>
> > (a) he has a significantly greater difficulty in learning than the majority of children of his age,
> >
> > (b) he has a disability which either prevents or hinders him from making use of educational facilities of a kind generally provided for children of his age in schools within the area of the local education authority, or
> >
> > (c) he is under the age of five years and is or would be if special educational provision were not made for him, likely to fall within paragraph (a) or (b) when over that age." (DfE, 1993, S156).

The 1996 Education Act presents the same definition of Special Educational Needs as the 1993 Education Act but adds the duty of local authorities to educate all children without Statements of SEN in mainstream schools, unless this is against the parent's wishes, or affects 'the provision of efficient education for other children' (DfEE, 1996, S316, 3b). This again illustrates the strengthening of parental rights, but could also be viewed as ableist, prioritising education for non-disabled children, with disabled children only welcome if they do not disrupt the environment. The Special Needs and Disability Act 2001 (DfES, 2001b) required parents to be given a copy of the proposed statement before finalising, again showing some development in parental roles in education of children with SEN. These developments build on evidence-based improvements in children's outcomes with parental involvement (Desforges and Abouchaar, 2003) and I would argue that these have been woven through policy documents ever since.

Alongside these changes in policy affecting disabled children and young people and those labelled with SEN, there were developments in the way professionals work together, establishing principles of multi-agency working, to safeguard and protect children's welfare and reduce harm (DfES, 1989). This includes the way information about families is shared between services and the way services act on this information and was strengthened again in Every Child Matters (DfES, 2003) and the Children Act 2004. Every Child Matters also emphasised improving the outcomes for children with SEN (DfES, 2003) in line with the principle of Aiming High, which I discuss next.

Aspirations

The 1990s and 2000s also saw developments in the English policy landscape around aiming high and aspirations for disabled children and young people. Building on Valuing People (DoH, 2001) and Valuing People Now (DoH, 2009) which aimed to improve social care and support for disabled adults, concepts such as aiming high, working in a person-centred way, and promoting choice and control for the individual became features of policy language. The green paper 'Support and Aspiration' (DfE, 2011) outlined the initial ideas for reforming the SEN system and used very aspirational language, for example, 'challenging the culture of low expectations for children with SEND' (P16), 'reform radically, statutory SEN assessment and statement' (p29), 'best chance of a fulfilling adulthood' (p80). I discussed the culture of low expectations in the Introduction, which is based on deficit constructions and understandings of disabled children and contributes to a lack of information and support for families (DfE, 2011). This existing culture of low expectations has also been linked to over-identification of SEN and the lack of appropriate support (DfE, 2011), and there are claims that addressing this could result in 'higher productivity gains and growth for the economy' (DfE, 2011, p.23). I go into further depth about economic contribution and productivity in the Discussion chapter, and I link this to perspectives on what it means to be human, and a rights-bearer, as I discuss next.

Rights-based approaches

The English policy developments in the 1990s and 2000s were happening in the context of important international developments that relate to SEN and inclusive education; the United Nations Convention on the Rights of the Child (UN, 1989), the Salamanca Statement

(UNESCO, 1994), the United Nations Convention on the Rights of Persons with Disabilities (UN, 2007) which formed arguments for children with SEN to have access to all areas of society as well as inclusive education with their peers based on rights, as opposed to economic or productivity arguments. For children and young people, the rights landscape has been developing from the introduction of the United Nations Convention on the Rights of the Child (UN, 1989), the first international rights treaty for children, ratified by the UK in 1989. Article 12 of the UNCRC is highly relevant in this context as it concerns Respect for the Views of the Child (UN, 1989, 12.1):

> ‘States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.’

This has been described as evolving capacities (Lansdown, 2005), whereby the capacity of a person to be involved in decisions evolves as their age and maturity develop, often used as a way of protecting children or working in their best interests, but which can be used to exclude children from these decisions. Lundy (2007) identified three barriers to the acceptance and implementation of article 12; adult scepticism about children’s capacity to understand and their ability to be involved in a meaningful way, more control for children means less control for adults (with the potential to undermine for example education institutions), and the effort that implementation takes, whether it would be better directed elsewhere. I reflect on these areas in light of the findings of this research, later in the thesis.

The implementation of these international treaties has attracted intense scrutiny both nationally and from international bodies, whereby the enshrinement of these treaties into national policies and guidance in England has been seen to be severely lacking (EHRC, 2017; Children’s Commissioner, 2019). In the UK, pioneered by disability rights groups and campaigners, legislation such as the Disability Discrimination Act (HMSO, 1995) was introduced. Though this does not link specifically to children and young people, it was supposed to protect disabled people from discrimination in employment and services. This was superseded by the Equality Act (2010) which brought together all legislation on discrimination, providing the legal basis for equality of access to public institutions on the basis of disability (among other protected characteristics) including schools. At the same time in the academic arena, research was emerging in an effort to reframe SEN. Drawn from established Montessori approaches, discussion of special educational needs was being replaced with the idea of educational rights (Runswick-Cole and Hodge, 2009) or shifting to using the language of barriers to learning and participation (Booth and Ainscow, 2011) rather than on intrinsic difficulties. Instead, in policy, the focus remains on a label for the individual which is underpinned by theory on social divisions- the process by which people categorise themselves and others in society, creating norms and alterity- otherness (Best, 2008).

These developments and approaches represent more contemporary understandings of childhood and call for a move away from dichotomous constructions of adulthood and childhood, towards a more spectrum-based understanding (Tisdall, 2012) similar to movements in disability. In more recent history, children were seen as a separate social group (Jans, 2004) and childhood defined as the absence of adulthood (Tisdall, 2012), with children positioned as incomplete beings; childhood being a construction that can only exist because of the construction of adulthood, and dependent upon it for meaning. This is defined as adultism in earlier theoretical perspectives in this field; the imbalance of power between children and adults, with adults exerting excessive control over children because of the belief that adults are superior to children (Flasher, 1978). This can be seen as in parallel with the ableism that exists in society today (Campbell, 2009); disabled people being viewed as dis-abled, defined by what they are not able to do, in comparison with non-disabled people. These deficit constructions have been challenged in theoretical debate, and by rights groups, and has resulted, in the case of disability, in the development of the social model of disability, to reposition disabled people as rights-holders. Childhood Studies and social science more widely have moved towards embodying an understanding of children as rights-holders too, though with arguably less impact politically (Tisdall, 2012).

Disabled children are said to experience a form of ‘double jeopardy’, whereby they are seen to fall short of the norms of adulthood and also ableist norms (Byrne, 2012). 2014 saw the introduction of Disabled Children’s Childhood Studies, and the need for this field to develop as a discrete entity, though inextricable from its influences and underpinnings (Curran and Runswick-Cole, 2014), given that disability is often excluded from discussions about children’s experiences (Goodley and Runswick-Cole, 2011), and children excluded from discussions about disability. The recognition of disabled children’s contributions to this also forms part of the question posed by Goodley and Runswick-Cole (2014) about what is valued as human, and what kind of society is worth fighting for. The ability of disabled children to be involved in discussions about their lives has been linked to person-centred approaches, which I discuss next.

Person-Centred Planning

The development of person-centred approaches evolved in the field of psychology and psychotherapy with humanist and client-centred approaches favoured by Rogers (1949). This was an important shift away from medical model perspectives, recognising the power and autonomy of the client and proposing new ways of engaging with the client that drew on this power and autonomy. This perspective developed further within the field of learning disabilities during the 1980s (O’Brien and Lyle O’Brien, 1988) when focus turned to deinstitutionalisation and positioning the individual as knowledgeable about their own life and central to planning it (Sanderson, Thompson and Kilbane, 2006). A shift is visible here, from high levels of professional power in doctor-patient relationships as described by Foucault (1969) towards recognising the power/knowledge the individual holds in their own life. For disabled children and young people, person-centred planning was brought into focus with Valuing People (DoH, 2001) which aimed to promote choice and control for learning disabled young people and their families and implementing person-centred principles specifically in transition between children’s and adult services. Valuing People Now (DoH, 2009) also outlined the importance of person-centred planning and approaches in improving outcomes and quality of life, and in giving disabled people more control over their own lives, in the context of deinstitutionalisation and empowerment of adults with learning disabilities in the UK. Principles of person-centred planning emphasize abilities and skills rather than deficiencies and needs, encourages the input of family, friends, and the person's wider social network, and advocates securing support to reach goals rather than setting goals that the person can likely already attain with the support widely available (Mansell and Beadle-Brown, 2004). It becomes crucial when the individual has contact with a variety of education, health and social care professionals, to ensure that the child or young person's voice (and indeed the parent's voice) does not get lost in the multiple dealings that they will have with professionals. This development was not without its issues; Johnson and Walmsley (2010), writing specifically about people with learning disabilities, stated of the time, 'the rhetoric of users being in the driving seat was subscribed to in theory but did not match the reality' (p158).

Despite these developments in rights-rooted person-centred approaches, and their application to the support of children with SEN, Statements of SEN were not ensuring children's educational rights were being realised; a report by Ofsted (2010) found that the implementation of the Statement of SEN was inconsistent, with many children receiving little or no support, and others receiving support that was not appropriate for their needs. A specific example of this is the finding that information on an individual's visual capabilities was often left out of Statements of SEN (Little and Saunders, 2014) which could have a significant impact upon the recommendations made in terms of support for that child. The discussion around the need for reforms to the SEN system often focused on the principle of putting families at the centre of decisions and provision and creating a less fragmented and more joined up system (Timpson, 2014) for the benefit of children with SEN and their families. I discuss the reforms in the following section.

Current Relevant Policy

The key documents governing support and education for disabled children and young people are known as the SEND reforms and combine the latest Children and Families Act (DfE, 2014a) and its accompanying SEND Code of Practice (DfE and DoH, 2015). The act provides the legal underpinning, definitions of terminology and processes and obligations held by different bodies, for example, the duty of the local authority to ensure and maintain an EHCP for children and young people who need one (DfE, 2014a). It also gives the definition of an EHCP with the required content (DfE, 2014a) which is then expanded further in the SEND Code of Practice (DfE and DoH, 2015) which is directed at health, social care and educational bodies and local authorities, explaining their statutory duties under the act. Indeed, it is under the auspices of this act, and the accompanying Code of Practice that the EHCP I explore in this research explores was created.

The principles of working together have been applied to the work professionals do with children and young people with SEN in the updated legislation (DfE, 2014a) and statutory guidance (DfE and DoH, 2015), with a stronger duty for professionals to work both in collaboration with each other, and in partnership with families. There is also a strong focus in both reform documents on aspirational outcomes for children and young people and putting appropriate support in place to support them in working towards them (DfE, 2014a; DfE and DoH, 2015).

Though there are a wider range of relevant policy documents underpinning other areas of the SEND Code of Practice, including legislation governing direct payments and personal budgets, these are not included for analysis as they are not directly related to the scope of the research; the EHCP process and plan. I have separated these elements from what I have discussed as a three-element concept; the process of application, assessment and creation of the EHCP (process), the EHCP itself (plan) and the implementation of provision outlined in the plan (provision). As outlined in the Introduction chapter, this research addresses the process and plan elements. I discuss the process first.

The EHCP Process

Under the Children and Families Act (DfE, 2014a), Education, Health and Care Plans (EHCPs) replaced the Statement of Special Educational Needs for children who have more complex needs that cannot be met by SEN support in school, or differentiated teaching strategies such as visual timetables, alternative communication (symbols or signing) and in-classroom support (Martin-Denham, 2015). One of the significant changes between the Statement of SEN and the EHCP is that the upper age of eligibility was extended from 19 to 25 (DfE, 2014a) which was intended to bridge the gap between child and adult services and ensure there is no drop-off in support. Unfortunately the financial implication of this extension was not necessarily considered in terms of the impact it would have on local authorities and education settings, leading to competition for a finite, inadequate and non-ringfenced budget between services within the local authority (House of Commons, 2020) and a focus on reducing the numbers of children who receive an EHCP, with numbers actually rising in reality (HM Government, 2023).

Responsibility falls to the local authority to identify and co-ordinate support for those with SEN, and if a child or young person's needs are not being met with internal SEN support at their school or setting via the Graduated Approach, then the local authority needs to be notified, by way of a referral, so that they can consider carrying out a needs assessment (DfE and DoH, 2015). A referral can be made by a parent or professional working with the child or young person, and young people over the age of 16 but under the age of 25 can also request their own EHCP (DfE, 2014a; Ko, 2014). Though the ability for families themselves to be able to request a referral for a needs assessment arguably evidences a shift towards a more equal power dynamic between families and professionals, concerns have been raised that this favours parents who have knowledge of the system over parents who are less able to navigate this, for example parents with English as an additional language (Crutchley, 2018); issues of capital, knowledge and ability to navigate the system are important to consider and will be discussed in the next section. If a parent or young person is seeking a referral, this is usually discussed with the school or setting first, so that the SEN support provided can be reviewed to see if it can better meet the child or young person's needs, since the local authority will ask for evidence that support has been reviewed and tailored to their needs (DfE and DoH, 2015). Once this process has happened, the referral is passed to the local authority, who have a duty to decide whether to conduct a needs assessment for the individual, considering their educational, health care and social care needs. This duty is provided for under section 36 of the Children and Families Act (DfE, 2014a) and a decision must be made within six weeks of the first request (DoH and DfE, 2015). Whoever has parental responsibility for the child must be consulted at this point; for children in care, this means the local authority, and for young people, they themselves must be consulted too. If the local authority believes, after views and evidence have been reviewed, that the child or young person has or may have special educational needs (SEN) or they believe that the child or young person will require special educational provision by way of an EHCP, then they have a duty to carry out the EHC needs assessment (DfE and DoH, 2015).

If a young person is denied a needs assessment for an EHCP, the local authority must notify them of the reasons for the decision, and if a child is denied a needs assessment for an EHCP, the local authority has an obligation to contact the person with parental responsibility to notify them of the decision made, and the reasons for the decision (DfE and DoH, 2015). At this point, families have the right to appeal this decision and must be told that they have this right and where they can access advice and support in doing this (DfE and DoH, 2015). The process for appeal follows this general order- mediation, appeal, tribunal, whereby issues should be resolved at local level where possible, before moving to formal procedures such as an appeal to tribunal, or further to judicial review (Bryant, Parish and Kulawik, 2022). The SEN tribunal was introduced in 1994 to make decisions where there had been a dispute between families and the local authority (then called the local education authority) (Runswick-Cole, 2007). It is now known as the first-tier tribunal (Special Educational Needs and Disability) and hears disputes relating specifically to the EHC needs assessment and EHCP itself, including the content of the plan (DfE and DoH, 2015). A large number of families have had to appeal to tribunal in order to either secure a needs assessment or appeal sections of the EHCP; over 9,000 in 2021-2022, up to 14,000 in 2022-2023 (MOJ, 2023), appealing where they have not been successful in securing an EHCP at all or appealing the content of the plan itself where agreement has not been reached in the EHCP, planning or provision (DfE, 2023a). 98% of families appealing to tribunal won their case in the most recent tribunal report (MOJ, 2023) up from 96% in previous figures (DfE, 2023a) which suggests a system that is overwhelmed and unprepared for the support they need to be providing to families by right, or a system that provides unhelpful and expensive obstacles to families receiving the support they are entitled to.

If the local authority is planning to carry out a needs assessment on receipt of the referral, they have an obligation to notify the young person, or the parent of the child of this, and of their right to express their views in writing or verbally to the local authority, as well as submit evidence to support their statements (DfE, 2014a). A needs assessment cannot be carried out without the knowledge of the parent or young person but may be carried out without their agreement (DoH and DfE, 2015) again giving rise to a question over whether this would be in the best interests of the child or young person, or whether this would create tension in the relationship at this unequal power distribution. In considering whether or not a child is eligible for an EHCP as part of the needs assessment process, according to the most recent Code of Practice (DfE and DoH, 2015), the local authority is supposed to take account of a wide range of evidence from multiple sources. This includes the milestones a child has or has not reached, the academic achievement or progress the child or young person has made, the support the school or setting has already put in place to support them but also,

> ‘evidence of the child or young person’s physical, emotional and social development and health needs, drawing on relevant evidence from clinicians and other health professionals and what has been done to meet these by other agencies’
>
> (DfE and DoH, 2015, S 9 ss14).

This evidence is not always forthcoming, as the findings in this thesis show. The local authority must use this evidence to decide whether the individual needs an EHCP; professionals involved in the child’s life in the health and/or education domains (where appropriate for the individual) are invited to undertake needs assessments for individuals and make outcome-based recommendations for care and interventions (Ko, 2015). The local authority must notify those who may need to provide information or support, including the young person or parent (and invite them to express their views), the health service, the local authority officers responsible for children with SEN, the headteacher or principal (if the child is at school or college) or setting manager (if the child is enrolled at an early years setting) (DfE and DoH, 2015). Clinicians and other professionals are given 6 weeks to respond to the request, and if the child or young person misses a specialist appointment, this can be seen as grounds for delaying the overall 20-week timeline (DfE and DoH, 2015). Once the needs assessment has been carried out, the local authority has an obligation to notify the young person or the parent of the child about the outcome of the needs assessment, whether or not the local authority has recommended that an EHCP is prepared for the child or young person, and the reasons for that decision. The role of the professional is privileged here, giving them a significantly longer timeframe to respond than parents and children are given to review the complete plan, creating a double standard, as seen in the Findings chapter. The power of the professional to delay the 20-week timeline could feel punitive and may go some way to explain the figures of local authorities operating outside this timeframe; only 50% of plans were completed in the 20-week timeframe from the latest figures (DfE, 2024). The local authority then has the responsibility of ensuring that an EHCP is created and maintained for the child or young person, under section 37 of the Children and Families Act (DfE, 2014a). The local authority is obliged to ensure that the draft EHCP is created, with input from the young person, or the parent of the child. This should take place in a multi-agency meeting format, and where plans are being reviewed, this is known as an annual review meeting (DfE and DoH, 2015).

The draft EHCP must be sent to the young person, or the parent of the child, who have a 15-day deadline by which to comment on the draft plan (DfE and DoH, 2015). The EHCP must be reviewed every 12 months from the date that the plan was made as a minimum requirement (DfE, 2014a) but headteachers (or equivalent- governing bodies, principals, managers of early years settings), parents, and the child or young person themselves may request a reassessment if they feel it is warranted. The local authority can also reassess at any point that they feel it is necessary. The EHCP statistics released by the government do not provide information on the number of annual reviews that are reviewed annually or where this has not been carried out; this is significant given that there is a legal requirement to review them at least annually and families report that this is not always the case, as I reflect on in the Findings chapter. The timeline for the creation of the EHCP is illustrated in the flowchart in figure 2 (below).

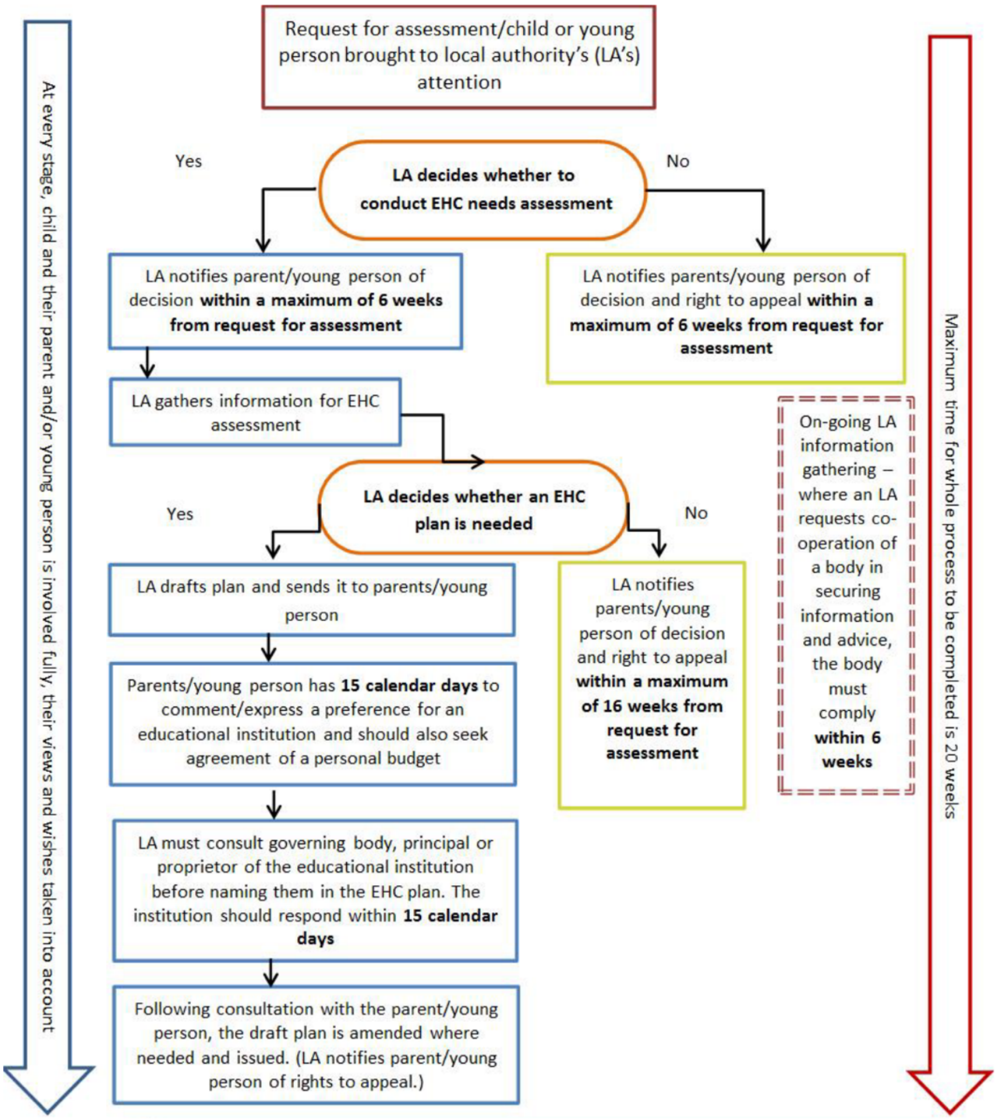

Figure 2: Statutory Timescales for the EHCP from the SEND Code of Practice (DfE and DoH, 2015, p.154)

When referring families for a needs assessment as part of the EHCP process, information must be given on the Local Offer and as part of this, the option for families to have a personal budget. Each local authority has a legal duty to provide families with information on the support and services that exist in the area to provide options for the spending of the personal budget, allocated to meet the needs outlined in part A of the EHCP, this is the Local Offer. This information should be widely available to families and published on the local authority's website (DfE and DoH, 2015) and is supposed to represent a transparency in eligibility, decision-making, appeals and complaints processes, and responsibility for different elements (Silas, 2014). If an EHCP is granted, families are entitled to request the personal budget (DfE and DoH, 2015) which is an amount of money allocated to meet the support needs of an individual, with the individual being allowed control over how the money is spent (Glasby and Littlechild, 2016) in their social care choices. This is not to be confused with direct payments, which families can request as part of the personal budget, where money is given directly to the family to be spent on services to meet the child or young person's needs (DfE and DoH, 2015) for example choosing and paying for a personal assistant themselves. These elements have been introduced in the name of personalisation, building on movements in disability and learning disability advocacy and changes implemented in adult social care (Glasby and Littlechild, 2016). More personalised ways of providing support were intended to move away from a 'professional gift' model of funding towards 'citizenship models'- with increased individuality and personalisation, flexibility on how this can help the individual engage in their community, and based on the principle that this money (as with citizenship) is an entitlement, not a gift (Duffy, 2014, p.170). For families of disabled children, personal budgets are used to meet the child's needs as set out in their EHCP- the plan, as discussed below.

The Education, Health and Care Plan

The EHCP needs to contain the following information:

- "(a)- the child's or young person's special educational needs;
- (b)- the outcomes sought for him or her;
- (c)- the special educational provision required by him or her;
- (d)- any health care provision reasonably required by the learning difficulties and disabilities which result in him or her having special educational needs;
- (e)- in the case of a child or a young person aged under 18, any social care provision which must be made for him or her by the local authority as a result of section 2 of the Chronically Sick and Disabled Persons Act 1970 (as it applies by virtue of section 28A of that Act);
- (f)- any social care provision reasonably required by the learning difficulties and disabilities which result in the child or young person having special

> educational needs, to the extent that the provision is not already specified in the plan under paragraph (e).” (DfE, 2014a- S 37, ss2, pt a-f).

A format for the EHCP is given in the SEND Code of Practice, confusingly also using letters. Each section must be included and must be labelled with the appropriate letter, as below in figure 3.

Section A: The views, interests and aspirations of the child and his or her parents or the young person.
Section B: The child or young person’s special educational needs.
Section C: The child or young person’s health needs which are related to their SEN.
Section D: The child or young person’s social care needs which are related to their SEN or to a disability.
Section E: The outcomes sought for the child or the young person. This should include outcomes for adult life. The EHC plan should also identify the arrangements for the setting of shorter-term targets by the early years provider, school, college or other education or training provider.
Section F: The special educational provision required by the child or the young person.
Section G: Any health provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN. Where an Individual Health Care Plan is made for them, that plan should be included.
Section H1: Any social care provision which must be made for a child or young person under 18 resulting from section 2 of the Chronically Sick and Disabled Persons Act 1970.
Section H2: Any other social care provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN. This will include any adult social care provision being provided to meet a young person’s eligible needs (through a statutory care and support plan) under the Care Act 2014.
Section I: The name and type of the school, maintained nursery school, post-16 institution or other institution to be attended by the child or young person and the type of that institution (or, where the name of a school or other institution is not specified in the EHC plan, the type of school or other institution to be attended by the child or young person).

Section J: Where there is a Personal Budget, the details of how the Personal Budget will support particular outcomes, the provision it will be used for including any flexibility in its usage and the arrangements for any direct payments for education, health and social care. The special educational needs and outcomes that are to be met by any direct payment must be specified.

Section K: The advice and information gathered during the EHC needs assessment must be attached (in appendices). There should be a list of this advice and information.

Figure 3: Content of the EHCP from the SEND Code of Practice (DfE and DoH, 2015, p.161-162)

Information collected during needs assessments including reports from professionals go in section K and are supposed to be used to help inform the needs sections (B, C and D), the outcomes sought for the child and young person (section E) as well as the provision sections (F, G, H1 and H2). These sections, however, are still supposed to be created in collaboration with families. Section A is where the child or young person can write about their aspirations and their own views; this can also be completed by parents or professionals, though it must be clear if the words included are the child or young person's or somebody else (DfE and DoH, 2015). This section is sometimes called 'All about Me' (IPSEA, 2023b) though first person must not be used if this is being written by anybody but the child or young person (DfE and DoH, 2015); it must be clear who has written it and what contribution the child or young person has made. The needs and provisions sections should mirror each other, so where an educational need is outlined in section B, there should be provision outlined in section F to meet that need. Section E refers to the outcomes sought for the child or young person. These need to be written in a SMART way- specific, measurable, achievable, realistic and time-bound, should be linked to things that are important to the child or young person (or their family) (DfE and DoH, 2015).

The statutory guidance (DfE and DoH, 2015) advocates for the use of person-centred planning and approaches, stating that the EHCP is to be developed using these approaches. The implications of this 'person-centredness' are that professionals must ensure children and their parents are involved in creating the EHCPs, taking into account their wishes with regard to recommendations, outcomes and meeting considerations, and using ordinary language rather than jargon. Young people and their parents are supposed to be involved throughout the process of creating the EHCP, and asked for their views at every stage, as well as informed of their right to appeal any decision made that they do not agree with (DfE and DoH, 2015; Ko, 2014). Core to this piece of research, I consider this requirement through the Findings and Discussion sections.

It is clear from this account of the EHCP process and plan that the principles discussed earlier in this section are embedded in the policy and statutory guidance documents; there is a focus on aiming high and being aspirational for children and young people, on involving families in decisions made about their lives- including the child or young person about whom the plan is created, and on professionals working together. The resulting documents, the EHCPs themselves are therefore long and complicated, and where evidence from various needs assessments and professional reports is included in section K, even more so. This means that understanding and engaging with these documents will require not only a high level of literacy but also significant availability of time for families, which I reflect on in the Findings chapter.

Summary

This section has shown the unique position disabled children and young people find themselves in in the context of English education policy, and how this has developed.
I have explored key principles underpinning policy developments including aiming high, collaborative working, person-centred planning, and the involvement of parents in their child's education. There is a need to examine the research specifically on the involvement that families have in decisions made about their lives within current policy, and I am applying this to the EHCP, which has a legal requirement for involvement. The next section will analyse the research that has already been done in this area; understanding the impact of the SEND reforms and specifically the EHCP, how families are constructed and understood in the statutory guidance, how professionals work with families, and how families have experienced this process. In doing this, I seek a gap in the literature and how research might be developed to address it.

Chapter 3- Literature Review

Introduction

This chapter explores the research that evaluates the impact of the SEND reforms, considers the development of the core underpinning concepts (collaboration, co-production and aiming high) and then analyses the research that has been carried out to understand the experiences of families of the EHCP process. There have been limited studies that consider the involvement of children, young people and their parents in creating the EHCP from their own perspectives, so some of the research included in this chapter is categorised as grey literature, including doctoral research and reports from charities and rights-based organisations. Whilst inclusion of grey literature is not a universally encouraged practice, it can improve how comprehensive the review is able to be, taking into account a broader context in terms of evidence, especially where there is a dearth of research (Paez, 2017). On balance, the benefits of being able to include this highly relevant (and methodologically rigorous) research outweigh the drawbacks.

Literature Search

My search strategy focused on use of the library resources at the University of East London, including open access texts and those sourced through databases including EBSCO, Scopus, Science Direct, JSTOR and ProQuest Central, and snowball searches from relevant articles. This includes using the reference lists of other authors to find additional relevant material. I used a variety of search terms that I employed in different combinations including ‘EHCP’, ‘Education AND health AND care AND plan’ (making use of Boolean features), ‘parental involvement’, ‘parents’, ‘participation’, ‘partnership’, ‘SEN’ ‘Special AND Educational AND Needs’, ‘disab*’, ‘co-production’, ‘collaboration’, ‘involvement’. My focus was 2014 onwards because of the introduction of the EHCP but I did expand my search beyond this as detailed below. I had a cyclical search strategy whereby I would conduct literature searches regularly throughout the doctoral journey; when I started in 2016 there were very few pieces of research in this area with the SEND reforms being very new, and gradually more pieces were published so I needed to revisit my searches. I also used search engines to find grey literature including research studies carried out by charities or rights-based organisations. I chose to include peer-reviewed journal articles published across a range of disciplines (for example, psychology, sociology, early childhood, social work, disability studies) to gain a broad academic understanding of the topic area, with qualitative and quantitative research included. I also included grey literature where appropriate, as discussed above as I felt the benefits of including this research outweighed the potential drawbacks. The grey literature I used includes charity research documents and research projects from rights-based organisations, many of which have input from families and children and young people themselves, which is an important element to research in this area, especially where I am looking to move in an emancipatory direction in this research, as I discuss in the next chapter. I also made use of doctoral theses where there was a lack of research specifically about the EHCP, which enabled me to draw on detailed, methodologically appropriate studies that had not yet been published as journal articles or book chapters.

Inclusion criteria for the literature necessitates research in an English context where the focus is the EHCP as this is a feature of English policy, however where research focuses on core principles underpinning the EHCP, for example, person-centred practice, collaborative or multi-agency working, working with parents, parental experiences and involving children in decisions made about their lives, I have widened this to include literature from other national contexts (for example, America and Italy) as a way of examining where good practice exists or where there are practices to be learnt from.

The scope of the literature search would ideally be limited to research published post- SEND reforms (2014-2015) however in the absence of sufficient literature examining the implementation and impact of the reforms and the EHCP specifically, I broadened this search to examine literature that focuses on other mechanisms by which children and young people are involved in decisions about their lives, for example the Statement of SEN that the EHCP replaced, and planning for futures. For this reason, the review of the literature begins with examining the implementation of the SEND reforms, the rationale behind the SEND reforms, then moves into more specific areas such as the involvement of families, children and young people in decisions about the support provided (including pre-2014 literature) and finally considering literature that has examined family involvement specifically for the EHCP (all post 2014, and includes grey literature).

I have divided the research into EHCPs into three areas- process (the process of applying for, being assessed for, and creating an EHCP), plan (the content of the EHC plan itself) and provision (whether and how what is outlined in the EHCP is implemented). This research project focuses on the first two areas, process and plan, in considering where and how children, young people and their parents are involved in the process of creating the EHCP, and how they feel they are represented in the plan itself. For this reason, though I briefly discuss some elements of implementation (as did families in the research, which I reflect on in the Findings and Discussion chapters), I focus in the main on process and plan.

The origin of the EHCP

As explored in the previous chapter, the EHCP was introduced in the 2014/2015 SEND reforms, replacing the Statement of Special Educational Needs (hereinafter known as a Statement of SEN). Where the EHCP focuses on needs and provision, the Statement of SEN focused on a diagnosis for the child or young person (Castro, Grande and Palikara, 2019). Statements of SEN outlined the support that could or should be available but did not always guarantee that the additional resources or financial support that the child required to be supported to achieve at school were actually provided (Armstrong and Squires, 2012). At the time, the Statement of SEN did appear to represent a move towards making specific considerations for supporting individuals and did appear to construct mainstream or inclusive education as an important right for children and young people. However, having been created by professionals, Statements of SEN did not always relate specifically to the child, and the voice of the child, young person, and parent was not considered. Statements of SEN were also found by parents to be vague or general in nature (Jones and Swain, 2001) not necessarily relating specifically to their child.

The Statement of SEN was supposed to be created by professionals within a 26-week window, but the complex assessment process was found to take up to 67 weeks (ILEA, 1985, cited in Barnes, 1991). These documents were often written in general language (especially in terms of what support should be made available to children and young people, for example ‘considerations should be made’ or ‘adaptations should be considered’) and could be written to mean whatever the local authority wanted them to mean (Thomas and Vaughan, 2004). Interestingly, this issue features as a finding in this research in relation to current policy. There were also inconsistencies between different local authorities in access to Statements of SEN, with pupils in one local authority receiving a Statement of SEN, where pupils in a neighbouring local authority with a comparable situation would be supported with School Action Plus (DfES, 2001) whereby school staff are expected to meet the needs of the student in school, with support from outside specialists (Ofsted, 2010). Financial constraints may have affected the local authorities’ decisions on who to give a Statement of SEN to and who not to (MacBeath et al, 2006). This ‘postcode lottery’ means that the provision that children and young people received was not a universal right, but in fact dependent upon where the child lived at the time of assessment, and potentially the disposition of the professionals in their local authority. This is still reported in literature to date; that provision can vary between and within local authorities (Sales and Vincent, 2018; Palikara et al, 2018; Robinson, Moore and Hooley, 2018). Acknowledgement of a fragmented, overly bureaucratic, adversarial system where parents needed to fight for each element of support for their children was written into documents around the time of the reforms (DfE, 2011; DfE, 2014c) and indeed will be discussed in more depth through the thesis. Key drivers for change from Statements of SEN to EHCPs include a move away from low expectations towards improvement of the outcomes of children and young people, more control for parents, greater involvement in the process for families, and improved working together practices for professionals (DfE, 2011). These principles underpin the Children and Families Act (DfE, 2014a) and the SEND Code of Practice (DfE and DoH, 2015) which come together to form the SEND reforms.

Background- Research to understand the impact of the policy change- SEND Reforms

The Children and Families Act 2014, described as ‘the biggest education reforms for children and young people with SEN’ (DfE, 2014a, p.1) and its accompanying updated Code of Practice (DfE and DoH, 2015) was borne out of years of consultation with stakeholders, and extensive Pathfinder studies with local authorities. Results of these consultations appeared positive, with families involved in the Pathfinder studies reporting that the reforms made them central to the process of the support and intervention system (DfE, 2014a). Certainly, early evaluations of the reforms by 5 Pathfinder areas (DfE, 2014b) found that the reforms meant that the process was focused more on outcomes for children and young people, and there was more family involvement in the process. This initial information showed promise, though the sample was relatively small, and there was not agreement among all participants in terms of their experiences.

There have been some important changes in the SEND reforms that have impacted positively on those with experience of the system, firstly, the principles of the reforms, including the focus on person-centredness have been well-received by families in research studies (Hoskin, 2019; Skipp and Hopwood, 2016). The addition of outcomes to the EHCP is a key improvement over Statements of SEN (Sales and Vincent, 2018) that can facilitate an ambitious and future-focused plan for children and young people. The SEND reforms represent a participation approach in theory, moving towards a more social model way of thinking (Castro, Grande and Palikara, 2019), with a focus on how the system can support children and young people, and how they can be included in the process. This is not widely accepted however; Boddison and Soan (2022) found that the language in the Children and Families Act (DfE, 2014a) upholds the professionals as experts model, doing little to move away from the power structures of past legislation. Language can create and reinforce regimes of truth (Foucault, 1980) that affect how, in this example, families experience the process; where professionals hold the power, parents experience disempowerment. This perpetuates the professionals as experts model, which can create a dichotomy between professionals with knowledge and families as having no knowledge, furthering unequal partnerships but also creating an expectation for professionals to know everything. This has been found to provoke anxiety and uncertainty in the practice of SENCOs about whether they know enough or are doing enough (Hellawell, 2018) and creating a culture of responsibilisation (Hellawell, 2019) where the individual is responsible for their own outcomes. This has been promoted under the label of autonomy, though this works better in some environments than others and can depend on school leadership teams and whether they focus on improving incomes for children and young people with SEND (Bernardes et al, 2015). Where there is good knowledge and practice this would be beneficial for children and young people but the change in policy does not necessarily mean a change in how it is experienced by families and professionals.

Core features of the SEND reforms have been found to be lacking in practice; early studies found the Local Offer for example to be of little or no value, with parents not aware of its existence (Bernardes et al, 2015). In some local authority areas, the Local Offer is 'unusable and useless' (House of Commons, 2019a, p.4) with the content dependent on the local authority (House of Commons, 2019a, p.24). The Local Offer and personal budgets have also been found to be 'paying lip service' (Hoskin, 2017, p.20) to increased control and choice rather than giving families meaningful choice and control in their own lives. The Local Offer is not delivering what was promised to families (House of Commons, 2019a), unfortunately appearing to exist more as a menu, where a family can only choose from options made available by the local authority, making it resource-led rather than needs-led. This moves away from the idea of aspiration and support, that the child or young person can outline their own aspirations and goals and receive support from education, health and care professionals to work towards these goals in ways that are meaningful for them, explored in depth in the next section.

Early findings also showed parents finding it difficult to navigate the system since policy reform (Bernardes et al, 2015), with young people getting to crisis point because parents were not being listened to about the support they need (House of Commons, 2020). This is contested however, with some parents and young people reporting general satisfaction with the EHCP process (Adams et al, 2017) though this differs by socioeconomic area- a larger percentage of families from lower socioeconomic areas report being satisfied with the process (Adams et al, 2017). In other research, there was a higher number of appeals brought to tribunal from families from higher socioeconomic areas (Bryant, Parish and Kulawik, 2022) suggesting that there may be inequality in representation of families from lower socioeconomic areas, and inequality in access to appeals processes. Parent capital and inequality will be explored within the Findings chapter.

There have also been issues with resourcing which affects the enactment of the reforms (Robinson, Moore and Hooley, 2018) with budgets not ringfenced or sufficient (House of Commons, 2019a) specifically affecting the ability of schools and professionals to meet children and young peoples' outcomes on their EHCP (Boesley and Crane, 2018). This resourcing issue has been linked to austerity (Hoskin, 2019) with funding decisions a result of ideological rather than financial choices, in the context of a financially difficult landscape for families. Even today, despite the pronouncement that 'austerity is over' (May, 2018) financial issues continue for families, in what is called a 'cost of living crisis' in the media (Independent, 2023) and by charities (Crisis, 2023) and the 'rising cost of living' in parliamentary documents (Harari et al, 2023). Again, evidence suggests that families with disabled children are among the hardest hit by this crisis (Krasniqi, Carr and Stevens, 2023) due to the intersecting of issues including the impact of rising inflation on household budgets, increased spending in families where children require specialised equipment or specific diets for example, disproportionate impact of rises in cost in gas and electricity on families with disabled children, impacts on parental employment in addition to the local authority budgets and related provision being impacted.

Besides the resourcing problems, issues have also been reported with accessing EHCPs at all- parents report long delays and being refused plans (NAS, 2021) and SENCOs report a lack of transparency in the decision-making processes at local authority level (Boesley and Crane, 2018) where families are denied plans or needs assessments. A significant number of families are having to appeal and/or go to tribunal to access needs assessments, or appeal against sections of the EHCP that they feel do not represent their child or their needs. In the last Ministry of Justice report, and as discussed earlier, there was a 24% increase in cases brought to tribunal in 2023 (14,000 cases) from the 2022 figures, with 98% of cases being won by families (MOJ, 2023). This rise in tribunal cases has been suggested to be due in part to a crisis in confidence in parents about the ability for mainstream schools to meet the needs of their child, and a 'golden ticket' narrative applied to parents in relation to the EHCP (House of Commons, 2019b) who are accused of using the EHCP to gain access to resources they or their child are not entitled to. It has also been described this way in other official publications (Ofsted, 2017; UK Parliament, 2020) as shorthand for a way of ensuring that children and young people are given sufficient, appropriate provision. It has also been linked to taking funding away from SEN support in schools (House of Commons, 2019b) thereby increasing the need for an EHCP to ensure children's needs are met, due to parent pressure and the need to 'achieve what they perceive as their child's right' (Marsh and Howatson, 2020, p.588). This portrayal has been criticised by parent-led groups and forums, for perpetuating narratives of parent blame (Smith, 2023) for increased requests for needs assessments and numbers of families going to tribunal. However, going to tribunal is described as a stressful process for parents (Cullen and Lindsay, 2019) and many parents report not knowing about the option to appeal or go to tribunal (NAS, 2021) despite it being a duty of the local authority to ensure families know about their right to appeal and where to get support to do this (DfE and DoH, 2015). Interestingly, appeals to tribunal are increasingly being brought against the content of the EHCP as opposed to refusal to carry out needs assessments or reassessments (Bryant, Parish and Kulawik, 2022), indicating issues at both 'plan' and 'process' level, as the findings of this study starkly document.

With these increasing pressures on the SEND system, rising numbers of EHCPs, and many local authorities already overspending on their budgets, the Education Committee made a call for the government to take action on these issues that are already well known about (House of Commons, 2020). The result has been a lengthy and delayed SEND Review green paper (HM Government, 2022), and a year later the associated improvement plan (HM Government, 2023). The focus of the green paper and improvement plan appears to be financial stability and future employment, though in relation specifically to the EHCP, reducing the number of children and young people with EHCPs (HM Government, 2023). A concern with a focus on reducing numbers of children and young people with EHCPs is that though this is proposed to be achieved with introducing national standards that govern practice with children and families alongside updating the SEND Code of Practice (HM Government, 2023), it risks losing sight of the individual (IPSEA, 2022) and potentially shifts focus to reducing numbers of EHCPs rather than supporting individuals to work towards their aims and aspirations. This proposal has been criticised as being too focused on finances at the risk of the rights of children and young people (ALLFIE, 2023).

The idea of a standard, digitised, national template for the EHCP was also a focus in the improvement plan (HM Government, 2023). This been welcomed by some (IPSEA, 2022; SEC, 2022) though with the proviso that digitisation will not necessarily improve the quality of EHCPs (SEC, 2022) so this would still need to be a focus. Similarly, whilst standardising the EHCP may eliminate some of the poorer quality examples, it might also risk the more creative, person-centred plans that have been produced by families and professionals working together. Others have suggested creating best-practice guidelines and ensuring more of a focus on accountability (Bryant, Parish and Kulawik, 2022) though there is still dispute over where the accountability should lie; with the local authority decision makers (IPSEA, 2022) or schools and settings (Bryant, Parish and Kulawik, 2022).

The government's improvement plan (HM Government, 2023) resulting from the SEND Review with the aim of overhauling the SEND system also commits to reducing adversarial, frustrating and costly processes for families, improving mediation processes, making it clearer about what should be provided to children and young people and who is responsible for resolving issues in the complaints and appeals process, with an aim to reducing the number of families who have to go through tribunal (HM Government, 2023). 'Adversarial' was a word used pre-SEND reforms when asking parents about the process of accessing support for their child (OFSTED, 2010) and again in the SEND Review (HM Government, 2022) showing that this is a long-standing issue, not necessarily improved by the reformed legislation. A concern with the focus on lack of clarity in the system is proposed by IPSEA (2022) who state that there is not a lack of clarity but a lack of accountability, and focusing on clarity risks the process becoming more adversarial rather than less, again, as the findings of this study reveal.

With most commitments timetabled for 2025 onwards (HM Government, 2023), with no significant change in legislation to underpin these changes, a lag in implementation, and now a 2024 change in government, there is still value in assessing the current system and how families experience it. The next sections will explore research in key principles underpinning current legislation (as well as the improvement plan 2023); aiming high, collaboration and co-production.

Aspirations

Raising expectations and thinking in an aspirational way for disabled children and young people has been a feature of English policy for decades now, as detailed in the previous chapter. However, the focus in some of the key documents underpinning these ideas is on improvement in productivity and economic growth (DfE, 2011). Focusing on productivity and economic growth is a suggestion of a neoliberal, marketised system that values perceived ability to contribute, which can place children with SEND at risk of being viewed as ‘non-marketable commodities’ (Blackmore, 2000, p.385). Rather than raising aspirations for and valuing pupils with SEN, this risks devaluing them and does not support their inclusion, for fear that school statistics would suffer (Duncan, 2003) with implications for school budgets and league table performance. Neoliberal underpinnings suggest a move back towards medical model thinking, with individuals responsible for their own societal contributions and functioning. Ableism has also been linked to functionalist body management perspectives in what has been termed neoliberal-ableism (Goodley, Lawthom and Runswick-Cole, 2014), the term under which neoliberalism and ableism ‘feed off each other’ to produce high levels of personal responsibility and low levels of state support (Scavarda, 2024, p.3). This has also been described as responsibilisation, whereby the individual is responsible for their own outcomes, and where they are not met, this is due to individual rather than systemic failure (Hellawell, 2019).

There is an argument here about what it is to be aspirational; whether this means that all children and young people should be aiming for the same goals and outcomes, or whether an individualised approach should be taken. This represents a dilemma for the planning of aspirations; if a normalised approach is taken, all children and young people aim for the same outcomes, ignoring individual preferences, capabilities and overlooking the reality of the support available. These norms often centre non-disabled people and their realities, creating ableism (Campbell, 2009); a bias towards paid work in the support young people get in planning for their future in their EHCP has been found for example (Robinson, Moore and Hooley, 2018). On the other hand, rejecting ableist norms risks depriving disabled children and young people from aiming for many of the goals that they may want to achieve. The research shows that many disabled children and young people seek the same outcomes as their peers; in education, training, employment, leisure time, a family, their own home (Sayce, 2011; Hoskin, 2019; House of Commons, 2019a; Goodley and Runswick-Cole, 2016; Darling, 2003). In this wider sense, it is important not to ignore some ableist ideals, because to do otherwise is to risk sacrificing a healthy life or general wellbeing (Goodley, 2014). In embracing these ideals, the support that may be needed to achieve them will differ from person to person and disrupting those 'normative notions' (Goodley and Runswick-Cole, 2016, p.13) is key in ensuring that even if outcomes are normalised, the support needed to work towards them will need to be individualised. This would ideally move away from having an individual, neoliberal approach to whether or not these outcomes are met.

When considering norms and normative notions, it is important to consider what is 'normal'. Waldschmidt (2018, p.192) considers the idea of 'flexible normalism' whereby what is perceived as 'normal' is shifting and changing; in modern society there is more room to be different, normal does not always have to mean conformity. There do still exist, however, normality boundaries that should not be crossed (Waldschmidt, 2018). These boundaries often exist around dependence and independence, whereby the people are positioned as lesser because of their dependence upon another person (Tisdall, 2012). For children this is often their parents or other adults, and for disabled people- non-disabled people. Often, lives worth living are seen to depend on expressions of normality like independence and ability to reason, areas which can exclude learning disabled people (Taylor, 2018). Young people can also experience expectations like independence as disabling, and it is the expectation that disables them, not their impairment, according to Swain and French (2000). Goodley (2014) encourages examination of aspirations for children and young people and whether they are aspirational enough, or whether practitioners are supporting children and young children to settle for existing support services and models of lives that are able to be lived, within these existing systems. The question here is whether having high expectations and aspirations for disabled children and young people is fair if the system does not support them to work towards and achieve them. This is challenging where expectations and aspirations are poorly expressed in support plans, or are not appropriately clear, as I reflect on in the Findings chapter.

Historically, with functionalist and medical models of disability, the individual condition is why the person is seen to be disabled and this is considered a ‘personal tragedy’ (Best, 2005, p.87). This links again to neoliberal ways of viewing the body as a personal responsibility, and casts disabled people as deviants (Sewell, 1981) as they are not able to perform their social role or duties (Parsons, 1951). It also links to humans as potential labour or productivity, with disability representing a threat to this. Finkelstein (1991, p.29) states that disability has ‘come to mean unable to work’ which constructs the impairment as rendering the person as unable to fulfil their labour role in society. The idea of socially constructed bodies is disputed and has a range of perspectives itself (Shilling, 1993) but can generally be seen as shifting and changing, linking physical elements to a wider regime of truth (Foucault, 1980) about what it means to have a body that looks or behaves in a certain way. These strong, normalising narratives, still visible in today’s media and public attitudes (Garthwaite, 2011; Hurst, 2019) that impact both children and young people with SEN and their parents, with parents who claim welfare assistance subject to harmful rhetoric around who is deserving and who is undeserving (Patrick, 2016). Constructions of worthiness of support form a dichotomy, “shirkers and scroungers” (Garthwaite, 2011, p.369) versus workers; strivers (Cameron, 2012) versus skivers, which continues to permeate society’s view of disabled people, contributing to demonisation (Ryan, 2019) based upon body function, ability to work or allocation of support or services. For children and young people with SEN, this is visible in budgets to meet SEN not ringfenced but used on other areas, with SEN seen as an area where local authorities can save money (House of Commons, 2019a). This is also seen in earlier Codes of Practice which mention obtaining the best value for the ‘considerable resources and expertise invested in helping children with special educational needs’ (DfES, 2001, p.III), leaving an impression of presumptions about who is worth spending money on and who is not. This can mean in practice decisions made based on financial considerations, rather than in the best interests of the child or young person (Hellawell, 2018).

Worthiness in terms of spending is also visible in harmful reforms to state welfare systems, described as creating a form of ‘psychological tyranny’ (Stewart, 2018, p.579) towards disabled people having to go through repeated assessments of their function, carried out by contractors who often have no knowledge or understanding of their condition (Mind, 2023) and no access to their medical records (Stewart, 2018). These repeated assessments create an air of suspicion around disabled people (even from other disabled people (Patrick, 2016)) and a culture of surveillance of their condition and function, as Stewart (2018) powerfully asserts; ‘reforms to social welfare policies allowed preventable harm by the State to creep into disabled people’s lives’ (Stewart, 2018, p.579). For families of disabled children or those with SEN, this welfare system can also lead families to have to ‘over-emphasise’ their child’s impairments to ensure that they are eligible for government support (Goodley and Runswick-Cole, 2011) creating exaggerated or false narratives, or the onus to ‘perform’ disability in order to be taken seriously or qualify for support, whether or not this forms part of their own identity.

In a move away from deficit models, Swain and French’s (2000) proposal for an affirmative model of disability encompasses identity, expression and the benefits that disability can bring. Benefits they suggest include escaping oppressive societal expectations and norms, and a greater capacity for understanding the oppression that other people face (Swain and French, 2000). The affirmative model is borne out of rejecting the idea of disability and impairment as a personal tragedy and focusing on the benefits and positives of disabled identity. The authors also move past the ideas of the social model, which they state just redefines ‘the problem’ and towards disability being about ‘a positive personal and collective identity, with disabled people living fulfilled and satisfying lives’ (Swain and French, 2000. P.571). Affirmative models of disability should not remain in the academic sphere but instead be grounded in practice and interactions with disabled people and their families. McCormack and Collins (2011) consider how affirmative models can be incorporated into healthcare practices for example; their focus is occupational therapy, traditionally a medical field with potentially normalising approaches that could alienate the individual. They suggest that to put the person at the centre of practice, there should be consideration of disability orientation (McCormack and Collins, 2011). This moves identity and self-understanding to the centre and requires practitioners to have knowledge of the ways that disability can be constructed and experienced. Arguably a blanket move towards affirmative approaches is to also make assumptions about an individual's relationship with their impairment and or disability- that it can be experienced positively- which could potentially alienate others. However, the heart of these models is rejection of the assumption that impairment and disability is automatically a tragedy especially where the power to label it as such lies with non-disabled people.

More recent examples of affirmative models are intertwined with self-advocacy movements which contribute to significant shifts in the way that a diagnosis or condition is conceptualised and discussed. An example of this is in autism discourse; autistic people redefining the way autism and autistic people are discussed and represented. This has been particularly visible in the shift from discussing autism as a disorder that brings deficits and is addressed with normalisation strategies, to the use of the neurodiversity paradigm as a core concept (Leadbitter et al, 2021). The neurodiversity paradigm (in opposition to a medical or pathology paradigm) positions autistic people as in the neurocognitive minority on a spectrum of neurodiversity, acknowledged as neurodivergent from neurotypicality (Walker, 2021). This move to acknowledging autism as a form of neurocognitive difference rather than a deficit builds upon the shift from autism as an acquired disorder to a (not inherently negative) part of a person's identity. There is still a way to go here in terms of the power to influence practice and action however; research by Autistica (2016) sought the views of autistic people about what autism research should focus on, finding the majority wanted research to focus on concerns around how autistic people can be understood and supported. The issues that autistic people would want to be researched however do not always map with the research that is actually carried out, the majority of which is focused on biology, brain and cognition (Pellicano, Dinsmore and Charman, 2014). Generally, the shift that can be observed is towards affirmative models that centre and amplify the voices and lived experiences of those defined by the discourse, though not all areas of society are at the same point, especially when it relates to disabled children, as I reflect on further in the Discussion chapter.

Foucault and Research in Special Educational Needs

Though commonly used in the fields of education and health more broadly, elements of the work of Foucault have also been used as the theoretical basis for the work of researchers in Special Educational Needs before, though not specifically in relation to the Education, Health and Care Plan. Closely aligned with this research and as discussed in chapter 1, Allan (1996) used Foucault's technologies of discipline to explore the process of identification, assessment and education for pupils with SEN. This included a specific focus on madness, medicine and discipline, as Allan's (1996) chosen Foucauldian tools. She concluded that Foucault's work could be used to better understand and improve pupil experience of SEN assessment and education. Similarly, McKay (2014) used regimes of truth and Foucault's theories of disciplinary power and governmentality to explore the participation of children and young people with SEN in decision-making processes in education. Like Allan, McKay uses her own selection of Foucauldian tools, though neither consider the EHCP process specifically because it had not yet been introduced when the papers were published. Perhaps because of the difference in dates between the papers, Allan's (1996) paper discusses medical and deficit gazes in more depth, where McKay's (2014) paper discusses a more participatory discourse and the construction of the 'participating child' (p.761). Both authors conclude that elements of Foucault's work can be useful in theorising this area, with slightly different foci.

Family roles and experiences of accessing facilities and support

This section examines the involvement of children, young people and parents in accessing and planning support as general principles and as seen in research before the implementation of the EHCP.

Child involvement in decisions and Person-Centred Planning- process

The principle of involving children in decisions made about their lives, and specifically in planning for their futures as the EHCP is supposed to do, is rooted in person-centred planning. Person-centred approaches are said to be; 'based on deep listening to discover what is important to people, what support they need, and their hopes and dreams for the future' (Sanderson, Thompson and Kilbane, 2006, p.22), similar to language which appears in the more recent SEND Code of Practice (DfE and DoH, 2015). In this sense, for person-centred planning to be truly person-centred, it needs to begin and end with the person, their hopes, aspirations and preferences, and for these to be genuinely listened to by the professionals in their life. Professionals need to be prepared to listen to and learn from children and young people in person-centred practice (Scott, 2021). Being person-centred means moving away from template thinking and instead, employing creative, thoughtful and crucially individual-led ways of listening and learning. Examples of this could include school staff engaging in ongoing discussions with families about what works for them, children and young people making videos to share with staff and trialling different ways of sharing their views, or even leading staff meetings about what can be supportive (Scott, 2021). Core to this concept is the idea of participation, inclusion or involvement. For practice to be person-centred, it needs to be driven by, and fully engaged with by the child or young person supposedly at the centre.

Person-centred approaches have been found to be beneficial in the literature, when employed meaningfully; having person-centred reviews created more of a sense of being listened to (White and Rae, 2015) by families. Person centred approaches are also considered key to developing metacognition and self-regulation (Scott, 2021) with the child or young person supported with these approaches to understand themselves, how they learn and engage, and what implications this has for their outcomes and support. Improved social and emotional wellbeing have also been seen from using person-centred approaches, in addition to a greater involvement of young people in planning for their transitions (Corrigan, 2014). Person-centred approaches can also move away from normative approaches, for example, adulthood as the 'gold standard' (Tisdall, 2012, p.181), seeking to understand and listen to the individual in a way that makes sense to them rather than expecting them to meet adult and non-disabled norms.

However, there are also some barriers and complications documented in the use of person-centred approaches, for example, a young person reporting feeling overwhelmed by being at the centre of a person-centred meeting, having too many questions asked of them (Corrigan, 2014). Person-centred approaches can also require significant structural changes (Adams et al, 2017), training and resources (Corrigan, 2014) which, within a system already under strain, may not be available, much less, prioritised. Person-centred reviews should not be considered a fix-all for involvement, and do not themselves improve choices and outcomes for individuals (Kaehne and Beyer, 2014), especially when professionals do not attend or when discussions are not followed up (Corrigan, 2014).

There are levels at which children and young people are included or involved in decisions made about their lives; in a medical context, Alderson and Montgomery (1996) suggest levels ranging from being told that something is happening, to being the ‘main decider’ (p.63) in the process. Similar research exists in children’s rights; most well-known is an adaptation of Arnstein’s ladder of participation (1969, cited in Hart, 1992). Hart proposes non-participatory rungs; manipulation, decoration and tokenism, through to differing degrees of participation; assigned but informed, consulted and informed, adult initiated but decisions shared with children, child initiated and directed, to child initiated and shared decisions with adults (Hart, 1992). This has been used in many varying fields, though the author warns against understanding the ladder as a set of stages, as a prescriptive method for including children, or indeed considering that the higher the rung, the better (Hart, 2008). The value of having models such as this is in the ability to adapt them to suit the individual, to use them to understand meaningful and appropriate ways to support children to be involved in decisions made about their lives.

There have long been barriers to the inclusion of disabled children in decisions made about and for them in general, that include lack of knowledge about how to support them to engage in processes, as well as few resources to facilitate this (Gough et al, 2014). Much of the research in this area has concerned the involvement of children and young people in their healthcare decisions, though important lessons can be learned from these findings. In the medical context, Taylor et al (2010) researched parents’ views on the involvement of children in consultations with their doctor and found there were varying opinions on the level of involvement that children should have; sometimes it was seen as more appropriate for parents to share certain information with their children rather than for the professional to do so. This can also represent a barrier, where parents do not want their child to be involved in a particular consultation. Psychologists have also reported having difficulty explaining what was happening in appointments and why, in a way that the children would understand, which led to the children feeling disempowered, and unable to voice their opinions (Galloway et al, 2013). In this study, children undergoing an assessment generally had very little understanding of the assessment process, and the decisions made about their lives (Galloway et al, 2013) which will impact upon the way they are able to engage in the process and how much they are listened to.

This needs to be contextualised, and children's understanding and capacity to understand discussions and decisions has to be taken into account, or as Lansdown (2005) suggests, the idea of evolving capacities, based on article 12 of the UNCRC- the right for children to express their views and have these taken into account depending on their age and or maturity (UN, 1989). An issue with this concept is that adults are responsible for deciding whether a child or young person is capable of expressing a view and how far this is listened to in practice, which can negatively impact for example, very young children (Wall et al, 2019) or in this case, disabled children. This means that adults can represent a barrier to the involvement of disabled children in decision-making processes (Franklin and Sloper, 2009) because of the presumption that they are not able to contribute. However, evolving capacities in terms of participation prevents a dichotomy that would construct children as either competent and able to contribute (or even be responsible for decisions), or non-competent and not able to be involved (or even ignored) (Alderson and Montgomery, 1996).

Despite this being an area of priority in policy relating to education and SEN, disabled children have still been less likely to be involved in decisions about their own lives than non-disabled children (Franklin and Sloper, 2009). This is perhaps due to a 'double jeopardy' effect (Byrne, 2012; Lansdown, 2005); the views and voices of children have been historically excluded or ignored (Clark et al, 2014) as have the views and voices of disabled people, even in issues concerning their own lives (Shakespeare, 2014). The result is that disabled children and young people are under-represented in the plans that outline their provision in education, health and care, as well as in research evaluating these areas. This is what I would describe as ‘dual layer under-representation’ rather than attributing the problem to the children and young people themselves; further acknowledgment of the social model and relocating the problems into society, and considered in the Discussion chapter.

There is also an even more serious impact to breakdown in partnership and inclusion, and a wider scope; Mencap (2007) presented findings that unveiled failings in the acute care of learning disabled people. This outlined the failure of health professionals to take into account the wishes of the parents of the patient, as well as ignoring verbal and non-verbal communication from patients themselves, leading to fatal outcomes (Mencap, 2007).

There needs to be a balance between the contributions from parents and contributions from children and young people themselves; in some cases it can be important to triangulate information from children with parents, where there is a possibility of receiving partial or factually incorrect (though not worthless) information (Preece, 2002), or where different information is received from parents and young people (Colver, 2010), or where the young person’s views differ from both parent views and professional views (Corrigan, 2014). Tates and Meeuwesen (2001) recommended further qualitative study into the role of the child in medical consultations, and supported a triadic model of participation, with doctor, parent and child as partners, also described as a tripartite model (Alderson and Montgomery, 1996). Much of the research published on interactions between doctor, parent and child (not specifically those who were disabled) described dyadic interactions (between parent and medical professional) where triadic interactions were concluded to be the best practice model (child, parent and medical professional) which illustrates that many children are left out of these discussions, not just disabled children (Tates and Meeuwesen, 2001). Children are not viewed as equal partners in these interactions, and there is great variability in participation between cases (Garth, Murphy and Reddihough, 2009). This shows the precarity of the child’s power in these situations and how contingent it is on powerful others. As Benson (2014) argues;

> ‘it is essential that policy-makers and practitioners strengthen their collaboration with children, families and communities to find evidence of what they want’ and ‘prioritise children’s voices and perspectives’ (Benson, 2014, p.52).

This supports the principles of person-centred planning and the idea of deep listening (Sanderson, Thompson and Kilbane, 2006) to understand the child or young person and their family and the outcomes they want to work towards, rather than what professionals think they should be working towards. Of course there is a balance; the UNCRC (UN, 1989) and the UNCRPD (UN, 2007) also emphasise taking action in the best interest of the child, ensuring their welfare and development are promoted and protected, however, this should be alongside families, rather than against them where possible. The process of carrying out an EHCP assessment and creating the plan is described as 'person-centred' (DfE and DoH, 2015 s9 ss23) and I explore the research on this in a later section.

Parents as Partners

Working with parents has been shown to positively impact children's educational outcomes (Desforges and Abouchaar, 2003) as well as increasing positive outcomes for children and young people in health-based research (Colver et al, 2019) though there has long been debate around what this looks like in practice. The role of parents in their child's education has been subject to fluctuations, and linked to shifting governmental ideologies (Duncan, 2003) and priorities. In 1967, the Plowden Report promoted parental involvement in their child's education in relation to all children, showing how it can be positively impactful, with examples of good practice, including parents being encouraged to give information to teachers to support with their child's education (Plowden, 1967). This was developed in a more significant way in the Warnock Report (DES, 1978) with parents recognised as partners in educating children, and specifically for children with SEN, given the right to contest their child's proposed Statement of SEN under the resulting 1981 Education Act. The inclusion of parents in the assessments that professionals were undertaking was tokenistic and concerned 'maximising the effectiveness of professional interventions' (i.e. using parents as tools to aid in the intervention) (Galloway et al, 2013, p.69) rather than engaging them meaningfully in order that they could contribute and make informed decisions about their child's support. The rights of children with SEN and their parents under the 1981 education act has been described as a privilege rather than a right (Barnes, 1991), and dependent upon the professionals involved. Sewell (1981, p.176) stated 'parents who can be trusted to be 'intelligent' and 'not make a fuss' are offered 'performances' in the name of partnership' though ‘It is possible for those who possess inside knowledge to resist’. This created divides among parents, those who are deemed to have the characteristics needed to qualify as good enough to be a partner (though in name only) and those who do not, and therefore results in inconsistencies in family experiences of the reality of these developments. This also suggests that there are differences in parent knowledge and involvement that can be linked to how well they are able to navigate the system, as I return to in the Findings chapter.

Under the Special Needs and Disability Act 2001 (DfES, 2001b) further efforts were made to include parents in a more meaningful way; before a Statement of SEN was finalised, a copy of the proposed Statement of SEN was required to be given to the child’s parent, though there is still not the involvement or engagement that would be expected under a partnership model. The development of parental role in education was further scrutinised by the findings of the Lamb Inquiry (2009) which found low levels of parental confidence in the systems for supporting disabled children, creating ‘warrior parents’ (p.2) in conflict with professionals, with parents positioned as the problem.

The partnership model, lauded as an ‘unquestionable ideal’ (Hodge and Runswick-Cole, 2008, p.638) was supposed to reduce the adversarial experiences of parents, and reduce conflict, however where there is a lack of clarity in the policy governing these relationships this can itself create further conflict (Hodge and Runswick-Cole, 2008) as there is no clear guidance on what this model entails or should look like in practice. There are many perspectives on what partnership with parents should look like, and models that depict varying levels of engagement and participation; Hellawell (2019) outlines a summary of models of working in partnership with parents in figure 4 below.

Model	Description
Expert Model	Parents receive information from expert professionals. Professionals make the decisions; parents are not active agents or involved in making the decisions.

Transplant Model	Professionals pass on knowledge and advice to parents and parents implement it.
Informant Model	Parents act as informants, passing on knowledge to professionals to input into professional decision-making.
Empowerment Model	Professionals determine the boundaries of the partnership but both parties are involved in decision-making.
Consumer Model	Professionals pass on information and available options to parents so that parents are able to make informed decisions.
Negotiating Model	Roles in the partnership can be negotiated and interchangeable, but decisions need to be agreed upon by both parties
Dual-Expert Model	Professionals and parents have separate and differentiated roles, contributing expertise on each side which is valued equally.

Figure 4: Hellawell's (2019) partnership models

The first three models are not necessarily representative of partnership working, as they position parents in a deficit way (Hellawell, 2019) and privilege professional knowledge, whilst the latter four show a more devolved power structure in partnerships that construct parents as capable and valued. The findings of this study indicate that many families are still experiencing ‘partnerships’ that privilege professional knowledge and do not include parents in decision-making processes, as I reflect on further in the Findings and Discussion chapters. Families have long experienced deficit-based and harmful constructions that impact the relationships they have with professionals; Wilde and Hoskinson-Clark (2014) searched ‘disabled family’ on the internet and were shown mostly resources related to medicalised understandings of disability in which families were constructed as ‘a problem in need of special help’, ‘dependent and deviant’ (p.56). What parents do at home can be seen through a deficit lens by professionals- i.e. what they are not doing or providing (Callan and

Morrall, 2009), with the concept of parenting becoming increasingly governed (Goodley and Runswick-Cole, 2011) and subject to enhanced scrutiny. This scrutiny could be due to overarching cultural understandings of what it is to be a ‘normal’ parent or child (Wilde and Hoskinson-Clark, 2014) and families needing to fight to reframe these constructions; ‘Families are more than a collection of ‘needs’ reliant on outside sources to ‘repair and fix’’ (Holland and Pell, 2018, p.407). These deficit models of parents have been seen in earlier statutory guidance too, with Hodge and Runswick-Cole (2008) identifying that in the SEN Code of Practice (DfES, 2001a) that parents are positioned as informants rather than partners. They also find a suggestion that parents might need help to see their child as a partner in their education, with no suggestion that professionals might also benefit from support in seeing children or their parents as partners (Hodge and Runswick-Cole, 2008). This also links to the construction of ‘parent as oppressor’ found by Ryan and Runswick-Cole (2007, p. 201) that sees parents limit their child’s experiences and involvement. This constructs families in a deficit way again, in need of help to value their child, with scrutiny on the parent-child relationship.

This scrutiny in addition to the government focus on improving parenting can be viewed as having elements of parent blame (Holland and Pell, 2018) which feeds into the culture of individual responsibility for a child produced by neoliberal society (Scavarda, 2024). This creates blame around disability placed at the feet of parents, or as Scavarda (2024, p.1) describes it, a dual ‘shame-blame complex’ for parents. Again, there is resistance to these depictions from families, but great difficulty in trying to escape them (Scavarda, 2024) which resonates with the findings of this study. Stigma is seen here to be multi-level for parents of disabled children; individualised shame in micro-interactions and structural blame in system-level power dynamics (Thomas, 2021; Scavarda, 2024). The implications of this for families is despite resisting being constructed and interacted with in these ways, there are still deeply entrenched shame-blame mechanisms working against them in their interactions with services and professionals who are supposed to be there to support them and their families. This means parents of disabled children themselves face surveillance from professionals (Read, 2001, cited in Goodley and Runswick-Cole, 2011) exclusion (Pratesi and

Runswick-Cole, 2011) and discrimination (Ryan and Runswick-Cole, 2007) based on these constructions and resulting dynamics.

Parents have experienced other barriers to involvement in their child's education. In addition to the privileging of professional knowledge and the dismissal of the knowledge the family holds, as discussed above, parents have described unequal power dynamics with school staff, for example, parents perceiving SENCOs as having power in these partnerships which can impact the way that they are able to work together (Green and Edwards, 2021), and parents experiencing inequality in involvement in person-centred planning for their children, even within the same programme (Darrah et al, 2012). This can lead to parents giving up (Green and Edwards, 2021) or becoming 'warrior parents' (Lamb, 2009, p.2), fighting for what they feel their child is entitled to, as I reflect on in the Discussion chapter.

Parents have long faced negative constructions when seeking support for their child; in relationships with professionals; as delusional (Ryan and Runswick-Cole, 2007), 'over-emotional or ill-informed' (Hodge and Runswick-Cole, 2008, p.645), and especially where parents themselves are disabled- constructed as 'difficult' (Wilde and Hoskinson-Clark, 2014, p.57). This is a common theme in literature exploring families who are seeking support for their child, with a number of negative stereotypes existing about families who feel they have to fight for support for their child (OFSTED, 2010) and continued use of the language of warfare to describe the relationship between families and schools (Duncan, 2003) for example, battle, ally, adversary, and also to describe the process of getting support for their child; 'in the trenches' (Runswick-Cole and Ryan, 2019). This is understood as a necessary fight in systems that do not work, or for limited resources (Jones and Swain, 2001) to secure support their child is entitled to by right (Lamb, 2009). This has also been found to be a source of guilt for parents, not wanting other children to lose out in the fight for their own child to receive what they are entitled to (Jones and Swain, 2001), showing the level of emotional involvement and empathy parents have in the process and indeed, as are important themes in the findings from this research.

In practice, parents have reported feeling like their views have not always been valued, for example, where they are participating in an annual review meeting for a Statement of SEN (Jones and Swain, 2001) despite rhetoric to the contrary in policy and statutory guidance.

Mothers

Due to prevailing gender roles and patriarchal constructs in the Global North (Best, 2008) mothers have traditionally been the ones constructed as most suitable for caring roles. This means that often the blame-shame complex (Scavarda, 2024), discussed above, can be focused in the main on the roles and responsibilities of the mother. There has been a particular focus on the role of mothers of disabled children in research, considering the way mothers are constructed and their role in seeking support for their children. Mothers of disabled children have been constructed as ‘feckless scroungers’ for claiming welfare support (Runswick-Cole and Ryan, 2019, p.6) and for having children that present or potentially present a burden to society (Runswick-Cole and Goodley, 2018). Mothers have also been constructed as responsible for ‘fixing’ their child (Runswick-Cole and Goodley, 2018) and often have to take on responsibility for campaigning for not just support resources but also recognition that their child deserves recognition as a human with value (Runswick-Cole and Ryan, 2019). This has also been phrased as mothers of disabled children not only having to socialise the child to be accepted in the world, but also having to socialise the world to accept the child (Kittay, 1999).

The mother-child dyad has been the focus for surveillance and intervention (Runswick-Cole and Goodley, 2018) with both mother and child constructed as problems that require monitoring and fixing (Ryan and Runswick-Cole, 2007) in line with medical model understandings of disability, and exclusionary practices. Mothers of disabled children are made to take on a challenging dual-role that requires the mother to be both worker (societal contribution) and carer (an enactor of interventions), with both roles undervalued and with low or no pay (Runswick-Cole and Goodley, 2018). This role of the mother of a disabled child represents a large amount of work that limits her other activities and can end up covering activities that are more representative of what professionals would be doing (Traustadottir, 1991) but without the credibility that professionals would have (Ryan and Runswick-Cole, 2007). This credibility is also devalued by being addressed as ‘mum’ in professional interactions, devaluing their role, knowledge and information, as well as undermining their name and identity (Nimmo, 2019). Resistance to this devaluing practice led to a parent-led initiative called ‘don’t call me mum’ whereby professionals are requested to call a parent by their name rather than address them as ‘mum’ or ‘dad’ in meetings (Wright, 2016). This recognises the knowledge and expertise that parents bring to discussions about their child, including any professional knowledge that they may have. Gender issues were raised by participants in the research and will be considered further in the Findings and Discussion chapters.

Having discussed these core concepts in relation to the literature in the field in general, it is now important to consider how these concepts have been experienced specifically within the process of creating an EHCP. The next sections situate collaboration and co-production in the EHCP process and analyses the research that has been carried out in this area.

Collaboration and co-production during the EHCP process

Given that in this research I explored the roles and experiences of families in the EHCP, it is crucial to discuss the concepts of collaboration and co-production specifically within the EHCP. There are overlaps and similarities in the concepts, but they have been described almost separately in the legislation and statutory guidance governing the EHCP (DfE and DoH, 2015). Several of the core principles discussed above come together to underpin the concepts of collaboration and co-production for the EHCP: person-centred planning, parents as partners, collaborative or multi-agency working, inclusion of children and young people in decisions made about their lives.

For the EHCP there are different areas of involvement, including a planning meeting or review meeting (annual review), discussions and decisions on outcomes and provision, and input into the plan itself. According to the SEND Code of Practice (DfE and DoH, 2015) families are supposed to be at the centre of the process, with their needs considered carefully at every stage, with professionals forming a team that works around the child or young person and their family at the centre. These concepts have evolved from practices in related fields, namely in safeguarding children and child protection (Team Around the Child, Multi-agency working). It is important to consider whether there are differences between family-centred provision and co-production (Boddison and Soan, 2022), the emphasis on co-production being the active involvement as an equal partner, with families as active agents rather than at the centre of decisions being made for and about them.

As observed by Boddison and Soan (2022), co-production has been written about in the SEND Code of Practice (DfE and DoH, 2015) but the word 'co-production' does not feature at all in the Children and Families Act underpinning this (DfE, 2014a), nor does the word 'partnership' in relation to families, leading to what Boddison and Soan (2022) describe as a 'co-production illusion' (p.91). Whether families are seen as part of the team working together to co-produce the EHCP or in the centre with a team of professionals working around them to produce the EHCP will therefore depend on the professionals working with the families and the partnership model they are using.

Co-production means there is a meaningful, equal partnership between families and professionals in decision-making for children and young people (Boddison and Soan, 2022) however there are issues with the concept of co-production, firstly with the understanding of what this should entail, and secondly with putting this into action. Co-production has been understood in different ways by local authorities too, distinguishing between tokenistic co-production (recognising a problem, finding a solution and then running this by families) and more meaningful co-production (sharing a problem at an early stage, working to understand and solve the issue together) (Bryant and Swords, 2019). Where children or young people have an EHCP, there are often multiple professionals involved in their support, through education, health and social care, and from the local authority, and in addition to partnering with parents and families, professionals need to be able to functionally work together or collaborate. These two principles; co-production and collaboration are often viewed separately, with one agency engaging in co-production with families (often the SENCO), so there has been some call to look for opportunities to engage in multi-agency co-production (Bryant and Swords, 2019), bringing the principles together to ensure professionals and families work together across the process.

Collaboration

A key principle identified in the SEND reforms is collaboration between education, health and social care services to provide effective support for children and young people to achieve their outcomes on their EHCP (DfE and DoH, 2015). This should take place on different levels; local authorities must work together from a commissioning standpoint, to understand the range and level of need in their area, and also work alongside health bodies to ensure services are commissioned jointly for disabled children and young people (DfE and DoH, 2015). This should also operate at individual level (Hellawell, 2018), meaning decisions at local authority level in the cases of individual children and young people.

Local authorities also have a duty under the Children and Families Act (DfE, 2014a) to ensure that services work together for improvement of children and young peoples' wellbeing and outcomes, which includes education, health and social care services and professionals. Collaborative working is not without criticism and discussion (Goodley and Runswick-Cole, 2011); and can be impacted by for example the quality of interactions that take place between professionals. Other barriers to working together are poorly defined roles in the process, lack of time or training, poor leadership (Cochrane and Soni, 2020) and unclear language, 'cooperation' 'collaboration' or 'coordination' used interchangeably, which can mean there is a lack of clarity over the processes (Boddison and Soan, 2022) and the roles that individuals take within these processes.

The purpose of working collaboratively between services in this area is to ensure provision is joined up, and to ensure that parents are not excessively burdened by the administrative and functional elements of the process (Ahad, Thompson and Hall, 2021, p.3). Where professionals worked together collaboratively, parents reported higher levels of satisfaction with the overall process (Sales and Vincent, 2018). Professionals working together has also been shown to have a positive impact on the clarity of outcomes and provision in the EHCP (Castro-Kemp et al, 2021), key to ensuring a quality plan.

However, there have been issues identified in literature about the ability of professionals to work together in creating the EHCP; SENCOs and school staff have reported difficulties in getting information or support from other professionals (Cochrane, 2016; Richards, 2024), and getting reports for the EHCP back on time (Tysoe, Vincent and Boulton, 2021). Issues have also been reported with the annual review meetings and the difficulty of getting professionals together for this (Sales and Vincent, 2018; Boesley and Crane, 2018), especially where these are external professionals from health or social care (i.e. outside the child or young person's educational setting). These findings have been corroborated by research findings with local authority leaders, who acknowledge that there are issues with buy-in from health and social care services, and a dependence upon education services (Bryant, Parish and Kulawik, 2022) to keep the process moving. More research is needed to explore broader professional perspectives, as much of the research already done has focused on SENCO experiences (Ahad, Thompson and Hall, 2021), with little done specifically about how professionals work with families, or how other professionals experience the system. This also extends to family perspectives of collaborative working, and whether this is understood as a team working collaboratively *around* a family, or as a team working collaboratively *with* a family, to co-produce the EHCP, its outcomes and provision.

Co-production in the EHCP- Family and child involvement in creating the EHCP

There has been a small amount of research carried out that examines the roles of parents, children and young people in the EHCP process from their own perspectives, as most has been carried out to examine SENCO perspectives on involving parents in the process. Co-production, whilst mentioned heavily in the SEND Code of Practice (DfE and DoH, 2015) is not mentioned in the Children and Families Act (DfE, 2014a), instead language such as involving or informing parents is used (Boddison and Soan, 2022). Parental involvement requires ensuring that parents have sufficient knowledge about the EHCP process and plan so that they are able to meaningfully contribute to (and co-produce) the EHCP, however this has been found widely in research to be an issue, with many professionals and parents reporting low levels of knowledge about the EHCP process and plan (Cochrane, 2016; Redwood, 2015; Skipp and Hopwood, 2016). There are conflicting findings about the levels of professional knowledge about the process, with some parents reporting that professionals have a low level of knowledge about the SEND reforms and processes (Hoskin, 2019) and others finding only 9% of families reporting that professionals did not have enough knowledge to support them in the EHCP process (Adams et al, 2017). Studies that have included professional views have found that SENCOs feel like they are doing most of the work (Gore, 2016) including sharing information with families about the process, guiding them through it and managing their expectations. There are clear themes within this area, but the findings do not always support each other's conclusions. Though progress has been made in this area in making involving families a statutory duty and has been seen in the experiences of some families and professionals (Cullen and Lindsay, 2019; Redwood, 2015), co-production has consistently been found to be absent or poor in local area OFSTED inspections (OFSTED, 2021) however there is a difference in findings between families and professionals and still reference is made to ‘involvement’ rather than co-production when referring to families.

Whilst professionals report being committed to the principles of co-production and respecting parents (Sales and Vincent, 2018), and working to involve parents in the process, parents have not always experienced this in reality (Cochrane, 2016). There have been power imbalances in the relationships between parents and professionals working to create EHCPs reported in the research too; some SENCOs report feeling like knowledge is power within the EHCP system, and that parents hold the power within this process (Gore, 2016) whilst families report feeling empowered in some ways but that there is still an imbalance in these relationships with professionals (Ecclestone, 2016) that favours the professional. SENCOs have also reported feeling anger, frustration and resentment towards parents about their lack of knowledge about the process or unrealistic expectations of it (Gore, 2016).

This appears to have been felt by parents of children and young people who have reported feeling labelled as problematic when seeking support for their children (NAS, 2021) and being in conflict with local authorities and schools (Hoskin, 2019). Involvement in the EHCP process is described by parents in research in terms of warfare as it has in been in previous mechanisms for seeking support and forming relationships with professionals (Duncan, 2003); fighting, going in for the kill (Bentley, 2017), battling (Hoskin, 2019). Some parents report that they have been directed through the EHCP process rather than being an active partner (Cochrane, 2016) where others found for example a person-centred review gave them more opportunities for active engagement in planning for children's outcomes (White and Rae, 2015). Parents in some studies felt they were listened to in the EHCP process and this meant they felt they had a level of choice and control over decisions in their child's life (Redwood, 2015) though other studies reported more mixed results (Sales and Vincent, 2018). Families have expressed that they would have liked more input in the annual review meetings (Sales and Vincent, 2018) though professionals in some studies have expressed concerns in what they think is parents being too involved in the process (Gore, 2016). This shows differing perspectives between professionals and parents and also among parents, and without clear understandings of roles within this process, issues will arise.

Involvement in the EHCP is shown to be demanding of parents; in terms of trying to balance this with other demands, and in terms of stress and anxiety (Bentley, 2017; Cullen and Lindsay, 2019). Parents are more likely to contribute to a review if they have capacity to do it (White and Rae, 2015) which could be more limited when for example a parent works, has other children, or has other competing demands. Another barrier that could be explored is from the family perspective, not all families will have the same access to this level of involvement in the process (House of Commons, 2019a). Families from a lower socio-economic background have been found to have less knowledge of educational policy and the school system (White and Rae, 2015) and varying levels of parent involvement and contribution, and their ability to advocate for their child has been shown to impact quality in the EHCP higher levels of parental engagement is correlated with a higher quality plan (Sales and Vincent, 2018). Levels of education, experience, confidence and engagement will invariably differ between families, though this only becomes problematic when it is correlated with the quality of EHCP or support that their child receives.

There must be a careful balance between parent views and child or young person views, especially as there has been seen to be contrasting views from parents and children and young people about the experience. Even with annual review meetings, parents reported dissatisfaction with how few professionals attend but a young person expressed that the meeting would be improved by having fewer adults there (Sales and Vincent, 2018), similarly, children reported feeling daunted by a person-centred review (as did some parents) (White and Rae, 2015). Several studies report greater parental involvement in the EHCP process than children's involvement (Cochrane, 2016; Redwood, 2015) and that attempting to balance child and parent voice can impact the person-centredness of the process (Sharma, 2021). Parent contribution must not be taken on behalf of the child or young person's views- these must still be sought (DfE and DoH, 2015), though SENCOs have reported that sometimes parents have been a barrier to involving children and young people (Sharma, 2021), though this does not account for where parents are protecting or honouring their child's best interests.

Children's involvement in the EHCP

Using person-centred approaches to involve children and young people in creating their EHCP has been written in to the statutory guidance (DfE and DoH, 2015). This principle has generally been received well by professionals (Sales and Vincent, 2018), parents (Cochrane and Soni, 2020; Hoskin, 2019) and young people (Ecclestone, 2016; RIP:STARS et al, 2018) but the requirement to include and involve children and young people in the EHCP process does not guarantee that this will be done in a person-centred way and describing it as such does not mean the principles will necessarily be applied meaningfully. There are barriers to person-centred practice in the process of creating an EHCP that mean these principles are not always implemented, and in a systematic review of the literature, person-centred principles have not been found to have been successfully implemented during the EHCP process (Ahad, Thompson and Hall, 2021). Examples of barriers to person-centredness include the length and detail of reports professionals need to create as evidence not being accessible to the child that they are about, the large caseloads professionals have to work with, and the large number of adult professionals at annual review meetings (Sharma, 2021).

There is also a question over the difference between simple provision of information, and how that represents a person's views or opinions, even where it may be relevant to the EHCP, as discussed by Pearlman and Michaels, using the work of Ware (2004, cited in Pearlman and Michaels, 2019). Eliciting information from a child or young person does not mean that an authentic representation of their opinions has necessarily been obtained, especially where a child or young person may not have been supported to share wider views on the EHCP process or plan. This is particularly important when children and young people communicate in ways that are non-verbal, or where they are described as having more complex needs (Palikara et al, 2022). SENCOs have reported that in these situations, trying to get a contribution from a child or young person feels problematic, and not necessarily in the child's interest (Sharma, 2021). Just managing to collect a contribution from a child or young person may not actually mean their views on the process or their own support are able to be authentically represented either.

The only area where there is space saved specifically for the voice of the child in the EHCP is in section A; 'The views, interests and aspirations of the child and his or her parents or the young person' (DfE and DoH, 2015, s9 ss62). Palikara et al (2018) looked specifically at section A of the EHCP and interestingly a significant number of EHCPs were excluded from their analysis because section A was either missing or minimally completed (26, where the analysis focused on 184 plans). They found the vast majority of the EHCPs analysed were written in first person, but of these, many of them did not indicate that they were written by the child or young person themselves. Only 16% showed how the voice of the child or young person was acquired (Palikara et al, 2018). This has been found in other projects too, including a lack of transparency in how the voices of children and young people have been obtained for section A (Pearlman and Michaels, 2019). Section A should not sit separately from the rest of the plan, and indeed there have been calls from young people to ensure that children and young peoples' voices inform the whole plan (RIP:STARS et al, 2018) however beyond Part A, children have not been found to be enabled to participate in the EHCP process (Cochrane, 2016).

There is also variation in how young people are involved in EHCP planning across different local authorities (Robinson, Moore and Hooley, 2018) and also depending on professionals, where positive relationships with professionals helped facilitate children's involvement in the EHCP process (Redwood, 2015). When parents and young people were asked whether being involved in the EHCP process was a positive thing for the child or young person, 41% agreed that it was (Adams et al, 2017) however it is not clear in this research what 'involvement' represents for the child or young person. Children and young people interviewed as part of a research studies also reported feeling involved and listened to as part of the EHCP process (Hoskin, 2019; Redwood, 2015) which shows positive implementation of this element of the SEND reforms for some. There is a question over the children and young people involved in the studies however; if they are able to be supported in engaging in research, they may be more likely to have been enabled to be supported in the EHCP process too, so care must be taken in interpreting and generalising these findings.

More research is needed into how to engage children and young people in the process (Cochrane and Soni, 2020), though some research and young person-led projects have provided guidance, support and practical suggestions for practitioners in eliciting children and young people's voices for the EHCP (Pearlman and Michaels, 2019; RIP:STARS et al, 2018; Rix Media, 2017). Examples include the use of augmentative and alternative communication methods where appropriate for the individual, use of video recordings where children and young people are interviewed in order to provide information, and crucially, methods adapted to suit individuals (Pearlman and Michaels, 2019), aligning with person-centred approaches.

The Plan

Having focused on the process of creating the EHCP from the perspective of families for the last few sections, this section will now look at research carried out into the EHCP itself; the plan. This will, where possible, take the perspective of families, but will also include research that assesses the plans themselves.

A key issue reported by families in existing literature is the vague nature of some of the outcomes that appear on the draft plan. The purpose of the EHCP is to set clear outcomes with information about what support will be put in place for the child or young person to achieve that outcome, who that support will be provided by, how much support will there be (in hours for example), but this specificity is not always present (Sales and Vincent, 2018). Families have reported plans are not always outcome-focused or SMART (Skipp and Hopwood, 2016). There has also been an over-emphasis on educational outcomes and an underrepresentation of health and social-care related outcomes (Boesley and Crane, 2018), indicating difficulties in the collaborative working relationship. Adams et al (2017) found that 3 out of 5 of the parents interviewed felt that the support outlined in the EHCP would help their child work towards meeting the agreed outcomes, and Castro-Kemp et al (2021) found that there was a link between how well the child's needs have been described and how specific the provision is.

Key to this in the current policy is ensuring provision outlined in the EHCP is specific, quantified, and with information about who will provide the support and the form it will take (DfE and DoH, 2015). OFSTED (2021) found that there is still an issue with poor quality EHCPs, which is also reflected in the research conducted with families and professionals (Cochrane, 2016; Skipp and Hopwood, 2016; Redwood, 2015). The quality of the outcomes on the EHCP have been found to be generally low, with a lack of specificity or measurability (House of Commons, 2019a; Sales and Vincent, 2018), with 33% of parents surveyed happy with the outcomes in their child's EHCP (NAS, 2021) in autism-specific research, though parents have reported in other studies that their outcomes have been specific to their child and measurable in nature (Redwood, 2015). This shows mixed experiences in terms of quality of plans in relation to specificity, however, there have been additional issues raised in terms of the plan itself.

There have also been shown to be general statements in the EHCP about the child or young person’s needs that are vague in nature and would not enable an intervention or support to be included to support them (Palikara et al, 2018), and again, general statements that do not specify or quantify support for the child or young person (Sales and Vincent, 2018). This means it would be difficult or impossible to implement appropriate interventions or measure their impact or outcomes.

There are differences in quality of outcomes between local authorities, with higher socioeconomic areas having better outcomes (Castro, Grande and Palikara, 2019), with the authors questioning whether this could be due in part to more educated and involved parents in these areas. The provision for children has also been found to depend on the parents’ education and engagement in the process (Bernardes et al, 2015) which reproduces inequalities. This issue of parent capital determining provision for children has been seen in other documents too (House of Commons, 2019a) showing potential class divisions in outcomes for disabled children.

The third principle of person-centred planning outlined by Mansell and Beadle-Brown (2004, p.2) states that support should be provided for a person to meet goals, rather than ‘limiting goals to what services typically can manage’. Including a section on the plan entitled ‘outcomes sought for him or her’ does not guarantee that those outcomes will be appropriate, or that they will be considered outside of the provision available in the local authority. In fact, SENCOs reported in one study that decisions were sometimes made based on what made financial sense, rather than what was in the best interests of the child (Hellawell, 2018).

When analysing the representativeness of EHCPs from family perspectives, Redwood (2015) found that it was adult perceptions of what the child’s hopes and perspectives were that was reflected in the EHCP itself. This demonstrates the issue raised above about balancing the views of parents with the views of children and young people themselves. Some EHCPs have been found to contain errors or omissions, resulting in a plan that does not fully or accurately represent a child or young person, for example, Cullen and Lindsay (2019) found there were errors such as the wrong name being used, drafts of the EHCP being lost and pages missing. This is an issue raised by a group of young disabled researchers who created EHCP guidance, including ensuring the EHCP does not contain errors or focus on deficit-based information about children and young people (RIP:STARS et al, 2018). The way that the views of children and young people have been included in the plan has been questioned too; in an analysis of the EHCPs of 12 young people, Gaona, Castro and Palikara (2020) found that there was often information included in the plan about the views of the young person (for example in section A) but no information about how these were collected, or how this was included in the EHCP itself. This can raise questions about how far this plan represents the views of the young person and whether or not they relate to it. Similarly, in a survey of over 3,000 parents and carers of autistic children, only 30% were happy with how their child and their needs were written about in their EHCP (NAS, 2021). There is a need to explore how families relate to their plan, and how far they see themselves reflected in the plan.

Implementation of the EHCP

With regard to the third element of the EHCP, implementation, families have reported in research that there have been issues with implementation of the EHCP (Cochrane, 2016; Skipp and Hopwood, 2016) even once the outcomes have been decided and the EHCP finalised. Though implementation is not the focus of this research, it is important to note that there are issues with all three elements of the EHCP, from the process of applying for a needs assessment, through creating the plan, reflection of families within the plan, on to how the plan is implemented. More research is needed in the area of implementing the plan (Cochrane and Soni, 2020) however this could be subject to difficulties in how this would be measured, especially where there are disagreements between families and professionals. This is reflected on further in the Discussion chapter.

Conclusion

The current legislation and statutory guidance (DfE, 2014a; DfE and DoH, 2015) has moved away from Statements of SEN to the Education, Health and Care Plan, which aimed to bring professionals together from education, health and social care agencies to work collaboratively and to engage with families to co-produce a set of aspirational outcomes that reflect the aims of children and young people with SEN, deemed eligible for an EHCP. Across the last two chapters, I have acknowledged the motivators for this move, considered the documents themselves and analysed the research that has already been carried out to understand the impact of the SEND reforms themselves and the EHCP process and plan. I have found that much of the research carried out in this area focuses on the views and experiences of SENCOs, and where research does seek to understand the experiences of families, this is either largely quantitative (Adams et al, 2017) or document-based (Castro, Grande and Palikara, 2019; Palikara et al, 2022). Where qualitative research has been carried out with families, seeking to understand their experiences, this has either been earlier in the process of implementing the SEND reforms (Ecclestone, 2016; Cochrane, 2016; Skipp and Hopwood, 2016) or focused on different specific elements of the process, for example disagreements in the system (Cullen and Lindsay, 2019).

I have also shown where there is confusion within the terminology of the reforms, specifically in the concepts of collaboration and co-production, and how this links to the ability to create aspirational outcomes with children and young people for their EHCP. Having reviewed the theoretical and research literature, as well as key policy developments in this field and identified the gaps in the literature, I decided to focus on the role and participation of families in the EHCP process and how well they feel they are reflected in the EHCP plan itself. This focuses on the first two elements of the EHCP, the process and the plan. My area of focus has also been influenced by the views of families themselves, about what they think is important to explore, gleaned from research I carried out (Arnold, 2013) where parents shared wider concerns about the process of accessing support outside the scope of that piece of research (accessing communication support), and from discussions I have been able to have with my advisory group. I explore these concepts further in the next chapter, the methodology and ethical considerations chapter.

In the next chapter I provide an account of the research process and give a rationale for my methodological decisions, as well as considering key ethical dilemmas that are present in research within this field and specifically within this project.

Chapter 4- Methodology

Introduction

In this chapter I provide the rationale for the research approaches and methods chosen in this research differentiating between justification of research methods as ways of collecting data, and the discussion of methodology, being the ‘science and philosophy behind all research’ (Adams et al, 2007, p.25). I also frame ethical issues and consider participant power and protection. I consider my own ontology, epistemology and axiology and my theoretical framework, given that these areas underpin the decisions made in the research process (Clark et al, 2021). I also discuss and justify my choice of research paradigm and then research design and approach, sampling and recruitment strategy, data collection process and analysis.

The research questions that guided this study are as follows:
Main research question:
What are the views of parents and young people on the Education, Health and Care Plan and process?
Sub-questions:
What are the views and experiences of families about their role and participation in the process of creating the Education, Health and Care Plan?
How well do families feel their Education, Health and Care Plan reflects the child or young person and their views?
What factors do families identify as important in how they experience the Education, Health and Care Plan process?

Philosophical Underpinnings

To embark on a project where there is a search for some kind of truth or knowledge (as in any research project), it is important to first consider what is understood by knowing and how knowledge is created and defined. Two core concepts in this endeavour are ontology and epistemology, ontology referring to knowledge of the existence of social world phenomena, and epistemology referring to the way that that knowledge of these social world phenomena is gained (Thomas, 2017).

Ontologically, I am concerned in this project with how children, disabled people and families are constructed and how definitions are created around who has rights and agency and who does not within the process of getting an Education, Health and Care Plan (EHCP). Some researchers believe that observed social world phenomena occur without influence from the people living within or observing the phenomenon (Clark et al, 2021) however this does not reflect my own ontology. My position is that children, disabled people, families and researchers are social actors with agency, capable of changing and influencing the social world. Accordingly, I take a constructivist rather than an objectivist position (Clark et al, 2021) to acknowledge the power and agency of individual social actors. This also aligns with post-structuralist frameworks and the work of Foucault, considering wherever power is to be found, there will also be resistance (Foucault, 1978a).

Epistemologically I value experiential expertise, and the importance of including people in the creation of research, to move towards more 'authentic' ways of collecting data; those that capture what they intend to capture, those methods that get as close to the individual's 'truth' (constructed within their own personal, social, economic and political context) as possible. My position is that in studying these social world phenomena, they can be influenced and changed, and that the process of carrying out the research, of having these conversations creates data, rather than data or knowledge existing on its own in a vacuum, ready to be discovered. This lends itself to designing a research project concerned with creating and collecting qualitative data; discursive, narrative data that reflects participants' feelings, views and experiences, rather than quantitative data that seeks to quantify a phenomenon with broad, large-scale collection of numerical or statistical information. The importance here is on ensuring the structure fits the research (Silverman, 2014).

In addition to my ontological and epistemological understandings influencing the research paradigm and design, the theoretical framework or stance that I bring also underpins and influences the research (Merriam and Tisdell, 2015). My own theoretical framework encompasses elements of sociological, rights-based and post-structural theories exemplified by elements of the work of Michel Foucault, namely power/knowledge, governmentality, regimes of truth and discourses, and the way in which power is wielded (and resisted). Having explored Foucault's concepts in the Introduction chapter, made reference to them in the Literature Review chapter and considered how they are at play in how I design and carry out the research, I revisit them in the Discussion section, where I use them to unpack the findings and structure my discussion.

In order to move beyond simply considering research methods as 'a technical exercise' (Cohen, Manion and Morrison, 2018, p.3) and develop a deeper understanding of the world and how meaning is created within it, it is also important to consider axiology in addition to ontology and epistemology (Cohen, Manion and Morrison, 2018). By this I mean I am not simply aiming to discuss what I did in the research and how this links to existing literature and structures, but to develop an understanding of myself and my relation to the research and its outcomes, in order to better interpret the contributions of others and show how this creates new knowledge situated alongside existing understandings.

Positionality and Power

Establishing researcher positionality is crucial (Barton, 2005), and this includes considering whether research is conducted from an insider or outsider standpoint. This generally refers to the biography of the researcher, and whether they have a familiarity with the experience of those with whom they are researching (Griffith, 1998). There are advantages and disadvantages of both insider and outsider research, with an insider having a deeper knowledge and experience of the phenomenon, where an outsider may see things that insiders no longer notice (Merton, 1972). As an outsider researcher when considering only the most obvious categories, a non-child, non-parent researcher, positionality is important, as is the ability to reflect on one's position and represent it honestly in planning, execution and analysis of the research (Herr and Anderson, 2005). As a researcher examining disability, the avoidance of acting in a parasitic manner (Hunt, 1981) is paramount. 'Parasite People' carry out research *on* disabled people, not *with* them, and do not strive for change where services are inadequate (Stone and Priestley, 1996). In these situations, the researcher benefits by collecting data but the participants can be left feeling embarrassed, anxious, and in some cases, having lost dignity, autonomy, and trust (Kidder and Judd, 1986). The aim is not to exclude certain groups from carrying out research on certain areas, nor to say that only disabled researchers may carry out disability research but to work towards creating a 'fundamental shift' towards an emancipatory style of research (Barton, 2005, and Oliver, 1997, cited in Barton, 2005 p.318).

It is also important that I interrogate my own motives for doing the research, where I position myself in relation to the research design, underpinning theory, and data collection, analysis and sharing of findings. Despite my own identity having shifted during the project to accept a label of disabled due to my own chronic and long-term health conditions and a recent diagnosis of neurodivergence, this does not change the importance of avoiding parasitic or exploitative practices. I need to consider the power relations at play in these dynamics too; reframing the idea of handing over power to disempowered groups (Bragg, 2007) and instead thinking about it differently, beginning with involvement from families from the start, acknowledging the power they already have.

Foucault's ideas of power/knowledge are woven into research relationships- the 'expert' role is not necessarily applicable as I am not involved in the care or support of my participants, allocation of resources to their support, and I am not claiming expertise in the medical or social care of their children. However, I have worked in practice with disabled children and young people, I teach at university on this topic, and I am now pursuing a doctoral qualification in this area so I must still be aware of this possible perception. My experience as a practitioner could be viewed positively (in that I have experienced settings and practices around providing support) or negatively (in that some of the issues children, young people and parents face could be linked to expectations of support from practitioners or organisations that did not align). My role as the researcher holds innate power that needs to be examined and deconstructed; these power relations illustrate a problem that can be found from micro-level interactions through to macro-level interactions, in theory, in practice and in research, especially when carrying out research in disability (Barnes and

Mercer, 2010) to ensure that participants are empowered by the process rather than left feeling oppressed or used. This is the preeminent point of the research, both in its subject and in its implementation, the idea that people should have their opinions regarded where actions taken will affect them.

Research Paradigm and Strategy

In identifying the research paradigm for this project, I must consider not only my own views and preferences, but those most appropriate for the research. I must also consider the strategy I am adopting for the research (Clark et al, 2021); whether I am collecting qualitative or quantitative data, or using mixed methods approaches. This ensures alignment in the research, from ontological and epistemological perspectives, through strategy and approach, on to data collection and analysis.

A paradigm itself is a way of looking at or understanding the world, phenomena within the world, or an 'accepted model or pattern' (Kuhn, 1962, p.23) for how the world is viewed and understood. Research that seeks a single truth about an issue is usually carried out under a positivist paradigm, using quantitative methods to understand statistical significance or scope of the issue (Adams et al, 2007) or to build models to test theories (Stimson, 2014). Research carried out within this paradigm requires the researcher to remain detached from the research, with little to no acknowledgement of the impact of the researcher upon the research, and little to no room at all for agency, interpretation or representation (Cohen, Manion and Morrison, 2018). It is seen to discover knowledge that is scientific, measurable, stable (Merriam and Tisdell, 2015) or objective. Focusing on quantifying experiences can take them from their contextual background and they can become dehumanised and wrongly positioned as objective rather than subjective (Cohen, Manion and Morrison, 2018). Social science more often studies a subject-subject relationship rather than a subject-object relationship (Giddens, 1976, cited in Cohen, Manion and Morrison, 2018); the meanings and experiences that participants have form part of their own construction and understanding of the world.

My ontology and epistemology are not in line with the demands of the positivist paradigm, as I do not ascribe to these values of singular truths, detached researchers and laboratory-mined nuggets of pre-existing knowledge. I therefore considered the interpretivist paradigm, the ‘other’ paradigm, for those not carrying out research suitable for the positivist paradigm. The interpretivist paradigm (a term often used interchangeably or in similar contexts with post-positivism, social constructivism, and the qualitative paradigm) posits that there is no one observable reality, instead there are many interpretations of an experience or event (Merriam and Tisdell, 2015). Interpretivism also espouses a concern for the individual, for understanding ‘the subjective world of human experience’ (Cohen, Manion and Morrison, 2018, p.17), moving away from claims of objectivity. In this paradigm, theory generally follows research, rather than research following theory (Cohen, Manion and Morrison, 2018) so it suits inductive data collection and analysis. There have however been many criticisms of interpretive research, mostly around the rigour that is seen to be lacking in this kind of research, the idea that some researchers may have ‘gone too far in abandoning scientific procedures of verification’ (Cohen, Manion and Morrison, 2018, p.21).

Many critiques unfortunately focus on exactly what interpretivism does not claim to do; discover ‘science facts’ that are applicable across populations, though researchers must still strive for quality in interpretivist research and there are still limitations associated with this paradigm. Kuhn (1962, p.18) states ‘To be accepted as a paradigm, a theory must seem better than its competitors, but it need not, and in fact never does, explain all the facts with which it can be confronted’. This described my unease with the interpretivist paradigm; that whilst it fits better than the positivist paradigm, it does not quite fit with my ontological or epistemological stance, or sufficiently fulfil my requirements to consider knowledge as not just socially constructed but ever-changing, historically situated, created in discussion, and dependent upon factors such as experience, demographic elements, socioeconomic factors, gender, disability, values. It should also move away from exploitation of participants, involving those who are being researched and written about. There has been an emergence and development of newer paradigms that do take account of these areas for a multitude of reasons; Mertens (1998) reports that there was a feeling of general unhappiness with the dominant research paradigms- much of the existing Sociological and Psychological theory had been developed by white, non-disabled males, by studying male subjects (e.g. Freud and Kolberg). There were also issues regarding power relations between participants and researchers with existing research paradigms and practices such as embarrassment, affronts to dignity, and loss of autonomy (Kidder and Judd, 1986). This is illustrated powerfully in what Oliver (1992) termed a rape model of research that was experienced as disempowering and alienating for disabled participants, with an overwhelming perception that researchers did not care about their participants or 'victims' (Zarb, 1992). The interpretivist paradigm has also received criticism for exclusion of participants, or 'silencing of voices' from the research process (Atkins and Duckworth, 2019, p.61) with issues pertaining not just to research design but also the relationships between researcher and researched (Atkins and Duckworth, 2019) so I felt I needed to go beyond interpretivism.

Going beyond the interpretivist paradigm leads to critical research and transformative paradigms, which show crossover in values from for example feminist theory and critical race theory, and seeks to 'critique and challenge, transform and empower' (Merriam and Tisdell, 2015, p.10). The difference between interpretivist research, and research that goes beyond into transformative or critical is '..between a research that reads the situation in terms of interaction and community and a research that reads it in terms of conflict and oppression' (Crotty, 1998, p.113). By exploring both overt and underlying discourses, regimes of truth (Foucault, 1980) and the other ways that power is wielded in the creation of the EHCP, I cross over into the area of transformative and critical research. Specifically, within transformative and critical research exists the emancipatory paradigm, which moves research away from exploitative practices, linking elements of feminist research, critical race theory, Critical Disability Studies and culturally sensitive research for social justice aims (Noel, 2016). The research paradigm that best suits research with disabled people is arguably emancipatory, following the rights movements of the 1960s and the slogan 'nothing about us without us' as well as the fundamental understanding that participation in matters concerning your own life is a right and not a privilege, for children as well as adults (UNCRC, 1989). Scholars in critical research have devised questions for reflection during the research process, when considering emancipatory disability research such as below, adapted from Stone and Priestley (1996), Noel (2016), French and Swain (1997) and Zarb (1992):

Does your research address concerns that disabled people have themselves?
Do you, as the researcher, have a commitment to disabled people's self-empowerment?
Will your research contribute to this self-empowerment, or remove disabling barriers?
Will your research be accountable to disabled people and their organisations?
Will your research give a voice to individual and shared experiences of disabled people?
Who controls what the research will be about and how it will be carried out?
Will the research methods meet the needs of the participants, and be based around these?
What happens to the products of the research?

Emancipatory research focuses on 'openness, participation and accountability' (Barnes, 1992, p.121, cited in Danieli and Woodhams, 2005) and seeks to 'change the social and material relations of knowledge production' (Danieli and Woodhams, 2005, p.285). The questions and principles above serve as a way of checking my planning, practice and writing to see whether I am contributing to oppression or emancipation, because if I am not moving towards emancipation, I am holding up oppression or oppressive practices. Conceptualising emancipation can be difficult, but it is generally accepted as having a common element; 'a movement towards a new way of being' (McCabe and Holmes, 2009, p.1520). In a transformative paradigm such as the emancipatory paradigm, Mertens (2007, p.213) states that the 'central tenet is that power is an issue that must be addressed at each stage of the research process'. Whilst I am not able to fulfil all elements of emancipatory research given the restrictions with doing research as part of doctoral studies, I can review the questions regularly to reflexively consider whether I am moving in the right direction or not, in addition to working alongside those with lived experience of the process, as I discuss in the next section.

There are however many difficulties with doing or trying to do emancipatory research; firstly, critical researchers will design research based on concerns they have about the social world already, so they may not be considered to be neutral (Newby, 2014). Emancipatory researchers may also already have ideas about how they want to carry out the research, which can lead to it becoming prescriptive (Danieli and Woodhams, 2005) or have personal ‘missions’ in the way they want to improve lives (Kiernan, 1999, p.47). These kinds of issues risk the inductive nature of the project, instead following the researcher’s chosen pathways. Researchers must ensure they use a ‘plurality of methods’ (Stone and Priestley, 1996, p.706) for data collection and analysis to ensure they respond to the needs of disabled people and focus on including disabled people from the start of the project. There are however challenges with this in terms of co-creation or co-authoring of a project- researchers must take care to define roles in the research process early (Herr and Anderson, 2005) and ensure that the value of the researcher’s role and skills is not ignored either (Walmsley, 2004). Doctoral projects may not be co-authored, so this boundary is not moveable, but involvement can still be sought at other points. Robson (2011) suggests having awareness of power relations between researcher and ‘researched’ and also the danger of loss of control over the project. There is an undeniable power imbalance when I am the only person writing up the project, so I needed to listen to the people I involved; not necessarily empowering people by handing out power, but by facilitating people to empower themselves (Oliver, 1992), honouring the power they already have. When involving people who have an influence over the research, as in an advisory group for example, as I did, it is also important to not assume that they will be able to represent all people in the same or similar situations as them, that the trap of assuming homogeneity of respondents is avoided (Stone and Priestley, 1996).

At the core of this is developing research that moves in an emancipatory direction; it is not simply making changes with methodological decisions but fundamentally changing the way researchers plan, implement and disseminate research (Clough and Barton, 1995) and putting researchers’ skills at the disposal of those who the research concerns, ideally alongside them (Kiernan, 1999). My research paradigm and theoretical framework is possibly best described as interpretivist with elements of transformative, emancipatory, and post-structuralist perspectives which embodies rejection of the idea of a single, incontrovertible ‘truth’ that gradually evolves, and instead considers that there are multiple realities and perspectives, and ‘discontinuity and difference’ (Burr, 1996, cited in Barnes and

Mercer, 2010, p.8), all of which is socially and politically constructed. My focus was to avoid exploitative research practices and to move in an emancipatory direction, with guidance from an advisory group, as I discuss next. Where I am not able to relinquish control of elements of the project, due to issues like having to be the sole author of the work, being accountable to the institution and the ethics committee, I use existing research and the views of disabled peoples' organisations to guide these sections and decisions. Using this combination of paradigms and perspectives and taking into account my ontology and epistemology means that I am seeking to collect qualitative data.

There are many ways to design qualitative research which have similarities but also distinct differences (Cohen, Manion and Morrison, 2018). The focus of qualitative research is to understand and report the multiple subjective realities of participants (Cohen, Manion and Morrison, 2018) and to assemble the data, make sense of the patterns being identified and consider what the causes might be (Newby, 2014). A difficulty in using qualitative data in disability research, is the inability to establish causal relationships with disabling barriers and their removal (Stone and Priestley, 1996), thereby rendering the data theoretical and hypothetical, without the option of broad generalisability. This puts researchers at risk of becoming parasitic (Hunt, 1981), so measures must be taken to ensure that the research is dynamic and responsive to the needs of the participants, for example discussing the project with an advisory group, reviewing consent from and comfort of participants regularly, being mindful of participants' time, and ensuring the focus of the questions is balanced. Qualitative approaches fit the project better than quantitative approaches, given the central focus of the project being around the experiences of families and that there is already quantitative data about the EHCP, mostly focusing on the number of families needing to use the tribunal system (DfE, 2023a).

Advisory Group

To ensure that the research moves towards the emancipatory principles outlined above, I recruited an advisory group who I worked with to design, execute and disseminate the research project. Whilst not necessarily considered a representative group, to avoid ideas of homogeneity (Stone and Priestley, 1996) or generalisability, a diverse advisory group meant that I was able to ensure that the issues under examination were aligned with the concerns of people who are experiencing or have experienced the EHCP process. It also ensures that findings can be disseminated in contexts seen to be important to the advisors. I decided to recruit my advisors from my own network, feeling that the relationships of trust we have already built would mean that they would be able to be frank with me about the research from the outset. This is framed as a partnership approach (Kitchin, 2002) whereby I act as the facilitator of the research, and the advisory group input on ideas for the questions guiding the project, the data collection and analysis and dissemination. Where my practice diverts from Kitchin's (2002) description of the partnership approach is in writing up the results of the research, since doctoral work must be authored solely by the student.

The reason I am labelling the research as moving in an emancipatory direction is because I do not feel I can necessarily fulfil every requirement of emancipatory and participatory research because of the restrictions, structure and commitments associated with doctoral study. I am, however, prioritising the 'voices' of the groups I am studying, reframing the role of the researcher as part of a team, and using a privileged position to draw attention to issues faced by marginalised groups. What this looked like in reality was a series of meetings with advisory group members at times that suited them, rather than whole-group meetings, with me providing ideas to discuss. I had 6 advisors in total, including parents of disabled children and a disabled young person, who have expertise and lived experience of the EHCP process that I do not have. I used the idea of research approaches being 'fit for purpose' when it comes to researchers and communities working together for socially just research (Atkins and Duckworth, 2019, p.15), valuing the perspectives of family members as part of my toolkit to work towards inclusive research (Andrews, Hodge and Redmore, 2022).

Advisory groups have been used in a range of studies for example a transition to adulthood study by Puyalto et al (2016) saw positive relationships between disabled and non-disabled researchers, in an atmosphere of respect, support and freedom of expression. An issue with advisory groups when involving disabled people is that those involved have usually what is perceived as a 'milder' learning disability (Bigby, Frawley and Ramcharan, 2014) leading the authors to question whether they can represent those with what they term ‘more severe’ learning disability. Another key issue in attempting to move research in emancipatory direction is that I needed to have ethical approval before involving anyone in the research. This meant I had to apply for ethical approval before I recruited my advisory group members, and to do this, I needed to set out what the project was likely to look like before I had input from advisors. I needed to be prepared to go back through the process of getting ethical approval to make changes to the design of the research. The first advisory meetings were held during the design phase of the project, once I already had ethical approval granted, checking that ideas that I was interested in researching addressed concerns that families had. Then more meetings happened when I was redesigning and adapting research questions and indicative topic guides, so we had discussions around the kind of data I was looking to collect and the ways in which I would do this. I also held meetings once I had collected the data to discuss the key themes that I was identifying during early stages of analysis, so that we could discuss how I was grouping these, how it related to their experience and how I would be representing this in the thesis. I also took this opportunity to ask about dissemination, i.e. who would need to hear these findings and different ways that this could be disseminated, and recommendations that could be made with the research.

Research Approach

In qualitative research taking place within the scope of interpretivist and emancipatory paradigms, there are a range of approaches to choose from that enables the researcher to plan and carry out an ethical and purposeful project. Research approaches that I ruled out early are longitudinal and ethnographical studies; despite the richness of data that these approaches allow researchers to collect, the authenticity of the conclusions researchers are able to draw, I did not have sufficient time for long-term data collection or to explore broader more open-ended questions (Hays, 2004). This was also not a suitable approach because ethnographical studies view the research data through a lens of culture (Merriam and Tisdell, 2015) which was not an appropriate lens for my study; I do not have membership of the groups I am studying, nor are they a distinct group or community. I am also not looking to build a substantive theory, as with grounded theory (Merriam and Tisdell, 2015) or to use phenomenology, despite arguably all qualitative research using elements of phenomenology because of 'its emphasis on experience and interpretation' (Merriam and Tisdell, 2015, p.26) and in the way that qualitative researchers are also encouraged to examine and explore their own assumptions about a topic before commencing a study (Merriam and Tisdell, 2015).

Having carried out research before using a case study approach, I explored this as an option early on. Case studies are defined in part as 'an empirical method that investigates a contemporary phenomenon in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident' (Yin, 2018, p.15) or 'a study of the peculiarity and complexity of a single case, coming to understand its activity within important circumstances' (Stake, 1995, p.xi). Case studies seek meaning, are inductive in nature and create 'richly descriptive' data (Merriam and Tisdell, 2015, p.37). So, to define a case study may be to plan research that focuses on a single case or set of cases linked by area, phenomenon or event. Case studies are different from general qualitative research because they examine a bounded system (Merriam and Tisdell, 2015) and in this research, because I sought views and experiences of a particular process embedded in a legal system, experienced only by those deemed eligible by the local authority, this qualifies as a case study because it shows the boundaries around the phenomenon. However, there is not always a consensus on what constitutes a case study (Candappa, 2017) and they are, as Tight (2017) expresses, 'messier and more complex' (p.5) in reality than in theory. Case study research, contrary to popular opinion, is not a simplistic way to do research, it is not quick or easy and can be 'all-consuming' (Hays, 2004, p.234).

Within case study research there are different types of case study that can be considered for use; firstly, a representative or typical case, though later termed 'common' (Yin, 2018) or an 'exemplifying' case (Clark et al, 2021) as there are issues with connotations around representation. This kind of case looks to show an everyday or common occurrence within a particular phenomenon, and whilst I am not looking to claim representativeness across a whole population or erase differences in experience, my position is that it is of benefit to show where there are similarities between the experiences of families accessing the Education, Health and Care Plan living in different local authority areas and attending different educational institutions, and consider what might be underpinning or influencing their experiences. There is a set of boundaries around the research area that make it suitable for a case study (Candappa, 2017) which is that all the participants involved have experiences with this very specific process, a bounded system that has eligibility criteria. This also makes it eligible for an evaluative case study (Yin, 2018; Candappa, 2017), the purpose broadly being to evaluate the process of getting an Education, Health and Care Plan, or a collective case study whereby individual experiences within a phenomenon could have similarities that would meaning a greater understanding of an even larger number of cases (Stake, 2003).

It is important to consider these different and potentially relevant categories of case study because as Stake (2003) states, studies do not always fit completely into one single category, that instead they should be considered as roughly divided for the purpose of heuristics. This means that arguably this research could sit on the intersection between exemplifying, evaluative and collective case study, with the proviso that the purpose of this research is not simply to present cases that are interesting for the sake of research, but to consider what this group of cases could reveal about the Education, Health and Care process for families, without broadly generalising findings such to say that everyone feels a particular way or has the same experiences. This also meets the aims of moving in an emancipatory direction- being able to give a voice to individual and shared experiences of disabled people (Stone and Priestley, 1996) and their families. Though not setting out to come to generalisable conclusions, case study research can be considered generalisable across multiple similar studies (Hays, 2004) and can demonstrate similarities between cases within the same study for the purpose of exemplifying, evaluating, and showing where collective similarities lie in the data, or to draw what Stake (1995, p.7) terms ‘petite’ generalisations, which is what I do, as opposed to making grand generalisations.

Case study researchers share ideas and meanings with participants, even when they do not intend to, reconstructing and reinventing knowledge and meaning in that context along with their participants (Stake, 2003). This constructivist approach to research follows naturally from my own ontology and epistemology and made it a good fit for this piece of research. This can also represent a drawback in case study research, however- where researchers share ideas and meanings with their participants, there is arguably a level of influence being exerted on participants, which could lead to skewed answers and data. This is perhaps true for all qualitative research, though especially true with case study research which is ‘highly personal’ (Hays, 2004, p.234). Case study researchers must consider alternative perspectives and interpretations (Stake, 2003) and be careful not to just look for what they want to see, which again links to my commitment to reflexivity.

Sampling

Sampling involves the selection and recruitment of research participants. There are many different sampling techniques, categorised into probability and non-probability approaches (Merriam and Tisdell, 2015). Probability approaches work well for quantitative, positivist research projects, random sampling being useful when allocating subjects or participants to groups where effects are measured. Probability approaches are not as suitable for qualitative research because qualitative researchers need to be able to select participants that have relevant experiences and are able to address the questions in the research, though they can be used in some qualitative research (Clark et al, 2021). The drawback of such approaches is that the sample can be skewed; all participants can be from a particular area, of a particular social class, or have similar experiences of the phenomenon for example. When using purposive sampling, a researcher can select participants that belong to the group of people that the research is concerned with (Silverman, 2014) in order to get the largest amount of relevant data possible (Yin, 2011) to address the research questions, rather than leaving it to probability approaches or attempting to get a representative sample from the population.

Purposive sampling can be situated as ‘the master concept around which we can distinguish different sampling approaches in qualitative research’ (Clark et al, 2021, p.377) which can involve using sub-categories of non-probability sampling. Snowball approaches can be useful alongside more general non-probability strategies (Silverman, 2014) whereby the researcher can ask participants to recommend others who may want to be involved. Convenience sampling allows the researcher to recruit participants because of their proximity to the researcher or their easy availability (Yin, 2011). In terms of my own sampling strategy, it can be described as a mix of purposive, convenience and snowball, always using opt-in methods. Members of the advisory group were asked to make recommendations for participants and make introductions (and often did this unprompted) in addition to the active recruitment I did myself via parent networks, Microsoft Teams and social media (Twitter, now X, and Facebook). I avoided recruiting through schools because I did not want to limit participation to families within a certain school or area or be associated with particular settings that may position me as the researcher in a professional or practitioner role, with power relations in mind.

Use of this mix of methods has been prompted by the drawbacks that using single sampling methods can produce; using solely snowball sampling can compromise the diversity of the population sampled, it is better employed as part of a range of sampling techniques (Ritchie and Lewis, 1993). Used alongside other non-probability methods including convenience and purposive sampling means I was able to expand my networks beyond a couple of branches, to avoid this becoming an issue. Snowball sampling can be good for groups who may be harder to reach or for topics that might be sensitive (Clark et al, 2021) but I did not want to only interview people who were from one small group or with the same views or experiences. There are also drawbacks of using solely convenience sampling; that it can produce less credible data (Merriam and Tisdell, 2015) and can lead to bias (Yin, 2011). By recruiting only participants from my local area I would be limiting my data to my own local authority only or even possibly from the same school. This could not only lead to skewed results but also compromise anonymity of participants. The benefits to my mix of sampling techniques means I was able to recruit from a wider area, from different circles and not rely one stream of participants who may have similar experiences (for example if all of their children attended the same school or had the same local authority). I could also seek out participants that may have had different views and experiences (Yin, 2011) for example in this research where they may have had a positive experience of a system that is often experienced negatively, or who have children who are outside the education system.

For inclusion in the study, participants had to be a parent of a child or young person with an EHCP with experience of the process and system, or a child or young person with experience of having an EHCP themselves. In research that addresses disability, researchers need to decide whether or not to recruit using impairments as categories (Wickenden and Kembhavi- Tam, 2014). I decided not to recruit by means of medical diagnosis, or label, as Connors and Stalker did in their research (2007) because there can be a hierarchy among impairments, with children with physical impairments seen as the easiest to work with and other impairments subject to further stigmatisation (Wickenden and Kembhavi- Tam, 2014). Instead, I focused on actively encouraging facilitation of all (Wickenden and Kembhavi-Tam, 2014) and I did not seek or store medical information or details about the child's label, diagnosis or condition. This information was shared by parents over the course of the conversation in order to contextualise their stories, and the children and young people of the parents interviewed represented a broad range of conditions and diagnoses including developmental, physical, multiple, intellectual, as well as a range of ages, from primary school age to college age, and a young person, reflecting on her experiences of the EHCP process through school and college. I purposely left the criteria open so that I would be able to hear about a range of experiences without specifying a particular condition, age or geographical area.

When I reviewed my recruitment strategies, finding it difficult to recruit children and young people as participants, I focused instead on pursuing the lines of communication opened by parents who wanted to participate in the research. I did not collect personal details from participants themselves such as age, ethnicity, occupation, socioeconomic situation, location, because of the principle of collecting and holding as little personal information as possible, but again these were often shared with me during the interviews. Asking for personal information like this at the start of interviews can feel threatening (Cohen, Manion and Morrison, 2018) and I did not request specific ethical approval to collect, store, analyse or disaggregate data by details such as these.

When recruiting to qualitative research, researchers agree that it is difficult to specify a minimum or ideal number of participants (Clark et al, 2021; Merriam and Tisdell, 2015), and a study will need fewer if there are specific aims, inclusion criteria is specific, there is a strong theoretical underpinning, and there is rich data with detailed analysis of 'narratives or discourses' (Clark et al, 2021, p. 386). This is what Malterud et al (2015, cited in Clark et al, 2021, p.386) call 'information power'; the strength of the data and its links to theory. One way of determining sample size is reaching saturation point; being at a point in data collection where no new perspectives or insights are being given (Merriam and Tisdell, 2015). If a researcher is using saturation point to judge sample size, there is no point in specifying a sample size at the start of the research- though the difficulty is, many researchers will claim saturation but not evidence it, which impacts credibility and integrity (Clark et al, 2021). Researchers can give a tentative estimate of sample size (Merriam and Tisdell, 2015) when this is required for the purposes of satisfying the ethics committee and planning for data collection and analysis, then adjust this to suit during the research, which is what I was able to do. Clark et al (2021) use the work of Guest et al (2006) to show that saturation point had been reached by the time they had analysed 12 interview transcripts in their highly specific research, with 92% of codes created by this point. I gave an estimated number of participants at the start of the research (10-15 participants) and interviewed 12 people: 11 parents (10 female and 1 male) and 1 young person who were located across the UK with representatives from 8 different local authorities, including 4 different London boroughs. I am not necessarily claiming to have reached saturation point, though strong themes were identified in the research as it progressed and there are very few outlying codes or themes that are not able to be tied in with others; usually these relate to areas of support that sit outside the EHCP process.

Data Collection Methods

It is important to note that in line with my ontology, epistemology and research paradigms, 'the idea that we 'collect' data is a bit misleading. Data are not 'out there' waiting collection' (Dey, 1993, p.15, cited in Merriam and Tisdell, 2015). As with more traditional ways of doing research, data has been in the past been considered already existing and in need of collecting, however with the paradigms and approaches I am using, I acknowledge that 'collection' is not the most appropriate term for the coming together of researcher and participants for discussion, meaning making and creation of knowledge and viewpoints about existing experiences around a particular topic. However, I also acknowledge that researchers have a language that is used to communicate with each other verbally and in written form, and that this forms more of a shorthand to communicating and understanding the way the project was carried out. In the interest of transparency, I use the most widely accepted terms for research design and methodology, including 'data collection'. In order to collect data, I carried out interviews with participants to explore their experiences with the EHCP.

Interviews with children and young people

My initial research plan included interviewing children but as I learnt from reviewing the literature, it is very difficult to recruit children as participants. One of the barriers to recruiting children and young people that I faced include the global Covid-19 pandemic; children and young people especially those with health conditions were shielding and not able or willing to take part in face-to-face interviews. Remote interviews were also harder to schedule having not being able to meet the family in person and build knowledge of their communication methods and preferences. I also faced barriers that were presented by the topic; in many cases, parents had not discussed the EHCP with their child because of the complications it had presented or because of the complexity of the process. There were also situations where parents felt that it would be uncomfortable or upsetting for their child to be asked about the EHCP, for reasons such as the child did not like having an EHCP, the child was keen to distance themselves from the process as it made them feel different, and also where parents felt their child did not understand the EHCP plan or process enough to be able to answer questions about it.

Another barrier to recruiting children and young people for research experienced by many other researchers can be gatekeepers and parents; Morris (2003) found that parents were a barrier in accessing children to interview and in her project in 1998, needed to be quite insistent with gatekeepers in order to interview children who do not communicate verbally and found again in 2003 parent attitudes ‘you won’t be able to interview him- he can’t communicate’ (Morris, 2003; Morris, 1998). Lewis and Porter (2004) also found barriers in their interactions with gatekeepers, who did not think their child could be interviewed- the issue here being the view of the child’s capabilities by the gatekeeper. This is not to criticise the role of the parent or gatekeeper in ensuring the child’s safety and well-being- but recognising how others can impact inclusion in research.

The rationale for wanting to include children and young people in the research was to explore a previously unexplored area of this topic; some researchers have explored methods of gaining the views and experiences of disabled young people, but not specifically about their care plan (Connors and Stalker, 2003; Morris, 2003; Preece and Jordan, 2009). Other studies have explored professional experiences of creating the Education, Health and Care Plan (Boesley and Crane, 2018; Sharma, 2021), analysed the content of the plans (Palikara et al, 2018) and written about the process and its limitations (Robinson, Moore and Hooley, 2018; Ahad, Thompson and Hall, 2021). Very few studies have sought to present views of families, young people and professionals about the process (Sales and Vincent, 2018) and none have co-created research with input from families, taking account of the participants’ preferred communication methods as I planned to do (though Sales and Vincent did communicate with parents beforehand to adapt questionnaires). However, given the difficulties faced in recruiting children and young people to the study and the feedback from parent participants, my plan shifted to focus just on recruiting adult participants. Much of the knowledge that has been created about disabled children comes from other agents (Rabiee, Sloper and Beresford, 2005) including parents, carers and advocates so it is important to seek original contributions, but despite my detailed plans, I was not able to recruit and interview children and young people currently going through the EHCP process. I was able to recruit and interview one young person (over 18 and at university) who was able to volunteer their participation via social media and retrospectively reflect on the EHCP process as they went through it at school and college. I felt it was important to keep this contribution in the research project because though the focus eventually shifted more towards parents’ experiences and views, the young person had important insights into where her views and input differed from her parents', and powerful reflections on the process itself from her experience.

Interviews with parents

Why include parents?

Parents have historically been recruited for research studies for the purposes of triangulation of data (or verification of what a child or young person says), to avoid the ethical issues with recruiting children or young people, or because of their own insights or perspectives on a process. I was interested in the experiences of parents as they are often responsible for seeking support for their child in navigating systems and processes, and because of the outcomes of my own earlier research (Arnold, 2013) when I sought views of parents on the process of seeking communication support for their children. Many participants of this previous research wanted to discuss the wider systems they had experienced difficulties with, not just the process of seeking communication support. Parents and especially mothers of disabled children have historically been positioned as occupying a 'liminal position' between disabled and non-disabled, between motherhood of a child and motherhood of a disabled child (Ryan and Runswick-Cole, 2007, p.199) which does not advantage them societally. Calls to reallocate responsibility from mothers as sole activists and advocates for their child to a collective and rights-based approach (Runswick-Cole and Ryan, 2019) demonstrate the importance of the work that families and especially mothers have done in advocating for their children and raising awareness and now the importance of moving towards action and change. I hope that by centring the voices of parents in this research (both in the advisory group and as participants) alongside disabled young people, the findings I am able to produce will authentically reflect the experiences of families going through the EHCP process, with recommendations linked to these.

The Data Collection Plan

There were many data collection options available to me as a qualitative researcher, including surveys, focus groups, and interviews. I preferred interviews initially because of my own experience in carrying these out with children, young people, and parents and I brought this up as a suggestion when discussing the ideas with advisory group members. In line with my choice of paradigm and research topic, I was looking for an 'interactive, personally involved style of data collection' (Mertens and McLaughlin, 1995, p.49) and with the ability to adapt my practice to suit the interviewee through use of multi-modal interview techniques for example, interviews seemed a strong choice. Though there is no one correct way of collecting data (Mertens and McLaughlin, 1995) interviews are often considered the most important kind of data that a case study researcher will collect (Hays, 2004). Advisory group members felt too that interviews would be a good way of collecting data, and liked the flexibility they could include. I carried out semi-structured interviews with all my participants which Thomas (2017) calls the 'best of both worlds' (p.164) between structured (with no room for deviation), unstructured (with participant having full control over topics); semi-structured interviews represent a wide range of approaches (Kvale, 1996). Having an indicative topic guide with prompts and suggestions but using this flexibly allowed me to retain some level of control over the direction of the interview (i.e. in order to address the research questions), whilst giving the participant the ability to discuss what is important to them, change the direction of the discussion or bring up issues they feel are important; it was 'flexible and dynamic' (Clark et al, 2021, p.426).

Caution must still be exercised when using interviews, firstly subjectivity can still impact upon the research account which is a risk when seeking views and experiences- acknowledging the co-construction is important (Clark et al (2014). The researcher must also seek to avoid 'reducibility' in interviews (Atkins and Duckworth, 2019, p.62), ensuring what is discussed with participants does not become over-simplified or out of context. With interviews, researchers have to gather, sort through and analyse a huge amount of rich data which is a very time-consuming process, though this rich data reflects more accurately the depth of the participants' answers and views (Clark et al, 2021) and can lead to greater quality and authenticity in findings.

The Data Collection Process

My data collection period started during a global pandemic, so I had to adapt my methods somewhat, whilst still adhering to guidance from the university ethics committee. I had included the option for telephone and online interviews in my ethics application, as I wanted to keep the options open for participants to be included ways that met their needs or preferences, so I was able to use these as primary methods. I also had to negotiate the gathering of data, since some participants were less comfortable with the idea of me audio recording telephone or online conversations. In total I interviewed 11 parents and 1 young person, in the form of 8 video call interviews and 4 telephone interviews (see figure 5 below) for a total of just over 18 hours. These interviews took place at times that suited the participants, so I was flexible about timings, interviewing mornings, afternoons and late at night to fit around participants' schedules. Several other people expressed an initial interest in participating but were not able to take part because of their own time demands which I discuss again in chapter 7.

The indicative topic guide for parents also shifted slightly during the data collection process as they do with semi-structured interviews; after a couple of interviews where parents were sharing many negative elements of the process, I added an optional prompt about anything that they would see as a benefit or positive of the process, in the context of what had been a challenging experience for them. This had the purpose of not leaving a participant feeling negative at the end of an interview, and also to see if there was anything they could think of that was useful or helpful about the experience, to be able to make recommendations for changes in policy or practice. This prompt was not needed when a participant was expressing how positive they found the process, but with semi-structured interviewing I was able to be flexible with how I used the topic guide.

Telephone interviews

4 participants chose telephone interviews, which have a different set of considerations to face-to-face interviews, given for example the loss of non-verbal cues and clues (Cohen, Manion and Morrison, 2018). Telephone interviews can be cheaper and more convenient to researcher and participant (Browning, 2013, in Cohen, Manion and Morrison, 2018) given

the elimination of travel and associated expenses. The quality of responses when discussing sensitive subjects may be greater with a telephone interview than a face-to-face one because of the relative anonymity it provides (Sturges and Hanrahan, 2004) though the cost can be the rapport that is more easily built with face-to-face interviews, which can possibly lead to awkward interactions and bland data (Newby, 2014). Participants in telephone interviews may have greater concerns about confidentiality than they would in face to face interviews (Browning, 2013, cited in Cohen, Manion and Morrison, 2018) which I did observe in this study, needing to provide greater reassurance to participants being interviewed on the telephone than video interviews, and forego recording for 2 telephone interviews. Telephone interviews can be quicker than face to face interviews as participants only usually want to talk for 10-15 minutes (Browning, 2013 in Cohen, Manion and Morrison, 2018) though this was not my experience; my telephone interviews were variable in length, representing both my longest and shortest interviews. They are also said to be more tiring for the interviewer who must remain focused for the whole interview (Lechuga, 2012, in Cohen, Manion and Morrison, 2018) though I found telephone interviews significantly less tiring than having to travel, interview in person and then travel home. Telephone interviews can give access to groups that may be harder to reach (Sturges and Hanrahan, 2004) and Browning (2013, cited in Cohen, Manion and Morrison, 2018) states they can also neutralise power relations between researcher and participant. I would argue that this method can reduce rather than neutralise power relations, given that as the researcher I still hold a certain level of power over the conversation and the topic, having to have a topic guide because telephone interviews do not lend themselves to unstructured interviews (Newby, 2014). I also have power over what I identify as meaningful from the conversation and how I transcribe and analyse the data resulting from it. There can be issues with the recording and transcribing of telephone interviews including technical issues or signal issues (Lechuga, 2012, cited in Cohen, Manion and Morrison, 2018) which I did experience with the telephone cutting out or the recording being difficult to hear.

Video Call Interviews

8 of 12 participants opted for a video call interview via Microsoft Teams. Again, there are a separate set of considerations to make for a video call, different from face-to-face or

telephone interviews. In some situations, video call interviews retain some of the benefits of a face-to-face interview over telephone interviews (and with reduced risk to the researcher (Cohen, Manion and Morrison, 2018)), but also have their own advantages (Clark et al, 2021). These advantages can include recruitment from a wider geographical area (Merriam and Tisdell, 2015) as with telephone interviews, greater flexibility in terms of timing and location of the interview (Cohen, Manion and Morrison, 2018), and convenience for those who may not be able to accommodate a face to face interview or who may require a greater range of time availability such as a night time interview without physical risk (Clark et al, 2021). These were all of advantage in this research, conducting some interviews later at night because of how busy my participants are in their daily lives. Additional benefits include the ability to see body language and facial responses (Cohen, Manion and Morrison, 2018) which can improve rapport between interviewer and participant and can be built as effectively on video calls as with face-to-face interviews (Clark et al, 2021). I was also able to keep my topic guide on the screen and avoid looking down or away, which I felt improved eye contact and connection. There are also drawbacks associated with video call interviews, including technical or connectivity issues (Cohen, Manion and Morrison, 2018) which can lead to issues with the recording of the interview, leading to patchy audio that can be more challenging to transcribe accurately (Clark et al, 2021), which I did experience.

There are difficulties with having a range of forms of interview and recording of data but this could also represent ‘plurality of methods’ (Stone and Priestley, 1996, p.706) because the purpose of this was not for my benefit as the researcher but to meet the needs of the participants and ensure that I could fit around their busy lives as much as possible. I was not looking to carry out interviews in a strongly structured manner so that they could be easily compared and analysed; I was more interested in carefully and authentically representing the views of my participants, even if that meant the interviews took different directions and covered different themes and ideas within the topic. By providing a range of options for interview format, I feel I was able to put the participants at ease as much as possible and ensure there was some level of choice and control over the situation, rather than being formally invited to a meeting that was scheduled without their input.

Transcription

Transcription is a very time-consuming process; Clark et al (2021) estimate that researchers should allow for 5 to 6 hours of transcription time per hour of recorded audio, even if using a machine to help transcription (Clark et al, 2021; Cohen, Manion and Morrison, 2018). I found I was able to transcribe an hour of recorded audio in more like 3 to 4 hours, however this was made slightly shorter than the estimation by the automatic transcription software that accompanies Microsoft Teams, the ability to slow or pause the audio, and my typing speed. I decided early on that I would be doing all my own transcription in order to ensure that I was familiar with the data that I had collected and able to make early links between datasets. I aimed to transcribe regularly after the interviews; to avoid leaving analysis to the end as one big task, but also to ensure I could amend the topic guide in response to issues that emerged in early interviews (Clark et al, 2021).

At times I questioned the necessity of my in-depth transcription practices; Cohen, Manion and Morrison (2018, p.646) urge researchers to consider whether 'close' transcription is necessary, because of the costs attached to it, including the time it takes to transcribe details such as the tone of voice of the participant, the non-verbal actions, and the volume and pace of the participant. These elements should be consistent through the project (Cohen, Manion and Morrison, 2018) with the same conventions applied to each interview. Sometimes there are parts of an interview that are 'not very useful or relevant' (Clark et al, 2021, p.44) and the researcher needs to decide whether or not to transcribe the whole interview. I would argue that a stronger reasoning for not transcribing parts of an interview is where participants might be identifiable, where participants are discussing the experiences of other families, and where they are sharing personal information about themselves or their families that is not related to the topic at hand. I made the decision to leave this information out of the written transcription so that it was not analysed and included in the findings. During the transcription process, there must be a balance between transcribing everything including repeated words, short form sentences and verbal tics, and paraphrasing what the participant said which can lead to inaccurate data, according to Clark et al (2021). I decided not to transcribe tone of voice, inflection, pace, or non-verbal information except where the participant was laughing when they said something or gave heavy or sarcastic emphasis to a word or phrase, as this would completely change the meaning of a statement. In order to minimise my impact on the data, I was careful to leave in as much detail as I could, my rationale here was that just because I did not think something was relevant, it does not mean that participants think it is irrelevant, so I would leave it in to be analysed in case there are patterns or similarities in the information being raised between interviews. I was also careful not to paraphrase participant contributions as I did not want to remove key words or the meaning behind the sentence or statement. This issue is contentious, as sometimes using direct quotes from participants can mean there is a danger that they are able to be identified because of their phrasing or tone (van Krieken Robson, 2021). I ultimately decided to leave participant quotes as they were because they were not all part of for example a small staff team (as with the research carried out by van Krieken Robson, 2021) so the danger of identification was low. I used pseudonyms to maintain participant anonymity, as below. Where participants made a request for a specific name, this was honoured. Most of the participants were female (with the exception of Mike), and I use ‘family’ in the research questions and in the thesis to include and honour the contribution of the young person who participated in the research, in addition to the parents.

Abbie, parent	Telephone interview	Written notes
Marina, parent	Telephone interview	Written notes
Louise, parent	Video call interview	Audio recorded and transcribed
Sarah, parent	Video call interview	Audio recorded and transcribed
Kate, young person	Video call interview	Audio recorded and transcribed
Elizabeth, parent	Telephone interview	Audio recorded and transcribed

Mike, parent	Telephone interview	Audio recorded and transcribed
Elmas, parent	Video call interview	Audio recorded and transcribed
Zuzanna, parent	Video call interview	Audio recorded and transcribed
Alison, parent	Video call interview	Audio recorded and transcribed
Amani, parent	Video call interview	Audio recorded and transcribed
Ellie, parent	Video call interview	Audio recorded and transcribed

Figure 5: Participant interview information

Data Analysis

My strategy for data analysis centres around a thematic approach including thematic coding; realist- reporting realities of life, or constructionist- thinking about how the experiences are 'effects of a range of discourses operating within society' (Braun and Clarke, 2006, p.81). This is named as reflexive thematic analysis (Braun and Clarke, 2022). In analysing qualitative data, researchers have many choices in sorting, reducing and making meaning from the data (Merriam and Tisdell, 2015) with phenomenology, grounded theory and thematic analysis among the most common approaches. I selected thematic analysis because of its inductive nature and ability to use data-led codes rather than theory-led codes, and therefore the ability to centre the analysis on the participant contributions. Reflexive thematic analysis also has space for linking to theoretical underpinnings (Braun and Clarke, 2022) which I was able to do in the discussion section in the context of post-structural Foucauldian theory, after I had inductively analysed the data from participants. I was not looking to analyse the way that the conversation happens, with the focus on the interaction itself, as with narrative or conversation analysis (Newby, 2014), and I was also not looking to generate theory from the data, as in grounded theory (Newby, 2014). I also wanted to move away from phenomenology and its focus on the ‘essence’ of a phenomenon or experience (Merriam and Tisdell, 2015) for what I felt could lead to over-simplifying or homogenising contributions.

The process of analysing the data itself includes multiple layers and stages (Braun and Clarke, 2006). This is conceptualised in different ways by different authors; ‘Sorting, re-sorting, organising, re-organising, labelling, re-labelling' (Hays, 2004, p.232), data reduction, data display and drawing and verifying conclusions (Miles and Huberman, 1994), and overall taking the data apart, looking for relationships and then putting it back together in order to ‘tell the story of the case’ (Hays, 2004, p.232). To carry out my analysis, I used the stages outlined by Braun and Clarke (2006): familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, producing the report. I felt that this covered all of these conceptualisations and divided them into clear categories. These overlapped and took place over many months.

Familiarisation with the data

To become fully immersed and familiar with the data, I conducted and transcribed all of the interviews myself. This can be of benefit in terms of creating low-inference descriptors and reliable written transcripts (Silverman, 2014) but the drawback is that it takes a significant amount of time for the researcher. The process of familiarising and transcribing enabled me to employ pattern recognition when listening back, typing and editing transcripts, identifying strong similarities between the data sets at an early stage and making notes of these. Towards the end of each interview, I would contextualise the participant’s contributions in terms of what I had heard already with a short comment, for example; ‘I’m hearing this from other parents too...’ (LA interview with *Sarah*, a parent) which prompted the participant to expand on their experience further, and ‘it’s been really lovely to have a positive conversation’ (LA interview with *Zuzanna*, a parent) which prompted the participant to again acknowledge that their experience is not usual; that they know from their own experiences that many families have difficulties with the EHCP process. The purpose of this is to see if participants recognise their own experience in the emerging data (Merriam and Tisdell, 2015) without providing further burden by emailing over multiple pages of written data from a lengthy interview that may have taken place quite a while ago or conducting member checking later down the line. I was not against the idea of providing full transcripts to participants, and if this was requested, I would have been able to do this before the data was anonymised and analysed, but no participant asked to see the transcripts or the data, or to remove or redact anything that they said during the interviews. This allowed me to reflect on the process whilst still engaged in it and allowed participants to see their contributions in the context of the wider dataset, recognising their experience in the context of the experiences of others.

Generating initial codes

I have used data-led (or, inductive) codes, allowing the participant views to form the key themes and findings of the research. This is important when carrying out research with groups and participants who have historically been marginalised from research processes and wider fields, as their voices and views need to have the primary focus. This also means the interpretation level is minimalised- the purpose being to minimise researcher skew or bias. Researcher subjectivity can be viewed as a valuable asset in qualitative data analysis if the research is able to work in a reflexive way (Braun and Clarke, 2022) rather than seeing bias as an issue to be eliminated. This also means that the codes and categories can shift and change through the process of coding (Braun and Clarke, 2022) because of the inductive nature of the process. I used NVivo to assist me with the coding and sorting process; I was able to upload all the transcripts to the software and run some word frequency and recognition processes first, before thoroughly reading and coding each transcript separately, with codes and patterns that were identified and evolved. NVivo was my programme of choice because my university subscribes to it- not a good justification on its own for doctoral research (Newby, 2014) but the university does also provide support to access and use it, and it also had data coding tagging and analysis features useful in this project. I am also already adept at learning how to use computer programmes, so the benefit of being able to organise and analyse the data in this way outweighed the cost in time of learning how to use it, an important consideration for researchers to make (Merriam and Tisdell, 2015). After this I was able to use these early analyses in addition to the patterns I had seen in the data from familiarisation and transcription to form some early codes. I worked my way through each transcript to identify elements that are 'interesting or potentially relevant' (Braun and Clarke, 2022, p.61) and either tag them with the early codes identified or assign them a new code. In addition to NVivo's electronic coding and storage, I also kept written notes as my thinking and the codes developed so I had a record of how this was developing in my research journal. I was then able to use NVivo to see all the data highlighted by code, to see if the code had brought together a coherent set, review each code using the inverse of the 'take away the data' exercise (Terry, Hayfield, Braun and Clarke, 2017, cited in Braun and Clarke, 2022) whereby I looked at whether I would be able to identify the code using just the data extracts.

Once I had completed these early coding stages, I was able to go back through each transcript to ensure that I was applying the codes similarly across the data set; as codes develop, there was a chance a newer code had not been applied in a transcript I had analysed earlier in the process. I did this in a different order to avoid uneven coding or the more sophisticated analysis being reserved for the transcripts viewed later in the process (Braun and Clarke, 2022). This process is not linear but 'recursive' (Braun and Clarke, 2006, p.86) whereby the researcher will need to move backwards and forwards through the data to make sense of it. A drawback of this approach is the time it takes to review data again and again, however in order to analyse evenly, this was necessary.

Searching for themes

Once the data has all been coded and a list of codes produced, the next stage is searching for themes; bringing the codes together to create overarching themes (Braun and Clarke, 2006). When bringing codes together to create themes, I used a coding table in a Word document (appendix 1), grouping codes that referred to similar areas, and looking at these by research question. I also used spider diagrams in a written notebook to see these connections visually, and where there are similarities or overlap (examples can be seen in appendix 2). I was inspired to do this by accessing written and video material by other researchers (Braun and Clarke, 2022; Adu, 2023; Cadigan, 2022). Some codes fitted easily together and were able to form themes and sub-themes, especially where I had noticed when coding that there was some overlap between them and found it difficult to separate them when identifying relevant material. Some codes did not fit into a theme, and I was able to group them for now as miscellaneous (Braun and Clarke, 2006). I wrote ‘the story’ of each code so I could see easily at a glance what it referred to and see where the similarities were. This is not the stage to leave anything out or discard ideas and codes (Braun and Clarke, 2006) so I left everything in for the next stage, despite this making for quite an unwieldy data set- over 30 codes linked to 12 written transcripts. This translated into 12 initial themes with sub-themes linked to the codes.

Reviewing themes

In reviewing the themes I identified initially, I found that some themes did not relate strongly to the research questions, some were descriptive, others did not expand beyond the initial coding, and there was some repetition and overlap in the themes. Sometimes multiple themes can be folded into one, or it becomes evident that an identified theme is not actually a theme, for example there is not enough data to support it (Braun and Clarke, 2006). To review the themes in more depth, I considered how I would move beyond doing this in an isolated way. Mertens and McLaughlin (1995, p.53) suggest a lengthy discussion with a ‘disinterested peer’ to process the experience of data collection and guide the researcher to consider how they will progress the research. Once I had brought together the data under each theme and sub-theme, I had a discussion with my partner, a fellow academic though with different research interests, in a sounding board exercise, to clarify my own thoughts about the themes and how I would discuss these with my advisory group. I also discussed these themes and sub-themes with my supervisors during their development. I conducted less formal validation by taking early identified themes from the data to advisory group members rather than member checking, as a way of improving validity. I took with me details of the themes in the form of theme title, ‘story’ of the theme (including a brief description of the theme itself and some key participant contributions to illustrate it) and an idea of the strength of the theme (how many participants had discussed it and how many contributions it was coded against). I was able to discuss these with advisory group members and take feedback about the issues covered and the construction of the themes. It is good practice to consider getting feedback on findings (BERA, 2018) and though there are still issues with this approach including potential researcher skew and the issue with advisory groups not necessarily being representative, this was the best way I felt I could get feedback on the themes before fully defining them and writing up the report. By the end of this stage, the researcher should have a good idea of what the themes are, how they fit together and how they explain the data (Braun and Clarke, 2006), which I felt by this point, I did have.

Defining and naming themes

Having had discussions with the advisory group members to check the relevance, relatability and organisation of the themes, I sought finalise each theme and give it a name that represented the ideas within it to give the reader a clear idea of what the theme is about (Braun and Clarke, 2006). This part of the process involves not just identifying the story of each theme but also how the themes come together to tell the overarching story, linked to the research questions (Braun and Clarke, 2006). I kept the theme names simple, not wanting to complicate the process or move too far from the core message of the theme; this sometimes included using words or quotes that participants had used in interviews. I was able to test out the distinctness and boundaries of each theme by writing a couple of sentences about each theme in the form of an abstract or summary (Braun and Clarke, 2022). I needed to ensure that the analytical intent was clear in the name of the theme, which meant moving away from single word theme names and making sure that I had not created topic summaries rather than themes (Braun and Clarke, 2022). I did not find this part fun, as Braun and Clarke (2022) report it can be, as it was extremely lengthy and stressful, and I continued to revisit it over many months and through writing the report. I also felt this was an important part of ensuring participant contributions and experiences were not obscured, made light of or taken out of context.

Producing the report

Writing up the data involves analysis, so must be considered part of the analytical process (Braun and Clarke, 2022) in which the researcher is encouraged to ‘Choose particularly vivid examples, or extracts which capture the essence of the point you are demonstrating, without unnecessary complexity' (Braun and Clarke, 2006, p.93). To avoid manipulating the data to show an incomplete or incorrect picture, sometimes it is helpful to include the question that prompted an answer or provide long excerpts from the written transcripts (Silverman, 2014) that contextualise a contribution. I have worked to balance providing detailed contributions and relying too heavily on participants' words when introducing and discussing the themes. This is because the purpose of the Findings section is moving past describing the data to make an argument about the data and address the research questions (Braun and Clarke, 2006). This is where I needed to move beyond just providing long participant contributions without situating it in the overall argument and the related topic literature. I also needed to consider the order in which I presented the themes. I decided to start with themes that focused on the process of creating the EHCP and move on to themes that consider the written EHCP itself with a broadly chronological order. These combine my analysis of parent and young person contributions alongside the contextual literature. When I had produced the report, or, written up the findings, I was then able to move to considering my chosen theoretical concepts and how these appear in the findings for the Discussion chapter. The Findings chapter containing the inductive analysis combines with the theoretical Discussion chapter to make up the process of reflexive thematic analysis (Braun and Clarke, 2022).

Quality in qualitative research

There are many ways of assessing quality in research, but many of these focus on attributes of research that are more quantitative in nature, for example validity, reliability and objectivity (Newby, 2014) which are not necessarily appropriate to try and measure in qualitative research. Similarly, triangulation is often used as a measure of reliability in research; Stake (2003) links triangulation to replication or repeatability, considering quality research to be repeatable and use multiple perspectives to confirm meaning. In this sense, this research is repeatable to an extent; I am providing enough information and being transparent enough that the study could be replicated by other researchers but different findings by other researchers would not undermine my findings, just as my findings would not undermine those found by researchers carrying out similar research. Reliability is considered problematic in all qualitative research (Clark et al, 2021) not least because reliability is ‘based on the assumption that there is a single reality and that studying it repeatedly will yield the same results’ (Merriam and Tisdell, 2015, p.250). This is at odds with my research design and frameworks so instead I consider whether the findings I present make sense in the context of the data collected, termed by Guba and Lincoln (1985, cited in Merriam and Tisdell, 2015) as consistency. This is a form of internal validity, rather than reliability, ensuring that I am collecting authentic data and drawing appropriate conclusions that make sense within my topic of study. Consistency can be improved in other ways such as pre-testing the interview schedule (Adams et al, 2007), or topic guide, which I did with the advisory group members, and providing an audit trail (Merriam and Tisdell, 2015) using the principle of transparency- ensuring that throughout the project, the researcher details carefully their decisions and how they came to them. This can include removing statements such as ‘data were processed with NVivo’ (Paulus et al, 2017, cited in Cohen, Manion and Morrison, 2018) and explaining exactly what was done in the project. Another way of showing transparency can be keeping a research journal or recording memos about interactions with the data (Merriam and Tisdell, 2015) which I did in the form of a written diary where I wrote about my own feelings about the process and a more formal record of entries where I made notes about which ideas were coming up after the interviews (a physical notebook and a Word document).

Validity in qualitative research looks different to validity in quantitative research- in quantitative research it asks for elements such as control of variables, neutrality of researcher, predictability and randomised samples (Cohen, Manion and Morrison, 2018) which are not suitable measures by which to understand qualitative research. Validity in qualitative research has been reframed and renamed by Guba and Lincoln (1985, cited in Merriam and Tisdell, 2015) in its two parts- internal validity as credibility (as discussed above) and external validity as transferability. Transferability relates to the ability to generalise findings to wider populations, though rather than trying to generalise small-scale studies across populations, focusing instead on providing enough detail on the study and its findings that other researchers may be able to apply it elsewhere- in different contexts, situations or settings (Guba and Lincoln, 1985, cited in Merriam and Tisdell, 2015). Transferability does not seek to claim broad generalisability, but to allow individuals to decide whether and to what extent the findings apply to them (Braun and Clarke, 2022). Emancipatory research is not usually seen to be generalisable (Kiernan, 1999), nor is case study research (Stake, 2003) and many case study researchers remain clear that representativeness or generalisability is not achievable in small-scale research like this. It does however help researchers find the limits of generalisability, as well as refining theory and finding areas that require further study and understanding. I would also suggest that user generalisability is applicable here too- the person who reads the research can decide whether or not it applies to them, in their case or in their situation, as long as the researcher has given sufficient detail for them to be able to make this decision (Merriam and Tisdell, 2015). In order to understand whether this might be applicable, I conducted validation 'out of sample' (Adams et al, 2007, p. 146) but not for the purpose of being able to generalise the sample over broader populations- just to see whether issues raised are in line with the knowledge of others who had experienced the process. I did this by taking the early findings back to my advisory group members to see whether they resonated with them. This is also linked to extrapolation (Patton, 2015, cited in Merriam and Tisdell, 2015) whereby rather than using a statistical generalisability concept, one gently and modestly considers whether it is likely that similar findings could be found to be applicable in similar situations. This concept recognises that generalisability is not possible in qualitative research of this nature; it would not be possible to create exactly the same conditions for this research again, but a question could be raised over whether the findings might be applicable for others who find themselves in similar contexts and situations. This also fits with the idea of a case study highlighting exemplar cases (Stake, 2003) and finding similarities and patterns across collections of cases (Yin, 2018) which is appropriate in this research. This is known as analytic generalisation (Yin, 2018) as opposed to the statistical generalisation that is usually linked with quantitative research.

Another crucial indicator of quality in qualitative research is acknowledgement of researcher position and the work to understand the impact of this on the research, or what would commonly be called reflexivity. Reflexivity is usually considered 'a concept of qualitative validity' (McCabe and Holmes, 2009, p.1518)- qualitative researchers bring their own set of values and experiences that will have an impact on the research they do in every stage, from conception and design, engagement with participants and analysis and interpretation of data (Cohen, Manion and Morrison, 2018). There is dispute amongst researchers however about whether reflexivity should be about working to reduce the impact of the researcher on the research or acknowledging and accepting that the researcher and their views and experiences will always have an impact on research. In the latter case, the discussion should be about what that impact looks like, as McCabe and Holmes state, rather than 'attempting to control social forces, we can identify the role and impact of the forces' (McCabe and Holmes, 2009, p.1522). Generally, there is agreement that researchers should attempt to be unbiased, whilst still acknowledging and working to understand the effect of existing researcher biases on the research (McCabe and Holmes, 2009) and this can include by employing Foucault's 'technologies of the self' to move reflexivity further towards emancipatory aims (McCabe and Holmes, 2009). Acknowledging the regimes of truth that exist around specific phenomena or discourses and the behaviours that are attached to them, and then working to create new selves and new behaviours move critical reflexive research towards emancipation (McCabe and Holmes, 2009). For me, in this research, I first acknowledge my axiology and positionality, when designing the research and at the start of this chapter. I approach this research from a rights-based position, with consideration of Foucauldian principles of power/knowledge, along with my own experiences of disability, SEN and the implementation of this specific element of policy (EHCPs and family involvement). Though I worked to limit my own influence on the research by working with an advisory group, adapting my language to fit with the recommendations of disability rights activists and scholars, attempting to pose open questions that were not leading in nature, carefully analysing the data and sharing themes and ideas with advisors, and drawing conclusions that relate strongly to the themes, I cannot deny that this research shows my influence throughout. The idea of 'continued reflexivity' is prompted by Bradbury-Jones (2007, p.291) in order to improve rigour, credibility and overall quality in qualitative research, rather than employing reflexivity after the fact. This example advocates for the use of a reflexive research journal throughout the process, which I did do however this was not as consistent as I would have liked it to be. A reflexive element that I did engage with consistently is the use of 'I' in the research and accompanying documents, which Finch (2016, p.6) states can demonstrate 'exploratory, questioning and reflexive researcher positioning that aims to get beneath the surface of everyday phenomena'. This is what I sought to achieve with this research, to move beyond researcher positioning that simply acknowledges ideas around reflexivity to engaging actively with them for the benefit of the research quality.

Ethical Considerations

In this sub-section I focus on the ethical considerations made as part of planning and carrying out the research. I discuss the positioning of the research as between educational and social research and taking account of the guidelines produced by the British Educational Research Association (BERA, 2018) and the British Sociological Association (BSA, 2017) with additional regard to the National Children's Bureau's Guidelines for Research with Children and Young People (NCB, 2011). I also consider the theoretical study of ethics, and how this has been applied in the work of others, and discuss my own ethical considerations and applications for approval, with Clark et al (2021) stating that engaging with these processes decreases the likelihood that researchers will 'transgress ethical principles' (p.7).

Ethical Approval

Throughout the research process I have been committed to upholding the ethical guidelines appropriate to my project. Given that this research sits between and within educational research and social research, I chose to use the British Educational Research Association (BERA) Ethical Guidelines for Educational Research, fourth edition (BERA, 2018), which at the time was the most up to date version, in combination with the British Sociological Association (BSA) Statement of Ethical Practice (BSA, 2017). I did this to ensure that I was acting ethically with every planned decision (procedural ethics) and with any issues that arose in the process of doing the research (micro-ethics) (Guillemin and Gillam, 2004).

This project was subject to intense ethical scrutiny from the university research ethics committee before approval was received (appendix 3). There is tension between ethical governance and participatory and emancipatory forms of research; where an ethics committee cannot be flexible or give staged consent, the details of the project must be given up front, including an illustrative sample of questions that could be asked during an interview, which I provided in the form of an indicative topic guide (appendix 4). The issue here is that I was aiming to design the research alongside my advisory group, but I could not approach or recruit my advisors before I had full ethical approval from the institution. I had to be prepared to re-negotiate ethical approval should the direction of the project not be as I anticipated.

The potential inclusion of children and young people constructed as ‘vulnerable’ by ethics committees and government of academic institutions meant that the project had to be carefully negotiated. The idea of vulnerability is highly contested, and whilst I recognise the need to protect participants who are at risk of being exploited, practices to prevent this can often exclude participants who have a contribution to make. Given the issues in recruiting children to the research, my focus shifted to recruiting parent participants, and young people who had themselves been through the EHCP process and wanted to share retrospective reflections. The considerations I had to make around having adult participants are quite different to those made for disabled children and young people, however there are still many elements to take into account.

I also made an application to amend my existing ethical approval for change in recruitment practices (appendix 5), in order to use Teams as a way of including students at my workplace who are parents of children with an EHCP and wanted to volunteer as participants in the research. I had to employ deep consideration of power relations in these situations because of the risk of students thinking this could for example give them extra credit in assessments. BERA (2018) suggest careful consideration of research that takes place between student and lecturer and urges researchers to be clear about their researcher role and make sure students know that they are allowed to refuse to participate. Where students showed an interest in participating, I wanted to ensure they were protected and that I was transparent about my recruitment and safeguarding of students before I recruited them. Students who did participate were able to show that they understood there was not a link between participating in the research and their own programme of study, and I did not interview any students that I directly taught or supervised in any capacity. They were able to express their own reasons for participating linked to their own experiences with the EHCP and their own families. I made a final application to the ethics committee in order to change the title of the research to represent the shifted focus (appendix 6).

Informed Consent

Adult participants were recruited by an opt-in consent process and were given the opportunity to withdraw their participation at any point during the data collection process, in accordance with BERA guidelines (2018). The information sheets and consent forms for adult participants (blank copies included in appendix 7) gave potential participants detailed information about the research project, its aims, and the methods that would be used to collect data. I designed different information sheets for parents consenting to child or young person involvement, and young people consenting to their own involvement, but these were not needed. I had also created different forms of information sheet for children with different levels of understanding and a script for a video information sheet with captions and annotations, but I did not use these. The considerations for including children and young people in research is quite different to including adults; a process of ongoing consent (Connors and Stalker, 2007) should be employed with children and young people, whereby an initial indication that the child or young person is interested cannot be taken as a final decision for their involvement in the research project, though I consider this appropriate for all participants.

I interviewed one young person (of adult age) who was able to communicate verbally, give informed consent and participate in the same way that the parent participants were able to, so whilst I was still aware of non-verbal communication and behaviours, I did not have to move into discussions around assent or implied consent at all for the project.

To remain in line with the BERA guidelines (BERA, 2018), the British Sociological Association guidelines (BSA, 2017) and the NCB guidance for research with children and young people (NCB, 2011) I did not pressure parent participants into allowing me to interview their children for the purposes of this research; I expressed an interest and asked where appropriate, but I did not repeat this request if the parent expressed reluctance or concern. Parents shared with me many reasons they thought that their child would not want to or be able to participate in the research including that the child had not been told about the EHCP, the child knew about but did not understand the EHCP, the child knew about and understood the EHCP but actively disliked being associated with it or talking about it, and that their child would not want to talk to somebody they did not know.

The information sheets provided to potential participants included information on the core ethical principles underpinning the research; right to withdraw, the safe storage of data including the use of recording and storage and deletion of this, use of data, confidentiality, renumeration and use of data. I needed to make clear to potential participants that they had rights in agreeing to participate in the research, and what those were (BERA, 2018). The benefit of providing this in written form, either on a physical printed copy or an emailed electronic copy is that participants are able to refer back to this information if they have questions, concerns, or need to contact myself or my director of studies (BERA, 2018). I have discussed each of these areas in the sections below.

Right to withdraw

It is important for participants to know their participation is voluntary and that they can withdraw at any time with no detriment (BERA, 2018) but once the data has been anonymised, analysed and included in the discussion, it will not be possible to withdraw data from individual participants. I made sure this was made clear to parent participants from first contact, when I emailed over the information sheet and consent form for their consideration before organizing an interview. I also reiterated this verbally, with the offer of an exact cut-off date, with assurance that the approximate date was a month or two in the future so they had time for a ‘cooling off period’ if they felt they had said something they did not want included. No participant wanted to withdraw once they had arranged an interview and no participant asked for a cut-off date by which they would be able to withdraw their data, but two participants did verbally check with me that all information would remain anonymous before signing the consent form; one asking if I would be playing the recording to anybody else, and one asking specifically if anybody from their local authority would be able to hear the recording. There were occasions where participants looked to me for reassurance either during or after the interview, asking questions to confirm what would happen with the audio recordings and who would have access to these, and also to check that details they gave would be made anonymous. I reiterated information about the safe storage of the audio recordings and that they are only for me to listen to so I am able to accurately transcribe our conversation. This however does demonstrate a level of concern that participants have about what happens to their contributions after the interview.

Storage, use of data and confidentiality

Data generated in the course of the research was retained in accordance with the University's Data Protection Policy, including stipulations from the ethics committee and as per the approved data management plan I created (appendix 8). In line with the guidance from the university ethics committee and in accordance with the 2018 Data Protection Act (HMSO, 2018), my audio files were stored on a password protected device, before being transferred securely to the university OneDrive, and written files were sent only via the university email and stored on the secure servers. Access to these was not shared with anybody else. Once audio recordings had been transcribed and I had checked them again for accuracy against the written transcription, I deleted them, as was my agreement with the university and the participants. The written transcripts have no identifying information in them; I removed peoples' names, names of boroughs, schools, services and schemes, any other specific or significant details that could reveal the identity of any of the participants, ensuring that participants would not be able to be identified from them. Transcripts were again stored on a password and fingerprint protected desktop computer and uploaded to the secure university OneDrive for storage.

Confidentiality and anonymity are important to uphold in protecting participants (BERA, 2018) and I worked to uphold these principles in recording, storing and reporting data. This included paying attention to what I was transcribing and also how, when and where I accessed recorded interviews in order to transcribe them- I did this privately in my home, using headphones to prevent this being inadvertently overheard. I was able to uphold confidentiality in all cases but participants were told in advance that if any disclosure was made that the participant or someone else is at serious risk of harm that I have to report that to the relevant authority, which I would have done after discussing it with my supervisory team, in accordance with the BERA guidelines (2018).

Remuneration

I did not offer payment to participants; remuneration is usually discouraged in educational research because of how this might become burdensome to the practice of carrying out research (BERA, 2018) and I did not have a budget attached to the research project. A linked issue is whether advisory group members should be paid for the time they spend involved in the research; though this is not mentioned in either of the ethical guidance documents I used in the research (BERA, 2018; BSA, 2017) it felt like an ethically difficult area for me but without a budget for the research project and without the ability to pay using accepted formats, I instead decided to send tokens of my appreciation and thank you cards after the final advisory group meetings.

Transparency

I was able to be completely open and honest with all stakeholders in the research, in line with BERA (2018) and share all relevant and appropriate information with the ethics committee, my supervisors, the members of my advisory group and my participants. Deception, or non-disclosure is thought to be justifiable in a small number of research topics (BERA, 2018) but this did not apply to the topics I am researching, so I was able to give clear information about what the research is about, what participants would be asked to do, what would happen to their data and how it would be stored and used (BERA, 2018). I am committed to avoiding deception of all forms in the research, but this does not mean I should overshare information that has not been invited. If participants ask about my background or experience, or if it helps in making a connection and keeping conversation flowing, I can share this with them, but I maintain a balance between connection and professional boundaries (Griffith, 1998). I used the concept of reciprocity (Cohen, Manion and Morrison, 2018) whereby to create a conversational experience, a researcher must give as well as take to foster the research relationship and avoid awkwardness; reciprocity is also seen as a core feature of emancipatory research by Oliver (1992). An example of this from the study is when a young person participant was discussing their experience of a condition we have in common, their tone became stilted as they were seeking to explain and justify their experience with a symptom. Once I had disclosed that I had recently been diagnosed with the same condition and that I experience the same symptom, the participant visibly relaxed and their laughter and the speed and enthusiasm of their speech increased. They seemed generally more comfortable and open in the conversation.

Risk, Beneficence and Non-Maleficence

Research that focuses on policy is not usually linked to immediate impacts on the situations of the people that it focuses on (Kiernan, 1999) so benefits that come from the research may be longer term. The hope is that this research contributes to firstly different and more ethical and representative ways of doing research, but also to the picture of the situation for the families of disabled children and young people, and those with SEN. Other more direct benefits of being involved in this kind of research for young person participants can include increased self-confidence and self-esteem, the opportunity to discuss their experiences, feeling that their voices are being heard and valued, making decisions, and increased feelings of independence which have been found in participants of similar research projects by Bailey et al (2014). Even in research in more sensitive topics, benefits for parent participants have been seen to outweigh risks, with Hopper and Crane (2019) reporting minimal burden and distress and increased empowerment, the ability to reflect on their own experiences and find meaning in them in research with parents of children with life-limiting illnesses (Gysels et al, 2012; Kavanaugh and Campbell, 2014; Aoun et al, 2017 cited in Hopper and Crane, 2019). This is reflected in not only the interviews I carried out to collect data but also the advisory group meetings I held, with participants and advisors reacting positively to interviews and discussions, for example, seeing the meaning in and the importance of the research, offering to help further, apologising for offloading or for discussing information they felt might not be relevant to the research, thanking me for listening and for the work I am doing, expressing that they had enjoyed having the conversation, excitement at being asked to be involved, saying how helpful it is to be able to discuss these issues with someone else.

No research is without risk, and in planning for this research project I identified a number of potential risks to participants. I had already identified some of the issues that families face in accessing the EHCP from reviewing the literature, so I was aware of how stressful the process can be for some families. I was also aware that the EHCP had been seen in some research as a ‘fight’, and often not the only situation where families had to fight for support, so I recognised that this topic had the potential to be upsetting for participants.

To mitigate these risks, firstly, the voluntary nature of the research was emphasised throughout so that potential participants were able to make an informed decision about whether participation was right for them. I was also sensitive to signs that participants may no longer want to be involved, including in video call interviews any non-verbal signs that may mean consent had been withdrawn. In planning for this I created a debrief sheet with contacts that can be used for support, though many participants had already mentioned most of the resources on the sheet during the course of the interview. The participants I interviewed were generally well-connected, linked to many sources of support and in some cases doing work for the charities and services I would have suggested for support. For those that were not and wanted to know more about the process, outside of the discussions we ended up having at the end of the interview and the information I was able to give, or access additional support, I was able to direct them to local and national services via weblinks.

Conclusion

My focus for this chapter has been to discuss and justify the research design decisions for this project, as well as giving an account of the process from conceptualising to write up. I was able to recruit an advisory group and then plan a piece of research with their input on focus and key methodological elements. I was able to interview 12 participants from 8 different local authorities across England and transcribe and analyse this data using inductive, data-led codes in a thematic format. I have also thoroughly considered the ethical issues associated with the research project, including informed consent, right to withdraw, safe storage of data and transparency in research. Throughout I have considered my own positionality and how this impacts methodological decisions, interactions with participants, analysis and interpretation of data and eventual identification of key themes, and crucially how I work to limit the impact of my own positionality on these areas, demonstrating reflexivity.

The plans I made for the project needed to be reviewed and amended through the process of carrying out the research, particularly in the context of a global pandemic. I needed to shift the focus and change my recruitment and interview plans to ensure I was able to include as many contributions as I could in the most ethical way possible. The results of the inductive analysis will be presented next in the Findings chapter, followed by a discussion of these findings linked to my chosen theoretical concepts in the Discussion chapter, which together make up the reflexive thematic analysis (Braun and Clark, 2022).

Chapter 5- Findings

Introduction

In this chapter I present the findings from the research project in the context of the existing literature. I have conducted a reflexive thematic analysis (Braun and Clarke, 2022), firstly using data led coding and thematic grouping of data, the themes of which I present and discuss below. I then take the key findings forward into the Discussion chapter, where I unpack and develop these themes in the context of the work of Foucault and the broader theoretical framework, examining power relations, discourses, regimes of truth and governmentality. Participant contributions have been anonymised and are represented by pseudonyms. The themes identified from the thematic analysis are displayed in the table below (figure 6).

Theme	Sub-Themes
1. Knowledge is Power	1.1 Expert Parents 1.2 Parents Driving the System 1.3 Disempowered Families 1.4 Experiential Knowledge and Solidarity
2. Problems with Partnership	2.1 Professional Power and Families 2.2 Differing Involvement of Children and Young People 2.3 Partnership Postcode Lottery 2.4 Problems with Collaboration 2.5 ‘That’s been manifested from above’; Politics and Power
3. Negative Impacts on parents	3.1 Time Burden 3.2 Financial Burden 3.3 Physical and Mental Toll 3.4 Blame and Reputational Burden
4. Expectations vs Experience	4.1 ‘What?! What do you mean this doesn’t work like this?!’ - Statutory Processes and Responsibilities 4.2 Overpromised and Underdelivered 4.3 Gratitude and Lowered Expectations
5. ‘It’s just a piece of paper in my name’- Where is the child in this plan?	5.1 Factual and Administrative Errors 5.2 Deficit Portrayals of Children and Young People

	5.3 Evidence and Outcomes- the importance (and lack) of clarity 5.4 A Piece of Paper.. With Power?

Figure 6: Summary of themes

Theme 1- Knowledge is power

The first theme relates to the knowledge that parents have developed through the EHC process and plan, and how they use this knowledge to navigate (and often drive) the process, and support others through it. Parents in this study report very different levels of understanding of the process and differing roles and levels of involvement in the process and in parent-led support communities.

1.1 Expert Parents

Many of the parents involved in this research had expert level knowledge about the Education, Health and Care Plan and Process, sharing how well they understand the plan and process, as *Mike* demonstrates;

> "Yeah, I've I've made myself, a specialist, haven't I really, in essence?"

Finding that many parents have expert level knowledge about the process is overall in contrast with much of the research carried out in this area, which usually finds parents reporting they do not have sufficient understanding of the process (Ahad, Thompson and Hall, 2021; Skipp and Hopwood, 2016; Ecclestone, 2016). Several participants felt the school or local authority did not do enough to inform them about the process or their rights in accessing it, represented by this quote from *Marina*;

> "Before diagnosis I didn't know it existed, it was spouted at me on the day of diagnosis- 'you can apply for this now'.. I didn't know it might be difficult to obtain or that we might not get it, we did it without thinking..I never understood what we could gain from it- nobody said what it could lead to- it was never really clear what we would or wouldn't get. I expected it to be a battle all the way."

Professionals have a key role in ensuring parents are signposted to important information about services (DfE and DoH, 2015; Holland and Pell, 2018) though parents in other research report not feeling that enough support is offered in terms of knowledge about the process or guidance in going through it (Hastwell and Moss, 2020). The way that parents in this study have learnt about the process differs. Some parents reported gaining knowledge about the EHCP process from their own career or experiences in education, as *Alison* did;

> "So I think with the EHCP and my involvement in it... I know they only change them when there's, like, huge differences in the child's needs or if there's a transition. But I only know that from work"

Some parents were advised by specialist SEN charities, for example IPSEA, and a few were given information about the process by their child's school. Most parents reported having to do their own personal research about the process which is summarised by the quote below from *Amani*;

> "I just say personal research.. there's never been an incident where I've sat down with a professional during the procedure with [child] and someone's gone 'let's fill you in with the EHCP, you won't need to go away and do any research. This is everything you need to know'.. actually, I don't think a single professional has ever gone through it actually to tell me what it is. You just. I guess you have difficulties and then you go away and do some research and you think 'what are my options?' and you go back and forth"

As well as learning as they go with the process, as *Sarah* did;

> "I guess maybe from just having a child with SEN, having to apply for one, seeing how chaotic that process was (laughs) and just having to figure it out really."

Often the level of knowledge that parents have about the process and the plan itself involves parents taking on roles and responsibilities that they do not feel they should have to take on, including writing the plan or sections of the plan itself, as *Abbie* expresses;

> "If I was a different person I might have signed it, but I refused. I had to re-write it with the school and now it's been the same for 3 years, it's her to a tee [daughter]. We tweak it to add goals etc"

Similarly, *Louise* expressed how she was asked to rewrite a key section in her daughter's EHCP;

> "The other thing they asked me to do was to rewrite section F [provision needed to meet the child or young person's educational needs] how I'd like it worded.. (laughs) like.. how do I know what provision there should be, you know, I could probably give it a pretty educated guess, this sort of thing, but also why should I have to"

Section F refers to the provision that needs to be in place in order to meet the child or young person's educational needs, which the local authority has a duty to ensure the child receives (DfE and DoH, 2015). This section should be co-produced with input from appropriate professionals, and should not be left to families, who report feeling resentful at having to know enough to do this, as *Louise* follows up to say;

> "you know as a parent, I don't wanna have to know the law... I think that there is a role for people who are professional, who are experts and who are trained and knowledgeable, and I don't wanna have to be trained and knowledgeable enough to know the whole EHCP process.. you know I'd just actually like as normal a life as possible (laughs) I don't wanna have to do this.."

Many parents also reported having to drive the process towards creating the EHCP themselves, as shown by *Elizabeth*;

> "Everything that's moved forward is off the back of the work that we do and what we pay for and what we drive forward"

Furthermore, parents questioned the knowledge of the professionals involved, as many reported that they frequently had more knowledge about the EHC plan and process than the professionals involved in their child's EHCP. This was important because many families felt that the outcomes of the meetings, annual reviews and having a good EHCP plan and or process was dependent upon the professionals involved in the support, as *Amani* expressed;

> "it depends as well how confident the people are that are involved in the process and how in tune they are."

Or as others shared, more specifically the school, the SENCO, or even the class teacher, as *Abbie* shared;

> “It just seems if you have a good teacher, you get a good plan, if you haven’t, you don’t.”

Differing knowledge of staff impacting upon experience has been seen in the literature before though from the perspective of a generally positive experience for families (Sales and Vincent, 2018) and from the perspective of SENCOs feeling that differing levels of knowledge was mostly observed in health and social care professionals (Boesley and Crane, 2018). Expert parents in my study often reported that their level of knowledge was not valued by the professionals involved in their child’s EHCP, when asked, as *Sarah* did;

> “I don’t know that they particularly like being challenged, so I wouldn’t say they value it....I don’t think that it’s perceived as a positive thing by the people in the room at all.”

Similarly, where parents had shared knowledge that contradicted that of the professionals, this was not welcomed, for example when I asked whether he felt his knowledge and contribution was valued by professionals in his example of a situation where he steered them towards following the law, *Mike* responded;

> “No, no, not not, in fact quite the reverse. It feels, or it.. I observe that people who are in their.. the place of work, in a position of some power, however limited that might be, feel belittled by someone who points them to the law and says you’re not following the law.”

In these scenarios, the knowledge parents have, gives them responsibilities that they do not necessarily want. The expert parent profile is characterised by high levels of knowledge about the EHC plan and process, a high level of involvement in the EHC plan and process, and often a key role in driving the process forward. This knowledge has mostly been gained from charity organisations, parents’ own research and learning from others who have already successfully navigated the system, as explored in 1.4. The high levels of knowledge that parents have about the process do not always translate into power to make change within the system, however.

1.2 Parents Driving the System

A significant number of parents in the research report having to resort to making formal complaints, taking legal action or making threats of legal action to move the process on, including using tribunal and judicial review processes. This includes taking action to get access to specific provision or support that had been recommended by professionals, as *Sarah* did;

> "So I submitted that report as part of the annual review, and after kind of, two formal complaints and a threat of tribunal, they put the OT [Occupational Therapist] recommendation [that was supposed to be there]"

And can also include taking or threatening action in order to get back a draft of the EHCP, which cannot be appealed until it is in draft form, as *Elizabeth* did;

> "So we've now got it back [written EHCP], but the review that should have been back at the beginning of the month and the only reason we got it back is because we went threatened pre-action"

Similarly in research by Sales and Vincent (2018), parents had to take a more supervisory role, specifically in chasing professionals to send reports to feed in to the EHCP process by the deadline, but this was described as parents being proactive rather than acknowledging the necessity (and potential inappropriateness) of this in order to keep the process moving to timeline. Other studies also find parents keen to be involved in the decisions made about their lives (Holland and Pell, 2018) but there needs to be a balance between involvement and responsibility for driving the process in a way that feels burdensome to families.
This finding illuminates the tribunal statistics published by the Department for Education (DfE, 2023a) and is in accordance with the House of Commons report (2019a) which found that parents were having to resort to this option where local authorities were failing to meet their statutory duties and then positioning themselves as adversaries. Having to use these complaint and tribunal systems has already been found as a cause of stress for families, with it being time- and energy-consuming, and also potentially expensive for families (Cullen and Lindsay, 2019) but one of the less stressful parts of engaging with the statutory processes- less so than giving their views for the assessment process or commenting on a draft EHCP (Cullen and Lindsay, 2019). This is significant given that there is provision in the legislation for parents to be supported to co-produce EHCPs, giving their

views and commenting on the draft plan being core parts of the process (DfE and DoH, 2015) with tribunal as a last resort after mediation processes have been attempted. There is also the option of a judicial review, where parents are unhappy with the way decisions in the EHCP were made (DfE and DoH, 2015). Parents in the research report that using these systems is not a first line response, that the tribunal is a process that they do not want to have to engage in, and it can impact further upon the relationship between the family and the local authority, as *Elizabeth* details;

> "no one goes 'oh I guess I'll go to tribunal'.. You're either going to be paying £70,000 or you've got to do it yourself, or you gonna get some legal aid help by someone that's paid minimum wage that's overloaded with cases that doesn't understand your condition but understands the aspects of the law. You've still got to do a lot of the work and know it, or you've got to do it yourself like we did. And it's really hard and there's going to be barristers sometimes up against you. So this is the situation. It's not supposed to be adversarial. Why are there barristers in there up against us?"

Some families have access to 'legal help' in preparing for a tribunal, though this is means and merit tested to a set of complex and strict eligibility criteria (LAA, 2024) and will generally not cover legal representation at the tribunal hearing (IPSEA, 2024). This contrasts with the local authority often being represented by either external solicitors or barristers in court (House of Commons, 2019a). If indeed tribunal hearings were rare and a last resort, this would perhaps be less worrying in terms of the costs incurred by local authorities, which could be instead used to fulfil the support listed on the EHCP. However, parents report that the tribunal now forms part of what many parents expect to experience when accessing support for their child through the EHCP process, as *Sarah* shows;

> "it's meant to be an easy system to navigate for parents, you know you shouldn't have to have legal representation but that's not the reality."

Families should receive information and guidance with regard to the complaints and tribunal process from their local authority (DfE and DoH, 2015) but this does not always happen in practice (Adams et al 2017). This leaves parents to seek out this information and support themselves. This has been found to be carried out most often by mothers, who have been found to be disproportionately impacted by this work (Thomas, 2021). I explored this in the Literature Review, but it was also discussed by several participants in this research project, unprompted. This was raised in relation to the impact of preparing for and engaging in planning or annual review meetings for the EHCP, for example, as *Louise* shares, she is well-placed to answer questions, but they are often directed towards her husband;

> "the other thing as well I find interesting is some of the gender stuff, erm I think that they have previously, the way that they talked to me or responded to me in a meeting is different to if [husband] is there. And if he's there, they defer to him. They ask him. And that drives me insane, because his knowledge of the SEN system is like.. He leaves it all to me. And he has no clue… He notices it too, because he'll say, why are they asking me? I don't know"

And for *Amani*, who shares that she prepares for meetings herself and also gives her husband notes and questions to ask;

> "This is then the.. unintentional sexist impact because all the people that are doing this extra research, I bet you, are the women. There's no way my husband's done all this research...even things like the amount of school meetings I turn up to it really grinds me sometimes that it's like 'you only turn up to the important ones and you're only reading off the notes and asking the questions I've asked you to ask'. It's not acceptable really. And then, like, that's embarrassing that I'm a feminist and I let you get away with that. It's just shit"

Mothers are often seen to be engaging in most of the driving of the process, doing the majority of gathering of information (Thomas, 2021; Runswick-Cole and Ryan, 2019) and fighting for resources (Thomas, 2021). This gender difference and focus on mothers specifically has been reported in research in the fields more broadly; Douglas et al (2021, p.40) discuss the construction of the 'mad mother' "who makes "unreasonable" demands on strapped education and health care systems in seeking support for her disabled child" which positions mothers as not only acting unreasonably in asking for what her child requires for support but also that she presents a burden to a system already experiencing shortages.

1.3 Disempowered Families

By contrast to the 'expert parents', other parents in the research felt that they do not have very much knowledge about the EHC plan or process at all, as *Ellie* shared;

> "it was very much the school went 'We're doing an EHCP for [child]. We wanna get started. Can you just consent?' And I basically just went along with what they wanted me to do...There wasn't a lot of explanation."

This is more consistent with research that has previously been carried out with parents, who have reported that they do not feel they have sufficient knowledge of the EHCP process (Ahad, Thompson and Hall, 2021; Ecclestone, 2016; Skipp and Hopwood, 2016). This was also apparent in my interview with *Kate*, a young person, who had experienced the EHCP process, but it had not been explained to them or their parent;

> "if somebody had just sat down and said to me, look, this is this, that would have been fine. You know, I would have got it. I would have understood it completely. I then would have been able to explain it to my mum, who again, she didn't understand. She honestly had no idea what was going on."

Disempowered families are characterised by a lower level of knowledge about the system and processes and a lower level of power within these systems. This should be addressed by the local authority duty to inform and educate families about the processes, system, and their rights within this (DfE and DoH, 2015), though this is not always the case, suggested by *Sarah* to be deliberate;

> "bizarre system, it almost benefits from the fact that it's not easy to understand"

Where families have been excluded from the process or have minimal input into the process, they reported higher incidences of provision being discontinued or issues not followed up by professionals, as *Ellie* experienced;

> "Because the last meeting that we had, they wanted erm to see if we can push for a ADHD assessment. But then they never helped me with that. They were said they were gonna help support me with that and send me the paperwork because the doctors weren't willing to listen. Erm but then that never happened. There was quite a lot at that last meeting, they said 'ok, we're gonna put this in place' and then none of it happened."

This finding suggests that the system relies upon the ability of families to fight for provision and support, rather than it being based on rights or entitlement. This can mean that parental social and personal capital can predict support and outcomes for children and young people, as seen before in research (House of Commons, 2019a).

1.4 Experiential Knowledge and Solidarity

Overall, parents were committed to supporting and informing other families about the EHCP process. The importance of sharing knowledge was central in this study; many parents in my study see other parents as their main source of information about the EHCP, in terms of discussing shared experiences and learning about the process, for example as *Amani* explains;

> "you talk to other parents, you find that there's others in in the same boat. You have a chat, you feed off, you do more research"

But also in terms of the areas of importance in the EHCP, the areas to concentrate on in terms of clarity or legal enforceability, as *Elizabeth* describes;

> "It was other parents that have been through the process that taught us how to go through an assessment. That's how I know, BBB, FF [referring to the emphasis needed on sections B and F in the EHCP]."

Sections B and F of the EHCP need to be accurate and carefully written because those are the areas of the EHCP that refer to the child's special educational needs and the provision the child needs to meet these needs, i.e. the input that the local authority has a duty to ensure is in place (DfE and DoH, 2015). Parents in this study also report a strong sense of community and support from other parents in similar situations to them, via group text chats, online advice and support groups, and via their friendships formed with other parents experiencing the same process. In some cases, parents report this solidarity as one of the only positive elements of their involvement in the EHCP process, as *Sarah* shares;

> "there is some positivity in the way parents are helping other parents to navigate it. That's the one positive that I would take from it… it's that sort of empowering other parents is the only positive really that I've seen from this that we all help each other"

Parents in my study all report a strength of feeling for parents they perceive to be in a worse situation than they are. This was expressed in a variety of ways; feeling sorry for parents who may not have the level of knowledge they have, or the means to appeal, as *Marina* demonstrates;

> "I never felt they were like 'that family need to know this..' and I have half a brain- there is a lot of wording and I feel people might struggle- if they had issues academically."

And also feeling worried about families that will struggle and not get the provision their child needs, as *Amani* shows;

> "But then it makes you think. What about all the parents..? I mean, I'm lucky that I can advocate to this level.. which I think in comparison to a lot of parents, I'm like I, although it doesn't feel like that, but I bet I'm miles ahead of a lot, a lot more. And so it's like, wow, I'm struggling. God I just feel for all the other people that can't shout or don't even know that an EHCP exists for their kids."

This was also related to the standard of the EHCPs that families may end up with, as *Sarah* says;

> "it's a really challenging process to go through for me, and I often think, oh god, yeah some parents just would.. you know.. and you just end up with sub-standard..terrible plans that you know.. you could never really enforce because it doesn't really say anything."

Other parents of disabled children have been described in the literature as 'key enablers' for parents (Hastwell and Moss, 2020, p.21) in terms of practical advice, emotional support and by sharing their own experiences. Many parents in my study discussed concrete ways that other parents had helped them, but also how they went on themselves to help other parents navigate the EHCP system, as shown by *Sarah*;

> "And I think there are a few of us, particularly at my son's school who.. are just so.. wanting to pass this onto other parents and wanting to sort of empower them to be able to do it themselves but so many of them, they're just not gonna be able to challenge the way that I do, and I'm in a very privileged position to be able to do that with the knowledge that I have and you know the training that I've had and my background"

Similar findings were highlighted pre-SEND reforms by OFSTED (2010) with parents reporting their concern about parents they perceived to be in a worse situation. This challenges research that has suggested that those seeking for example welfare support turn on each other, using ‘scrounging’ narratives (Patrick, 2016) to further their own cause. Parents addressed what they feel is a pitting of parents against each other for limited resources, and their resistance to this, as *Elizabeth* shows;

> “the words they use is because it ‘takes money out of the pot for every other child’... I don't just want it for my child, I want it for all the children.”

Another way that families give each other support in the EHCP process is through sharing and learning from the stories of the children and young people who have experienced the process themselves, as a young person, *Kate*, shares;

> “yes I feel like a positive that’s come out of it is definitely just like..wanting to..share my experience with other people… well you know this thing happened, you know I had the EHCP process, it wasn’t necessarily a positive for me, but I’ve managed to turn it into a positive by you know, pushing my own.. thoughts out there and getting my opinions out.. Well.. nothing’s ever gonna change if people aren’t having these conversations and being like, ‘well, actually this didn’t work’.”

This experiential knowledge was felt to be an important part of learning in the EHCP system for some parents, as *Alison* demonstrates;

> “sometimes I think.. professionals aren’t always like, you know, the best place to give advice. Yeah, I think it’s, you know, tried and tested examples and response. And also the stories of neurodivergent people themselves. I think that really helps too. Definitely. And how they’ve overcome stuff”

In addition to learning from families who had experienced the process themselves, several parents in my study discussed being neurodivergent themselves, which they saw as a strength in navigating the system, as *Elizabeth* says;

> “But people be thinking, how can you do all of these rational things if your life is falling apart and you’re barely sleeping and I think that’s why they don’t believe us. Well, I’ve got autism and ADHD haven’t I? I do a lot more than most people”

Parents’ own experiences of neurodivergence have been discussed by Bentley (2017) as generally a negative factor in their experience, but with the positive of acting as a motivator in their fight for provision for their child. Parents who discussed their own neurodivergence in this study felt that it was as a strength, driver and protective factor for them in the EHCP process, giving them a strong sense of social justice and determination.

This theme is linked together and effectively summarised by a quote from existing research, ‘Parents currently need a combination of special knowledge and social capital to navigate the system, and even then, are left exhausted by the experience. Those without significant personal or social capital therefore face significant disadvantage. For some, Parliament might as well not have bothered to legislate’ (House of Commons, 2019a, p.19). The burden of the system falls on the families involved, elements of which I explore in theme 3, and their experience can vary enormously depending upon their own knowledge, experiences and the people around them. So, despite knowledge of the system being linked to the power to navigate it, this power is not always seen to be effectual, valued or equitable.

Theme 2- Problems with Partnership

The second theme outlines issues in terms of the power dynamics and lack of partnership between families and professionals, issues in relationships between professionals, and problems in the broader political system. Many participants reported not being listened to or feeling like their contribution or role was not valued as part of the EHCP process, even when they report high levels of knowledge about the process. Both parents and children and young people should be involved in the process of creating the EHCP (DfE and DoH, 2015) with their views forming a core part of the plan- this was not the case for many families in this research.

2.1 Professional Power and Families

Co-production as a concept is enshrined in core documents governing the processes for creating the EHCP and accessing support (DfE and DoH, 2015; DfE, 2014a), as explored in chapters 2 and 3, however many parents in this study reported issues in communication and collaboration between home and school or setting, affecting co-production and seriously impacting relationships between home and school, as *Amani* shares;

> "I was like, actually, I think we're coming to a point where the relationship between me and the school are about to really.. Well...it was just not healthy. If we were married we'd be going through divorce for sure, or at least speaking to a solicitor about it.. (laughs)"

Parents also shared where they felt they had not had an active role in partnering with their school or setting, as *Alison* felt;

> "Well, um, to be honest, my role's been quite passive. However, I mean the strategies that they do at school, some of course can be translated into home. However, there seems to be a disjoint when it comes to, you know, I mean cause there's a need at school because it's, you know, it's about his education, health and care plan at school. But I think there's that expertise that how that can you know what elements can be used at home as well, you know, cause obviously. I don't know. I think I think that would be really helpful."

There is a difference in the findings between passive roles and active disagreements. Some parents shared that there are active disagreements in their relationships with professionals. These home-school or family-school relationships have been characterised as challenging in research for a long time, with the language of warfare being used (Duncan, 2003), for example battle or fight. This was seen in the research in relation to not just school or setting but in broader relationships as part of the process of creating the EHCP, as shared by *Elmas*;

> "And I feel like just had to battle so much with the local authority, with the doctors, with the schools."

Many other parents in this study also reported problematic relationships between themselves and other professionals in their child's EHCP, including caseworkers (and the local authority more broadly), social workers and educational psychologists. Language my participants used in interviews included the terms 'nasty', 'rude', 'vile', 'cruelty', 'gas lighting', 'malfeasance', 'battle', 'talked down to.. patronised' to describe relationships or communication with local authority caseworkers, which highlights power imbalances that underpin these relationships, captured by *Elizabeth*;

> "The cruelty is... the way that we all get treated. The gas lighting…. But so yeah, so for me, I think that word was it that's something I struggle with. The one thing I find really difficult in the world is cruelty. And it's just the the gas lighting and just the malfeasance just stopping responding.. I'm harder to dismiss. They try. But I'm

> relentless. I cannot give up. I will not go away, even though it takes me longer than I'd like to because they will just leave it. but you're not, you're just nobody"

This shows just how challenging parents can find trying to collaborate with professionals, especially in this example where there is no reciprocal communication from the professionals, leading to distress for the parent. There are also issues even when collaboration is expected as part of the process, for example when families have the right to comment on a draft EHCP and be respected as co-producers of it, but this does not always happen in reality, as *Mike* expresses;

> "whenever they say, 'Oh yeah, we want we want to be collaborative... We'll give you a draft plan and you send your thoughts', but if you send your thoughts back and you say 'look, put this table in and take everything else out'…then what you get back is exactly the same thing and nothing's changed"

In making decisions, some parents felt very strongly about how problematic the system is in parents being able to work together with professionals, needing to utilise formal services to move the process forward, as *Elizabeth* exemplifies;

> "You have to use the complaint process and the tribunal process and the judicial review process so the person that you're pitted with at the front line gets permission to do the job."

Part of the issue as seen above is characterised by parents as a lack of communication from the professionals responsible for making decisions about their EHCP, with some parents discussing how difficult it is to get in touch with anybody from the local authority, who hold responsibility for the final decisions, as demonstrated by *Louise*;

> "its always really hard to get through to the local authority as well. You email, you call, they've now got a triage service and you call and they decide whether you can be put through to.. a worker or not. Or whether they can just get rid of you. But if you email then I mean you're not gonna get a reply at all, its very very rare that you get a reply."

A key element of whether families felt the partnership between themselves and the professionals involved in the EHCP process was functional was whether they were listened to as part of the process. Professionals are required to take parent concerns seriously in addition to involving children and young people (DfE and DoH, 2015) but a large majority of the participants in the research felt they were not truly listened to or valued as part of the process of creating the EHCP. Though this was discussed as being characteristic of the process in general, the quotes below demonstrate this in the context of the review and planning meetings, which participants felt particularly strongly about; for *Elmas*, not feeling listened to in the meeting was significant;

> "And I said, well, hang on, I've been telling you since year seven. And you know, nobody's obviously listening to me, that was the only thing that got to me in the meeting that that day"

Similarly, *Elizabeth* felt that her involvement in the meeting was tokenistic;

> "it's almost like you, you're not there. They pretend. there's all these little tick box exercises that they do, but it's not real. It's a tick box. You are not included."

And for *Kate*, as a young person who is supposed to be centred in the process, and despite being at the meeting, she did not feel listened to;

> "I just remember sitting there thinking nobody is actually listening to anything I'm saying"

Some parents discussed measures they took to try and improve their chances of being listened to or taken seriously in meetings for the EHCP, for example the planning that *Louise* puts in ahead of a meeting;

> "you have to perform to get things rather than actually just have people respond to you, you know, that took a lot of thinking, a lot of planning and even things like we would think about and plan what clothes are we gonna wear as to how formal do we want to appear today when we go to this meeting, and does my husband put on the suit? Does he go in his jeans?.. do I wear heels? And it's ridiculous"

Families not being listened to is an issue that has been raised in successive inquiries and reports including the Lamb Inquiry (2009) and has been highlighted in research in the area too; Hoskin (2019) found that communication was problematic, with the health authorities in particular, Sales and Vincent (2018) found mixed results with some parents feeling heard and others not feeling listened to at all and Adams et al (2017) found that 80% of parents in their study felt their opinions/wishes were included in their child's EHCP. Giving views as part of the assessment and planning process for the EHCP has found to be one of the more stressful areas of involvement in these statutory processes (Cullen and Lindsay, 2019) despite this being an area of focus in policy for so long. This undermines the principles of parent partnership and person-centred planning, central to the EHCP process (DfE and DoH, 2015), that rely so heavily on being listened to. Not being listened to is underpinned by an imbalance in power between professionals (holding a high level of power) and families, who often report that they feel as though they do not hold power in these relationships. Some parents in the research explicitly related their experiences in the EHCP process to an imbalance in power relations between families and professionals with families given less power in this process, for example;

> *Sarah*: "…it's the power imbalance as well"
> L (researcher): "The power imbalance you've just mentioned.. in terms of how that feels as a parent, where does the power lie, I suppose?"
> *Sarah*: "Erm, well it doesn't lie with parents and it doesn't lie with children.... you have to be ridiculously professional, you can never show any emotion, you have to know, you have to sort of almost try and put yourself in a level playing field, erm, and it helps to know how to do that in terms of the language to use, but ultimately you're still 'a parent', you're still 'mum' So yeah there's a huge power imbalance"

Linked to underlying power relations, several parents raised the issue of double standards in the EHCP process- that families are held to different, and more stringent, standards than professionals. This is shown where professionals are providing evidence for input into the EHCP but do not meet deadlines, as *Abbie* demonstrates;

> "We really struggled in the bit up towards getting the diagnosis, keep going keep going keep going.. but with the plan we weren't informed it would take longer than the timeline. Parents have got til this date, really strict, but hang on, the educational psychologist took 4 months instead of 6 weeks."

And also where parents are given the draft EHCP for their input, *Amani* was sent this late by the caseworker which then meant she was not able to comment;

> "I remember when I got the first EHCP plan I wasn't happy with it. So I emailed the council and said sorry I'm not, I want to make an amendment to this cause I

> haven't had.. I'm not happy with everything I've read and they went 'ohh you missed the deadline' and I was like but you've just emailed it to me!"

Double standards was also raised as a concept in terms of the differences between families and professionals in terms of accountability in the process, as *Mike* shares;

> "Just honestly, it's just.. It's tick box exercises and and again, you know, you look at the only people that will ever get prosecuted and put in prison and it's parents. Parents or children that are failed. And that's the truth of the matter, Louise, it's it's just.. look at where the sanctions are for these areas of law."

Despite the issues experienced, many parents in the study still report wanting to work more closely with professionals, being open to collaboration and recognising the importance of professional knowledge, as *Marina* says;

> "When you look up the EHCP online there is so so much information- if it's not what you do every day of the week it's difficult. It's like rewiring your house if you're not an electrician- they have got the expertise to do it but it's like where do you want the light switch to be because it's your house, and your expertise about what you want. Same with your child's needs and wants."

This demonstrates the understanding that parents have of the different roles that families and professionals play in the process, and their willingness to work together for the benefit of the child or young person's outcomes despite having experienced problematic relationships and communication.

2.2 Differing Involvement of Children and Young People

The statutory guidance is clear in that children and young people also need to be consulted and involved in this process, and that parents should not be used as a proxy for the child or young person's views (DfE and DoH, 2015). Though consultation and involvement are different from co-production, as explored in the literature review, issues are still reported in the way that children and young people are able to engage with the process. The practice of including parents but not children or young people is common but has implications, as discussed by *Kate*, the young person I interviewed;

> “me and my mum had different mindsets, different views about what I needed and what would best support me”

> “we’re going through the aims and the aspirations, she’s [educational psychologist] talking sort of, you know, ‘in six months time, where would you like to be and what would you like to achieve?’ And I remember my mum butting in and saying ‘ohh, she’s really looking forward to prom.’ I was not looking forward to prom at all”

Some parent participants in the research were not aware that their child has a right to be included in the process, as *Amani* shares;

> “He didn’t have any involvement in the process at all. But then I mean what, he’s just turned 7 so that might be it. I don’t know.. unless there’s schools out there or providers out there that do involve kids, I don’t know… I just felt like I was sat there advocating for him. And that was it. No. He didn’t have a voice and he his voice was very much shut down this academic year that has just gone.”

Several parent participants in this research project felt that their child was not included at all in the process of creating the EHCP, as with *Sarah’s* son;

> “Not at all, I mean not at all”

And other parents in the study felt that their child could not be involved in the process, and that this was justified because they did not feel their child was able to understand or participate in the process, as in the case of *Abbie’s* daughter;

> “No input, purely because of her level of understanding she wasn’t able to contribute at all.”

And similarly for *Elmas’* son;

> “he doesn’t understand what the EHCP really is and the importance of it and why it’s in place.”

This is linked to a finding by Adams et al (2017) with many parents in their research reporting that steps were not taken to help their child understand what was happening in the process of creating an EHCP. This is despite it being a requirement in the SEND Code of Practice (DfE and DoH, 2015). On the contrary in this study, some parents reported other reasons that their child was not involved in the process, for example because they did not want to be involved, as with *Marina's* son;

> "He hates it all. He sees it as everything on there [EHCP] is stuff that makes him different.. he appreciates it's there to help him but doesn't want to be different."

Many parents felt their child was able to have some level of contribution but that this was at a basic level, as with *Ellie's* daughter;

> "I think her SENCO did sort of say to her, you know, how.. is this good for you? Do you enjoy doing this? Do you enjoy doing that? But that was kind of the extent of it."

Some children of the families in the research did have the opportunity to attend meetings and gain an understanding of the process and the plan, and contribute to it, for example with *Zuzanna's* son;

> "So when we had that meeting back in April, he [child] was there.. he heard everything and I think.. he knows and.. feels comfortable hearing… he will say how how it is, what he needs. So I think it's quite good at that. He can put his voice there so, so he knows as well what he will expect."

However, *Kate*, the young person I interviewed reported feeling that she was physically there in meetings but not feeling meaningfully involved in the process;

> "it is very disheartening to know that, you know, as as that child who's meant to be in the middle of that, I was sort of.. detached from it. And I I felt like, you know, I was in the room, but I wasn't there. I wasn't present..looking back now if somebody had explained it to me properly, you know I had full capability to have understood it and I think actually I would have benefited from it more if I'd understood entirely, you know what it was, what it what it and also what it could do. You know sometimes I think back and I think, you know, were there things I missed out on because I didn't understand"

Parents in the research reported that where there was any meaningful or significant involvement of their children in the process of creating the EHCP, they were the ones working to achieve this, as with *Louise*;

> "But we really wanted it to be driven by her and have been really pushing for that.. she was sort of [involved] for her first EHCP. But again this was us. We pushed for this."

This finding is in accordance with Sales and Vincent (2018) who found there was much room for improvement in the way that children and young people were involved in the EHCP and their ability to contribute to it meaningfully. Similarly Sharma (2021) found that practitioners faced many barriers when trying to involve children and young people in the process, including lack of resource in the local authority, parents and carers representing a barrier to their child's involvement, as well as reporting that professionals can be reluctant to engage in the work to support the child or young person to contribute. This also diverges from the key principle of person-centred planning in the creation of the EHCP, leading to questions over whether enough is done by professionals to include and involve children and young people in the process, or whether the process itself prohibits their involvement and engagement.

2.3 Partnership Postcode Lottery

There was inequality in the way partnerships were experienced by families in this study, and they linked this to the outcomes they were able to secure for their EHCP. Where collaboration has eventually worked well, parents report joined up practice and communication between home and school, trust in staff, and an understanding of the roles of those involved, as *Ellie* shares;

> "it became good because I didn't really have anything to do with the SENCO before that. But once the EHCP started getting rolling I did get.. a lot more chatty with her, and she ended up actually being.. one of her year six teachers as well. So in year six it did become quite an open conversation kind of relationship, erm I knew if I had any problems, I would be able to drop her an e-mail. And I knew she would get back to me… And I felt like I trusted the school to do what the EHCP said as well."

Other families reported positive relationships with professionals at their child's school where they felt that teachers or SENCOs were invested in their child getting the EHCP and making progress, and where they felt that school staff were confident in their knowledge of the EHCP process and were able to be creative with how support could be provided. This included language such as 'on the ball', 'creative', 'supportive', 'confident', 'invested', 'on-board', 'forthright', but this is not common or consistent. Inconsistency is one of the main barriers to communication and progression with the EHCP that parents discussed in this research. This included inconsistencies in staff within school, at the local authority, and with other professionals, which impacts the ability to form relationships with the professionals involved and move the process on. Many of these discussions related to local authority caseworkers, as with *Ellie's* case;

> "Yeah, the caseworker's kind of just disappeared, to be honest... She was moved around. I think she had three caseworkers in the end."

This was also the case with social workers, as *Abbie* commented;

> "in 3 years we've had 4 social workers- the latest social worker, and bear in mind I'm at a transition point and I need experience and knowledge of what's out there, was on her second day in the job- she was clueless and still is."

For some parents, this felt like a deliberate act on behalf of the professionals, as *Elizabeth* suggests;

> "we had a different case worker within a couple of months.. and I think that to some degree that's deliberate because you can't build a relationship, you can't get to know this child's case. You can keep people pretty ignorant"

Other discussions related to professionals writing reports for the EHCP, including Educational Psychologists (EPs), Speech and Language Therapists, for example, in *Sarah's* case;

> "yeah I don't think I've had a good relationships with EPs but I've never really had the opportunity to build a relationship with an EP because they just pop up once a year, give their report, I then get a bit vocal about how it's not you know fit for purpose and then they're gone (laughs) And then next year it's a different EP so yeah."

This inconsistency in staff has been found in other research, for example House of Commons (2019a) and linked to issues such as turnover due to the process itself (Palikara et al, 2018; Hellawell, 2018) and shown to impact the quality of EHCPs produced (House of

Commons, 2019a). This was also discussed in terms of attendance at annual review meetings by some parents, for example, *Abbie*;

> "when you do them [annual review meetings] you expect outside agencies to be there.. no-one ever tells you they won't be unless you invite them- you need to invite them as individuals to the review, so the last few years it was me and [daughter's] teacher, but the social worker comes now, for the last few. Up until then it was only ever really myself."

There has long been an understanding that the process is engaged with mostly by professionals from education, with input from health and social care noticeably absent (Boesley and Crane, 2018). The finding from this research suggests that there are issues with partnership within the EHCP process, with issues between home and school (as explored earlier in theme 2.1), but also issues with the professionals who provide reports to be used as evidence in the EHCP, and those who are responsible for decision-making within the EHCP process.

2.4 Problems with Collaboration

Several parents reported issues with the professionals involved with their child's plan and their ability to work together, despite this being a focus in the statutory guidance (DfE and DoH, 2015). These issues most often focused on a lack of co-operation between departments or external authorities, and shifting of responsibility among professionals, with a lack of accountability visible here, exemplified by this quote from *Louise*;

> "So I'm saying somebody needs to do this and education are saying it should be social care and social care are saying it should be education and then education said it should be adult services and adult services saying we don't do anything until they're 18."

This opposes the findings of Sales and Vincent (2018) who reported that 4 of the 7 parents involved in their study felt as though they had experienced effective multi-agency working in their cases, and Adams et al (2017) who found that 74% of parents surveyed felt that professionals worked together to create the EHCP some or all of the time. The collaboration (or lack thereof) between health, education and social care was identified as a key theme in the systematic review conducted by Ahad, Thompson and Hall (2021), leading them to call for improved communication, ring-fenced funding and re-establishment of roles in the process.

2.5 'That's been manifested from above'- Politics and Power

The issues experienced by families in this research in creating the EHCP are broader than the school or setting their child attends, or the professionals involved in their case. Many parents discussed issues of funding and systemic difficulties, with an understanding that many of these issues are out of control of the local authority, that they exist at a systemic level, as *Mike* says;

> "I would suggest is that we we need to go, we need to go step higher than that, we need to go to central government because they devolved the power for education, health and social care to local authorities. It used to be centralised. It used to be a national standard. OK, that got changed, that got devolved to local, local authorities… And we wonder why there's a lack of consistency. Well, that's that's been created, that's been manifested from above..it should be that that the funding is secured to the people so that it can't be misused for anything else"

Parents also acknowledged where schools or settings are trying to make things work, but that they are impacted by the broader system, as *Marina* shares;

> "The school are backed into a corner and they are doing what they can… the school have done their best but it's the system that's broken rather than the people who have to implement it."

Similar awareness about issues outside the direct environment including local authority and funding were found by Sales and Vincent (2018). Professionals themselves have also reported issues with funding, especially where they feel stuck in a situation where they need to make decisions that may not necessarily be in the best interests of the child but may save money (Hellawell, 2018) or unable to offer services to families because of a lack of funding (Krasniqi, Carr and Stevens, 2023). Issues between the corporate responsibility of the local authority and the rights of the parents and children as a tension in the law (Cullen and Lindsay, 2019) have been identified in previous research and acknowledged in policy developments over the last 40 years, seemingly unchanging in that time.

Theme 3- Negative Impacts on parents

Theme three illustrates how much of a burden the EHCP process represents for families. Within the research, all parent participants discussed how the EHCP process impacts upon them in a variety of ways, showing what a burden the process of getting the EHCP for their child is on parents, including the time involved, the financial burden and the emotional and physical toll that this process has on parents. Parents also report a reputational burden of this process, linked to parent blame.

3.1 Time Burden

Though parent experiences and views should form part of the EHCP (DfE and DoH, 2015), many parents in the research discussed how much of a time burden the system places on them when their child needs an EHCP. These issues include having to find out information for themselves, spending time writing or rewriting areas of the plan or managing their child's support or education. These create a significant amount of work for parents, as *Sarah* shows;

> "it's just a massive admin burden really"

Parents in this research project did not always see this time as well spent, as exemplified by *Elizabeth*;

> "And you spend ages doing the first one [EHCP contribution], I did. I went through the early years framework…and then I did it. I put all the school stuff in… then I said what was happening in our day-to-day life. I spent hours on it. Complete waste of my life. hardly any of that went in."

Part of the burden of involvement in this process includes parents feeling as though there is no choice in this for them, as *Mike* shares;

> “very often people say to me like how, how do you do all the things you do and it’s like well what option is there?. There is no other option, you have to do.. you have to do what your children need”

This finding is at stark odds with the research carried out by Adams et al (2017) which found that 72% of parents surveyed would say that the work involved in getting an EHCP for their child was ‘reasonable’.

3.2 Financial Burden

Within this research, parents reported a range of direct and indirect financial impacts on families going through the EHCP process. In an example of a direct impact, some parents have had to pay for their own assessments so that there is evidence to support what their child needs as part of the EHCP, as *Sarah* did;

> “His EP [Educational Psychologist] report highlighted that he needed occupational therapy involvement, but the wait list in our borough is 2 years, so I then got a private assessment for £500”

Other parents report feeling that there is an expectation to pay for their own reports but resist doing this, as *Louise* shares;

> “We’ve gone to tribunal and we had to submit our section K evidence and I don’t have any except from a speech and language report and the school reports.. I think this is why parents end up going and spending hundreds and hundreds and hundreds of pounds on private assessments whereas I’m too bolshy to do that (laughing).. I basically said ‘your lack of assessment shows you haven’t done this properly therefore you need to do the assessments and I’m not gonna go and pay for the assessments that tell you basically what you should be doing’”

This has been reported before, and linked to inequality for children, based on parental income (Bernardes et al, 2015) and is in the context of an already challenging situation for parents of disabled children, who already report barriers to being able to work. Many parents in the research discussed the difficulty of being able to work at all with having a disabled child and the difficulty of navigating the system, as an example of an indirect financial impact, where families are unable to work around the requirements to support their children, as *Abbie* shows;

> “so I’m paying £40 for care but also paying to have activities within the community, and I have to take her there, pick her up and if there’s no staff there’s no activity. So I still can’t work! Unless I have a job that I can work 10.30-2.30..”

Or they are expected to manage their child’s complete education and care arrangements, as with Mike*’s* example;

> “it’s not our job. I mean, we’re full time, we’re full time carers 24 hours a day, 365 days a year, we’re also teaching assistants, teachers, plan leaders, healthcare workers, legal experts.. advocates (laughs) trying to think of what other hats we have to wear.. Social care workers, healthcare... whatever you wanna call it, that’s what it is.”

With children out of education, some families are not able to work at all, and in addition to the time impacts as above, families also share wider impacts on their finances, as *Mike* goes on to describe in this powerful example;

> “we’ve lost pension contributions, we’ve lost income. We don’t receive any assistance with mortgage. We’ve got equity in our home because we used to work and we used to be professional people.. but we can’t release any more because our debt to borrowing is now at the extremity.. You’ve got £67.50 income a week as a carer for you to live off. And you know, this is the situation that you’re left in because you know the system is so broken that if you do give up and just put your child wherever that you’re effectively putting them to death.”

In an example of another direct financial impact, parents who do work often discuss having to work part time, or having their work or their business impacted by the amount of work they are having to do in the interest of supporting their child to access what they are entitled to, specifically in relation to the work they are doing in the EHCP process, exemplified by *Louise*;

> “..husband works and pays for the house, I do part time work so I can commit… You can’t ever have like a full-time job, you can’t do this and work full-time. Things crop up.. you can’t have that sort of normal life, especially if you think, these processes take up to a year, we had an annual review in September, we’ve got a tribunal hearing in July, that whole year will be taken up with me having to deal with that. And then we’ll start the process again. It’s just exhausting”

Parents’ employment being impacted by their child being disabled or having SEN has featured in research for a long time (Duncan, 2003) though this has often historically been attributed to the needs of the child, with the DWP (2014) reporting that where children have serious health issues or disability there is reduced parental employment and lower household income. The finding in this research links parents not being able to work, or having their work impacted directly with the pressures of their involvement in the EHCP and the difficulties in accessing support, rather than with the child’s condition, diagnosis or disability, in a shift away from deficit or medical model thinking. Employment impacts are crucially linked to the number of families with a disabled child who live in poverty, which is significantly higher than for families without a disabled child (Shaw et al, 2016). This can be due to additional financial penalties that families experience in terms of travel, specialist equipment, additional resources or provision to meet their child’s needs (Hastwell and Moss, 2020) and because of broader structural issues and barriers that families with disabled children face (Shaw et al, 2016). The ability of parents with children with SEN to work is affected most for married mothers and lone parents (McKay and Atkinson, 2007), which highlights another link with poverty which is family breakdown (DWP, 2014), which has been found to be higher in families who have a disabled child (Hartley et al, 2010; Hatton et al, 2010). Research has specifically found greater divorce rates for families with a child with a cognitive delay or life-limiting impairment (Hatton et al, 2010) along with parents reporting they did not feel equipped to support each other when things go wrong with the EHCP process (Hastwell and Moss, 2020). This represents ‘significant stress for parents’ (Hastwell and Moss, 2020, p.6) as experienced by many of the participants in this research, and as explored below.

3.3 The Physical and Mental Toll

Most of the families involved in the study expressed that being involved in the EHCP process is a deeply emotional experience. Again, this has been a long-standing issue, with research also showing these ideas before the 2014/15 reforms; parents reporting anger, guilt and frustration during the process of accessing support for their child (Duncan, 2003). These were all discussed in this project, in addition to parents feeling dread, as *Sarah* shares;

> "I think I've given you an accurate description of what a nightmare it is (Laughs) you just dread it every year the annual review, every parent I speak to is like 'oh God oh God I've got that annual review'"

Parents also report feeling upset or traumatised by their involvement, as *Elmas* demonstrates;

> "It's a shame we went through so much struggle. I'm actually very traumatised from what we had to go through to get the EHCP"

And parents also report feeling a mix of strong emotions, and confusion about why this is such a difficult experience, as *Elizabeth* exemplifies;

> "I've had to fight so hard. It's changed me… I sit down and cry because I didn't have the best upbringing... I've seen some very broken people and seen and experienced some very broken things..but I sort of understood that. But I couldn't understand this because that's their job and they're supposed to be the good people, aren't they? Or are we the good people? ..and they was doing this to the most vulnerable people.. Cruel. That's why I cried. Because it's cruel.. that's how convoluted and disgusting it all feels… and people are oblivious until it happens to them."

The additional work parents do to drive the system can also have negative impacts upon parents' emotional resilience (Hastwell and Moss, 2020) and mental health; the emotional burden of this system is also explored by Bentley (2017) who found mostly negative experiences from parents, including physical and mental health issues. Though mental health issues were more frequently brought up in this research project, alongside stress, dread, fear and other deeply emotional experiences, some participants did also discuss the physical impact of these experiences, for example, impact on sleep, as *Zuzanna* shares;

> "it's lots of work and lots of stress and lots of not sleep… like you wouldn't sleep for a month sometimes before. But it's all worth it."

And on physical health impacts as for *Elizabeth* and her family;

> "You're dragging yourself to get through the day trying to care for these kids, and you're searching for ways to find to understand their needs because no one's helping you.. my husband has gallbladder issues, because of the lack of sleep we've both put on quite a lot of weight and been in hospital quite a few times.

> Where he's not fought off infection now, he's already had sepsis at one point. He was getting to that point and obviously gallbladder.. and all of that acid and that, a lot of that's stress related, we live off the cortisol because that's what your body does."

Additional impacts on parents have been found in research, for example, fatigue and lack of personal time (Hastwell and Moss, 2020) loneliness and isolation (Hastwell and Moss, 2020). These impacts have been discussed as life and death situations by some parents, including *Elizabeth*;

> "we're used to getting a kicking and I'm very much well you're kicking me anyway, not everyone's got that resilience. You're kicking me anyway, you know, and I know you're not going to stop kicking me. So, do you know what? I'm going to keep going because...and it's killing me. And I, but I do it because this is about my kids' survival."

This finding shows an extremely worrying level of impact on families, considering the EHCP process is supposed to be a way of seeking support, suggesting that it is not fit for purpose.

3.4 Blame and Reputational Burden

Many of the parents in this research project discussed feeling like they were being portrayed as problematic by the professionals involved in the EHCP process. Words and phrases used by parents to describe how they felt professionals saw them include 'difficult', 'hate', and 'pain in the bum', and the majority of parent participants felt that there had been issues in their relationships with professionals that were constructed as being the parents' issue, as *Elizabeth* shares;

> "Now it's like we're the enemy, we're asking for something unreasonable.. It's a vexatious parent. You know, they deliberately trigger you to wind you up to, to make you upset and then say that you didn't treat them appropriately, so they don't have to deal with you yet they're acting unlawful."

Parents have reported in other studies to feel that they are labelled as problematic (NAS, 2021) and professionals have been found in other studies to have a perception that parental demographics are correlated with the support the child receives (Ahad, Thompson and Hall, 2021; House of Commons, 2019a; Sales and Vincent; 2018). This forms part of a narrative around parent blame, which many parents in this study felt that they had experienced as part of the EHCP process. Parents reported that there was an element of blame and shame placed on them for difficulties experienced in the process and for seeking support in the first place, exemplified by *Louise*;

> "wanting the golden ticket, looking for the rolls Royce, I mean all of these sort of things, the whole parent blame is huge within the narrative around EHCPs, but I think the real issue actually is that...maybe it's only those parents who can actually navigate it"

The harmful narrative around EHCPs representing 'golden tickets', a fast-track ticket to receiving perks and benefits is well documented in the media (Hurst, 2019), in parliamentary publications (UK Parliament, 2020) and in parent-led publications (Smith, 2023). This narrative comes with the implication that what families receive because of the EHCP is not warranted or deserved. This is also linked to the perception that EHCPs and related provision is fought over by parents with more capital and power than others (middle-class parents for example), with provision for children and young people subject to their parents' ability to understand and navigate the system (House of Commons, 2019a). Other parents were aware of these depictions and felt they were an unfair representation of what they were seeking with an EHCP, as the quote from *Elizabeth* shows;

> "that's the picture they paint of us that we want this golden ticket. There is no golden ticket to your kid not being able to go up to school in the community with their siblings, with the people that live around them..The Golden ticket is local with your community and having a nice life. Nothing fancy, but just having a nice life where you can just do things like go to the local school. You can do things like be with your peers, you can do things like be with your family. You can do things like go to this local pool and when everybody else goes, you can go to the park when everyone else goes. That's the golden ticket. But we don't get that"

Parent blame is often discussed in the context of SEND, but usually in relation to the assessment and diagnosis process, with parents feeling blamed by their friends, family, professionals, and society as a whole (Holland and Pell, 2018) for the difficulties their child experiences or the issues they face in accessing diagnosis or support. It has also been linked to constructions of scrounging (Garthwaite, 2011) where again parents are constructed as being out to get something they do not need or deserve. Several parents in this study were also aware of wider societal portrayals of parenting disabled children that they felt impacted upon them for example, *Elizabeth* said;

> “no one else wants anything to do with you, you suddenly become the scum of society, apparently..everyone’s rude and they think they know better…. the minute it’s my child with additional SEN needs, you think you’re the fucking expert and everyone’s just plain nasty, ‘oh now you’re not working? Ohh, you’re just poncing off society’ and stuff like that, taxpayers.”

And *Abbie* used language similar to that in other research;

> “getting these things [the EHCP and the provision outlined on it] makes you feel like you’re scrounging off the state- you are made to feel grateful.”

Scrounging discourse (Garthwaite, 2011) is underpinned by constructions of families as worthy or unworthy, and perpetuated by systems that create competition for scarce resources because of inadequate budgets. I explore this in the Discussion section, linked to power/knowledge and regimes of truth (Foucault, 1977b) about SEN, disability and parents, whereby power is not only held and exercised, it produces the regime of truth around families. Parents have shown in this research the significant burden that their involvement in and driving of the EHCP process has on them in a myriad of ways, and this still does not necessarily mean the process, plan or outcomes for their children will meet their expectations, as I explore in the next theme.

Theme 4- Expectations vs Experience

This fourth theme relates to the gap between what families’ expectations were of the EHCP plan and process and what they experienced. Families I interviewed discussed how their expectations of the process were not met as an important factor in how they experienced the process. These expectations relate to the policy and statutory guidance, what families had been promised the process would represent, and what families had hoped for from the process. Eventually, parents report lowered expectations to match what they have come to expect from experience.

4.1 ‘What?! What do you mean this doesn’t work like this?!’ - Statutory Processes and Responsibilities

Surprise, anger and disappointment in the EHCP process was reported by parents, in some cases because of the knowledge they had of the policy and how it should be implemented more generally, as *Amani* demonstrates;

> “I remember like my first meeting like cause I’d already read the send code of, code of practice.. and I remember going ohh, that’s fine. There’s loads of things that we can have here. There’s like a list of professionals that you can access through the EHCP plan. So I’ll just go into the EHCP meeting as his mum and say, OK, well, these are the people that he needs help with and we basically got laughed out, it was like, ‘no, that’s not going to happen’.”

And similarly, with expectations that the system will work as it should, as *Sarah* shares;

> “it makes me really angry.. when I first kind of landed in this world (laughs).. being from a corporate background I was just kind of like, what?! What do you mean this doesn’t work like this?!”

Some parents discussed this with regard to specific elements, like failure to meet statutory timelines, as in *Elizabeth’s* case;

> “the law said it should be back within 12 weeks. So now I’ve just had another [annual] review. And we didn’t get the paperwork back.”

The statutory timelines are documented to have not been met in many cases- the latest figures show that less than 50% of plans are issued within the specified 20 weeks (DfE, 2023b). Other parents discussed issues such as failure to issue draft plans after annual review meetings, as *Louise* details;

> “they didn’t even issue a draft plan so I couldn’t appeal it so I was stuck I was literally like ‘I can’t appeal it until you issue it’, they wouldn’t issue it, they refused to issue it.”

Another issue in terms of professional failings is not holding annual review meetings in order to make changes to or update the EHCP, as *Elmas* details;

> "I could count on one hand, like I said, my son got his diagnosis at three and he's now nearly 14. I can count on one hand how many times he's had the annual review. That's how bad it is. I think he's had about four reviews, if I'm being honest."

Another issue in relation to the expectations parents hold for the EHCP process is around the knowledge, understanding and professionalism of professionals. Some parents found that the local authority caseworkers had a lack of understanding of the process or an inability to meet the demands of it, as *Louise's* example shows;

> "I think our caseworker.. she had no clue how to deal with what I was feeding back to her, I genuinely think she's not received the training, doesn't have the knowledge, wasn't getting the reports that she needed, and I think she genuinely did not know what to do."

Surprise at the attitude of caseworkers in a system designed for support was also mentioned, shown by *Sarah's* quote;

> "What is this world that I've stepped into? Where people can be just so unprofessional and so.. you know, confrontational. It was really surprising, I did not expect it."

Surprise in terms of the understanding professionals have has been reflected in earlier research (Holland and Pell, 2018) and represents another way that the expectations of families do not always match up with what they experience. Similar issues were found in research with parents who had gone through complaint or tribunal processes, with reports that parents' views of the professionals' roles, competence, professionalism and knowledge of the law often fell short of their expectations (Cullen and Lindsay, 2019). Accountability for professionals in carrying out their roles was a key recommendation from Ahad, Thompson and Hall (2021) in considering how to improve the EHCP system. Accountability was also key in the House of Commons report (2019a), with recommendations against financial penalties for local authorities (given the financial shortfalls they are experiencing) but instead a mechanism for non-compliance with scorecards to be reviewed regularly. Accountability was raised by participants in my study, where calls for accountability for professionals were much stronger, including punishments for those not working with or abiding by the law in the EHCP processes, as shown by *Elizabeth's* example;

> "this is where the weakness is- people are not personally accountable and they just get to say 'I'm sorry', while they lose the public purse payout compensation."

Without accountability for professionals, it falls to parents to police the system (House of Commons, 2019a), which again relies upon their knowledge and resources within the system. The idea of focusing on accountability could be challenged by findings from Hellawell (2018) who reported on findings with professionals; where accountability was the focus, professionals could end up engaging in performativity in their role rather than exercising professional expertise, or they could become conflicted about how to move forward. Parents in this research project did however feel strongly that professionals should be held to the standards outlined in policy and guidance, and several felt there should be consequences for those that do not meet these.

4.2 Overpromised and Underdelivered

A common theme raised by almost all participants in this research project is disappointment in the process overall, sharing what their hopes were for the process and then what happened in reality; many parents expressed similar sentiments to *Elmas*;

> “..I kinda feel like we was kind of...what’s the word? Not tricked, but just made to believe that we would have so much, you know, say in what was in the EHCP and we’d have a lot of decisions around my son’s education.. I kind of feel like we were sold a dream and it wasn’t at the end of the day because I feel like with the silly [activities] stuff .. asking us questions surrounding what my son likes doing, we had obviously a say in that and you know, even my son was.. given some input as well and and able to stay [in the annual review meeting]. But I just feel like around the serious stuff, things like, as I said, schooling and just other resources and measures put in I just feel like we wasn’t given much say...it’s just so sad that you’re promised a lot of things, and when it comes down to it, it’s it’s not given. It’s it’s not being delivered. It’s it’s just really disappointing for myself and my son.”

And similarly for *Kate*, the young person I interviewed, the reality of the process did not meet her expectations;

> “I remember.. a teacher.. talking about this and being like ‘ohh you know, it’s gonna be great because you know everybody’s coming in [professionals].. everyone’s got like a fresh eye set and you know you’re going to be one of the first pupils that we’ve got at the school with like, the new EHCP and it’ll be great’. And erm I just

> sort of sat there and I remember thinking it doesn't seem that great, erm, I don't really feel like I've got much out of it"

Some parents talked specifically about the SEND reforms of 2014-2015 and how their hopes for the change these would bring have not been realised, as *Mike* did;

> "It was really aspirational. And it talked about, you know, we're going to get the best outcomes possible for these children. We're we're going to make sure the resource is there for them to use, etcetera, etcetera, etcetera. And that got watered down and then it got watered down further, and all of the teeth that were in there to make sure that people did their jobs, all of that was removed."

Families overall expected a more inclusive and aspirational system but felt that this was not being delivered. Similar findings were included in the House of Commons report (2019a) whereby parents' expectations have been raised by the 2014-2015 SEND reforms but that their reality is not matching up with these higher expectations for support.

4.3 Gratitude and Lowered Expectations

On the other hand, some parents reported gratitude about how the system and the EHCP process provided support and input for them and their children, with the validation that the evidence provided by professionals brought to the plan, for *Alison*;

> "it did help seeing it down in black and white. It really did. It's. Yeah, it helped me to accept it and to just not be afraid what other people thought… when you've got it in black and white it's just reassures you that you're not this like paranoid person who's not parenting their child properly"

Gratitude was also raised regarding the support provided by the education professionals in the EHCP process, for *Zuzanna*;

> "they support us so much. They take care of everything. Um, so I need to be just grateful"

Notwithstanding, more parents report being made to feel grateful for support that should be provided by right, as a negative emotion rather than a positive one. This has been discussed in relation to the local authority as a feeling of being made to feel guilty for what they are receiving or have a right to receive, as *Louise* shared;

> "'I'll let you know.. we don't usually do this'.. it was almost trying to guilt trip me into thinking I'm costing extra money, I shouldn't be doing that, where actually they just should have done that EP assessment three years ago or whenever. It should be part of the standard."

Or through formal appeal and tribunal processes, as *Mike* shared;

> "when, when we talk about the appeals and and people talk about the win rate for parents, you're not really winning anything, you're you're winning what they should be given anyway."

The latter perspective of being made to feel guilty or grateful for what should be received by right was raised much more often than the former, with parents sharing that their expectations had eventually lowered to anticipate poor treatment and being surprised when a minimum standard is met, summarised by *Louise*;

> "I think that's the thing about parents is that we don't have high expectations because we are so used to just being treated (laughing) really poorly.. you become grateful for somebody doing what they say they're gonna do. And, to live your life like that, where you always anticipate you're actually gonna be treated really badly…It's very rare you get surprised in a positive way."

This surprise over rare occasions where their expectations have been met has been seen in the literature before (Holland and Pell, 2018) but has been linked by professionals to parents having unrealistic expectations, for example SENCOs (Boesley and Crane, 2018), though the findings in the current research highlight a lowering of parental expectations below what is outlined in policy, rather than parents expecting more than there is legal accommodation for.

Theme 5- 'It's just a piece of paper in my name'- where is the child in this plan?

This final theme considers the plan itself and how it reflects the child or young person. Many participants in this research raised issues with the content of the plan, these included factual or administrative errors in the plan, children and young people written about from a deficit perspective, and the plan being based on inaccurate or incomplete evidence, leading to outcomes on the EHCP that are not representative or measurable.

5.1 Factual and Administrative Errors

Some parents reported inappropriate, incorrect or outdated content in their EHCP, for example, misgendering the child in the plan, making reference to school when the young person attends college, and several plans had evidence that was relevant from several years ago but not applicable now, for example with *Sarah's* experience;

> "So that [EHCP] would land on the SENCO's desk and it's describing a 7-year-old child and this is a SENCO of a secondary trying to consult on whether.. they can meet that child's needs.. really odd."

There were also reports that the EHCP did not accurately depict the child or young person they were written about, as in *Abbie's* case;

> "we were given it [draft EHCP] back by the school and told to read it and sign it and I wasn't prepared to sign it.. anybody reading it wouldn't actually get her- it's not a true reflection of her"

Similar administrative type issues and lack of attention to detail has been found in research by Cullen and Lindsay (2019), and 57% of cases brought to tribunal relate to the content of the EHCP (DfE, 2023a) so this is a known issue, though my focus is specifically on the representation of the child. Many families I interviewed discussed the alienation of the child or young person from the EHCP, and how the written EHCP itself does not reflect them, their views or experiences. Firstly, *Kate*, the young person I interviewed experienced issues with the way she was written about in her EHCP;

> "I feel very indifferent to my report and I don't relate to it. I read it and it's like I'm reading somebody else.. I don't relate to it at all because I feel like it doesn't tell me or my story, or you know anything that I need so.. Yeah."

Other studies have found that parents are dissatisfied with the way their child has been written about in the plan; NAS (2021) found that just 30% of parents of autistic children surveyed were happy with this element of the EHCP. If there are factual errors or misrepresentations of children and young people in their plan, there is a risk of misunderstandings among professionals and unhelpful outcomes suggested and unsuitable provision offered.

5.2 Deficit Portrayals of Children and Young People

When children and young people are written about in the EHCP itself, several parents in the research felt that the EHCP presented overly negative aspects and framed their child in a deficit way either by emphasising difficulties that the child is experiencing, as *Amani* explains;

> "they prepare you and say things like 'ohh when you read the EHCP it's way worse than it actually is. Like the language has to be that way'. So they have to describe your child almost like this awful child in order to get the money. And it's just like, well do you really need to be using language like that and using the absolute worst case scenarios of every single day? Is that what we've set this EHCP system up for?"

Or with the use of specific, deficit-focused language, as *Alison* describes;

> "one thing I've asked to be changed, it's regard to um, the language.. It was one word to describe [child]'s behaviour and it was described as 'horrifying'… I think there's.. connotations which I mean, 'shocking' is, you know, you can be shocked. There's no kind of like value, good or bad.. but 'horrifying'. It's like, you know, it's making him to be some horrendous sociopath. I don't know. It's just got connotations. It's not good."

And there were also examples of inaccurate information included that contributed to a negative portrayal of the child, as in *Zuzanna's* example;

> "And when I saw all these observations, what they wrote about him, it was like, that's not my child. It's like it's not like he is. It was really hard, especially with SENCO writing like he doesn't have any eye contact."

Similarly in my interview with *Kate*, a young person, the issue of deficit language and misrepresentation was raised;

> "I'm not gonna say... 'I'm the brightest person ever', but I did well academically throughout all of it and it was very disheartening when I sort of read reports about how you know, I've got poor concentration and, you know, poor understanding of things"

> “when my mum sort of first started going through the process... erm she kept being told by everybody write about her worst day. And you know everybody who always says that thing.. and..I think that by doing that actually it was very detrimental to my EHCP because I wasn’t like that every single day... But I think a lot professionals kept saying that to my mum in a sense of like ‘ohh if you don’t do what on her worst day she’s not bad enough for it.. that she’s then not deserving of the EHCP’”

Having to create overly negative narratives of children and young people when seeking support has been reported before (Goodley and Runswick-Cole, 2011) with implications for how well children and young people are then understood and supported, and wider implications for the way they are viewed and constructed. Some participants in this research felt that the EHCP process itself represented issues in how disabled children are viewed and understood more broadly within society, with deficit language coming from government level attitudes, as *Mike* exemplifies;

> “you then have a government that was no longer a coalition and was a right wing, you know ‘these people are never going to contribute in society because they’re, you know less than average’... and this is the language they use, they use the language of deficit and the language of cost. When you think of someone as being lesser and always going to be a burden to the state and you think, well actually if I don’t do anything at some point you know these people are going to go away. Via one method or another... they’re seen as less, they’re seen as having no value in society, they’re seen as being a cost and a burden not not a a value and a resource that enriches..so they are left to die basically”

This deficit perspective of children and young people is problematic and can be counterproductive to achieving aims and aspirations (Holland and Pell, 2018), as deficit perspectives perpetuate low expectations. These low expectations were visible in the EHCP by some parents too, who reported a lack of aspiration in the outcomes sought for their child, as *Abbie* shared;

> “There should be a governing body that looks at them and can say ‘that’s not good enough’.. so little outcomes and aspiration”

Some parents felt that the issues with collaboration and inconsistency in professionals impacted these aspirations too, as *Sarah* shared;

> "And when you look at outcomes you know, they're not aspirational.. And that's been drafted by you know an Ed psych who's met him for 20 minutes, like how much do you know about my child's aspirations? Not a lot."

This was in addition to a lack of joining up of sections of the EHCP in order to support the child or young person to fulfil their aspirations, as *Sarah* shared in a further example;

> "in the 'all about me' section [Part A].. child wants to be a train driver.. But there's nothing linking that, do you know what I mean, so that's not, it's not then linked to 'OK then let's look at the provision how can we help him be a train driver, what does he need?' that's not a factor."

The SEND reforms of 2014/2015 were supposed to be ambitious and aspirational (Timpson, 2014) but where the system creates competition for limited and non-ringfenced local authority budgets, these aspirations appear to come second to what is convenient or what the local authority can afford.

5.3 Evidence and Outcomes- the importance (and lack) of clarity

A crucial element to a quality EHCP that accurately represents a child or young person's needs and a key factor in how families experience the process is having appropriate evidence; many parents I spoke to discussed their knowledge of how important this element is, as *Sarah* shows;

> "if it's not from a professional's report they will not put it in section B and F.. like if they can't copy and paste it from a professional report then they will not put it in."

This importance and emphasis on the evidence from professionals can make parents feel that their contribution is not valued, as shown by *Elizabeth*;

> "What you say is not worth a thing. Unless there's a specialist that says it, you don't count for shit."

Some parents have also questioned the accuracy of the evidence provided by professionals, which feeds into the EHCP, similar to how *Sarah* describes;

> “for example his last annual review the EP [Educational Psychologist] had to go back to the report erm.. I’ve got three versions of it because the first version I had to challenge, the second version I had to challenge, erm just because he you know, he’d spent barely any time with my child, erm and a lot of what was in there just wasn’t an accurate reflection of him.”

And this again was raised by *Kate*, the young person in my study;

> “the educational psychologist report again.. I had a different person come and again some of it I sort of think like I don’t know what you’re on about there, but I think that happens with everything you know, come back from a doctor appointment and think well actually I didn’t say that at all.”

This situation again alienates the child or young person from the process and creates inaccurate depictions of them in planning for their outcomes. With the EHCP based on the evidence provided by professionals, and parents feeling as though their contributions do not count, it is even more important that the professional reports are accurate and representative of the child or young person. Many parents in this research discussed how outcomes for their children in the EHCP were phrased in an unclear way, with examples in the wording such as ‘fluffy’, ‘woolly’ and ‘wishy-washy’ to convey the lack of clarity or ability to measure progress against them, as *Mike’s* example shows;

> “When you got something that ambiguous and wishy washy; ‘access to’.. ‘regular intervals’.. ‘Enhanced ratios’...Well.. pardon my language, what the fuck does that mean? How do you measure that? How can you have a plan where you don’t know how much of what, how, what method, how frequent?”

There is an emphasis on the importance of clear and quantifiable outcomes in EHCPs (DfE and DoH, 2015) and quality, quantified outcomes have been recognised as important by professionals in similar studies (Sales and Vincent, 2018), as discussed in the Literature Review. Many parents in this research gave examples of professional-speak wording such as ‘will have access to’, ‘will benefit from’, ‘could have access to’ in addition to the above examples, which shows a lack of SMART objectives within the EHCP, which prevents the ability to measure progress against objectives, decide whether they have been met or assess whether they would need reviewing. Where parents have mentioned the importance of specification, this relates to for example what input is recommended, how many hours of support are needed, from whom (named professional) and from which budget this will be drawn, which should all be included as standard (DfE and DoH, 2015).

5.4 A Piece of Paper.. with Power

Families in this research project shared complex feelings about the EHCP itself. Participants discussed the overall value of the EHCP, with many feeling that it was not worth having, describing it as a piece of paper with little value with similar wording to what *Amani* shared;

> "it's not worth the paper it's written on, really."

Within these discussions, many parents, including *Elizabeth*, also recognise that despite feeling as though the plan itself is of limited value, without it they would not be able to access support at all, as below;

> "And it's just the situation is that yes, if they didn't have the EHCP they would have nothing.. the only reason they have an EHCP that was of any use to them is because we found the law and we used the Tribunal and the complaint process to make them follow the law."

And these feelings were similarly complex for *Kate*, the young person in the research study, in these two thoughts she shared;

> "I'm not, you know, at college for anything. So what am I supposed to use it for? Nothing really. So it's just a bit of paper that is in my name"

> "I'm glad that I had the opportunity to have one, and I'm glad that I had the opportunity to sort of be involved in it kind of. Erm you know, cause without it I probably would have been down a completely different path now."

This positions the EHCP as a passport to provision, with many families feeling that it has been the EHCP that has enabled them to access the support that they have managed to access. However despite the EHCP being viewed and understood in this way by many families, it does not always translate into appropriate implementation and provision. Though this research does not focus on implementation, many parents raised issues in how (and whether) the provision outlined in the EHCP is delivered in practice. This final sub-theme summarises general feeling about the worth of the EHCP but does not reflect in depth the disappointment many families expressed about the lack of implementation of the provision detailed on the EHCP. Many felt that even where the EHCP had (eventually) been of a higher quality, often once they had taken a key role in re-writing it, it did not mean that this would be delivered in practice. Issues with accessing appropriate provision was raised by many of my participants, sharing how difficult they had found or were finding it to access appropriate provision for their child in line with what is in their EHCP. Families in this research experienced general offers of support that did not always align with the outcomes on their child's EHCP, and many report that these did not meet their child's needs, leading to examples of exclusion within the classroom, placement breakdown, children out of school and not receiving any form of education, and breakdown of relationships between families and professionals. This is linked to the third element of the EHCP- provision, or implementation.

Summary

This chapter has presented the findings of my thematic analysis with themes from my interviews with participants. I discussed 5 key areas all linked to the EHCP process or plan, moving from planning and the process through to the plan itself. These key areas are; power/knowledge and solidarity among families, the issues with partnership in the process, the different ways that the process takes a toll on parents, the gap between family expectations of the plan and process and their reality, and finally how well the plan represents the child or young person. Next I take the findings forward into the Discussion chapter, where I discuss them firstly in the current context and then using Foucault's work and my theoretical framework, examining power/knowledge, governmentality, regimes of truth and resistance. I take key elements of the findings, some of which build upon existing research, some that challenge it, and some that are original, and examine them using my chosen theoretical perspectives.

Chapter 6- Discussion

Introduction

In this chapter I report the second stage of the reflexive thematic analysis, as outlined by Braun and Clarke (2022). This involves viewing the inductive, data-led findings I reported in the previous chapter through relevant theory to interpret them in the context of broader theoretical debates. I have chosen to combine post-structural theory, using elements of the work of Foucault, with key elements of rights-based theories, including children's rights and disability rights. The post-structural theory allows me to apply Foucault's theories from my 'box of tools' (Deleuze 1972, cited in Foucault, 1977, p.208) in order to examine the power relations through the process of creating an EHCP from the families' perspectives, as well as to unpack the discourses, regimes of truth and the surveillance and governmentality that these experiences suggest. It is important to remember that 'where there is power, there is resistance' (Foucault, 1978a, p.95) which will also be a focus in the discussion.

I am not using structured or prescriptive theory to analyse the dataset; with post-structuralism, rather than telling me what I will find, it is more about understanding dynamics in relationships and considering how these experiences could be explained. I am not looking to see if the data confirms any theoretical perspective, approach or assumption, but rather using post-structural theory to explore the data in an open-minded and flexible way (Braun and Clarke, 2022) after the inductive analysis of participant contributions. This leads to tentative links and acknowledging where there are elements that do not fit with this perspective (Braun and Clarke, 2022) and using this to raise questions.

I start with a brief summary of the findings, before considering the context operating in society, the most clear and convincing influence on the experiences of families in the research. Many of the issues families experienced could be linked to neoliberalism in society so this is an important place to start. I then move to considering how the findings can be understood through elements of Foucault's work and my chosen tools. Where the Findings chapter considered what families experience, within the Discussion chapter I use Foucault's work to shed further light on why or how these issues may arise for families. To do this I first examined where power/knowledge was visible in the findings, then discourses and regimes of truth and finally where surveillance and governmentality could be seen.

Summary of Findings

The findings from this research suggest that much of what the SEND reforms (DfE, 2014a; DfE and DoH, 2015) promised with regards to the EHCP has not been delivered. This research has found that families are not experiencing co-production in the creation of the EHCP, with unequal and often hostile relationships with professionals, parents not being listened to, and children and young people often not involved in the process. Families are still having to fight for provision and support, with the many burdens of this falling to parents, and disproportionately, mothers. Families are impacted by deficit perspectives of their children and negative constructions of parents, including 'scroungers', and many have internalised the guilt and shame that accompanies these narratives leading to guilt and lowered expectations. Families have received low quality plans, with a lack of aspiration or clear outcomes. Families have found other families to be their main sources of support, information and solidarity, working together to resist negative perspectives and overcome unequal access to support and provision.

Interpretation of Findings

It is important to acknowledge again my positionality as a sociologist and social justice driven researcher here, acknowledging that there are many theoretical perspectives that could be used to interpret the findings of this research. There are a number of themes that could be used to situate the findings using for example, psychology-based or psychosocial approaches, considering mindsets and motivations. My position and what I see as significant in the findings is how they shed further light on how policies are implemented and experienced and what may influence and or underpin policy decisions, in this case, focusing on one particular policy in England. I have found Foucault's theories useful as one way of understanding why and how these issues that families experience can happen, but I recognise that other theories may be equally valuable and illuminate other areas of the findings.

There are approaches rooted in post-structuralism that represent a more nihilistic and hopeless position, indeed Foucault has been accused of pessimism by other scholars for offering ‘no recipes for social change’ (Allan, 1996, p.229), though along with Allan (1996) my position is that Foucault’s work offers hope. Core in Foucault’s work is not being prescriptive but seeking to understand the conditions in which power emerges and is perpetuated (Hodgson and Standish, 2009) so recipes for change are antithetical to this position. For me, the hope in Foucault’s work comes from his focus on resistance, the acknowledgement of the power in those influenced by the technologies of power, surveillance and discipline. Hope, and resistance to dominant and in this case disabling paradigms can also be seen in Disability Studies, Childhood Studies, and rights movements, as discussed in chapter 1.

Context- Neoliberalism and Ableism

Neoliberalism, though not raised in name by the participants of this research can be seen across the findings. This refers to the commodification of children and young people in a marketised education system, that excludes disabled children and young people and those with SEN as ‘non-marketable commodities’ (Blackmore, 2000, p.385) and sees the responsibilisation of parents rather than the state (Doherty and Dooley, 2017). Indeed, participants commented that they feel like they are individually responsible in many ways during this process, driving the EHCP process, having to chase professionals, re-writing plans, sourcing suitable provision and feeling guilty for accessing provision they are entitled to. As discussed in chapter 2, theory and policy is supposedly moving away from a neoliberal understanding of the body, disability, SEN and family, towards a shared understanding, the ability to identify goals and aspirations and be given support to work towards them (DfE and DoH, 2015). The findings of this research project suggest there are still neoliberal understandings and attitudes underpinning the education and support of disabled children and young people, with many families having to take the lead in accessing support, driving the process, and helping other families in the process. Aspirations themselves identified in

EHCPs have been shown to not always be clear, SMART, appropriate or even aspirational. This in my view reflects lower expectations for the lives of disabled children and young people and those with SEN, and a lack of quality in the EHCP, as seen in existing literature (Cullen and Lindsay, 2019; Skipp and Hopwood, 2016; House of Commons, 2019a; Sales and Vincent, 2018). A disproportionate burden of administrative processes is being reported to be falling on parents and families, who are already driving systems forward, which potentially shows the neoliberal elements of this; responsibility for difficulties being faced in education falling on the family and placing blame on parents for asking for support that is deemed unreasonable. Parents felt that they had been constructed negatively by professionals for engaging in the work around the EHCP or taking an active role in the process. This can perhaps be linked back to constructions of parents and families as out to get something and this is especially pervasive in the discourse around mothers; or so-called 'mad mothers' (Douglas et al, 2021). Mothers are constructed in that way as a way of wielding power over them (Ryan and Runswick-Cole, 2007; Douglas et al, 2021) and this serves as a way to reduce or undermine requests for support and reduce spending; an ableist and neoliberal way of viewing what a family has a right to or what was recommended by education, health or social care professionals. This can again contribute to scrounging discourse (Garthwaite, 2011) whereby families are constructed as taking advantage of welfare systems or state support and taking from other children or families.

In this research I found evidence of parents internalising deficit and negative constructions of families and children and struggling to overcome these in exchanges with professionals. Mothers in particular have been seen in research before to have awareness of these depictions and have to work to advocate for their children- in order to secure resources but also for their humanity to be recognised (Runswick-Cole and Ryan, 2019).

As discussed in the Literature Review, these neoliberal influences view the body as a personal project that the individual is responsible for, with resulting financial penalties to be borne by the individual. I can extend this to parents of disabled children or those with SEN; families seen as responsible for their own child and deserving of any financial hardship that this might bring. Here there is a distinction between individualisation in terms of social and economic responsibility (which appears to be linked to a system of gatekeeping resources and deciding who is worthy), and individualism in terms of a person's preferences, needs and requirements (which is linked more to ensuring an individual has the resources they need to lead the life they are entitled to). The latter is visible in the policy context however the former is visible in the findings of this research. This individualisation contributes to a neoliberal view of disability and the body as a personal project, spawning notions of personal responsibility for disability and accepting the resulting financial penalty.

In the context of austerity, disabled people have been affected in the most profound way, and the financial penalty for being disabled was shown to be nineteen times as much for disabled people as for the rest of the population (Duffy, 2013) through individual, local authority and social care cuts. Indeed, at the time of writing, the cost of living crisis is also thought to be disproportionately impacting disabled people because of the rising food costs and energy bills, amenities that households with disabled members use more than households without disabled members (Harari et al, 2023). The impact of this is not simply financial; this relates to those in most need, those who receive social care support, so it can also mean the withdrawal of vital support systems- socially, and at the expense of independence or freedom to make choices. In addition, this does not only relate to personal benefits payments; 50% of cuts during austerity for example were being made to local government and social welfare budgets- targeting the most vulnerable in society (Duffy, 2013). This takes the form of individual budgets or benefits and services usually provided by the local authority as part of social care provision (for example day centres or support services) which supports the idea that these cost of living crises are ideological rather than financial, with suggestions of ableism.

Families in this research also reported significant financial impacts associated with their involvement with the EHCP and its processes, including impacts on their own businesses, careers and wider finances. Again this is in the context of an already difficult financial landscape globally and nationally with the cost of living crisis, continuing impacts from Covid-19 impacts and austerity measures, rising inflation and the impacts of these on not only individuals but local authorities and charities. Charities have for example reported that the cost of living issues are impacting their ability to provide support to children with SEND, impacting children's mental health (Krasniqi, Carr and Stevens, 2023). These issues can also be linked to longer waiting times for intervention and assessment in a health system already under intense pressure made worse by this cost of living crisis (NHE, 2022). The waiting times for assessments and other barriers to accessing them have led to parents experiencing greater scrutiny in accessing support, and paying privately for assessments, as I found in the research, leading to an additional financial implication for parents trying to gather evidence in their application for or review of an EHCP. Families experiencing financial difficulties and needing support from the state or the local authority as a result of the system in which they did not choose to be involved in creates a power dynamic where they are afforded less choice and control over their family life, finances and outcomes, and greater state intervention.

The intervention of the state in the lives of individuals positions the state as comparable to the head of the family responsible for his household. This ensures control over 'wealth and behaviour' (Foucault, 1978b), the function of which is not for the 'common good' but to achieve 'ends which are convenient' (Foucault, 1978b, p.87). In this context, the most convenient outcome for the allocator of financial resources is arguably to avoid paying for support, or to reduce numbers of those eligible for support, as suggested in the SEND Improvement Plan (HM Government, 2023). This dynamic can be linked to societal perspectives on disabled children and families, for example, who is 'deserving' of support, linking constructions of disability and ideology; deficit constructions of disabled children and 'scrounging' constructions of parents, and how this is contextualised within a capitalist system of competition and ableism. The narrative around an EHCP representing a 'golden ticket' is well documented (Smith, 2023) and pervasive through official and informal channels and this has been raised again in the media in 2023, linked perhaps in no small way to the current cost of living crisis and local councils reporting being in financial difficulty or even on the verge of bankruptcy (LGA, 2023). The issues that local councils face are worded in the media as being due to the rising need for social care services in addition to the issue of rising inflation (e.g. Butler, 2022) which again directs the focus to the people who are in need, but does not reflect the reason for this rising need or the complex social factors surrounding this.

This contributes yet again to the neoliberal discourse around undeserving families draining limited budgets for their own gain, at the expense of others. Families in the current research were aware of these discourses, using the language of golden tickets, unreasonable demands and parent blame for problems in the process. The argument that families made in this research is that the golden ticket narrative is harmful and false; there is no shortcut to additional or undeserved support, and the requests families make are for what most families are already able to enjoy, such as access to their community and local facilities, appropriate educational provision and positive life outcomes. In other words, things that their children have a right to expect under the UNCRC and UNCRPD (UN, 1989; UN, 2007). By constructing families' requests as somehow additional, costly and unreasonable, and making families feel grateful for resources or support they have a right to, the charitable model of disability is evident again; constructing local authorities as beleaguered benefactors, making value-laden decisions on who is worthy of their charitable efforts. This forms part of the disabling process; to construct a person's needs as exceptional (Arnold, 2014) rather than considering them through the perspective of what a person has a right to. This also suggests a deeply entrenched hierarchy in terms of power relations; disregarding the lived experiences and rights of disabled children and young people and the ability of the family to express what would be supportive to them. The parents in this study generally understood the local authority as the face of an adversarial system, wording that has been documented many times before (HM Government, 2022; DfE, 2023b, House of Commons, 2019a) though there was also acknowledgement among many of the participants that the local authority is constrained by broader issues such as finance and lack of ringfencing of budgets.

The many impacts that the EHCP process has on families reach beyond financial and reputational; in this research I heard from families who have experienced significant emotional impacts from their involvement in the EHCP process, reporting for example stress, trauma and disappointment. Though stress and anxiety have been reported before in the literature (Bentley, 2017; Cullen and Lindsay, 2019) the strength of the language used by parents in my study (for example, ‘traumatised’, ‘dread it’, ‘it’s killing me’) show the acute impact of the process on them.

For the EHCP then, a concern is that the issues that families face in accessing support could be viewed as ideological rather than financial. Some of these issues are long-standing and highly publicised (House of Commons, 2019a) and indeed families in the research recognise that local authorities are often underfunded and experience their own problems in relation to staffing numbers and turnover, contributing to poorer experiences for families. The compounding factors of neoliberalism and ableism, or neoliberal-ableism (Goodley, Lawthom and Runswick-Cole, 2014) therefore could be seen to position disabled children and young people and those with SEN and their families in a negative way, with an inferior position in society.

The next sections of this chapter explore elements of this ideological perspective, using three key areas of Foucault’s work; power/knowledge, discourses and regimes of truth, and surveillance and governmentality to consider some of the reasons why the families in this study may have experienced the process in the way that they have.

Power/Knowledge

Firstly, I looked at Foucault’s theory of power/knowledge to consider how power is evident through the findings and how this may underpin the experiences of families. Many of the key findings in this research can be understood by a perception of unequal power and entrenched hierarchies, and whilst there are links throughout to power/knowledge, I also challenge it as a concept. Some parents raised power relations despite me not asking about power at all or using that wording, and others focused on how they felt excluded, not listened to or disempowered, in more implicit discussions of power relations and hierarchies. These were apparent across the findings and in relation to roles in the process, in the meetings and in the plan itself. The findings showed that many of the parents involved in the research could be categorised as expert parents, with high levels of knowledge about how the EHCP process works, however this did not translate into actual power in terms of having any control in the process. The majority of parents reported not feeling listened to or valued in the process, with a lack of partnership with professionals evident. Power, for Foucault (1975) is not an object or a possession, but an action, a relationship, a way of impacting the actions of others (Foucault, 1982). Though power/knowledge are inextricable for Foucault (1978), with power created and upheld by knowledge, and some forms of knowledge being more powerful than others, parents in this research experienced resistance to their inclusion as a partner in decision-making for their children by professionals. This represents a disjoint between their power/knowledge- they are necessarily not one and the same for parents in these cases.

A key finding from the research was families feeling that they were not being listened to by professionals in the process of creating the EHCP. Where groups are experiencing exclusion from processes like this, they can be impacted by the privileged right to speak (Foucault, 1969) which influences how and whether they are listened to, trusted or involved. Where parents are not constructed as legitimate holders of that knowledge, they are not given the respect that professionals are when they hold it, similar to the lack of credibility Ryan and Runswick-Cole (2007) report when parents (specifically mothers) have to do the work that professionals would usually do. This was also raised by participants, specifically in relation to where evidence from professionals about children and young people’s needs and support is felt to be given weight in the EHCP where parent reports are not.

Whether or not parents feel listened to or valued in the process is strongly linked in the findings to the relationships between parents and professionals and the hierarchies at play in these relationships. This is despite parental partnership being a policy focus for many years with many drivers, for example for the benefit of their general education (Plowden, 1967), to improve parental confidence in the system (Lamb, 2009), and to ensure a more appropriate match between their needs and the services being provided (DfE and DoH, 2015). This is also in the context of person-centred approaches and co-production, as advocated for in the current statutory guidance (DfE and DoH, 2015) whereby deep listening and respect for the individual should be central (Sanderson, Thompson and Kilbane, 2006).

Many of the participants raised issues in their relationships with professionals as a complicating factor in creating the EHCP; issues with school staff, external professionals and the local authority were most commonly raised, with emotive wording like ‘cruelty’, ‘patronised’, ‘vile’, ‘ignored’. Similar findings have been seen in the literature before with parents reporting that professionals sometimes behaved in ways that were described as ‘unpleasant and unprofessional’ (Cullen and Lindsay, 2019, p.7) though building on this, some participants in the current research project felt that in some cases creating difficulties in communication or relationships was a deliberate tactic by professionals. Power imbalance between professionals and parents has been said to be ‘a long way from being fully addressed’ (Holland and Pell, 2018, p.397) with issues such as parents feeling that professionals used power to make the system work in their own advantage (Duncan, 2003) rather than for the benefit of the child or young person and their outcomes. This is reminiscent of other elements of work by Foucault (1982) and Sullivan (2015) around doctors and patients, with doctors taking the role of knowledgeable expert with the power to construct patients as subjects, ignoring the evidence and expertise of the patient’s experience in their own condition and care. This also has resonance with disability rights movements and the experts by experience movement as a form of resistance as well as research showing the importance of listening to those who have lived experience of welfare systems to undo ‘vilifying discourse’ (Garthwaite, 2011, p. 372).

Many parents are still experiencing models of partnership that privilege professional knowledge; expert, transplant and informant models (Hellawell, 2019). Parents in these ‘partnerships’ are constructed in a deficit way, though are also subject to scrutiny and surveillance in their parenting, depending on their proximity to the norm, for example if they are disabled themselves (Wilde and Hoskinson-Clark, 2014). Professionals need to move away from the idea that they are the only experts in this situation (Holland and Pell, 2018) though parents in the current study did also recognise the need for professional expertise and knowledge and welcomed more balanced partnerships.

Additionally, parents who have high levels of knowledge reported this knowledge being a factor in problematic relationships with professionals. They report this leading in some cases to relationship or communication breakdown, and escalation of concerns to formal complaint or appeal processes. In this situation, parents report feeling responsible for moving processes forward for the benefit of their child, but without having the power to do so, and without feeling listened to or valued by the professionals involved. These situations sit outside the accepted partnership models, instead creating what I would label a Dysfunctional Model, with decisions not being made at all, resulting in long delays in drafting or reviewing the EHCP, as reported by participants. Alternatively, I suggest that a Conflict Model arises, where decisions are made against parents' wishes, or as the result of a tribunal, and in some cases are the subject of a judicial review.

Some parents in the research felt there were power issues and hierarchies between professionals too, which impacted upon their experience of the EHCP process. This included a lack of external professionals (those from health, social care or the local authority) attending EHCP annual review meetings, as seen in other research (Boesley and Crane, 2018) which impacts the quality of the EHCP that is produced. This could also be seen in the way that services and professionals shift responsibility for financing or fulfilling support requirements of the EHCP, demonstrating issues in collaborative working which could be underpinned by hierarchies between professionals and their impact upon the way families experience this process.

Discourses and Regimes of Truth

I next considered the discourses and regimes of truth visible in the findings from this research. I identified a set of discourses and regimes of truth that affect how disabled children and young people and those with SEN experience the EHCP process and how they are written about in their plan. The most prominent discourses and regimes of truth from this study include SEN as a deficit label, deficit perspectives governing SEN and disability more generally, and negative portrayals of parents seeking support for their child. Discourses and regimes of truth are underpinned by and diffused with power/knowledge

(Foucault, 1991); they can be described as technologies of power (Foucault, 1978) or, ways of wielding power. Discourses subjectify individuals, creating groups and hierarchies between and within groups, and creating specific ways of thinking or talking about the individuals or groups in question (Foucault, 1969). This usually serves a purpose, for example in Foucault's work (1975) a discourse of criminality is created for the purpose of punishing. These discourses operate at both a societal level (in terms of how societies construct and understand others) and at an individual level (how the individual constructs and understands themselves) (Foucault, 1975). Regimes of truth are discourses that society upholds as true (Foucault, 1980), how it is determined what counts as knowledge and who gets to claim they have or can create knowledge (Foucault, 1977b). Discourses and regimes of truth can legitimise action taken against a group, individual or concept for the benefit of society (Foucault, 1980), which is visible in media reports in chapter 1.

Firstly, there is an issue with the label of SEN or SEND, along with the broader debate on labelling theory as discussed in chapter 2. SEN/SEND is not simply a diagnostic label, or a way of categorising children to allocate support resources, SEN/SEND as a label brings with it a set of 'truths' about the children it describes. This is core in Foucault's (1980) discussions of regimes of truth and discourses, that the language that is used and shared goes deeper than an initial or surface level division, to moral divisions and stratification. The label creates a regime of truth that affects how children and young people categorised as having SEN experience education, community and broader life outcomes. These regimes of truth do not allow for change and flux in a significant way, and they bring with them defining, controlling and normalising ideas about who they describe.

Some of these discourses are long-standing, for example, child development and learning milestones, by which children are measured and situated as close to or further from a norm. The subsequent interventions based on these assessments can be linked to Foucault's (1977) concept of biopower, whereby the bodies and actions of children and young people are controlled and changed by the more powerful in society. Other discourses have been seen through more recent publications, for example, the low expectations for disabled children and those with SEN (DfE, 2011; Lamb, 2009) and are still visible in the deficit language, negative narratives, and lack of appropriate, clear, measurable outcomes visible in the EHCPs of the families in the current research.

I suggest that all children could be described as having special (or individual) educational needs and strengths, and that ownership of the term ‘Special Educational Needs’ has been taken from those with the label and used in a negative way. There is a regime of truth that has been created around SEN and it comes with negative connotations and wider implications about fixed capacity, intelligence and value. With a subverted meaning, the term ‘Special Educational Needs’ is therefore not appropriate to use in a policy context, or in a system that has purportedly been created to provide support and a more equitable experience for children and young people. It has, in reality, become a disabling discourse.

This disabling discourse was visible in the research in terms of involving children in the EHCP process, which I found was not a reality for many families. Though there was a range of experiences discussed by participants in the Findings chapter, many of these represent lower levels on Hart’s adaptation of Arnstein’s ladder of participation (1969, cited in Hart, 1992) with very few reaching the rungs that represent any form of participation. As discussed previously, the discourse surrounding SEN and disabled children and young people constructs them as inferior, with deficit perspectives permeating societal and professional perceptions of SEN, despite larger movements towards affirmative perspectives more broadly, as seen in the chapters 2 and 3. Cannella (1999, p.38) summarises Foucault’s (1969) governance of discourse; ‘most discourses are governed by rules and principles of exclusion that include prohibition, ritual, the privileged right to speak, the appeal to reason, and the will to truth.’. To apply this to the topic area, the discourse around SEN and disabled children is impacted by perceptions of who should be listened to, who can be reasoned with, and who is excluded from the narrative.

Privileged right to speak is particularly important for disabled children who are excluded by virtue of being a child but also by virtue of being disabled, so they are seen less regularly in research and in decisions made about their own lives. This is true for this piece of research, in its findings and in its implications; parents reporting that their child does not have knowledge of the process, is not involved in the process, and then children not being involved in the research itself because they do not understand the EHCP, would not like talking about it, or parents thinking they would not be able to make a contribution. This was also true for the young person I interviewed, who was invited to annual review meetings but did not feel listened to whilst there. This also resonates with Lundy's (2007) barriers to the implementation of article 12 of the UNCRC (UN, 1989); the right for children to express their views and to have them given due weight. Lundy (2007) suggests that adults being sceptical about a child or young person's ability to understand and be involved can be a significant barrier, in addition to the effort that including a child or young person takes to achieve. This can contribute to a regime of truth about children and young people lacking the capacity or capability to be involved in important processes such as the EHCP, further excluding them from sharing their views and aspirations, when in many cases, appropriate support could enable them to understand elements of the process and express a view.

Parents and families of disabled children and those with SEN do not escape disabling and excluding discourses, as was clear in this piece of research. Parents were acutely aware of the ways in which they feel they are constructed within society, with examples such as 'scum of society' and 'scrounging off the state'. Many parents in the research felt that they were being constructed even by the professionals involved in their child's support as problematic for seeking support for their child. Where families had experienced breakdown of their child's educational placement, they found themselves responsible for their child's education and care arrangements 24 hours per day because there was no suitable provision. Parents in my study also reported that their involvement in the EHCP process and the broader processes of securing support for their children impacts their ability to work. In a capitalist system that values the body as a tool for labour over everything else (Bengtsson, 2017) this positions many of these parents as deviants, as not fulfilling their societal role (Sewell, 1981). I argue that this constructs parents of disabled children as disabled by proxy when considering these regimes of truth; parents of disabled children may not have access to the norms and goals of the cultural majority (Darling, 2003) and experience a kind of social exclusion of their own (Pratesi and Runswick-Cole, 2011).

Surveillance and Governmentality

The final elements of Foucault’s work I used to interpret the findings are surveillance and governmentality. I observed these concepts as I collected and analysed the data, noting initially that parents often mentioned feeling judged for seeking or obtaining support for their child, leading to changes in behaviour or thinking. Surveillance and governmentality can again be described as mechanisms of power (Foucault, 1978); ways in which power can be seen to impact the individual. Power, in governmentality, acts not directly upon the individual, but on their actions through normalising technologies (Foucault, 1982). This means that much of governmentality relies upon the individual to regulate their own behaviour according to what is seen to be acceptable. For Foucault this is technologies of discipline. Surveillance is one example of a technology of discipline (Foucault, 1975) alongside hierarchical observation, normalizing judgement and the examination (Foucault, 1975, p.170-184), as discussed in the Introduction chapter. These technologies involve observing and measuring individuals and their behaviour, judging them against a norm and using this as a form of control.

Technologies of discipline have been applied before in the context of mainstream schooling for children with SEN and resulting in a Statement of SEN (Allan, 1996) but when looking at the findings from the current research, it is possible to expand this analysis further. This is seen in three parts, firstly by understanding hierarchical observation, which is apparent where professionals occupy a more powerful role, as reported in the findings from this research. Secondly, considering normalising judgement, which is seen in the very definition of SEN which compares children to others of the same age, in addition to the EHCP needs assessment seeking evidence of where a child or young person is in ‘need’. Thirdly, in the ‘examination’ (Foucault, 1975) which is extended, not just to a child or young person undergoing a statutory needs assessment, but to their parents too. It has also been found in the literature that involvement of services for families can represent a form of surveillance and lead to additional stress on parents (Holland and Pell, 2018) even though this is supposed to be a mechanism for support. So more than simply in the context of the formal needs assessments, being involved with support services at all can impact families in ways that shape their behaviour.

With the EHCP, hierarchical observation is seen in how children or young people are deemed as eligible or ineligible for a needs assessment (as outlined in chapters 2 and 3, though not a focus of this research) but also in how professionals observe children and young people for the purpose of creating reports to be used as Section K evidence (DfE and DoH, 2015) and deciding upon outcomes and provision. This combines with normalising judgement, with professionals giving their opinions about how much support an individual should have based on their own judgement.

These technologies of discipline can be seen in the findings from parents too; some parents reported feeling as though they had to ‘perform’ or behave in a certain way to be taken seriously by professionals, for example paying attention to how they dress. Though this was raised by participants about the process in less apparent manner than the other concepts I have discussed, this suggests that the process as well as the document itself can be used as a form of surveillance, and as a way of creating ways of behaving; culminating in the ‘examination’ (Foucault, 1975). Other parents discussed feeling judged or viewed negatively for seeking support for their child, with problematic relationships between parents and professionals common in the findings. Some parents reflected upon where their expectations of the process had lowered to expect poor treatment, some felt that they had become disengaged, where others were spurred on to action, resonating with the dichotomy presented in the literature review; parents fighting (Lamb, 2009) or giving up (Green and Edwards, 2021).

Another core issue in the research related to surveillance and governmentality is in the domain of budgetary control and constraint. Issues related to finances and budgetary considerations were commonly raised in interviews by parents, though it is interesting to note that I did not specifically ask about these issues. Some of these issues were in direct relation to the EHCP process and plan, and the problems they create in terms of accessing provision for the child or young person, or the broader financial impact that this has on the family, where others were more indirectly related. It is important to remember that the families that this research has been designed with and for are often already experiencing heavy surveillance and scrutiny over their lives, relationships, decisions and finances and the impacts of that, for example with applications for financial support like Disability Living Allowance (DLA) being a cause of anxiety for families (Hastwell and Moss, 2020). I also discussed in the Literature Review the dehumanising processes of needs assessments for the purpose of accessing support in the broader context (Stewart, 2018; SMF, 2021) and the scrutiny, surveillance and governmentality that this represents.

Additionally, families in the research reported being made to feel guilty for fighting for support, and for provision that their child receives. Guilt and shame can work as regulatory mechanisms in the control of the self or others; the technologies of discipline can be wielded by reminding parents about their child's distance from or closeness to the norm and comparing them to other children. Some parents reported elements of this in the research, being told to count themselves lucky for what they do get or reminded that what they are receiving is more than other families receive. This forms part of Foucault's technologies of discipline (1975) as explored in chapter 1; creating a feeling of guilt, shame or gratitude in families for what should be provided by right in order to regulate their behaviour. This also links to the dual 'shame-blame complex' as described by Scavarda (2024, p.1) whereby the blame for the child being disabled or having SEN is placed with the parents. As regulatory mechanisms, these feelings can prevent families from fighting at all or stop them pushing further for what their child is entitled to. This works in the interest of budget-holders and those who govern the process, but not in the interest of the child or family and can impact the support and provision they receive.

Resistance

The final element to discuss in relation to the findings is resistance, which was visible throughout the findings. This took the form of families resisting negative portrayals, resisting the power hierarchies and helping and supporting other families navigate the complex process. Having considered power and technologies of power throughout this chapter, it is important to remember that children, young people and their families can also demonstrate power, and this is seen through resistance. As Foucault stated; ‘where there is power, there is resistance’ (Foucault, 1978a, p.95). There are examples through the research of parents resisting inappropriate power wielded by professionals, and of parents wielding their own power, for example, in refusals to sign draft EHCPs that do not represent their children and in challenging inaccurate reports provided by professionals. I also found examples in the current research study of parents and families resisting and challenging deficit-focused and fixed depictions of their children in favour of more strengths-based and affirmative constructions, or in some cases, flexibility and balance. In these cases, this required work from families to contribute to or in some cases rewrite the EHCP so that it accurately reflects their child. This became a key theme in the findings; the enormous amount of work that many families do to not only contribute to the process but be the driving force behind it. Though some parents reported feeling alienated or excluded from the process, many families felt that without their work (in learning about the EHCP and process, supporting their children to be involved, correcting, writing or re-writing sections of the EHCP itself and chasing professionals for their contribution) they would not have got to the point where they had a plan at all. They generally reported that this work was not valued by professionals, and in some cases, it impacted the relationship with the school, external professionals or the local authority negatively. Despite this, families were keen to share the knowledge, skills and expertise gained through these adverse experiences with other families, to support them in their own fights for provision and support.

There were also examples of more formal ‘fights’ taken up by families in the form of legal pre-action, complaints and use of tribunal and judicial review, in accordance with other findings (House of Commons, 2019a) to secure appropriate provision. These fights show a shifting of power, of using knowledge, connections with other families and charities and support organisations to move towards more positive outcomes for their child. This also challenges power hierarchies, in a move to secure provision that is a right for their child and not a privilege.

Families also reported resistance in their solidarity with other families; firstly, resisting the idea that they are in competition for resources, as seen in other research with welfare support (Patrick, 2016), with quotes from participants like, 'I don't just want it for my child, I want it for all the children'. This shows strength and resistance in a system that can feel as though it is pitting them against each other and constructing them as scroungers and shirkers (Garthwaite, 2011). Secondly in the information sharing, warning and preparing other families who are new to the EHCP process or not as far along as they are, and thirdly in the strength of feeling they showed towards other families they feel might not be as well-equipped as them. The young person I interviewed shared her hopes that by talking about her experiences and where things had not gone well for her in the EHCP process, both in this research and outside of it, that this would contribute to positive change for others. This is a clear message of the families involved in the research, that the one clear positive they took from the process is the support and solidarity they received from other families, and the support and solidarity that they now offer to others.

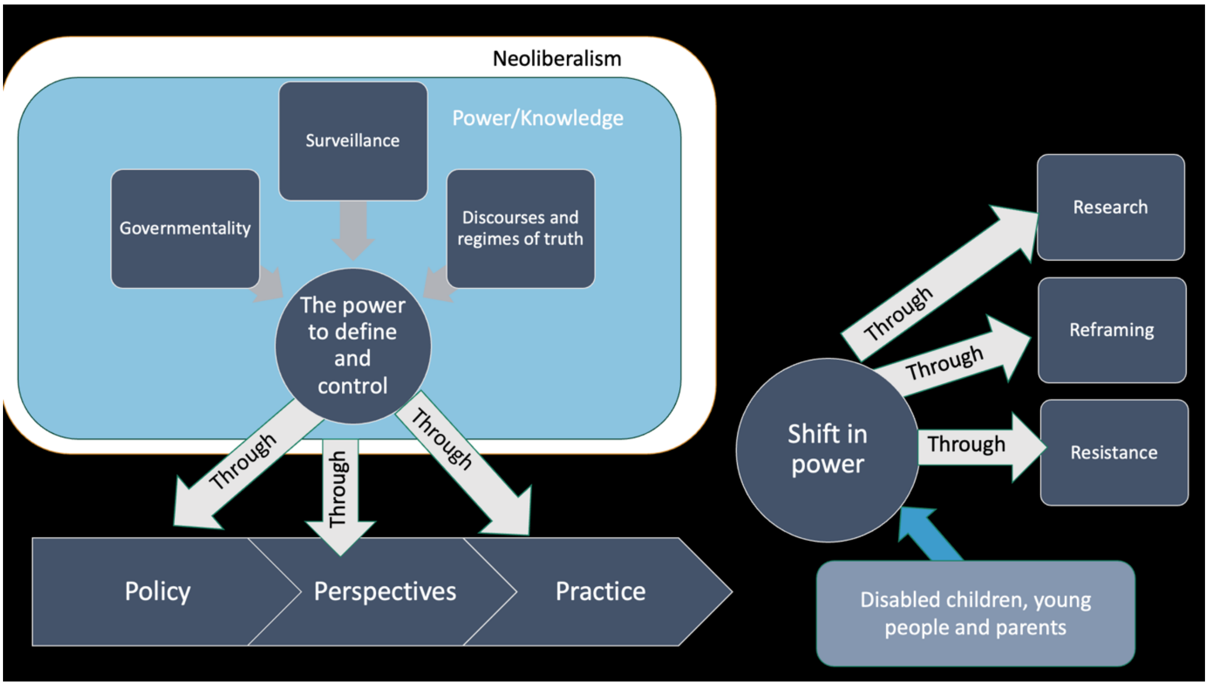

Figure 7: A representation of Foucault's work in my writing

The diagram above (figure 7) shows how I see the work of Foucault in the findings from this piece of research, summarising the Discussion chapter.

Implications for Practice

Considering implications for practice is an important part of the Discussion chapter whereby learning from the research can be translated into suggestions for changes in practice. For this research, it is not an easy task because the discussion has suggested that there are complex forces underpinning the dynamics of creating the EHCP and no simple answers for what could or should be changed in the process. This is also complicated by the use of post-structural theory, which rejects the concept of a fixed, singular truth (Hodgson and Standish, 2009). I do however, go on to make suggestions in chapter 7, though here I consider some of the complexities in making these suggestions, and what could be taken from this research in practice. This discussion could provide practitioners with an opportunity to reflect on the systems within which they work, and the discourses that they (intentionally or not) uphold in their practice. For families, this discussion may show that many other families are experiencing similar things in their fights for support and that they are not alone. They are also using their power to contribute to shifts in perspectives that can benefit all families. This discussion also repositions families in a way that does not blame them for the difficulties experienced, as is usual in media publications.

Families in the research reported a lack of co-production in the EHCP process, with parents sharing that they are not involved or meaningfully listened to, and that their children are often not involved in the process at all. Involvement of children and young people in decisions that impact them has been a long-standing right (UN, 1989) and has featured in the SEND reforms documents (DfE, 2014a; DfE and DoH, 2015). Co-production with children and young people has been open to debate however; there are few other areas where a child would ever be expected to have this much input into their aspirations or educational outcomes when compared with non-disabled children for example. There is the potential for higher levels of involvement (for example in co-production) to become a burden rather than a positive experience, for the child or young person, or an additional task for their parents to manage. There is also a question over who decides how involved is involved enough; Hart (2008) emphasises that though the widely used ladder of participation is presented as a literal hierarchy, the higher rungs are not necessarily better. The higher rungs (for example, child-initiated decisions) may not be appropriate (or able to be honoured) in the EHCP process or may not be suitable for the child or young person in question. For professionals, working together with families can help determine appropriate levels of involvement for children and young people, along with ways to engage children and young people in a meaningful way.

Whilst there is a focus on normalised outcomes for disabled children and young people and those with SEN, there is also a focus on all the ways they are different, or deficit. The EHCP is a document that in many ways is designed to be written from a deficit perspective, highlighting the child or young person's areas of need to allocate support, despite the SEND Code of Practice moving towards more affirmative and strengths-based language (DfE and DoH, 2015). Whilst it is necessary to outline where a person may need support in order to work towards their aspirations, the findings from this research show that in several cases, parents were not able to recognise their child in the EHCP or they shared how overly negative, or deficit language has been used to describe their child or their child's behaviour. Parents are often recommended to focus on the bad days with their children when making applications for support (Scope, 2023) and this has been seen in parents feeling they have to over-emphasise impairments to access support (Goodley and Runswick-Cole, 2011) as well as practitioners over-emphasising needs (Trussler and Robinson, 2015) for the same purpose. This can create overly negative and, in some cases, unrepresentative depictions of children as a necessity in a system that requires families to fight for resources, as I found in this research. The implication of the perpetuation of this deficit perspective traps disabled children and young people in a regime of truth that positions them as inferior and undermines their rights, strengths, potential and aspirations, both for being disabled or having SEN and for being children. This could serve to further exclude them from processes that seek their input, such as the EHCP, contributing to 'Dual Layer Underrepresentation' as I suggested in chapter 3. This also questions the purpose and benefit of labelling children as having SEN when it can lead to these deficit depictions but still no guarantee of additional support.

There is a clash visible here, as reflected in the literature, which is the normalising of disabled children and young people and those with SEN but also the differentiating of them. With newer, more flexible definitions of what is ‘normal’ (Waldschmidt, 2018), disabled children and young people and those with SEN are still not able to qualify, reflecting again the narrow parameters of what it is to be human (Goodley, Runswick-Cole and Liddiard, 2016) and a pervading dehumanising discourse (Taylor, 2018). Disabled children being seen as both the same and different has been discussed as constructing the dishuman (Goodley and Runswick-Cole, 2014) and whilst this marks people out as different, it can also contribute to rethinking what is ‘normal’. This is a key theme in Critical Disability Studies, which focuses on the ability to challenge or resist disabling discourses and mechanisms (Cameron and Moore, 2014), as families are doing here. Much of this fight focuses on firstly recognising that disabled children and those with SEN are worthy, and ensuring their rights are upheld.

Parents themselves have also been fighting for balance in their relationships with professionals, with extremes seen in the findings; some parents are leading the EHCP process and others feeling excluded by it. I have suggested in this chapter that the partnership models (Hellawell, 2019) most often experienced by parents in this study are still those that position the professional over the parent in these relationships. I have also proposed Dysfunctional and Conflict models to describe these relationships, with families experiencing delays and dysfunction in the process, or decisions made in opposition to their wishes or as a result of a protracted legal battle. In this research, none of these models depict co-production or balance in relationships between families and professionals, and even where parents have specialist knowledge of the process and plan, this is not valued by their professional counterparts. This chapter has not proposed a new way of conceptualising partnerships between families and professionals but rather has sought to understand why and how the dynamics underpinning the relationships have come about, considering the neoliberal context, regimes of truth governing parents, and the power diffusing existing roles. The partnership model (Hellawell, 2019) remains an important tool for understanding and building relationships, and professionals seeking learning points from this chapter may consider assessing their own practice using this model.

For many families in this research, the EHCP ultimately represented a piece of paper, with connotations of uselessness, judged only by how it was implemented. This was an issue in this research as my focus was on the process and plan rather than on the implementation. Within the scope of the research however was the way knowledge about the process and the support available was built, shared and withheld. Many parents reported not knowing what was available in their area for their child in terms of support, activities or education, having to find this information out themselves rather than being given information on the Local Offer, as they should be able to expect (DfE and DoH, 2015). The Local Offer should form a starting point for available services and support but not constrain the way that aspirations are written about in the EHCP, controlling what goes into an EHCP, nor should it be an exhaustive list of the only things that families are able to ask for. Though this has been documented before in research (NAS, 2021; Hastwell and Moss, 2020; HM Government 2022), I heard some extreme examples in this research whereby children had experienced school exclusions, both fixed term and permanent, and long periods of time with no education at all. Many more families in this research experienced this than I would have expected given the findings of the most recent research (Long and Danechi, 2023) where only a small percentage of families were reported to experience this.

I also heard examples of families feeling that though their educational arrangements may not be ideal, they were able to trust the school or staff to meet the needs of their child with creativity and flexibility. Trust was a key concept here, where families and professionals had built a trusting and positive relationship there were more positive experiences reported of the EHCP process. This was dependent upon the professional, both the relationship and the quality of the plan achieved in the process; families reported that this relied heavily on the teacher or SENCO. Families used terms like ‘creative’, ‘supportive’ and ‘invested’ to describe teachers and SENCOs that they had been able to work well with for positive outcomes in the EHCP. This also hints at resistance by some education professionals, in working to use budgets and resources carefully and creatively to support families, and in building trusting, positive relationships with families, all of which families reported have led to better EHCPs and provision. There is hope in this finding, that despite all the complexities in the process and the competing demands on education professionals' time, where positive relationships are built, outcomes are said to improve.

With ten years having passed since the EHCP was introduced (not including the time that many local authorities spent in the Pathfinder phase), questions arise about the status of the EHCP within education, health and social care and whether it is receiving the investment and attention that it requires or whether it represents a neoliberal way of viewing disabled children and those with SEN and their families, pushing responsibility back to parents and families. The rationale behind the introduction of the EHCP and its status in policy is strong (DfE, 2014a; DfE and DoH, 2015) and many families in this research still report having faith in the reforms themselves, however the commitments made in these documents are not always delivered in reality. This discussion suggests that this lack of delivery could be at least in part, an ideological decision, rather than financial, considering the way disabled children and young people and those with SEN and their families are constructed in society at this time.

Moving forward

As with all research endeavours there is always a need for further research, in relation to this specific topic but also into the broader themes that I identified as part of the research.

Family Experiences of Implementation of the EHCP and Accessing Support

Future research could continue to examine the power relations governing the experiences of families in different elements of their journeys to seek support. These could include engagement with health and welfare systems to examine and understand families' experiences and roles in these journeys. It is also important to engage in more research that seeks to engage and include disabled children and young people, carefully, meaningfully and from the beginning of the research. Families in this research, both members of my advisory group and research participants raised additional issues, outside of the scope of the research questions. Some of these were linked to the EHCP, for example, the difficulties that families face in accessing the support that is outlined in the EHCP even once this has been agreed upon. Within this, issues raised included support not being implemented, support being denied, support or interventions implemented inconsistently, and support being implemented and then discontinued without discussion. Similar findings have been reflected in the work of Hastwell and Moss (2020) who found specifically that therapeutic interventions included in the EHCP were often not implemented, for example speech and language therapy. Aside from this being a legal requirement- to implement what is outlined in section F (DfE, 2014a, section 37 (2)) this hinders progress towards outcomes and aspirations. Where the local authority fails to provide for the child based on section F, families can make a complaint, contact the ombudsman or bring a judicial review (SOSSEN, 2023), again, making families responsible for holding professionals to account. As identified in the findings, this often comes at both financial and personal costs to families.

Families in this research also raised issues with the Local Offer and the lack of support, services or facilities in their local area that are suitable for their child. Examples include families feeling pressured to accept support that they neither want or need (in lieu of personalised or appropriate provision) and families being expected to source provision themselves or play a significant role in that provision themselves (for example, driving their child to and from education or community activities through the day, or educating their child at home without support). Inappropriate provision can be seen across the literature as an issue facing disabled children and young people, with issues such as inaccessibility of facilities including activities and leisure facilities, through rules, physical design and attitudes (Hastwell and Moss, 2020). Another issue families face is dissatisfaction with school provision; 75% of parents surveyed by the National Autistic Society were unhappy with the school place their child had, feeling that it did not meet their needs (NAS, 2021). Overall, 2.6% of children who have an EHCP are not in education, employment, or training (NEET) and 3.4% are 'educated elsewhere' (home education, awaiting placement or having been permanently excluded) (Long and Danechi, 2023). Appropriateness of provision has again been identified as an area for improvement in the SEND Review (HM Government, 2022) however the wording here appears to shift blame to 'increased numbers of requests for EHCPs' (p.12), in reduction of places available in specialist and alternative provision, and in pulling expertise out of mainstream provision. More research is needed from family perspectives to resist and challenge the family blame narratives.

Eligibility for the EHCP

I did not discuss in too much depth the eligibility criteria for the EHCP, as this was outside the scope of the research, but it is highly contested, leading to many tribunal challenges, the vast majority of which (98%) are won by families seeking an EHCP and support for their child (DfE, 2023a). This should be considered as a future area for in-depth, child- and parent-initiated research, so that their own concerns can be addressed. This is a highly charged area of experience for many families and it was not within the scope of the research to discuss and critique the processes by which families access a needs assessment for the EHCP and whether or not they are given an EHCP, but this is an area that needs further attention, as the many tribunals have shown; 28% of the appeals brought to tribunal in 2021-2022 related to the refusal of an EHCP (DfE, 2023). For this piece of research, my focus was on the experiences of those going through the process themselves, once they had already had a needs assessment and been given an EHCP, though the discussions did also focus on family experiences of the assessment process in addition to annual reviews, waiting times and sharing of documents related to the EHCP needs assessment. Future research could focus on eligibility criteria from multiple perspectives but could also focus on families who have been refused an EHCP and their experiences.

Anxiety about the Future

Many families also reported feeling anxious about the future for themselves and their child or young person. There is an awareness among families that outside the relative safety of school, there can be continued issues with accessing support. Despite the challenges families faced with the EHCP process and plan, there was heightened awareness among participants that this was perhaps the best things were going to get, with anxiety about what happens once young people leave education. This issue was supposed to be addressed by the SEND reforms, with transitions and preparation for adulthood being a core focus of the SEND Code of Practice (DfE and DoH, 2015) but was again identified as an area requiring improvement in the SEND Review (HM Government 2022). Though not covered by the research questions for this study, many families raised the issue of the future post-education as a source of stress and worry, showing that the challenges that families face in the EHCP process is just another part of a large, complex and challenging system that they have to navigate in order to secure support. Future research could identify specific areas for improvement, alongside families and those with experience of the process.

Understanding the Impacts of New Legislation

There are changes ahead as outlined by the SEND and Alternative Provision Improvement Plan (HM Government, 2023) with the aims to reduce the number of children and young people with an EHCP and to standardise the plan itself. In light of the findings of this research, these changes could be problematic, given that there is already an issue with more children and young people needing an EHCP than the system is able to accommodate, from the statistics on timelines show (DfE, 2023b). There is also an issue with quality of plans, which standardising may address on one end, keeping children and young people from receiving the poorest quality plans, but may also discourage creativity in plans seen in the highest quality plans. Systemic issues will not be addressed by a standardised plan, though there are also plans for a set of National Standards that purport to address issues in identification of SEN, improve evidence-based provision, increase clarity about what support is available to families and who will deliver this, with information about which budget this will come from (HM Government, 2023). However, this is again linked to reducing numbers of children and young people with an EHCP, with improved in-school support, rather than focusing on improving the systemic issues affecting families accessing EHCPs, like the problems I have identified with collaboration and co-production. Accountability in the system has been mentioned in the Improvement Plan (HM Government, 2023) but this focuses in the main at executive level, and clarity around who is responsible for complaints. This does not address the issues that families experience before they have got to complaint stage, where they report not being listened to or treated as a partner.

The Improvement Plan states that these changes in the system, including the National Standards are going to be co-produced with children, young people and their families via Regional Expert Partnerships (HM Government, 2023) which is an important acknowledgement. Again, research will be needed to understand how this can be successfully achieved, including how families who are marginalised are reached and meaningfully included. Lessons can be learnt that can be used in practice, through the sharing of case studies or vignettes, and through practice toolkits.

In research conducted by the Social Marketing Foundation with disabled people about how the welfare system could be reformed, participants raised these issues of poor experience; "One way [to improve the system] would be kindness – not always assuming that everyone is trying to do the system over...to be dealt with a sense of kindness and humanity (participant from SMF, 2021), and “The one thing they need to change more than anything is to make it more person-centred and find out what the person in front of them needs.” (participant from SMF, 2021).

Conclusion

In this chapter I discussed the key themes from my reflexive thematic analysis in the context of the wider theoretical framework, using a post-structural theory with Foucauldian tools, and drawing upon rights-based theories. Though the findings of the research as a whole were not surprising when reflecting on the literature, I was not anticipating the direction that the conversations took in many instances. I was also hopeful of finding more pockets of good practice to draw upon and share, however this was not realised in full.

In this chapter I suggested that there are many complex power relations in operation in the process of creating an EHCP. These are seen in whether and how children and young people are supported to be involved, the roles that parents take on and how these are understood and acknowledged by the professionals, the power dynamic between child and parent, the relationships between the professionals involved, the role of the local authority and the use of the plan itself as a tool for defining and controlling. Within these dynamics there is variability, with differences linked to parent knowledge and relationships between families and professionals.

I have also made links to rights-based theories in Disability Studies and Childhood Studies research, considering where there are deficit-based discourses, and the resistance that families show to perpetuating these. Parents of disabled children and young people do not escape the negative, deficit-focused discourse surrounding disability and SEN, in fact pernicious discourses arise and regimes of truth (Foucault, 1980) are upheld to define and control them in different ways, as seen through the findings. I have also shown where surveillance and discipline can be useful tools to understand these forces, where interactions and documents can represent forces by which behaviour is controlled, externally or by self-regulation. Next, I conclude the research, presenting limitations, recommendations and the contributions that this project makes.

Chapter 7- Conclusion

Introduction

In this chapter I present recommendations based on the project findings, at policy, local authority and practice level. I then offer a critical account of the research process, identifying some of the limitations of the project, and my plans for dissemination. I discuss my learning and what I consider to be my original contribution to knowledge. Finally, I summarise the findings and discussion and situate them within the research questions that guide the study overall.

Recommendations

In the process of creating the recommendations for this project, I had meetings with my advisory group members. We discussed the key themes and findings from the research, and I asked about any reflections or suggestions they had in relation to these. I present below their suggestions along with my own reflections on the findings in the context of the broader policy and literature landscape, the recommendations from this project.

Policy Level Recommendations

Further reform in the SEND system has been said to be urgent now, by OFSTED (2021) in light of the issues faced by families being worsened by the pandemic, however not all families in my study agreed; advisory group members generally thought that the 2014/15 SEND reforms themselves were positive, though not always implemented effectively. One parent advisory group member felt the system needs reform, 'whole system, ground up' where another felt that reform may 'throw the baby out with the bathwater'; that the focus should be on implementing existing policy developments which are good but not always followed. Similar opinions exist in research reports; House of Commons (2019a) remain confident in the SEND reforms but urge the government to focus on implementing them effectively, including getting the funding right. This is the position of IPSEA too, rather than reforming, 'making the system work as it should' (IPSEA, 2023, NP). It is clear that whilst the 2014/2015 reforms promised huge changes for families, these have not always been delivered.

Recommendation 1: Rather than rushing to reform a system that some professionals and families are still learning how to navigate, ensure that the changes made in the 2014/2015 reforms are delivered, with transparency and accountability.

Recommendation 2: Where reform *is* indicated, ensure that this is done in meaningful partnership with families, with a range of opportunities to engage on all key issues, in a variety of ways. This could include online and alternative engagement, synchronous and asynchronous modes or timings to suit working families and those who are engaged in full-time education and care of their children.

Funding was also a key recommendation from the discussions with my advisory group members; though with the proviso that 'it's support, not just money, money doesn't solve everything' (advisory group member). With a realistic perspective on this, the focus for funding should be appropriate ring-fencing of budgets allocated to ensure that every child and young person who needs an EHCP is able to access one, in partnership with appropriate authorities and in a timely manner. Budgets should be adjusted to account for need, rather than set low and then blame placed on families for overstretching services. Caseworkers and other professionals need time to get to know the families they are working with, in order to improve the quality of the service (Ahad, Thompson and Hall, 2021) which is made challenging by the existing extremely high caseloads.

Recommendation 3: Appropriate, realistic and ring-fenced funding for local authorities to be able to meet the timelines and processes of the EHCP and ensure that they have a robust and varied Local Offer to support the aspirations of children and young people in their area.

Themes of parent blame were strong in the findings from this study, with many participants feeling accused of being out to get something they were not entitled to, with scrounging narratives underlying in interactions with professionals. This is perhaps still underpinned by the culture of blame, positioning parents as the problem in these complex relationships

(Lamb, 2009) or by neoliberal influences about family responsibility. Families from the research, both participants and advisory group members also reported feeling unseen or unheard by the government in issues affecting their children that were wider than the EHCP, including welfare, health, education, deputyship, banking. They report that these systems do not match real life, that there are barriers to them engaging in processes that designed to support themselves and their children. In some cases, parents reported feeling ignored or marginalised by government ideology; that they were not listening to parents about the reality of life and implementing policies that meant they were subject to accusations, continual financial reassessments and punitive measures.

Recommendation 4: A shift is needed from a neoliberal-ableist parent-blame standpoint of policymaking towards understanding and support; listening to families about their experiences and enacting policies and guidance that aim to alleviate their stressors and difficulties rather than adding to them.

Local Authority Level Recommendations

One key finding from this research included a lack of consistency or continuity in support, in some cases from the local authority caseworker assigned to the EHCP. Parents report not being able to contact anybody to discuss the EHCP, finding themselves in a call system or speaking to somebody who did not know their case or plan. As an advisory group member stated, they needed 'Someone to talk to, not a call handler'. This is linked to local authorities being seen as gatekeepers to the EHCP and associated support, with a high level of professional power and very low level of power for families.

Recommendation 5: Position EHCP caseworkers as members of the team working to support the child or young person to achieve their aspirations, on an equal standing with other members of the team, including parents and the child or young person themselves. Ensure working conditions support lower staff turnover and higher staff satisfaction, and high levels of knowledge and training in the legal requirements of the EHCP. Ensuring

named caseworkers can be reached by families and other professionals would improve continuity, communication and co-production.

A strengthened system of guidance and education is needed for parents and families, so they know their rights, how to navigate the system, what to expect from the process and how to go about seeking support. Information and offers of support should be forthcoming, as an advisory group member suggested; 'you're blundering through the dark trying to find the pathway through- someone should take your hand and lead you through, and that should not have to be another parent'.

Recommendation 6: In addition to the information on the Local Offer, local authorities should be proactive in sharing information with families about their rights, the EHCP process itself, additional support they could be entitled to and how to apply for this, what to expect from the process, and how they can receive support in navigating it. This should be provided from first contact on an equitable basis.

Practice Level Recommendations

In order to focus on the outcomes and aspirations of children and young people, their families need to be empowered and supported (Holland and Pell, 2018) to engage in this process and share their perspectives. Listening to families is a relatively easy change that professionals can make (Holland and Pell, 2018) that could impact upon their experiences of the system. There must be a meaningful shift away from high professional power to more genuine partnerships and co-production, where families are recognised for their own expertise and experiences. In all education, health and social care agencies, professionals need to understand and engage with co-production and collaboration processes. Whilst this may represent a challenge in the context of busy settings and competing demands, this is a legal requirement, and leadership teams should prioritise the sharing of this knowledge in the form of training, toolkits and case study examples.

Recommendation 7: Get to know the child or young person, their strengths, hopes and aspirations. Together, build an aspirational plan that truly reflects the child or young person, and details specific support strategies that empower them to move towards their goals and aims.

Recommendation 8: Prioritise partnerships with families; consider parents as true partners in creating the EHCP, use the combined expertise to work together for the best outcomes for children and young people.

Recommendation 9: Ensure professionals have access to training opportunities, toolkits and examples from practice, so that creative and personalised ways of co-producing EHCPs are seen as achievable.

Dissemination

It is interesting to reflect now on dissemination. At the start of the project, part of the ethics approval process required me to have a plan for dissemination of the findings of this research, however this has developed in a more meaningful way as the project has come to an end. I consider dissemination through my duties and accountability as a researcher- to 'educational professionals, policymakers and the wider public' (BERA, 2018, p.32), or in a broader sense to share my findings 'as widely as possible' (BSA, 2017, p.10). As an academic, I am familiar with the traditional ways of sharing research findings, and I am committed to engaging with these. These include presenting my findings at academic conferences, not simply disability-centring conferences but also at wider educational conferences for the benefit of educational researchers and practitioners. They also include writing journal articles and other publications that break down my project and findings to examine different elements in more depth- methodology-focused elements as well as topic-focused elements. Journals that I may consider include the British Journal of Special Education and the British Educational Research Journal, due to the English specific nature of the research. I am also committed to research-informed teaching with my own higher education students; I teach on modules across undergraduate and postgraduate courses relating to inclusive education, disability and 'SEN' with national and international policy consideration, research methodology specific to 'SEN' and broader modules with sociological underpinning, and plan to further embed the findings of the research into my teaching. The element I am not as familiar with is how best to disseminate findings to the people that the research participants feel they need to reach, so I worked with my advisory group to understand their thoughts and priorities for this section. Suggestions made by my parent advisors include making links with parent and carer-led organisations, forums and resource websites to write shorter articles, blogs, and magazine articles, continuing to support parent and carer-led movements that engage with policymakers and select committees, and bringing my findings to the attention of local authorities and decision-makers.

Limitations of this Research

The limitations of this research centre on three areas; firstly, methodological elements, secondly, on scope and focus, and thirdly on researcher decisions within the project. No project is without limitations, and it is important to reflect on these not just within the Methodology and Ethical Considerations section of the project to ensure a robust project, but in the concluding section, to ensure that they are examined in depth and learnt from in further research.

I concentrated on elements of the work of Foucault to examine the power relations at different levels within the EHCP as well as mechanisms of control and surveillance, which may have limited my focus to one area of theory and therefore limited my interpretation of the findings. To inhibit that, I ensured that I carried out data-led coding, an inductive analysis before introducing post-structural concepts into the discussion to try to limit my own impact upon the findings. Another researcher preferring other theoretical perspectives could have seen the findings differently so my decision to use post-structural theory to understand the findings could be seen to have weaknesses as well as strengths, which I have discussed in chapters 1 and 3.

With regard to my methodological choices, to try to address geographical limitations and issues with travel I extended my recruitment efforts online. This meant that I was only able to offer online or telephone interviews to some participants, where I was able to offer face-to-face interviews with those who were more local to me. In fact, all participants requested online or telephone interviews, even those who were offered a face-to-face interview. This possibly limits the data collected and then my ability to interpret participant contributions, and ultimately leads me to question whether face-to-face interviews would have yielded different results. Of course, it was more important to offer participants the choice of format, especially when considering how busy and complex their lives are, and how much time they were taking to share their stories and experiences with me. I also experienced complications with recruitment; I started recruiting participants as the first lockdown came into force in England and whilst interest in participating in the research was high, sometimes the reality of busy family life prevented families from engaging. I was not able to recruit any children in the research, despite this being an early aim for the project; I made a decision not to recruit via schools or settings to avoid possible impacts upon the way participants perceived me. I felt that by using educational settings it may mean they expected me to try and find examples of particular elements of practice rather than keeping discussions open. This means that my sample included parents and a young person, which is reflective of my advisory group too. Though not seeking to make generalisable findings with this piece of research, the sample size is still small, and this can be seen as a limitation, despite the large amount of data generated from this number of interviews and meetings. The purpose of having a smaller sample size is the depth that can be reached in interviews, and the ability for participants to raise issues that are important to them, but I would still have liked to be able to recruit a greater number of participants, time and project permitting.

Children could not, of course, join the research project without parent permission, and so parents became the main gatekeepers in the research, and whilst it was important for me to try and recruit children to the research, the more important matter was avoiding exploitation and discomfort. For this reason, I did not pressure any parent participant to allow me to interview their children, who, by their accounts, did not know about the EHCP, did not feel comfortable discussing it, actively disliked anything to do with it, or were not interested in participating.

I felt I was able to recruit a good sample of parents across several different counties and boroughs, representing different social groups and ethnicities (which were all discussed informally) with children with a range of diagnoses and conditions, however since I had decided not to seek ethical approval to collect and store data on participant demographics, I did not include this specifically as part of the analysis or disaggregation of data. In future research, patterns in parental experiences could be linked to demographic information, with appropriate ethical approval and careful collection and storage of data. Indeed, there is existing research that highlights inequitable access based on parental capital in general (House of Commons, 2019a) and studies that consider ethnicity data in satisfaction measures (Adams et al, 2017) however this has not been explored in depth.

Another methodological consideration to make is with the research design. I decided to use a case study design that encompassed multiple categories of case study, sitting on the intersection of exemplifying, evaluative and collective case study (Candappa, 2017; Clark et al, 2021; Stake, 2003; Yin, 2018). I could have made alternative decisions with this piece of research, given that it is not always clear what constitutes case study research (Candappa, 2017). I could have labelled this work as simply exploratory, or as having a qualitative methodology, though I ultimately decided that considering the project as a case study helped me in defining the scope of the research as a ‘bounded’ area (Merriam and Tisdell, 2015). It also supported with determining the purpose of the research, and how I was able to draw conclusions; sharing examples, providing a level of analysis or evaluation of the process from a particular set of perspectives, and sharing a collection of similar experiences and views.

In terms of scope and focus, the EHCP is a comparatively small area- with a change in policy this area may find itself irrelevant, however the new proposed Improvement Plan (HM Government, 2023) focuses on keeping the EHCP, reducing the number of children who are given an EHCP and standardising it. However, questions could be raised as to whether the

EHCP is fit for purpose when so many families report that the child is not able to understand or contribute. This creates a paradox; social model thinking would promote change of system to support the children and young people who use it however reducing the rights of children and young people to involvement could contribute to the lowering of expectations.

My Learning and My Original Contribution to Knowledge

In this section I reflect on my development as a researcher and my experience of completing this research, as well as identifying my original contribution to knowledge and what my thesis adds to the field. I began this project in January 2016, invited to do so by my managers, encouraged by colleagues, and egged on by family and friends. What has followed has been the hardest 8 years of my life. The magnitude of this task and the importance of its outcomes were at times overshadowed by my own mental and physical health and wellbeing, as I became more and more unwell and was eventually diagnosed with multiple long-term chronic health conditions, resulting in an extended break from study. An occupational therapist told me, “Whether you accept the label or not, you *are* disabled”. This parallel with my research and reading was interesting; I was already invested in Critical Disability Studies, ableism, sociological and post-structural understandings of disability, already driven by social justice motives, and then I found myself processing changes in my own identity and how and whether I could claim the label of disabled. This, alongside a period of burnout and a diagnosis of neurodivergence, changed the way I work as a researcher and academic, and how and what I prioritise in my work and study. I have also worked to overcome issues in my social and cultural capital, a habitus clash of sorts (Bourdieu, 1986), a lack of confidence, and imposter syndrome. These issues, rather than deterring me from study, have encouraged me to become the kind of researcher who does not slot into existing roles, but to use my experiences of the (not always very kind) world to carve out my own role in research and academia. Far from being a ‘I’m not like other researchers’ kind of researcher, I look to the role models in my academic life who have created niches for themselves and supported others to carve out their own niches.

This movement away from the gatekeeping of success, achievement and power suits me well, and it is exactly what I hope to show to those who are new to academia or research. This is also important to me in the research itself, and what prompted a core element of the research project- the movement towards emancipatory approaches and the use of an advisory group. Given that examination of power relations is crucial in the aims of the research, I was keen to embed this in my own practice too, in advisory group meetings, through the data collection phase with participants, to writing up the research. As Foucault stated,

> ‘The intellectual's role is no longer to place himself “somewhat ahead and to the side" in order to express the truth of the collectivity; rather, it is to struggle against the forms of power that transform him into its object and instrument in the sphere of "knowledge,” “truth,” “consciousness,” and "discourse.”’ (Foucault, 1977, p.207-208).

My aim was to devolve the power relationships in research, or in a more Foucauldian sense, to recognise where different forms of power already exist and honour them in the creation of this research. By working with more knowledgeable others, those who are experts by experience (and who have made themselves experts in the policy and process too) throughout the project, from planning to dissemination, I hoped to contribute to a shift in research practice, towards more emancipatory approaches. I did this by moving away from traditional advisory group methods, away from larger collectives and towards smaller, family group discussions. By doing this I feel I was able to fit better around the schedules of my advisory group members, meet them in places that suited them, create a more reciprocal and balanced relationship and more authentic reflections. I feel that this is the first original contribution I have been able to make, not original in research more generally, as researchers have grappled with the complexities of using emancipatory approaches in disability doctoral research before (as an early example: Garbutt and Seymour, 1998) and in research with disabled children (as an example: Morris, 2003) but the attempt to do this in this particular devolved way, with disabled young people and their families, as part of doctoral research on the topic of the EHCP is an original contribution. Moving in an emancipatory direction in research and not looking to tick a box in a tokenistic way is key here, as informed by Barnes; it's a process, not a project (Barnes, 2001). I also considered where disabled children and young people and those with SEN experience ‘dual-layer underrepresentation’, excluded for not meeting both adultist norms and ableist norms. Whilst not a new idea, labelling it as such shifts the focus from an inherent issue within the child or young person to an external, more social model way of thinking.

Another original contribution this research makes, is the examination of the EHCP process from the perspective of families, and then subsequently utilising a range of theoretical perspectives to interrogate these findings further, specifically using post-structural theory and using a Foucauldian toolkit. The gap I identified in the Literature Review concerns the lack of research exploring family experiences, roles, participation, and reflections in the EHCP, and this project contributes new and original knowledge in this area. I was also able to consider the power relations that exist between these families and professionals and apply power-based theories to this. I considered the power relations and hierarchies within the process of creating the EHCP and proposed additional models of ‘partnership’ between parents and professionals- Dysfunctional model and Conflict model. I also importantly found where there is resistance to power hierarchies among families, and commitment to supporting and empowering other families. I also considered how discourses are created and perpetuated through the EHCP process, including deficit discourses of disabled children and young people, those with SEN and their families. I used Foucault’s ideas to consider where there are elements of governmentality and surveillance, and how the EHCP process and plan maps on to the technologies of discipline; hierarchical observation, normalizing judgement and the examination (Foucault, 1975). Other research has been carried out within the broader topic area that uses elements of Foucault’s work, notably Allan’s (1996) project linking SEN with madness, medicine and discipline, and McKay’s (2014) study that considered children’s voices and advocacy through a Foucauldian lens, also using the technologies of discipline. Burch (2017) also carried out a critical discourse analysis of the SEND Code of Practice, considering the construction of adulthood and transition, which included viewing the SEND Code of Practice as a technology of government. My work used a range of elements of Foucault’s work to focus specifically on the EHCP process and family experiences within this, combining them with rights-based perspectives, which is new. Though it contributes to a growing body of knowledge concerned with making positive change with children, young people and families, the application of these theories to this area in this way is original to this project.

Summary of Key Findings

Through the thematic analysis, I was able to construct 5 key themes linked to the research questions. These were explored in chapter 5 and I summarise them here.

Theme 1- Knowledge is Power? In the research I found that families occupied different roles within the EHCP process, and this was largely linked to their knowledge of the process itself. I contrasted different roles that parents hold in the process, from expert parents who are very knowledgeable about the process (often more than the professionals involved) and take an active or even supervisory role, to excluded parents who do not know very much about the process and do not always feel that they have a role in the process. I found where parents have a lot of knowledge about the process this does not always mean they experience the power to change things about the process. I found solidarity between parents, with expert parents working hard to share knowledge with their excluded counterparts, through official and unofficial channels, and expressing concern about those who are not able to advocate for their children in the same way.

Theme 2- Problems with Partnership. I found that there were problems with partnership throughout the EHCP process, including between families and professionals, affecting co-production. This included inconsistency in communication and support, a lack of involvement for children and young people, problems with school and external professionals, and issues extending to local authority caseworkers and the system as a whole. I also found issues reported by families between professionals and other professionals affecting collaboration (or, multi-agency working).

Theme 3- Negative Impacts on Parents. I found that involvement in the EHCP process brought about a range of negative impacts on parents, including the time burden and financial implications of being involved in the process, in addition to the physical and mental toll and the reputational burden that their involvement incurs.

Theme 4- Expectations vs Experience. I found that families' expectations of the EHCP process and plan were generally not met, with issues including statutory processes not being delivered and deadlines not being met, and the promises that families had from professionals and the reformed system about the inclusive and aspirational nature of the EHCP and the process of creating it not being realised. I found that among some parents, their expectations had eventually lowered to anticipate poor treatment, support or communication.

Theme 5- 'It's just a piece of paper in my name'- Where is the child in this plan? I found that in many cases, the EHCP itself does not accurately represent the child or young person, either in draft form or in the final plan. Issues here included factual inaccuracies, administrative errors, overly-deficit depictions of children and young people, and problems with the outcomes contained in the EHCP. Many families felt that the EHCP represented just a 'piece of paper' with limited meaning, but that this was often their only way of accessing support.

Summary of Findings and Discussion

I present a summary of my findings and discussion and how they address the research questions that provide the structure for this study.

RQ1- What are the views and experiences of parents and young people about their role and participation in the process of creating the Education, Health and Care Plan?

Findings in this project show varying levels of participation in the EHCP process for parents and the young person I interviewed. The roles that families in this research took showed both extremes in terms of participation; some families have to be the driving force behind creating the EHCP, supporting, instructing, chasing and challenging professionals and documents, where some families feel that they were not supported or encouraged to participate at all. Through the discussion I have made links to high levels of professional power (Foucault, 1969), discourses and regimes of truth (Foucault, 1977b) around parents, and surveillance and governmentality in terms of parent behaviour. Parents have shared that their active involvement in and their knowledge about the process has not always been welcomed by professionals, leading to issues in models of participation, with a suggestion that these relationships represent new models- Dysfunctional and Conflict models.

For families involved in this research, the meaningful engagement of their child in the process was not a reality; almost all children of the parents in this research were not involved in a way that would constitute co-production (having full participation in and a sense of ownership of the EHCP) as called for in the SEND Code of Practice (DfE and DoH, 2015), and neither did the young person I interviewed. I linked this in the Discussion chapter to a disabling discourse and processes of normalisation, as well as to rights-based literature.

RQ2- How well do families feel their Education, Health and Care Plan reflects the child or young person and their views?

A significant majority of the families interviewed for this research have felt alienated from the EHCP at draft or final plan stage, with a young person not recognising herself in the plan, and parents reporting administrative or factual errors, inaccurate, exaggerated or overly negative depictions of their child and unrealistic or unclear aims and aspirations. The exception to this was where parents felt they had a very high level of involvement in writing the plan, for example they had written it themselves or re-written it alongside their child's class teacher. In these situations, families felt their child and their views were well reflected in the EHCP. I discussed the EHCP as a document by which families can find themselves under surveillance, experiencing Foucault's (1975) constructs of hierarchical observation, normalizing judgement and the examination. I also discussed outcomes and aspirations linked to normalisation (Waldschmidt, 2018) and what it is to be human (Goodley, Runswick-Cole and Liddiard, 2016).

RQ3- What factors do families identify as important in how they experience the Education, Health and Care Plan process?

Families identified many key factors that influenced their experiences of the EHCP process, including the relationships between themselves and the professionals involved, the quality and availability of evidence provided by professionals in order to create high-quality plans and outcomes, their own knowledge of the process itself and the community that they form around supporting each other to go through this process, and finally, their understanding of policy, timelines, recommendations and implementation versus their reality. Many of these factors are drawn together by their roots in policy and guidance documents, and what families expect from the process, for example collaboration and co-production, timelines for draft plans to be returned, the ability for families to comment on drafts, and where these are not realised. Some parents mentioned their own neurodivergence as a strength in navigating this process, with a focus on their strong sense of social justice and their determination to see the law followed appropriately. In the discussion, I focused on discourses and regimes of truth around parents and their experiences and the resistance that families show in coming together to provide support and solidarity for each other, in the face of a system that would have them compete. I considered neoliberalism as a common factor across families' experiences of the process and questioned whether the issues seen within this process have an ideological underpinning.

To Conclude

I have focused in this piece of research on one small, specific area of the system designed to support disabled children and young people and those with SEN, from the perspectives of families. This has taken the form of a qualitative case study, planned and produced alongside families who have experienced the EHCP process themselves. I have created inductive themes from interviews with parents and a young person about their views on the EHCP process and on their plan, and then considered these themes through post-structural theory, using elements of Foucault’s work and grounding this in rights-based theories. I have made recommendations at policy, local authority and practice level, linked to literature and the research findings, and made recommendations for further study. My hope is that this piece of research contributes to positive social and political change for disabled children and young people and their families.

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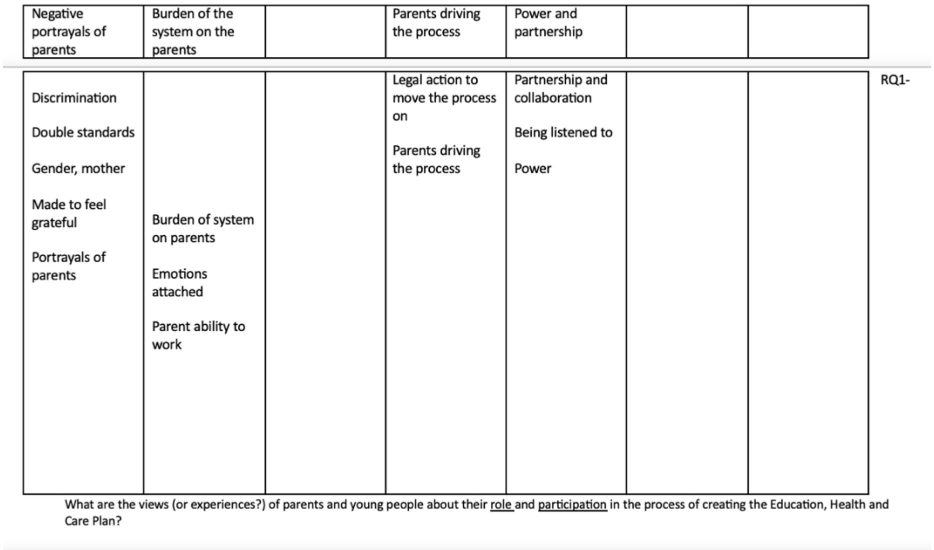
Appendices

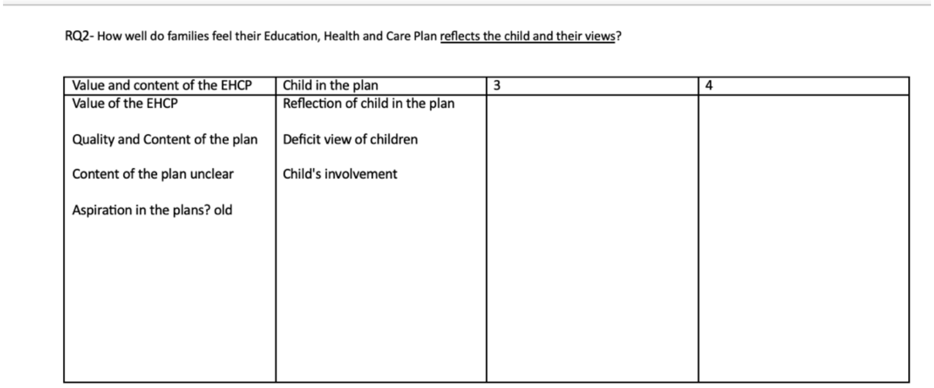
Appendix 1- Coding Table



Negative portrayals of parents	Burden of the system on the parents		Parents driving the process	Power and partnership		
Discrimination Double standards Gender, mother Made to feel grateful Portrayals of parents	Burden of system on parents Emotions attached Parent ability to work		Legal action to move the process on Parents driving the process	Partnership and collaboration Being listened to Power		

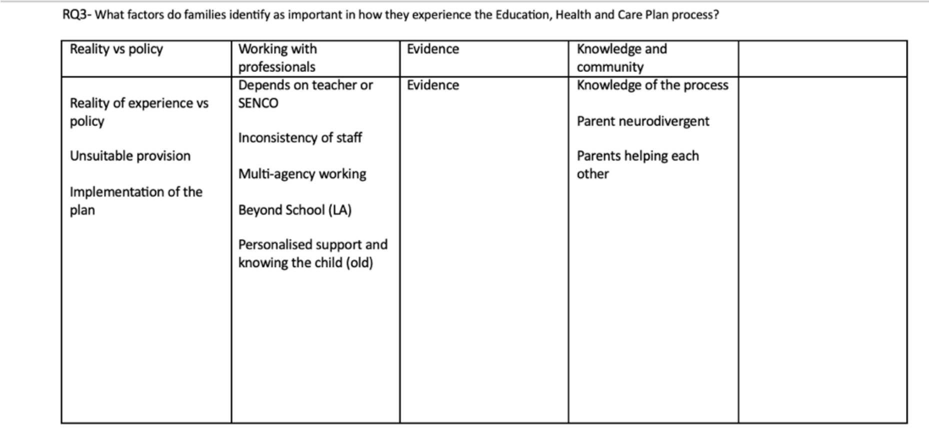
RQ1-

What are the views (or experiences?) of parents and young people about their role and participation in the process of creating the Education, Health and Care Plan?



RQ2- How well do families feel their Education, Health and Care Plan reflects the child and their views?

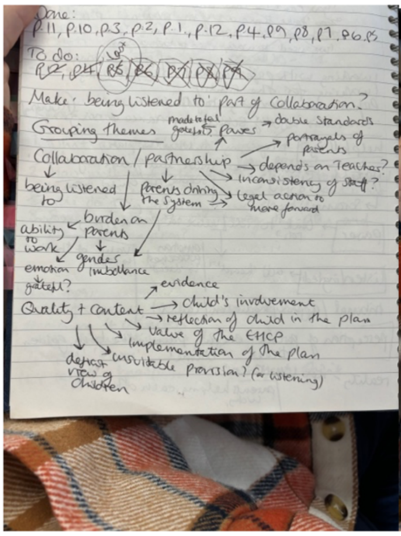
Value and content of the EHCP	Child in the plan	3	4
Value of the EHCP Quality and Content of the plan Content of the plan unclear Aspiration in the plans? old	Reflection of child in the plan Deficit view of children Child's involvement		

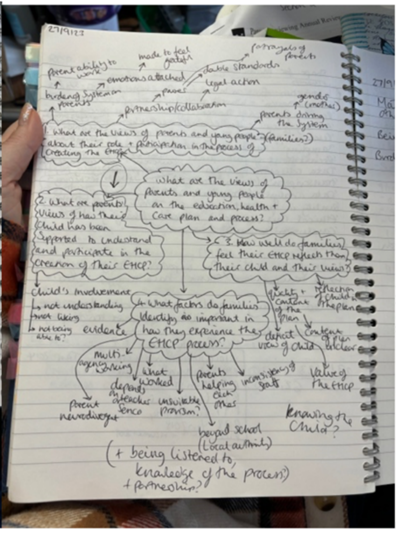


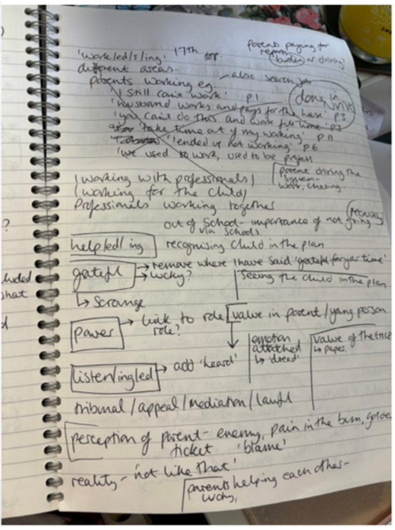
RQ3- What factors do families identify as important in how they experience the Education, Health and Care Plan process?

Reality vs policy	Working with professionals	Evidence	Knowledge and community	
Reality of experience vs policy Unsuitable provision Implementation of the plan	Depends on teacher or SENCO Inconsistency of staff Multi-agency working Beyond School (LA) Personalised support and knowing the child (old)	Evidence	Knowledge of the process Parent neurodivergent Parents helping each other	

Appendix 2- Spider Diagrams







Appendix 3- Ethical Approval

9th February 2017

Dear Louise,

Project Title:	**Listening to disabled individuals under 25 and their parents; the layers and levels of partnership and inclusion within the process of creating Education Health and Care Plans**
Principal Investigator:	**Dr Jo Finch**
Researcher:	**Louise**
Reference Number:	**UREC 1617 29**

I am writing to confirm the outcome of your application to the University Research Ethics Committee (UREC), which was considered by UREC on **Wednesday 18 January 2017.**

The decision made by members of the Committee is **Approved**. The Committee's response is based on the protocol described in the application form and supporting documentation. Your study has received ethical approval from the date of this letter.

Should you wish to make any changes in connection with your research project, this must be reported immediately to UREC. A Notification of Amendment form should be submitted for approval, accompanied by any additional or amended documents: http://www.uel.ac.uk/wwwmedia/schools/graduate/documents/Notification-of-Amendment-to-Approved-Ethics-App-150115.doc

Any adverse events that occur in connection with this research project must be reported immediately to UREC.

Approved Research Site

I am pleased to confirm that the approval of the proposed research applies to the following research site.

Research Site	**Principal Investigator / Local Collaborator**
- South east England (Kent/London) and online if requested (skype) - Interviews will be carried out in the participant's home (with an adult present in the same room, or with all doors remaining open and an adult in another room), or in their public location of choice (for example the local library or café, and accompanied by an adult).	Dr Jo Finch

Approved Documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	***Version***	***Date***
UREC application form	2.0	9 February 2017
Appendix 1 – Interview Schedule - Parents	1.0	21 December 2016
Appendix 2 – Interview schedule for child/young people	1.0	21 December 2016
Appendix 3 – Participant Information sheet - Parents	1.0	21 December 2016
Appendix 3 – Consent form - Parents	1.0	21 December 2016
Appendix 4 - Participant Information sheet - child/young people	1.0	21 December 2016
Appendix 4 – Consent form - child/young people	1.0	21 December 2016
Appendix 5 - Easy Read Information Sheet	1.0	21 December 2016
Appendix 6 - Easy Read Consent/assent Form	1.0	21 December 2016
Appendix 7 – Recruitment Poster	1.0	21 December 2016

Approval is given on the understanding that the UEL Code of Practice in Research is adhered to.

The University will periodically audit a random sample of applications for ethical approval, to ensure that the research study is conducted in compliance with the consent given by the ethics Committee and to the highest standards of rigour and integrity.

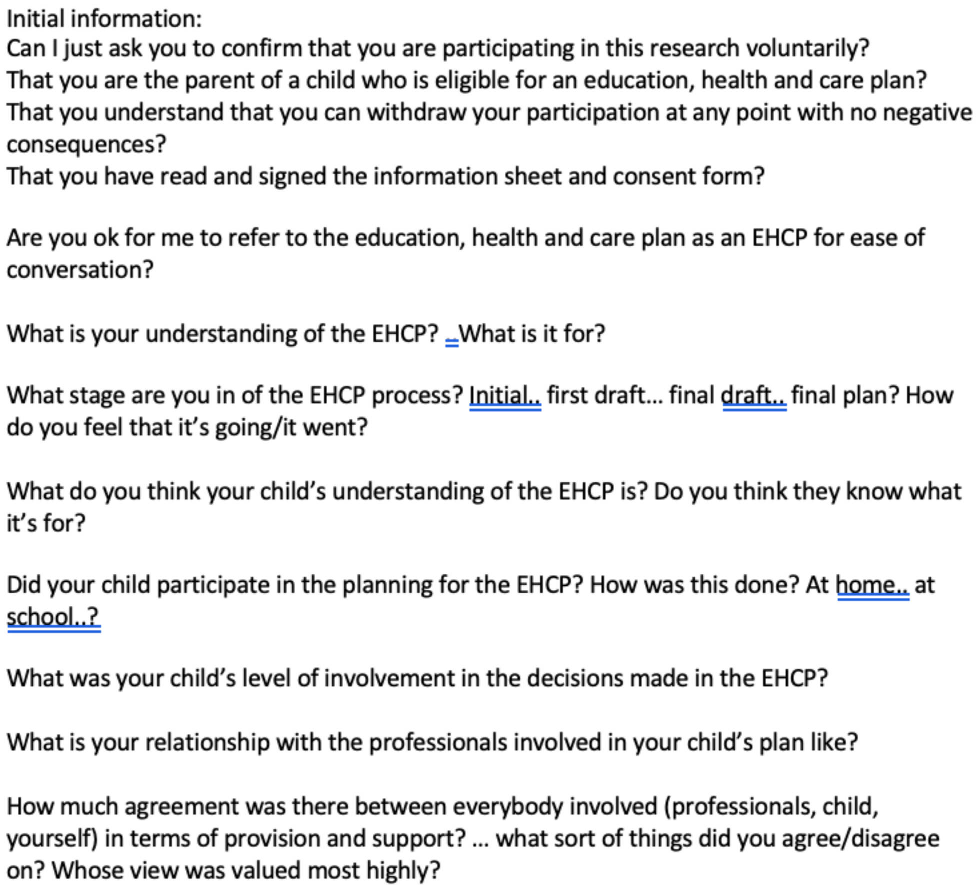
Please note, it is your responsibility to retain this letter for your records.

With the Committee's best wishes for the success of this project.

[redacted]

Fernanda Silva
Administrative Officer for Research Governance
University Research Ethics Committee (UREC)
Email: **researchethics@uel.ac.uk**

Appendix 4- Indicative Topic Guide



Initial information:
Can I just ask you to confirm that you are participating in this research voluntarily?
That you are the parent of a child who is eligible for an education, health and care plan?
That you understand that you can withdraw your participation at any point with no negative consequences?
That you have read and signed the information sheet and consent form?

Are you ok for me to refer to the education, health and care plan as an EHCP for ease of conversation?

What is your understanding of the EHCP? What is it for?

What stage are you in of the EHCP process? Initial.. first draft… final draft.. final plan? How do you feel that it's going/it went?

What do you think your child's understanding of the EHCP is? Do you think they know what it's for?

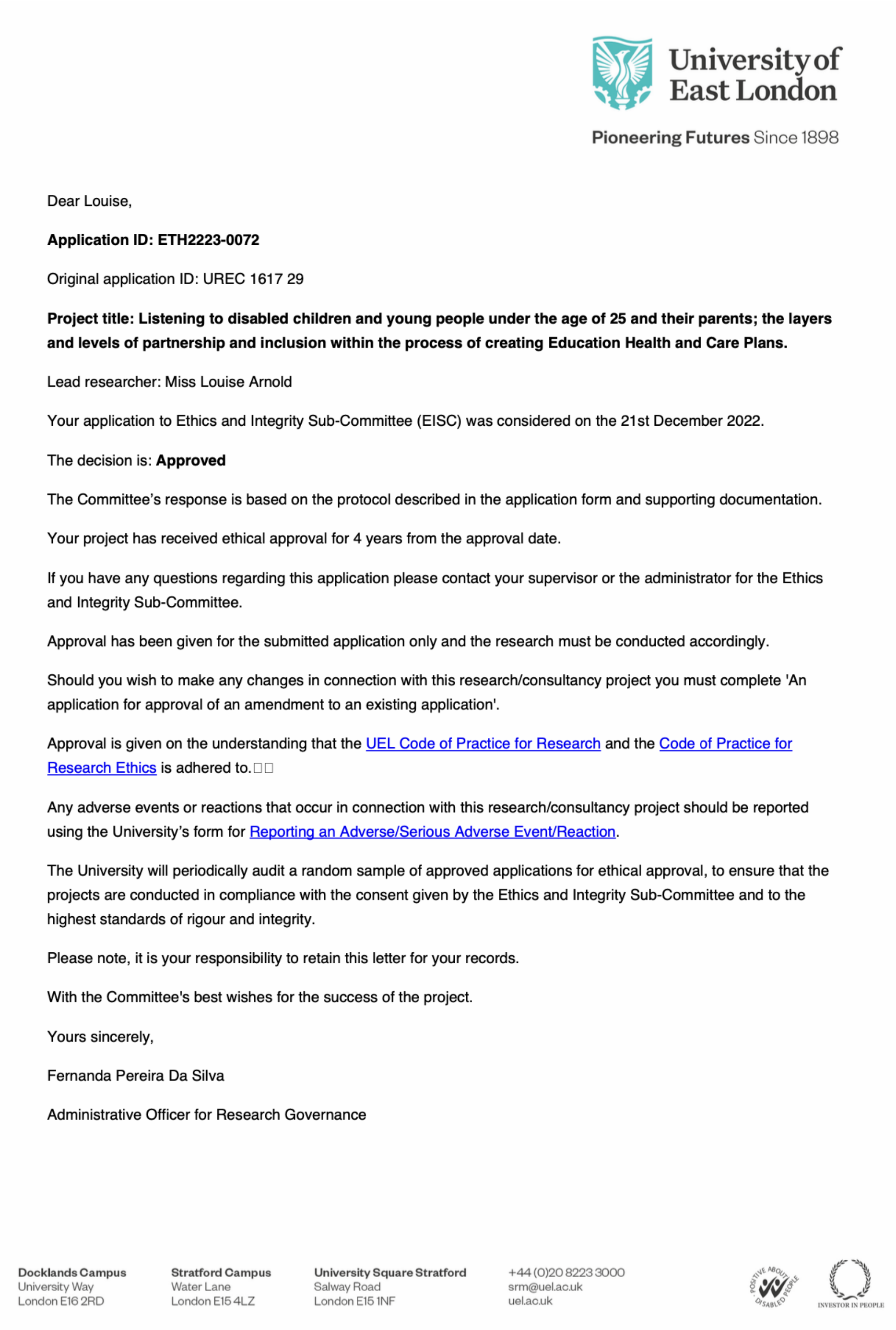
Did your child participate in the planning for the EHCP? How was this done? At home.. at school..?

What was your child's level of involvement in the decisions made in the EHCP?

What is your relationship with the professionals involved in your child's plan like?

How much agreement was there between everybody involved (professionals, child, yourself) in terms of provision and support? … what sort of things did you agree/disagree on? Whose view was valued most highly?

Appendix 5- Ethics Amendment Approval



University of East London
Pioneering Futures Since 1898

Dear Louise,

Application ID: ETH2223-0072

Original application ID: UREC 1617 29

Project title: Listening to disabled children and young people under the age of 25 and their parents; the layers and levels of partnership and inclusion within the process of creating Education Health and Care Plans.

Lead researcher: Miss Louise Arnold

Your application to Ethics and Integrity Sub-Committee (EISC) was considered on the 21st December 2022.

The decision is: **Approved**

The Committee's response is based on the protocol described in the application form and supporting documentation.

Your project has received ethical approval for 4 years from the approval date.

If you have any questions regarding this application please contact your supervisor or the administrator for the Ethics and Integrity Sub-Committee.

Approval has been given for the submitted application only and the research must be conducted accordingly.

Should you wish to make any changes in connection with this research/consultancy project you must complete 'An application for approval of an amendment to an existing application'.

Approval is given on the understanding that the UEL Code of Practice for Research and the Code of Practice for Research Ethics is adhered to.□□

Any adverse events or reactions that occur in connection with this research/consultancy project should be reported using the University's form for Reporting an Adverse/Serious Adverse Event/Reaction.

The University will periodically audit a random sample of approved applications for ethical approval, to ensure that the projects are conducted in compliance with the consent given by the Ethics and Integrity Sub-Committee and to the highest standards of rigour and integrity.

Please note, it is your responsibility to retain this letter for your records.

With the Committee's best wishes for the success of the project.

Yours sincerely,

Fernanda Pereira Da Silva

Administrative Officer for Research Governance

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University Way
London E16 2RD

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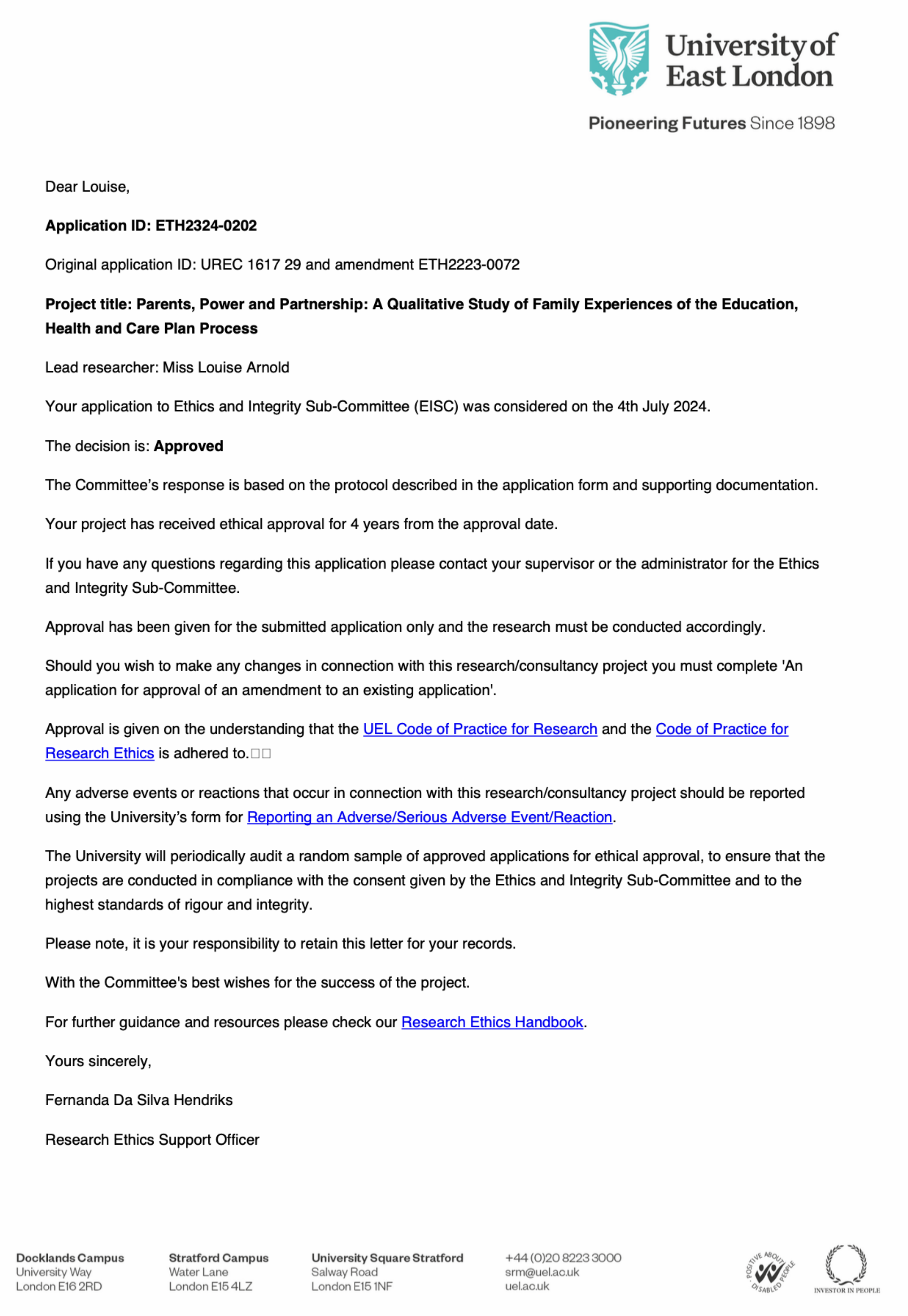
POSITIVE ABOUT DISABLED PEOPLE
INVESTOR IN PEOPLE

Appendix 6- Ethics Amendment- Title Change Approval



University of East London

Pioneering Futures Since 1898

Dear Louise,

Application ID: ETH2324-0202

Original application ID: UREC 1617 29 and amendment ETH2223-0072

Project title: Parents, Power and Partnership: A Qualitative Study of Family Experiences of the Education, Health and Care Plan Process

Lead researcher: Miss Louise Arnold

Your application to Ethics and Integrity Sub-Committee (EISC) was considered on the 4th July 2024.

The decision is: **Approved**

The Committee's response is based on the protocol described in the application form and supporting documentation.

Your project has received ethical approval for 4 years from the approval date.

If you have any questions regarding this application please contact your supervisor or the administrator for the Ethics and Integrity Sub-Committee.

Approval has been given for the submitted application only and the research must be conducted accordingly.

Should you wish to make any changes in connection with this research/consultancy project you must complete 'An application for approval of an amendment to an existing application'.

Approval is given on the understanding that the UEL Code of Practice for Research and the Code of Practice for Research Ethics is adhered to.□□

Any adverse events or reactions that occur in connection with this research/consultancy project should be reported using the University's form for Reporting an Adverse/Serious Adverse Event/Reaction.

The University will periodically audit a random sample of approved applications for ethical approval, to ensure that the projects are conducted in compliance with the consent given by the Ethics and Integrity Sub-Committee and to the highest standards of rigour and integrity.

Please note, it is your responsibility to retain this letter for your records.

With the Committee's best wishes for the success of the project.

For further guidance and resources please check our Research Ethics Handbook.

Yours sincerely,

Fernanda Da Silva Hendriks

Research Ethics Support Officer

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Appendix 7- Information Sheet and Consent Form

University of East London
Stratford Campus, Water Lane
London, E15 4LZ

Research Integrity

The University adheres to its responsibility to promote and support the highest standard of rigour and integrity in all aspects of research; observing the appropriate ethical, legal and professional frameworks.

The University is committed to preserving your dignity, rights, safety and wellbeing and as such it is a mandatory requirement of the University that formal ethical approval, from the appropriate Research Ethics Committee, is granted before research with human participants or human data commences.

The Principal Investigator/Director of Studies
Dr Jo Finch
J.finch@uel.ac.uk
[redacted]

Student researcher
Louise Arnold
L.arnold@uel.ac.uk
[redacted]

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Project Title

"Listening to disabled individuals under 25 and their parents; the layers and levels of partnership and inclusion within the process of creating Education Health and Care Plans"

Project Description

With this research, I would like to find out whether disabled children and young people are included in the creation of an Education, Health and Care Plan (EHCP). The Children and Families Act (DfE, 2014), introduced the EHCP which replaced the old 'statement of Special Educational Needs'. The 'statement' was seen to be imposed on the child, with little to no input from the child in how to meet their needs, where the EHCP is supposed to be written in collaboration with the individual and their parents.

Participants will be asked to take part in an interview, which might bring up uncomfortable or distressing memories or experiences. The researcher will be sensitive to this, and will give opportunities to stop and discontinue regularly, but you as the participant can also stop or withdraw participation at any point during the interview too. The researcher will be able to give contact numbers of organisations that provide support to parents, or more general emotional support if required. The researcher will also make follow-up contact to ensure no adverse effects.

The investigators have passed appropriate Disclosure and Barring Service checks- enhanced.

Confidentiality of the Data

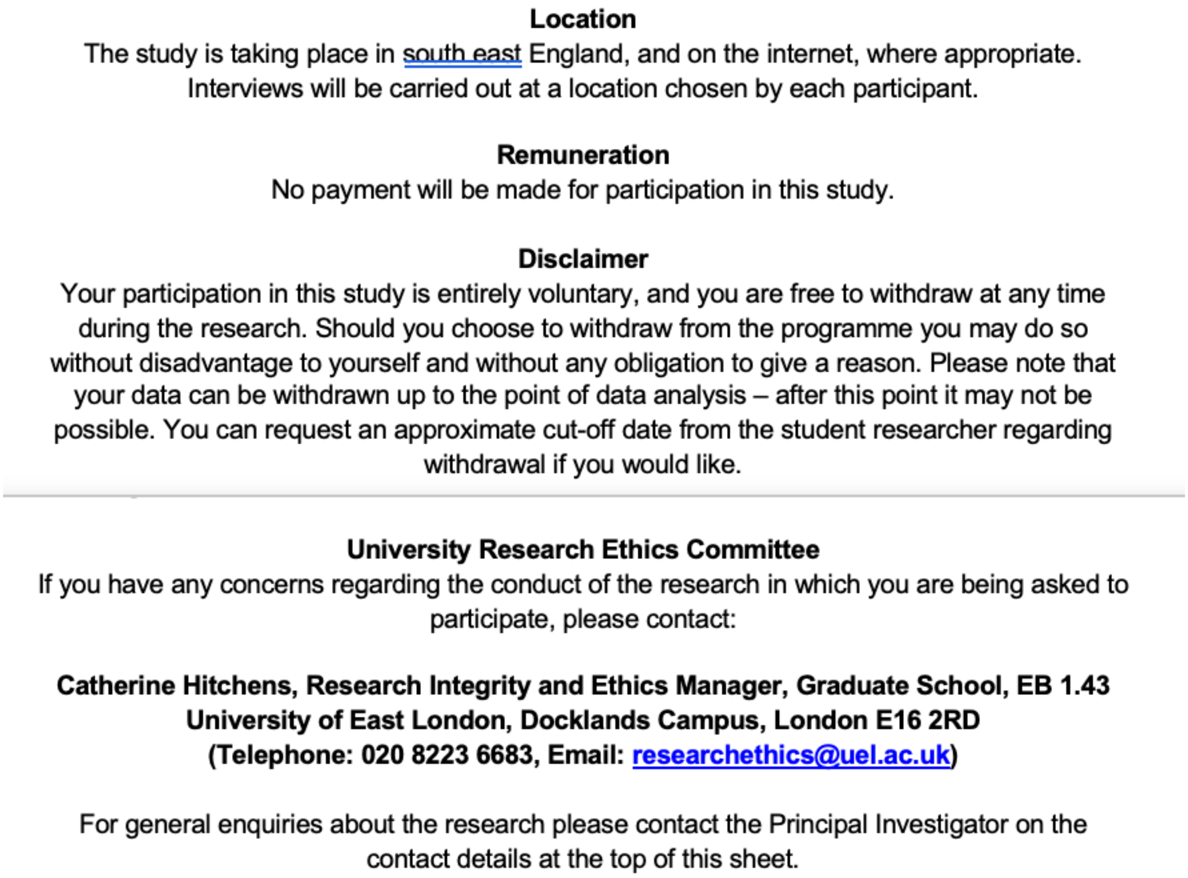
The participants' confidentiality will be maintained unless a disclosure is made that indicates that the participant or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authority.

The data will be stored on a password protected laptop, until it has been analysed and transcribed by the student researcher, and it will then be deleted and the files overwritten, so no audio data remains. Names will be changed during transcription, to maintain the participants' anonymity.

Because the sample size is small, this may have implications for confidentiality / anonymity, but the researcher will endeavour to keep any statements that could identify individual participants anonymous and will not transcribe information of this nature, such as the name of the child's school, teachers or other involved professionals.

Where participants are in a dependent relationship with any of the researchers, participation in the research will have no impact on assessment / treatment / service-use or support.

Data generated in the course of the research will be retained in accordance with the University's Data Protection Policy.



Location

The study is taking place in south east England, and on the internet, where appropriate. Interviews will be carried out at a location chosen by each participant.

Remuneration

No payment will be made for participation in this study.

Disclaimer

Your participation in this study is entirely voluntary, and you are free to withdraw at any time during the research. Should you choose to withdraw from the programme you may do so without disadvantage to yourself and without any obligation to give a reason. Please note that your data can be withdrawn up to the point of data analysis – after this point it may not be possible. You can request an approximate cut-off date from the student researcher regarding withdrawal if you would like.

University Research Ethics Committee

If you have any concerns regarding the conduct of the research in which you are being asked to participate, please contact:

Catherine Hitchens, Research Integrity and Ethics Manager, Graduate School, EB 1.43
University of East London, Docklands Campus, London E16 2RD
(Telephone: 020 8223 6683, Email: researchethics@uel.ac.uk)

For general enquiries about the research please contact the Principal Investigator on the contact details at the top of this sheet.

UNIVERSITY OF EAST LONDON

Consent to Participate in a Programme Involving the Use of Human Participants- Consent form for Parents/Guardians.

"Listening to disabled individuals under 25 and their parents; the layers and levels of partnership and inclusion within the process of creating Education Health and Care Plans"
Louise Arnold

Please tick as appropriate:

	YES	NO
I have the read the information sheet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.		
I consent to the interviewer using AUDIO recording for the purpose of accurately representing my views.		
I understand that my involvement in this study, and particular data from this research, will remain strictly confidential as far as possible. Only the researchers involved in the study will have access to the data. *(Please see below)*		
I understand that maintaining strict confidentiality is subject to the following limitations: If the sample size is small, this may have implications for confidentiality / anonymity, Participants' confidentiality will be maintained unless a disclosure is made that indicates that the participant or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authority.		
I give consent for anonymized quotes to be used in publications.		
I give consent for the data collected to be used in peer-reviewed journals		
It has been explained to me what will happen once the programme has been completed.		
I understand that my participation in this study is entirely voluntary, and I am free to withdraw that at any time during the research without disadvantage to myself and without being obliged to give any reason. I understand that my data can be withdrawn up to the point of data analysis and that after this point it may not be possible.		
I hereby freely and fully consent to participate in the study which has been fully explained to me and for the information obtained to be used in relevant research publications.		

Participant's Name (BLOCK CAPITALS)

…………………………………………………………………….

Participant's Signature

………………………………………………………………………………………..

Investigator's Name (BLOCK CAPITALS)

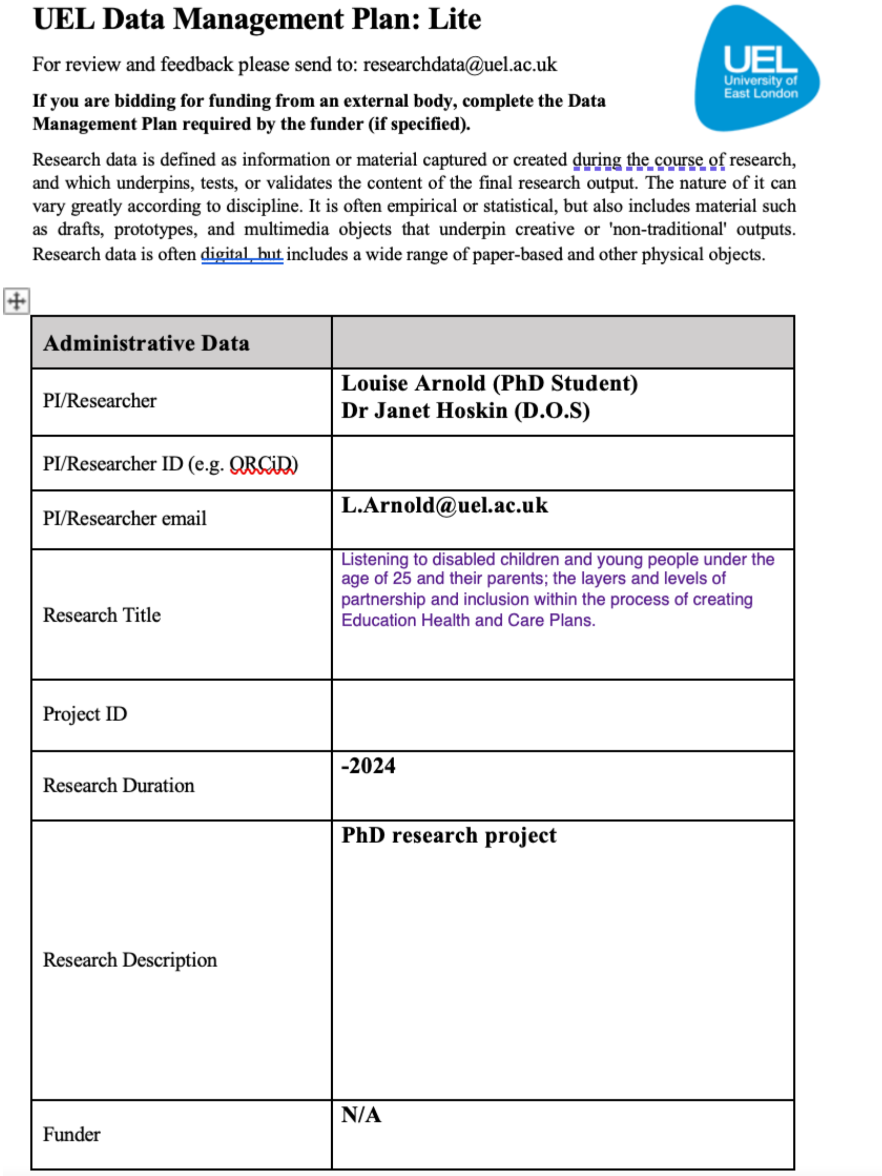
…………………………………………………………………..

Investigator's Signature

……………………………………………………………………………………….

Date: ………………………….

Appendix 8- Data Management Plan



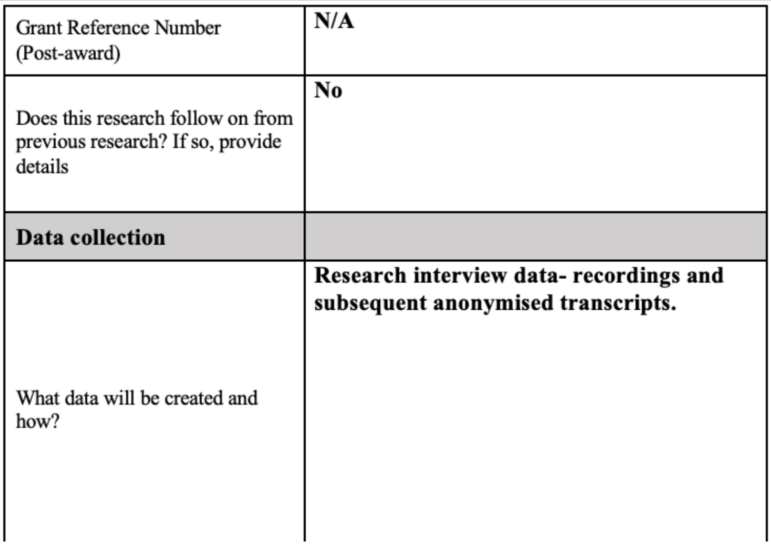
UEL Data Management Plan: Lite

For review and feedback please send to: researchdata@uel.ac.uk

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	**Louise Arnold (PhD Student)** **Dr Janet Hoskin (D.O.S)**
PI/Researcher ID (e.g. ORCiD)	
PI/Researcher email	**L.Arnold@uel.ac.uk**
Research Title	Listening to disabled children and young people under the age of 25 and their parents; the layers and levels of partnership and inclusion within the process of creating Education Health and Care Plans.
Project ID	
Research Duration	**-2024**
Research Description	**PhD research project**
Funder	**N/A**



Grant Reference Number (Post-award)	**N/A**
Does this research follow on from previous research? If so, provide details	**No**
Data collection	
What data will be created and how?	**Research interview data- recordings and subsequent anonymised transcripts.**

Ethics and Intellectual Property	
What ethical and intellectual property issues will be considered?	**Participants will give informed consent (adult participants) and in the case of children, their parents will give informed consent and consent or assent will also be sought from the children. The researcher is experienced in interviewing children and is aware of the non-verbal signs that consent or assent has been withdrawn. Consent will be seen as an ongoing process.**
Storage and Backup	
Where will you be storing your active data, and how will it be made secure?	**Recorded on password protected device and stored on UEL OneDrive**
Data sharing	
Who will be interested in reusing your data and how will you share it with them? Are there any reasons not to share this data?	**N/A**
Selection and Preservation	
How will you decide what data should be kept for long term preservation, and where will this be?	**Recorded data is deleted once transcription is complete, the only data kept is anonymised transcripts.**
Review	
This DMP has been reviewed by:	**Joshua Fallon** **Assistant Librarian RDM**
Date: 09/12/22	Signature: Joshua Fallon