



*Exploring inclusive partnerships: parents, co-production, and the SEND code of practice (2015)*

FLEMING, Katarzyna

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**Exploring inclusive partnerships: parents, co-production, and the SEND  
Code of Practice (2015)**

Katarzyna Fleming

A thesis submitted in partial fulfilment of the requirements of  
Sheffield Hallam University  
for the degree of Doctor of Philosophy

April 2021

# Candidate Declaration

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I hereby declare that:

1. I have not been enrolled for another award of the University, or other academic or professional organisation, whilst undertaking my research degree.
2. None of the material contained in the thesis has been used in any other submission for an academic award.
3. I am aware of and understand the University's policy on plagiarism and certify that this thesis is my own work. The use of all published or other sources of material consulted have been properly and fully acknowledged.
4. The work undertaken towards the thesis has been conducted in accordance with the SHU Principles of Integrity in Research and the SHU Research Ethics Policy.
5. The word count of the thesis is 78064.

Name	<i>Katarzyna Fleming</i>
Date	<i>April 2021</i>
Award	<i>PhD</i>
Faculty	<i>College of Social Sciences and Arts</i>
Director(s) of Studies	<i>Dr Lisa McGrath</i>

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I would like to end these acknowledgements with the lyrics of a song from the 1945 Rodgers and Hammerstein musical 'Carousel'. It resonates with my whole doctoral journey, full of people who always made me feel that I had someone to turn to:

**'You will never walk alone'**

When you walk through a storm

Hold your head up high

And don't be afraid of the dark

At the end of a storm

There's a golden sky

And the sweet silver song of a lark

Walk on through the wind

Walk on through the rain

Though your dreams be tossed and blown

Walk on, walk on

With hope in your heart  
And you'll never walk alone  
You'll never walk alone  
Walk on, walk on  
With hope in your heart  
And you'll never walk alone  
You'll never walk alone.

## **Abstract**

The Special Educational Needs and Disability (SEND) Code of Practice (2015) sets out principles for partnership working to address the historical power imbalances and ineffective communication between services and parents; however, it remains unclear how these partnerships could be formed in practice. Although co-production was proposed as an enabler of effective partnerships on the local government level, the institutional or individual levels where parents are most likely to experience partnerships were not discussed. Therefore, firstly, this study aims to explore parental contributions to decision-making processes in partnerships following the implementation of the Code, and secondly, to investigate whether co-production could become a vehicle for inclusive partnerships between parents and practitioners in public services.

A Mixed Methods Research, utilising an explanatory sequential design, comprising an online survey followed by interviews, was conducted between November 2017 and June 2018. The study was situated within the theoretical framework of pragmatism and employed the 'appreciation' and 'dream' elements of an Appreciative Inquiry structure. 144 survey responses from parents/carers were analysed through descriptive analysis and formed the foundation for the second stage of the study – the interviews. Three group interviews and eight individual interviews with 25 parents were analysed using thematic analysis (Braun and Clarke, 2006). The following main themes emerged: parental lived experiences of partnerships; practitioners' attributes, attitudes, and knowledge; discrepancies between the Code and parental experiences; practices enabling inclusive partnerships; and systemic barriers to effective partnerships.

Participants reported that they continue to be mostly positioned as unequal contributors to decision-making for their children and young people following the changes in legislation. Despite the lack of guidance on co-productive partnerships at institutional and individual levels, this study reveals how co-production could empower parents to become equal and valued contributors to decision-making within partnership working. Furthermore, connections among the principles of co-production, the desired by parents approaches to equal and contributory partnerships, and the Code's guidance on partnerships,

demonstrate the potential co-production could offer to inclusive partnerships with parents. A framework that illustrates these connections culminates the discussion in this thesis.



## Glossary of terms

In this thesis, I refer to various acronyms and use terms which can have an ambiguous meaning. Therefore, I present a list of the pertinent terminology in this section. These include the following:

**SEN** - Special Educational Needs; used in educational, health and care contexts to signal a condition an individual is categorised as having, and which impacts on their ability to learn within the expected trajectory of progress or to access learning opportunities.

**SEND** - Special Educational Needs and/or Disability.

**Parents** - this term refers to parents and carers of children and young people categorised as having SEND or any other guardians with caring responsibilities for them.

**Practitioners** - this term refers to all professionals engaged in working with children and young people categorised as having SEND; it also includes workers in 'front of house' who do not necessarily participate in decisions or direct provision of service; however, they are present within the services, e.g., receptionists, administrators, etc.

**The Code** - this term refers to the latest code of practice – the SEND Code of Practice (2015).

**EHC** - Education, Health and Care services, e.g., schools, educational psychologists, GPs, respite centres, social workers, etc.

**EHCP** - Education, Health, Care Plan, which is a legal document that replaced SEN Statements operating under the previous Code of Practice. EHCPs outline current and future provision to enable individuals to meet the outcomes and are supposed be designed and agreed between the family and relevant practitioners.

**C/YP** - Children and young people categorised as having SEND. Since the latest reforms, the Code applies to individuals between 0-25 years old. Therefore, this thesis explores experiences of parents and carers of C/YP within this age range.

**Partnership** - for the purpose of this study, I use the definition of partnerships by Gascoyne (1996) who defines it as collaboration where partners in the relationship are equally valued and recognised for their knowledge, experience, and skills.

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# **1. Chapter 1: Introduction**

This chapter presents the rationale for my research, the aims and research questions, an overview of the methodological and theoretical framework and how the thesis is structured. The chapter begins with a vignette that captures a moment I consider influential in my teaching practice; an experience that signifies a prominent shift in my ideology as a practitioner working within the field of SEND, and which has shaped my research focus. Secondly, a rationale for my research is explained in relation to my professional experience in working with parents and carers when considering the implementation of the Special Educational Needs and/or Disability (SEND) Code of Practice (2015). Fourthly, I describe the aims of my research and the research questions.

Finally, a flow chart representing the methodological and theoretical frameworks that informed the design and the practice of the research is presented. This chapter concludes with short summaries for each consecutive chapter in the thesis.

## **1.1. Vignette**

### **The Lioness**

On that golden autumnal day, which was only touched with the warmth of the last sunrays of Summer, I was armed with my plans and resources in the green folder, and my 'beginning of the school year' teacher enthusiasm was in full bloom. Venturing through the complexities of the quirks and personalities of my class, I liked to think I knew where we were starting and where the journey was going to take us. Driven, passionate and embracing every challenge – I thought of myself as caring deeply for the pupils under my care, eager to learn their stories and embrace their individualities, in hope of being prepared, knowing the answers, planning for every eventuality – a little naïve in the faith that the strength of a practitioner has the power to change the world.

My naïve 'enthusiastic' intentions were, however, disturbed by the tense atmosphere when I entered the meeting room. The woman who sat opposite the school's family link worker was clearly distressed, wearing a mixture of what I interpreted as sadness and anger on her face. She was a mother of one of the children in my class and I had only met her briefly before. My knowledge of her family's context was minimal, just as were the potential reasons for her request of a meeting. However, I was clearly aware of the conflict that I was about to witness. The introductions were not necessary as the parent began to list her concerns immediately upon my arrival. My head was spinning in panic; to understand the reasons for her concerns and to establish the core of where my actions were lacking. She cried. She raised her voice. She apologised. She scrutinised our approaches to learning. She pointed out the lack of communication. She appeared to be frustrated. She was repeating her and her child's story for the Nth time.

I felt ashamed. The kaleidoscope of the 'glory' of planning, knowing the answers and being prepared had lost its gleaming light. While I was holding on to the comfort of what I held dear and what I valued in my professional domain, for an instance in my head the shame turned into a defence. I was trying my best... A best that was deemed best through my professional perspective. I was sorry. I realised that the space and opportunities for parental perspective were not considered in the school's practice. I was sorry. She was sorry. The family worker was sorry.

In an attempt for reconciliation, the family worker, with her undeniable understanding and compassion for families' perspectives, proposed to use this parent's concerns as a way of improving school's communication with families. We co-created a plan forward. Figuratively, the family worker compared the parent to a lioness who fought for their cub and would not let anyone hurt or undermine him; a lioness who protected their young as she felt it was her duty, a duty for which one should never apologize. In her openness, the family worker acknowledged that we, the school community, failed to build this parent's trust in us, failed to ensure she knew that her 'cub' was safe and understood in our environment. Our apologies were accepted, and the edges of the meeting were somewhat softened. A very important path in my journey truly began then, although without my immediate realisation.

In retrospect, I now know that 'The Lioness' shifted my teacher identity and by offering me the gift of her story and her patience in moving forward, she enabled my openness towards and appreciation of other families' stories. This critical encounter meant that 'The Lioness' has not only alerted me to my role in partnerships with parents and carers, but paved a path of opportunities for me to learn from and with the families that I have encountered throughout my teaching career since. In time, I grew to understand that while being a practitioner, one should shape one's practice with, and not solely for the people it is intended for.

*To this day, I still see you as 'The Lioness', with a powerful 'roar' that needed to be heard by me, by others; the 'roar' that I will always endeavour to emphasise in my work within the partnerships between parents and carers and professionals engaged in working with children and young people categorised as having SEND. And for that, I will forever be grateful to you and your story.*

## **1.2. Rationale for the choice of the subject**

This section provides a rationale for this research study, both in relation to my own professional background and in relation to the main themes evident within the discourse of parent-practitioner partnerships. I also position my study here within a broader context of policy and practice since the implementation of the SEND Code of Practice (2015).

### **1.2.1. SEND and 'labels'**

During my 13-year career in the field of Special Educational Needs (SEN), I have worked with numerous families. Initially, as an enthusiastic graduate of childhood and special pedagogy studies, I was convinced that the knowledge gained at the higher education level had equipped me in essential skills to cater for the diverse needs of pupils under my care. As a practitioner in special education, I saw my duties as supporting, planning, designing, delivering, and evaluating provision for C/YP categorised as having SEND. Initially, I never

questioned their placement in the setting I worked in. Only through my doctoral studies did I realise that special education settings were constructed by some as an example of segregation and oppression, rather than inclusive practice (Graham, Medhurst, Tancredi, Spandagou, & Walton, 2020). Prior to engaging with such issues my focus was more on making practice within the special school setting inclusive rather than on considering what inclusion might mean on a broader basis. I was focused on ensuring that my practice was enabling these pupils to achieve their potential and meet their needs as identified by the label. At that time, I did not position labels as being the construction of a deficit-focused approach (Ferrell, 2010). Instead, I considered labels as serving an important role in the identification and delivery of suitable provision for each pupil (Rowland, 2017). However, during my studies, I came to a realisation that the negative connotations related to the labels of difference can have an impact on the power dynamics between people who assign labels to those who receive them (Farrell, 2010). I also recognise that there are instances where 'person first language' is not preferential for individuals; therefore, I would always confirm this preference with the individual in question and consider the implications for the use of labels within the context. For the purpose of this thesis, I choose to refer to the pupils I discuss as children and young people categorised as having SEND to reflect the wide range of individuals with labels and characteristics assigned to them by society (some of whom, I recognise, might accept them and some that might be rejecting them (Botha, Hanlon & Williams, 2021)).

### **1.2.2. Collaboration**

I valued collaborative work with colleagues highly, and always welcomed the expertise and guidance from other professionals, including those outside of my immediate team; however, seeking and using parental contributions in my planning, development or delivery of provision did not form part of my everyday practice. Although the need for collaborative work with parents and carers was acknowledged through my training and outlined as part of my duties, its explicit importance was only emphasised through the introduction of the Achievement for All (AFA) scheme that my place of work implemented in 2011 (Humphrey &

Squires, 2011). This scheme enabled 'structured conversations' with all parents and served as an opportunity to jointly plan and review children's progress in and out of school in a collaborative manner. Coupled with my already altered attitude following the encounter with 'The Lioness', the scheme further transformed my understanding of the importance and value of parental contributions.

As a result of both influences, I became increasingly willing to invest my time in getting to know the families I worked with, with the intention to use this knowledge to plan a more holistic and meaningful provision for the C/YP. This transformation in practice, alongside my growing experiences of diverse families, encouraged shifts in my pedagogy that would have not been possible without parental input. These changes included: targeted support for children at school, which impacted positively on tasks mastered in home environments; fruitful communication between home and school, which often resulted in a stronger and more stable network around the child to support the family's circumstances in a broader context; and planning for extracurricular activities with parental guidance to ensure the children's full potential was enabled and that their individualities were appreciated within a wider community perspective. These conversations were not always easy, nor were they always immediately effective; building trusting and reciprocal relationships often required time, multiple attempts at collaborative approaches where both sides of the partnership were able to express their point of view and be reassured that their contributions were recognised, respected, and acted upon (Needham, 2007). Nonetheless, the partnerships formed through these, at times challenging, conversations were always worth pursuing, in my view, as they resulted in enriched networks and meaningful outcomes for the children and young people I worked with. Furthermore, these experiences contributed to my own professional satisfaction that my input and impact was effectively supporting the pupils I worked with.

### **1.2.3. Changes in legislation**

Only by embarking on the PhD did I realise that the positive experiences with families I used to work with were not necessarily reflected in others' practices. Working in a silo within one setting as a practitioner, I was vaguely aware of the challenges other teachers experienced in forming partnerships with parents. Only through my research did I become acutely mindful of the nature and range of difficulties that parents continue to experience in partnerships. These realisations evoked a range of emotions and provoked a deep reflection on my own understanding. I started questioning how inclusive and enabling my own concepts of partnerships working were. I did share some of this thinking with my colleagues and, mostly, received encouragement to think that 'these difficulties' were not present in our practices and 'our parents' were happy with what we had to offer. Very rarely did I encounter a colleague who was ready and open to question their power in partnerships; the practitioner's dominance in decision-making prevailed in these conversations (Seligman & Darling, 2007), and initially, I, too felt inclined to reassure myself that my approaches were inclusive of parental views. With time, I became more attuned to the subtle power dynamics in meetings and gatherings as I observed and witnessed them with more conscious attention. Examples of these included the language used to communicate with parents, or the conversations where parental views required a confirmation from a practitioner to be regarded as valid (Hodge & Runswick-Cole, 2008; 2018).

As I continued to expand my knowledge of the subject of partnerships, I became hopeful that the latest legislation, the SEND Code of Practice (2015) was going to achieve its aim of more equal partnerships with parents. As I witnessed many barriers that parents needed to overcome in the partnerships, I became increasingly determined to focus my research on an area that would inform the development of effective partnerships. In the spirit of sharing the collaborative space with parents and allowing their expertise to impact the work of practitioners, I turned my attention to parental views and the work of co-production. The concept of co-production was new to me and to many of the colleagues I had worked with. However, while exploring the concept and

learning about it, I realised that it was very much aligned with the ethos of reciprocity and inclusion in partnerships while focussing on empowering the parental voice which I, too often, witnessed to be disempowered and disregarded in practice (Murray, 2000; Keen, 2007; Bacon & Causton-Theoharis, 2013; Adeb, 2014). By participating in the transfer from the 'old system' of SEN statements into Education, Health and Care Plans (EHCPs) during the annual reviews that served as a platform to generate the EHCPs, I witnessed the frustrations and disparities between what the legislation aimed at addressing and the actual practice. These included lack of adequate information that would enable parents to make informed decisions about their C/YP's future; practitioners' unawareness of what was available within the Local Offer; or practitioners' inability to accept and understand the holistic picture of a child as a part of a wider context of their family.

#### **1.2.4. Summary**

My observations and experience from practice, coupled with the discourse of 'professional – the expert' within the partnerships (which I explore in detail in the next chapter) inspired this research study. As a result, I decided to explore parental experiences of partnerships following the implementation of the Code. Consequently, I used this knowledge of parental views, together with the analysis of policy and pertinent literature, to discuss what co-production can potentially offer as a model for parent-practitioner partnerships. In the next subsection, I present my positionality in a wider context of inclusion, disability and social justice.

### **1.3. Aims of the research and research questions.**

Informed by my experience as a teacher and relevant literature surrounding parent-practitioner partnership, the aims of the research were to:

- Investigate parental experiences of partnerships with practitioners in EHC sectors after the implementation of the Code;
- Establish representations of inclusive and co-productive practices that are meaningful for families;
- Provide a platform for parents to share their experiences;
- Consider how parental expertise can enrich practitioners' knowledge to improve partnerships with parents.

To address these aims and ensure parental views were at the forefront of this research study, I asked the following research questions:

1. **Research question 1:** What are the parental experiences of being acknowledged and treated as valued contributors to parent-practitioner partnerships in the EHC realm, since the SEND Code of Practice (2015)?
2. **Research question 2:** What is the potential of co-productive practice to enable inclusive partnerships from the parental perspective?
3. **Research question 3:** How can practices in Education, Health and Care services be developed to enable more equal, reciprocal, and participatory partnerships with families from the parental perspective?

#### **1.4. The importance of this research**

Although this research study focuses predominantly on parental views and lived experiences, it is designed to enrich practitioners' knowledge of how to improve partnerships with parents. By drawing attention to practitioners' awareness of their influence and power in decision-making processes, this study focuses on the impact practitioners have on determining the direction of partnerships with families. Furthermore, this study introduces crucial dimensions of inclusive practice within the partnerships and connects them with the, proposed by parents, effective approaches in working together. Therefore, a range of aspects, previously examined in research, that influence and affect the partnerships, are examined here. These include factors that practitioners would find pertinent and vital in their own reflections to investigate their [practitioners'] own positionality and how this positionality influences the effectiveness of partnerships with parents.

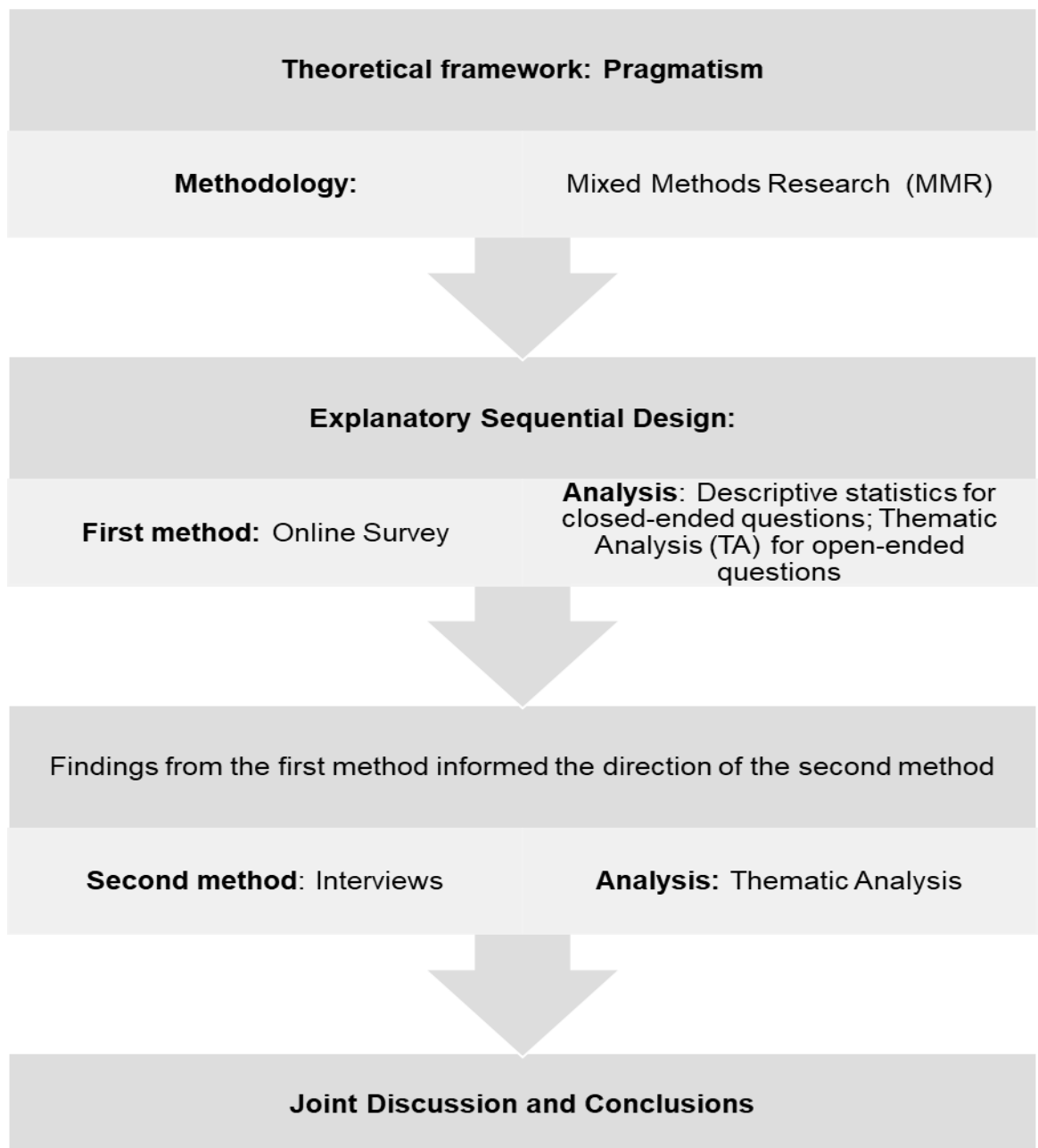


Considering that the Code aimed to improve parental confidence in the relevance of provision for their C/YP and in the development of participatory partnerships with services, this study considers the extent to which these aims have been met.

The findings from this research are relevant to any practitioner working within the SEND field, whether that might be in a direct or indirect capacity of collaborating with parents of C/YP categorised as having SEND. They will also support and, hopefully empower parents, through coming to know that others share their experience of partnership working, that the responsibility for breakdown usually lies within the system and not themselves.

### **1.5. An overview of the methodological and theoretical frameworks**

This section identifies the research process, theoretical and methodological frameworks utilised, the sequence of the methods employed and the subsequent modes of analysis of findings which informed the joint discussion and conclusions for the study. These are summarised in Figure 1. The detailed rationale for each of these choices and the steps undertaken in the processes of data collection and analysis are illustrated and appraised in Chapter 3.



*Figure 1 Methodological and theoretical frameworks-overview*

## **1.6. Thesis structure**

In this sub-section, I provide a short summary of the content for each of the chapters which follow.

The thesis does not follow a prototypical structure. Following the introduction, research context and methodology chapters, the thesis is divided into Stage 1 in which the survey method is described, and survey data are analysed. The survey findings are then identified and their influence on the formation of Stage 2 is indicated. Stage 2 in which the interviews method is described, and interview data are analysed is subsequently followed by the Discussion chapter, which refers to both methods and is followed by the Conclusions chapter.

### **Chapter 1 – Introduction**

This chapter outlines the rationale for research on partnerships between parents and carers of children and young people (C/YP) categorised as having SEND and the practitioners in the Education, Health and Care (EHC) services in light of the latest legislation, the SEND Code of Practice (2015). The relevance of this study is also discussed here. Drawing on the review of this policy and my own experience and observations of partnerships, I outline my aims and research questions. Furthermore, this chapter outlines the research process and concludes with short summaries for each consecutive chapter in the thesis.

### **Chapter 2 – Research Context**

This chapter reviews the literature on policy and practice surrounding partnerships with a particular emphasis on how the Code encourages more balanced collaborations that value parental contributions and gives parents confidence that their wishes are acted upon. Despite changes in legislation, the evidence suggests that the partnerships continue to be dominated by practitioners. To address this imbalance in power, co-production is analysed in relation to the principles of partnerships outlined in the Code to evaluate its

potential as an alternative model for inclusive partnerships. Attention is also given to the need for practitioners to become more aware of their own positionality towards models of disability and the impact this positionality has on the partnerships with families.

### **Chapter 3 – Methodology**

This chapter demonstrates the rationale for using a mixed methods approach through an exploratory sequential design. Research design consisting of an online survey and the interviews is discussed in detail, including pilot studies conducted. Critiques of the methodological framework and the theoretical underpinnings of pragmatism within the approach are followed by the rationale for the analytical frameworks of descriptive analysis (Field, 2015) and thematic analysis (Braun and Clarke, 2006). This chapter also explores how the theoretical framework of Appreciative Inquiry (AI) influenced this study, with further discussion on its particular role being presented in Chapter 4.

### **Chapter 4 – Stage 1: The Survey**

This chapter demonstrates the details of the design and conduct of the first stage of this study, the survey. Rationale, design, distribution, results and analysis are presented here with a discussion on how ethical considerations have been addressed before and throughout the survey data collection.

This chapter also presents the findings from the survey and identifies a series of findings that were used to guide further exploration in the interviews, namely:

- inequality of parental expertise vs practitioners' opinions,
- the availability of information and advice for parents/carers to make informed decisions in the bureaucratic tasks that families are required to complete,
- and the detriment of practitioners' misconceptions or lack of understanding of disabilities/and or life of families with C/YP with SEND.

## **Chapter 5 – Stage 2: The Interviews**

This chapter delineates the processes involved in planning, conducting, and reflecting on the interviews and present the findings from these interviews. It highlights a number of themes that emerged from the interview data that suggested that parental experiences of partnerships continue to be inconsistent: sharing experience; professionals' attributes, attitudes and knowledge; discrepancies between the principles of the Code and parental experiences; systemic barriers; and parental experiences of effective partnerships. These depict a range of challenges to the formation of inclusive partnerships and illustrate how individual practices can enable these partnerships in valuing reciprocity, mutual trust, and empathetic dialogue.

## **Chapter 6 – Discussion**

This chapter addresses each research question and draws on the findings from the survey and interviews to answer the posed questions.

The discussion, building on the literature and data analysis explored through this study, uncovers that parents in this research reported that they remain unequal contributors in decision-making and that, although some practices foster reciprocal and contributory relationships, the attitudinal and systemic barriers resulting in 'professional dominance' still prevail.

## **Chapter 7 – Conclusions**

This chapter explicates implications for practice, policy, and further research into how co-production can enrich partnerships with parents on an individual and institutional levels. Drawing on the connections between the principles of co-production, the Code's guidance on partnership working and the findings from this study, I consider the potential co-production has for partnerships. I argue that fulfilling this potential relies on practitioners' capacity and ability to facilitate often challenging conversations, the development of a deeper understanding of parental lived experiences by practitioners, and practitioners' awareness of their own assumptions and values surrounding inclusive practice. The methodological approach is evaluated, and the limitations of the study are

discussed here. A plan for my post-doctoral research that would engage parents and practitioners within the field of SEND in further research on co-production concludes this chapter.

## **2. Chapter 2: Research context**

This chapter provides a review of legislation and research related to working with parents of C/YP categorised as having SEND. I begin by reviewing the literature on policy and practice surrounding partnerships in order to present the historical changes to parental agency and empowerment in decision-making processes. I do this with particular emphasis on how the SEND Code of Practice (2015) encourages more balanced collaborations that value parental contributions and give parents confidence that their wishes are acted upon. The main themes occurring within the research on partnerships are discussed to analyse how and if the Code has affected the partnership working.

Furthermore, I analyse models of partnership working and their relation to the concept of co-production. I then discuss principles of co-production to evaluate how they correspond with the principles of partnerships outlined in the Code and with the values of inclusive education. This discussion aims to argue for and illustrate the potential co-production could offer as an alternative model for inclusive partnerships.

Finally, I discuss models of disability and how they may affect practitioners' understanding and execution of inclusive practice within the partnerships with parents.

I conclude this chapter by summarising pertinent dilemmas of current partnerships and their links to the research questions that this study aims to examine.

### **2.1. The historical landscape of legislation governing partnerships between services and parents of C/YP with SEND**

This section outlines the history of legislation referring to parental input within the realm of SEND with the intention to signify the transformation the Warnock Report (1978) aimed to bring to partnerships with parents. I present key

legislation, dating back to 1893, through to the legislation leading up to 1978 in the first section. Section two delineates the development of legislation following the Warnock Report (1978), and section three focuses on the acts and government guidance that directly influenced the SEND Code of Practice (2015). Conclusions following this overview are presented in the summary.

### **2.1.1. SEN Pre-Warnock Report (1978)**

Since the late 1800s, the legal requirements for the education of children with SEN has evolved. For example, the Elementary Education (Blind and Deaf Children) Act 1893 and Act 1899 for Defective and Epileptic Children considered provision for those specific pupils with SEND; however, parents or guardians were required to contribute financially to those provisions but did not hold any rights to influence them.

Although the Mental Deficiency Act (1913) gave right to special education for persons with mental health illnesses, that right was dependent on the decision granted by the Board of Education and their perspective on the level of detriment potential disruptive behaviour caused by the individual could have on other children. Consequently, all decisions remained within the power of practitioners and parents were not consulted.

The Amendment to the Elementary Education (Defective and Epileptic Children) Act from 1914 alludes to parental rights to knowledge about their child's education, which suggest that the consideration for parental input was recognised. The Act required Local Authorities to endeavour to respect the wishes of the parents in relation to the provision, if possible. However, ultimate decisions about what was or what was not possible remained within the professional remit, leaving the parent reliant on these outcomes.

Furthermore, although the 1918 Education Act imposed the duty to educate disabled children, their education was usually limited to special boarding schools. This continued the trend of decision-making processes remaining within the power of professionals as parents had limited access to these institutions and no input in decisions surrounding their functions.



Only many decades later, with the introduction of the Education Act (1944), was the term special education first used to address pupils who did not fall into the 'mainstream' category and to enforce a mandate to offer provision in special schools for these pupils. However, children with mental health illnesses were often institutionalised and their welfare and educational provisions were governed by National Health regulations (e.g., 1946 National Health Service Act, Mental Health Act 1959, and The Education of Children in Hospitals for the Mentally Handicapped 1978) until The Education (Handicapped Children) Act 1970 transferred the responsibility for education onto the local authorities. This suggests that educating children categorised as having SEN was perceived and practised as a domain within health, rather than education, as the functions of these acts were predominantly based on the medical rather than educational needs of the C/YP. Additionally, neither of these pieces of national health legislation addressed the rights or responsibilities of parents, leaving the decision-making processes in their entirety to professionals.

The Education Act (1944), however, made it possible for parents to request examination of their children's specific special need to be conducted by a medical or an educational official. Local Authorities were subsequently obliged to create arrangements for either special school places or supported provision within maintained schools, whichever case was more practicable from the Local Authority's point of view. In doing so this legislation transparently designated power in decision-making processes to professionals. The role of parents or guardians of pupils with SEN was constrained to the opportunities to request an assessment of needs and/or disability from the child's age of two and for parents to be present at the examination. Parents or guardians were also provided with a written report describing the impairment of the child and its severity. Ultimately, all the decisions surrounding type and frequency of provision were still determined by professionals.

It was not until the 1981 Education Act that parents were formally formulated as partners in decision-making processes, following the Warnock Report in 1978 (Warnock, 1978). Baroness Warnock argued for the importance of the partnership between professionals and parents of children with SEND, recognising the uniqueness of each child and their family circumstances. Furthermore, the report constructed partnership as an equal dialogue in which

parental opinions are valued and considered by professionals who learn from parental experiences to build their understanding about the children they care for or teach:

*‘...It is a partnership, and ideally an equal one. For although we tend to dwell upon the dependence of many parents on professional support, we are well aware that professional help cannot be wholly effective — if at all so — unless it builds upon the parents’ own understanding of their children’s needs and upon the parents’ capacity to be involved. Thus, we see the relationship as a dialogue between parents and helpers working in partnership.’ (Warnock, 1978, p. 151).*

Practitioners were not regarded as the only root of knowledge and expertise, but as facilitators who can enrich provisions and parental abilities, but only with parental involvement. This change of perspective in practice has influenced subsequent legislation in the field of SEND and continues to be referred to in debates to this day (Norwich, 2014; Webster, 2019; Hodgkinson, 2019).

### **2.1.2. SEN Post-Warnock Report (1978)**

The discourse of parent-practitioner partnerships within the realm of SEND has been explored at length since the recommendations of the Warnock Report (1978) stressed the importance of engaging with parents of C/YP with SEND. This could be regarded as a revolutionary approach as none of the previous acts or guidance before it considered parental input or parental influence on provisions as essential. In response, the Education Act (1981) defined the usage of the ‘special educational needs’ (SEN) and imposed an obligation on local educational authorities (LEAs) to communicate with parents regarding the provision identified in the SEN statement. Parents were then granted the right to appeal decisions made by LEAs and the arrangements for the appeal system had to be clearly signposted for them. Assessments for SEN could not proceed without parental consent. Parents were welcomed to be present at the examinations and could disagree with any aspects of the statement within a stated period. To ensure parents understood the proposed agreement, they had an opportunity to discuss it with the guidance of ‘relevant advice’ given by an ‘appropriate person’. However, the decisions about the relevance of this advice

and the appropriateness of the person providing it were judged solely by the authorities, not the parents. Furthermore, despite parents being able to request an assessment of their child aged at least two years, the LEAs could refuse the request under the legislation if they deemed it unreasonable, thus continuing to hold parental views inferior to those of professionals. Importantly, this Act failed to address the rights of guardians or carers, leaving those who cared for, but were not parents of, vulnerable children inadequately represented in the legislation.

The subsequent Education Act 1993 placed additional responsibility on LEAs to publish a Code of Practice outlining all procedures and regulations within the realm of SEN. The first Code of Practice published in 1994 stated that 'the knowledge, views and experiences of parents [were] vital if effective provision [was] to be made for their children' (DfE, 1994, p.7). This statement implies that parental input is of value and that practitioners should seek it to ensure all provisions were meaningful and appropriate for C/YP categorised as having SEND.

Communication with parents was also mentioned by both the 1993 and the following 1996 Education Acts. They called for the support of National Health Services to sustain clear lines of communication with LEAs to ensure parents were well informed about their children's impairment and about the decisions made for provisions and services. In addition to those changes, the Green Paper (DfEE, 1997) suggested that by 2002 all parents of children with SEN who were being assessed would have the opportunity to receive advice from an independent 'named person', enabling parents, in theory, to build a closer relationship with a key practitioner who took part in decision-making processes. Furthermore, parent partnership schemes would not only be present in every local authority in England but would also be pivotal in reducing the number of appeals by promoting dialogue between parents, schools, and LEAs.

The 2001 SEND Act reflected the theoretical attempts to include parents as partners in partnerships and imposed the duty of educating pupils with SEND in mainstream schools unless otherwise desired by parents, or if it was incompatible with efficient provision for other children. The terms 'partnership' and 'incompatibility of provision for other children' were not defined by this legislation and therefore remained ambiguous and open to interpretation. The

right to appeal the decisions of local authorities were explicated in more detail, claiming that it would provide families with more opportunities to understand the process, if required. The 2001 Code of Practice also introduced the role of a Special Educational Needs Coordinator in mainstream schools, providing families with one point of contact for collaboration. Considering these changes, it can be concluded that the legislation and government guidance aimed at including parents in decision-making processes; however, practical implications for these processes and communication between practitioners and parents continued to lie within the discretion of practitioners.

### **2.1.3. Regulations and inquiries directly influencing SEND Code of Practice 2015**

Despite the changes in legislation discussed in the previous sub-section, partnerships with parents continued to be problematic in relation to parental involvement in decision-making processes (Murray, 2000; Keen, 2007; Hodge & Runswick-Cole, 2008). In response to these challenges the Lamb Inquiry (2009) examined the causes and effects of the instability of partnerships between services and families. This report, which influenced the Children and Families Act (2014) that governs the latest Code, called for radical changes in working with parents of pupils with SEND. The section 'Special Educational Needs and Parental Confidence' of the inquiry suggested several changes in practice and law to address the unsatisfactory state of the collaboration. They included:

- comprehensive information about SEN provision to be shared with parents and carers;
- seeking and meeting the needs of the parents (in relation to the needs of their C/YP) by strengthening the partnership schemes with appropriate advice in regulations and the law;
- providing greater transparency in the system;
- enabling effective communication with knowledgeable and approachable practitioners who know the limits to their expertise;

- 'the core offer' being presented to and promoted to parents and carers clearly stating what the families can expect (instead of parents having to find out what can be available);
- parental statutory rights must be explicit and procedures of complaints and appeals widely available for them;
- training for practitioners across the workforce who have frequent contact with parents and carers as well as those who are in training;
- parents' views to be sought by Ofsted inspectors;
- the annual reviews for statemented children to be reflective of the needs of parents and their children/young people and focus on identifying the outcomes for disabled pupils and pupils with SEN.

These recommendations required a shift in thinking and working patterns of practitioners. The government addressed the points listed above in the Green Paper which promised radical changes in SEN reform in the last 30 years (DfE, 2011). The publication welcomed feedback from parents and professionals on proposed changes emulating a sense of collaborative practice where all stakeholders had the opportunity to shape this intended transformation.

Furthermore, in relation to parental entitlement, under The Equality Act from 2010 (Part 6, c. 1), exclusion of a person from education due to their disability meant that this person was discriminated against or victimised. This clause moved the pressure from the SEN or disability of the child being focused on to the provision working on its effectiveness through dialogue with parents of that pupil.

As a result of these publications and the Equality Act 2010, the principles of partnerships between parents and practitioners under the Code encompassed:

- collaborative work between education, health and care services and families of children and young people aged 0-25;
- communication of relevant information and how/where to access them;
- transparency of provision and its funding;

- ability to request a personal budget and identify a preferred school by families;
- professional jargon free assessment and review process focused on high aspirations and forward-looking improved outcomes reflected in Education, Health and Care plans (replacement for statements of SEN) devised by all involved practitioners in conjunction with parents/carers of the individual child/young person;
- guidance regarding 'graduate response' to identification and support of SEND needs in mainstream settings and importance of encouraging and promoting effective and equal relationships with parents/carers;
- and lastly the statutory obligation for LEAs to co-produce and publish the local offer stating all relevant information and their accessibility for families and minimising ambiguous guidance and information.

#### **2.1.4. Summary**

The landscape of legislation that shaped the current Code has impacted on the nature of parent-practitioner partnerships for over three decades, constantly aiming at addressing the power of decision-making being positioned in the hands of practitioners. Although the most recent regulation intended to bring more control for parents through validation of their views and their expertise in decision-making processes, it remains unclear whether these well-intentioned aims have been experienced by families through their encounters with practitioners.

In the next two sections, I illustrate how parental lived experiences, that are related to partnerships, have been reported on in research prior to and following the implementation of the Code.

## **2.2. Parent-practitioner partnership Pre-SEND Code of Practice (2015) (1981-2013)**

This section focuses on the themes evident in research into parent-practitioner partnerships leading to the introduction of the Code. The themes presented below were designed to elicit the main factors as discussed by researchers since the SEN Education Act 1981.

### **2.2.1. Inequalities of power in partnership**

In this sub-section I review the history of unequal power in partnerships with parents and argue that this inequality persists in practice. Since the Education Act (1981) was the first act defining SEN, it consequently prompted a debate around partnerships with parents of C/YP categorised as having SEND. Researchers as far back as in 1981 have explored inequalities in partnerships and the need for more inclusive, collaborative approaches (Sonnenschein, 1981). Differing perspectives of the child, goals and appropriate routines have been identified as some of the factors contributing to the problematic dynamics of those partnerships (Lake & Billingley, 2000; Case, 2001; Stoner et al, 2005; Prezant & Marshak, 2006). In Gascoigne's (1996) definition of partnership, partners in the relationship are equally valued and recognised for their knowledge, experience and skills, yet research conducted by Murray (2000) evidences how the partnerships were built on professionals' terms and parents remained disregarded when decisions about their children were made. Similarly, the lack of clear definition of the term 'partnership' left both sides of the partnership to create their own meanings of that term. This ambiguity led to disparities when relationships were enacted in practice, creating a divergence in what standard of service families experienced (Gascoyne, 1996; Hodge and Runswick-Cole, 2008; Adeb, 2014). Consequently, practitioners' power in decision-making processes prevails and as a result determines the validity of parental views (Armstrong, 1995; Swain & Walker, 2003; Hodge & Runswick-Cole, 2008; Bacon & Causton-Theoharis, 2013).

### **2.2.2. Empathy and Communication**

To address the disparities between the expectations both sides may hold for partnerships, it is argued that channels of communication need to be established (Seligman & Darling, 2007). Issues surrounding the development of practitioners' empathy and effective communication skills have been explored in tandem in research frequently. On one hand, it is argued that the variety of emotions that parents experience requires acknowledgement by practitioners to build positive relationships (Orphan, 2004; Sen and Yurtsever, 2006; Dobbins and Abbott, 2010; Zeitlin and Curcic, 2014). However, in order to be able to provide this acknowledgement, practitioners need to be aware of and understand those emotions.

Developing understanding of a lived experience of another person in order to improve empathy is deemed a complex process (Haugh & Merry, 2001). This process evolves on cognitive (making sense of the situation), affective (making sense of the emotions felt) and somatic levels (making sense of the bodily effects resulting from that experience) (Haugh & Merry, 2001). To develop knowledge of these levels, researchers have advised that professionals could be exposed to diverse stories from families and be prepared to accept them as valid, even when their own experiences appear to be very distant in comparison. Every parent's story is different; some might find it difficult to accept the SEND label assigned to their C/YP, some treating that label as a constraint in their family's life and means of obtaining essential support, others considering it as an intrinsic part of their child's identity that evokes a sense of pride and joy in their lives (Seligman & Darling, 2007). Broomhead (2013) illustrates the strength of parental stories shared with pre-service teachers and its positive impact on these trainees' development of empathy towards the practical and emotional aspects of day-to-day lives of families with C/YP with SEND. However, it is crucial to point out that the parents in Broomhead's (2013) study argued that empathy 'cannot be learnt from the book' and suggested that only practitioners with personal affiliations and experiences of SEND can understand what parents contend with.

As it is impossible for all practitioners to have personal affiliations with C/YP with SEND (Seligman & Darling, 2007; Broomhead, 2013), the need to develop



effective means of introducing a variety of stories that emulate the socio-emotional dimensions of these families can be perceived as imperative. It could be argued that through hearing the accounts of positive, challenging, endearing and thought-provoking occurrences, practitioners would be able to reflect on similarities and differences between these and their own experiences. These reflections could therefore ignite development of empathy.

Likewise, reflecting on the use of language and jargon when communicating with parents could also improve the partnerships (Keen, 2007; O'Connor, 2008). Moreover, parents felt understood and listened to when practitioners took time to answer any questions parents had during collaborations (Millia Borg, 2010). Whereas when parents struggle to access the information or are unable to understand what is presented to them, the communication is broken and precludes adequate provision from being determined. Therefore, I decided to explore the extent to which parents felt the complexities of their lives were known and understood by practitioners.

### **2.2.3. Blame**

The concept of blame has emerged as a pertinent feature of partnerships within the existent research. For example, Carpenter (1997) elaborated on the mutuality of blame between families and professionals where the accusations are often directed at each other due to the failures of inadequate services provision. Blame is also often directed at parents by practitioners who perceive some of the C/YP's behaviour or characteristics being a result of inadequate parenting skills (Wolfendale, 1997; Broomhead, 2013; Bacon-Theoharis, 2013) or blame parents for their C/YP's disability (Green, 2003). Importantly, mothers, more often than other members of families with C/YP with SEND, can be subjected to blame, including self-blame while operating within the 'oppressive' societal boundaries that perceive disability of their children as undesired (Ryan & Runswick-Cole, 2008). Although this outlook may not be shared by the whole of society, it is important that practitioners consider their own stance and attitudes towards disability in order to minimise judgement based on own deep-seated beliefs (Graham et al., 2020).

#### **2.2.4. Trust and confidence**

The aspect of trust in the partnerships by parents has been widely explored by researchers as a major challenge contributing to the failure of the partnerships (Minke & Scott, 1995; Orphan, 2004; Sen & Yurtsever, 2006; Zeitlin & Curcic, 2014; Adeb, 2014). Although the Lamb Inquiry (2009) affirmed that parental confidence in professionals requires urgent attention and the Code (2015) called for practice that would enable this confidence to flourish, the evidence in research resembles very unsatisfactory developments in this area of partnerships. Parents reported on how their distrust towards practitioners was developed through the processes of assessment (Armstrong, 1995). In Armstrong's (1995) research, parents felt judged for their parenting skills and positioned as 'the outsiders' within the schools their children attended, rather than partners. Likewise, Wolfendale (1997) reported how participants who were parents exemplified instances when practitioners in education exhibited mistrust towards parental accounts of their children's behaviour outside of the school context; often this mistrust resulted in blame on parental disengagement or 'lack of interest' in their children's education. Gascoyne (199) and Seligman & Darling (2007) assert that some parents might have also been subjected to prejudice or lack of sensitivity from various practitioners for seeking support from a service without adequate reasons.

As parents are required to work with multi-agencies and the range of practitioners when establishing adequate provision for their C/YP (Seligman & Darling, 2007), once the trust is lost for one agency, it might affect parental trust towards other practitioners, too (Gascoyne, 1996). When parental expertise in their children is not recognised, parental confidence in the practitioners becomes unstable as parents may question the appropriateness of the decisions made for their C/YP (Gascoyne, 1996). A lack of confidence that practitioners are making adequate decisions based on the holistic knowledge of an individual often results in parents feeling that they have to become vocal about their opinions. However, parents who are 'being vocal' in advocacy for their children are often categorised as 'problematic parents' by practitioners

(Todd, 2007) and this perception further perpetuates the divide between practitioners and parents.

Importantly, Lake and Billingsley (2000) identified the point at which parents lose their trust in practitioners working with their child as pivotal to the partnership. While practitioners are often unaware of when that moment occurs (Lake & Billingsley, 2000), it can affect the future of the partnership, often irreversibly. This assertion indicates the importance of open and honest exchanges of views within partnerships; otherwise, practitioners remain oblivious to facets of the relationships that require consolidation or improvement.

### **2.2.5. Bureaucracy**

Lastly, the maze of bureaucracy that parents are continually involved in when caring for their C/YP with SEND affects their time, perseverance, and collaborative capacities (Bacon & Causton-Theoharis, 2013). The complexities of paperwork required for a range of tasks that relate to obtaining EHC services are already strained by additional responsibilities and the resources families have available (Seligman & Darling, 2007). The conflict between systemic responsibilities of practitioners and the needs of families leads to the disparity between the outcomes of bureaucratic tasks on both sides (Lipsky, 2010). As some practitioners deal with these bureaucratic tasks without a direct contact with families, they may be unaware of the impact of their actions on the lives of people these administrative tasks affect. Furthermore, researchers have argued that, not only should the level of bureaucratic burden on families be minimised (Seligman & Darling, 2007), support should also be given to families to enable them to cope with this burden (Millia Borg, 2010), and the professionals should show sensitivity to families' circumstances (Dobbins & Abbott, 2010; Adeb, 2014).

### **2.2.6. Summary**

Prior research demonstrates that the partnership between parents and practitioners has a long, problematic history. Mistrust, lack of communication, inequality of contribution in professional dialogue and exchange of information, and high levels of bureaucracy, have contributed to the necessity for change. The latest SEND legislation was intended to achieve such a transformation. Therefore, the section that follows focuses on themes identified through research on partnerships following the implementation of the Code.

## **2.3. Parent-practitioner partnership Post-SEND Code of Practice (2015)**

This section outlines evidence of inclusive partnerships as experienced by parents since the introduction of the most recent legislation. I focus on the effects the implementation of the Code has had on the partnerships to indicate whether and if so, how, these partnerships have evolved.

### **2.3.1. Choice**

The Code accentuated the choice parents now have to influence which setting their C/YP attend. Although an outcome desired by parents (Lamb, 2009), the choice of schools has been reported as an 'empty rhetoric' (Lehane, 2017) and not achievable in times of austerity (National Audit Office, 2019). For example, parental choice is reported to be hindered by nationwide academisation, which often results in decreased intake of pupils with SEND (Lehane, 2017). By enabling the academies to decide on the numbers of C/YP with SEND being offered a place in particular schools, parental choice is driven by the availability of places, rather than by parental decisions. Furthermore, national policy contributes to the disparity between what provision C/YP need and the priorities the schools are required to fulfil; until the newest Ofsted Framework (Ofsted, 2019), schools were unable to be autonomous in the adaptation of the

curriculum for pupils with SEND and the progress of these pupils was measured in the same manner as the progress of other pupils. This lack of recognition for differentiation could be said to be responsible for some settings being under pressure to display achievements in performance acceptable within the league tables (Ball, 2003). Consequently, 'slower' or non-linear progress of pupils categorised as having SEND would distort the measurement of attainment across those settings, resulting in some of the schools refusing to accept parental choice of the placement.

In contrast, Bajwa-Patel and Devecchi (2014), report that the majority of parents feel satisfied with the provision that chosen schools offer; however, they argue that there is a need for more information for parents about the choice of schools and Parent Partnership services. Likewise, Hellowell (2017) asserts that the language of choice and preference in the regulation contributes to conflicting views between what can be chosen by parents and what the provision is able to offer. Similarly, a report on the transition between SEN statements and EHCP (Adams et al., 2017), conducted with parents and young people involved, states that 4/5 of the parents agreed that the practitioners were knowledgeable about the process to some extent and approximately 55% of respondents were informed about the advice and support their local authority had on offer generally. This shows that parents can make choices out of restricted options that are predetermined by professionals.

This dilemma of choice illustrates the ambiguity parents and practitioners face when navigating legislation and forming partnerships.

### **2.3.2. Individual in the context of a family unit**

Research evidence suggests that individuals experienced a more holistic approaches which recognise their place within the context of their family to a larger extent (Adams et al., 2017), and this can suggest a positive shift in partnerships between services and families in this respect. For example, the Code advocates that 'support should be family centred and should consider the individual family's needs and the best ways to support them' (DfE & DoH, 2015, p. 85). This assertion suggests that the acknowledgement and integration of the

holistic view of the family, while the needs of individuals with SEND are examined, is crucial.

Hellawell's study (2017), conducted with 14 practitioners, found that it is essential to consider that different parents might be at different place in their journey, and to include those who express that they do not feel adequate or equipped enough to plan their child's EHC future. This corresponds with Mann et al.'s (2020) and Seligman and Darling's (2007) view that the stages of developments in the family life affect the dynamics between its members. Additionally, the fluidity of these changes does not always align only with the life developments of the individual with SEND, but is often affected by other factors to which the family is subjected (e.g., caring for elderly or ill relatives, or changes in home life like the departure of a sibling to university). As parents and C/YP with SEND exist in these closely intertwined relations, treating any of them as separate entities without consideration for those relations risks gathering an incomplete picture of the family. This incomplete picture can result in inadequate needs assessment and skewed decisions about appropriate provisions where the C/YP fails to be recognised as a member of a larger family unit (Hirano and Rowe, 2016).

Similarly, the DfE (Adams et al., 2017) surveyed families and C/YP with SEND regarding the views on the EHCP processes, which resulted in over 1300 responses from parents and young people. Those findings, gathered between July and November 2016, indicated that 75% of respondents stated that the process was family centred and 48% reported that their individual family's needs were considered.

This finding is therefore crucial to my inquiry as it indicates how important it is for practitioners to learn about the family context when creating a meaningful provision for any individual.

### **2.3.3. Language used in communication**

The Code recognises the conflict between effective communication and professional jargon as an area requiring attention (DfE & DoH, 2015). The

language used throughout the communication between parent and professionals can be the root of ineffective partnerships (Keen, 2007; Hellowell, 2017; Hodge & Runswick-Cole, 2018). Not only is the jargon unwelcomed by parents and emblematic of the extent to which the power imbalances in partnerships prevail in practice, even the language that appears to be jargon-free can contribute to conflict between both parties. Hodge & Runswick-Cole (2018) depict the differences in perception that the same words or phrases can present for parents and practitioners. This disparity between what is being said and the emotional value certain words/phrases might hold for parents, some of whom have been advocating for their C/YP for a long time, are reported to be essential for practitioners to consider (Hodge & Runswick-Cole, 2018). Acknowledging that parents and practitioners create their perceptions and understanding of the partnerships from very different standpoints can support the collaborations (Connor & Cavendish, 2018). The presence of these debates illustrates the extent of the complexity of communication and the need for opportunities that would enable practitioners to acquire, understand and reflect on a deeper knowledge of parental perspectives.

In relation to sustaining and maintain partnerships, Broomhead's (2018) study explored the responsibility to develop productive communication by both sides of the partnerships. Some of the parent-respondents asserted that the responsibility lies within families to initiate and clearly indicate how they wish to be communicated with; on the other hand, educational practitioner-participants expressed unity in accepting the responsibility for building effective communication with families. Furthermore, the divergence of needs different families might experience determines the preferences in means of communication (Seligman & Darling, 2007). Nevertheless, communication must take place (DfE & DoH, 2015) and, by acknowledging the disparity of longstanding power imbalances between professionals and families, it appears that positioning parents as more than just 'informants' is essential to improve current practice regarding the contribution of parental perspectives (Hodge & Runswick-Cole, 2008 & 2018).

Although communication channels continue to be challenging (Kendall, 2017; Hellowell, 2018), there is some evidence that effective communication between families and professionals is taking place; this includes SENCOs' perspectives

(Curran, Mortimore & Riddell, 2017) and parents' accounts (Holland and Pell, 2017). It can suggest that there are pockets of practices that could be built on in order to form effective partnerships with families.

#### **2.3.4. Attitudinal change, accountability, and performativity**

Sales and Vincent (2018) suggest that there is a bigger requirement for 'attitudinal barriers' in practitioners to be shifted than there is a need for a change in policy governing inclusive partnerships with parents. Mann and Gilmore (2021) draw attention to the continuous hold on professional expertise that teachers display, and how this hold might be the reason why the teachers are reluctant to learn from parents. Hodge and Runswick-Cole (2018) argue that, to aid practitioners' understanding of parental lived experiences, practitioners need to engage in critical reflection on ways of engaging with families and accept that their understanding might vary significantly from those of families, this includes the front-line workers who have constant contact with families.

As described in detail in Section 2.6.1. practitioners' awareness of their own beliefs and values that drive the interactions with families are major contributors to the effectiveness of these partnerships. With inclusive partnerships requiring a change in practice and in attitudes, the current system, which is heavily embedded in performativity discourses, requires re-evaluation; however, the limitations of the professional workforce to overcome systemic barriers preclude that change in attitudes and underlying assumptions (Glazzard et al., 2015). Following on from the systemic barriers, Norwich and Eaton (2015) questioned the, now desirable, collaborative abilities between local authorities and families. In the view of the authors, the user-led spirit and capacity for different agencies to transform current ways of working within multi-agency collaborations is significantly impeded by the budgetary restraints caused by austerity. Furthermore, more recent research on multi-agency working revealed that collaborative practice causes an array of frustrations for both parents and practitioners (Cochrane & Soni, 2020). These include instances of unattended meetings, difficulties in accessing some agencies, or differing levels of



practitioners' expertise in collaborative working across agencies (Cochrane & Soni, 2020). Likewise, the issue of underfunded and irregular support offered by local authorities contributes to the varying experiences of planning for education, health and care provisions for C/YP (Robinson, Moore & Hooley, 2018).

Furthermore, budgetary strains on services and the unclear distribution of responsibilities for maintaining parent-practitioner partnerships contributed to professionals' limited capabilities to channel their focus to transform these relationships as guided by the Code (Broomhead, 2018). Conversely, Mann and Gilmore (2021) argue that the responsibility of ensuring that partnerships are positive and productive falls onto all practitioners within the educational context, from administrators to leadership teams. In their study, parents appeared to be more invested in maintaining a strong and productive partnership with teachers who seemed less open to sharing the learning journey with parents. Whether or not the reason for ineffective collaborations resides within the performative and accountability targets (Gore, 2016; Hellawell, 2018), the focus of practitioners on partnerships in public services is compromised. Therefore, I was interested in hearing from parents on whether they thought the expectations to meet the set goals as a priority affected practitioners' awareness of the impact these bureaucratic tasks may have on the service users. I was also curious to hear from parents how the culture of collaborative working could be cultivated and encouraged in practice (Mann & Gilmore, 2021).

### **2.3.5. Summary**

The research synthesised above indicates that there are some positive effects of the implementation of the Code experienced by parents in partnerships. However, the need for further improvement or change in practice is evident. These changes relate to: attitudinal changes (on institutional as well as individual and societal levels); raised awareness of practitioners' understanding of parental lived experiences and practitioners' positionality within the partnerships; and systemic barriers including performativity measures and bureaucratic tasks.

In the following section, I address the values and theories that underpin different forms of parent-practitioner partnerships by discussing models of partnerships with parents. This illustrates how practitioners' values and their awareness of these models can support the development of more effective partnerships with families.

## **2.4. Models of partnerships with parents**

This section outlines a number of existing models of partnerships with parents and distinguishes the particular assumptions that underline each model. Furthermore, I argue here that it is important that practitioners working with parents are aware of these assumptions and of the models within which they operate.

Since the Warnock Report (1978) researchers have strived to operationalise the concept of partnerships between parents and practitioners with varying results. Furthermore, guidance for parent-practitioner partnership, particularly in the context of inclusive education, is widely available, providing a range of useful and practical tools to enable the partnership to flourish (Nasen, 2015; Goepel, Childerhouse & Sharpe, 2015). Despite the term 'partnership' being difficult to define (Murray, 2000; McNab, 2010), and relevant legislation continuously failing to provide a working definition (Gascoyne, 1995; Hodge & Runswick-Cole, 2008; Keen, 2007, Lehané, 2017), researchers have attempted to produce a number of models of partnerships (Mittler & Mittler, 1982; Cunningham & Davis, 1985; Appleton & Minchcom, 1991; Dale, 1996; McNab, 2010, Adeb, 2014). These are summarised in Table 1.

Table 1 Models of partnerships with parents and carers of C/YP with SEND

Models of partnership (adopted from McNab, 2010, p. 84)				
<p><b>The Expert model</b> (Cunningham &amp; Davies, 1985; Mittler &amp; Mittler, 1982)</p> <p>Professionals may seek information from parents or inform them about decisions made, but they take little account of parental views when they make professional judgements about appropriate provisions for C/YP with SEND.</p>	<p><b>The Transplant model</b> (Cunningham &amp; Davies, 1985; Mittler &amp; Mittler, 1982)</p> <p>Professionals determine how 'active' parental roles are by 'transplanting' essential techniques parents are to adopt to meet the needs of their C/YP (Beveridge, 2005) and enlisting parents as co-teachers or co-therapists.</p> <p>Parental skills or unique contributions are not recognised (Hatcher &amp; Leblond, 2001).</p>	<p><b>The Consumer model</b> (Cunningham &amp; Davies, 1985)</p> <p>Parents are encouraged to use their in-depth knowledge and experience of their own children to determine the most appropriate services and interventions (Beveridge, 2005)</p> <ul style="list-style-type: none"> <li>- cause for dilemma on the type of consumerism here and the inequities that arise when so little choice is available for the majority of children and their families.</li> <li>- parental rights with respect to information and involvement in decision-making processes are recognised, but the model does not discuss appropriate support on offer if parents are to develop the confidence and competence to exercise these rights (Beveridge, 2005).</li> </ul>	<p><b>The Empowerment model</b> (Appleton &amp; Minchcom, 1991)</p> <p>Parental power and control are visibly desired, and professionals are required to build on each family's strengths and ensure parent's sense of being a partner in decision-making processes, while identifying areas of support to enable this empowerment.</p> <ul style="list-style-type: none"> <li>- power still lies with professionals who must ensure that parents are treated as partners. Professionals might have varied understanding of what it means to be a partner, and therefore, some parents may be at greater risk of entering into inequitable partnerships.</li> </ul> <p>The model focuses on just one type of empowerment, but other forms may be needed to truly address the power imbalance (Dale, 1996).</p>	<p><b>The Negotiating model</b> (Dale, 1996)</p> <p>Builds on the consumer and empowerment models but sees negotiation as a key transaction for partnership work, where "the partners use negotiation and joint decision-making and resolve differences of opinion and disagreement in order to reach some kind of shared perspective of jointly-agreed decision on issues of mutual concern" (Dale, 1996, p.14).</p> <p>Both contributors are valued despite potentially differing perspectives and levels of abilities/willingness to negotiate. Although a bridge between the varying perspectives, the emphasis is on the professional to carry out the negotiation and resolve any differences which are likely to be complex and deep-seated, and this model appears to over-simplify this.</p> <p>This is more beneficial to more articulate, confident parents.</p>

These models differ in the extent to which they engage with parents as partners, however, the negotiating model can be argued to be most closely related to the inclusive partnerships as I explore in detail in Section 2.5.3.

Contrary to the notion of working with parents as partners (Warnock, 1978; DfE & DoH, 2015), all these models were created through the lens of a practitioner's judgement without input from parents (McNab, 2010). Despite this, Hornby (2011) argues that these models can contribute to constructive partnerships between parents and professionals with various elements of each of the models supporting divergent scenarios in practice. In Hornby's (2011) view, the heterogeneity of families calls for diverse approaches to partnerships and he builds on the seven principles of effective partnerships that were proposed by Turnbull et al. (2011). These include:

- trust (built through professionals' reliability, confidentiality, sound judgements, openness, and honesty in all interactions with parents);
- respect (manifested active listening to each other's points of view, consideration of each other's standpoints, respecting of diverse cultural heritage, treating others with dignity and affirming their strengths);
- competence (exhibited in acts of developing parental confidence in professionals' ability to optimise every child's potential for fulfilling life), communication (two-way dialogue with clarity and sensitivity);
- commitment (presented by availability and accessibility to families, being sensitive to family needs and going above and beyond expectations when necessary);
- equality (both sides of the partnership to be involved in planning, solving and decision-making, professionals to share the power and 'fostering the empowerment of parents');
- and advocacy (allowing proactivity in identification of difficulties by parents and acting on this information to prevent problems from developing further).

These aspects of partnership closely correlate with the principles of co-production, which will be discussed further in the next section, to illustrate how the framework of co-production could support productive and inclusive partnerships with parents.

### **2.4.1. Summary**

Although the models of partnerships provide frameworks for practical approaches to effective parent-practitioner partnerships, they have not been utilised in legislation directly. The models derive from longstanding scholarly examinations but have been mainly designed by practitioners and researchers without direct contributions from parents. This lack of parental participation and contribution serves as yet another reason for the use of co-production as a framework for partnerships. By involving parents in the designing of models the services operate in, practitioners would enable two-way dialogues, which could contribute to a more equitable assessment of current ways of working together. Similarly, this participation by parents in design could provide more opportunities for the lived experiences of families with C/YP categorised as having SEND to become a more pertinent feature of all decisions made about them.

In the next section, I argue that, to enable essential reflection and to provide practitioners with space and time to learn from families, the framework of co-production could be utilised as a more substantial model for partnerships. While the negotiation model acknowledges the need for effective negotiation, co-production provides additional space to reflect on pertinent values underpinning partnerships. Through this reflection, both sides of the relationships would evaluate whether the proposed principles by Turnbull (2011) are fulfilled and whether they are enabling equitable roles in negotiations.

## **2.5. Co-production**

In this section, I present connections between the concept of co-production, the guidance for partnerships as outlined in the Code, and the rationale for the role of co-production as a more effective framework for partnerships with parents. I begin with a brief history of co-production and its application in research within public services. I then compare the principles for partnerships outlined in the Code with the values underpinning co-productive practice. Next, I describe the

advantages and challenges of applying co-production in practice within public services, whilst in the final subsection, I argue for the potential co-production offers to partnerships with parents.

### **2.5.1. Development of co-production**

Co-production was first defined by Eleanor Ostrom in 1970s as the *‘process through which inputs from individuals who are not “in” the same organisation are transformed into goods and services.’* (Ostrom, 1996, p. 1).

The framework was initially used in a neighbourhood watch project which involved citizens in supporting public services to prevent local crime and resulted in decreased numbers of offences. The concept was later incorporated in the education system in the United States of America (USA) to invite students and their parents to participate in the design and delivery of provision (Davis & Ostrom, 1991). This collaborative approach showed how citizens can complement the work of public services, fostering the interconnectedness of valid contribution from both sides (Cahn, 2000). Although a well-established concept internationally, in the UK co-production has been adopted more in health and social care than within education (Voorberg, Bekkers & Tummers, 2015). For example, Realpe and Wallace (2010) report on the efficiency of co-productive practice in identification of patients' needs, at the same time urging for more training that would enhance the front-line staff's ability to build lines of effective communication with service recipients. Unlike the Code (which lacks a definition of co-production), the Care Act 2014 defines co-production as operating

*‘when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered’* (DoH, 2014, p. 17).

Boyle and Harris (2009), who elaborated on the impact of the framework of co-production and its influence on all public services, broaden the definition to:

*‘Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and*

*their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change.'* (Boyle & Harris, 2009).

Although varied in wording, all definitions advocate for service users to be active partners in designing, planning, and/or delivering services. By enabling end-users to become active agents in how these services are produced (Needham, 2007), equality of relationships between the parties is reliant on their contributions being given equivalent value (Cahn, 2000). Furthermore, Cahn (2000, p. 24) asserts the four main pillars of co-production, which, in any context, he deems as not having controversial values as they all serve to enrich society. These include:

- People as assets that are recognised as bringing something valuable to contribute to the collective 'good' in society.
- Redefining cultures and structures in operation to ensure social justice for marginalised groups and sustainability of democratic ethos.
- Reciprocity where two-way exchanges prevail (i.e., 'you need me' is turned into 'we need each other').
- Social capital where the collective knowledge, strengths and expertise of citizens are utilised to support the development of safe, thriving, and supportive communities.

These core values could be transferred into partnership working where parental expertise is acknowledged through reciprocal practice and where a culture of collaboration enriches the lives of C/YP with SEND. This requires a shift in power from practitioners to parents to be enacted in practice (Realpe & Wallace, 2010), which can be problematic as it would rely upon practitioners parting with some of their inherited power. However, as expected by the Code, parental contributions need to be incorporated in decision-making processes. To enable this change, ways of communicating between citizens and services require transformation (Needham, 2007). When applied effectively, co-production can serve as a 'therapeutic tool' (Needham, 2007, p.223) where all members of the partnership, through a facilitated sharing of perspective and experience, come to new understandings of what the partnership means to the others and how it impacts upon them. Therefore, while bridging the epistemic

gap between different understandings, Alford (2014) proclaims that co-production can enhance partnerships between governments and their citizens; partnerships that will not only involve consulting recipients of services on their views, but enabling the services being shaped and designed as a result of these views (Fairlie, 2015). The ownership of that involvement would, in return, increase citizens' trust in services that they have jointly designed, planned, or delivered (Needham, 2007).

Since the growing interest in co-production and its relevance to improving public services (Cahn, 2000; Boyle & Harris, 2009; Realpe & Wallance, 2010; Pestoff & Brandsen, 2010; Alford, 2014; Fairlie, 2015), its practical limitations have not been examined empirically at length (Fenwick, 2012). This leaves the ideal of co-production within the sphere of rhetoric and a prescriptive framework, rather than a well-established practical model. Beside the premise that both sides of the partnership must share enabling and participatory values, perceptions, and attitudes (Williams, Seong-Cheol Kang & Johnson, 2016), the issue of responsibility and accountability for delivery of services where outcomes of this delivery might be unexpected or undesirable continues to be an obstacle to the reciprocity and the ideal of equal partnerships underpinning co-production (Needham, 2007; Fenwick, 2012; Fairlie, 2015; Bell & Pahl, 2018). Fenwick (2012) depicts the multi-layered complexities of co-production in practice in her research on policing rural Scotland and reveals that the nuanced characteristic of long-term relationships with citizens in particular settings often requires professional 'knowing-in-practice' expertise and resourcefulness to enable these partnerships to function. 'Knowing-in-practice' expertise and resourcefulness in this context refer to the 'insider' knowledge that the practitioners would gain through building relationships with the end-users and then utilise this information to support their partnerships. How equal and reciprocal this functioning might be is also continually determined by the dilemma professionals face between the demands to care and demands to contain, control and manage scarce resources (Needham, 2007; Fenwick, 2012).

Another challenge in co-productive practice could be practitioners' resistance to work co-productively as evident in Pestoff's (2006) research exploring children's welfare services in eight European countries. Pestoff (2006) reports that



practitioners felt their expertise and experience was undermined by having to share the domain of provision design and delivery with unqualified parents. This threat could be translated to practitioners supporting C/YP with SEND, as they may feel that their professional qualifications and their experience of a range of C/YP with SEND is superior to parental knowledge and expertise of their children. The uncertainties of the roles in this scenario can result in professionals' reluctance to adopt approaches which they may feel would distort their professional status. It is also unclear whether the end-users always wish to be actively involved in co-producing services (Fairlie, 2015), and it is reported that some citizens might wish to undertake tasks that require or develop their self-efficacy, whereas others might refuse it (Bovaird, Flemig, Loeffler & Osborne, 2019).

Furthermore, in the field of SEND, little is known about what practical implications co-production can offer to partnerships. In 2011 DfE (2013) set a SEND Pathfinder Programme with parents forming one of the stakeholder groups being consulted about the planned changes in legislation. Co-production was considered as enabling parent participation when consultations between parents and the government took place suggests that parents would welcome its application (Britton, Taylor & MacDonald, 2013). However, this proposal was not included in the guidance of the Code. Whether or not the practicalities of co-production within the partnerships were deemed too complex to define remains unknown. As Jenhaug and Askheim (2018) argue, co-production needs to be defined and framed within practice to transform the shift in partnerships and empower service-users. Furthermore, the rationale for its use should not only focus on the 'how' but on the 'why' and 'what' aspects of the concept in practice (Voorberg, Bekkers & Tummers, 2015). Therefore, to gather a more holistic reflection on what co-production is intended to achieve and to evaluate the extent to which it does so, more research into the practice of co-productive partnerships is required. To further explore the 'what' and the 'why' of co-production within partnerships with parents, I gathered data in this study on whether the co-productive principles are empowering parent participation and how parents perceive their usefulness.

## 2.5.2. Co-production and the Code

As this study focuses on the impact of the Code on the partnerships, I now turn to illustrate the connections between the Code's guidance and particular elements of co-production.

EHC services are required to work collaboratively under the latest SEND legislation. Multi-agency collaboration between practitioners also requires all involved to establish effective ways of working with families while developing required working relationships with each other. This complex but essential shift in interactions can be perpetuated by the requirement to adapt the power distribution within the relationships in order to reflect equal validation of professional and non-professional opinions and contributions. Decision-making processes have been historically driven by professional expertise (see Section 2.2.1.), but the premise of the Code calls for parental expertise to be valued and acted upon. Co-production was mentioned in the Code only once under the work between Local Authorities and families in construction of the Local Offer (DfE & DoH, 2015). This opportunity to design the Local Offer in partnership with parents and agencies has achieved varied outcomes due to inadequate training for practitioners (Palikara, Castro, Gaona & Eirinaki, 2019). Although deemed as a positive aspect of the legislation, co-production has been found to be 'only symbolic and [...] used to suggest that parents endorse the local offer' (House of Commons Education Committee, 2019, section 77, p. 25). Therefore, the recommendation in the SEND report (House of Commons Education Committee, 2019, section 78) urges Local Authorities to strengthen their leadership to demonstrate effective use of co-production when the Local Offer is produced.

Although the Code refers to co-production only in relation to the Local Offer, the principles of co-production are invoked in the Code's guidance for effective partnerships with families numerous times. Similarities between the Code's guidance and the dimensions of coproduction identified above are mapped in Table 3.

*Table 2 Corresponding principles of co-production and guidance on partnerships in the Code*

CoP's guidance on partnerships	Dimensions of Co-production
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<p>"Local authorities should do this in a way which ensures that children, young people and parents feel they have participated fully in the process and have a sense of co-ownership. This is often referred to as 'co-production'. Local authorities should take steps to ensure that their arrangements for involving children, young people and parents include a broadly representative group of the children with SEN or disabilities and their parents and young people with SEN or disabilities in their area."</p> <p>SEND Code of Practice (2015), p.61</p>	<p>"Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. "</p> <p>(Boyle &amp; Harris, 2009, p.11)</p>
<p>At a strategic level, partners must engage children and young people with SEN and disabilities and children's parents in commissioning decisions, to give useful insights into how to improve services and outcomes. Local authorities, CCGs and NHS England must develop effective ways of harnessing the views of their local communities so that commissioning decisions on services for those with SEN and disabilities are shaped by users' experiences, ambitions, and expectations. (p. 42)</p> <p>Families should have confidence that those overseeing the assessment process will be impartial and act in their best interests. (p. 150)</p>	<p>The model permits the individualisation of service delivery, which is based upon effective information exchange and shared decision making that respond to complex and unique service users' needs (Realpe &amp; Wallace, 2010).</p>
<p>Reviews must be undertaken in partnership with the child and their parent or the young person, and must take account of their views, wishes and feelings, including their right to request a Personal Budget (p.194)</p> <p>Local authorities, early years providers and schools should enable parents to share their knowledge about their child and give them confidence that their views and contributions are valued and will be acted upon. At times, parents, teachers and others may have differing expectations of how a child's needs are best met. Sometimes these discussions can be challenging, but it is in the child's best interests for a positive dialogue between parents, teachers, and others to be maintained, to work through points of difference and establish what action is to be taken. (p.21)</p>	<p>It can enable building trust and communication between participants, allowing bureaucrats and citizens to explain their perspective and listen to others, as well as revealing citizens' needs, identifying the main causes of delivery problems, and negotiating effective means to resolve them (Needham, 2007).</p>
<p>Staff working in Information, Advice and Support Services should be trained to support, and work in partnership with parents. (p.32)</p>	<p>Staff on the frontlines of public services are recognised as having a distinctive voice and expertise as a result of regular interaction with service users and, often, a user's experience of the service is shaped almost entirely by their interaction with the frontline provider (Needham,</p>

These interconnections suggest that co-production could, in fact, become the desired model to transform parent-practitioner partnerships, beyond the remits of collaborations aimed at the Local Offer. Before providing a detailed rationale for that argument, a succinct history of how the concept of co-production interconnects with other pertinent concepts linked to partnerships is outlined in the subsection that follows.

### 2.5.3. The role of co-production in partnerships with parents

This sub-section outlines the rationale for the use of co-production as a framework for parent-practitioner partnerships.

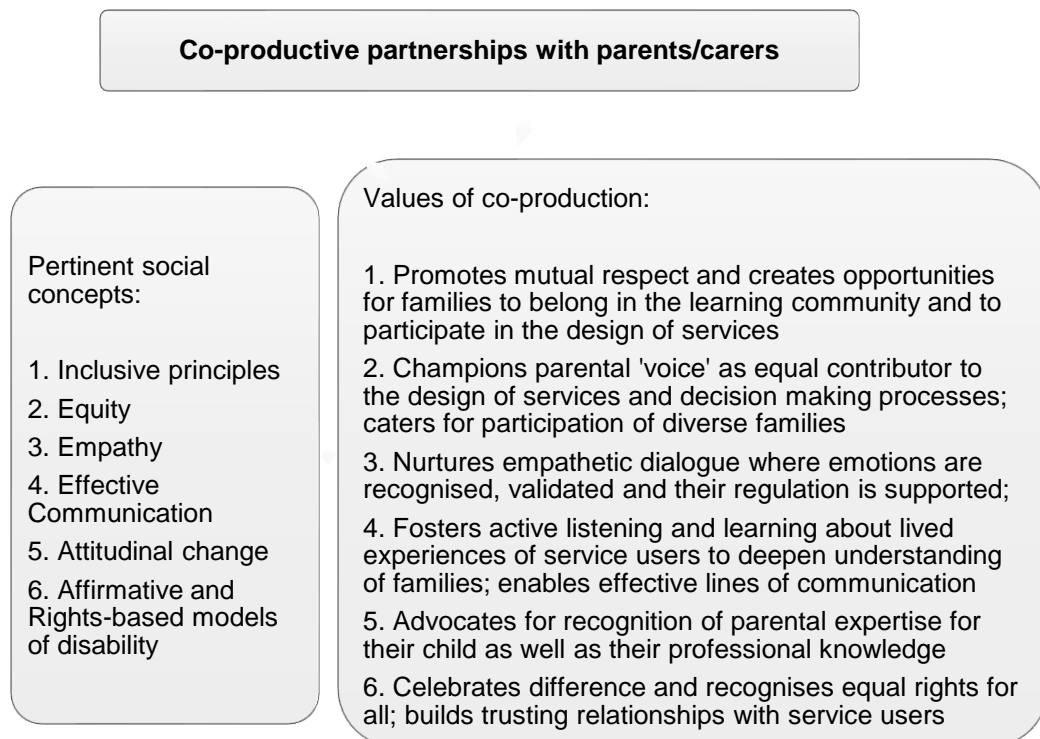
Firstly, I build on the previously discussed models of partnerships (see Section 2.4.). The corresponding aspects between the negotiation model and the co-productive principles are discussed first (see Table 3) as this model, through a shared perspective and process of mediation, supports the resolution of differences and has been often identified as the most empowering for parents (Carpenter, 1997; Case, 2000, Adeb, 2014).

*Table 3 Connections between the negotiation model of partnerships and principles of co-production*

Negotiation Model of partnerships	Principles of co-production
<ul style="list-style-type: none"> <li>Combination of empowerment and consumer model.</li> <li>Negotiations are a crucial aspect of partnership working.</li> <li>Differences in opinions are resolved effectively.</li> <li>Mutually agreed goals form the basis for joint decision-making.</li> </ul>	<ul style="list-style-type: none"> <li>Enables consumers/citizens to make decisions and design/deliver services they use.</li> <li>Values expertise of producers and consumers equally and enables negotiations to ensure services reflect consumer's needs.</li> <li>Promotes values of respect, empathy and 'two-way dialogue' where both sides can express their concerns, standpoints, and reasoning.</li> <li>Both sides of the partnership are engaged in decision-making processes and decisions are fully informed by the negotiations between them.</li> </ul>

Furthermore, co-production aligns with the principles of partnerships discussed by Turnbull et al. (2011); namely co-production advocates the acknowledgement and appreciation of the diverse backgrounds of families, parental expertise, and advocacy, and through participatory and reciprocal collaborations, increases trust.

As presented in Sections 3 and 4, these partnerships are complex and affected by a range of factors, such as the individual family's needs, the history of partnerships with services, and the individual practitioners' attitudes and values that often drive those partnerships. Perhaps due to this complexity, several social concepts are repeatedly present in the research on partnership and this section illustrates the interrelation between these concepts and the underlying values of co-production (see Figure 2). In this sub-section, I examine these concepts in detail.



*Figure 2 Co-productive partnerships with parents and social concepts*

## **Inclusive principles**

Inclusion as an internationally recognised concept emerged with the UNESCO's Salamanca Statement in 1994, where a range of dimensions promoting inclusive practice, in educational settings as well as in a wider society, was encouraged (UNESCO, 1994). Inclusion has been repeatedly defined as an immensely complex subject (Mittler, 2001; Trussler & Robinson, 2015; Hodkinson, 2019) and one that has a power to influence various strands of societal progression. There are also different discourses of inclusion accompanying various models of disability, which will be explored in detail in Section 2.6.

Main tenets of inclusion aim at ensuring that all children have opportunities for choice and self-determination (Mittler, 2001); ensuring accessibility and enabling widening participation for all (Warnock, Norwich & Terzi, 2010); and assuring equality, respect, participation in decision-making, rights, democracy, social justice and collective belonging for marginalised groups (Glazzard, Stokoe, Hughes, Netherwood, & Neve, 2015). Importantly, inclusion is in a constant 'state of becoming' and therefore practitioners are required to work towards their own understanding of the concept through the development of professional knowledge and practice (Nutbrown, Clough & Atherton, 2013). However, in the context of SEN, practitioners' reflection is too often drawn to the deficit discourses that accentuate difference, rather than the premises of inclusive practice (Robinson, 2017).

Inclusion is one of the fundamentals in partnerships with parents, as the ongoing debate of segregation and inclusion leads to divided views on what is appropriate and in the best interest of a C/YP identified with SEND (Mittler, 2000; Allan, 2003; Booth & Ainscow, 2002; Graham & Slee, 2008; Walton, 2015; Robinson, 2018). This is often the choice parents are faced with when deciding on a special or mainstream setting for their child – a choice which may be in conflict with the judgements offered by practitioners. An example of when inclusive principles have been heavily distorted within the realm of SEND is the amendment issued by the government in relation to timescales and fulfilment of Education, Health and Care Plans during, what at the time of writing is, a worldwide Covid-19 pandemic (DfE & DoH, 2020). This amendment decreed that delays in producing EHCPs became acceptable, which undermined the

processes in ensuring adequate and timely provision was secured for C/YP with SEND. This could be argued to have undermined these C/YP's rights to equality of opportunity (COVID-19 DRM, 2020). Although in action from 1<sup>st</sup> of May 2020, and withdrawn on the 31<sup>st</sup> of August, this guidance on EHCPs allowed for further delays in ensuring C/YP with SEND had access to appropriate provision. Moreover, the school closures and limited access to relevant services during the pandemic were reported to have left C/YP with SEND 'forgotten, left-behind and overlooked' (APPG for SEND, 2021). With school closures, families have lost access to vital support and respite which continues to affect their lives, as attending schools for C/YP with SEND is not only about education but also about participation and invaluable therapy (APPG for SEND, 2021).

Whether it comes to a choice of education or other services supporting the C/YP, it is the inclusive practice that interconnects with co-production which can enhance the partnerships. The plethora of facets of inclusion is undeniable and beyond the scope of this study; however, its resonance with co-productive partnerships is addressed here to demonstrate their close interrelation. All the above-mentioned inclusive principles align with the ethos of co-production (see Figure 2). However, the main premise of this alignment can be seen in the societal aspect of inclusion whereby families are enabled to belong to a community where, through respectful co-design of provision, all members hold a sense of a meaningful participation (Britton, Taylor & MacDonald, 2013). Only through participation and development of the sense of belonging can a C/YP be considered as included, whether that refers to the education system or society in general (Booth & Ainscow, 2002). As parents of C/YP with SEND often play the role of their advocates, maintaining both benchmarks for inclusion – belonging and participating – requires effective partnerships with families and their application extended to family members (Trussler & Robinson, 2015). This is particularly important in partnerships with public services, which are already established as professional domains and parents usually enter them as outsiders. The following table illustrates how particular aspects of inclusion link with principles of co-production, indicating their interrelations.

*Table 4 Corresponding principles of inclusion and co-production*

Inclusion	Co-production
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Choice and self-determination	The model permits the individualisation of service delivery which is based upon effective information exchange and shared decision making that respond to complex and unique service users' needs (Realpe & Wallace, 2010).
Accessibility and widening participation	Making each experience of co-production unique to the individual family's circumstances (Alford, 2014). All families are welcome to participate in co-creation of services regardless of class, educational status, background, abilities.
Equality Respect Participation in decision-making Rights, democracy, social justice Collective belonging for marginalised groups	Equality of relationship is dependent upon the contribution of each party being attributed equivalent value (Cahn, 2000). Co-production can enable building trust and communication between participants, allowing bureaucrats and citizens to explain their perspective and listen to others, as well as revealing citizens' needs, identifying the main causes of delivery problems and negotiating effective means to resolve them (Needham, 2007). Co-production is also defined as operating 'when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered' (DoH, 2014, p. 17).

As many C/YP with SEND rely on their parents' advocacy, it is essential that practitioners understand and apply these inclusive principles when working with families by adapting current and established practices (McNab, 2010). For some practices this might require a change in approaches and long-standing traditions of working with end-users. Glazzard, et al. (2015) assert that changes in public services in any form are challenging, whether on the systemic, political, organisational levels or on the individual level. However, as Mittler (2001) affirms, the greatest obstacles to change can be found within individuals' attitudes and fears. Similarly, Boshoff, Gibbs, Phillips, Wiles and Porter (2016) emphasise the impact of individual practitioners on the strength and effectiveness of partnerships with families. Equally, to work within inclusive principles, practitioners are required to have a broad understanding of them (Nutbrown, et al., 2013; Graham, et al., 2020) and their ability to support development of effective relationships where personal attitudes need to be challenged and reviewed. The nuanced language used surrounding inclusion, particularly in the educational domain (Allan, 2003; Walton, 2015) can heighten



difficulties in collaborations. For example, this can be evident when children are categorised through the behaviours associated with their conditions rather than individual characteristics. Furthermore, assigning a status of vulnerability to individuals often prevents them from accessing opportunities that they would have if they had not been categorised as having SEND. Continuous debate of the meanings of inclusion translates into practice where professional and families enter collaborations with divergent views of what inclusion means to them and therefore, are exposed to potentially conflicting standpoints from the start of the partnership. Co-production challenges conventional ways of working between public services and citizens, with the latter being given more authority in decision-making processes (see Section 2.5.1.). Therefore, by working co-productively, both sides are enabled to make meaning of what they understand and value about inclusion in the context of partnerships and determine how inclusion can work in practice within their local context.

It is essential to acknowledge that a partnership cannot be sustained as equal only by one side (Broomhead, 2018), and the Salamanca Statement affirmed that ‘parents and professionals need each other, and neither can make significant and sustainable progress alone’ (UNESCO, 1994, p.46). This could suggest that the recognition for parental input in decision-making processes has been a sign of an inclusive approach for scholars and leaders worldwide for a long while. The next subsection will build on the question of equitable partnerships in more detail.

## **Equity**

The concept of equity involves adaptations required to enable individuals to have an equal chance of access to participation (Graham et al., 2020). Whether that refers to education, recreation or any other activities leading to a fulfilling life for that individual, in the case of parental advocacy, it encompasses efforts to recognise and accept individual circumstances and needs of families. To enable equality of opportunity for individuals who require different or additional support, reasonable adjustments need to be provided (Graham et al., 2020; DfE & DoH, 2015), resulting in equitable designs of services for all. In practice,

equitable provision might at times seem to be unequal treatment, as individuals categorised as having SEND will receive different or additional support (Graham et al., 2020). This perception may often cause a dilemma of fairness and conflict between what families might perceive as necessary and reasonable, and what practitioners may perceive as appropriate within the remits of their organisational capacities (Hodkinson, 2019). This problematic aspect emphasises, once again, how important it is for practitioners to understand the parental view and to validate their contribution in decision-making processes. To strengthen this understanding, practitioners could also recognise the different stages of parental journey and be mindful that individual families require support that is specific to their circumstances (Seligman & Darling, 2007). The importance of this realisation and the variations of perceptions between families and practitioners are explored at length in the section that follows.

### **Empathy, effective communication and attitudinal change**

UNESCO's affirmation promotes reciprocal relationships between parents and professionals (UNESCO, 1994). These are also equally valued within the co-productive approach to partnerships. However, the nature of this reciprocity remains difficult to define as the groups of parents and the practitioners working with their C/YP are heterogenous (Gascoyne, 1995; McNab, 2010, Seligman & Darling, 2007). It is therefore crucial to acknowledge the diversity of families that practitioners in EHC provisions work with, and how each individual circumstance can shape parental attitudes and expectations. Accepting that families are at different points of their journey, whether that relates to their C/YP's SEND or a particular milestone in their family life in general, and acknowledging the fluidity of these journeys, would enable co-production of an inclusive system where the diverse needs of C/YP and their families become a natural phase in partnerships (Mann et al., 2020). However, as families of C/YP identified as having SEND form a minority in the society (Seligman & Darling, 2007), it is unlikely that all practitioners working in the field would have had some affiliation with SEND which would deepen their understanding of these

families' lived experiences (McNab, 2010). To better understand families' standpoints, opportunities that would enable to get to know end-users and to understand their needs and lived experiences should be created. Through collaboration, where value is placed on professional and non-professional expertise, empathetic practitioners would contribute to a diminished divide between 'us and them'. This, more equal, approach could increase citizens' trust in the ethos of public services. Furthermore, Hirano and Rowe (2016) and Goldman and Burke (2017) argue that development of empathy could also ignite more trust in public services.

The 21<sup>st</sup> century has brought a renewed interest in exploring the concept and practical implications of empathy (Howe, 2013). This could be related to the recognition that in order to understand people and their situations, one needs to find a meaning within those situations, rather than only explaining how they occur (Howe, 2013). Although difficult to define (Swan & Riley, 2015), some researchers have proclaimed empathy to be 'the spark of human concern for others, the glue that makes social life possible' (Hoffman, 2001, p. 3), 'an important human characteristic to identify another person's emotions and thoughts, and respond to these with an appropriate emotion: a way to make sense of, and predict another person's behaviour (Baron-Cohen, 2003 as cited in Swan & Riley, 2015), 'a mechanism underlying social and emotional intelligence and permits us to know the minds of others and ourselves' (Sigel, 2009, as cited in Howe, 2013, p.15). Buber (2006, as cited in Veck, 2013) builds on the foundations of empathy to define how it can lead to inclusion. While empathy enables deep understanding of another human being on the cognitive, affective, and somatic levels (Haugh & Merry, 2001), Buber asserts that inclusion moves towards 'a dialogical relation' away from separation and domination as 'one person expands their comprehension of reality so that it includes the other's experience of reality' (Buber, 2006, p.115 as cited in Veck, 2013, p. 47). Furthermore, Shady and Larson (2010) point out that Buber accentuated the importance of this 'dialogical relation' in understanding each other without the need to necessarily agree with each other. Therefore, this 'dialogical relation' can be connected with the values of co-production. Firstly, to enable the negotiations within potentially differing standpoints. Secondly, enabling a culture where practitioners actively listen to stories shared by

families to expand their own understandings of the needs and realities of these families. And thirdly, by inviting these stories to become a driver in shaping and designing services where practitioners and parents would co-produce a more effective and purposeful system of support and effective communication.

#### **2.5.4. Summary**

Parent advocacy has been a growing phenomenon for over two decades now (Bacon & Causton-Theoharis, 2013; Boshoff et al., 2016). As examined in Section 2.1 the legislation in England has recognised the ‘voice’ of parents and the need to include this ‘voice’ in the design of services and decision-making processes surrounding provision for C/YP with SEND. Although the rhetoric of effective partnerships has received substantial attention in the field, partnerships continue to be problematic (see Section 2.2. and 2.3.). The dominating discourse of austerity and its effects on public services often culminates in the blame for many services’ failures being directed at systemic structures that prevent practitioners from forming effective partnerships with families (Norwich & Eaton, 2015; Hodkinson, 2019). And it is evident that bureaucratic tasks involved in arranging services for C/YP with SEND are complicated, disjointed and unclearly signposted, perpetuating the ineffectiveness of the systems of communication with and between services (Adeb, 2014).

Nonetheless, the attitudinal barriers witnessed by parents in their interactions with EHC services have been identified as even more disabling than systemic drawbacks (Sales & Vincent, 2018). This conclusion is often linked with a bigger dilemma of inclusive practice, whether in primary schools (Glazzard et al., 2015; Goepel, Childerhouse & Sharpe, 2015), secondary schools (Briggs, 2016), special schools (Ferrel, 2009) or within society in general (Booth & Ainscow, 2002; Equality Act, 2010; Trussler & Robinson, 2015; Hodkinson, 2019), all of which rely on individual professionals or institutions to enable the partnerships. Furthermore, for families who are heavily involved in multi-agency meetings and negotiating their views and opinions with professionals, who often know very little about their C/YP, the attitudinal barriers from practitioners may prevent

access to support for families at the very onset of any collaborative work (Cochrane & Soni, 2020). Misconceptions can be formed as a result of attitudinal barriers and, equally, the attitude towards certain concepts may cause misconceptions. Misinformed professionals are more likely to contribute less effectively to partnership working, allowing for the misconstruction of provisions that do not ultimately reflect the needs and wishes of C/YP appropriately. Transformation of attitudes, however, is a lengthy process and requires more input than just changes in legislation. Although the systemic constraints that practitioners face when working with families contribute to the problematic partnerships (Hellawell, 2017; Broomhead, 2018), the attitudinal factors are affected by individuals and can be addressed almost immediately, while systemic factors require a more labour-intensive intervention into governing structures. Furthermore, the lack of a clear definition and a framework that the partnerships could be formed on have both contributed to the ambiguities in expectations for practitioners and families (Hellawell, 2017; Kendall, 2017; Hellawell, 2018; Broomhead, 2018).

Practitioners' attitudes are a manifestation of ontology and they illustrate how those delivering and receiving SEND services are operating within a variety of models of disability that influence their understanding of disability and their response to it. Therefore, the next sub-section focuses on the models of disability and their influence on partnership working.

## **2.6. Models of disability**

This sub-section presents an overview of models of disability and a discussion on how these models can guide and affect practitioners' approaches to working in partnerships with families.

The consideration of models of disability has a dual purpose within the discourse of partnerships; one is to delineate how practitioners perceive C/YP categorised as having SEND and their families within the frame of their conditions, and the other is to illustrate the connections between the models and current practices predominating in EHC services.

It has been argued that the realisation, particularly for practitioners, of their own association with either of the models of disability is vital for analyses of their own assumptions and attitudes that drive the ethos of their partnerships with families (Graham et al., 2020). Despite this assertion, the previous Codes of Practice do not engage in the discussion of this influence on partnership working (Lehane, 2017).

The ability to recognise and understand the difference in perceptions between people with and without disability can further aid non-disabled practitioners, who make decisions for persons with disabilities (McKenzie & Scully, 2007). This realisation could enable practitioners to accept that their professional expertise needs to be complemented by the lived experiences of C/YP with SEND and their families.

### **2.6.1. Medical vs Social Model of Disability**

The medical model exclusively occupied policy, legislation, and practice until the 1970s (Mittler, 2000; Mann et al., 2020; Seligman & Darling, 2007; Trussler & Robinson, 2015; Hodkinson, 2019; Graham et al., 2020). Then Oliver (1996), alongside other disabled people and their organisations, proposed an alternative direction in disability studies – the social model of disability. The main difference between these two models refers to how disability is understood and responded to within society. Within the medical model the focus is given to the physical nature of a person with disability and how the condition this person ‘suffers’ from needs to be, and can be, moderated, cured or minimised in order for the individual to ‘fit’ more effectively into the mainstream systems embedded in the EHC services and society as a whole (Shakespeare, 2004; Glazzard, et.al., 2015). The social model, on the other hand, redefines disability as a social rather than a personal issue. As a result, it maintains a focus on how people only become disabled through the creation of exclusionary environments and practices. Within the social model, the emphasis is on the role of society, including services, in assessing and diminishing societal and structural barriers that prevent a disabled person from participating (Goodley, Hughes & Davis, 2012; Trussler & Robison, 2015). Levitt (2017) asserts that the social model has

had an impact on an immeasurable amount of disabled people, because the societal barriers previously overlooked were addressed; for example, access to public transport or public buildings. Likewise, Oliver (2013) argues that this new disability discourse and the development of social consciousness have been reflected in media, transport, some accessibility in buildings and within the legislation that made it unlawful to discriminate against disabled people (Equality Act, 2010). However, Shakespeare (2013; 2017) argues that the social model of disability emphasises the structural and societal aspects too strongly, which can result in overlooking the individual, psychological and personal dimensions of living with an impairment. Similarly, Levitt (2017) affirms that the wording within the social model of disability could be altered to reflect his stance that disability can be shaped by many factors, including society, but not exclusively by society. This amalgamation of factors affecting society is not a new concept and was proposed by Engel (1977) when he considered the effects the impairment and the environmental barriers have on an individual in the biopsychosocial model. Focusing on biological (genetic), psychological (personality) and social (cultural) factors, this model was predominantly used by the World Health Organisation. However, the model's imbalanced and focal attention to medical considerations led to its rejection within inclusive practices (Graham, et al., 2020).

More recently, due to the impact of austerity on services, the importance of impairments and divergent needs of people with disabilities has caused the re-emergence of medical model practices (Oliver, 2013). Identified as a politically driven change (Oliver, 2013), it comes as a result of budgetary cuts and re-assessment of the criticality of disabled persons' impairments; the more critical the disability, the more likely the support is granted. While parents and practitioners navigate through the current systems, it might mean more emphasis is given to the needs of an individual to prove the 'deficits' in order to gain access to support. These instances can be perceived as drawing on the medical model of disability and this tendency corresponds with the dilemma parents often face when asking for adequate support for their children. For example, parental requests are being denied due to their children's 'insufficient' level of impairment or due to the local services' inability to offer appropriate support within the current financial and/or organisational constraints (Lehane,

2017). As a result, I used these examples as a point of interest when analysing my data.

The dilemma between operationalising either of the models is pertinent in practice for many practitioners (Trussler & Robinson, 2015). It is imperative to acknowledge that instances of having to adopt the medical model within practice is not uncommon; for example, when a practitioner is required to secure resources or access to services by identifying a C/YP's impairment and its severity (Trussler & Robinson, 2015), or within choices between 'commonality (inclusiveness, equality) and the relevance (differentiation)' in placements of C/YP with severe SEND in ordinary classrooms, known as the 'dilemma of difference' (Norwich, 2008, p. 302). Nonetheless, practitioners who have an awareness of the difference between these models can make informed choices on how to recognise the impairment and its remits while preventing disabling and or discriminatory attitudes and approaches (Mittler, 2000; Trussler & Robinson, 2015). This awareness could also support partnerships with parents as practitioners would be able to understand parental positionality within the models and therefore become more empathetic to parental views. Furthermore, the knowledge of different models of disability would enable practitioners to understand the differences between their own and parental standpoints. This understanding would be beneficial for addressing differences in approaches and perceptions while working collaboratively on finding 'the middle' ground in partnership working (Hodge & Runswick-Cole, 2018).

### **2.6.2. Affirmation Model**

To oppose the previously assumed, 'tragic' and 'pathetic' existence of such individuals, lived experience of families with C/YP identified as having SEND were further explored in, proposed by Swain and French (2000), an affirmation model of disability. Situated within the principles of the social model, the affirmative model nurtured the ideology of difference and rejected the stereotyped concepts of perceived 'normalcy' and 'happiness' valued by non-disabled people, proposing that disabled people should have control over their lives and be able to emulate their individual strengths, emotions and pride in



who they are (Hodkinson, 2019). The values underpinning this model are closely linked to the fundamental principle of inclusive practice where every person is treated as having an equal worth (Booth & Ainscow, 2002). Within this model, by fostering the assumptions of difference being a continuum to the divergence of humanity (Shakespeare, 2017), practitioners working with families would create a culture of inclusion that would challenge the stereotypes of segregation of people who are different. Therefore, promoting the affirmation model in partnerships with parents would recognise and accept parental views and consider their unique circumstances as a part of their individuality, and not as a detrimental aspect which requires a professional's intervention.

### **2.6.3. Rights-based model**

Although the affirmative model challenged the assumptions and preconceptions of what 'being normal' and leading a fulfilling life' meant (Swain & French, 2000), this model was criticised for its liberal nature as it prevented inclusion of disabled people in the governing structures (Vanhala, 2010, as cited in Hodkinson, 2019). To address this issue, the rights-based model challenges the predominance of non-disabled people who occupy the positions of power in all arenas of life: societal, educational, economic or political (Allan, 2003). Furthermore, this model argues against educational segregation (Johnstone, 2001); ensures that societal barriers to inclusion are removed through the enablement of disabled people to participate in mainstream politics (Shakespeare, 2006); and works towards elimination of fear, prejudice and ignorance towards disability (Mittler, 2008).

An approach that can be utilised within this model is the capability approach (Norwich, 2014 a), which calls for the rights for disabled people to either choose or reject any model according to their individual stance. By adopting this approach, practitioners could gain invaluable knowledge of the views of the C/YP and/or their parents, which in return could prevent any preconceptions or misunderstanding from forming in the process of the partnership working.

The principles of the rights-based model link intrinsically to the newly acquired rights by parents through the 2014 Children and Families' Act, the rights of

choice and the rights of personal budgets and influence of provision for their C/YP with SEND. The increasing number of tribunal cases related to the implementation or inadequacy of the EHC plans have escalated since the legislation was implemented (Marsh & Howatson, 2020) and this could suggest that public services have not been prepared to adapt their structures, attitudes and practices to reflect the changes required to build partnerships with families in the light of these transformations. Reflecting the continually observed resistance to implementation of inclusive principles by practitioners who claim they are limited to do so through systemic barriers and a plethora of priorities to fulfil (Ainscow, Chapman & Hadfield, 2019), the equal rights to education of all children remain peripheral, inducing further dispute between services and parents. Unless practitioners recognise the need for attitudinal and societal change and policy makers reflect that need in systems, the everyday practice, policy and cultural ethos will continually inflict difficulties in partnerships between services and families.

#### **2.6.4. Reflection on models of disability evident in my teaching practice**

As mentioned briefly in Section 1.2.1, within my own professional practice using labels was focussed on the deficits – ‘problems’ that needed to be addressed, fixed or attended to (Shakespeare, 2017). Ultimately, this focus on labels could be seen as a representation of a medical model of disability where the attention is drawn to the needs of the individual with the intention of ‘fixing’ the manifestations of the needs so that the individual can ‘better fit’ into the societal structures, in this case the educational context. However, in fulfilling my duties as practitioner who tailored the provision and the learning environment to meet the needs of the pupils through diverse curricula, resources and opportunities, my approaches could also be said to be situated within the social model of disability (Trussler & Robinson, 2015).

As mentioned in Section 1.2.2. it was not until the ‘structured conversations’ (Humphrey & Squires, 2011), when I incorporated regular discussions with parents and carers that revolved around the C/YP in a more holistic fashion,

that the C/YP's strengths, likes and aspirations were at the centre of the discussions, as much as the needs that required addressing. That is also when my understanding of the role that parents played in these exchanges changed significantly. It is also perhaps the time when my practice began to be more aligned with the rights-based model of disability and I considered the 'voice' of the individuals and their advocates while also prompting recognition for equality of opportunity (Graham et al., 2020; DfE & DoH, 2015). Furthermore, while ensuring that the individuals were placed at the centre of my practice, I utilised the capability approach to focus on the freedom, agency and well-being of these individuals (Warnock, Norwich & Terzi, 2010).

Consequently, I began to engage in self-reflection on the knowledge, approaches and attitudes that I had held and displayed in my professional context. The values I held about theory and knowledge that I gained during my academic studies became not the sole knowledge that informed my practice; I commenced a quest to incorporate the expertise of parents into my practice. Unknowingly then, this shift in approach not only transformed my practice, but influenced my openness to learning from and with families which decreased my 'professional dominance' (Seligman & Darling, 2007) in the decision-making processes we engaged in.

This change in perception and practice resulted in my broader understanding of the tensions the label of SEN carries within education, but also within a wider society context (Glazzard et al., 2015). I grew to learn that it is important to acknowledge the person behind the label and that can be achieved by using 'person first language' or 'identity-first language' (Botha, Hanlon & Williams, 2021), by celebrating the differences and wider context the individual operates in (Warnock, Norwich & Terzi, 2010), and by embedding a culture of fostering inclusion of all persons to participate, achieve and feel a sense of belonging in the space we created for and with them (Ainscow & Booth, 2002; Trussler & Robinson, 2015). Although the importance of these nuanced differences has only become part of my ongoing reflection when I began my doctoral studies, I perceive them as an enriching part of my professional development.

### **2.6.5. Summary**

It is essential for practitioners in the field of SEND to be familiar with the essence of models of disability and to reflect on the impact these models have on their approaches towards inclusive practice (Graham, et al., 2020). The fundamental differences in these models would manifest themselves in attitudes and adopted ways of working with families (Cochrane & Soni, 2020); therefore, practitioners who are not aware of their positionality towards the models of disability could unintentionally jeopardise the effectiveness of partnerships with families. This could also reflect on those models of disability that implicitly inform parents' perspective. Although the official legislation does not allude to models of disability, they are considered a critical dimension of discourses on inclusive practice by scholars worldwide (Seligman & Darling, 2007; Trussler & Robinson, 2015; Glazzard et al., 2015; Graham, et al., 2020).

### **2.7. Conclusions**

The evidence presented in this chapter delineates how complex parent-practitioner partnerships within the field of SEND and beyond can be. However, the partnership remains a crucial part of working towards inclusive education and society as parents are recognised as invaluable stakeholders who can support and own the process of change alongside their C/YP (UNESCO, 2020). The ultimate goal of The Education 2030 Framework for Action (UNESCO, 2015, p. 7) within the context of education is to 'ensure inclusive and equitable education and promote lifelong learning opportunities for all'. The role of parents within this aspiration is essential as their wealth of knowledge and skills can multiply the efforts of practitioners and provide extension to available resources (UNESCO, 2020). Therefore, as we look into future collaborations, parental equitable input holds an immense value in partnership working.

Through the changes in legislation, the emphasis for partnerships has been extended from mainly education-focussed to involving health and care relationships (DfE & DoH, 2015). Deeply rooted in embedded cultural,

legislative, systemic, and attitudinal conventions, these partnerships remain challenging and frustrating (see Sections 2.2. and 2.3.). There are some examples of enabling practice (Bajwa-Patel & Devecchi, 2014; Adams et al., 2017; Curran, Mortimore & Riddell, 2017; Holland and Pell, 2017), but the majority of parental accounts reveal that they feel at best an inferior partner and at worst a receptacle for practitioner wisdom (House of Commons Education Committee, 2019). And although bringing the focus to the parental perspective in isolation has attracted some criticism (Broomhead, 2018), it is crucial to acknowledge that the prolonged imbalance in decision-making processes between professionals and families can only be diminished if attitudes and traditional ways of working together are challenged and transformed. As this review of the research context illustrates, there continues to be a significant and disabling gap between how practitioners construct and practice the notion of 'partnership' and what it means to parents and how they expect to receive it. My study sought therefore to provide data about parental experience so that it might aid in bridging this epistemic divide and so enable practitioners to develop more appropriate ways of working.

The focus on parental views does not imply that practitioners' expertise and views are not valid – they have been and continue to be. However, to allow for parental expertise on their children and for parental standpoints to be at the forefront of the decision-making processes, practitioners' judgements need to be inclusive of these aspects at a non-superficial level. For example, gathering parental views via questionnaires designed by professionals and deciding a course of action without the input of parental inference does not represent inclusion of parental views meaningfully, as practitioners ask these questions based on their perceptions and make decisions that are deemed appropriate through their eyes. To achieve more equal partnership, views from both sides of the partnership need to be valid, respected and weighed equally in power, access, and contribution to the design of the desired services. Co-production offers a strong pillar for the values described in Section 2.5, and its principles have been utilised effectively by charities and other organisations working in the field of SEND (e.g., [Involve.org](http://Involve.org), [pipstockport.org](http://pipstockport.org), [councilfordisabledchildren.org](http://councilfordisabledchildren.org), or [coalitionforcollaborativecare.org](http://coalitionforcollaborativecare.org)). However, co-productive partnerships require a significant shift in attitudes, mindsets, and

traditions in working together by developing empathy in practitioners and policy makers who, currently, affect the nature of these relationships more than parents. With heightened empathy, which can flourish through an effective and wide sharing of families' lived experiences (Broomhead, 2013), practitioners would be enabled to adopt a more inclusive and versatile approach to working with families; approaches that would celebrate difference and value each contributor to the partnership equally (Cahn, 2000). This, in turn, might level the power-field that currently divides the partnership into 'them' and 'us' (Murray, 2000; Keen, 2007; Adeb, 2014; Hodge & Runswick-Cole, 2018).

In addressing these concerns, this study aims at gathering and illustrating a broad range of lived experiences of parents and examines the connections between the concept of co-production, parental experiences of current practices and the desired improvements families would like to witness in future partnerships. These connections, illustrated in the chapters that follow, depict whether and how the latest the Code, may be shaping the partnerships with parents and whether parents perceive the values of co-production as a more effective model to the ongoing difficulties in partnerships with practitioners working with their C/YP.

In the next chapter, I outline the rationale for, and the processes involved in, the chosen methodological framework.

### **3. Chapter 3: Methodology**

This chapter provides a rationale for the mixed methods approach that was used in this study. The chapter begins with a presentation of the rationale and an evaluation of the contribution of the mixed methods approach. It is followed by a critique of the underpinning philosophical framework of pragmatism. This was employed to enable the mixing of methods and to best address the purpose and the objectives of this study. I conclude this chapter with a brief overview of the research design and the analytical frameworks for the quantitative and qualitative data that I collected.

#### **3.1. Rationale**

Throughout the study, care and consideration for the participants and their lives were paramount. Parents of C/YP with SEND are involved in a variety of additional meetings and appointments in comparison to parents of mainstream pupils (Adeb, 2014). Involvement in a range of collaborations limits the time and energy that parents of pupils with SEND have available to spend on other tasks and engagements. Consequently, I was aware that potential participants for my study were likely to be less accessible, not due to their unwillingness to participate in research, but due to their limited availability. In light of the changes in legislation and the importance of effective parent-practitioner partnerships, I was inspired to gain the views of parents on their lived experiences.

I chose Mixed Methods Research (MMR), which combines study methods from different paradigms for a range of reasons. Firstly, I was able to gather a variety of data, quantitative and qualitative, which enabled me to consider the magnitude of the phenomenon, as well as to understand it in more depth through detailed stories of individual experience. To enable this data collection, I utilised an explanatory sequential design, which is described in detail in Section 3.3.1. And secondly, using a mixed methods approach opened doors to more versatile options for participation, namely in person or through an online

platform which was accessible at the time/place most convenient to participants. My approach aimed to increase the opportunities for participation, as parents would either be able to share their views in an online survey or, if possible, take part in the interviews, whichever method suited their style of communication and caring responsibilities more practically.

Furthermore, the inclusion of the quantitative data sets could potentially be perceived as more influential to policymakers, as changes in policy are more often driven by larger scale quantitative research (Scotland, 2012). The 'mixture' of methods within this design also meant I was able to elaborate on the initial data collection in more depth, giving the statistical analysis further strength with the analysis of qualitative data.

The essence of this methodological framework and its relation to the context of this study is discussed in the following section.

### **3.2. Theoretical Frameworks**

This section illustrates how I framed my study in the philosophy of pragmatism. I consider here the values and beliefs underpinning this philosophy, how pragmatism has influenced my practice as a practitioner and a researcher in the field of SEND, how it serves as a theoretical framework for mixed methods research, and the implications for my study.

It is argued that establishing a theoretical framework is a crucial step in many research studies, since it provides a guiding structure, keeping the projects within their boundaries, while at the same time allowing discovery of new insights (Evans, Coon and Ume, 2011).

In this section, I identify the principal tenets of pragmatism. This is followed by an explanation of how this theory interconnects with the mixed methods methodology utilised in this study. I also discuss the implications of pragmatism for my research design, and the pertinence of pragmatism in practice in relation to parent-practitioner partnerships. As one of the fathers of pragmatism, William James stated "philosophy is at once the most sublime and the most trivial of human pursuits. It works in the minutest crannies and it opens out the widest



vistas" (James, 1910, p.10); within my study pragmatism underpins the methodological design and purpose of this study as a whole, and informs the foundation of particular steps in this research (e.g., the research questions, the sampling design).

### **3.2.1. Philosophy of pragmatism**

The school of pragmatic thought was established in the early 20th century. It was concerned with the understanding of how our actions inform the acts of social justice of 'tomorrow' beyond the synthesis of doctrines and theories that have shaped the philosophical scene historically (Cherryholmes, 1992).

Constructed and developed by the works of Pierce, James, Mead and Dewey, classical pragmatism aimed to discover the ultimate solutions to human problems (Parvaiz, Mufti & Wahab, 2016) and to engage more directly with the world outside of academia in order to reach those who seek answers to everyday dilemmas in their pursuit of creating a more humane society (Hildebrand, 2019). Within more contemporary teachings of pragmatism, often named neopragmatism, Bernstein (1992) alludes to pragmatists as 'responsible intellectuals', concerned with current injustices, who seek to reach beyond the academy in their quests to establish common language for the educated and non-educated that would enable resolving these injustices. However, pragmatism is often criticised for placing overall emphasis on 'what works', rather than considering the epistemological underpinnings of research (Friedrichs & Kratochwil 2009, as cited in Nowell, 2015). For example, it is argued that the intricate dimensions of philosophy and theory are often omitted in studies utilising Pragmatism, minimising the framework to only find solutions to the 'what works' question (McCready, 2010). And although this might be true in some cases, 'what matters for pragmatists is devising ways of diminishing human suffering and increasing human equality, increasing the ability for all human children to start life with an equal chance of happiness' (Rorty, 1999, p. XXIX). Rejecting the implied simplicity of a 'what works' premise of pragmatism, Rorty (1999) argues that the underlying values within this worldview reach into moral principles and beyond only the practical implications of the research questions. Correspondingly, the Deweyan argument for more empirical,

concrete and critical analysis of one's experience within the societal institutions that are empowered to influence a positive change, places emphasis on social justice, rather than merely on a 'what works' outcome (Hildebrand, 2019).

Drawing on the works of Peirce, James, Dewey, and Mead, who were the precursors of Pragmatism, Goldkuhl (2004) identified five main theses driving the pragmatist paradigm. They are:

1. Action (with consideration of what is taking place, who is conducting the action and why, as well as what the effects of this action are);
2. Actions in their practice context ('a practice is a web of actions that are related and combined in a meaningful way' (Goldkuhl, 2004, p. 5); this premise questions who initiates the action and what the action causes, who governs the valuing of the result and when is the value perceived as positive, as well as what is learnt through the action undertaken);
3. Acknowledgement of an action's permeation on knowledge (the knowledge people hold of the world is formed by what people do, can do or want to do; the intelligence is not used to gain knowledge by accurately mirroring what is existent, but by considering ways of adapting the environment in favourable ways by one's actions);
4. Practical consequences of knowledge (practical difference that gained knowledge has in practice; the consideration of the transformative value of the performed action and its influence to make a positive difference);
5. What works and what does not work? (for particular people in particular context).

With these premises in mind, I examine the influence of the philosophy of pragmatism on my professional practice and on different stages of my research project in the following sub-sections.

### **3.2.1.1. *Pragmatism and my professional practice***

As a researcher I began exploring the philosophy of pragmatism while I was considering my methodological approach and investigating practical

implications for participation of the chosen population. However, since I started discovering the breadth of pragmatism, I drew some close connections between its principles and my teaching practice. For example, I often relied on 'the dialogue through differences' (Striano, 2019, p. 385) when engaging with parents of the C/YP I taught or with other practitioners involved. In this 'dialogue through difference', I engaged in conversations that enabled me to understand the other stakeholders' perspectives, which prompted me to include their views in the planning processes. Moreover, I was able to develop more person-centred approaches where the holistic knowledge of the individual enabled me to shape a clearer understanding of their needs/wants and capabilities. This learning through reflection that informed my actions resembles the Deweyan vision of social justice where inequalities are addressed, the uniqueness of an individual is emphasised, and practice is reconstructed in accordance with a new frame of shared values (Striano, 2019). This connectedness of the underlying moral values of pragmatist philosophy, once again, accentuates how pragmatism deals with more than just practical solutions to address everyday challenges. Applying this philosophy to my study provided a useful moral framework that was utilised in reflections on ethical considerations for this study.

As explored earlier, this study was inspired by the observations and experiences drawn from interactions and relationships formed during my work as a practitioner in special educational needs settings for 13 years. In line with the pragmatist paradigm (Arthur, Warring, Coe & Hedges, 2012), my research aims were heavily influenced by my values, beliefs, my professional practice, and the perceived behaviours of individuals I have encountered in it.

As I observed and shaped my relationships with parents and drew inferences from those encounters, I was inspired to find out from parents how to instigate ways to improve the relationships between parents and practitioners. This process was embedded within the pragmatism worldview, which involves the researcher continually immersing themselves in a chain of interpretations while analysing their own and others' actions (Ansell, 2015; Morgan, 2014).

Pragmatism highlights action resulting from these interpretations as its fundamental aim (Ansell, 2015), thus the action is ignited by a researcher's reflections aimed at driving changes for improvement. This aligns with the

perspective of pragmatism stating that humans act in a world that is in a constant state of becoming (Goldkuhl, 2012). Furthermore, as noted by one of the precursors of the philosophy of Pragmatism, John Dewey, in his concept of experience, 'beliefs must be interpreted to generate actions and actions must be interpreted to generate beliefs' (Morgan, 2014, p. 1046). Consequently, my beliefs as a practitioner and researcher informed the action I took to initiate the study, and resulted in a continuous cycle of learning about parental perspectives and acting upon the knowledge gained. This guided my growth and understanding in the realm of co-productive relationships, as exemplified at the start of this sub-section.

John Dewey also identified action as the way to change existence (Dewey, 1931, cited in Goldkuhl, 2004), which closely resembles the purpose of my research. In the context of this study, the evidence of parental realities creates grounds for consideration of change on the part of practitioners when partnerships are formed. One of the main aims of this research thus focuses on creating opportunities for parents to express their stories and for these stories to serve as learning material for practitioners to extend the knowledge of how parents envisage building co-productive relationships; as a result, these stories are intended to impact current collaborations.

Considering these principles, a pragmatic perspective clearly resonates with the essence of the initiation of my project, where the results of many years of evolving interactions influenced its direction and guided its purposefulness. Inevitably, my doctoral research exposed me to a more extensive exploration of the implications of pragmatism. These implications, in relation to particular stages of my study, are illustrated in the subsequent sub-section.

#### **3.2.1.2. *Pragmatism and my research design***

Pragmatism is widely utilised as a philosophy in MMR studies (Onwuegbuzie & Leech, 2005; Morgan, 2007; Wahyuni, 2012) where the duality of the knowledge enables simultaneous discovery of the magnitude of the problem and the individual experiences of the population in question (Greene, 2008).

In accordance with Goldkuhl (2012) action must be based on purpose and knowledge to result in changes that will be created according to preconceived plans. This indicates that human knowing, and human action, are strongly intertwined, and this connection is reflected in the direction of my data collection; my research engages both with the need to change practice (purpose) and the nature of practice to be changed (knowledge).

To identify dimensions of difficulties in partnerships between parents and practitioners, the views and experiences of an identified group of participants were explored through a survey (see Section 4) with open-ended and closed questions followed by individual and group interviews (see Section 5). This use of mixed methods is aligned with the principles of the pragmatic paradigm, where the objectivist and subjectivist perspectives are both deemed as acceptable approaches to be used to comprehend social phenomena (Wahyuni, 2012).

Similarly, and in line with the philosophy of pragmatism, my project also involved capturing participants' proposals for future improvements. Participants were asked to position themselves and their experiences in relation to the principles of the SEND Code of Practice (2015), and to think about positive elements of practice as well as those that required improvement. Individual and group participants had the opportunity to elaborate on their experiences, interpret them in the light of anticipated changes the Code aimed for, contemplate why these experiences had taken place, and identify what actions would further improve practice. This strongly correlates with Dewey's pragmatist stance regarding the connection between a researcher's beliefs and actions in a process of inquiry as a principle of any search for knowledge (Morgan, 2014).

Pragmatism also influenced my approach to data analysis. The first aspect of pragmatism connected to data analysis in this study is illuminated in its intersubjective nature, which allows for dual meaning-making through both approaches. This means that both quantitative and qualitative data bring their complementary insights and the understanding of the phenomenon in question. Within the quantitative approach the 'real world' is perceived as a single, generalised domain while the qualitative approach accepts that every individual holds idiosyncratic perceptions of that world (Morgan, 2007).

By using a 'bi-focal' lens for data analysis, pragmatic researchers can intertwine the macro and micro levels of research perspectives; thus, examining the phenomenon from a broader and individual stance (Onwuegbuzie & Leech, 2005). The use of pragmatism as a philosophy in mixed-method research is also widely practised for this reason (Onwuegbuzie & Leech, 2005; Morgan, 2007; Wahyuni, 2012). In the context of my study, this 'bi-focal' lens was important, as I intended to establish a wider perspective of the problem, as well as learn about the individual perspectives of participants.

Another essential link between Pragmatism and my data analysis is the transferability of the data; Morgan (2007) asserts that the researcher ought to scrutinise the determinants affecting the knowledge they acquire to establish its transferability to other settings. Following on from this premise, my study aimed to investigate how partnerships can be improved, rather than whether these improvements can be applied to different contexts; this aim resonates with the function of pragmatism that advocates for practicality in a particular context (Johnson & Onwuegbuzie, 2004).

To conclude this sub-section, I found the tenets of the underpinning values of pragmatism which focus on transferability of data, and its 'bi-focal' perspective to establish practical improvements in the lives of the research participants, supportive in enabling me to fulfil my research aims.

### **3.2.1.3. Conclusions**

In this section, I expanded on the nature of pragmatism and how it underpinned each stage of my research – from design, through analysis, to discussion of the findings.

To conclude, the philosophy of Pragmatism underpins many aspects of this study. It helped shape the reasoning, the conduct and the conclusions of the inquiry, illustrating strong influences on every dimension of this research. It demonstrates purposeful connections between what is happening and what could be taking place with the application of the desired action (Nowell, 2015). As pragmatism is often applied within a mixed-method research (e.g., Collins, Onwuegbuzie & Sutton, 2006; Feilzer, 2010; Biesta, 2010; Morgan, 2014;

Parvaiz, Mufti & Wahab, 2016) I was able to draw on a range of studies to utilise this approach in my inquiry.

### **3.2.2. Appreciative Inquiry (AI)**

This section presents how the model of Appreciative Inquiry (AI) served as a vehicle to design open-ended questions in survey and interviews.

The open-ended questions in the survey (and the group and individual interviews in stage two of this project (See Chapter 4 and 5) were designed with the use of the first two components of the Appreciative Inquiry (AI) model. Cooperrider, Whitney and Stavros (2008, p. XV) define AI as a 'philosophy that incorporates an approach, a process [...] for engaging people at all levels to produce effective, positive change. Therefore, within the philosophical framework applied in this study, AI links to a pragmatist view of finding solutions that would transform practice for the better (Goldkhul, 2004). Although, historically, this model was applied in organisational settings, it has also been promoted to change social systems (Bushe, 2001). In this project, it takes the latter role, aiming to encourage a change in partnerships between practitioners from EHC services and families of C/YP with SEND - in general, not in a particular region or within one organisation. The collaborative nature of AI (Bushe, 2011) is utilised to move the collective thinking 'from edges of the known to the unknown (mystery) in ways that broadens and opens minds, ignites real curiosity and expansive questions, and inspires fresh images of possibility' (Cooperrider & Srivastva, 2017, p.6). However, Bushe (2007) warns that 'the appreciation' element needs to co-exist alongside critical thinking to render fruitful dialogue. Therefore, a discussion on why 'the appreciated' aspects are desired is needed. This discussion took place during interviews where participants were asked about potential solutions to experienced challenges in partnerships, and they were also given opportunity to express their views on why the challenges might have appeared in the first place.

The two stages of AI employed in this project encompassed the stage of 'discovery', closely followed by the stage of 'dream' (Kessler, 2013). In both the survey and the interviews, during the discovery stage participants reflect on and

discuss the best of their experiences evolving around the subject in question (Bushe, 2011). The stories exploring positive structures are used to create new, generative ideas or images that aid in developmental change of the collective discussing them (Bushe, 2001). Frederickson (2006) also asserts that positive emotions affect people's resilience, open mindedness and creativity, which in turn improve the quality of relationships, decision-making and 'overall success' of various social systems. In the context of my study the questions asking for the 'positive' in parental view experiences were designed to uncover these approaches and attitudes that enabled effective and reciprocal partnerships.

The 'dream' stage involves participants imagining their group, organisation, or community at its best in an attempt to identify the common aspirations of system members and to create some, often symbolic, representations of what that might look like (Bushe, 2011). The emphasis here is placed on imagining a community where the unique gifts and strengths of the members are recognised, appreciated, and utilised where applicable (Whitney and Trosten-Bloom, 2010). The essential aspect of these collaborations is also focused on how change is affected by and through relationships, which, when strong, they can become the foundations for managing inadequate designs or plans; however, effective plans are less likely to compensate for weak relationships (Fredrickson, 2006). Likewise, in my study, this stage encompassed the last open-ended question in survey and interviews, where parents were asked to elaborate on potential improvements to experienced difficulties and challenges in partnerships. By asking for parental views/ideas/expertise, I was hoping to gather data that would not only present the struggles that parents experience, but also build on their wealth of knowledge and offer a platform where their solutions can be presented.

Cooperrider, Whitney and Stavros (2008) believe that appreciative inquiry enables the creation of a 'deliberately supportive context for dialogue' as it focuses on exploration of positive aspects of collaboration, rather than only concentrating on 'what is not working well', which has been a subject of many earlier-mentioned studies around parent-practitioner partnerships. The tenet of 'what works well' is also one of the principles of the philosophy of pragmatism, further strengthening the pertinence of that framework within the design of this study.



### **3.3. Mixed Methods Research (MMR)**

This section presents the steps taken in designing the methodological framework with the use of a mixed methods research approach drawing on an explanatory sequential design. The definition of MMR, its strengths and weaknesses of application and considered limitations are discussed in detail. I describe the research design and all related decisions in the process in order to demonstrate the intricate steps undertaken in structuring the blueprint of this project which aimed for transparency and connectedness in all parts of the study.

#### **3.3.1. Definition**

Johnson and Onwuegbuzie (2004) claim Mixed Methods Research (MMR) as the solution to an 'over century-long' paradigm war between quantitative and qualitative orientations; not to place it on a pedestal of superiority above the others, but to stress its advantage in combining strengths while minimising the weaknesses of both approaches in a single research study. Similarly, Greene (2008) asserts that MMR, when utilised within the social sciences, promotes the acknowledgement of the impact of the research context, simultaneously investigating the particular and the general aspects of research. This bi-focal perspective, which enables multi-dimensional results, contributes to the understanding of the magnitude of the problem (through quantitative data) and the lived experiences of the population in question (through qualitative data) (Brierley, 2017). For example, a study investigating post-surgery pain management depicts how an MMR approach enriched understanding of their research problem (Carr, 2009). This project aimed to establish more effective ways of administration of the medication in post-surgery pain management. The researchers demonstrated how the initially gathered statistical data in the survey was enhanced by patients' in-depth knowledge of practical considerations. The author's evidence strongly supports the use of this research

design to produce far-reaching findings that can have more practical implications than a mono-method investigation.

In the context of partnerships, this interconnection particularly resonates with the possibility of establishing the most commonly occurring difficulties in partnerships for parents, as well as gathering a deeper meaning of individual circumstances present within partnerships.

Creswell and Plano Clark (2007) provide a definition that captures the multi-layered dimensions of the approach and this definition served as the main reference in this project:

*As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis and the mixture of qualitative and quantitative approaches [...]. As a method, it focuses on collecting, analysing, and mixing quantitative and qualitative data [...] (p. 5).*

Furthermore, the central premise of MMR is to use a combination of quantitative and qualitative approaches in order to enable a better understanding of research problems than either approach would if employed on its own (Creswell & Plano Clark, 2007; Creswell & Garrett, 2008). In the traditional style, quantitative research yields data from a large sample and far-spread geographical regions, which can represent a wide context experienced by the targeted population, whereas qualitative research focuses on the contextualised accounts of individuals' lived experiences and the meanings they assign to these occurrences.

As a result, when considering the methods and the methodological framework for this project, I concluded that a MMR approach would provide the most suitable scaffolding to answer my research questions. If I had employed a larger sample survey on its own this could have gained more statistically significant results but would not have provided elaborative and detailed accounts of the experiences described. Furthermore, the survey was particularly important for participants who would not have been able to participate in interviews, as the survey enabled them to share their views in the comfort of their own time and space. The survey served also as a tool to identify which particular aspects of partnerships parents experienced as most and least problematic. Importantly, beside the logistic advantage of employing MMR methodology, the

philosophical underpinnings of MMR enabled me to gather data that would best answer my research questions.

As reported by Collins, Onwuegbuzie & Jiao (2007), the researcher, in mixing and combining quantitative and qualitative research techniques in logical and practical ways, makes choices between inductive (discovery of patterns), deductive (testing of theories and hypotheses), and abductive (uncovering and relying on the best of a set of explanations for understanding one's results) reasoning to find the ultimate solution to their research problem. In this two-stage project, the first stage aimed at discovering patterns in parent-practitioner partnerships through an inductive process, utilising the survey method. It was followed by the second stage in which deductive and abductive reasoning was applied in interviews (see Section 5.2.3.).

To support the choices of 'mixing' design, and to examine other research that utilised MMR approach, I turned to several examples of studies that utilised the explanatory sequential design. For example, in Li, Worch, Zhou and Aguiton's (2015) study, conducted within the field of education, exploited the explanatory sequential design to further explain the survey results and identify their qualitative data sample purposefully. By interviewing a nested sample of teachers who provided responses to the quantitative phase, the researchers were able to enhance their understanding of the data gathered. Furthermore, this study established further dimensions of the teachers' experiences in using technology in the classroom, which were not asked about directly in the survey. This further demonstrates that using MMR can enrich and extend data that would be gathered through one method.

Similarly, in Newton, Chandler, Morris-Thomson, Sayer & Burke's (2015) study exploring the recruitment processes for newly qualified nurses, the explanatory sequential design examined how the systems were perceived by the health providers who were responsible for recruitment. The interviews in phase two explored the perceived advantages and limitations which were identified in analysis of the survey from phase one. Similarly, the data gathered in this design provided more insightful information revealing additional aspects of inter-institution traditions and historical influences on current practices, which did not form a direct focus of the study, but provided an additional understanding of the phenomenon in question.

The application of MMR is noticeably increasing across different disciplines (Ågerfalk, 2013), bridging the gaps between paradigms and traditional approaches in an attempt to answer the complexity of research questions that reflect the complexity of today's world. By crossing the boundaries of philosophical and methodological traditions, MMR presents opportunities for intersectionality and interdisciplinary research despite the differences of views and principles existent within different paradigms. Exemplified studies are merely a notion of the extent to which this approach can enhance the researcher's understanding of the research problem.

### **3.3.2. Advantages of using MMR**

The advantages of using MMR have been debated by scholars for over three decades (Creswell & Plano Clark, 2011). It is believed that the combination of strengths of the qualitative approach offsets the combination of weaknesses of the quantitative approach and vice versa. To apply this reasoning to my study, the quantitative part that provided a more general overview of the state of the parent-practitioner partnership was complemented by the personal accounts which supplied detailed explanation to the findings from the survey. Conversely, the personal reports were strengthened by the numerical data from the quantitative method as they illustrated that the experiences discussed were lived by other families across the country.

MMR also focuses on the centrality of answering the research questions rather than debating over the superiority of either quantitative or qualitative approaches (Venkatesh, Brown & Bala, 2013). This focus on processes is also prominent within the theory of pragmatism which underpins this study (see Section 3.2.).

Being classified as an alternative to qualitative or quantitative approaches, MMR has been described as the 'third methodological movement' following the preceding quantitative and qualitative research developments (Creswell & Plano Clark, 2011). Arguably, in the rapidly changing world of social sciences and everyday life, research approaches also continually evolve and change. This could be said to be taking place in response to the needs of complex and

interconnected global communities (Creswell & Garrett, 2008). Denscombe (2008) further asserts that mixing methods that gather both qualitative and quantitative data, and by proxy, worldviews, offers a flexible, permeable, and multi-layered approach to accommodate the various ways in which the complexity of each paradigm can be utilised to answer more interdisciplinary research questions.

Furthermore, MMR can support research projects that require overcoming some additional barriers, for example when:

- one data source may be insufficient,
- initial results require further explanation,
- exploratory findings require generalisation,
- the study needs enhancing with a second method,
- a theoretical stance needs exploration,
- multiple research phases are designed to enable understanding of the research objective.

Shaped by a pragmatist philosophy, in this study, MMR was employed for a range of reasons; to further explain the initial results, to enable participation for this particular cohort, and to ensure the research question was answered by the most effective choice of method/s.

### **3.3.3. Challenges in using MMR**

Besides the advantages that the use of MMR presents, there are also challenges that the researcher must consider when designing and conducting their study within this approach.

Firstly, I recognised that the skills I, as the researcher, had to acquire in relation to methodological knowledge of both paradigms, as well as my ability to utilise that learning in the particular phases of the study, needed consideration (Onwuegbuzie & Collins, 2007; Halcomb & Andrew, 2009). This meant I had to undertake additional training within the field of statistics and be able to apply it to the gathering and analysing of the quantitative data. Although these tasks required extended time, by taking part in this learning, I joined a community of

researchers where I was able to discuss and embed my new knowledge in a supportive learning community.

Secondly, gathering data in both quantitative and qualitative sets can be significantly more time consuming, while access to expert advice/training might become more extensive (Halcomb & Andrew, 2009). Therefore, I engaged in a lengthy reflection through the process of the project design and planning to address these elements; I explore these considerations in detail in Section 3.3.5. By identifying a clear structure of my research training and schedule of data collection for both methods, these obstacles were minimised.

Thirdly, I adopted a methodological, rather than methods orientation in this study (Creswell & Garret, 2008). This meant that instead of viewing mixed methods as tools to collect, analyse and interpret both quantitative and qualitative data, I classified my approach of mixed methods as a methodological approach, including the broad philosophical assumptions as discussed in Section 3.4. (Tashakkori & Teddlie (2003). Additionally, the 'mixing' of the methods and paradigms occurred in tandem and the 'mixing' was closely connected with research questions and philosophical assumptions applied in this project (see Section 6).

Inevitably, some reject this complexity as a viable approach, arguing that such distinct and distant paradigms cannot be compatible (Sale, Lohfeld & Brazil, 2002). Nonetheless, Buchholtz (2019) emphasises the criticality of the 'value-added' when results from both phases, the quantitative and the qualitative, are integrated. Therefore, in this thesis I illustrate the findings from each method subsequently and these chapters are followed by a discussion dedicated to the 'mixing' of the methods together in an endeavour to enrich the answers to research questions.

Fourthly, I ensured that the research design was reflective of the relationships between the quantitative and qualitative data sets. I achieved that by clearly addressing the purpose of each method in data gathering, which within the explanatory sequential design meant that the data from the survey was built on through the further exploration during the interviews (see Section 3.1).

And lastly, I addressed the issue of representation (sometimes referred to as generalisation), which is often linked to the legitimisation of MMR projects. I achieved that by recognising and acknowledging this aspect within the research design and in the study's limitations. To support transparency within all

decisions made, I also maintained audit trails (Onwuegbuzie & Johnson, 2006) (see Appendix 1 and Appendix 2).

### **3.3.4. Researcher positionality**

Researcher positionality 'reflects the position that the researcher has chosen to adopt within a given research study' (Savin-Baden & Howell-Major, 2013, p. 71). As a fluid process that continually undergoes transformation (Bourke, 2014), my positionality and its effects on the study are illustrated throughout this thesis. This section outlines the factors that have shaped my positionality prior to conducting this research and how my own thinking and understanding has evolved during the process of my inquiry.

In engaging with this reflexive activity aimed at the development of my positionality (Day, 2012), firstly, I discuss the influences of my professional context on my prior understanding of the realm of special educational needs, with relation to the concept of 'labels' and 'professional dominance'. Secondly, I discuss how this study has influenced a shift in my perception and understandings of inclusive education and how my reflection on these aspects has led me to connect partnerships to the underlying values of egalitarianism, co-production and social justice.

Clough, Goodley, Lawthom & Moore (2004), in their analysis of processes involved in researching life stories, draw attention to the role of the researcher being interconnected with how, where, what and why that shape the focus of the study. These choices, despite the life story being told by the participant, are inevitably intertwined with the positionality of the researcher (Clough et al., 2004). This entanglement between the researcher and the participants was also defined as an ethical responsibility the researcher should always consider in their studies (Kuntz, 2015). I engaged in the process of this recognition throughout the project and, as it was not always a linear process, the implications of this engagement differed in intensity. For example, I was conscious that parents whose children I taught before might be more reluctant to discuss their concerns with me in fear of this information having any detriment to their children's education. I considered that a high probability during interviews (as the survey was anonymous) and reiterated the

confidentiality protocol on every occasion when introducing, arranging, and conducting interviews. While I ensured that the parents were reassured about the confidentiality and anonymity of their participation, I also reflected on what this interconnection between my professional practice and the role of the researcher meant for the study. The realisation that my known role of a practitioner in the field could have been construed by participants as being problematic prompted me to ensure that participants were clear about the purpose of this study, which had no connection to my place of work (Robson, 1993). Reflections related to the impact my professional practice have had on the direction of this study have also been extensive, as discussed in Section 1.2.

Furthermore, in my quest to establish parental views, I ventured into experiences which could have portrayed my colleagues, or even my own practice, in a detrimental view for a range of reasons. As methodological responsibility of truth-telling can, at times, interfere with the 'status quo' (Kuntz, 2015) – in this case the power imbalances in partnerships – I did consider the potential effect the findings from this study might have on other practitioners in the field. I was aware that the findings could, at times, challenge my own perceptions, practice and standpoints and I was conscious to maintain the integrity of my research by not allowing these personal characteristics to cloud my judgement. As researcher I could not become entirely neutral (Cohen & Minion, 1994), however, by reflecting on my rationale for all choices undertaken in the processes of my study as described throughout this thesis, I ensured my choices regarded ethical dilemmas as well as enabling my reflexivity.

My continuous passion for a change in practice was also an element that I worked on throughout the project to ensure that the views and experiences of participants were the focal point of my study, rather than my own position and opinions (Fenge et al., 2019). At the same time, I recognised the influence my background and position had on the research processes (Fenge et al., 2019). To achieve clarity of when my roles between practitioner and researcher were influential, I used a reflective journal as a methodological tool (Henter & Indreica, 2014). While reviewing and evaluating the purpose of my actions and the underlying assumptions that drove them, the reflective journal enabled me



to engage with the process of metacognition where I challenged my own thinking (Henter & Indreica, 2014). For example, in 2017, following an attempt to distribute the survey in person during parents evening in one of the identified schools, I wrote:

*‘December 2017. The result of my presence at the parents evening did not bring expected engagement in the survey. Although this is very disappointing, I question my previous reasoning about the appropriateness of this space for the distribution of the survey. This decision was made in collaboration with the head teacher and we both, as practitioners, had certain assumptions about parental engagement in face-to-face interactions being more effective. This leads me to question our understanding of what parents require, need or find useful, bringing me back to the need to distinguish between my own perceptions and those of my participants.’*

Beside the ability to reflect on the ‘thinking about my thinking’ (Henter & Indreica, 2014), evaluating my steps in methodological decisions (see Section 3.3.6. and 5.2.3.) (Braun & Clarke, 2013), the frequent revisits of the reflective journal made me conscious about which aspects of my work I ‘noticed’ more or less in relation to the progress of my study (Mason, 2002). This ‘discipline of noticing’ (Mason, 2002) enabled me to also become more aware of how my personal and professional values and assumptions have shaped my research and contributed to constant reflection on what kind of a researcher I was becoming. Although this reflection continues to be in a state of ‘becoming’, I now recognise that my willingness to work with parents and carers to ensure that their knowledge and expertise was formally recognised in my, and potentially other practitioners’ work was a sign of an activist action to influence the ‘status quo’ of partnerships I encountered. With my continually evolving and expanding understanding of the tensions in these partnerships, I did not only intend to transform my own practice but became ingrained with the idea that the practice required changes in general. Tomlinson (1982), almost four decades ago, argued that the assumptions of ‘capable experts’ being most equipped to make decisions about the ‘less capable’, ‘less knowledgeable’ groups of pupils and their families within the realm of SEN needed to be questioned. Despite many changes in the legislation and practice, that ideology of ‘professional dominance’ (Seligman & Darling, 2007) continues to prevail, perpetuating the

marginalisation of families with children and young people categorised as having SEND (Glazzard et al., 2015).

### **3.3.5. Planning the MMR in this study**

To plan my study, I followed Halcombe and Hickman's (2015) steps and considered the following:

1. examine the rationale for using mixed methods.
2. explore the philosophical approach.
3. understand the various mixed method designs.
4. assess the skills required.
5. review project management considerations
6. plan and justify the integration of qualitative and quantitative aspects.
7. ensure that rigour is demonstrated.
8. disseminate mixed methods research proudly.

Bryman, Becker & Sempik (2008) argue that elaboration on the rationale for using MMR in social policy research is critical. In doing so, I also intended to address the reported lack of this aspect in many MMR studies to foster the transparency of this project. While presenting my rationale for the use of MMR in this study, I also explored the intricacies of the approach to discuss and address the limitations (see Section 3.3.1., 3.3.2. and 3.3.3.). This was followed by the discussion of theoretical framework (see Section 3.2.). Furthermore point 6 and 7 were integrated into the Survey and Interviews chapters and presented respectively in those chapters, whereas point 8 has been interwoven throughout the study, and consequently throughout this thesis.

### **3.3.6. MMR process design**

Following on from Onwuengbuzie & Collins (2007), who challenged the transparency of detailed choices in design through analysis of different MMR studies, and Buchholtz (2019), who stressed the importance of justification for

MMR design and the explicit outline of the processes involved, I illustrate the stages of my research design in this section.

Collins, Onwuegbuzie, and Sutton (2006) propose four stages of research design: formation, planning, implementation, and finalising. These stages follow 13 steps. Each of these steps is presented in relation to my research in Table 6.

*Table 5 MMR design process (Collins, Onwuegbuzie & Sutton, 2006)*

<b>Prescribed steps</b>	<b>Application in this study</b>
<b>1. Determine the goal for the study</b> (To understand the complexity of the phenomenon in question/test hypothesis/develop ideas)	<ul style="list-style-type: none"> <li>To collate parental perspectives on co-productive partnerships with practitioners in EHC provisions.</li> </ul>
<b>2. Formulate Research Objectives</b> (To explore the phenomenon in question)	<ul style="list-style-type: none"> <li>To establish parental experiences of partnerships, including parental contributions to decision-making processes.</li> <li>To establish whether and, if so, how the implementation of the SEND Code of Practice (2015) impacted on the nature of parent-practitioner partnerships.</li> <li>To establish what parents perceive as effective partnerships in order to identify further improvements in partnerships working.</li> </ul>
<b>3. Determine Research/Mixing Rationale</b> (To identify the use of MMR in the context of the study)	<ul style="list-style-type: none"> <li>To identify why survey and interviews yield richer data than individual methods would if applied in their entirety (see subsection 3.2.6. Rationale for this study)</li> </ul>
<b>4. Determine Research Purpose</b> (To triangulate, complement, develop, initiate, or expand)	<ul style="list-style-type: none"> <li>To develop and complement the findings from the survey by interviews in both group and individual modes.</li> </ul>
<b>5. Determine Research Question (s)</b>	<ul style="list-style-type: none"> <li>Research question 1: What are parental experiences of being acknowledged and treated as valued contributors to parent-practitioner partnerships in EHC realm, since the SEND Code of Practice (2015)?</li> <li>Research question 2: What is the potential for co-productive practice to enable inclusive partnerships in parental view?</li> <li>Research question 3: How can practices in Education, Health and Care services be developed to enable more equal, reciprocal, and participatory partnerships with families in parental view?</li> </ul>
<b>6. Select the Sampling Design</b> (To identify the relationship between the quantitative and qualitative samples (identical, parallel, nested, or multilevel) <b>-Select the Individual Sampling Schemes</b> (To determine the use of random or non-random research sampling schemes; corresponding with the generalisability of the findings or the	<ul style="list-style-type: none"> <li>To adopt nested sampling design where the sample members selected for interviews represent a subset of those participants chosen for survey. These enabled participants of the survey to elaborate on their and others' answers provided in the survey.</li> <li>To apply a non-random sampling scheme following the Convenience Sample (choosing settings, groups, and/or individuals that are</li> </ul>

choice made based on the respondents/settings being considered 'information rich')	conveniently available and willing to participate in the study) thus opening the opportunity to participate for parents/carers in one or both phases of the project.
<b>7. Select Mixed Methods Research Design</b> (To determine the time for research design according to the time orientation: concurrent or sequential)	<ul style="list-style-type: none"> <li>To adopt explanatory sequential design where the findings from the first method survey (including QUANT and QUAL components gathered and analysed concurrently) as foundations for the following method (survey followed by interviews).</li> </ul>
<b>8. Collecting the data</b> (To establish tools of data collection)	<ul style="list-style-type: none"> <li>To collect data through online survey (containing QUANT+QUAL data) and Interviews (QUAL data)</li> </ul>
<b>9. Analysing the data</b> (To establish tools of data analysis for chosen methods)	<ul style="list-style-type: none"> <li>To analyse survey data using descriptive analysis and thematic analysis; to analyse interview data using thematic analysis.</li> </ul>
<b>10. Validating/legitimizing the data and data interpretations.</b> (To maintain rigorous approach to both sets of data)	<ul style="list-style-type: none"> <li>To ensure the processes in quantitative and qualitative data collection and analysis are transparent and designed in line with traditions in each paradigm.</li> </ul>
<b>11. Interpreting the data</b> (To draw inferences from the combination of both data sets)	<ul style="list-style-type: none"> <li>To discuss inferences from analysis of both methods.</li> </ul>
<b>12. Writing the final report</b>	<ul style="list-style-type: none"> <li>To produce the thesis.</li> </ul>
<b>13. Reformulating the research question(s).</b> (To propose recommendations for future research that could draw, extend, or replicate the current study (Leech & Onwuegbuzie, 2010)).	<ul style="list-style-type: none"> <li>Research question 1: How parents and practitioners experience the equality of their contributions to decision-making within parent-practitioner partnerships in EHC realm since the SEND Code of Practice (2015)?</li> <li>Research question 2: How is co-production experienced by parents and practitioners within partnerships in EHC sectors?</li> <li>Research question 3: What are the effects of co-production on the partnerships between parents and practitioners in EHC sectors?</li> </ul>

### **3.3.6.1. Formation stage**

In the Formation stage of this research (steps 1-5 of Collins, Onwuegbuzie, and Sutton's (2006) framework), I identified the goal of this study, which was to collate parental perspectives on how they experience co-productive partnerships with practitioners in EHC provisions, following the implementation of the SEND Code of Practice (2015). In MMR, all of the components at the formation stage are interconnected (Onwuegbuzie & Collins, 2007). Therefore, the collection of parental perspectives fulfilled the research objective, which aimed at enabling a platform for parental perspectives. Likewise, the aims of the research (see Section 1.3) led to the identification of the methodological framework in which MMR was chosen to gather data using two methods (see

Sub-section 3.1.). The rationale for the application of the MMR approach was followed by establishing the research purpose, which was to complement findings from the survey by the group and individual interviews, but also to enable the participation of parents who had extensive caring commitments. The identified purpose consequently drove the formation of the research questions. It is essential to note that the formation stage of the research did not follow a linear trajectory; it was formed in a relational process where I, the researcher, was moving between the steps in an arbitrary fashion that was driven by the development of the study (Leech & Onwuegbuzie, 2010). For example, I continually reviewed my research questions while I continually engaged in developing my understanding of the phenomenon I was investigating.

The next stage of the process involved identification of sampling procedures.

#### **3.3.6.2. *Sampling and design***

The process of defining sampling strategies in MMR is essential to illustrate the quality of inferences drawn by the researcher from the underlying findings of the study (Kemper, Springfield and Teddlie, 2003). Prior to conducting both survey and interviews, the number of participants (sample size) and the method of recruitment of these participants (sampling scheme) were decided (Collins, Onwuegbuzie & Jiao, 2006).

As this study was not focused on generalising the findings to a wider population of parents, the sampling scheme that was chosen was of a non-random category (Cohen, Manion & Morrison, 2018). This category focuses on representing only the cohort in the study or instances of that cohort in a similar population, rather than providing representation to the whole undifferentiated population, as it occurs within the random sampling scheme (Cohen, Manion & Morrison, 2018). However, it can be argued that for practitioners and parents working together in the field of SEND, the findings of this study could serve as a base for reflections. In line with so called 'fuzzy generalisation' proposed by Bassey (2001), researchers can make tentative assumptions that their findings may apply in other contexts, as tentatively implied by this study.

The potential time and energy constraints experienced by most parents of C/YP with SEND (see Section 2.3 and 2.4) and their impact on parental participation in research, also contributed to the choice of the sampling scheme. This meant the sampling scheme had to be adopted to suit the particular needs of the intended participants. Therefore, a non-random convenience sampling scheme was employed within a nested design (Onwuegbuzie & Leech, 2005). As a result, the cohort of participants consisted of those who were available to take part and who were knowledgeable about the subject in research through their lived experiences; the participants for the second phase were recruited through the first phase (nested design). Furthermore, the main aim of this study was not to generalise to a population, but to obtain insights into the parent-practitioner collaborations in practice through 'information-rich' individuals or groups of participants (Onweebguzie & Collins, 2007).

As each sample is designed to generate a sufficient amount of data to enable answering the research questions and make clear inferences from both numerical and qualitative data (Cohen, Manion & Morison, 2018), the time the survey was active was determined by the number of responses rendered. Hill (1998) speculates on the 'rule of thumb' when the sample size for the online survey is considered and he asserts that the absolute minimum of responses should vary between 25-30 participants to generate enough data for analysis. The number of respondents to the surveys would also be scrutinised against the proportionate representation of the underlying population; however, it was impossible to identify the cohort of parents who are active online. Therefore, I used a combination of Hill's (1998) rule of thumb and the monitoring of the responses within the research timeframe to decide about a relevant period of time for the survey to be active online. Subsequently, the length of accessibility of the survey was extended from an initial 3-month period to six months and the links sent to different platforms were distributed in spaces of two to three weeks between each other to maximise the probability of access by different families. The online survey in this project was attempted by 289 participants; however, only 144 responses provided data that allowed analysis as some of the responses were aborted before any data was inputted. One of the reasons provided by a participant who contacted me online was that they were based in Wales and wished to conduct a similar study within their community; therefore,

they attempted the survey out of curiosity about its structure. Following 6 months of activity and the 'rule of thumb,' the sample size proved sufficient for analysis.

The sample size in the second phase of this study was determined by 'expert opinion', rather than being based on probability calculations (Onwegbuzie & Collins, 2007). In line with one of the principles in qualitative research, appropriate sample size can be indicated when the researcher decides to discontinue data collection or analysis due to reaching data saturation point (Saunders et. al, 2018). The process of arriving at data saturation point is illustrated in detail in Chapter 5. While collecting data through interviews, I continually employed the process of data saturation analysis through information redundancy (Saunders et. al, 2018). Information redundancy was achieved by a process whereby each interview was analysed and coded, and the analysis of consequent interviews either aligned with the existent codes or extended the codes further. When no new findings emerged through analysis of the latter interviews it was deemed that the saturation point was reached. Altogether 25 participants were interviewed (see Section 5.2.3.).

Finally, the process of sampling led to the identification of the time orientation in which both phases were conducted. This illustrates how the multileveled samples are sequenced (Collins, Onwuegbuzie & Jiao, 2007). MMR provides a variety of design frameworks to suit individual research interests and cohorts of participants. In this study, an explanatory sequential design was used, and the online survey was analysed to inform the process of interviews where the data gathered through survey was elaborated on (Creswell & Plano Clark, 2011). Table 6 illustrates the sequence of the design:

*Table 6 Explanatory sequential design*

<b>Online survey (November 2017- May 2018)</b>	<b>Interviews May 2018- July 2018</b>	<b>Mixing inferences from both methods</b>
<ul style="list-style-type: none"> <li>• Descriptive analysis of quantitative data (N=144)</li> <li>• Thematic Analysis of qualitative data</li> <li>• Survey data analysis shapes the</li> </ul>	<ul style="list-style-type: none"> <li>• Pilot group interview (N=6)</li> <li>• Group interviews (N=5, N=6)</li> <li>• Individual interviews (N=8, incl. 2 telephone interviews)</li> </ul>	<ul style="list-style-type: none"> <li>• Quantitative and qualitative data analysis from the survey informed the interviews.</li> <li>• Combining analysis of both methods into</li> </ul>

questioning in interviews.	<ul style="list-style-type: none"> <li>• Thematic analysis for all interviews</li> </ul>	a joint Discussion Chapter.
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### **3.3.6.3. *Implementation stage and data analysis***

As this study is presented in two stages, Chapters 4 and 5 focus in turn on the survey and then the interviews. In each case I elaborate on the process of analysis used and the findings generated. In Chapter 6 I go on to present and discuss my findings by drawing across these two datasets. In this section, however, I outline an overview of the processes that were employed in data analysis.

According to Collins, Onwuengbuzie and Jiao (2007), data analysis within MMR studies can be organized in a process involving seven stages. However, not all these stages are always utilised in every project as their use relies on the context of individual research. They are:

1. Data reduction (where the dimensionality of the qualitative data is reduced through e.g., thematic analysis or creating memos, and quantitative data is reduced through e.g., descriptive statistics)
2. Data display (representing qualitative data visually through matrices or charts, and quantitative data through tables or graphs)
3. Data transformation (where quantitative data is transformed into narrative data to be represented qualitatively and where qualitative data is transformed into numerical codes to be represented statistically)
4. Data correlation (entails establishing correlations between both orientations of data)
5. Data consolidation (where both data orientations are combined to either conclude new or joint variables)
6. Data comparison (requires the researcher to compare and to contrast quantitative and qualitative data)
7. Data integration (where both data sets are blended into one whole set or two coherent wholes).



This project employed the 1st, 2nd, 4th, 5th, 6th and 7th stages and intermittent elements of the 3rd stage of the proposed process. The diagram below (Table 7) summarises these processes. (More detail on these processes is provided in Chapters 4 and 5).

*Table 7 Research data analysis design*

<b>Data Reduction</b>	
<b>Quantitative</b> (descriptive statistics of closed Qs in Survey)	<b>Qualitative</b> (Thematic analyses of open-ended Qs in Survey and all interviews)
<b>Data Display</b>	
Survey analysis of <b>Quantitative</b> data (table, matrix)	Survey and Interview Thematic Analyses of <b>Qualitative</b> data (diagrams, tables)
<b>Data Transformation</b>	
Open-ended Q 2 in survey transformed into <b>Quantitative</b> statistics (presented in a graph, see Section 4.4.1.2.)	Numerical correspondence included in analysis of <b>Qualitative</b> data
<b>Data Correlation, Consolidation, Comparison and Integration</b>	
Analysis of <b>Survey</b> data combined with analysis of <b>Interviews</b> data.	Matrix of cross-references presented in Discussion: integration of both methods where each component is discussed in detail.

### 3.4. Summary

In search for practical solutions to widely debated problematic partnerships between practitioners and families, MMR allowed me to gain detailed insights into parental experiences of partnerships since the implementations of the SEND Code of Practice (2015).

Further similarities between the processes of data collection, analyses and integration of all findings, as evidenced in the following chapters, illustrate how the MMR design addressed my research questions and generated possible solutions to difficulties in parent-practitioner partnerships within the SEND field.

## **4. Chapter 4 – Stage 1: The Survey**

### **4.1. Introduction**

This chapter identifies and demonstrates the processes of planning, conducting, and analysing the online survey. Firstly, I describe the quantitative components of the survey, followed by the qualitative approaches.

Responses were gathered through closed and open-ended questions, rendering quantitative and qualitative data simultaneously. The main findings deriving from the survey are summarised at the end of this chapter. As explored further in Chapter 5, these informed the design of stage two of this project.

### **4.2. Survey design**

This sub-section outlines the rationale for the closed and open-ended questions within the survey. Firstly, I present the rationale for using the survey to elicit parental views. Secondly, I describe how the closed questions were informed by the construction and intention of the Code. Thirdly, I depict the design process of open-ended question.

#### **4.2.1. Purpose of the survey**

The main purpose of the survey was to:

- o Offer an opportunity to capture voices of those who cannot attend a group or individual interview;
- o Recruit respondents to the qualitative aspect of the work;
- o Inform the design and interview schedules for the qualitative work.

### 4.2.2. Closed-ended questions

The survey began with 10 closed questions presented with 5-point Likert Scale answers ('strongly agree', 'slightly agree', 'neither agree nor disagree', 'slightly disagree', 'strongly disagree') (Likert, 1932). The Likert scale tool was used to measure respondents' satisfaction of their experiences with practitioners involved in the EHCP processes. The questions were designed to reflect those parts of the SEND Code of Practice (2015) that related to parent-professional relationships to understand how the intentions of the Code were experienced by parents in practice. The closed questions were created as a result of the literature review and were also informed by the aspects of the Lamb Inquiry recommendations and the CoP guidance as presented in Table 8.

*Table 8 Closed-ended questions in the survey and the Code*

<b>Survey statements</b>	<b>Rationale for creation</b>	<b>Aspect intended to be explored</b>
1. The outcomes of the EHC plan reviews are clear to me.	CoP, p.148 'Local authorities should support and encourage the involvement of children, young people and parents or carers by: • providing them with access to the relevant information in accessible formats...'	-clarity of language in EHCPs and during the reviews.
2. I feel confident to ask professionals for support if I don't understand something about the review.	CoP, p. 21 'Parents' views are important during the process of carrying out an EHC needs assessment and drawing up or reviewing an EHC plan in relation to a child. Local authorities, early years providers and schools should enable parents to share their knowledge about their child and give them confidence that their views and contributions are valued and will be acted upon.'	-trust and confidence in services acting in the best interest of the C/YP and acting upon parental wishes.
3. I am actively encouraged to express my opinions at the reviews.	Lamb Inquiry, p.3 Parents need to be listened to more and brought into a partnership with statutory bodies in a more meaningful way'; CoP, p.148 'Local authorities should support and encourage the involvement of children, young people and parents or carers by: ...dedicating time in discussions and meetings to hear their views'.	-encouragement to contribute to design of provision.
4. I feel my opinions are taken into account when outcomes for the reviews are being created.	CoP, p. 194 'Reviews must be undertaken in partnership with the child and their parent or the young person, and must take account of their views, wishes and feelings, including their right	-being listened to, regarded as a valued contributor to all decision-making processes.

	to request a Personal Budget'; p. 148 'The assessment and planning process should: ... • enable children and young people and their parents to express their views, wishes and feelings'.	
5. I am informed regularly about the progress of the outcomes agreed at the reviews.	CoP, p. 22 'Local authorities should work with children, young people and parents to establish the aims of their participation, mark progress and build trust...and that there are strong feedback mechanisms to ensure that children, young people and parents understand the impact their participation is making'.	-communication on progress, needs, successes/limitations of the provision.
6. I feel I can express my opinions openly.	CoP, p. 21 'At times, parents, teachers and others may have differing expectations of how a child's needs are best met. Sometimes these discussions can be challenging, but it is in the child's best interests for a positive dialogue between parents, teachers and others to be maintained, to work through points of difference and establish what action is to be taken.'	-having a respectful and open platform to express views that might be contradictory to the views of the provider/services.
7. I feel I can ask for advice/clarifications openly.	CoP, p. 32 'The provision of information, advice and support should help to promote independence and self-advocacy for children, young people and parents', 'Staff should be clear about the transfer of some rights and responsibilities to young people, and work sensitively with parents to help them understand their role.'	-parents/carers being able to advocate for their C/YP and learn how to adapt to the new roles they might not have taken on before.
8. I feel I can plan my child's education with the support of other professionals during EHC plan reviews.	CoP, p. 149 'Authorities must work with parents and children and young people to understand how best to minimise disruption for them and their family life. For example, multiple appointments should be co-ordinated or combined where possible and appropriate.'	-Multiagency practitioners contribute and understand the C/YP in the context of their family life and their unique needs.
9. I feel there is enough information and professional advice available for me to make informed decisions about my child's future.	CoP, p. 32 'Staff working in Information, Advice and Support Services should be trained to support, and work in partnership with parents'; p.149 'Local authorities must provide all parents, children and young people with impartial information, advice and support in relation to SEN to enable them to take part effectively in the assessment and planning process. This will include the EHC needs assessment process, EHC plans and Personal Budgets (including the take-up and ongoing management of direct payments). This should include information on key working and independent supporters as appropriate.'	-information/advice available to make informed decisions is clear and readily available for all families.

10. I feel my opinions have equal value to those of professionals?	Lamb Inquiry, p.3 'Face-to-face communication with parents, treating them as equal partners with expertise in their children's needs is crucial to establishing and sustaining confidence.' CoP, p.95 'In particular, parents know their children best and it is important that all professionals listen and understand when parents express concerns about their child's development.'	-parental views/opinions/wishes are treated with the same regard as those of professionals/services.
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Although I was aware of many of the dimensions of parents' and practitioners' experiences of the partnerships, e.g., lack of trust, miscommunication, or difficulties in obtaining personal budgets as witnessed in my professional observations and literature review, I, purposefully, did not name any of these aspects in my questions. This was intended to limit my own influence on the direction of participants' thinking.

Through these questions, I intended to establish whether the changes in processes and practice that the legislation targeted were evident in the everyday experiences of parents. They included the following aspects:

- parents being presented with opportunities to express their opinions,
- parental views being regarded as valid contributions to decision making processes which were to be conducted in the spirit of co-production between parents and services (including: trust in services, effective communication with services, mutual respect and valuing each other's contributions)
- lastly, information and advice being readily available to enable families to make informed choices.

The survey was created, distributed (see Section 4.3.), recorded and analysed in Qualtrics software. Some additional analyses were performed in SPSS (see Section 4.6).

#### **4.2.3. Open-ended questions**

To design the open-ended questions in survey, I utilised part of the Appreciative Inquiry (AI) model, as mentioned previously within Section 3.2.2. Here, I present the details of how this model contributed to each open-ended question in the survey.

Although the first two stages of AI focus on positive experiences/images/memories, the founders of the model argue that the risk of not acknowledging negative elements can result in their occurrence in most unexpected and unhelpful ways and can be detrimental to the AI process (Bushe, 2001). Therefore, the three open-ended questions asked in the survey explored both the positive views in parental experiences of partnerships, and the dimensions that required improvement.

Reframing the questions to focus on 'what would they like to see more of or what an ideal situation might look like', was designed to prompt development of these images and statements that would enable the participants to see the difference between what is and what they would like to see (Bushe, 2007). Therefore, the first open ended question in the survey ('What are the positive aspects of the EHCP process?') aimed at gathering positive recounts of any aspects of partnerships during the EHCP reviews; the second open-ended question ('How would you describe the relationship with professionals who work with your child?') investigates insights into the relationships with each sector separately, to allow the respondents to present different experiences and for the researcher to gather more specific data; the third open-ended question ('If you could ask for any changes/improvements what aspects of the work between parents and practitioners would you like taking place?') was aimed at respondents imagining the most desirable future, where partnerships between families and services would flourish (this question required reframing for the survey as the word 'dream' could have contentious connotations within the circles of families who struggle to navigate the system).

Although a space for focus on partnerships, whether negative or positive, was enabled through these open-ended questions, the first and third questions were intended to stir contemplation of positive and/or desirable experiences to encourage respondents to share ideas about effective partnerships in current practice and in the future.

Furthermore, these two stages of AI could contribute to the ethos of any future dialogue between professionals and parents of C/YP with SEND, for which this study will, hopefully, create a comprehensive starting point.

#### **4.2.4. Maximising return rates**

Maximising response rates is essential to the success of any survey; however, 'a reasonable response rate' is determined by the impact different respondents have on gathered data (Baruch, 1999). This section details strategies used to maximise response rates in this study.

Initially, my project sought the views of parents using postal questionnaires accompanied by an online version (see Section 4.2.3.2.) to offer the respondents flexibility of access (Fowler, 2013). However, following low return rates (see Section 4.2.3.3.), an amended online version of the survey captured most data used in this study. Outlined strategies were applied across both phases of the project, unless stated otherwise.

The survey was considered likely to be of high interest for participants (Edwards et al., 2009) as it related to their children; however, I recognise that this cannot be generalised to the whole studied population as their outlooks would differ individually. To enhance consideration for my chosen population effectively, I critically reflected on the characteristics of participants (Anseel et al., 2010). Beside individual respondents' circumstances affecting their participation, I also considered the effects of wide and frequent survey distribution on 'respondents' fatigue' and how it can result in resistance to participation (Porter, Whitcomb, & Weitzer, 2004). At the time, led by the enthusiastic response from some potential participants, I believed that these obstacles to participation would be outweighed by respondents' willingness to share their stories.

To minimise any confusion, I emphasised that, although some participants may know me from my role as a practitioner, this was secondary to my role as a researcher in this instance. All questionnaires had the university letterhead and contact details included to maintain clear affiliation with the research organisation (Gore-Felton et al., 2002). I used my photograph to personalise the

questionnaire (Edwards et al. 2009) and provided a brief description of my relation to SEN settings and rationale for the project.

The close-ended questions were succinct and explored only one piece of information per statement (Arthur, Waring, Coe & Hedges, 2012), with jargon-free language (Parsons, Lewis, Davison, Ellins & Robertson, 2009) and the respondents were offered opportunity to feedback on the findings (participants were given an opportunity to include their email address if they wished to be contacted with the results; however, none of them opted in for this option).

Language used in surveys is also linked to cognitive and cultural influences on the behaviour of the respondents where the researcher is dependent on what “society at a particular time in history allows and then encourages us to do” (Dillman, 2002. p.476). This point is especially relevant for this research, where there is a changing and turbulent nature of stakeholder relationships (see Section 2.2 and 2.3), and where it could be expected that both myself and individual participants are likely to have different interpretations of meaning for the language used. To sustain clarity between respondents’, my own and my supervisory team’s understanding, I continually reflected on the consistency of the language used in my survey; addressing any ambiguities by acting upon the insights into this aspect received in the pilot phase, which I discuss in the next sub-section (see Section 4.3.1.).

Paper and online versions were designed to fit onto 1 A4 page and take no longer than 15 minutes to complete (Edwards et al., 2009). Questions were pretested (Gore-Felton et al., 2002; Fowler, 2013) with three parents of C/YP with SEND and three Head Teachers of SEN schools involved in the study. It was confirmed that the questions posed were clear, they led to meaningful answers and the online version was user friendly (e.g., through access to it on desktop or mobile devices). Following the feedback, question 9 was added and question 1 was slightly re-worded.

To enhance return rates for postal questionnaires, pre-paid return envelopes were provided (Adams, et al., 2017).

Once surveys had been initially distributed, polite reminders were sent one month later via the schools’ administrative team in the form of SMS messages to encourage completion. I decided that due to limited resources and to limit the



intrusion of this research into the lives of potential participants, repeat hard copies would not be sent, although these may have been more successful at prompting completion (Hoddinott & Bass, 1986). Sending reminders was not possible for the final online version as there was not a defined group with linked contact details.

To trial a more informal, face-to-face opportunity for participation (Adams et al., 2017) I also attended one of the parent's evenings. It was evident that the parents were significantly less receptive to engage with the research as they came to the meetings with premeditated agendas and most of them were accompanied by their children. Some of the parents showed interest in the project but took the questionnaire home rather than having support to complete it at the time. I empathised with their response and concluded that the parent evenings were not conducive environments for that purpose.

#### **4.2.4.1. *Barriers for implementation***

Considering the scale of this project and the cost of multiple attempts to contact participants, I was aware that maximising return rates for my research could be challenging. Time and cost constraints led to barriers potentially affecting return rates. These included the labels for return envelopes and meter postage being printed out 'en masse', therefore not being individually personalised; questionnaires being printed in black ink minimising a visual appeal to respondents and the survey being offered only in English language to multilingual audiences, which could have hindered participation from potential respondents who were not confident using written English. I also relied on the schools' administrators to distribute the questionnaires and send reminders without a system ensuring that this had been carried out as agreed.

Although offering more flexibility, the online version also limited the audience to those who were IT literate and had access to electronic devices. Despite these limitations, the online version was more effective in reaching respondents who were already actively advocating for their children via various platforms and these groups proved to be more willing to engage in research as discussed in the section that follows.

Upon reflection, I concluded that the crucial aspect of low return rates was also the bias of my personal judgement and aspirations. Having worked with parents for over a decade and having listened attentively to their concerns, I held a firm belief that my passion for and willingness to conduct a study aiming at improving practice would motivate participants to the same extent it drove me. I grew to learn that there were many other factors that I had to regard as essential in carrying out effective research with the studied group.

### **4.3. Survey distribution**

This section demonstrates processes involved in the data collection in the survey. Firstly, it describes the pilot study, then it presents the choice of participants and data collection, and it concludes with ethical considerations.

#### **4.3.1. Pilot Study**

To refine the techniques and tools planned for the survey, a pilot study was conducted (Arthur, et al., 2012). Firstly, it was conducted to analyse the paper questionnaire with its accompanying consent and information sheets, and secondly to seek feedback on the online survey with its consent statement. Three acquainted parents/carers of C/YP with SEND (aged 8,16 and 21) and the headteachers of schools taking part in the project provided verbal feedback on the clarity and suitability of questions in the hard copy to ensure the language was unambiguous (Kelly, Clark, Brown & Sitza, 2003; Fowler, 2013). The response to this pilot was unanimously positive and no further changes were applied at this point. Due to low return rates following the distribution of the questionnaire, I took a decision to access potential participants through different communication channels and redesigned the online version of the questionnaire.

Subsequently, I reviewed the online survey with the same parents and my supervisory team by asking them to complete it online and report on its user-friendly functions, clarity of the language used and its completion time. The

feedback provided on the online survey led to some minor adaptations in the navigation of the site to ensure multiple options for certain questions were activated; and, similarly to another research using mixed methods (Bryman, Becker & Sempik, 2008), the online survey was active for a particular period (4 months) to maximise access for participants, with detailed report on data collection depicted in the next section.

#### **4.3.2. Participants and data collection**

As mentioned above, the survey was initially conducted via hard copy questionnaires delivered in home-school diaries to 463 participants amongst parents and carers in three secondary special schools in the North of England. Additionally, the link to the online survey was included and sent via electronic communication means by school administrators. The questionnaires were delivered to parents with the information and consent letters, including the link to an online version of the survey and two pre-paid envelopes, one for the questionnaire and one for the consent forms (see the Appendixes 3, 4, & 5). As a result of this distribution, followed by a reminder sent electronically by the school administrators, 7 paper questionnaires were returned (around 2%). These responses were received only in paper copies and were subsequently included in the data gathered online at the later stage in order to respect the time and effort the respondents contributed to the project.

Following the low return rates from the phase above, I engaged in a period of reflection and discussion with the supervisory team regarding the possible causes and defining a new outline of data collection. Beside the barriers of maximising return rates discussed in previous section (see 4.2.3.3.), I recognised that the nature of constraints for participation in research for this group of respondents was vastly varied and I needed to engage with parents/carers who were already actively contributing their perspectives to shaping the societal awareness of their stances. I also acknowledged the fact that despite the sincere statement defining my role as researcher being superior to my role as a practitioner, my study was seeking views on the work with practitioners, which, for some participants, could have been difficult to separate

as I was also a practitioner working with C/YP with SEND. These realisations led to a change of approach to the recruitment of participants and I decided to approach parents and carers who were already actively involved in communicating their views and with whom I did not have a professional affiliation. Therefore, I contacted multiple organisations and online platforms that were actively working with parents of C/YP with SEND and they agreed to share the link and an introductory statement about my project on their social media. These included two different Parent and Carer Forums, an organisation run by parents to support Asperger's C/YP and their carers, the National Autistic Society, KIDS Charity, two organisations involved in research and partnerships with Autistic persons, a large city organisation working with schools and parents, and Special Needs Jungle (some of these organisations have been anonymised to ensure confidentiality). Some of these action groups were local and some were national; therefore, the data collected represents parental statements from across the country. The amended survey distribution resulted in 144 completed responses rendered between January and May 2018. All participants' C/YP were within the age range from 0-25 at the time (see Figure 9). In line with the 'rule of thumb' explored by Hill (1998), the absolute minimum of respondents varies between 25-30, I concluded that 144 responses were substantial enough to provide an effective base for data analysis (see Section 3.2.5). Furthermore, I continually observed the developments of the answers provided by respondents and was able to gauge the range of aspects discussed. The survey also served as the initial means of data collection and preceded the second phase of the study where the points raised were explored in depth during the interviews. These inferences reassured my decision to close the survey as saturation was reached by rich accounts of varied experiences from the open-ended questions and data from the closed questions which illustrated clearly defined points for conclusions.

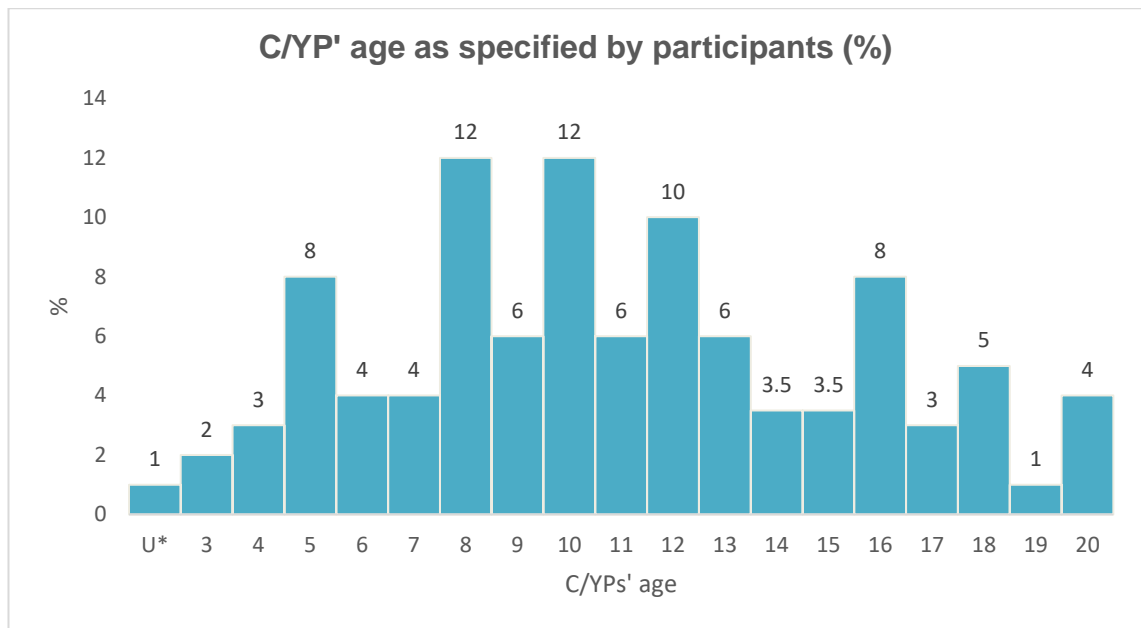


Figure 3 C/YP's age as specified by participants.

Noteworthy was that the identified SEND of C/YP in the survey resonated with the national trend where ASD and Asperger diagnoses were of the highest proportion (Figure 5). This meant that the respondents did not come only from one particular action group designed for families experiencing certain conditions, but from varied groups inclusive of all parents.

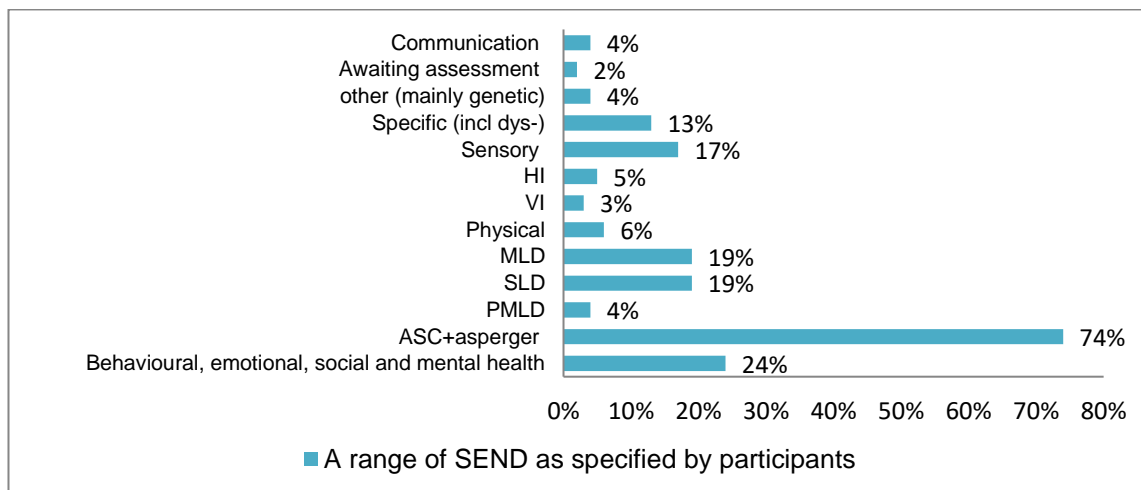


Figure 4 A range of SEND as specified by participants.

#### 4.3.3. Ethical considerations

Ethical approval was granted prior to data collection in accordance with the Sheffield Hallam University Ethics Committee guidelines (see Appendix 6). Participants were made aware that their participation was voluntary and that the findings of the study were going to be anonymised and could be used for publications in the future (see Appendix 3, 4 & 5). When the survey was adapted and the decision of gathering data only via online mode was taken, an additional approval was granted by the committee (see Appendix 7). The key ethical concerns that arose were the use of language, the clarity of informed consent, and the reassurance of anonymity. In relation to language, I paid attention to the language the questions were formed in to ensure that it would not cause any offence or convey assumptions about families in line with the 'no harm' tenet of ethical research (BERA, 2018). For example, I focused more on decision-making, rather than asking how the needs of C/YP were or were not met or whether their impairments were understood. Regarding the informed consent, I was conscious about having to include the information sheet and consent form as a whole introductory paragraph that would appear before the survey questions on the online platform. As some of the respondents would have used mobile phones, I had to ensure its conciseness while including all the essential information. The critical ethical issue for me here was the fact that the respondents could not ask any questions about the introduction. To address this issue, I included my email address as part of this introduction in hope that if there were any queries, I would be contacted. However, I am aware that, perhaps for anonymity reasons, respondents might have not opted to do so. The final concern regarded the anonymity for those respondents who wished to participate in the interviews as an extension of this study. I asked for their emails at the end of the survey, which could have been linked with their answers. To ensure this issue was addressed, I also provided my email address at the end, so that if respondents preferred to contact me individually, their survey responses were not linked to their identity.

#### **4.4. Survey Results and Analysis**

This section presents the findings following from the analysis of the quantitative and qualitative data sets gathered through the survey. Firstly, I outline the processes involved in analysis of each set of data. Secondly, I present the analytical frameworks utilised to interpret each data set, respectively.

#### 4.4.1. Quantitative data

This section illustrates the different types of analyses that were undertaken to establish the meanings being conveyed within the data and to depict potential correlations between variables. Qualtrics software employed to distribute and record data from the survey was used to generate the tables of raw scores and complete data sets were transferred from there to SPSS software to allow the calculations described in this section.

The purpose of this data was to establish what parents and carers think and therefore it was not designed to make predictions or test hypotheses (Cohen, Manion & Morrison, 2007). Consequently, this made the descriptive statistic a suitable strategy to present and analyse the data.

##### 4.4.1.1. Descriptive statistics

The first type of analysis utilised to interpret quantitative data was the tool of descriptive statistics. Prior to the calculations for descriptive statistics, I analysed the raw data and their relative frequencies (scores in a form of percentages) to investigate possible patterns (see Table 8) (Fraenkel, Wallen & Hyun, 2011). The scores in the table are presented in an absolute frequency (numbers) and corresponding percentages to illustrate participants' answers indicating the actual number of respondents (Lavrakas, 2008).

Table 9 Absolute and relative statistics

Survey statements	Strongly agree		Slightly agree		Neither agree nor disagree		Slightly disagree		Strongly disagree		Total
1. The outcomes of the EHC plan reviews are clear to me.	17%	23	24%	34	24%	34	15%	20	20%	28	139

2. I feel confident to ask professionals for support if I do not understand something about the review.	41%	58	22%	31	11%	16	13%	19	13%	17	141
3. I am actively encouraged to express my opinions at the reviews.	29%	41	23%	33	18%	25	17%	24	13%	18	141
4. I feel my opinions are taken into account when outcomes for the reviews are being created.	16%	23	29%	40	16%	22	22%	31	17%	24	140
5. I am informed regularly about the progress of the outcomes agreed at the reviews.	13%	18	14%	20	17%	24	24%	33	32%	46	141
6. I feel I can express my opinions openly.	34%	47	25%	35	13%	18	14%	20	14%	19	139
7. I feel I can ask for advice/clarifications openly.	29%	41	27%	37	17%	23	18%	25	9%	12	138
8. I feel I can plan my child's education with the support of other professionals during EHC plan reviews.	15%	21	21%	29	19%	26	22%	31	22%	31	138
9. I feel there is enough information and professional advice available for me to make informed decisions about my child's future.	9%	13	18%	25	14%	19	22%	31	37%	52	140
10. I feel my opinions have equal value to those of professionals.	13%	17	13%	18	12%	16	20%	27	42%	56	134

Analysing the relations between the questions and the responses gathered, I observed that parents feel quite confident to ask for support or clarifications (Q2), however, their opinions are less likely to be taken into account when decisions are made (Q4), and hold lesser value in comparison to the opinions of practitioners (Q10).

Through further analysis of categorising answers most frequently indicating 'strongly agree' in an ascending order, a pattern emerged; this pattern illustrated a clear division between questions that scored significantly under 29% and questions that were 29% and above (see Table 9). This division was created by identification of the largest distance in the frequencies of questions (there is a notable difference of almost 12% between Q1 and Q3). This distinctive variation in frequencies could be explained in the following dependence:

- although parents feel they are encouraged to express their views, are able to share their opinions and ask for support if they do not understand something about the reviews, the outcomes of the reviews are less clear to them. Furthermore, their views are not always taken into account as they are experienced as carrying a lesser value to those of professionals. Likewise, the



exchange of feedback related to a child's progress is not frequent enough and the level of information and professional advice to make informed decisions is inadequate.

Noteworthy is the observation that in the ascending order of 'strongly disagree' answers 7 out of 10 questions correlate with their respective values of lower than 29% or 29% and over. The discrepancies can be noted in question 1 'the outcomes of the EHCP reviews are clear to me', question 4 'I feel my opinions are taken into account...' and question 8 'I can plan my child's education with ...' which all fall into the opposite category of either significantly under or significantly over the 29% respectively. This could suggest that the answers to those questions have the most equally spread proportions of experiences being positive and negative. Equally important is the fact that the three highest scores in 'strongly disagree' correlated with the three lowest scores of 'strongly agree', making these three questions (Q5, Q9 and Q10) the constant occurrence in this data set.

Following on from this observation, I calculated a combined score of answers in agreement and disagreement without their range indicating strong or slight positions. I was curious to find out if the results would mean any changes to the questions within the division explored above.

In combined scores of answers from both 'strongly agree' and 'slightly agree' I investigated whether the tendency between the questions changes. As a result (see Table 2) the grouping of questions did not change; however, there was a slight difference in their order with the lower group placing question 9 in third rather than first place of the ascending order. As can be seen in Table 9, for the purpose of this grouping I assigned the following similarities between the scores: group 29% and below=group 52% and below, group 29% and over=group 52% and over.

Table 10 Combined scores for answers with agreement

Survey statements	Strongly agree		Slightly agree		total
9. I feel there is enough information and professional advice available for me to make informed decisions about my child's future.	9%	13	18%	25	27% 38
10.I feel my opinions have equal value to those of professionals.	13%	17	13%	18	26% 35

5. I am informed regularly about the progress of the outcomes agreed at the reviews.	13%	18	14%	20	27% 38
8. I feel I can plan my child's education with the support of other professionals during EHC plan reviews.	15%	21	21%	29	36% 51
4. I feel my opinions are taken into account when outcomes for the reviews are being created.	16%	23	29%	40	45% 63
1. The outcomes of the EHC plan reviews are clear to me.	17%	23	24%	34	41% 57
3. I am actively encouraged to express my opinions at the reviews.	29%	41	23%	33	52% 74
7. I feel I can ask for advice/clarifications openly.	30%	41	27%	37	57% 78
6. I feel I can express my opinions openly.	34%	47	25%	35	59% 82
2. I feel confident to ask professionals for support if I do not understand something about the review.	41%	58	22%	31	63% 89

In combined scores of answers from both the 'slightly disagree' and 'strongly disagree' components the groupings of answers did not change either; the highest difference between the frequencies meant that the groupings were determined by the 11% difference between Q8 and Q5.

Table 11 Combined scores with answers with disagreement

Survey statements	Slightly disagree		Strongly disagree		Total
7. I feel I can ask for advice/clarifications openly.	18%	25	9%	12	27% 37
2. I feel confident to ask professionals for support if I don't understand something about the review.	13%	19	12%	17	26% 36
3. I am actively encouraged to express my opinions at the reviews.	17%	24	13%	18	30% 42
6. I feel I can express my opinions openly.	14%	20	14%	19	28% 39
4. I feel my opinions are taken into account when outcomes for the reviews are being created.	22%	31	17%	24	39% 55
1. The outcomes of the EHC plan reviews are clear to me.	14%	20	20%	28	34% 48
8. I feel I can plan my child's education with the support of other professionals during EHC plan reviews.	22%	31	22%	31	44% 62
	23%	33	33%	46	56% 69

5. I am informed regularly about the progress of the outcomes agreed at the reviews.					
9. I feel there is enough information and professional advice available for me to make informed decisions about my child's future.	22%	31	37%	52	59% 83
10. I feel my opinions have equal value to those of professionals.	20%	27	42%	56	62% 83

#### 4.4.1.1.1. Summary

Based on this survey data, alone, however, the following conclusions were drawn (which were used as the starting point for reflection during interview discussions, as explored further in Chapter 5:

- parents feel confident to ask for advice and information;
- they can mostly express their views openly;
- they feel they can ask professionals for support if they do not understand something
- they are actively encouraged to express their opinions.

Despite these positive findings illustrating practices where parents can voice their standpoints, survey data also suggest that what takes place in response to these communications creates problematic situations in partnerships. Parents stated that there is not enough information and advice available; they are not informed about their child's progress regularly enough; the outcomes for their children are not always clear to them and their opinions do not seem to bear the same strength and value as those of professionals, nor are they often taken into account when decisions about their children are made.

It can be concluded that however positive the developments of allowing parents to voice their stances can appear, they cannot be successfully applied if what is being said is not taken into account when decisions about children's futures are made, when the questions asked are not answered adequately with enough advice and information available, when jargon used by practitioners is prevalent or when the communication about children's progress outside of home is not efficient.

Although this study represents a small convenience sample which might not be reflective of general trends, the quantitative data from this survey did identified the discrepancies between what the Code's guidance promotes and the lived experiences of families. This indicates the need for further considerations regarding practices of services involved in education, health and care provisions for children with SEND and their co-productive partnerships with these families. Indeed, this diversity of experience was also suggested by some additional data generated through an initial quantitative analysis of responses to open-ended questions presented below.

#### **4.4.1.2. *Additional quantitative data***

During the initial analysis of the data gathered through question 2: 'How would you describe the relationship with professionals who work with your child?', I discovered that participants provided very short examples of their experiences, mostly resulting in one, two- or three-words descriptions. Through the process of initial thematic analysis, I grouped them into categories that would capture similar types of answers. The discovery of the types of answers led me to present these findings in a quantitative form as this illustrates the tendencies. Displaying the findings in the graphs allows for an instant visual representation of the comparison between parental experiences of the core provisions as presented below (see Figure 11, 12 and 13).

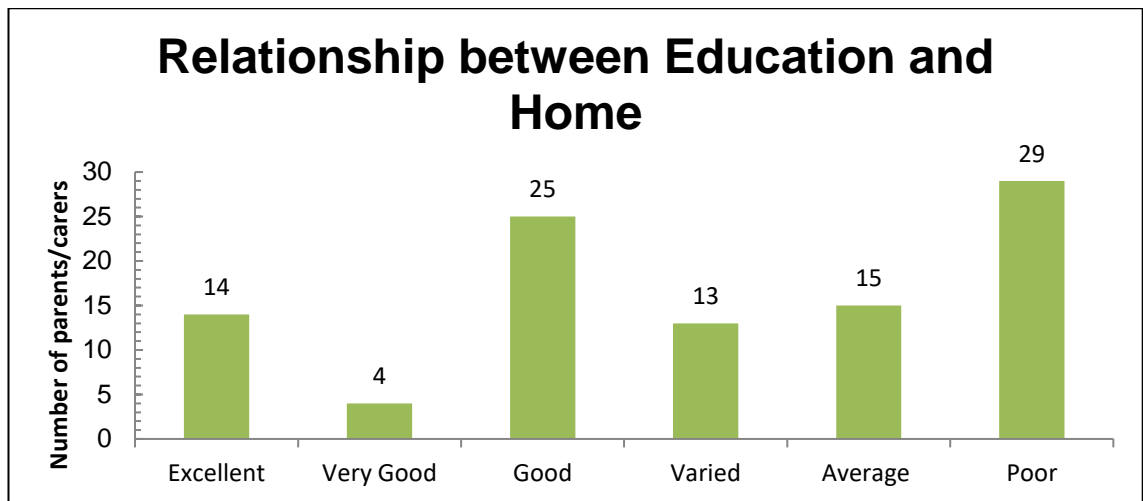


Figure 5 Relationship between Education and Home

The number of 'good' relationships is very close to those deemed 'below good', which suggests that the relationships between parents and practitioners vary significantly (43 against 57; 15% difference). This calculation, however, is only representative to this particular cohort of participants. Although there are many instances reported to be 'excellent-good' in relation to relationships, there are still families whose experiences have been inconsistent or satisfactory, which can be read as the principles of the Code not being effectively reflected in practice. The similar levels of 'good' and 'poor' relationships being on similar levels was a point that I decided to further explore in the interviews, as this was also a repeated pattern in 'relationships between care practitioners and home'.

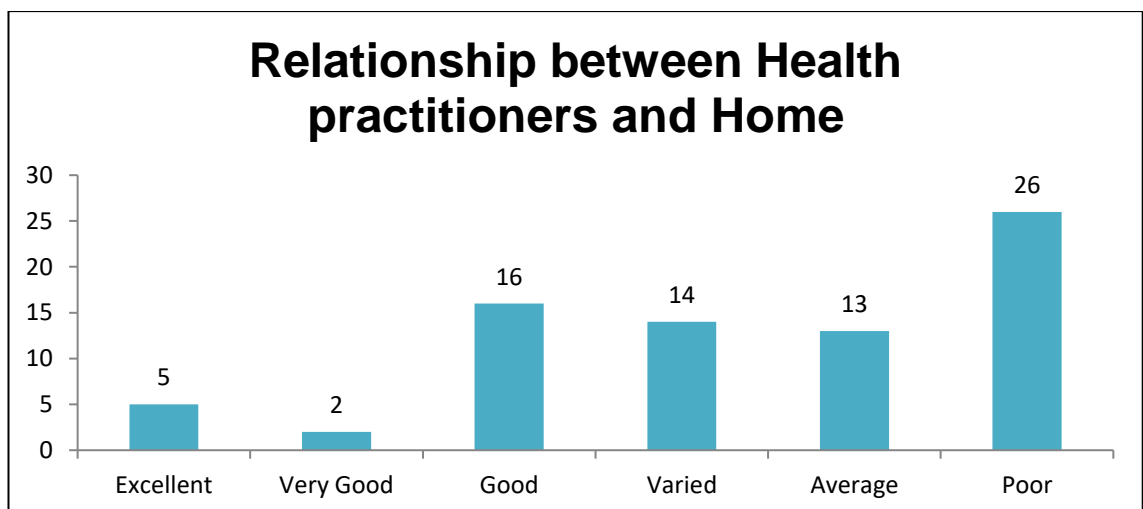


Figure 6 Relationships between Health and Home

Relationships between families and health practitioners tended to be viewed less positively than those with educational professionals. The level of +‘poor’ relationships is clearly the highest and the ‘varied’ and ‘satisfactory’ relationships are significantly higher than the good/very good/excellent ones, suggesting the experiences of families are more negative than positive (calculations show the disparity of around 50%). Given these points, it is evident that the health practitioners could be perceived as less inclusive of parental expertise than the educational and care practitioners. In reflection, I contemplated whether the educational practitioners are more frequently exposed to working with parents than health practitioners due to the nature of the profession, e.g., all children require education but not all children require medical attention, therefore the health practitioners might see the family infrequently in comparison to practitioners in education. Therefore, the educational professionals have more opportunities to develop their working relationships with parents/families than the medical professionals.

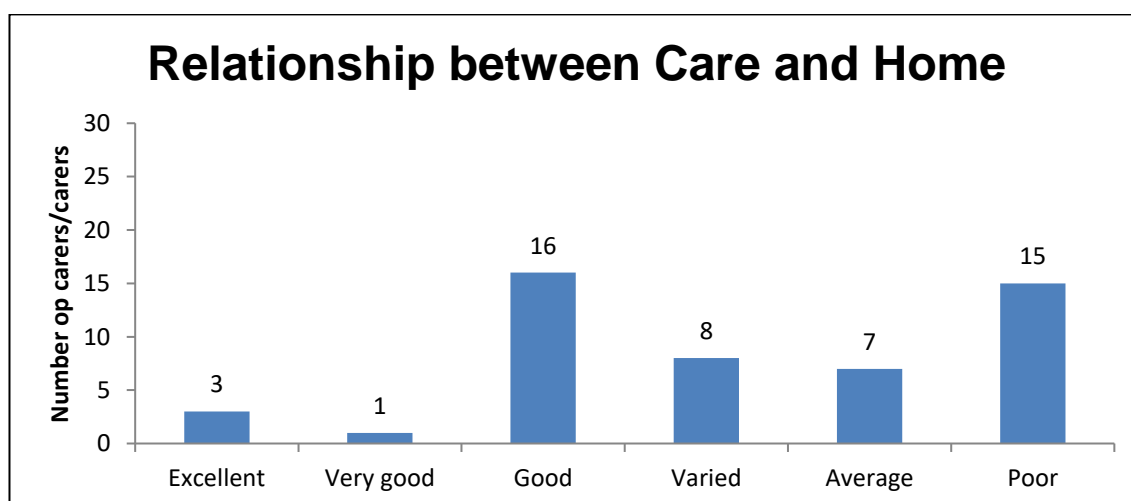


Figure 7 Relationships between Care and Home

Responses reflecting relationships with care practitioners were 25% less frequent than those for health and 50% less frequent than those for education. However, it is noteworthy that the tendency of poor and good relationships being on par is prevalent. 50% more respondents identified their relationships with care practitioners as less than good. The evidence for excellent or very good relationships was significantly lower than those with education

practitioners but on a similar level for those with health practitioners. It suggests a similar similarity between the frequencies of use in services as care provision is not necessarily accessed by all pupils, unlike the education provision. It is essential to point out that the expression 'varied' can imply some positive and some negative experiences, which these statements do not specify and can therefore be either divided between both good and poor examples or treated as an unknown quality together with the 'unsure' statements. This, however, would not affect the calculations for the similarities between good and poor practices, but it would place the relationships in more equal scale between 'good and more than good' statements in opposition to 'less than good' statements.

#### 4.4.1.2.1. Summary

The breadth and the length of the experiences of each respondent's experience would have affected their opinion of the services and practitioners representing them. There is a visible difference in the frequency of accessed services as 100 respondents reflected on relationships with practitioners in education, 76 in health and only 50 in care. The overall number of participants in this survey was 144, illustrating that the participants who answered the closed questions did not always respond to the open-ended questions. Some parents indicated that they had no experience of health or care practitioners because their children have not required these services. This could indicate that the number of responses reflected those families' need or families' lack to access care or health provisions rather than not having an opinion on the nature of these relationships.

Another particularly notable finding is the similarity of the frequencies of 'good' and 'poor' indicators in education and care services being plotted on similar levels. This can be interpreted as the evidence of those practices being extremely varied. The examples of these variations and the possible reasons for them will be further explored in the process of interviews.

Finally, these findings suggest that in all three core provisions the 'above good' practices have received the lowest score. In consequence, it can be concluded that those practices are still less experienced by parents than those of a more inadequate or ineffective nature, classified as 'below good' level. However, this conclusion is tentative as statistical tools of analysis were not used in this project.

#### **4.4.2. Qualitative data**

This sub-section presents the data analysis framework and the results rendered from both open-ended questions. Processes involved in a Thematic Analysis (TA) framework are detailed first and are followed by a section illustrating the identified themes.

##### **4.4.2.1. *Thematic Analysis (TA) framework***

Thematic analysis (TA) is a widely used approach to analysis of qualitative data, and it aims at systematic identification, organisation and depicting patterns of meaning, so called themes, across a data set (Braun & Clark, 2012). Although, historically being undermined as lacking clear outlines of procedures (Terry et al., 2017), Braun and Clarke provided a robust framework of TA, which since then gained popularity worldwide as a reputable method of analysis for qualitative data.

The flexibility of the TA approach also offers a theoretically independent orientation and is sometimes described as a bridge between the qualitative and quantitative data analysis (Terry et al., 2017). However, the main premise of TA, as described by Clarke and Braun (2013) is situated within the qualitative paradigm, therefore addressing the multiplicity of the 'truth' and the significant role of the researcher's subjectivity (Cohen & Manion, 2014).

The main tool supporting the TA analysis is the coding process; this process can be either deductive or inductive in nature. While deductive coding relies heavily on coding reliability, it is situated more within the positivist orientation,



where the codes require cross-checking with another researcher to minimise bias and the researcher's subjectivity ((e.g., Boyatzis, 1998; Guest et al., 2012, Joffe, 2012). This assumption opposes the inductive coding process, where the researcher familiarises themselves with data and the codes are driven by data, rather than predetermined theory, thus creating a more organic process of coding and theme development (e.g., Braun and Clarke, 2006; Langridge, 2004). There can also be an amalgamation of both, which was adopted in my study; however, the researcher needs to state which variety is the driver for the analysis as this will reflect the theoretical underpinnings and the nature of data affected by the semantic factors of the language (in the deductive approach). It is also important to acknowledge, that even an inductive approach cannot be fully inductive as the researcher comes to their interpretations with knowledge and certain positionality, all of which will contribute to their inferential processes of data analysis (Braun & Clarke, 2006). This amalgamation of worldviews also correlates with the underpinning philosophy of pragmatism, where the researcher adopts the most suitable methods to seek answers to their research questions ((Wahyuni, 2012; Morgan, 2014) (see Section 3.2.3.).

As the interpretation within the inductive approach remains within the subjectivity of the researcher and their subject knowledge, research skills and positionality, the quality of analysis follows a range of strategies to ensure rigour and systematic approach is maintained throughout. Due to the development of themes and continuous revisits of data as part of the processes involved in analysis, the researcher can produce a comprehensive trail track of all his choices, substantiated by notes and reasoning showing a greater depth of engagement with the data, rather than focusing on 'accuracy' of coding.

Although described as inductive in orientation, TA analysis applied in this study, as in the case of any other research using TA, requires the researcher to identify their theoretical underpinning. Due to TA's flexibility within the theoretical lens, it can cater for different paradigms and methodological stances (Clarke & Braun, 2013) making it a valuable analytical tool in this mixed methods study.

As I progressed with the coding process, I focused on the latent meaning of participants' utterances, enabling a more critical approach to deducing what the participants might have meant by their expressions (Clarke & Braun, 2013).

This focus was employed as opposed to the semantic meaning – the meaning of the language – which would aim to analyse the surface of the language used by participants (Clarke & Braun, 2013).

#### **4.4.2.2. *Thematic Analysis process for survey data***

##### **4.4.2.2.1. Reflexivity exercise**

Following Clarke and Braun (2013), I have adopted the reflexivity exercise they recommend before completing the process of analysis. It consisted of answering two questions: ‘what are the assumptions, if any, I hold about the research topic?’ and ‘what are my values and life experiences, and how might all this shape how I read and interpret the data?’ (Clare & Braun, 2013). Below, I illustrate my thinking at the time.

##### **Open-ended Question 1:**

The research topic has been ignited by my passion for working closely and effectively with parents of C/YP with SEND. Within my career in the SEND field, I have met many inspiring parents who have shaped my teaching approaches and contributed to my growing understanding and the empathy I have developed as a practitioner. I have always valued parental contributions and guidance; therefore, the outcomes of the parent-practitioner debate evident in research were surprising for me. My assumptions varied significantly from the reports of disempowerment and exclusion parents have recounted within academic publications. It took me a considerable amount of time to appreciate that what I have created within my teaching practice was not resembled in many families’ experiences. This realisation contributed to the dilemma I encountered, in which I was the researcher-practitioner writing about professionals and their approaches, attitudes and practice. I was fully aware of the systemic constraints practitioners, like myself, were under, and I still believed that some of the practices could be changed without the transformation of policy necessarily. My assumptions revolved around practitioners’ empathy, active listening, and non-defensive behaviours in (as can often occur) interactions that are emotionally

charged. I was also conscientious of not comparing parental stories with my own practice and defending practitioners whom I could associate with on some levels.

### **Open-ended question 3:**

Following deeper readings around critical disability studies and the discourses addressing conceptions and misconceptions of dis- and ableism, I was aware that I did not represent the lived experiences of the participants in my study. This awareness contributed to my conscious reflection on not taking a role of a 'saviour' but trying to engage with the participants and their stories in an exchange that accentuated their knowledge as experts on the subject. I also acknowledge that as a young parent of a non-disabled child, I have encountered many situations where my parental opinion was received as an over-emotional reaction and dismissed by practitioners within Children Services; the feeling of disregard towards my worries about my young child influenced my future interactions with these particular practitioners, leaving me unsupported with unanswered questions. Although these encounters could have been similar in nature, I recognise the need to look at the lived experiences of the participants in separation to my own when examining data.

By employing this reflexivity exercise, I have scrutinized and appreciated my positionality towards the project and data and have gained deeper awareness of how my thinking and inferring processes could affect the outcome of the analysis process. Furthermore, it enabled me to become more conscious of my own deep-seated values and the understanding I held about the subject of partnerships.

#### **4.4.2.2.2. Thematic analysis process**

TA is defined as a process divided into 6 phases; I will now delineate how these steps were fulfilled in the analysis of the qualitative data from the survey. It is essential to note that the nature of the analytical processes is iterative and recursive as the researcher moves forwards and backwards between the phases, not necessarily in a linear fashion (Braun & Clarke, 2006).

## 1. Familiarisation with data.

At this stage I read all the answers and ensured that the punctuation and grammatical accuracy was maintained. I recognise here that this process was influenced by my understanding of what some sentences meant, although the punctuation was unclear. This could have led to some misinterpretation, which I was not able to clarify, as the responses were anonymous. However, there were minimal instances of idiosyncratic punctuation, therefore this limitation was insignificant. Consequent readings enabled me to start identifying some broad areas I noted within the data. These included:

- The extended age limit of C/YP being increased to 25 within the guidance of the Code. This meant there were legal obligations placed on the public service to plan provision for people with SEND beyond the age of 18.
- The lack of expertise and guidance for the EHCPs, which often did not reflect C/YP's actual needs.
- The mistrust towards LEAs, and other services within the EHC domains.
- The miscommunication between families and services.
- The lack of collaborative practices.
- The impact of practitioners' knowledge and attitudes on partnerships with parents.

Reflection on the above points of interest, in addition to the 'reflexivity exercise' made me more aware of the concepts I am drawn to as a researcher. For example, as discussed above, I was looking for examples of empathetic, reciprocal practices, but some parents might have expected the practitioners to be the 'more knowledgeable others' – the experts. Therefore, I was open to listening to different views of what parents deemed as 'positive' practice of partnerships in their opinion. Consequently, I continued to diligently analyse all the data to ensure I dedicated enough time and consideration to all the participants' utterances, not only those which resonated with my own observations (Terry et al., 2017).

## 2. Generating codes.

To begin this phase of analysis, I considered the theoretical assumptions that underpinned data analysis (Terry et al., 2017) and situated this project between the inductive and deductive approaches to TA – a hybrid approach (Fereday and Muir-Cochrane, 2006; Swain, 2018; see Section 3.3.1.). In the inductive part of this approach, I initially coded all the data that related to participants' experiences following the implementation of the Code in 2014, making all references to past experiences from before 2014 redundant. I also decided that any accounts of parental perceptions of what other parents are or might have thought or experienced were redundant, as they did not reflect participants' direct lived experiences and could have been misinterpreted. All redundancies are clearly marked in the Codebook (Appendix 8) and the Coding document (Appendix 9) (Guest, MacQueen, & Namey, 2011). The deductive part of the hybrid approach involved looking back through the data to indicate parts that corresponded with debates around partnerships that were already established within the literature. The combination of perspectives in the hybrid approach enabled me to analyse the data in relation to the parent-practitioner discourse, for example the issues of empowerment or expert knowledge, as well as to make inferences of less obvious or less documented aspects parents reported on. For example, I realised that there was strong evidence in the data that parents were offered opportunities to express their opinions, however their contributions were not included in the shaping of policies or practice. At a first glance, the data could be suggesting that the practice is moving towards the Code's expectation that encourages parental contributions to be valued and sought after; however, as I shall explore in Section 4.4.2.3. the evidence also suggests that this expectation is often fulfilled on a more superficial level. As data sets do not require coding of every line, some segments of data might also be coded multiple times. I stated explicitly what each segment represented to ensure that I could accurately assign the codes into themes without having to revisit the whole raw datasets to ensure accuracy (Terry et al., 2017). The codes also underwent revisits and re-wording as I progressed through the analysis to ensure that there are not many very similar codes with overlapping content, as this would oppose the purpose of data reduction which codes are aimed at (Braun and Clarke, 2006). Following thorough coding, I compiled a list

of codes that adequately identify both patterning and diversity of relevant meaning within the dataset.

### 3. Constructing themes

In the third phase, I began identifying prominent patterns in meanings between codes that I generated. I examined the codes further by clustering, combining, or splitting them to ensure the themes remained representative of the codes that I included in them (Braun & Clarke, 2006). None of the codes took a role of a theme; however, theme 1 engulfed theme 4 in the process of analysis. To illustrate the preliminary themes, I mapped the originally emergent themes in Table 12.

*Table 12 Initial themes map for survey*

Theme 1: EHCP process	Theme 2: Practices enabling parental 'voice'	Theme 3: Practitioners' attributes, knowledge, and attitudes	Theme 4: The legal scene of EHCP	Theme 5: Systemic changes required
Person-centred approach  C/YP's views and needs in present and future.  Theory v practice  Extended age limit and legal strength of the EHCP	Seeking parental 'voice'  Sharing information  Change in practitioners' approaches.	Empathy  Treating parents as equal partners	Extended age limit and legal strength of the EHCP  Communication  Meaningful content  Practicalities of EHCPs reviews	Accountability  When the trust in Public Services is lost  Implications for training in co-production  Implications for policy changes

Through further analysis, a slightly adjusted map was created to reflect the changes made (see Table 13). The adaptation in the themes occurred as a result of realisation that theme 4 had many overlapping pieces of information with theme 1, namely that the legality of the EHCPs were an integral part of the EHCP process.

*Table 13 Reviewed themes map for survey*

Theme 1: EHCP process	Theme 2: Practices enabling parental 'voice'	Theme 3: Practitioners' attributes,	Theme 4: Required systemic changes

		knowledge, and attitudes	
<ul style="list-style-type: none"> <li>• Person-centred approach</li> <li>• C/YP's views and needs in present and future.</li> <li>• Theory v practice</li> <li>• Extended age limit and legal strength of the EHCP</li> <li>• Communication</li> <li>• Meaningful content</li> <li>• Practicalities of EHCPs reviews</li> </ul>	<ul style="list-style-type: none"> <li>• Seeking parental 'voice'</li> <li>• Sharing information</li> <li>• Change in practitioners' approaches.</li> </ul>	<ul style="list-style-type: none"> <li>• Empathy</li> <li>• Treating parents as equal partners</li> </ul>	<ul style="list-style-type: none"> <li>• Accountability</li> <li>• Trust in Public Services</li> <li>• Implications for policy changes</li> </ul>

#### 4. Reviewing potential themes

In this stage of the analysis, it is important to ensure that clear boundaries between themes are maintained (Terry, et al., 2017). This often means that the majority of the codes are only assigned to one theme (Braun & Clarke, 2006). Following the adjustment of the themes map, I reached that goal, and all the codes were related to different themes. This phase also played a crucial part in ensuring that all the codes were representative of what the theme aimed at encapsulating (Clarke & Braun, 2013). To ensure this step was fulfilled, I, once again, scrutinised each code with the raw data excerpts for meaningful relations and representations (see Appendix 10).

#### 5. Defining and naming themes

To ensure clarity, cohesion, precision, and quality of the developing TA (Clarke & Braun, 2013), this phase of the analysis provided a definition for each theme. This process aimed at supporting the clarity and the scope of each theme and ensuring that the researcher was confident that the names and descriptions for the themes represented their content. A codebook that outlines each theme with its definition and respective codes was constructed for this purpose (see Appendix 11).

## 6. Producing the report

The final stage of the analysis involved creating an overall 'story' by using the themes and their meanings to provide an interpretation of the data gathered (Braun & Clarke, 2006). The 'story' about the data is supported by excerpts from participants' responses to posed questions to illustrate the diversity of meanings that were represented (Terry et al., 2017). These will be presented in the following sub-section.

### **4.4.2.3. Findings**

This sub-section demonstrates the report of findings and their analysis. Four themes (see Table 13) will be discussed with the support of relevant data extracts.

#### 4.4.2.3.1. Theme 1: EHCP process

The aim of the first question was to identify any aspects of the EHCP process that met parental expectations of co-productive practices, which were inclusive of families' contributions, needs and wishes. It was formed in accordance with one of the stages of the Appreciative Inquiry process employed to design the questions: the appreciation for the discovery stage (see Section 4.2.2.). It was intended to elicit those elements of the EHCP process that were perceived by parents as collaborations that effectively lead to meeting their C/YP's needs.

Despite the fact that around 20% of participants asserted that there were no positive aspects of the EHCP processes in their experiences, 101 participants who provided their answers to this open-ended question specified numerous examples of practices meeting their expectations, which are captured in this report.



## Person-centred approach

Participants expressed how important it was for them that the plan contained all the provisions in one document that was available to them and to all practitioners who are involved in Education, Health or Care services. For example, as stated by Parent 118:

*'It's an opportunity to think about all of your child's needs and get it down on paper'. (Parent 118)*

The combination of all services being specified in the plan was also identified as an improvement from the Statements:

*'There is more of an expectation on other professionals involved with your children to attend and submit a report as opposed to just teachers.'* (Parent 22).

This further supported all parties involved to discuss the needs of an individual and ensure that the planned provision is clear to all involved:

*'Acknowledgment that he has a problem, and it needs addressing universally with all staff and parents running from the same plan'* (Parent 132).

The shift towards a more holistic approach in assessment of children's needs was identified as a positive facet of the process:

*'Pulling everything together including social care and health to 'aim for' the young person being assessed holistically'* (Parent 78).

*'These plans totally look at the child as a whole e. g. regarding anxiety and being away from the family or in large groups'* (Parent 98).

The space for collaboration between services that the EHCP review process allowed meant that parents could explore potential future provisions and engage in discussions where their concerns could be addressed, providing parents with reassurance about their C/YP's future:

*'Offers time to consider and air concerns and fears that a parent or carer may have about future provisions'* (Parent 23).

## **C/YP's views and needs at present and in the future**

Besides being identified as crucial to the positive outcomes of the collaborations through the EHCP review, the person-centred approach employed to discuss the individuals' needs was also described as a means to ensure the plans are reflective of the child's changing needs, allowing the provision to be reviewed and adapted accordingly:

*'Allow you to review progress at least annually and to express views as to whether provision is still valid, or things need changing' (Parent 131).*

And as the needs change, they are being monitored to ensure the provision is efficient and what is and is not working well is adequately addressed:

*'Change to see what is working and what is not. For example, first plan advice for the use of fidget toys and emotion cards, these were not as effective so could look at other options' (Parent 6).*

The additional focus of the EHCPs on the needs outside of core curriculum, like personal care, social skills and speech and language skills were appreciated by parents:

*'Positive aspects are addressing needs off curriculum like personal care, social skills, and speech therapy' (Parent 72).*

Following on from the person-centred approach, participants praised the prominent existence of opportunities for their children being offered platforms to express their views, ultimately affecting the direction of the provision, for example:

*'That my son and his wishes are absolutely central to the process' (Parent 44).*

The effectiveness of the collaboration which leads to appropriate provision, was also reported to be successful through the creation of SMART targets:

*'Smart targets-where targets are broken down into smaller more achievable measurable targets' (Parent 87).*

*'the EHC gives a clear plan of future goals and how they will be achieved and in what time frame' (Parent 23).*

Two participants stated that, in their circumstances, the EHCP allowed their children to be placed in an appropriate setting altogether, perpetuating the strength the collaborative process the EHCP can have on adequate support for C/YP with SEND:

*'It allowed me to get my son into a more appropriate school than without EHCP'* (Parent 62).

*'The EHC post 19 gave support to go to residential college'* (Parent 84).

### **Theory versus practice**

Beside the 20% of participants who did not provide responses to the positive aspects of the collaborations, around 10% of participants sounded reluctant about the enactment of the assumptions of the Code in practice, claiming that the idea of the EHCP collaborative and co-productive qualities was "only a great idea in theory" in their experiences:

*'Brilliant reform in theory in application appalling. after repeated letter/emails of enquiries formal complaint and contact via councillor SEN are now actually communicating with me. The plan was appalling and no better (probably worse as things are in the wrong sections so in effect, I cannot enforce them) than her statement, but as they are finally regularly communicating, I am hopeful of resolving this'* (Parent 144).

While there was indication that some of the EHCPs were appropriately designed, this parent's account suggests that the document might sometimes be ignored by the school:

*'If it is right, with detailed and SMART objectives with detailed provision, then you have a tool to use with the school which they should not ignore'* (Parent 55).

An equally frustrating facet that was reported was the ineffective collaboration between services, sometimes driven by poor attendance of practitioners at the reviews:

*'Make professionals get together to focus on your child if they bother turning up'* (Parent 36),

*'The idea is great, but always a fight to include mental health issues etc. Council never ever listen without a fight'* (Parent 24).

Parent 26 listed the advantages of the EHCP becoming a 'living document', which can be adapted according to changing needs of a C/YP and through reflection on progress an individual makes allowing for their future to be planned effectively:

*'I like that it tries to be person centred and I think that it has a lot of potential to be more of a 'living document', used by families as a tool for reflection on what has been achieved and planning for the future – do not think we are there yet!'*

The number of those less complimentary comments were significantly lower than the overall number of statements providing the examples of positive practices (10 out of 101) which could suggest that the tendency in collaborative relationships is increasing and some parents feel more able to affect the provisions for their children. Nonetheless, families whose views are disregarded and C/YP's needs are not met continue the struggle of ineffective partnerships.

The exemplified summary of parental views related to positive aspects of the EHCP process and the features of parent-practitioner relationships that are shaped through this process suggest some parts of increasingly collaborative practices are present. They include all provisions contributing to the plan, which is created in a holistic approach relevant to particular pupils' current and potential future needs. The process continues to be affected by individual parental circumstances and individual professionals contributing to the experiences. This is prominent in the sceptical accounts of some respondents where the trust in the success of those collaborations appeared to be undermined. The interviews explored the reason for this occurrence, seeking examples of how this trust can be rebuilt.

### **Extended age limit and legal strength of the EHCP**

The process of EHCP is guarded by the Children and Families Act 2014 and this legislation results in the EHCP being a legal document, which can be appealed to through a tribunal. Parents in the survey agreed that the legality of the EHCP is perceived as a positive change in the process. However, it can only be positive if the knowledge about the law and the legislation is amalgamated with practice that reflects the adherence to that law:

*'I would just like the plans to be followed. Everybody gets together but then it is all ignored' (Parent 79),*

*'Practitioners to have a better understanding on their legal duties and SEND Code of Practice' (Parent 78).*

This can suggest that despite the fact the legislation was implemented over 4 years ago the *'system is just a tick box process...'* (Parent 29).

This respondent further elaborated on their statement indicating that, in her experience, the plan was not reflective of her wishes when they were different from the practitioners' opinions:

*'...In my son's last EHCP meeting my views were listened to but dismissed and ignored. I felt the professionals had made decisions and were inflexible to changes' (Parent 29).*

The legal obligation of the content of the plan covers the execution of the provision outlined in that plan, including processes of assessment that would inform diagnosis or indicate a level of support required:

*'That assessment actually took place when obviously indicated' (Parent 45).*

Many participants asserted that the effectiveness of the new system is strengthened through the legal status of the EHCP document and the fact that it puts the obligations on services to create opportunities for the reviews to take place and for the agreed actions to be fulfilled by practitioners involved in core provisions:

*'The legal aspect and weight that it can carry in obtaining support for child's needs' (Parent 55),*

*'There is a legal framework to work to although the refusals and appeals should not be necessary' (Parent 78).*

The legal obligation permeates to educational provision respecting and accepting the advice from health provision:

*'legal obligation for son to be tube fed in school so he can access education. Education has a legal obligation to listen to and follow all medical advice'* (Parent 33),

Similarly, the health and social care practitioners have a legal responsibility to provide support for young adults with SEND beyond the age of 19 years old:

*'The only one is that professionals and health and social cannot wash hands of young people at 19'* (Parent 84).

## **Communication**

The most repeated statement in this category implied that parents want to feel 'heard':

*'Parents' concerns and opinions taken seriously'* (Parent 29).

This could be achieved by enabling frequent feedback gathering parental views and by accepting parental perspectives on their child and treating them as valuable contributors of equally worthy expertise in decision-making processes:

*'There needs to be more opportunity to be heard'* (Parent 119),

*'To feel that parental input was of equal value to professional input'* (Parent 11).

The divide between families and professionals is furthered by the time and effort that is spent in opposing each other's side rather than ensuring co-productive practices are developed:

*'More working together and not fighting against; it is way too draining for parents to get what a child needs...Parents have enough on their hands, to add the extra fight to get there EHCP right, is making people ill'* (Parent 9).

Parents described communication (5 instances) as requiring further consideration in order to ensure it is: consistent, proactive, easily accessible, frequent and individually centred:

*'respect for parents' views and situations. [Be] Proactive - parents not to do all the chasing' (Parent 32),*

*'I get very little information about my child's day, other than what lessons he has had and if he has had any behavioural episodes. I would like more information about the strategies they are using with him, SLT input and any good moments, interactions with peers and staff' (Parent 105).*

Improved communication in return would enable parents to support their child more effectively:

*'The LEA and so-called experts should listen, listen again. Without a dialogue set to the understanding of the parent/carer how is anything going to improve. Moreover, without understanding the carer cannot support the work in school' (Parent 24).*

Consistent collaboration between home and school has been identified as another facet that could be improved:

*'I would like to discuss on regular basis difficulties of my child and be informed about the progress. I would like to work as a team with school, teachers, social services, with anyone who could help me do improve my child's attitude and prepare him to his adult life' (Parent 82).*

Furthermore, participants felt that effective communication would support successful collaboration, not only between home and school, but also between families and other services involved. Fruitful collaboration between the professionals of multi-agency support teams would also allow productive sharing of necessary information that would affect the timings of provisions being implemented and avoid the need for repetition of lengthy or complex information by parents:

*'...no long delays, repeating information, sharing information with the right, vital agencies so this does not happen' (Parent 69).*

Similarly, it was reported that detailed information would enable parents to make informed decisions about their children's future, especially the transition to adulthood services:

*'Greater information about processes, particularly the strange and different worlds of post 16 and post 19, and how social care might need to have some involvement in your young person's life, even if this was not needed previously'* (Parent 64).

If a central hub of all provisions was available to 'first port of call' practitioners, transparent and consistent information would be shared between services and families:

*'Them know what is on offer instead of asking a parent what they want them to do'* (Parent 77),

*'To give clear information that is consistent from department to department and from professional to professional'* (Parent 46).

Finally, there are pupils whose needs are not substantial enough to warrant the EHCP referral, but their needs are great enough to affect their functioning in the learning community. Those C/YP who are likely to 'fall through the net' are equally entitled to individualised plans, but there are accounts of parental concerns in these instances being 'brushed off' and any support becoming impossible to obtain:

*'That the plans be more widely available to the likes of children with ASD. It seems unlikely my child will have an EHCP which means there will be no legal requirement for the school to meet his needs from my understanding. They agree he has needs but is not as needy as others and is therefore overlooked. It also makes it difficult to obtain help from other agencies and professionals where a plan is unlikely'* (Parent 51).

## **Meaningful content**

For the EHCPs to be reflective of children's changing needs participants felt that the plans need to be accompanied by the child centred approach, including the context of their family and the child's voice, which should be enabled and considered in the planning process:



*'At primary level I would like to see more respect for the child's viewpoint - actually listening to him/her. My son was moved to an integrated resource when he was nine and for the first time, he was actually asked about situations that were distressing to him and included in meetings between me and the member of staff when I raised concerns' (Parent 118).*

Parents stated that it is essential to provide families with clear information including contact details of where to receive further information or support should they require it:

*'Also knowing who to contact if there is an issue, and how best to do this and to get a response. Particularly with college communication, it has been very poor, and we have on occasion struggled to get hold of the key people to discuss issues with' (Parent 5).*

Inseparable to everyday activities, school transport should also be included in the plan alongside all provisions out of school that will influence progression into the adulthood:

*'I would like school to home and vice versa transport. It would help me immensely and let my young man feel more independent' (Parent 41),*

*'In my experience the EHCP covers school but not home life. Needs to help families feel less isolated out of school hours for children that need specialised groups for activities and to encourage some type of independence for child as they get older' (Parent 72).*

Lastly, urgency for flexibility in the approach from practitioners was voiced as a means of promoting a holistic understanding of individuals:

*'Video footage and other media can be useful in pinpointing difficulties, as different contexts will often present different issues' (Parent 119),*

*'Removing restrictions and attitudes for thinking outside the box' (Parent 61).*

## **Practicalities of the EHCP review process**

Although the legislation was implemented in September 2014, these findings suggest that many services are still in the continuous process of adapting their ways of working to fully reflect the obligations of the Code. Parents argued that the system of requests for assessments and reports from different professionals should be easily accessed by parents, not only through the referral from the practitioners:

*'appropriate assessments from qualified practitioners upon request from parents'* (Parent 78).

The reports compiled by practitioners through various assessments, however, should be more thorough to truly represent the child in different contexts, not only through a short snapshot observation:

*'Professionals may have an hour observation with your child in one setting and all of their report and EHCP is based on this. Ludicrous!'* (Parent 19).

Furthermore, learning materials used in EHC provisions should be shared and available for families to extend the learning experiences into the out-of-school environment.

*Schools and authorities to be more transparent when planning for the SEN child. Parents to be kept informed. Learning materials to be shared with parents so they may support the child effectively.'* (Parent 57).

Difficulties in the plan being fulfilled, or fulfilled in a timely manner, create further disparity between the document and the reality of provision:

*'Not addressing concerns about the allocation not being provided and letting the situation drift on'* (Parent 39).

The continuous and contentious factor of 'time' is also reflected in the expressed need for more frequent reviews, the time practitioners should have allocated to read the reports in preparation for reviews and the timing of the meetings determined by the availability of practitioners, some of whom often present poor attendance:

*'More frequent and better communication- knowing about problems/ issues early rather than when things have already gone badly wrong.'* (Parent 5),

*'More updates on documents to support the plan. Or if one good day this can have a dramatic effect if the plan is based on this and is not the normal as a plan can only give support based professional reports' Parent 14,*

*'No one turns up to school meetings apart from teachers' (Parent 104),*

*'Professionals should have time to look at the review first so questions can be answered there and then at the meetings.' (Parent 72).*

The presence of a representative should be widely accepted to ensure parents are able to advocate for their children, especially when a higher ratio of staff to parents occurs during collaborations:

*'The chance to have a representative with you. I am OK, I am a social worker, but I know many people struggle to speak to and do not know what to say or what they are entitled to for their child' (Parent 94).*

#### 4.4.2.3.2. Theme 2: Practices enabling parental 'voice'

One of the principles of the SEND Code of Practice (2015) was to ensure parents and carers of children with SEND had the right to affect their educational, health and care provisions. It became explicit in my data collection that there are parents who experienced this in practice and those instances are illustrated in this theme.

#### **Seeking parental 'voice'**

Eight participants elaborated on their views in this category, providing evidence that some practices are enabling the parental voice to be 'heard'. For example:

*'I can try and direct the education to address what is important for son and us as a family rather than just what is on school curriculum' (Parent 53).*

This can suggest that the problematic power relations are still prominent between parents and services, with parents beginning to affect the design of provisions to reflect the needs of the C/YP and the family's circumstances.

Similarly, many parents feel more able to express their views more openly in the growing culture of acceptance towards what is now legally defined as unequivocal parental expertise on their own children:

*'We can give a better idea of the difficulties our youngsters are facing without the school judging our thoughts or twisting our actions to suit their league tables' (Parent 107);*

with another parent stating that the EHCP process

*'makes school listen!'* (Parent 43).

This changing culture enables parents not only to express their point of view, but also to persevere with referrals for assessment if they choose to do so based on their knowledge and understanding of their child in various contexts, not only at school:

*'A parent can apply even when school do not see a problem (without the understanding they are not always trained or qualified to comment to the extent they do' (Parent 78).*

## **Sharing information**

Respondents stated that it is helpful to use the EHCP for reference as the provision in it is clearly stated. Furthermore, the review process is beneficial to the evaluation of which particular aspects of the provisions are working well and which need improving, adding or changing to reflect the individual's needs and progression achieved:

*'A chance to catch up and review progress made while checking the provision at school is still meeting his needs' (Parent 15).*

The plan can also provide a good sense of succession and enable self-evaluation for aspects that persist to be crucial, but might have not been addressed due to individual families' circumstances:

*'To change things you did not have the energy to push for when you first got the EHCP' (Parent 9).*

The reviews seem to provide a space where parents can also discover and acquire knowledge about their child's learning and reflect on what else can be implemented in practice to support their child:

*'chance to understand more about child's learning' (Parent 2),*

and what strategies can be used to help them further:

*'I find out what he needs more help with. I also find out what programs are helping or what programs would help' (Parent 4).*

To build on from that, one of the participants pointed out the usefulness of gaining knowledge about other providers and information that can enrich their children's lifelong learning experiences:

*'The reviews are also a good place to discover and learn about providers that the parent may not have previously been aware of' (Parent 23).*

### **Change in practitioners' approaches**

Some evidence of increased openness and more frequent attendance at the reviews could be indicating that there are some pockets of practitioners who have been meeting parental expectations and have worked co-productively to enable parental voice:

*'I want to add that my son attends a specialist school and it's the staff who explain all of the above adequately and encourage me as a parent to have a lot of input' (Parent 126),*

*'There is a strong culture of listening to parent carers and young people in [the name of the city] I am very aware that not every parent carer has the confidence, or is encouraged/empowered to have the confidence I have, but I know this is something that is being strongly promoted in the borough' (Parent 64).*

Whether this shift in practice can be interpreted as a result of the changes in legislation remains unclear. However, it certainly evokes the hope that the co-productive partnerships are and can be achieved in practice.

It appeared that some of the positive aspects of the EHCP process have been experienced by the majority of the families participating in this survey (101 out of 144 participants responded to this question). They include:

- the multiagency approach to the reviews, gathering views of all core providers in one document;
- all professionals focusing on all of the child's needs at the same time enabling a holistic approach in a person-centred manner that captures the changing needs of individuals (including planning for the adulthood/future);
- child's and family's voice being expressed;
- inclusion of parental views during the evaluation of provisions;
- evidence for positive changes in some of the professionals' approaches;
- extended age limit to capture the transition into adulthood;
- the legality of the process enabling parental power to contest decisions made by practitioners without parental acceptance or agreement.

It is apparent that some provisions have started changing their approaches and ways of working even if practice more broadly still requires improvements; this was recognised by parents in the survey who provided examples of some of those instances illustrating their existence. Hopefully, this may encourage reflection and adaptation by other practitioners in the field.

One might argue that to experience adequate changes in practice following implementation of a new policy, a substantial time must be allowed; whether 3 to 4 years can be deemed a reasonable period for the adaptations or not, the above accounts portray the beginning of positive variations experienced by families who have witnessed some change in the system.

#### 4.4.2.3.3. Theme 3: Practitioners' attributes, knowledge and attitudes

The focus on professionals and their abilities to facilitate a more inclusive reception of family's voices was explicit in the survey responses. This theme concentrates on personal and professional attributes of practitioners to

demonstrate the importance of those qualities for parents. The sub-themes reflect parental views on the practitioners with whom they have worked and those with whom they would like to work in the future as the question was designed to allow participants to provide examples of desired practices alongside possible improvements.

## **Empathy**

The reference to lack of empathy in practitioners occurred the most frequently throughout all the responses (8 times). It sparked my further reflection on whether empathy was one of the main qualities that affected the relationships between families and practitioners. A call for practitioners to acquire knowledge of and to display a deeper understanding of what family's lives may entail was prevalent in the survey:

*'I have x3 Sen children all with ASD and other differences, schools seem unable to see us a struggling family unit and ignore this complexity when planning or arranging communications' (Parent 111).*

Respondents gave examples of instances where practitioners were driven by their assumptions and preconceptions about families' individual circumstances, rather than building their knowledge on thorough investigation and dialogue with families.

*'Listen to parents, consider what they are saying, do not take the attitude of 'we know best'' (Parent 33),*

*'health seems to work in isolation and do not consider the impact to siblings and whole family or what is actually manageable for a family. The child/family have to just fit into services offered even if it's not possible. They are reluctant to adjust and can cause family to feel threatened' (Parent 78).*

These preconceptions can create a thread of unsuccessful and straining negotiations, leading, in one of the recounts, to an unnecessary tribunal:

*'... if a child is off school the school actually support child with finding cause rather than draconian threats of court to parent' (Parent 45).*

It was reported that it is essential for practitioners to express their empathy when working in partnerships. Similarly to the need for having empathy when choosing a role of a practitioner working in the SEND field, parents have asked for this quality to be displayed through the acknowledgement of parental views being valid:

*‘Practitioners to provide the climate that enables parent carers to have a voice and to communicate to parent/carers that their voice is equal’ (Parent 64).*

This further resonates with the weight those views carry for practitioners. To demonstrate deep empathy for individual circumstances practitioners need to regard parental views as having an equal strength to theirs:

*‘Valuing parental input - our LA will not put anything in EHCP if a parent says it but will if a teacher backs it up’ (Parent 83).*

Maintaining the levels of equality of ‘voice’ could diminish instances where parents experience condescending attitudes from professionals who perceive their own knowledge and expertise as more valuable. Noteworthy is the connection between the ramification for professional conduct where the practitioners are faced with rules and regulations to follow, and the implication that this ‘process driven’ approach can prevent practitioners from being empathetic towards parents:

*‘The send workers are far too process driven, they were supposed to be advocates for parents, able to oversee all the professional input. They do not do that, instead I take on the role of coordinating all aspects of my son's support... SEND workers need to be more person centred - caseload burden does not allow for this’ (Parent 26).*

This suggests that there are dual constraints that affect the expression of empathy: the systems, as much as practitioners’ personal characteristics. Although the systems may require lengthy processes to be transformed, the need for dedicated and compassionate practitioners is even greater in times of austerity and limited support:

*‘Also not give up or pass the buck if they have not got the answers straight away’ (Parent 73);*



and the need for recognition of equal rights for people with SEND and deeper understanding of how their needs are met in the ableist world of practitioners, who most often are not subject to SEND labels:

*‘Training and understanding for staff working with my child and that they have chosen that role instead of it being assigned’* (Parent 65).

In responses exploring issues of transparency, honesty and accountability, the participants expressed a belief that information they receive from practitioners in some instances is not thorough and suggested that some aspects of that information are missing or hidden:

*‘Schools and authorities to be more transparent when planning for the SEN child’* (Parent 57).

Lack of honesty and transparency can undoubtedly create mistrust towards services, and this is what the participants identified as a reoccurring problem:

*‘[...] do not mislead about both the law and what is actually going on, e.g., if EHCP says weekly SaLT with a qualified therapist and the child has never seen the therapist then do not imply otherwise’* (Parent 33).

Although participants suggested for professionals to admit when something ‘goes wrong’ and show that they pursue with reparation:

*‘Make amends when things go wrong’* (Parent 46),

the fear of ‘being accused’ could play a significant role in the ‘heightened’ issues in honesty between services and families.

### **Treating parents as equal partners**

To demonstrate that practitioners understand and welcome parental perspectives, participants repeatedly requested professionals to acknowledge their expertise on their children (11 instances):

*‘Greater respect for the parents understanding of the child and less blaming the parent’* (Parent 118),

*'There is an assumption that the professionals know, and the parents do not'*  
(Parent 139).

*'I would like professional to take on board the specialist knowledge that parents have about their child'* (Parent 56).

However, respondents stated that recognising parental expertise on their child should not immediately translate into a general and broad knowledge of their particular disability, appropriate teaching methods or filling in legal documents:

*'Whilst parents have a wealth of expertise when it comes to their child, they are not experts in the curriculum or teaching methods. Some teachers have expected us to write the outcomes, but we feel we need guidance on this'*  
(Parent 55).

Despite the increased parental advocacy and its strengthened impact, parents express the need of often having to create a persona of expected characteristics in order to be positively received by practitioners:

*'I have positioned myself as a non-threatening 'useful' parent, I became SEND governor at my son's old school and developed a relationship with the SENCO. As parents we can take on two roles - combative or supportive, either role is still playing a game to a certain extent; you are still trying to play a system for best outcomes for your child'* (Parent 26).

This could suggest that the relationships can be artificial as there is a certain level of expectation that parents fulfil to build those partnerships without sharing their real thoughts or worries. An element of fear in asking questions or expressing disagreement with professionals can be found in responses stating that parents attract labels of 'being obstructive, hostile or aggressive in their approach' as a result of vocal resistance to decisions being made for them:

*'That parents are considered obstructive if they ask professionals to explain their reasoning'* (Parent 17).

The complexity of this situation requires a deeper analysis into how these instances could be repaired or avoided. If parents feel practitioners do not understand their situations and do not treat their expertise or views as valid and equal, they might become more vocal about their issues, which in result can be perceived by practitioners as being aggressive. However, the issue that is

raised here is the way the practitioners display that perception and how they could change their attitudes to judge those situations as being formed out of a parental concern for the child rather than as an act of hostile behaviour. This leads me to the final part of the impressions being made and impressions being received – the blame parents feel is sometimes directed at them or their child's disability:

*'I am an OT working in special schools with kids with ADS. The most frequent statements of blame I hear from staff are directed towards parents' (Parent 119).*

The effect of the 'unspoken' blame contributes to the further divide between 'them and us':

*'It seemingly like it is a them and us situation rather than working together for the best outcome for the child' (Parent 39);*

perpetuating the continuous tendency of preconceptions and judgements being inflicted on parents and creating an atmosphere of deep disconnection between parents and practitioners.

#### 4.4.2.3.4. Theme 4: Required systemic changes.

Participants' responses suggested that for practice to be reflective of co-productive approaches, the systems surrounding processes involved in EHC services require further consideration.

### **Accountability**

The reoccurring issue of the lack of accountability for action or lack of action agreed was explicit:

*'More accountability of professionals and local authorities' (Parent 49),*

*'There is no accountability of delivery of service and the quality of it.'* (Parent 48).

The comments included reported situations of inadequacy of provided services with an emphasis that the child needs to 'fit' into the offer of provisions where decisions are made based on prioritising cost rather than the needs of C/YP:

*'[...] teachers, NHS therapists, council officers- for them the priorities are cost, making the child fit the service on offer not fitting the service to the child, even if that means lying about the child's needs' (Parent 53).*

Indeed, one of the respondents stated that as part of accountability measures such as a penalty fee for non-attendance from practitioners could encourage responsibility for their actions:

*'I would like health and social care to be more involved and maybe given some kind of penalties if they do not fully engage' (Parent 70).*

The experiences described suggest that private services outshine the public sector as the former tend to employ more knowledgeable and experienced staff members and therefore the quality of their work is of a higher standard with adequate child centred approaches:

*'I find public sector professionals lack training and so lack confidence in their skills (with good reason they are often poor at what they do for Sen) and so they try and cover this up and either exaggerate how well the child is doing (and so how effective they have been) or blame the child's disability for lack of progress and set low expectations to cover up poor teaching [...]' (Parent 53).*

This, however, furthers the gap between the families who are able to source private support and those who rely on national health services; with the historical evidence that families of C/YP with SEND often carry a burden of additional cost or strained support circles, the private/public inequality in services contributes to further violation of these C/YP's rights.

### **Trust in public services**

The mistrust towards public services and its connection to the overruling power of the Local Educational Authorities was emphasised:

*'I have witnessed with both my children and with others that professionals, particularly educational psychologists do not feel able to express a professional opinion and are tied by their local authority to give little information or state what they feel the child needs' (Parent 55).*

Where the budgetary constraints determine the availability of provisions, the trust in inclusive principles constructing the SEND practice also becomes increasingly fractured:

*'My huge issue is the Local Authority. I would like them to have far less power & forced to listen to & take on board professionals wishes. We have a situation currently where all his teachers, his SW, all his many clinicians, him & me think he should attend a certain college. The LA disagrees based on cost. [...]' (Parent 44).*

This evidence suggests strong interrelations between trust in and accountability of public services with their mutual influence on current relationships with families.

### **Implication for policy changes**

This section comprises parental views on required changes in policy that would subsequently affect changes in practice. The most reoccurring facet identified by participants was the problem of budget, which has dominated the scene of austerity:

*'EHCP are supposed to adopt a strengths-based approach - what people can do. However, this conflicts with the fact it is a funding request form - so as one professional told me 'I have written the report as worst case scenario so you get the funding' I must say this particular report and how it represented my son made me cry! Things aren't going to change until we can trust funding panels to make the right decisions, even when they read best case scenarios!' (Parent 26).*

Such comments suggest that unless budgets are managed in a different way through policy, those shortages will continue to have a detrimental effect on the

resources, e.g., through the high frequency of changes in staff undertaking roles in the SEND field due to the strain on their capacities. Budget constraints also further perpetuate the problem of waiting times/lists being significantly prolonged, which create additional burden on the lives of families:

*‘worse than poor, waiting over 5 months for child’s [multi-disciplinary assessment] mdt assessment (should have been conducted in 28 days) and have been waiting 9 months for adult mental health’ (Parent 25).*

The administrative workload is echoed in the reported level of workload SENCOs must endure and its effect on their effectiveness and support offered to families involved:

*‘SENCO - good, but time constraints mean slow progress’ (Parent 55).*

Parents also hypothesised about more home visits being incorporated into the assessment process to enable practitioners to understand the child's needs in a wider context:

*‘more home visits (I appreciate this may be difficult due to budget constraints etc but all profs working with a child should get to see the young person in their home environment at least once a year’ (Parent 22).*

From a logistical point of view, separate rooms in hospitals or GP surgeries would enable more privacy for children who struggle to wait in busy environments:

*‘One thing I would like to have available is a ‘side’ waiting room, separate from the main waiting room. In the past I have noticed other patients in the room staring at my child due to her behaviour on occasions (especially when the waiting room is busy and there is a back log of patients and a long time to wait). This has also been a major issue in A & E in the past [...]’ (Parent 23).*

Although some might argue this could contribute to segregation, it should be available for parental/young person’s choice when needed to aid emotional regulation, which in turn could also be beneficial to all other patients.

Lastly, co-production was one of the core assumptions of the SEND Code of Practice (2015) in relation to collaborative practices with parents of

children/young people with SEND. Parents reflected on this concept in some of their statements arguing that there is a lack of it in their experiences:

*'The Lancashire SEND report from Ofsted sums up the lack of coproduction in this county and that filters down into school as well'* (Parent 35);

equally calling for more awareness training in the area:

*'All services to provide training around co-production'* (Parent 64).

The lack of staff's knowledge was also mentioned with the need for more training for mainstream teachers and more inclusive curriculum changes to reflect the world of SEND so stereotypes caused by unawareness in mainstream pupils could be addressed, raising more inclusive attitudes in future generations:

*'it should be introduced into learning about wider ranges of disabilities so there is more understanding and less judging'* (Parent 73).

#### 4.4.2.3.5. Summary

The responses to open-ended questions reflected issues across all core provisions, practical issues that could be improved and ideas of what the partnerships would involve in 'an ideal world' scenario.

It is explicit that the issues reflecting the legality of the EHCP process have been given a lot of attention, from both perspectives: the positive effects the legal implications brought to the collaborations and the challenges that parents still identify in practice.

Participants have expressed how they would solve some of the stated difficulties; however, it is impossible to elaborate on those further as some statements were not detailed enough to convey the context of the opinions.

In essence, the number of improvements identified in this section suggests that there is a significant plethora of reflections to be had for further changes in practice, training, and policy.

## **4.5. Conclusions**

The survey was valuable in providing wide-ranging insights into partnerships with parents and education, health and care services involved in supporting C/YP categorised as having SEND. Although these data suggest that parents in this study feel more empowered to express their opinions, they are not offered regular enough feedback and opportunities to affect the choices that will shape their children's future. The disparity of power in decision-making processes between parents and practitioners also requires further investigation.

These findings uncovered some partial answers to the research questions explored in this study. Firstly, they indicated that parent-practitioner partnerships are changing in the light of the current legislation by clear evidence of parental 'voice' being sought after by services. However, evidence gathered through the survey also confirmed that the power of decision-making continues to be held in practitioners' domains. Secondly, the partnership remains 'varied' with all services, mainly depending on locality of the service provider and sometimes on the approaches exercised by individual institutions or practitioners. Thirdly, participants provided occasional solutions to experienced challenges in partnerships. These included examples of active listening, acting upon parental guidance, providing space and time to form relationships with families, or improving practitioners' knowledge of disabilities and legislation.

The survey however did not afford detailed insights into individual circumstances or practices. Therefore, it would be useful to know how these instances are manifested in practice and individual circumstances.

As the survey served as the basis for the subsequent method of interviews, these three main themes following the analysis of the Survey data were presented to the participants in interviews as part of the prompts:

- inequality of parental expertise vs practitioners' opinions,
- the availability of information and advice for parents/carers to make informed decisions in the bureaucratic tasks that families are required to complete,



- and the detriment of practitioners' misconceptions or lack of understanding of disabilities/and or life of families with C/YP with SEND.

These three aspects formed the basis for further examination of parental views on parent-practitioner partnerships alongside some additional tasks and prompts as discussed in the next chapter.

## **5. Chapter 5: Interviews**

This chapter sets out the rationale for the methods used after the survey to acquire a more detailed account of the nature of the experiences reported on within the survey. The methods are identified, described, and evaluated. The pilot study is discussed first, and each consecutive interview follows the same pattern. I have elected to write the chapter in this way because I wanted to capture how my reflections on each interview influenced subsequent interviews. The chapter concludes with the key findings that emerged from this part of the study.

### **5.1. Introduction**

The interviews were the second stage of the explanatory sequential design employed in this study (see Section 3.2) and enabled the exploration of individual circumstances in depth, expanding on the findings from the preceding survey stage (Arthur et al., 2012). Therefore, the main findings from the survey informed the interview questions. The interviews followed a semi-structured format. This means that I asked some questions, but space was allowed for participants to influence the direction of the topics discussed. This space enabled participants to reveal their own perspectives, rather than being limited to only exploring the aspects predetermined by myself (Kitzinger, 1995). The following sub-sections describe the process of conducting each interview and illustrate how subsequent interviews were adapted in light of the reflections that followed the previous interview.

### **5.2. Rationale and design**

This section illustrates the rationale for the type of interviews involved, the timeline of the interviews, the processes of recruitment of participants, planning

preparations and communications with participants, as well as my reflections that informed the following interviews.

### **5.2.1. Rationale for the types of interviews**

A combination of group and individual semi-structured interviews were conducted between April and June 2018. A pilot group interview was followed by two further group interviews and eight individual interviews. Six of the individual interviews were conducted face to face whilst the other two were by phone upon request from participants. As the group pilot interview enabled me to check for clarity of questions and the practicalities of conducting an interview, I decided that a pilot interview for an individual context would not be required. This decision was prompted by the unique circumstances of each participant and the realisation that each context would vary. Therefore, I was prepared to adapt the individual interviews to the needs of each participant accordingly. This was possible as I had more flexibility in the logistical aspects of the interviews as well as in enabling more organic sharing of participants' stories as they were not affected by the group dynamic.

Group interviews, often referred to as focus groups (Arthur, Warring, Coe and Hedges, 2012), were chosen as the initial method in the belief that these might enable participants to feel more confident to discuss potentially sensitive topics in the company of those who share the same values or concerns about the subject (Kitzinger, 1995; Arthur et. al., 2012). This opportunity was intended to provide parents/carers with the benefit of 'the strength in number' factor. Being often categorised as a marginalised group in research and practice (Glazzard et al., 2015), this opportunity was intended to empower the expression of their views as a collective. This was particularly pertinent for the participants in my study who have endured a prolonged history of 'not being heard' by practitioners within the field (e.g., Sales & Vincent, 2018; Hodge & Runswick-Cole, 2018). Group interviews are also deemed useful in exploring or explaining survey results (Kitzinger, 1995) as they provide a platform for a collective meaning-making of the answers given in the survey. Another consideration for group interviews was the possibility that the individual

participants could refrain from answering questions that they had not felt comfortable providing details for; whereas in individual interviews, parents might have felt more exposed to discuss circumstances of a sensitive nature. Furthermore, group interviews allow for economical use of time and resources and carry a higher potential of collective perspective on the topic (Sim, 1998) with access to a larger number of participants (Arthur, Warring, Coe, & Hedges, 2012).

However, group interviews also present some limitations: confidentiality is an issue as participants are exposed to each other in person (Alshenqueeti, 2014; Cohen, 2018); group dynamics where opinions might differ may generate conflict; a range of cultural, physical, emotional or societal factors can also contribute to participants' capabilities to share their input or attend the interviews in individual or a group context (Arthur, Warring, Coe and Hedges, 2012). In addition, participants who are less confident in expressing their views in a group might feel excluded (Arthur, Warring, Coe and Hedges, 2012). The researcher's ability to manage conflicting debates, to analyse often complex verbal and non-verbal responses, and to maintain a flow of the interviews to ensure adequate data is gathered, can also pose challenges (Arthur, Warring, Coe and Hedges, 2012). Coordinating late arrivals, early departures, refreshments, name badges, recording equipment, materials or individual needs of the participants, recruiting, briefing, and debriefing participants, checking, and rechecking the recording equipment and transcribing and analysis of the data can also prove very laborious (Wilkinson, 1998).

Despite the array of limitations and challenges in conducting group interviews, I decided to employ this method as my reflection made me increasingly aware of the complex circumstances that could prevent or enable parents/carers to participate in research, one of which could be the apprehension of individual interviews. As a result of this realisation, all other factors impacting on the study, for example the time constraints for data collection, became secondary to the needs of individual participants and their ability to attend the interviews. Therefore, participants received a choice of group or individual interviews and following a pilot group interview and two further group interviews, individual interviews were conducted. These complemented the previous methods of

survey and group interviews as they were better placed to fit with the personal caring demands on the time of participants. This method enabled more flexibility to suit a participant in relation to a time and place (Gaskell, 2000). This had the additional benefit of potentially mitigating the risk of non-attendance as the time and place arrangements are determined by the participant (Gill, Stewart, Treasure & Chadwick, 2008). The flexibility in arrangements is particularly pertinent for parents/carers C/YP with SEND due to the nature of their caring demands (Seligman & Darling, 2007; DePape & Lindsay, 2015). For those who felt less confident in expressing their opinions in groups, they had the same opportunity as the participants who preferred to share their stories collectively.

Individual interviews have been described as a 'path to discovery' that enables better understanding of the experiences other people encounter and the sense they make of these (Seidman, 2006, p. 9 cited in Arthur et al., 2012, p.171). Individual interviews provide more detailed accounts and present deeper insights into an individual participant's personal thoughts, feelings, and the view of the world than group interviews (Knodel, 1993 cited in Guest et.al., 2017). Therefore, I felt individual interviews could potentially uncover more nuanced aspects of the experiences in comparison with group interviews. I also regarded the opportunity for a safe space where parents/carers could share their stories as an essential part of this study and, through exchanges with parents, I grew to learn that some participants would prefer to contribute their narratives individually. One parent expressed that they did not want to talk about their experiences in front of the other parents, and another parent felt less pressured in the context of an individual interview as they did not have to position themselves in relation to other people's experiences. Although this method had meant increasing the timeline of interviews, its use provided more flexibility for participants and also enabled the collection of fuller accounts of experience.

In conclusion, employing group interviews without the use of individual interviews would have prevented many respondents from participation. Therefore, within this inquiry I employed a mixture of group and individual interviews. Participants could select which of these they felt most comfortable with and/or best fitted with their personal circumstances. Both types of interview

were designed to explicate responses from the survey to provide more detail on the nature of the experiences identified by respondents.

### **5.2.2. Pseudonyms for participants in each interview**

This subsection illustrates the pseudonyms used in each interview. This table is referred to throughout the findings sections in survey and interviews chapters.

*Table 14 Pseudonyms for participants in the interviews*

<b>Interview</b>	<b>Pseudonyms</b>
Pilot group interview	Ally, Adam, Janet, Veronica, Dannie and Bev
2 <sup>nd</sup> group interview	Linda, Mary, Kathy, Julia, Ella and Sam
3 <sup>rd</sup> group interview	Anna, Carrie, Barbara, Sue and Dale
Individual interview 1	Chloe
Individual interview 2	Val
Individual interview 3	Rory
Individual interview 4	Mimi
Individual interview 5	Annie
Individual interview 6	Holly
Individual interview 7	Lily
Individual interview 8	Sally

### **5.2.3. Design**

In this subsection, I demonstrate how the interviews were planned, conducted, and reflected on. Firstly, I present the group interviews and then the following sub-section delineates the process followed in conducting individual interviews.

#### **5.2.3.1. Group interviews**

This subsection illustrates processes involved in planning, delivery, and evaluation of the group interviews. It depicts implications for the group

composition, design of the questions, ethical dilemmas, researcher's reflexivity and pilot study, and it outlines the structure of each group interview. Each report on a group interview follows a structure of recruitment process, participant characteristics, structure of the interview and reflections on the process of conducting these to demonstrate the differences between each interview and how each interview affected subsequent interviews.

#### 5.2.3.1.1. Group composition

Following Arthur et al. (2012) who suggest that each group should range between 4-12 participants to maximise the effectiveness of the method, a group of 6-8 participants were invited to each interview. This size of the group also enabled me to over-recruit effectively, in case of non-attendance. All interviews resulted in a sufficient number of participants that meant the conversation could be generated and none of the participants were left out.

Aligning with the goal of qualitative research, my aim was to gather a group of participants that is best suited to answer the research question (Arthur et al., 2012). This meant recruiting participants who might share the unique nature of their individual story (Cohen, 2018). As such these participants are not intended to be representative of all parents of children with SEND. However, commonality of some experiences across participants suggests that other parents of children with SEND might also be encountering these. Despite the lack of "a perfect fit" in relation to the cohort of participants in the group, I was aware that a range of characteristics like age, gender, social status, or familiarity between the group participants can impact on the data collection (Gill, Stewart, Treasure and Chadwick, 2008). However, my main concerns were the possible constraints in parental commitments that might impede access to parents. Therefore, I decided to maximise my chances of recruitment by keeping inclusion characteristics to a minimum. I opened participation therefore to all parents of C/YP with SEND who had direct contact with practitioners. Details of each group composition are provided in subsections (5.1.2.1.5., 5.1.2.1.6., 5.1.2.1.7. and 5.1.2.1.8.)

#### 5.2.3.1.2. Questions and structure

Firstly, when designing questions for the interviews, in addition to reflection on the findings from the survey, I considered the rationale for all the questions in the interviews and their connection to the research questions. This exercise enabled me to sustain my focus on the main questions in case of potential diversion in discussion. These diversions could occur particularly during the act of probing for a 'critical event' account, which often occurs to enhance participants' answers (Hannan, 2007). It also enabled me to ensure that the questions were directed at a particular area of theory or field, were not leading questions and were not repetitions of research sub-questions (Agee, 2009). To sustain participants' focus, I chose three main findings from the survey (see Section 4.5) to form the first part of the questioning. These findings were chosen because they were the most commented upon parts of the data collected through the survey. They comprised of references to:

- inequality of parental expertise vs practitioners' opinions,
- the availability of information and advice for parents/carers to make informed decisions in the bureaucratic tasks that families are required to complete,
- and the detriment of practitioners' misconceptions or lack of understanding of disabilities/and or life of families with C/YP with SEND.

Secondly, I employed the 'dream' and the 'design' stages of the Appreciative Inquiry Model (see Section 4.2.2.) to guide respondents' attention to solutions and productive partnerships with practitioners. I elected to do this because I thought it would drive the focus of the interviews towards effective examples of practice and the collective solutions to experienced difficulties, rather than only focusing on what is not working in practice. Finally, a 'card game' and mind-mapping task were implemented to diversify the structure of the session and to enhance group interactions through some 'cross-comparison between group members' (Kitzinger, 1994). The card game included statements from the Whole School SEND Review Framework (LLS, 2015), which outlines processes



that would enable effective partnerships in special and mainstream settings across England. Although mainly aimed at educational practitioners, the statements (see Appendix 12) could apply to multiagency teams, i.e., health and care professionals. Furthermore, the 1<sup>st</sup> and 3<sup>rd</sup> part of the interviews were designed to explore partnerships with all services, therefore retaining the balance for exploration of all services in question.

The following structure was utilised for group interviews (Breen, 2006):

1. The welcome.
2. The overview of the topic.
3. Statement of the ground rules of the focus group and a reminder of the need to maintain confidentiality within the group.
4. The questions (beginning with general experiences and progressing to specific problems)
5. Collection of background information (gender, age, etc).

Detailed plans for each interview are included in appendices (see Appendix 13 for group interviews and Appendix 14 for individual interviews).

#### 5.2.3.1.3. Ethical considerations

There were several ethical considerations that I reflected on, during and after data collection. As ethical dilemmas can present themselves at any stage of the research (Silverman, 2000), the issues which arose before the interviews were discussed in my positionality section (see Section 3.3.4.) and those related to the survey in Section 4.3.3. In relation to interviews, I considered how I was going to ask my questions, ensure that participants understood them, ensure that everyone had an opportunity to speak, and plan for the eventuality of a parent wishing to withdraw their contributions (Creswell, 2003). The right to withdrawal at any point was stated in the consent form and subsequently discussed at the beginning and end of each interview (Braun & Clarke, 2013), ensuring that the participants were aware that they could execute this right after the interview, but also during the interview.

To minimise any confusion in relation to expectations, the ethical protocol, information sheet/consent form (see Appendices 17 and 18) were sent to participants a month before the interviews to reassure the attendees that their contributions would not be shared or even included in the report until they had given their written permission (Hannan, 2007). Data management details, right to withdrawal and anonymity, structure, potential benefits of the study and the offer of a post research brief, main questions, and practical information (e.g., time, location, refreshments) were also included in this correspondence (BERA, 2018). To ensure that all participants felt comfortable to participate in a dialogue in each other's company (Rabiee, 2004) and to aid participants' understanding and decision making around their disclosures, I stressed that the group interviews were more of a "public meeting" as opposed to a "private meeting" (Tolich, 2009 cited in Arthur et al., 2012). Participants' names were also anonymised with the use of pseudonyms from transcription through to analysis and report writing. However, the confidentiality within the group was reliant on each participant agreeing to maintain the content of the interviews confidential thereafter.

Being aware of how the researcher's questions might affect participants and how the questions may influence participants' impressions of the researcher is essential (Agee, 2009). Therefore, I used a reflective journal to carefully arrange the questions and systematically examine them in the light of the developing literature review and experiences with parents as participants (Ortlip, 2008). For example, I changed all questions that started with 'how did you feel when...' into 'what was your experience of ...'. This decision was formed because of my developing understanding of how parents are often regarded as emotionally charged and therefore their accounts are often treated as more emotive rather than factual evidence of partnerships.

Differences in background between participants and the researcher can be beneficial because the researcher provides a platform for discussion embedded within the discourse, but the participants enrich the discussion with their lived experiences, enabling the 'emergence of diverse voices' (Smithson, 2010). For my study, the difference between me, being a practitioner, and the participants, being the parents, required continuous reflections which were invaluable in retaining the reflective, empathic, and ethical considerations throughout (Parker

& Tritter, 2006). For example, to ensure collected data were represented ethically, I was mindful of not asking leading questions based on my own experience of partnerships, but to ask open questions that would enable answers which would portray parental experiences as accurately as possible. Furthermore, acknowledging that participants' experiences were very different from my own practice, or that which I observed, created a sense of mutual understanding and openness between me and the groups of participants. This, in return, allowed for what felt to me to be more honest and detailed exchanges, even in the case of more sensitive topics. I was fully aware of not being able to eliminate all potential subjectivity in my actions or assumptions (Starfield, 2012) but the more I reflected on them, the more aware I became of their influence on how to ask the questions and how to navigate through the interviews ethically. For example, by using less emotive language to ask about experiences or by allowing participants to share the parts of the stories they wanted, even if the stories did not directly contribute to the experiences of partnerships.

As some of the parents who attended the interviews were parents I knew through my professional experience, I considered the possibility that some of the information disclosed by participants could be harmful to the reputation of the schools they referred to (Creswell, 2003). Therefore, I felt a need to reassure participants that their anonymity was going to be maintained despite my knowledge of the context of some of their responses, unless, of course, maintaining that anonymity would breach the safeguarding of others (BERA, 2018).

One potential tension that was related to reciprocity and beneficence of the project (Punch, 2009) for individual participants was the impact of the project on particular contexts, for example schools, colleges or localities attended by participants' C/YP. Due to anonymity and confidentiality measures, I was unable to share the findings with particular institutions, and participants were made aware of that fact. Although the purpose of this study was not to focus on a chosen locality, but to create an overview of what some parents experience in practice and how partnerships can be more inclusive despite the differences in geographical location, I underwent some reflection on my further responsibilities as a researcher. Kuntz (2015) argues that the methodological responsibility of the researcher encompasses more than the procedural aspects of the study – it

has a role to transform the world around them with impacts on social justice. This assertion connected with my dilemma in relation to being a practitioner, who ultimately asks participants for opinions on the work of my profession, yet, who is not in a position to guarantee a change in practice in return for participants' input. I was aware of participants' willingness to contribute to that transformative action, which we all collectively were hoping for during the study, despite not necessarily being able to witness the change in relation to their personal circumstances:

*'And it takes people like yourself who listen and understand. Hopefully, this is a good beginning of a very good change. Even if it is not going to help our child, it will help other children in the future, so they do not have to through the same bumps in their journey. It would be so wonderful to look back in ten years and say 'look, if my child were at school now, they would love it' Annie.*

I recognise that the impact of this study might be a long-term process, and therefore the element of beneficence to participants might be perceived as less substantiated for some.

I continually attempted to ensure I was sensitive to the range of features regulating human behaviour, including emotions, unconscious needs, and interpersonal influences that can impact the understanding of the interview process as being a social encounter, and not only a platform to gather or exchange information (Cohen et al., 2018). In my reflections, I considered aspects of self-awareness, self-regulation, empathy, power and politics of a group dynamic as I recognised that participants' emotional intelligence and personal and social competencies played a vital role in self-management and handling of relationships (Collins & Cooper, 2014) (see Appendix 15). I was prepared for challenging conversations, conflicting views, and participants' disagreements due to differing views and experiences, and pre-empted these through acknowledgement of the ground rules to alleviate the tensions, should they appear. Being conscious of the impact the interactions between myself and the interviewees had on the data produced from the interviews (Rapley, 2001), through the continuous processes of reflexivity and reflectivity I tried to ensure each interview was planned with sensitivity towards participants' lived experiences, for example, through the ethos of empathy towards individual

circumstances, equality of views in the group, or the allowance for all stories to be shared regardless of their relevance to the research questions.

#### 5.2.3.1.4. Pilot study

The pilot study was conducted in the form of a group interview due to the group interviews presenting more complexities in logistics and facilitation than individual interviews (see sec. 5.2.1.). I wanted to conduct a pilot group interview to discover whether the questions planned were clear to participants and whether the structure of the interview required changes/clarifications, but also to judge my effectiveness as a group moderator (Breen, 2006; Bell, 2014). Prior to conducting the pilot group interview I decided to use the technique of "interviewing the interviewer" (Chenail, 2011) to develop the structure of the interview. This technique required me to play the role of the interviewee, recording the interview with a supervisor and then analysing the questions in the interview. What I learnt from this process was that I needed to continually reflect on the questions I asked and the potential effects they might have on the participants (see Section 5.2.3.1.3., p. 137); it also strengthened my focus as the supervisory team complemented my reflections with their own perceptions of the questions and the structure of the interview.

#### **Recruitment process**

Most of the participants were recruited through the survey; however, some (1 of 6 in the pilot study) discovered this opportunity through the other participants. An initial email was distributed to the participants to introduce the details of the group interview (see Appendix 16). I decided to offer a thank you voucher. I did this because I wished to reimburse participants for their travel expense and to recognise the value of their time spent to contribute to the research. I also offered refreshments because I wanted to create an ambiance of hospitality and togetherness where participants could feel comfortable and welcome. Participants were informed about the 'thank you' vouchers, refreshments and were provided with a detailed map of the campus and car parking facilities for

ease of commuting. I decided to conduct the interviews on the university campus as it was a central point where all participants could travel to with relative ease. The campus also provided flexible arrangements in terms of accessible rooms. Following responses to the invitation email, a group of 8 participants was identified and the date, time and a planned structure for the interview was confirmed via email to all participants. 6 participants attended the interview.

Although it was announced as a pilot interview, I made clear that the data collected through that group interview would form part of the overall data in the study. This decision was explicitly made to honour the time and effort of the participants and recognise the importance of the contribution of their individual or collective stories to the research.

## **Participants**

The group consisted of 5 females and 1 male. Females were aged between 40-50 (3), between 50-60 (2) and the male was between 60-70. There were five parents of C/YP attending special provision and one from mainstream provision (currently excluded and home schooling). All participants' C/YP were aged between 0-25, three in compulsory education age and three in post 19 provision.

## **Structure**

The interview opened with welcome remarks and ground rules which were developed in light of the guidance in literature, and they were displayed throughout the session. Participants sat around a table and were presented with the Whole SEND statements on cards and asked to assign each card to a 'traffic lights system' (with green meaning embedded, orange meaning on its way, and red meaning not implemented) and give examples of their experiences. The following three main questions that emerged from survey findings were explored alongside the cards game as they related to some of the statements:

1. What are parental experiences of their views being regarded equally to the views of practitioners in EHC services when decisions are made?
2. What is parental experience of access to information and advice to make informed decisions about EHC provisions for their C/YP?
3. How do parents/carers experience practitioners' understanding of their lived experiences and their C/YP's individual needs?

Following this activity, participants were asked to think of what a 'dream' provision within the EHC services would look like and these were prompted by the pictures of family, children and practitioners around it as described in the interview plan (see Appendix 13).

Finally, participants were asked to give examples of any practices that enabled effective partnerships in their experiences or that they would like to see more of in practice.

A break was provided midway through the session. For full details of the session, please see Appendix 13.

## **Reflections**

The process of recruitment for group interviews, including the pilot, developed a fair amount of interest. The card games worked well as they gave a clear focus for the group discussion. Some stricter diversion techniques were required when respondents diverged from the topic. Following reflections on the process and further correspondence with some participants, the decision to employ individual interviews alongside the group interviews became inevitable.

The main reasons stemming from the pilot group interview were:

- some parents being less vocal than the others and therefore not contributing their views to the group equally,
- many participants, due to their care arrangements and unforeseen circumstances involving their family life, had to cancel their attendance at the very last minute. An individual interview could have been a more suitable option for these participants.

- a break in the middle meant some participants had to leave earlier, therefore, in the future, refreshments can be served just before and after the session.

Some of the answers provided were concise and did not provide the depth of experience that I was seeking; therefore, the next group interview commenced with the three main findings from the survey, followed with the card game and the 'dream' and 'destiny' stages of the appreciative inquiry. This structure worked more effectively as the findings from the survey provided them with clear indicators for the focus of the discussion.

#### 5.2.3.1.5. 2<sup>nd</sup> group interview

The individual interviews only became an option following reflections on the pilot interview and some participants were still keen to take part in group interviews. Therefore, two further group interviews were conducted. The first one took place outside of the university, in the offices of one of the parent networking organisations who were involved in publicising the survey. All the 6 participants were parents/carers who had previously completed the survey. Similarly to the pilot interview, two respondents did not attend on the day. All correspondence with the participants took place via email including the information sheet/consent form while its hard copy was signed at the interview. All respondents were female, aged between 30-40 (3), 40-50 (1), 50-60 (2) and they were parents/carers to C/YP within the ages of 0-25 years old with four C/YP currently attending mainstream schools and two special settings.

#### **Structure**

The procedural structure was adapted to address the reflections from the pilot interview (see Section 5.2.2.1.5) with the same ethical considerations reiterated at the beginning of the session. The participants were presented with the main findings from the survey and, following the discussion, the card game was also implemented. The interview lasted an hour and a half followed by 10-15 min time for refreshments.



## **Reflections**

Verbal feedback from respondents was gathered at the end of the interview when the recording was stopped and, perhaps, enabled participants to express their opinions less formally. The card game proved to be very effective for all involved and the participant who seemed to make the least contributions was more vocal with their opinions then. This could have been due to a more informal discussion around the table, rather than expressing own personal views in front of others. Visual ground rules displayed in the room were effective in managing the balance of talk during discussion as I subtly referred to them before each section of the interview. It was apparent from the comments that that the group members were all very experienced in negotiations with practitioners in the field, and their willingness to work collaboratively was prominent. This group was also much more expressive than the group in the pilot interview about the nature of co-productive practices within the services, illustrating their knowledge of co-production well. As a result of these reflections, no further changes were made to the interview structure for the following session.

### **5.2.3.1.6. 3<sup>rd</sup> group interview**

## **Recruitment and Participants**

The 3<sup>rd</sup> interview took place in the same parental networking organisation as the 2<sup>nd</sup> interview and followed the same recruitment process. All 5 participants were female, aged between 30-40 (1), 40-50 (3) and 50-60 (1). Three C/YP represented by their parents/carers were attending mainstream schools, one a special setting and one was out of special education but still under the age of 25.

## **Structure**

The structure was the same as the previous interview (see Appendix 13) and the session lasted for an hour with some informal exchange of verbal feedback at the end.

## **Reflections**

The group dynamic was slightly different to the previous group as the participants did not seem to know each other as well. This might explain the group's initial reluctance to express views at the start. I noticed that two particular members of the group did not take part in the exchange and therefore I asked them if they would like to contribute any of their views halfway through the interview. While I wished for them to participate, I also wanted to maintain the right for them not to say anything. The feedback on the structure was positive, but participants only commented on the overall experience of the interviews rather than any particular aspects. This could have been reflective of the earlier noted dynamic of the group, where respondents did not know each other or were less comfortable in each other's company for reasons that were unknown to me.

Being aware of potential drawbacks that the group interviews could present (see Section 5.2.1) impacted on my reflectivity, reflexivity and sensitivity during the interviews and enabled me to remain focused on the purpose of the interviews while adapting my actions in response to participants' behaviour with respect and compassion. I grew to appreciate the strength of the planning processes as these preparations provided me with the tools to manage unforeseen aspects of the processes effectively. One example of this was in how I gently encouraged responses from participants who had not provided their views by opening the question for further elaborations before moving onto the next question.

### 5.2.3.1.7. Individual interviews

## **Recruitment**

The individual interviews were designed to complement the group interviews in that they catered for individual requirements such as time or location. All participants had completed the survey and were contacted with the arrangements of the interviews via email. Those whose interviews were conducted via telephone provided their consent verbally and signed the consent forms electronically via email prior to the scheduled interview.

## **Participants**

Participants were aged between 30-40 (4), 40-50 (2), 50-60 (2). Seven participants were female, and one participant was male. The C/YP whom they were representing attended a range of mainstream provision (5), special setting (1) and a post compulsory special provision (2).

## **Structure**

Eight interviews took place, two via telephone, one at a respondent's home and five at the university. Each interview lasted between 1-1.5 hours and followed a similar structure to the group interviews (see Appendix 14). However, I decided not to include the card game and started the interviews with the main results from the survey to ensure the interviews had an atmosphere of a conversation, rather than a structured task. I did this because I felt that it would make the participants feel more comfortable to share their stories, rather than being provided with a structured activity that they needed to follow (see Appendix 19). I made this decision due to the length of the statements in the card game. Over the phone, participants would not have been able to read or re-read the statements. This lack of visual support may have impacted on the capacity of the participants to reflect. Furthermore, following the process of transcription I completed after each interview, I realised that there was a pattern in answers to

the card game. I discovered that the questions on the cards steered participants more towards experiences with educational practitioners, rather than all three services. Therefore, instead, I asked more general questions about individual participants' experiences with the services to create the space for their narrative to unfold in a less structured form (see Appendix 14). This decision was also influenced by my reflections on the discussions during the card game activity in group interviews. The card statements generated a good foundation for comparison of experiences of the group members and prompted an instant decision from participants. However, during the individual interviews, I intended to create a more participant-driven ambience as there was no risk of another member taking over their narrative or monopolising the topic. I paid attention to the focus of the narrative and used gentle prompts to guide the participants back to the focus I had constructed where needed. However, participants appeared to be fully engaged and keen to discuss the questions that were sent to them in advance.

## **Reflections**

Individual interviews provided an effective extension on data collection to the group interviews. Because time was permitted for longer elaborations, participants in individual interviews were able to give more examples of their experiences and extend their reflections through time and across different services.

The diversity in the modes of the interviews has also impacted on my reflexivity and reflection on how the dynamic between the participants and the research evolves through different tools of data collection. For example, in future research, I would ensure that different modes of interviews are provided as, although part of a certain group, some participants may not wish to share their experiences with others openly; whereas the anonymity of an individual interview would allow them to do so.

#### 5.2.3.1.8. Summary

As exemplified in this section, the strengths and weaknesses of each mode of the interviews illustrate how they complemented each other and enabled a choice for participants' preference. Each mode contributed differently to the success of the interviews and enabled participants with varied commitments and demands of their parental/caring role to take part in this study. Data gathered from both group and individual interviews is presented and analysed collectively in the section that follows. Each data excerpt is labelled with the data source so the reader is able to distinguish between data from individual and group interviews.

### **5.3. Data Analysis**

This section outlines the structure of the Thematic Analysis Framework (TA) used to analyse the data and presents the findings. The 6 phases of TA, as described in detail below, are followed by a thematic map and a presentation of each theme and its content.

#### **5.3.1. Thematic Analysis Framework (TA)**

A detailed rationale for using TA in this study has been discussed previously (see Section 4.4.2.1.). This subsection demonstrates the stages of data analysis and the formation of obvious, semantic, and latent meanings. An obvious meaning is one that does not require any interpretation as it does not contain any particular terminology; a semantic meaning or 'surface meaning' is one that is explicit and does not contain any further exploration of what the participant might have meant, however it might contain terminology only known to individuals operating in a particular context, e.g. an annual review; and a latent meaning is one that is a subject of inference based on its significance in relation to existent concepts and theories, e.g. references to inclusion (Braun &

Clark, 2006). These meanings are indicated in the code book (see Appendix 9). I now turn to a step-by-step description of how I analysed the interview data.

#### **5.3.1.1. Process of analysis**

Following the reflexivity exercise (see Section 4.4.2.2.1.), I commenced the analysis of the interview data and each of the 6 phases (Braun & Clark, 2006) of the analytical process is described in detail below.

#### **Phase 1 Familiarisation with data**

In the first phase of data analysis, I familiarised myself with all the data by transcribing each interview and ensuring that all the transcripts were accurately punctuated to maintain the meaning of participants' utterances (Braun & Clarke, 2006). In addition, I made notes of some non-verbal utterances that could add meaning to my inferences further on in the process of analysis. These included group agreement or disbelief, which the participants expressed by shaking their heads, nodding, or rolling their eyes. The subsequent close reading of all the data allowed me to make observational notes of the main ideas appearing in the data before I commenced phase 2 of coding (Terry et al., 2017). The main ideas that I initially identified in the data were driven by the literature on the subject of partnerships and the known themes that I had already identified in the literature review. For example, I looked at words like understanding or misunderstanding, listening or being heard, working together, trust or information. This comment by Bev exemplifies how some of the pertinent words were clustered in identified segments of interest within the data:

*'the schools give the opportunities for parents to come and talk but whether they listen is another issue. They are good at letting us talk but I have not necessarily always seen them adhering to my wishes.'* Bev

The observations, listed below, that I made based on the first reading of the data became a starting point of my analysis:

- discrepancies between what needs to be done according to the regulations and what is taking place in practice (lack of meaningful targets/plans/outcomes in EHCPs; presumed changes in practice are artificial as parental opinions continue to be disregarded; transitions between children and adult services fails to cater for the needs of the YP with SEND).
- some professionals' attributes, attitudes and competencies prevent effective collaborations.
- there are pockets of effective practice across sectors, and this work needs to be celebrated, not only at ground level (schools, particular GPs, respite centres) but at a regulatory level (Ofsted report, Clinical Commissioning Groups reports/evaluations).
- The dichotomy between the examples of some individual practitioners working with parents more co-productively and the, still predominant, collective culture and ethos of professional as expert.
- Parents/carers want to work together and recognise the ambiguities and demands placed upon practitioners by the systems they are required to adhere to while building relationships with families.
- Ongoing battles in negotiations can create a 'fight fatigue' and some parents believe that the system relies on this phenomenon that prevents families from asking for support and as a result leaving them unsupported, often in critical and crisis situations.

Forming a part of my reflective journal (see Section 1.3.2.), these notes enabled me to remain conscious of my own positionality and the aspects of partnerships I was drawn to in the data. As a result, I also diligently analysed parts of the transcripts that did not seem to align with the aspects of partnerships noted above. This further analysis enabled me to ensure that all relevant data was coded, not only the aspects I 'cherry-picked' as essential due to their connection to a research question (Terry et al., 2017). This meant that regardless of the initial apparent irrelevance of some text, I returned to it during further phases to

verify its applicability again. However, this process did not generate any additional insights.

## **Phase 2 Generating initial codes**

The theoretical approach to data analysis in the interviews followed the same reasoning as that of the analysis of qualitative data generated in response to the survey (see Section 4.4.2.2.). My systematic approach to coding meant that I remained alert for words and phrases that for me seemed to capture the meaning of interactions between parents and practitioners. These meaningful segments were either relevant to the research question or to the concepts derived from the literature review (Terry et al., 2017). The following extract exemplifies the process of coding applied:

***‘We talked to the teacher and a lot of the causes for this behaviour was because she was an able child she was put on the table with underachieving boys as she was definitely going to hit her targets. That was making her stressful. She was having nightmares about the boys who she worked with. We finally got the teacher to stop it and her mental health improved’*** Val.

The words that stood out to me in this transcript were ‘we talked to the teacher... We finally got the teacher to stop it’. For me these conveyed the challenge that parents often face when initiating conversations about their concerns and that the teacher did not understand how the child was experiencing school. The word ‘finally’ implies that this parent’s view was, most likely, doubted by the teacher and was not acted upon immediately, causing further distress to the child and to the parent. I also sought out words that captured the emotional experience of these interactions for parents. Examples of these include: ‘was made very, very small’, ‘it is intimidating’, ‘it is very difficult to explain your reality to people’, ‘being assertive is always perceived as being aggressive’, or ‘it is important to note that sometimes the parents have not got the emotional energy because actually looking after a child with significant needs is draining and it is tiring.’.



Coding each interview and including all the interviews in one document enabled me to identify the data saturation point, where no new codes were established upon reviewing new data from subsequent interviews (Castleberry & Nolen, 2018). Two Codebooks were created, one with the definitions of the codes and all subsequent changes undertaken after each interview was coded (see example excerpt in Appendix 2). The other contained all extracts from the raw data to represent how each code was created with all the excerpts assigned to them (see example excerpt in Appendix 10). In addition to the semantic meanings of each code, more conceptualised meanings behind the statements of the participants were assigned under the 'Latent' connections in each code (Appendix 2) (Ando, Cousins, & Young, 2014). Some segments of data were coded multiple times with reference to different codes to enable me to accurately assign the codes into themes without having to revisit the whole row of datasets to ensure accuracy (Terry et al., 2017). Each code was identified with a different colour; the colour coding strategy was used to maintain a clear trail of decisions made, ensure transparency of the process and to enable effective cross-referencing for the theme identification stage (Ando, Cousins, & Young, 2014). My unit of coding was each utterance.

*Table 15 Example of the cross-referencing coding*

Code	Definition	Extracts
Practitioners' competencies	<p>References to practitioners' understanding of systems, SEND and their attitudes and approaches towards working collaboratively with families. This includes leaders of EHC services and their role in implementing ethos of inclusion.</p> <p><b>Latent:</b> Performativity, empathy, inclusion, equality</p>	<p>Chloe: Yes, they have lost trust. I do <b>not</b> think they <b>always fully understand the law themselves</b>. You have to be armed with a huge bank of knowledge to go to one of those meetings and also try not to feel intimidated and actually question them but you can find if you do question them, as with my experience with some teachers I have spoken to, <b>they take it so personally as it is an insult for them</b>. Which it is not meant to be, that is hard to accept. (+ Parental expertise + <b>Emotional journey of a parent/carer</b>)</p>

In this example, the whole utterance is colour-coded in green, which corresponds with the code; however, the parts in bold were the parts that grabbed my attention in particular. These bold statements served as the pertinent chunks of data that represented the code strongly and which I could use to illustrate the themes further on in the analysis stage. The differently coloured highlights in the brackets refer to cross-coding with other codes.

The competencies that are depicted here demonstrate how the requirement for information upon which to make informed decisions by parents and by professionals is extensive. Although practitioners are required to know the law and regulations surrounding the support for C/YP with SEND, the data suggest this often is not the case. This excerpt also illustrates how parents, despite often being from a different professional background or a non-professional background, need to acquire the same knowledge as practitioners within SEND to be able to challenge the information and support on offer if they disagree with it. While addressing the, often complex, information, parents are also exposed to dealing with the power dynamic within the partnerships as it is experienced by them – that sometimes practitioners can treat that query as an assault on their professionalism.

### **Phase 3 Searching for themes**

In the third phase of analysis, I examined the codes for further associations between the research questions and I identified salient patterns of meaning within the generated codes as themes. For example, I grouped all codes that referred to aspects of practitioners' characteristics and behaviours to one theme, but when I looked at barriers to effective partnerships, I evaluated them by examining the context the barrier was experienced in, i.e., whether it was experienced on the structural/systemic level or individual/personal level. This divide enabled me to determine whether the barriers could be addressed within practice by individuals or groups of practitioners, or whether they required more legislative/organisational changes, which usually are lengthier in process of transformation. Following the continuous revisits, the codes have undergone

transformations in wording, their definitions and content; some have been engulfed by others, renamed or split to accurately represent the raw data (Guest, MacQueen, & Namey, 2011). For example, the code 'Helplessness' was renamed to 'Left unsupported in crisis' as situations described by parents that were assigned to that code illustrated parental resourcefulness in helpless situations, rather than their helplessness.

Themes were formed by clustering, combining, or splitting codes to ensure the themes were represented by the codes included in them (Guest, MacQueen, & Namey, 2011; Braun & Clarke, 2006). For example, all codes that were clustered to represent the theme 'Discrepancies between the principles of the Code and parental experience' were representative of particular elements of the partnership that were asserted by the Code; this included growing confidence and trust in services, opportunities for more participatory contributions to the design of the services, or respectful and honest exchanges of vital information. As a result of this review process, only one code (Practices enabling effective partnerships) became a theme as it contained a great range and depth of examples to describe the theme (Nowell, Norris, White, & Moules, 2017). The preliminary themes were initially generated and presented visually to illustrate their connections and distinctions between them (Guest, MacQueen, & Namey, 2011) (Figure 9). The oval shapes illustrate the themes, the corresponding coloured rectangular shapes indicate which codes contribute to which theme, and the codes and themes that cross over are linked with each other.

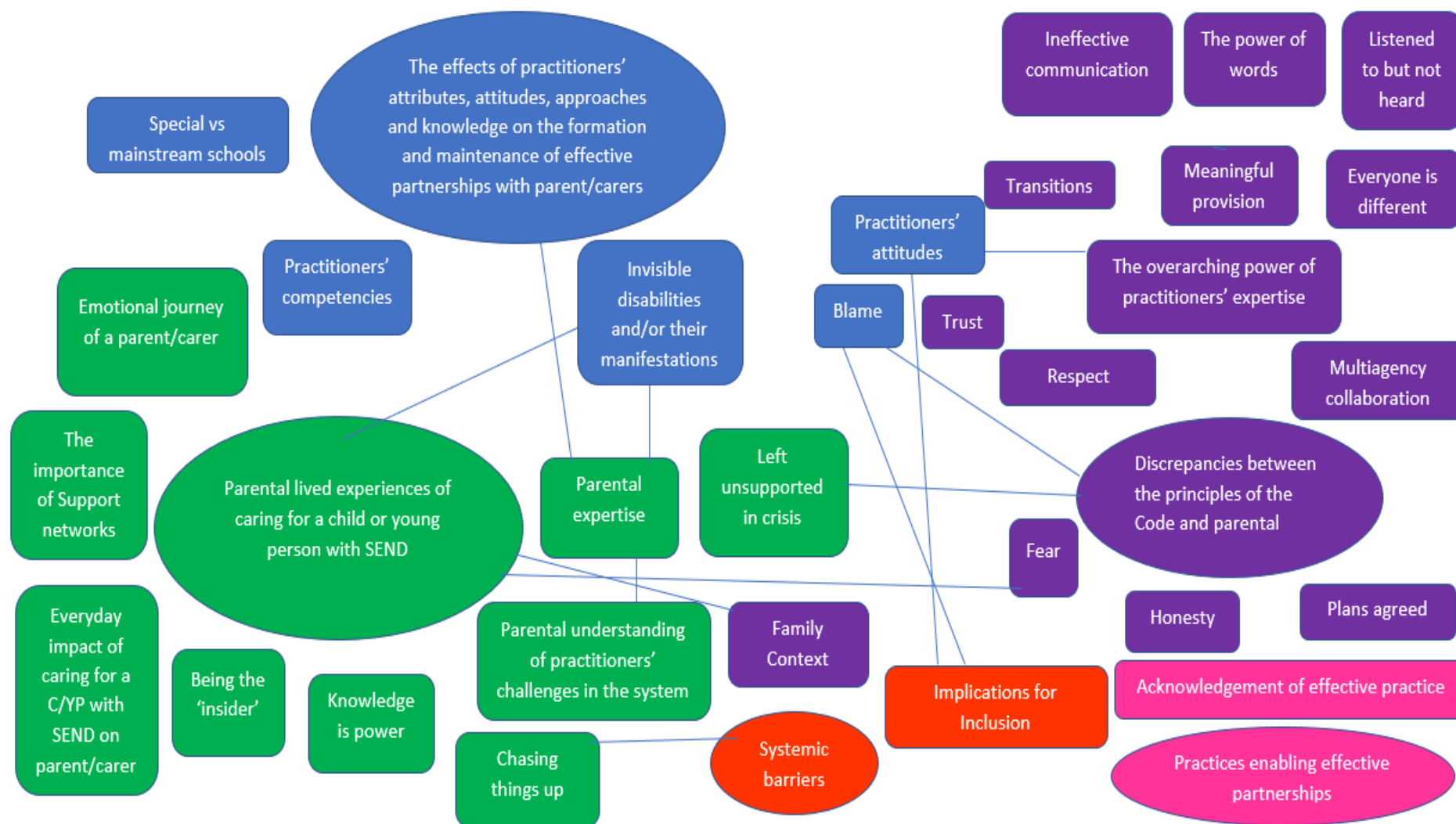


Figure 8 Preliminary Themes map

## **Phase 4 Reviewing themes**

In the fourth phase, I scrutinised the themes again and adapted them to ensure the blurriness between them was minimised (Terry et al., 2017). To determine clear boundaries between the themes as much as possible, I evaluated the codes that contributed to each theme and, where applicable, I indicated additional overlaps of codes that belonged to more than one theme (e.g., the code 'Communication' was initially only assigned to the theme 'Discrepancies between the principles of the Code and parental experiences', but through the review, I decided to assign it to the theme 'The effects of practitioners' attitudes...' to signal that the experiences captured by that code had a significant amount of references to the communication with individual practitioners). This realisation could present implications for reflection by individual practitioners on their assumptions and practice, being appropriately representative of both themes.

My aim of ensuring that each theme was meaningful and contributed to the research questions, with minimal overlaps of the codes, was then achieved. Following reflections, re-reading of the data, and assigning data excerpts to each code, a final theme map was created (Figure 10). All changes that occurred during the processes of further analyses were reflected in the final Codebook with the themes maintaining a clear trail of all decisions made (Vaismoradi, Jones, Turunen & Snelgrove, 2016) (Appendix 2).

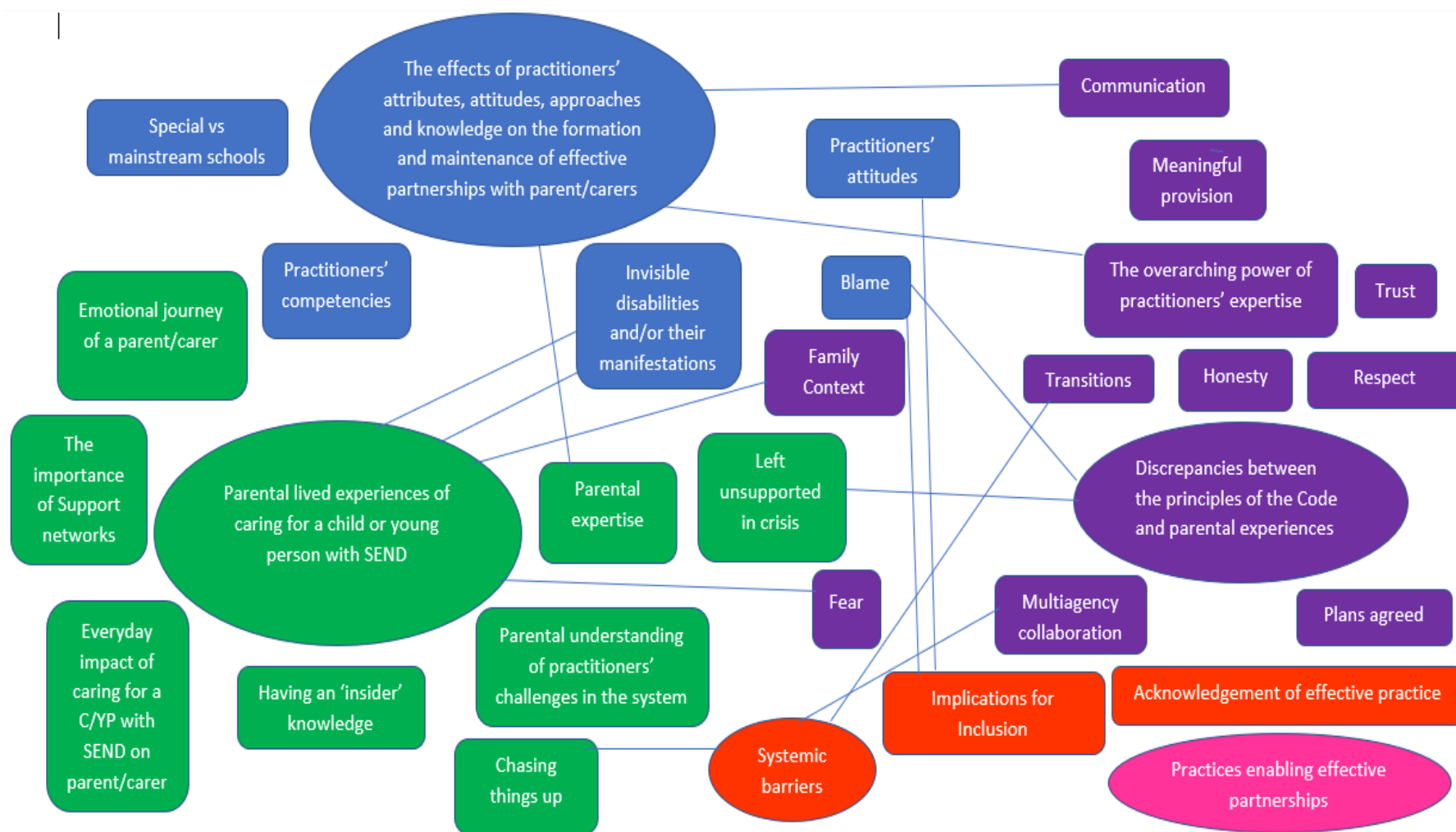


Figure 9 Final Themes map

## **Phase 5 Defining themes**

In this stage, I developed each theme's definition to ensure clarity, cohesion, precision, and quality of the developing TA (Vaismoradi, Jones, Turunen & Snelgrove, 2016). These definitions were incorporated into the final Codebook (Appendix 2). Following the defining process, I engaged with final review of the names for my themes to ensure the raw data that contributed to the codes was accurately represented by the names of the themes. I guided my decisions by references to the Code and the aims of my research. Therefore, the first two themes relate to parental experiences that illustrate the dynamics with practitioners on the individual level; the third and fourth themes refer to pertinent aspects of the Code and explore partnerships on the systemic level; and the fifth theme encompasses the effective representations of partnerships that are experienced by parents in practice, in the hope that these can encourage others to consider discussed approaches and celebrate the work of those practitioners who work with parents co-productively. Upon completion of this phase, I arrived at clarity of what each theme represented and began the last phase of analysis, which is described below.

## **Phase 6 Producing report**

In the last phase of the analysis, I engaged with a more interpretative position, which involved seeking to establish more intricate and less obvious meanings of participants' utterances. I looked beyond the semantic connotations and description of what parents said and how these expressions linked together into a theme. I analysed the codes within each theme to determine what parents may have meant by certain comments and how this might relate to their experiences of partnerships. This process was designed to tell the story about the data and capture the sense of patterns and diversity of meaning (Terry et al., 2017). My intention was to articulate what each theme meant and what

assumptions underpinned it and its implications (Braun & Clarke, 2006). To create the overall story, a narrative was constructed with data extracts, which is presented in the next subsection (see Section 5.3.2.).

### **5.3.2. Findings from interviews**

The five themes that were generated are presented in the report below, in an order that indicates how the themes were constructed (Braun & Clarke, 2006; Nowell, et al., 2017). I present the themes in turn to reveal how parents experience engagement with practitioners.

#### **5.3.2.1. Theme 1: Sharing Experience**

Many of the participants reported on the importance of being able to share their story as a service user with practitioners who deliver the service – Holly conveys this as:

*‘I think having some input on what lives of people with disabilities are like would be beneficial to those professionals working with our children. There are different perspectives of the same situation through the lens of different people, parents, children, or practitioners.’* (Holly)

One element of the experience that the parents felt is particularly important for practitioners to understand is the impact on them of caring for a child with SEND.

#### **The impact of caring for a C/YP with SEND**

Although a few participants felt that there is a place for specialist practitioner knowledge regarding disabilities, they argued that to build empathy and understanding of the reality of families with C/YP with SEND, practitioners need to become more familiar with parents’ life stories. Participants exemplified how



these stories need to represent emotional and bodily experiences to evoke an empathetic response and present opportunities for practitioners' reflection on the potential associations they may build with their own life stories. These differences between parental and practitioners' perspectives can present a challenge in partnerships. Mimi reflects on some of the things she knows others perceive as abnormal and she sees as part of her daily, albeit often challenging, routine:

*'[...] If you are with that person 24/7 even for two days in a row, let alone for weeks and weeks on end, that routine is so monotonous you can scream! It is like a prison! You know what you have got to do next, but it is not what you want to do next. Everything is on their terms. [...] And it is stifling, and you just feel like screaming out loud sometimes. He is bigger and stronger; his hormones kick in and lots of behaviour occurs. It gets crazier and crazier.'*  
(Mimi)

In Holly's view, to explain the nature of what 'normality' means for families with C/YP with SEND to people who have never experienced it is complicated and requires active listening and openness to accept that disabilities are divergent, similarly to the differences present in non-disabled persons:

*'none of us actually know what it (Autism) is and no matter how many people you know with ASD, you will always find something new from somebody else. I think another thing is also putting themselves in parents' shoes and thinking beyond what they see and what life might actually be like'* (Holly)

The impact of caring for a C/YP with SEND on a family as a unit is still reported as challenging when partnerships are formed, as practitioners often fail to recognise the wider context of family dynamics, including instances of parents caring for other family members. The act of caring for other family members is made even harder as parents negotiate this around the care of their disabled child. Often parents have to live fragmented lives, as one always needs to be caring for the child. The impacts of this ripple through the family and the effects of this can only be appreciated if practitioners are very familiar with the lives of families:

*'But my parents are getting elderly and my husband's mum is very poorly, so we are having to get down to (the name of a city around 200 miles away) at the weekend. I go when my son is at respite, then I travel back up, we sort of wave at each other as we pass each other on M1. It is never just this person that you look after, you have extended family too' (Mimi).*

Linda identifies the impact on families too where one parent has to compromise their career in order to meet the bureaucratic demands placed on them:

*'We were watching her deteriorate before our eyes. And I actually took three months off work at that point so I could take time out to deal with school. To get everything put in place with my daughter.'* (Linda).

Beside the frustration of continually having to 'chase things up', and facing 'regular' parenting dilemmas, participants discussed powerful emotions of guilt, self-blame, or grief, which they found too intimate to share with practitioners openly. Rory and Mimi depict the impact these emotions have on their parenting experience:

*'It is very difficult to explain to people your reality; I think it is incomprehensible for some. We ache in the privacy of our own thoughts [...] This guilt is being reinforced when you struggle to get services, it is a torture. And the difficulty for me is that I cannot understand why my son does not receive the service that he needs.'* (Rory),

*'[...] we mourned him and the life he could have had had he been different. We mourned the other children and life we were going to have. And until he was 8 or 9 years old, we were still in that grieving stage and we came out of that now [...]' (Mimi).*

Practitioners' sensitivity to the fact that there may be pressures on parents that, even within supportive relationships, they might not feel able to share, is therefore paramount. To become attuned to these different experiences, practitioners' knowledge of parental accounts becomes even more essential.

## Fighting for support

While dealing with the host of conflicting emotions described above, the parents related how they feel they must relentlessly persevere in advocating for their C/YPs to obtain adequate support. This advocacy was compared to a constant combative action between parents/carers and practitioners:

*‘Actually, you feel like you are in a war and each bit of it is a battle and you have to think is this battle worth fighting?’ (Holly),*

Within this combative arena the parents told of how negative labels, such as ‘aggressive’, are attached to those of them who question the systems or provisions:

*‘Being assertive is always perceived as being aggressive. Those parents are not liked, we are the troublemakers.’ (Rory).*

Chloe revealed how she felt compelled to adopt a particular non-emotional persona when she communicates with practitioners. This is in response to learning through experience that expressing emotions is not welcome in conversations with some practitioners. However, approaches like this may result in the emotionless recounts of deficits, ‘worse case scenarios’, and, at any cost, avoiding confrontation and being labelled as ‘a difficult parent’.

*‘I’ve learnt to play a role. When I go to the meetings, I tell myself that I am my child’s advocate and not their parent. So, I would have a meeting as if my child were not mine, like a support role for another child as if I am one of the other people seated in the room. If they see anger, you lose their attention’ (Chloe).*

Furthermore, the overwhelming feeling of needing to always be grateful and expressing gratitude profusely to practitioners leaves parents feeling at unease:

*‘[...] there is also that thing of having to always say how grateful you are. And if you say how grateful you are, you are going to have a better response back. But if you do not say that, then... sometimes I said it, even if I had not really*

*thought it. And I just think parents end up with a battle fatigue. It is totally draining, it is horrendous.'* (Holly).

Chloe and Holly point out all the additional emotional labour (Seligman & Darling, 2007) that is put upon them to manage relationships with those who are meant to be there to support them. The emotional and physical costs of this mean that parents are no longer emotionally available for partnership working.

Having to document often 'invisible' difficulties or discuss difficulties that are still persistently stigmatised perpetuates a further lack of understanding between parents and practitioners. For example, the issues surrounding puberty and sexuality of YP with SEND through their adolescence and adulthood are continuously offered less support:

*[...] So, you know, what a lot of parents do not talk about out loud is the sexual behaviour, which is there. And it is hard to talk about it as it still is a great taboo. [...] When my son gets up at 3am, he comes to my bed, he has got his tablet on and I wrap myself around him so then if I do fall asleep and he moves, I can feel him move-how appropriate is that for a 20 years old man and his mother??? Very difficult.'* (Mimi).

In helping to manage the tensions around relationships with practitioners, parents often turned to other parents of disabled children for support:

*'[...] we have more services, and you can be signposted to them when you need them, mostly by other parents who use or have used them though.'* (Linda).

These relationships with other parents are strengthened by the shared experience that is lacking with the majority of practitioners:

*'To be honest, the best source of information are other parents that had already gone through the system [...] Because these parents are people who know what you are going through. You know, they understand you because they have it 24/7.'* (Mimi).

## Expertise Denied

Some parents asserted that they hold knowledge of their child that could be invaluable to practitioners. However, parents experience their knowledge and insights as being often disbelieved by practitioners:

*'That is the point really, we know our kids better than anyone else would. So why they just do not believe us?'* (Sam).

Sam offers an example of the paradox within the acknowledgement of her parental expertise where she talks about being denied recognition of her knowledge, but at the same time experiencing practitioners' expectations that she would extend the specialist provision at home:

*'[...] because actually we are not therapists either, we are not trained to deliver interventions, we just want to be parents when we get home at the end of the day. I challenged that recently as my son was put under physio and they gave us a programme of exercises to do at home [...]. I said that I am not refusing to do it, but I physically cannot do it. I work full time and I have got another daughter and I said I am not a physio therapist either'* (Sam).

This may suggest that, to a certain extent, parents are perceived as expert enough to follow therapeutic programmes to enhance their C/YP's development. However, their expertise is still perceived as inferior to that of practitioners as the parental role is only to be directed by instructions from 'the experts'. Denying parental agency in decision-making feels to parents like a perpetuation of the power imbalances in the partnerships:

*'Initially I had to stamp my feet with the school. To kind of get me heard. Because my son's behaviour was happening more at home than at school. But then it did start happening at school and once that happened in school they went: "ok, maybe we do need to have that meeting that you were talking about [...]"'* (Sue).

The dominating rhetoric of 'only the professional is the expert' still affects the nature of partnerships and results in parents feeling that practitioners perceive them as being of a lower status in terms of knowledge about their child:

*'There is a big imbalance in power in these environments (reviews) and it is intimidating and not productive [...] And to be made to feel like you are not at the same level as practitioners or that you do not matter is just wrong, really wrong.'* (Chloe).

To alleviate these imbalances parents provided examples of resistance. Mimi, for example, elaborates on using all her skills, qualifications and 'speaking the professional language' to present herself as an empowered and equal contributor within the decision-making process:

*'a lot of practitioners speak in jargon and if you can understand and use that jargon in context, you get treated as an equal. Whereas a lot of parents do not get treated as equals within the setting. It is because they do not know the jargon and can be easily excluded from the discussions [...]'* (Mimi).

Likewise, Carrie referred to the need to 'be clever in the system' and use her professional knowledge to present a strong argument that would be sufficient to obtain appropriate support, while still working to keep practitioners onside:

*'So, I felt it was important not to be in conflict with people who cared for my child or for my young person. But I needed to do my research and to prepare my argument. And because I know the system, I would know what my rights are [...]'* (Carrie).

In Val's experience she argues that she has to treat practitioners with particular care in order to be able to negotiate concerns:

*'When issues arise, I also always make sure I know both sides of the story. I learnt it the hard way, your child comes home from school and tells you she was mistreated you do not go there shouting, you ask gently: "My daughter came home very upset, could you tell me please what had happened?". And then you get a totally different story.'* (Val).

Similarly, Sam recognises that both parties have a responsibility for the effectiveness of the dialogue:

*'...I would never go to school shouting and angry [...] There are other children in that school, and I see parents going in shouting and being angry and demanding and swearing and I know their kids are not doing so well in that school. Because as a teacher how can you work with that situation. So, it needs to come from us as parents as well' (Sam).*

### **Summary of the theme**

The critical elements of parental experience of relationships with practitioners captured within this theme are the lack of practitioners' understanding and acknowledgement of parental experiences and expertise. Despite the impact shared stories may have on particular practitioners whom they reach, parents perceive that many approaches and attitudes of practitioners are heavily embedded within systemic culture. It would seem that the historically inherited ethos of public services' professional expertise still prevails. Furthermore, the expected systemic changes guided by the Code that call for empowerment of parental expertise present a challenge as they require a shift in collaborative practices. Without empathy and understanding of lived experiences, these parents feel that practitioners will remain unable to work inclusively and co-productively with families; however, current structures in EHC services prove to be a barrier for practices to be transformed correspondingly. The next theme depicts how practitioners' attributes, attitudes and knowledge affect partnership working.

#### **5.3.2.2. Theme 2: The effects of practitioners' attributes, attitudes, approaches and knowledge on partnerships**

This theme captures parents' perceptions of practitioners' dispositions: the essence of the values that drive their attitudes and approaches. This theme focuses on capturing the aspects of practitioners' conduct that practitioners can self-direct and impact on individually, rather than necessarily through the policy or the culture of their institutions.

#### **Empathy and Understanding**

The interpersonal qualities of individual professionals can make a significant difference to their overall experience of the partnership. Julia observed that practitioners who possess the quality of approachability, even if they are not necessarily specialists in the field, are experienced by parents as more effective enablers of partnerships, particularly when they are open to learning from and with families:

*'Some practitioners who have experience and think they have gained a lot of knowledge can be more detrimental in their stiff approach than those who have not got any of it' (Julia).*

Some parents asserted that practitioners are sometimes constrained by the limitation of the system:

*'I think in mainstream teachers are under a lot more pressure about outcomes, it is all about hitting the targets and getting the right grades. Where I think that pressure is taken away in special schools.'* (Dannie).

Special schools' practitioners were associated with openness and readiness to accept parental expertise, whereas mainstream schools operate a more authoritarian approach:



*'I feel special schools are more open, willing to listen to parental advice. I feel that mainstream it is this is what happens and that is it.'* (Dannie).

As a former public service practitioner, Linda feels sympathetic to the organisational constraints that practitioners experience within the system. However, she and Barbara point out the lack of practitioner reciprocity with the challenges parents face:

*'I worked in the public sector [...] And I completely empathise with services around budget and organisational constraints [...] and can see it from both sides. But the empathy is one way actually'* (Linda).

Although for Adam empathy is deemed a quality that is inherent, something that can only be acquired through first-hand experience:

*'You have to have an awareness of what certain situations which certain disabilities require. But empathy is beyond that, it is within you. Until you have a child you cannot totally empathise with parents...'* (Adam).

For Annie, the only option for practitioners to develop their empathetic approaches and understanding of what families' lived experiences mean, is to engage with parents and carers and learn from them:

*'You always need the background information before you make any judgements or plan for any provision-and the best root of information are parents.'* (Annie).

## **Misconceptions about SEND**

The parents reported that invisible disabilities can cause a divide between parents and practitioners and become a source of misconceptions formed about families. For Julia, the failure of practitioners to recognise the needs of her less assertive child creates tensions in dialogue:

*'[...] if you have a lot of children with big needs and Kathy's son is not in your face, it is not his behaviour, it is anxiety, it is not always obvious. So, my two*

*children, same diagnosis but one you have to scrape off the ceiling but the other you have to always lift up because he has no self-esteem. They (the professionals) always see the visible'* (Julia).

In Mary's view, practitioners' lack of understanding and mistrust towards parental knowledge leads to judgements made about parents:

*'parents get accused now of fabricated or induced illness the minute they start challenging. And I got accused of that when I started challenging.'* (Mary).

For Janet, the lack of knowledge about specific impairment groups that is demonstrated by some professionals causes significant concern:

*'Somebody at the DLA once said to me that my son might grow out of his down syndrome one day'* (Janet).

The misconceptions some practitioners may have about disabilities and their embodied manifestations can contribute to misjudgement of potential risks for individuals, of their abilities to function in society without support or their mental/physical and cognitive capacity to undertake tasks presented to them. Misconceptions based on 'visible level of disability' can also create a barrier when families are trying to obtain adequate support:

*'one of my children heard or rather had been told, in one of the specialist provisions [...] that he was not as disabled as the other children and he did not need as much help [...] They literally pushed him over the edge. Because they could not see his difficulties fully because they did not understand his condition fully'* (Barbara).

Some parents, such as Annie, identified an urgent need for more awareness of the severity, diversity and fluidity of SEND for non-specialist staff. This is because for Annie the experience with some 'front-of-house' practitioners are more challenging than the collaboration with the services themselves:

*'Actually, for me the worst bit is to get by the receptionist [...] If I get through to the receptionist and try to explain things to her, she often just says: "take her to the walk-in centre". They do not understand that in the walk-in centre you might*

*have to sit down for three hours [...] So there is no point to take her there [...] She will just curl up in a ball and bang her head.'* (Annie).

## **Competencies**

The navigation through the system for practitioners in various services was unequivocally identified as one of the challenges contributing to ineffective partnerships. Parents reported a range of inaccuracies and incompetent support received since the implementation of the Code in 2014. For Veronica, the fact that a whole institution works on a premise that views C/YP with Autism Spectrum Condition (ASC) as misbehaving, points out practitioners' misconceptions, which can become a root cause for a conflict in partnerships:

*'at college when she went on a day trip and refused to get on the tram back. So, they excluded her the next day [...] And then we had this massive meeting about behaviour. Like she was not special needs. She was presented as being naughty.'* (Veronica).

Parents also pointed out that besides recognition for 'invisible disabilities, some practitioners were unaware of the law and policy that guide their work:

*'I think that the practitioners do not know it is now to 25 [...] and people within it do not get it. Like educational services are still learning how to work the new system.'* (Carrie).

Furthermore, parental expertise proves essential when practitioners are expected to conduct assessments with limited knowledge of the C/YP and their SEND. In Anna's experience, a judgement about her son was made based only on measures or snapshot observations, rather than a holistic view of him as an individual:

*'[...] The social worker said: "Aw, B, do you know how to get into town on a bus?" He said yes. "If you got lost in (the name of the city), would you know how to find a way back?". And B said: "aw yeah, I can do that, I would ask at the*

*ticket machine and the ticket man would tell me" [...] So, when she left, I said (to her in private): "you do realise that this person does not ever leave the house? So how is he going to get to (the city) and not get lost to ask the ticket man??" And she went: "aw but he seems to know what he is talking about". He knows it is the 109 into town because that is what my partner gets to get to work every day. But that does not mean he can do it' (Anna).*

As part of the circle of support for many C/YP, teaching assistants (TA) play a crucial role in educational provision. Although parents/carers recognise their importance and are grateful for their support, they also recognise that TAs' expertise varies significantly, with some having years of practical experience and continuous knowledge development and some carrying their roles with minimal expertise albeit, most often, well-meaning intentions and compassionate attitudes:

*'...my son is assigned to a lady, who worked as a lunch supervisor, then helped with reading and [...] now she has been assigned to help my son. She is such a caring lady, lovely qualities, she makes him feel calm, she recognises when he needs a break and over the year, with my help, she developed strategies to sort of talk to him to help explaining thing to him. But when it comes to sort of teaching him, there is no knowledge of teaching strategies to help him [...]' (Chloe).*

Where the best intentions of ill-informed practitioners fail, parents are left to deal with the aftermath of the crisis:

*'Recently we had to go to the hospital, and she had to be sedated to have a brain scan [...] By the time we were done it was 6.5 hours, she just wanted to go home. They kept asking if she wanted a drink and it showed how little they knew.' (Annie).*

And, as Mimi discusses, the honesty in practitioners admitting their lack of knowledge is sometimes used to excuse the incompetency that follows:

*'We have just changed a social worker and the first thing she told me when she entered was: " I've never done disability, never done special needs, I only had to work with elderly".' (Mimi).*

## **Summary of the theme**

This theme suggests that practitioners need to modify their behaviour and approaches when collaborating with parents to enable more inclusive practice. Although participants discussed the effects the lack of knowledge of some practitioners have on their competencies within the system, parents/carers emphasised that open-mindedness and willingness to learn from families was more important in partnerships than having extensive knowledge. Furthermore, parents reported that they welcome practitioners who exhibit awareness of their own limits but expect that those who support their C/YP have a certain level of knowledge and skill. At the same time, there was an expectation that while practitioners realise the need to enquire about unfamiliar or unknown 'territories' within the realm of SEND, they should do so in a sensitive way and not form conclusions without confirmation of all facts, particularly by seeking and acknowledging parental expertise of their C/YP.

### ***5.3.2.3. Theme 3: Discrepancies between the principles of the Code and parental experiences in practice***

This theme refers to particular tensions between aspects of practice that the Code aimed to transform in relation to parent-practitioner relationships. These tensions encompass cultural changes in communication channels between services and families, where parents are supposed to gain confidence that their views are accepted and acted upon when decisions about their C/YP are made. Parental views were also to be valued in relation to the wider family context in recognition of its impact on the C/YP and vice-versa. Within this cultural shift, the expectations that services will work together effectively, and that information will be shared in a timely manner, were intended to develop more trusting and transparent practice. However, this theme reveals that the intentions of the Code are often not represented in practice.

## Communication and Trust

A lack of clear structure that would indicate the responsibilities of EHC providers from local to regional capacity was reported to be preventing practitioners and families from accessing relevant services in a timely manner. Experiences of accessible information and advice were unsatisfactory in the reports of parents in this study:

*'[...] you are sent from pillar to post...' (Dannie).*

*'[...] So, we are often knocking on the wrong doors because somebody referred us wrongly.' (Rory).*

Groups of parents who have worked closely with one local authority have contributed to such an overview and top tips in the past, but due to changes in management, this particular element of practice has not been passed on:

*'maybe when that [top tips of what disabilities warrant which pathway of support] was first introduced, they all thought yeah that is great but then you get new GPs and they do not follow it up.' (Linda).*

Ally expressed how practitioners lack tact and consideration for the impact some of the correspondence may have on parents/carers reading it. For her, some of the messages she received from school sounded accusatory, even if that was not what was intended:

*'I think sometimes schools are not very careful about how they word things. [...] when you write things on a piece of paper and there is no personal conversation when you could read someone's body language. For example: "we have noticed this bruise in here and he has not got it in school" and then immediately as a parent you think: "aw, you are accusing me!" [...]' (Ally).*

While emails, home-school diaries and phone conversations can all aid the line of communication between families and services, they remain inconsistent and are based on individual services' embedded practices and the relationships built with particular practitioners:

*'we get three parents' evenings and one annual review. And you can phone up and his respite place are really good, and I can have correspondence. They are much more proactive than the school. [...] it goes down depending on schools. If you have got school-home link worker who is pro-active and good, they can often be helpful' (Ally).*

Instances where 'things are done to, rather than with families' persist and, in Dale's case, leave her reliant on other parents to enable her feel equally prepared for the discussion in the professional domain:

*'Not sure what is going to happen when we get to the assessment centre. The communication with that is: "aw I will speak to other parents to find out what is going to happen". Because I just got a letter with the appointment and there is no sort of agenda and we are going to be there for two hours. So, I wonder "what's going to happen in those two hours?".' (Dale).*

Repeatedly reported instances of practitioners not reading essential information about the C/YP appear to be a cause for a great frustration in partnerships for these parents. In witnessing inappropriate support being provided as a result of broken communication, parental trust is also affected:

*'They do not read even my son's EHCP. So, I highlighted it and it says in his plan that he needs 1:1 support to make choices. But no one had looked at it, it is still in his bag. Nothing gets written in his book, I do not know what he is doing day to day' (Janet).*

*'They have his folder but whether they have read it thoroughly? I know he has one-page profile and I know the other teachers have not read that. Because there were incidents that happened with other teachers and how they have dealt with him. Even when I was there.' (Dale).*

*'yeah, and then the trust starts to wobble because if that information has not been passed on, what else has not been passed on.' (Barbara).*

Parents find it exceptionally hard to know all services that they are eligible for from the start, but the responsibility for finding out this information is always

placed on them, with, sometimes, a 'lucky' discovery about useful services through others:

*'Like carers credit we did not realise that we could have had it since the age of 12! [...] So, I got that notification on Facebook [...] we get some information and we just send it to everybody on social media' (Janet).*

Inadequate information shared by LEAs can also impede parents' choice and parents have reported instances where they were subject to emotional manipulation used as a tactic to encourage them to accept the choices offered by LEAs. For example:

*'[...] They [LA] rolled over at the end and gave us a direct payment of what it would have cost them to send him to their chosen provision and I put extra 4 pounds in a week. I was made very very small about that and I was told: "you were told the situation by your social worker, you are taking money off of another child, if you persist to fight for the other respite", I was made to feel that it was hundreds of pounds difference. In which case, you do feel awful because there is a limited amount of money to go around' (Ally).*

Parental choice of provisions, specific support, and the ability to affect it by sharing their expertise of their child, is still often disregarded. The equity of provisions is inconsistent, and these parents were sometimes told that it is impossible to accept their wishes and that their requests conflict with the ethos of the school or the current approaches embedded in practice:

*'[...] So, I am then saying to my daughter's school, look this is happening, relationship with my daughter is breaking down, could you try this and that..."no, we are not doing any of that, we are not letting your daughter dictate to us what she does and does not do in school [...]. Within a space of two months she was out of school. She could not cope...' (Linda).*

Although reasonable adjustments form part of the regulation for provision for C/YP with SEND, families are still denied differentiated programmes that would reflect the needs of individuals and support their learning journeys:



*'Why am I not entitled to have a family life? When small adjustments in education would stop him going over the edge and keep him happy and healthy.'* (Bev).

In instances, where the adjustments are made, it can be the 'make or break' aspect of the C/YP success and future. EHCP outcomes are often related to set targets in assessment criteria rather than meaningful SMART targets that reflect the individuality and specific progress for each C/YP.

*'[...] They [the outcomes] are not differentiated down of how he is going to move through each step. I only put things down like: "he needs to have access to a sensory space". But that is not a smart target, it does not say how long, it is only to do with an outcome.'* (Ally).

*'It is just that some of the EHCP outcomes are unrealistic. One for my son is: "to let the teacher know if he does not understand something". But he does not understand that he does not understand something, ha ha! So, it is not something that he can achieve.'* (Janet).

In Danny's view, asking for her views to be incorporated into plans, is still now within the remit of practitioners, illustrating the continued power imbalance in partnerships:

*'we are conditioned to what is offered to us and say thank you, we do not ask for more'* (Dannie).

A tendency of being offered a platform for expression of views has been reported by participants as one of the major changes they have noticed since the Code's implementation in practice. Examples of practice where parental opinion is considered do not always translate into change in provision, or the fulfilment of agreed plans in practice.

(XY) *'you will have some empathetic personalities, all supportive and unfortunately you will also come across those who will think yes you have to be heard but that is as far as it is going. It might even be put in an action plan but there will not be a timetable of when it is actually going to be delivered'* Barbara.

*'it is all tokenisms. Yes, we would like to hear your voices, but we do what we see fit anyway.'* (Bev).

Although some parents feel they now have more opportunity to express an opinion that does not mean that they are more likely to be listened to; parents feel as though they are treated as unreliable witnesses:

*'I feel like I have to justify myself at all the time for his needs. That it is not believed and that I am just making it up.'* (Kathy).

The need for constant justifications and evidence exaggerates the burden of bureaucratic tasks that could be avoided through more effective assessment systems where parental and professional expertise would be weighed equally.

The issue of trust extends to the C/YP's faith in the services and professionals they come in contact with, and can affect the nature and quality of relationships formed between them, and potentially, other relationships these C/YP will form throughout their lives. For those YP who can verbalise their wishes, the disbelief from practitioners can be very challenging in future exchanges.

*'she was out of school with anxiety so there was an assumption that she must be out drinking or smoking, having sex. But she is quite the opposite, she is very prudish, she is very anti-drugs, she is risk averse. Had they listened to what I had to say, they would have known this was not the case. The relationships then for my daughter with that service completely broke down. Because she could not believe they said these things about her, completely offended'* (Linda).

Carrie illustrates how having a trusting relationship with practitioners enables parents to believe that practitioners are driven by the best intentions for the C/YP:

*'the teacher who changed my attitude a bit had to build a lot of communication with me before I let her try things with my son'* (Carrie).

## Transitions between provisions and into adulthood

The age limit for provisions is currently extended to 25 and when children transition into adult services, different sets of regulations apply for them to obtain or maintain service support. What once worked in children's services does not immediately transfer to adult services and different routes to acquire support pose a difficulty for families. Some parents asserted that many C/YPs 'go off the radar', unnoticed as they stop being monitored by children's services and are not yet referred to adult services, placing the responsibility for care, education and support on families who may not always be able to stimulate adequate progression and learning for the YP:

*'There is no linkage whatsoever! [...] It is like you are dropped out of one system and then you have to wait for the other system to pick it up [...] And all the work the schools have done to help these young people to socialise, to give them lots of skills to cope in their adult life-they end up at home with their parents and carers and then they lose all their skills, and their worlds implode'* (Mimi).

Although it is infrequent, some colleges offer special provision for YP with SEND. In Janet's experience, many practitioners working in colleges lack knowledge and experience in comparison to practitioners working in mandatory education. This can often cause additional difficulties in forming partnerships due to misunderstandings and results in parental doubts about the safety and adequacy of the provision on offer:

*'they say when you go to the meeting that they support your child fully and they are secure. And then when you tell them something, like one of my friends' children got out of the college and managed to cross the road, ...then all you get is: "aw well, we are not a special school"'* (Janet).

Anna is concerned that young people's opinions are assigned a higher status than parents. This is experienced as frustrating when the parent knows that really the young person has not yet acquired the capability to make these life decisions for him/herself. In Anna's case, her son's opinions were treated as

superior to hers when he turned 18 as his ability to articulate his wishes and his façade represented higher-level abilities than his actual cognitive capacity:

*'because he said he did not need any support...he has not got social worker now either. So, his EHCP is going to be education only, based on that one lady who comes to see him once a week. I do agree on the fact that people must listen to parents even if the child is 18. Because he does not know what he needs. Yeah, he is like a little professor the way he talks. He knows about life, the government etc but he is not capable'* (Anna).

### **Person-centred and family context**

Equitable provision revolves around the person-centred approach, as guided by the Code, where each C/YP should be treated as an individual within the context of their immediate family and community. However, some of these parents commented on how the rigidity of the assessment criteria did not allow for recognition of a child's individual characteristics and nature.

*'This is a very real problem of putting things in boxes. Our children are highly individual, and they will never fit into boxes that are created. Professionals have to be able to think outside of the boxes'* (Bev).

This can cause differences between parental and practitioners' perceptions of individuals when working in the partnerships.

Mary discussed how the lack of recognition for the interconnection between an individual and their family results in conflict with practitioners. This difference in understanding results in practitioners sometimes expecting auxiliary support for individuals from their parents, but fail to accept parental responsibilities towards other members of the family:

*'there is no acknowledgment that you are a part of a wider family. So, it is like "you need to do this, and you need to do that" but I have got two other children as well. And one of them has their own needs which conflict the other's needs.'*

*And what you are telling me to do means I cannot do stuff with the other child. It just was not practical in our instance but there was no acknowledgement, and it was like "aw, the mother is refusing to do XYZ". And I was not refusing to do it, it was impossible for us as a family to do it' (Mary).*

As C/YP often display varying behaviours in different contexts, Sue depicted how these differences have fuelled practitioners' disbelief of her accounts, raising the issue of how important the acknowledgment of contextual characteristics is in partnership working. For Sue, practitioners value their own judgment of what is happening above hers. But when practitioners listen to parents and reflect on what they are hearing, then real partnership starts to happen:

*'she is not presenting all these issues at school but once I began to raise things and they began to take more notice and watch her more closely, they started to say "actually, we can see where you are coming from. We can see that when this happens, she goes really quiet." In school she is a total yes girl, she is a classic girl on a spectrum. Because at school she sits there and nods, nods. She would do everything, first to put the hand up, knows all the answers, gets home-goes off like a rocket! [...]' (Sue).*

## **Experiences of multi-agency collaboration**

Although prescribed in the Code, the parents report that collaborative work across services seems to continually present challenges. These include exchange of information, appropriate signposting and focusing on the best outcomes for families, rather than adhering to individual services' agendas, budgets, and priorities:

*'Departments constantly send you to someone else's department because the Care system and the Heath system do not work together in partnership. Even though they are supposed to, they still work in autonomy. I go to health and they say: "aw, we cannot do this, this is under care system" [...]' (Mimi).*

Mimi's experience points out that parents can see when practitioners cannot work in partnership together, which could be perceived as a sign that partnerships with parents are even less likely to be effective. If practitioners are not open to work collaboratively with other services, it could be argued that the challenge is not only placed in the 'non-expert' view of parents, but in the way, practitioners are not open-minded to the views of anyone outside of their own field.

*'The schools need advice what to do and how to do it. But they often work in isolation from us and other services. They are not communicating with each other. When the forms are being filled it gives them such a snapshot, it does not reflect the whole child. And then in isolation, every professional makes their own judgement, based on their own agendas. And then you have a GP who looks at it from a totally different perspective and budget' (Sally).*

Beyond multiagency collaborations, participants accentuated the importance of clearer and more cohesive inclusion of transport provision in the EHCP:

*'transport must work together too.'* (Janet).

For Dannie, this particularly refers to C/YP who share long journeys with peers, all of whom may find the travel distressing and challenging:

*'They [the transport workers] spend so much time with our children. So why do not get it in the EHCP, I do not know. [...] if you have that journey every day and the person sitting next to you drive you mad for all the years [...]'* (Dannie).

## **Summary of the theme**

This theme reveals the current and/or persistent challenges parents have experienced in practice since the implementation of the Code. The assumed transformation of communication channels that aimed at enabling parental confidence in public services remains problematic when partnerships are

formed. Despite an array of examples that lack transparency, trusting relationships, effective communication between services and with families, participants also reflected on the practices that enabled inclusive partnerships. These encounters could suggest that more participatory and reciprocal practices take place. These are elaborated on in the next theme.

#### **5.3.2.4. Theme 4: Practices enabling effective partnerships**

While practices and the characteristics of practitioners within EHC services vary (see Section 4.4.1.), the constant factor that enables communication, mutual trust and leads to effective provisions for C/YP with SEND, is the relationship between families and services (see Section 2.1). While time-consuming and requiring empathetic qualities, when formed and maintained, these relationships can transform the lives of families and the work of practitioners. Parents expressed that, beyond extensive knowledge of and acceptance of different manifestations of disabilities, professionals who made the biggest positive difference to their lives were those who treated them ‘simply as other human beings’, without the hierarchical difference in status:

*‘[...] But our GP [...] found it difficult to negotiate what he needs and assigning him to the right services, [...] and said, "I need support with the medication side of it, I really do not know". So, she rang me at home, told me what she had done, just very human, not any power difference. We were just like two women talking together, negotiating it together. That felt good, you know’ (Carrie).*

Moreover, the flexibility in approach and willingness to adapt embedded practices reasonably, builds parental confidence that their C/YP is being recognised, appreciated and treated as an individual, and their specific needs are at the forefront of the decisions being made:

*‘My GP has been very proactive, talking to me, coming to see what it is like for the family, seeing my son not just when he is ill but she sees him on regular 6 monthly visit so she gets an understanding of how he is when he is ill [...]’ (Mimi).*

For Ally, being empowered to affect how provision is designed for her son with her knowledge of him and his needs, is invaluable when collaborating with practitioners. It enables her to prevent crisis and ensure the distress for her son is minimised:

*'[...] when he [my son] started in his new secondary school, I could basically pick how I would like this transition to go. So, I could decide whether I wanted him straight in or whether I wanted him staggered. And I knew if I sent him for a couple of hours and then went and got him, we would have massive problems.'* (Ally).

While empathetic approaches are exercised by professionals, for parents/carers, being able to witness that professionals see the positive qualities in their C/YP as opposed to constant discussions revolving around needs, deficits and difficulties, is crucial in building effective relationships:

*'She [the practitioner] treats my son as a person, she comes in and talks to him. Before, at school he was always seen as the child with bad attitude or the child that is just naughty. But this lady comes in and every time she leaves she would say: "I've had a really good session with you today and I have really enjoyed it and I like us having our conversations because you really make me want to go away and look up what you are telling me"'* (Anna).

Similarly, when professionals display the 'above and beyond' approach to supporting a family and consistently communicate that to families, parents/carers feel their concerns have been regarded and validated:

*'the officer who came out was wonderful and she came and sat and listened to what we had to say, she was very helpful. She went back, she did things for us that were above and beyond her job remit. That she should not have to do, and I was very grateful for that officer'* (Linda).

A range of additional services that support families were named by participants as a bridge between them and the main EHC services. While SENDIAS (SEN & Disability Information Advice and Support) provides invaluable legal support for families, link workers and 'early support' workers were exemplified as proactive professionals who advocate for families in different circumstances, e.g.,



completing DLA (Disability Living Allowance) forms. The Visual Impairment team was praised for excellent support in identifying possible equipment and sourcing funding to meet the needs of the individual. Parent and Carer Forums were described as hubs of information, expertise, and support, as they affiliate hundreds of parents who have or are about to experience the system. The support, reassurance and the breadth of knowledge that is shared by parents for parents is experienced as invaluable and can be relied upon as all the advice given is rooted in experience and frequent exchange of families' lived experiences between the members:

*'...we have 12 employees and volunteers and we cannot meet capacity in terms of people contacting us and yet, we had a meeting with the deputy chief executive of the clinical commissioning group because he had heard things about us. And he wanted to come and find out what we did, and he said that we are evolving into that role, where we do have that holistic approach and that overall knowledge. Just because we spend all our time talking to families and listening to their experiences. And because we have got around 1000 members, somebody might come to us with a question and we might not necessarily know the answer, but we have a pool of thousand people who might know the answer' (Sam).*

It could be said that the parent and carer forums seem an underused resource that could enrich practitioners' knowledge and understanding of families more effectively, rather than only being used as a point of contact for when parents require support.

Whether in primary, secondary, or residential settings, parents unanimously agreed that the expertise of professionals and parents is essential in designing adequate provision for C/YP. For this to be successful, lines of communication that are flexible and mindful of parental commitments and families' lived experience require regular input from both sides. Parents/carers who can contact practitioners regularly when in need and be reassured that their C/YP are safe and cared for while in provisions, reported increased confidence and trust in services. Equally, being contacted frequently by practitioners working with C/YP aids the transparency and individuality of support. When parents are

given reasonable time to process the information and clarify it, the relationships become more meaningful and personalised:

*'We are fortunate that the school has a policy that they do not ring us every time they had a problem. But we have this email communication and if it is negative it is between us adults, so it does not bring my son down. The teacher now emails me with any changes if there are meetings or whatever and I can prepare my son. Then the person covering is always the same person. We have been built relationships with school, we are not perfect, and we do not expect you to be perfect' (Sally).*

Listening actively to parental concerns, and the C/YP's needs, wants and interests, transforms the way families interact with services and optimises the positive experiences of relationships formed:

*'when you meet people, who are actually prepared to sit and listen, even look at you as an individual rather than just a number, you just feel, well I felt somebody has actually found the time to listen to me and accept what I had to say. [...]' (Anna).*

Puberty can be a very difficult transition for C/YP with disabilities and Annie talked about the importance of knowing that the school would ensure her C/YP is supported from relevant services to enable her transition through the challenging period:

*'They would listen to what the practitioners are saying but if I want something implemented for my child and if it is within their capabilities they will do it, or they will find out how to get it for me. I have a very good relationship with the school. At the moment we are getting mental health team for my daughter because she started biting herself [...] as she does not know what is happening to her body. [...] It is processing for her. [...] They said: "let's get together", they are calling CAMHS services to see if there is anything, we could implement to improve the situation [...]' (Annie).*

Beyond individual professionals across the EHC services, the significance of the SENCO role was accentuated by parents. As the first point of contact for parents of C/YP with SEND, the relationship with the SENCO has a significant

impact on the overall educational experience of the individual and their family. With the SENCO applying the principles of inclusion, the ethos and culture of the school can be transformed and partnerships with parents and C/YP flourish:

*‘Every time we meet other children, they would say he is the naughty boy. So, the SENCo did a lot of work with the other children about ASD so they would look at him differently, not as a naughty boy. In school, we are very protected...’* (Sally).

SENCOs were described as passionate and dedicated to their roles as fully qualified practitioners. The parents felt that following the requirement for a NASENCO award, they provide parents/carers with confidence in inclusive practice being celebrated in their schools. When the role is split between two members of the SLT team, parents reported it enabled more effective contact accessibility and availability.

Parents who have experienced the SENCO exerting a high influence on the whole school ethos and priorities, expressed the appreciation of the culture where all pupils are educated about diversity and where everyone belongs and is welcome to thrive on their own terms:

*‘In my daughter’s school the SENCo is really passionate and she is doing her qualification, and they are doing a lot of stuff at that school for SEND. It is very high on their agenda, the SENCo has a full support of the senior leadership team, they have a massive inclusion team, they offer a variety of different even environments now. Children who cannot be in mainstream classrooms can still be there in the unit and still be taught by teachers’* (Mary).

## **Summary of the theme**

Despite the plethora of challenging aspects in partnership working, this theme provides evidence that some practices and practitioners achieve effective partnerships with families. Compassionate, empathetic, and humane approaches reflect the ethos of inclusion with fruitful efforts to hear ‘all the

voices' and enabling collaborations where 'everyone can have a seat at the table' and contribute to the meaningful provisions for C/YP with SEND. However, the most willing efforts of practitioners and parents are still often jeopardised by structural barriers, which prevent the transformation of attitudes and cultures of working together. These will be illustrated in the following theme.

#### **5.3.2.5. Theme 5: Systemic barriers affecting the attitudinal and cultural shift towards co-productive partnership.**

This theme illustrates the systemic challenges that were reported by participants as impeding and/or preventing the receipt of adequate and timely support.

#### **Practitioners' capacities**

In Julia's experience, individual practitioners are willing to work with parents; however, they are restricted in doing so by the systemic barriers that are not designed to cater for the individuality of cases. Instead, these are usually policies and procedures that are intended to 'fit all' but effectively, do not fit many:

*'I have yet to come across any practitioner anywhere, either at a director or a ground level, who does not want to work with me. But they are not able to...the last thing I need for the people who work with my children is [for them] to be dis-empowered. What the government needs to be doing, instead of saying "you must do this or that" is to think why is the system broken? What are we doing to our workforce and why have they not got the capacity to know what they should be doing? [...]' (Julia).*

Parental concerns about the competency of SENCOs revolved around the extensive overload of this role. When the designated SENCO is also a

headteacher, and their deputy is often another member of the SLT, parents feel they are positioned against a whole team when something 'goes wrong' and they need to negotiate provision for their C/YP. SENCO competency could also be compromised when their focus as a member of SLT is directed across the school, rather than being concentrated only around SEND input. Equally, the lack of time to fulfil the duties of this role, can often appear to parents to lead to insufficient scrutiny of classroom practice, resulting in parental concerns about the effectiveness of educational provision and well-being of their C/YP:

*'She is a full-time class teacher in a very high SEN school. So, her capacity just does not allow time to look at a child in a classroom. I have met with her several times and things get said around the table but then to put them in practice is a different matter'* (Kathy).

For Chloe, the importance of the practitioners' understanding of what inclusion means on micro and macro levels is essential. She points out how some practitioners' assumptions, that are likely to be influenced by cultural understandings of disability, and which drive their practice, prevent them from adopting a more holistic approach to the C/YP and their family:

*'Or how autism affects the wider society and look at how they have come to form their opinions. What bases they have got to form their assumptions about an individual and look at how we have evolved beyond the medical model of autism diagnosis, we need to look at the holistic picture of that individual'* (Chloe).

Beyond the influence of individual practitioners on the working of partnerships, Sam asserts the importance of the leadership team and their inclusive ethos, which cascades down onto the ethos of their staff and their institutions; and without which SENCOs can often struggle to build co-productive partnerships with families:

*'Individual passionate practitioners can be very effective when supported by the leadership team. I think like we said it is about people, like you said about that SENCo-she is really passionate, and she would have gone to a senior leadership team and explained and got their backing'* (Sam).

Furthermore, some professionals, regardless of their own inclusive ethos, are not able to make informed decisions when they are undermined by their leaders who might have a differing personal or professional view:

*'[...] and the response we got, that was not coming from that guy, that was actually coming from his manager' (Linda).*

Parents also recognise that the limited resources and, at times, ambivalent guidance about the change in practice and/or shift in culture, can pose prolonged difficulties in transformation of the services:

*'they said: "aw, you know it takes a bit of time for us to change". It has been three years since the act-they said: "aw, at least his report is a little bit better now, is it not?"' (Mary).*

The importance of adequate training for all public service staff is an issue, as presented by Chloe. In her view, her son's SEND is not adequately represented through courses for practitioners that she has encountered. Chloe depicts a wider issue – the marginalisation of persons with SEND, who remain on the periphery of the normative societal groups:

*'[...] GPs, NHS in general, hospitals, every public service that we encounter needs some kind of autism training, not just briefly, brush over it, only getting at what a typically autistic person is. You need to know how to speak, what tone of voice to use, explain things, just actually have some time and patience [...] well, it is part of a society and at the minute it is just an add on. They [C/YP with SEND] do not fit in and that is it. But there is going to be more and more people diagnosed with autism, adults especially, who have suffered with mental health throughout their life [...] And you cannot ignore it anymore.'* (Chloe).

The, then current, Ofsted framework (2012) was described by participants as one of the main assessment tools that did not reflect inclusive principles and prevented schools from embedding inclusive practice and commissioning adequate support, because the main driver for meeting the criteria through the framework focused on academic achievements. Instances of the restructure of schools to enable integrated units, where achievements of mainstream pupils

would be classified as separate from their peers with SEND, demonstrate how the practice of segregation still occurs:

*'Ofsted framework has absolutely nothing, nothing fits into that in terms of the principles of the code or the actual code'* (Julia).

*'they [Ofsted] should measure progression, rather than academic achievement. If they did that some of the schools that might appear not to do too well, suddenly would be right up there.'* (Linda).

## **Bureaucracy**

Bureaucratic tasks, related to caring for a C/YP with SEND, were compared to a full-time job by respondents. Participants reported that it requires expert knowledge to interpret some of the jargon and legal guidance provided as instructions to navigate the realm of SEND. The complications that come with filling in of, often legal documents, add to parental heightened anxiety and the need to seek adequate support, which is not always available. And although many parents/carers manage to navigate through the system successfully with the support of additional information and support services (Parent/carer forums, advocacy groups, etc.), they often resort to having to 'chase things up' repeatedly in their own time, learn new law or use 'buzz words' to access the support their C/YP require:

*'[...] and you have to know what to put in them. My son's DLA form was filled in, so he was, for years, only on the middle band for care. And he wakes in the night, he is non-verbal, he cannot cut his food up, could not feed himself at that point, cannot dress himself. [...] But you have to know exactly what word to put in that form that will trigger the right service. The parents and carer forum said these are the trigger words you have to put in there, so I did. [...]'* (Ally).

Janet raised the issue of parents who are less inclined to ask for support, and the fact that this puts them at a disadvantage, as the services that should be

readily available and explained to them in an accessible way are hidden in the mountain of bureaucratic tasks and are not clearly sign-posted:

*'You know what we need is ... advocacy [...] Because not everybody knows how to do this [...] And some people are quite vulnerable and do not have a clue of where to start and what to do. You know the other boy's mum and dad, my son's friend. His dad rings me a lot and: "oh, I had a £100 fine from the dentist, what do I do?". I explained he needed a certain form. He is always ringing me and asking me for help, and I do help him, but they have got kind of limited intelligence and they do not know how to deal with these things. They need a voice to speak for them' (Janet).*

Often, bureaucratic procedures also mean that families are left without support for months as the processes involved appear to them to be meaningless and are conducted by staff who 'tick the boxes' and make judgements on set criteria that cannot possibly reflect the holistic view of the person. For example, Veronica recounted how her daughter's needs were not met for months, due to the barriers in assessment system:

*'So, she has had a blue badge since she was 4 and suddenly, she does not. Now, when she is bigger, stronger, and more stubborn. Typical example with the transport for the college [...] I got letter from PA, my GP, and from the college stating the difficulties they have experienced. And I sent all these documents to the badge team saying they really needed to review this situation. They never replied to me [...] So 7 weeks we have been without a blue badge, we have had so many issues in that time. We have been sitting in car parks, lounging around, running in front of the taxi because we did not have a blue badge. We had to cancel some of the trips out with the PA' (Veronica).*

Bureaucratic workload also affects the professionals working within the system, some of whom were reported to 'go beyond their remits' to accommodate the needs of families (unofficially as the structural barriers prevent them from offering that support):

*'[...] Often, you will find one organisation that will provide far beyond their remits because of the gap in services. Those people feel bad for the situation's*



*families are in. I have experienced it and it was not official, as you can imagine.'* (Rory).

## **Budget constraints**

In times of austerity, public services across the country face cuts in their budgets, which, in the view of participants has been a major contributor to the failings of the reform. Parents feel that the new regulations might have been well meaning, but with constant cuts in budgets, services have significantly limited the number of support options. Furthermore, mental health provision appears to have less funding and attention than physical health provision, which results in challenges to obtain adequate support, in families' experiences.

*'It is evident that health services for physical health have much more funding than mental health and disabilities like autism. And this is a battle wherever you go.'* (Rory).

Janet described how budgets agreed were taken away without much notice, placing her family in a precarious position, because they then had to manage their needs independently until the support was reinstated:

*'what they have done, because I need a PA to pick my son up from college because I work-they put that in place but took all the respite money away because of that. So, I have to chase it up again...I have got a pile of invoices to pay but I have no money'* (Janet).

Support is provided on an available budget rather than on need, as services seem by these parents to be stretched to their limits. Participants reported how this results in frustration when collaborating with professionals, as both sides report being frustrated in trying to create adequate support for C/YP with limited available resources, and this often leads to costly and time-bound appeals:

*'my daughter's placement now costs £100 000 a year. Which for taxpayers is absolutely massive. But there is no local provision for her here. My son's is 65*

*000. If they had done what they needed to do and when, they could have stack up 10 grand or so at most. But because everyone was like "no, no, no we will avoid, avoid, avoid". So, it then comes to that. [...] But it was a big cost emotionally and financially for that. Her experience was just before the children and families act but I do not see it has changed as I had the same experience with my son a few years later' (Mary).*

It seems to these parents that while educational practitioners plan their settings' outgoings with all pupils in mind, the budgets are sometimes spent to cater for the majority, which leaves the needs of some individuals not adequately met when they require additional input:

*'[...] in my son's school they put TAs in every single class in the school, which meant that because he needed something that was not part of the main provision, there was no money to provide what he needed. Because they spent it to meet the majority of the school's needs.'* (Mary).

## **Process of assessments**

It is common practice amongst these parents that they fund the assessment process privately so appropriate provision for their C/YP can be received:

*'there is a lot of us that had to go down this route [private assessment]. And it is a need, if your child needs it and you have nowhere else to go, then...'* (Julia),

*'[...] And when I had a conversation with the psychiatrist and psychologist at CAHMS saying he needed this information [their reports], they said they were not commissioned to provide advice. I said: "you find that you are actually under the Children and Families Act", they said: "aw, you know it takes a bit of time for us to change". It has been three years since the act [...] So, I had to fund a private assessment. Second time I had to do this. Ah I spent £8000 sorting my daughter's needs' (Mary).*

Participants also pointed out the conflict of interest in the connections between assessment services and services deploying budgets for the provisions. While they are closely related, parents felt that they should function under different managements, otherwise their decision can be perceived as driven by the budget ramifications, rather than by the needs of C/YP:

*'There is a financial incentive not to assess properly and while you don't identify needs you save money.'* (Kathy).

Mary describes how proactivity in referrals made by practitioners would help to minimise the 'gate keeping' of the referral processes and enable adequate support:

*'It still feels as though it is a very reactive service, reactive system, the evidence has to be there to some degree before they can make the referral. Because that is how the criteria are. And it is not like we know there can be an issue, they might have seen a little of it now, why do we not refer that child to this provision, e.g. CAMHS, ed psych and then we can make plans so these people can come and work with that child before the family is in crisis. But no, they wait until the child is in crisis.'* (Mary).

Sally recalls how she was left on the edge of despair trying to look after her children, while continually asking for assessment. What she reveals in her account is the reactive nature of the services, which seem to wait until families are in crisis before they can offer support:

*'Like safeguarding e.g. I have had to make a choice between my son or the other son who is little when one ran to the river and what was I supposed to do, run after him while leaving the pram unattended? I thought I had to speak to someone about safeguarding as I felt I could not safeguard my children because of son's ASD related behaviour. I have been asking Social Services to come and do the assessment for two years! It is almost as if until you say I'm walking out, I cannot cope, that someone is going to listen'* (Sally).

The anomalies of the system – for example, having to leave the system and reregistering, rather than waiting to be seen – illustrate its ineffectiveness, leading to parental frustration as they lead lives from crisis to crisis:

*'[...] the SALT team came with such a backlog that it took them two years to do the assessment on him. Because so much time passed and even though there were things that needed to be done, now it is only time to be discharged because if he is referred again it is quicker to get back in the system than stay there and wait.'* (Sally).

The process of assessment, diagnosis and support, being centred around what are perceived within a medical model of disability as 'deficits' in individuals, means all procedures require descriptions of challenges, deficiencies, or inabilities to function within the community. This negative approach can fuel parental combativeness when practitioners fail to recognise the person behind the label and the qualities of their uniqueness:

*'until they change their perspective of viewing autism as a negative and sort of not embracing the qualities that it can bring, it is not productive. The language is all negative. It is all about what your child cannot so, what they are not achieving. The behaviour that is not acceptable, everything about the whole process is negative. It does not celebrate anything that could be encouraged or enhance the future in a positive way'* (Chloe).

## **Summary of the theme**

Despite the array of practitioners' attributes that participants described as desirable in Theme 2, the systemic structure challenges the best-meaning practices and approaches, when the capacity to fulfil the roles assigned to services are restricted by budgets and resources. This theme delineates the factors contributing to parental frustration when dealing with practices that prevent the practitioners from fulfilling their roles and C/YP from receiving appropriate support. While mainly focusing on practitioners' restrained capacities, bureaucracy, budget constraints and assessment processes, this theme also refers to the attitudinal barriers within the culture that are fuelled and perpetuated by the organisational systems currently in place. It would seem from parents' comments that this culture, which continues to obstruct inclusive

practice where individuals are valued equally and regarded in a holistic manner, with their families and communities forming a part of that picture, unfortunately still prevails in practice.

### **5.3.3. Conclusions**

The analysis presented in this chapter outlines the factors influencing effective partnerships with parents. The themes present how these partnerships have been affected since the implementation of the Code, and what parents perceive as desirable approaches in enabling co-productive partnerships in the future. Co-production is evident in many aspects of the partnerships and has been identified by parents as effective in enabling parental contributions to decision-making. The next chapter presents a discussion on the findings from both the survey and the interviews to address my research questions.

## **6. Chapter 6: Discussion**

The overarching aim of this study was to explore parental experiences of partnerships since the implementation of the SEND Code of Practice (2015). This chapter positions findings from this study within the context of previous research about, and the practice of, partnerships within the realm of SEND. I situate each research question within relevant literature to demonstrate parental experiences of partnerships since the implementation of the Code, and to evaluate what my findings can reveal about the potential of co-productive practice in enabling inclusive partnerships.

### **6.1. Research questions**

To investigate parental experiences of partnerships following the implementation of the SEND Code of Practice (2015), three research questions were explored in this study. These are presented and addressed in the next sub-sections.

#### **6.1.1. What are parental experiences of being acknowledged and treated as valued contributors to decision-making within the parent-practitioner partnerships in the EHC realm, since the SEND Code of Practice (2015)?**

As explored in Chapter 2, the SEND Code of Practice (2015) directed practitioners within EHC services to build relationships with parents in more equal and inclusive ways. The Code obligated services to form partnerships that would enable parents to have confidence that their wishes would be listened to and acted upon; where multi-agencies engage with families in decision-making processes; where parents have a choice of schools; where all communication is jargon-free and where highly inspirational outcomes can be planned and

reviewed with the use of accessible information to enable parents to equally contribute to decisions for their C/YP (DfE & DoH, 2015). Since the implementation of the Code, research suggests that some parents are satisfied with the level of their autonomy in making choices about their C/YP's schools (Bajwa-Patel & Devecchi; 2014), Adams, et al., 2017); however, it is also argued that the choice available to parents is formed from the options that are predetermined by practitioners (Lehane, 2017; Hellowell, 2017). This can suggest that parental views are only regarded at the final stage of decision-making processes, which would oppose the aim of the Code that obliged local authorities to co-produce the local offers with parents at the local government level. As a result, this prevented the available provisions being shaped by the needs of the local families. In exploring of these interconnections, my findings revealed that parents have experienced being reassured that their views regarding decisions about their C/YP were acted upon. However, practitioners' attributes and attitudes varied in being enabling, but sometimes preventative in ensuring parents could contribute to decisions. Below, I discuss what parents in this study perceive as being the systemic barriers to inclusive approaches in decision-making processes. These points are explicated below.

#### **6.1.1.1. *Parental confidence***

This study uncovered that there is an increased tendency for practitioners to seek parental opinions, views and feedback following the changes in legislation. Practices that parents consider 'life-changing' and genuinely enabling of effective dialogue are appreciated by them (for example see: Section 5.3.2.4., p. 216, Sally; Section 4.4.2.3.2. p. 146). Following examples of individual practitioners who 'make a real difference' to the lives of C/YP and their families illustrated in the literature (Curran, Mortimore & Riddell, 2017; Holland & Pell, 2017; Ryan, 2020) this study exemplifies similar instances of 'pockets of brilliance'. These practitioners engage in inclusive practices that foster parental contributions to decision-making processes by inviting parents to collaborations where parental views and expertise are perceived by parents as being of an

equal value to that of practitioners. Parents in this study were also keen to recognise that these practitioners commit to inclusive practice, and should be officially recognised for their practice, for example through the Ofsted framework (see Section 5.3.2.5., p. 221, Linda). Although effective dialogue is often attributed to individual practitioners (see Section 5.3.2.5, p. 222, Rory), participants asserted that the attitude of the leadership team within an organisation can have a significant influence on the inclusive ethos of staff working in these institutions (see Section 5.3.2.4., p. 217, Mary). Therefore, this accentuates the role of the leadership teams in establishing equal and reciprocal partnerships with parents.

In addition to these positive accounts, however, my findings also reveal that some parents continue to experience their contributions being side-lined and treated as being of a lesser value to those of practitioners within the field. This illustrates how the Act has made few in-roads into the culture of parental disregard, long reported in studies on partnerships (Murray, 2000; Armstrong, 1995; Swain & Walker, 2003; Hodge & Runswick-Cole, 2008; Bacon & Causton-Theoharis, 2013). Participants in this study exemplified a range of circumstances where their contributions were disregarded, and the final decisions were made by professionals leading the reviews of individual cases (for example, see Section 5.3.2.3., p. 207, Barbara). This dismissal of parental input by practitioners has been, unsurprisingly, received with disappointment and growing parental reluctance to trust public services. Previously identified as one of the barriers to effective partnerships (Adeb, 2014), unfortunately the findings of this study suggest that issues of trust have been exacerbated by the changes in legislation. Parents in this study reported that some practitioners seem not to comply with the law surrounding the Children and Families' Act 2014, which underpins the Code. Examples of these instances included refusal to refer a C/YP for assessment for needs (see Section 5.3.2.5., p. 224, Mary), refusal to provide placement in a setting chosen by the family, which was based on misleading cost figures to undermine parental objections (see Section 5.3.2.3. p. 206, Ally), or a failure to offer reasonable adjustments in curriculum to enable inclusion within mainstream setting (see Section 5.3.2.3., p. 206, Linda).



As parental frustration with the failure to include C/YP in EHC provisions increases (National Audit Office, 2019), parents are taking action to combat the system through tribunals. According to the National Audit Office (2019), tribunals in 2019 have been won by families in over 90% of cases, which could be indicative of the unlawful treatment C/YP of these parents have been receiving. As parents exercise their right to question the provisions, it becomes transparent that parental expertise does not only lie within their deep knowledge and understanding of their C/YP, but also requires knowledge of the law surrounding the processes of assessment and support that is required for C/YP with SEND (see Section 4.4.2.3.1., p. 135). Described as emotionally draining, expensive and time consuming (Runswick-Cole, 2007), the tribunals won by parents suggest that the practice can often be ineffective and against the premises of the law as outlined in the Code. Parents in this study refer to their advocacy as a 'constant battle' (see Section 4.4.3.2.1., p. 135; Section 5.3.2.1., p. 194, Holly), which is often perceived as the only way the vulnerable C/YP can receive the appropriate support they deserve.

Building on the previous studies that have explored the systemic challenges that occur in partnerships with parents (Glazzard et al., 2015; Lehane, 2017; Hellawell, 2018; Broomhead, 2018), my data reveal how, while practitioners are perceived as gatekeepers, parents also recognise the impact of the failure of the system. Examples of systemic factors impacting negatively on the partnerships were identified by parents as not providing adequate time, training, and resources to enable all professionals to acquire, understand and implement appropriate strategies and adapt their practices in accordance with the guidance of the Code (see Section 4.4.2.3.4., p.154; Section 5.3.2.5. p. 218-219, Julia and Kathy). Lack of clear implications for what partnerships should look like in practice in the Code further perpetuates the ambiguity the practitioners are subject to. However, as discussed above, parents in this study also reported on practices and individual practitioners in EHC sectors who have been working 'above and beyond their remits' to support families effectively. These findings offer hope, however, that despite the challenges the new legislation might present in gaining parental confidence, individual practices can

overcome these barriers and enable adequate support. Further details on how these enabling practices can be developed are discussed in Section 6.1.3.1.

Another aspect that is contributing to lack of parental confidence in services is the level of information and advice available for parents to make informed decisions and to know where to seek support. Parents have described the amount of knowledge and jargon that accompanies the systems surrounding provisions in SEND as incomprehensible (e.g., see Section 4.4.2.3.1, p. 135; Section 5.3.2.5. p. 222, Janet). This finding adds to the evidence from previous data that reflects the prevalence of confusing language, which has been identified as a significant barrier to effective communication before and following the implementation of the Code (Keen, 2007; Hellawell, 2017; Hodge & Runswick-Cole, 2018; Connor & Cavendish, 2018). Parents in this study reflected on the time since 2014 when the Code was implemented, and reported persistent experiences of confusing, ambiguous and unclear language surrounding essential guidance and signposting to support services (see Section 5.3.2.3. p. 204, Rory; Section 5.3.2.5. p 221, Ally, p.222, Veronica). On the other hand, my findings do offer hope in relation to this persistent barrier. The parents reported on practices that have enabled simplification of language and have worked on effective communication for and with parents, suggesting that the difficulties in this area can be supported by effective solutions. These include allowing time to explain terminology/procedures to parents and fostering a culture where parents are welcome to ask questions without being judged (see Section 4.4.2.3.2, p.146).

#### **6.1.1.2. *Attributes and approaches enabling inclusive dialogue***

Historically, partnerships have been predominantly deeply embedded in the 'professional as expert' model, with a higher value being given to the knowledge and experience the professionals have to offer (Mittler & Mittler, 1982; Cunningham & Davis 1985; Murray, 2000; Seligman & Darling, 2007). In exploration of this aspect of partnerships, the findings from this study reveal that parental expertise is often still treated as supplementary knowledge, rather than

being given the degree of equal recognition in partnerships that has been called for by researchers prior to the introduction of the Act (Hodge & Runswick-Cole, 2008). With regards to potential reasons for lack of inclusive dialogue in partnerships, participants attributed this to the influence of structural and individual barriers.

Firstly, although the culture of working in partnerships is created by people who work together, the structural challenge in this instance includes the historical perpetuation of practitioners holding the power to make and affect decisions (Seligman & Darling, 2007; Sales & Vincent, 2018). The ingrained ways of working/not working together are very well illustrated in Mary's example of a practitioner who openly stated that it takes services a long time to adapt their practice, despite the legislative guidance (see Section 5.3.2.5., p. 220, Mary). This finding shows that even several years after the Act came to being, its regulations are being disregarded under the excuse of a delay in operation.

Secondly, as the ethos of organisations is affected by the combination of institutional and personal values (Glazzard, et al., 2015), the importance of practitioners' awareness of their own positionality towards the models of disability they function within is imperative (Graham et al., 2020). Parents argued that if any practitioner involved in EHC provision is not clear on their own values related to inclusion and models of disability, the provision these professionals offer and the approaches they employ are often misinformed and followed in a mechanical, unempathetic manner (see Section 5.3.2.5., p. 219, Chloe). This lack of the awareness of disability models can prevent practitioner's understanding of the changing world within the context of working with C/YP categorised as having SEND. Currently, the capability approach affirms individuals' ability to make their own decisions (Norwich, 2014), including the choices of special or mainstream schooling, or vocational or academic pursuits following post obligatory education provisions. As the choices for many C/YP with SEND are advocated by their parents, it is inevitable for practitioners to liaise with parents to ensure these choices reflect the wishes and preferences of the individuals. Therefore, practitioners who are not aware of their own assumptions within the models of disability can

unintentionally prevent inclusive dialogue with parents, which can lead to inadequate considerations for individuals' choices.

Furthermore, the impact of individual practitioners was presented by participants as a frequent example of the power it represents in partnerships (see Section 5.3.2.2., p. 198, Julia), on one hand as enabling effective work together, and on the other hand having the potential to jeopardise positive relationships and to prevent effective communication from taking place, should the power executed by this individual be misused. Professional attributes of individual practitioners have been identified by parents in this study as drivers to productive, inclusive, and effective partnerships with parents (see Section 5.3.2.4., pp. 213-218). To enable two-way dialogue (Turnbull et al., 2011) and equitable exchanges where parents feel part of the community of practitioners making decisions around provisions for their C/YP, the findings of this study highlight how important empathy and understanding of disabilities are to the core characteristics of practitioners. These two qualities were positioned as fundamental to the development of effective communication, as was the ability to change the continually prevailing culture of 'professional dominance' and to cultivate the inclusive view of 'everyone having a seat at the table' (TED, 2019), everyone having an equal value (Booth and Ainscow, 2002), and fostering the principles of belonging (Trussler & Robinson, 2015), achievement and participation (DfE & DoH, 2015). Enabling families to share their stories and learn with and from parents and their C/YP was identified by participants as the main route to expanding practitioners' empathy and understanding. Illustrated as one of the means to form and maintain effective partnerships, the story sharing will be discussed in detail within the third research question (see Section 6.1.3.).

#### **6.1.2. What is the potential of co-productive practice to enable inclusive partnerships in parental view?**

The Code alluded to the concept of co-production with parents in relation to Local Authorities and their creation of the Local Offer (DfE & DoH, 2015) (see

Section 2.1.3.); however, the concept was not further explicated as a means of forming partnerships with parents on the organisational or individual levels. My study has an important contribution to make, therefore, in how it evaluates the nature and value of co-production post the introduction of the Code. As discovered by this study, parents are most likely to experience partnerships working on the individual and institutional levels and therefore, I anticipate the potential of co-production in relation to three main aspects of partnerships with parents: firstly, in the potential for co-production to enable an effective exchange of information and enable deeper understanding of parental lived experiences for all practitioners, including the work of multi-agency teams; secondly, in how co-production can empower the parental 'voice' so that parents are treated as equally expert when decisions are made; and thirdly, in how employing a framework of co-production could enable inclusive and mutually respectful partnerships. I deal with each of these in turn below.

#### ***6.1.2.1. Partnership working with individual and Multi-agency teams***

Through the advocacy for their C/YP, parents encounter working with different teams; sometimes it is working with one particular team, other times parents are required to navigate partnerships when working across different teams (Seligman & Darling, 2007; DfE & Doh, 2015). As explored in Section 2.1.3., the Code placed emphases on collaborative work between EHC agencies as much as within individual teams, to ensure ambitious outcomes for C/YP with SEND. Within Section 5.3.2.3. (p. 203), where the disparities between the assumptions of the Code and the experiences of families are discussed, parental experiences suggest that multi-agency collaborations lack cohesion and consistency, with individual professions often working in a disjointed manner where essential communication about a C/YP's needs and progress does not take place (See Section 5.3.2.3, p. 203). These findings confirm that when collaborative working within public services, which is continually described as problematic, disjointed, and not supported by appropriate training (Norwich &

Eaton, 2015; Walker, 2018), it remains a root for concern. With the common principle of joint working, the creed of 'working together for the best outcomes for the C/YP' (Walker, 2018; DfE & DoH, 2015) continues to affect the lives of many families. It can be argued that agencies fail to fulfil this duty when they preclude effective communication exchange as demonstrated in my study (see Section 5.3.2.3., pp. 203-218). It is, however, argued by the participants and researchers (Norwich & Eaton, 2015; Cochrane & Soni, 2020) that these difficulties are caused by the systemic barriers, through lack of clarity in how to establish, monitor and conclude joint-working between agencies from different cultural and organisational backgrounds that have varying capabilities to resolve power dynamic issues or disagreements (Walker, 2018; Anning et al., 2006).

One of the ways to address these systemic difficulties could be through a wide adaptation of the co-productive framework across all services. As explored in Section 2.5.3., co-production can enable dedicated space to express each party's standpoint and negotiate an equitable way forward. This approach could also enable seeing parents as another agency within the joint-working; an agency that has belief systems in place, that consists of contributors who hold a different perspectival knowledge of the C/YP and who deserve equal consideration when decisions in the best interests of C/YP are made. Acknowledging that parents might hold numerous years of experience of C/YP in various contexts and how this knowledge can be incorporated into a holistic picture of an individual, would also reflect the inclusive ethos of working together. As a result, all parties would be recognised as creators of a comprehensive and appropriate provision that adequately meets the needs of the C/YP under their provision. Participants have provided some examples of how this recognition and change in 'traditional' ways of working together can operate in practice; from setting a clear outline of values which are designed together with parents (see Section 4.4.2.3.4., p.154; Section 5.3.2.4., p. 216, Sally), to engaging with parents to design a provision and train the staff (see Section 5.3.2.4., p. 213, Mimi). Although evident in some parents' experiences, these approaches continue to be inconsistent and reliant on the interpretation of

the partnerships by leadership teams who may or may not enable these practices to flourish (see Section 5.3.2.4., p. 217, Mary).

#### **6.1.2.2. *Empowerment of parental ‘voice’***

The notion of empowerment of parental ‘voice’ has been interwoven in the discourse of partnerships (Carpenter, 2000; Runswick-Cole, 2007; Broomhead, 2018), but as a concept in practice, it can pose difficulties. Firstly, the question of who might be responsible to empower parental ‘voice’ is not always clear (Broomhead, 2018); secondly, parental perspectives vary in that some parents might present a belief that it is the prerogative of professionals to make decisions and to impart their ‘specialist’ knowledge with parents in expectation that parents will accept it and follow its guidance accordingly. With an increasing movement of parents who advocate for their C/YP (Boshoff at al., 2016) and for their own advocating ‘voice’ to be recognised as equal in expertise to the ‘voice’ of practitioners, it is essential to acknowledge that this movement does not represent all parental wishes. It is therefore important that parents who might be less inclined to share their views, are encouraged to participate in the decision-making processes to the same extent as parents who are more likely to have been engaged in dialogue already. As discussed by the participants in this study, the motivation to raise awareness of the need to include parents in decision-making processes is not always only caused by personal experiences, but by observing other families in crisis who are less able to seek support and voice their concerns (see Section 5.3.2.5., p. 221, Ally and p.222, Janet).

As parents are the extension of the child’s voice in the context of this study, parental perspectives on the adequacy of provision and approaches employed to deliver it appear to be essential for services to design their practices with the ‘recipients’ in mind. Co-production aims at enabling that perspective to be shared, understood, and considered when services are planned and delivered (see Section 2.5). It is, however, predominantly used in the health and care domains (Voorberg, Bekkers & Tummers, 2015), and less evidently within the

education sector. Multiple health and care settings have adopted the approach to develop understanding of the ‘user’ perspective, needs and preferences, through the employment of co-productive principles (e.g., Involve.org, pipstockport.org, councilfordisabledchildren.org, or coalitionforcollaborativecare.org). Working co-productively with service users enables practitioners to incorporate different lenses to the rationale for design and delivery of services (Needham, 2007). Particularly in the health and care context, co-production is known as enabling individuals, often categorised as marginalised, to express their views on the quality and appropriateness of the service they are receiving (Realpe & Wallace, 2010). Therefore, it draws a close association with the need to incorporate parental wishes and opinions within the partnerships working in SEND.

Some participants in this study concluded that the deep divide between the professional and non-professional expertise present in many educational settings, might be the reason some settings are reluctant to adopt constructs like co-production in practice (see Section 5.3.2.2., p. 200 Julia and Mary). Others pondered over the professionals’ capacity to enable co-production and empowering of parental ‘voice’ (see Section 5.3.2.5.). Particularly, when teachers are constantly subjected to a pressure of performativity procedures that often equal to ‘fitting into league tables’, rather than focussing on holistic and pastoral care for individuals (see Section 5.3.2.2., p. 198, Dannie; 5.3.2.5., p. 221, Linda). The issue of practitioners’ capacity closely links to the reported pressures in performativity services are subjected to, alongside the ongoing challenges presented by the cuts in budgets (Hellawell, 2017; Lehane, 2017;). It can be argued that even if individual practitioners fostered a culture that would empower parental ‘voice’, these practices often rely on resources that, in the current climate, might be unavailable.

### **6.1.2.3. *Employing the construct of co-production***

As explored in this thesis, the framework of co-production has been effective in engaging with perspectives of ‘service users’ (Needham, 2007), and the



framework has provided opportunities for building effective communication between public services and citizens in various contexts (Boyle & Harris, 2009; Realpe & Wallance, 2010; Pestoff & Brandsen, 2010; Alford, 2014; Fairlie, 2015; Voorberg, Bekkers & Tummers, 2015). This study accentuates the connections between the co-productive principles of mutual trust, empathetic dialogue, respect, and shared ownership of design and delivery of appropriate aspects of provisions with the desired practices in parental views. Fulfilling these values would additionally utilise parental expertise in building the social capital of the whole community (Cahn, 2000). These connections suggest that the co-productive framework could enable inclusive partnerships between families and services (see Section 2.5.).

In proclaiming the qualities of trust, effective communication and empathy as the superior aspects of working in partnerships, parents agreed that partnerships based on these values can be developed despite the current constraints of the ill-equipped systems. This can be achieved through the changes in individual practices and professionals' attitudes and approaches. Participants unanimously expressed their willingness to support the individual practices and professionals in efforts to minimise the effects of systemic barriers on the quality and accessibility of provisions by engaging in processes of learning together, processes that could provide a different direction in power dynamics between parents and practitioners (Mann et al., 2020).

While co-production would not provide answers and solutions to all experienced difficulties (Fairlie, 2015), it can enable the platform to share families' stories (Needham, 2007), to engage professionals and parents in reflecting on each other's positions within the system (Needham, 2007) and to offer opportunities to recognise the possibilities of working together towards the best outcome for the C/YP.

Although co-production has been previously criticised as being an idealistic approach to collaboration in practical terms (Fenwick, 2012), its underpinning values of parity, reciprocity, mutuality, and developing social capital of the community are not controversial and can be identified as universally desired principles (Cahn, 2000). Furthermore, co-production follows the Deweyan idea

of transformation of embedded social structures to achieve social inclusion, where multi-perspectival social inquiry conducted through communication, exploration of, and commitment to individual and collective social agency enables achieving the best conditions to live and grow for the democratic society collective and its individuals (Striano, 2019). In the spirit of creating opportunities for parents to affect the manner in which services engage with families, professionals could minimise the professional/non-professional barrier to collaborations by enabling dialogue which celebrates inclusion that cannot exist without participation of those who it aims at including (Todd, 2007).

To address the connection between the Code, the framework of co-production and the findings from this study, I further elaborate on the links presented in Section 2.5, where I highlighted an alignment between principles underpinning the policy (The Code) and the co-productive framework. Here I expand on these alignments by linking them to parental recommendations for inclusive partnerships and then draw on these to identify a number of considerations for co-productive practice in future in this context. The essence of these interconnections is presented in the table below:

*Table 16 Framework for co-productive partnerships with parents and carers*

<u><b>The Code</b></u>	<u><b>Co-production</b></u>	<u><b>Parental recommendations for inclusive partnerships</b></u>	<u><b>Considerations for co-productive practice</b></u>
<b>Equal, reciprocal, and participatory partnerships</b>			
Full participation of C/YP and their families and co-ownership of decisions	Equal and reciprocal relationships	Being recognised as an equal and valued contributor to decisions	'Open door policy', co-production interwoven into institutions' strategies and ethos; parents engaged in planning and delivery of provisions/community events/training
<b>Learning from parents to shape services</b>			
Decisions on services are shaped by users' experiences, ambitions, and expectations	Effective information exchange and shared decision making that responds to complex and unique service users' needs	Shared stories to inform practice and practitioners' reflections	Celebration of parental input; parents invited and supported to deliver training/raise awareness of practitioners; parents actively engaged in shaping provision/making decisions
<b>Acknowledging and working through differences</b>			

Parents to be enabled to share their knowledge about their child and be given confidence that their views and contributions are valued and will be acted upon. A positive dialogue maintained to work through points of difference and establish what action is to be taken	Building trust and communication between participants, allowing bureaucrats and citizens to explain their perspective and listen to others, as well as revealing citizens' needs, identifying the main causes of delivery problems, and negotiating effective means to resolve them	Parents to be recognised for their expertise on their child, but also for that related to practice and policy surrounding SEND	Sharing the same values of reciprocity, equality, and respect by acknowledging the need to learn together and from each other, the premise of 'everyone being imperfect' and the commitment to reflect on and learn from mistakes
<b>Inclusion: 'everyone's business'</b>			
Staff working in Information, Advice and Support Services should be trained to support, and work in partnership with parents	Staff on the frontlines of public services are recognised to have a distinctive voice and expertise as a result of regular interaction with service users and, often, user's experience of the service is shaped almost entirely by their interaction with the frontline provider	Understanding of disabilities and lived experiences of families with C/YP categorised as SEND as inclusive principles for services	All staff (support, administrative and fractional) to engage in training delivered by parents; co-produced multi-modal materials to be made available for staff across organisations operating within the SEND field; organisations' mission statements to refer to inclusion explicitly at all times.

The connections presented in Table 16 aim at a concise depiction of the potential and relevance of co-production within partnerships with parents. Column 1 and 2 are embedded in literature and research, column 3 encapsulates findings from this study, and column 4 is an amalgamation of all the literature, findings, and my own reflections on practice. Although not prescriptive in nature, this framework is more of a fundamental guide that could underpin partnerships with parents. Cahn (2000) proposed four dimensions that ultimately drive co-productive practice:

1. every person being an asset to a collective;
2. restructuring cultures to serve marginalised groups;
3. reciprocity in collaborations;
4. and everyone contributing to the social capital of a community.

All four of these facets are intertwined with the points outlined in Table 16, indicating that the framework resonates not only with current policy guidance, but equally with approaches to partnerships that parents reported to be inclusive and effective.

However, before co-production can be utilised as an effective framework for parent-practitioner partnerships, a joint, parent-practitioner inquiry into meaning-making of co-production is needed. In line with the principles of co-production this inquiry could present opportunities for both sides of the partnership to establish their perception of the concept, potential advantages and barriers to implementation and initiate the sought-after two-way dialogue. I elaborate on this assertion in Section 7.4.

### **6.1.3. How can practices in Education, Health and Care services be developed to enable more equal, reciprocal, and participatory partnerships with families from the perspective of parents?**

As part of the Appreciative Inquiry structure, which was employed in the design of the research questions in this study, participants were invited to contemplate effective practices, as well as the potential solutions to experienced difficulties in partnerships with practitioners. The previous research question investigated the reasons why co-production offers potential as a model of partnerships. This section depicts practices that parents proposed as those that support development of inclusive partnerships. These practices encompass practical examples of how learning from parental stories can aid practitioners' understanding of parental standpoints, but also practitioners' awareness of what inclusion may resemble in practice and how it can be achieved in the context of partnerships to ensure parental 'voice' is accepted and acted upon. To achieve these premises, a discussion on attitudinal shifts in relation to embedded and 'traditional' ways of working together, is presented. I conclude this section with reference to the impact of systems on the partnership with parents.

### **6.1.3.1. *Learning through parental stories***

In agreement with Broomhead (2013), parents in this study argued that sharing life stories with practitioners would enable the growth of practitioner empathy. As practitioners' knowledge about disabilities is seen as essential by parents and researchers in the field (Graham, et al., 2020), learning through the narratives of families in the system could transform professionals' understanding beyond the description of conditions and characteristics, enabling the empathetic responses to others' circumstances (Haugh & Merry, 2001). Thus, what we learn from the participants in my study is that the need for learning from families (Seligman & Darling, 2007) through inclusion of their narratives in training and knowledge exchange is imperative. Furthermore, Mann (2015) asserts that through shared stories, the persons categorised as having SEND are perceived in a more holistic manner and not only through the lens of the categories assigned to them. Time to reflect on these narratives could enable a shift in culture and awareness for the practitioners entering the professions within public services and those who will educate, govern and shape future generations. Additionally, reflection and shared stories could create opportunities for a dialogue (Buber, 2006, as cited in Veck, 2013) that engages with issues of equality, respect, diversity, fairness, freedom and being equally human despite differences (Freire, 1972). These, in turn, would create conditions for practices to immerse their ethos and work in co-production.

Based on the results from this study, I argue that partnerships with parents can be strengthened by enabling a wide sharing of stories about parental lived experiences. Participants felt it was important for these stories to be available not only to those who seek them, but become part of the training for practitioners in EHC services, including 'front-of-house staff' (see Section 5.3.2.2., p. 200, Annie).

Participants suggested that their life stories could be shared more widely with a range of practitioners and society in general to raise awareness of the reality families with C/YP categorised as having SEND experience (see Section 5.3.2.5., p. 218, Chloe). They suggested that this sharing of stories could be

incorporated into all training for EHC practitioners and through co-productive practice with parents (see Section 5.3.2.1., p. 190, Holly). These opportunities could enable professionals already in practice to deepen their understanding and ignite opportunities for reflection on their own assumptions and approaches within the realm of partnerships in SEND.

Although the value of shared stories is prominent in the context of partnerships, it is undeniable that systemic barriers prevent many effective practices, and need to be addressed by policy makers to aid practitioners' capacity and ability to form effective, and inclusive partnerships with families (see Section 5.3.2.5.).

### ***6.1.3.2. Understanding and employing inclusive principles***

What we learn from participants in this study is that forming and maintaining inclusive partnerships between families and EHC services continues to be challenging. In addressing the concerns of parental confidence outlined in the Lamb Inquiry (see Section 2.1.3.), the Code prescribed guidance aiming at development of productive relationships with families (see Section 2.1.3.). Although it appears that the onus of creating opportunities to build partnerships falls into practitioners' responsibilities, it remains unclear how this role translates into practice exactly (Keen, 2007; Lehane, 2017, Broomhead, 2018); nor is it transparent which practitioners' responsibility it is, while all services are required to work effectively through multiagency collaborations. While in practice this ambiguity persists and either side can feel obliged to initiate or sustain the partnership (Broomhead, 2018), these negotiations take place in professional domains. This often contributes to the assumption that it is the responsibility of practitioners to form and maintain partnerships with parents, rather than inviting an equal opportunity to work together collaboratively (Broomhead, 2018). Furthermore, the Code alludes to practitioners' responsibility to seek parental opinion, include it in the decision-making processes, and develop parental confidence in partnership working (DfE & DoH, 2015), which can emphasise that forming partnerships resides within professionals' duties.

In practice, the educational sphere often becomes a hub of multiagency working; the power dynamics between the professionals and with families become complex (Boesley and Crane, 2018), and open to interpretations of what good practice means. This is when the principles of inclusive education could support the formation of partnerships, providing that the individual professionals and settings develop deep awareness of their own assumptions, critically reflect on their attitudes, and understand the values underpinning their approaches to partnerships (Graham et al., 2020). And although the educational domain is perceived as the predominant profession within the context of partnerships in SEND, participants in this study emphasised the transferability of the inclusive principles into all public services and the wider societal context to ensure all families can belong and participate in their communities (Booth & Ainscow, 2002).

While practitioners deepen their understanding of inclusive principles, the qualities of their two-way dialogues with families are likely to become stronger as they learn from their stories and expand their professional knowledge through parental expertise. These understandings could then contribute to practitioners' development of skills to negotiate through, often 'difficult', conversations with parents. The term 'difficult' does not imply parents being difficult in this context, rather it signifies the range of dimensions these dialogues often entail; from emotional aspects of overcoming various challenges in practice and life (see Section 2.2.); e.g., grief, bureaucratic burden, societal exclusion) to working towards positive outcomes for C/YP. Therefore, employing co-productive principles could enable parental engagement where practitioners genuinely and consistently value parental knowledge, input and expertise in design and delivery of the services within the realm of SEND.

#### **6.1.3.3. *Attitudinal shift towards 'everyone having a seat at the table'***

For the parents in my study the most critical enabler of inclusive partnerships with families was practitioner empathy. As a significant factor affecting relationships, empathy was identified as influencing individual professionals' attitudes. Although these attitudes can be more permeable than labour-intensive changes in systemic structures, they are often described as more difficult to shift (Mittler, 2003; Glazzard et al., 2015). Both the systems and the attitudes of practitioners working within them, can be seen as contributing to the problematic partnerships, and participants discussed these two elements at length (see Section 4.4.2.3.3.; Section 5.3.2.2.). Here, the knowledge surrounding disabilities, models of disability and foundations of disability rights movement, play a key role in practitioners' awareness, at the same shaping practitioners' approaches and attitudes (Shakespeare, 2017; Graham et al., 2020).

The underlying creed of 'all of us being human' (Shakespeare, 2017; TED, 2019; Ryan, 2020) has been emphasised in discussions surrounding disability movements, including learning disabilities. This emphasis continuously uncovers the unjust treatment and perception of people with disabilities and SEN in society. Particularly pertinent are examples of maltreatment and abuse of people with disabilities in residential institutions (Shakespeare, 2017; Ryan, 2020), and the hierarchical approach to prioritised healthcare in time of worldwide pandemic, where people with learning and other disabilities do not share the same rights as other groups (COVID-19 DRM, 2020). Furthermore, a report on disability rights in the pandemic, current at the time of writing, stated that children with disabilities have not had the same access to healthcare, social care and education as their peers (COVID-19 DRM, 2020). Likewise, education provision during this period that took the form of home-schooling placed responsibilities solely on parents. Parents of C/YP with SEND reported that the learning materials provided were inappropriate for their children and the learning often took a flexible, more 'life' driven form (Greenway & Eaton-Thomas, 2020). Parents in that study also reported that C/YP took part in decision-making and home tasks, which could potentially have resulted in an increased gap between their academic skills and those of their peers (Greenway & Eaton-Thomas, 2020). Reported practices where healthcare was



determined by the level of person's disability and treatment for COVID-19 was denied to people, including children, with disabilities, reflect how current societies operate within the ethos of the eugenics approaches (Shakespeare, 2017; COVID-19 DRM, 2020; Ryan, 2020). Historical and cultural influences are still persistent and discriminatory towards C/YP with SEND, as described above. Therefore, in light of the recommendations offered by the report on disability rights in the pandemic (COVID-19 DRM, 2020), the 'voice' of people with disabilities, whether learning, physical or mental, is crucial in the design of future provisions that will be inclusive and reflective of the needs of the whole society. Considering these circumstances, the relevance of co-productive partnerships seems that much more crucial in addressing the continuous imbalances of power between the practitioners who enact the legislative obligations and the citizens who are at the mercy of receipt, or denial of receipt, of services designed without their input. In a poignant but very undeviating assertion by a parent and activist for disability rights: "everyone needs to have a seat at the table" (TED, 2019).

#### **6.1.3.4. *Systems and resources***

Despite the efforts of inclusive practitioners and some changes in the culture of partnerships with families being evident, parental concerns in this study highlighted the systemic constraints that the services and families have been experiencing. These constraints included persistent trends within the public services policy where the individuals' disability is perceived as a demand on the non-disabled citizens (Birch & Hodkinson, 2015; Glazzard et al, 2015) (see Section 5.3.2.5., p. 217, Chloe), or the limited access to services fuelled by the time of austerity (Lehane, 2017; National Audit Office, 2019) (see Section 5.3.2.5., p. 223, Rory or Janet). Therefore, all public services have experienced shortages of budgets, resources and, at times, opportunities to source professional expertise of experienced practitioners (Hodkinson, 2019). These inadequacies impact on the navigation through continually heavily bureaucratic tasks that are not designed with service users in mind, and often pose

difficulties in manoeuvring through the system for practitioners (Lipsky, 2010); this often results in bureaucratic tasks having a superior importance than the people they are being completed for. Due to the change in regulations, public services are still grappling with adjustments of their adherence to the expectations of service-led initiatives (Norwich and Eaton, 2015; Hodkinson, 2019), which is evident in practice where parents resort to studying law and using it to gain adequate access to support for their C/YP (see Section 5.3.2.5., p. 221, Ally). Although many families remain unable to utilise this knowledge to seek support, occurrences when services do not fulfil their obligatory responsibilities fuel parental mistrust towards the state, and result in prolonged combative exchanges which have detrimental effects on partnerships and carry financial implications of official appeal processes (Boshoff et al., 2016) (see Section 5.3.2.1., p.193, Holly). These findings represent a different view to previous findings that portrayed general parental satisfaction with the aspects of transfers between the old and the current systems of EHCP (Adams, et al., 2017).

Within the extant discourse of austerity and its impact on the function, resources and effectiveness of public services, the expectations of the Code have been criticised for following highly inspiring aims with, less clearly defined practical frameworks and definitions of what partnerships would resemble in practice (Norwich & Eaton, 2015; Hellawell, 2017; Kendall, 2017; Hellawell, 2018; Broomhead, 2018; Hodkinson, 2019). This disparity between the legislation and practice has also been evident in the data gathered in this study, where parents asserted that the Code was a 'good idea in theory', but an idea that has not been well executed in their experience (see Section 4.4.2.3.1., Parent 144, p. 138).

Despite the confirmation of scarce resources within the services (Hellawell, 2017; Lehane, 2017) and lack of appropriate training for practitioners to effectively adapt their practice (Boesley & Crane, 2018), it is the attitudinal barriers that are perceived by parents in my study as more pertinent issues in problematic partnerships than the structural challenges (Sales & Vincent, 2018)

(see Section 5.3.2.2., p. 200, Julia, Mary or Janet). It is also on those individual levels where the partnerships are the most likely to be formed and where maintaining interactions with individual professionals matter to parents the most, as explored previously within the context of co-production (see Section 2.5.).

Furthermore, parents reported that the changes in legislation have failed to address the continuing challenges the bureaucratic tasks present for families who are experiencing additional care commitments while looking after C/YP with SEND. Parents continue to experience prolonged waiting times for assessments, for example waiting 2 years for Speech and Language assessment (see Section 5.3.2.5., p. 226, Sally); inadequate protocols in place in essential services where vital support is prevented from being obtained like receiving a blue badge for a C/YP with SEND (see Section 5.3.2.5., p. 222, Veronica); or having to gather extensive written evidence for parental concerns as parental opinions are disregarded or deemed as 'too emotionally involved' (see Section 5.3.2.1., p. 195, Sue).

The agenda of performativity within the realm of services perpetuates systemic barriers where humanisation of service-users can pose accountability issues for professionals (Hellowell, 2018) as the system of assessments, referrals and diagnosis has time and resource ramifications which result in insufficient provision on offer. On the one hand, parents shared the awareness of these constraints on practitioners. On the other, parents observed a lack of accountability for some services that continue to function in traditional 'professional-the expert' culture, preventing inclusive dialogue to be initiated (see Section 5.3.2.3). These conflicting positions illustrate the ineffectiveness of current reforms and the incompatibility of the available provision with the needs of families as described in the report from National Audit Office (2019).

The recent temporary 'relaxed' measures applied by the government to the regulations governing the time frames in agreeing and implementing EHC plans and proceeding with the assessment of needs (DfE, 2020), could be perceived as an example of how challenging the bureaucratic procedures are for practitioners; equally signifying how families are dependent on the practitioners'

‘reasonable endeavours’ (DfE, 2020) to ensure the needs of C/YP with SEND are assessed and met in a timely and effective manner.

#### **6.1.4. Summary**

In the view of participants of this study, parents mostly remain unequal contributors in decision-making, and although some practices foster reciprocal and contributory relationships, the attitudinal and systemic barriers resulting in ‘professional dominance’ still prevail in practice. Co-production appears to open possibilities for a ‘two-way dialogue’ between parents and practitioners and to challenge the culture of professional-only expertise; however, it requires careful consideration to establish its meaning for both sides of the partnership and the implications for delivery and applicability in various contexts of EHC services. These implications are explored in Table 16 (p. 241). The potential of co-production as a model for inclusive partnerships is evident in the way its principles align with the principles of inclusive practice and the approaches and attitudes in partnerships desired by parents. Therefore, the evidence from this study that parents would welcome and be enabled by a framework of co-production is applied and further explored in the context of partnerships in SEND. As a construct, co-production goes beyond enabling the voice of the ‘service user’; it aims at shifting the dynamics between the ‘producers and consumers’ or the ‘professionals and clients’, towards mutual support, reciprocity, trust and parity (Cahn, 2000). Therefore, it could not only transform the way parent-practitioner partnerships are formed and maintained, but also shift the thinking that underpins these relationships and the culture of working together. As a more cohesive framework, it could also have implications in the realm of SEND, and more globally in societal inclusion where services, provisions and support are done ‘with’ and not ‘to’ recipients of services (Todd, 2007).

## **7. Chapter 7: Conclusions**

This chapter explicates implications for practice, policy, and further research into how co-production can enrich partnerships with parents/carers on individual and institutional level.

In Section One I depict how the aims of this study were fulfilled. I draw on the connections between the principles of co-production, the Code's guidance on partnership working and the findings from this study to discuss the potential of the co-productive model in partnerships.

Section Two explores the limitations to this study, including the evaluation of the methodological framework.

In Section Three, I present the contributions to knowledge made by this thesis.

Finally, in Section Four, I discuss the imminent need to engage practitioners within the field of SEND and parents in further research surrounding the applicability of co-production, and I offer an outline of the potential plan for my post-doctoral research.

### **7.1. Meeting the aims of the research**

This section addresses each aim of the study in connection to existent literature and the findings from this research. The aims of this study were to:

- Investigate parental experiences of partnerships with practitioners in EHC sectors after the implementation of the Code;
- Establish representations of inclusive and co-productive practices that are meaningful for families;
- Provide a platform for parents to share their experiences;
- Consider the links between The Code, co-productive framework and parental recommendations for effective practice.

### **7.1.1. First Aim**

To fulfil the first aim of this study, participants were asked questions that referred to their experiences in education, health and care services. For parents in this study, partnership working where parental views hold equal value to the views of practitioners has been only evident in practice on rare occasions. The previously mentioned challenges in communication between parents and professionals (Hodge & Runswick-Cole, 2018) continue to pose an obstacle in forming effective partnerships. To enable a two-way dialogue (Turnbull et al., 2011), participants in this study accentuated the role of and the need for ‘an open and honest communication’ which builds on the recommendations from the Lamb Inquiry (2009), and which could enable transparency in the planning and delivery of services. According to parents, the transparency of how budgets are spent (see Section 5.3.2.3.) and why certain support is denied (see Section 5.3.2.3.), affects parental trust in public services and can be the driver to costly, ‘emotionally draining’ and potentially avoidable tribunals (Runswick-Cole, 2007). Despite the Code’s guidance encouraging practitioners to develop partnerships where parents would feel confident that their opinions were listened to and would be acted upon (DfE & DoH, 2015), participants reported that their ‘voice’ remains mostly disregarded when decisions about their C/YP are made (see Section 5.3.).

### **7.1.2. Second Aim**

Despite the continuous difficulties in partnerships between parents and practitioners in EHC services, participants identified practices where, through a two-way dialogue, their opinions were valued and incorporated into decision-making processes. Parents reported having experiences of working with practitioners who displayed a humble attitude about their own knowledge and were willing to learn from and with parents. These attitudes supported establishing solutions that not only supported the pupils, but also enabled parental confidence in reciprocal and contributory partnerships (Cahn, 2000;

Needham, 2007). Although systemic barriers were often alluded to as an overarching barrier to inclusive partnerships, parents reported that practitioners who used creative ways to work collaboratively were able to overcome some of these hurdles. It was evident in the findings that the factors affecting the nature of partnerships are multi-layered and interlinked. This suggests that it is difficult to identify which factor has the most significant impact on partnerships. However, participants agreed that by having opportunities to contribute to the design, and/or delivery of some provisions, and having their expertise recognised, leads to more fruitful partnerships with public services.

### **7.1.3. Third Aim**

Sharing stories about lived experiences can be a powerful tool to raise others' awareness of the reality the group in question confronts in their daily lives (Broomhead, 2013; Mann, 2016). In this study, parents were able to tell 'their stories' with the intention to ignite reflection in practitioners in the field. The following themes could be classified as 'the take-home messages' for practitioners:

- The acknowledgement of parental expertise on their child and in the professional context, including law and policy surrounding SEND, can lead to more equal partnerships;
- By providing opportunities for parents to tell their own story, practitioners can affect future practice, and build a culture that contributes to the understanding of the marginalised community, which would raise awareness and potential for inclusion of a diverse population;
- The awareness of the 'professional dominance' in practice and how it affects partnerships from the parental perspective can be a powerful catalyst for a deep reflection on the practitioners' own practice;
- Practitioners' awareness of their own assumptions and values in regard to inclusion, models of partnerships and models of disability is essential as it broadens practitioners' understanding of the meaning of inclusion;

- Building partnerships with parents means creating communities where two-way dialogue is ignited by reciprocal, equal and respectful interactions;
- The value of humanity is superior to the value of performativity; practitioners and parents contribute equally to practices that are inclusive and underpinned by the principles of equity, participation and belonging.

This study, in comparison to other studies on parental experiences, provides an extensive overview of a range of factors contributing to the partnerships.

Furthermore, participants proposed solutions for future collaboration that could shape effective and inclusive practices, besides describing what works and does not work within current practices.

#### **7.1.4. Fourth Aim**

The aim to ‘consider how parental expertise can enrich practitioners’ knowledge to improve partnerships with parents was addressed throughout the thesis, and more succinctly presented in Table 16 (p. 241). Building on the connections between co-production and parental expertise, it is important to reflect on the nature of inclusion, partnerships and co-production as concepts that are in a ‘constant state of becoming’, rather than an end product of the joint endeavours of practitioners and families. Nutbrown, Clough and Atherton (2013) have explored this ‘state of becoming’ in relation to inclusion and argued that to work towards inclusive practice, one needs to engage in challenging one’s own assumptions within the subject. This premise, which also applies in the context of co-production in partnerships, requires both sides of partnerships to reflect beyond the obligations of participation in activities/approaches in order to meet the performativity measures imposed by the employers/legislation; it requires us to venture into questioning our own motives, prejudices and ways of thinking. The intention behind adopting the framework of co-production in partnerships with parents is to change the culture these relationships function in, to expand practitioners’ understanding of parental lived experiences and to enable inclusive, empathetic, and two-way dialogue between both parties. Therefore, this framework would require a long-term commitment to transformative



practice, rather than engaging in a series of prescribed activities to meet a presumed outcome.

## **7.2. Reflection on positionality**

Conducting this research brought many realisations to light in my experience. The previously mere understanding of parents as a marginalised group, is now transformed into foregrounding of the 'silenced voice' of parents in decision-making processes (Tomlinson, 1982). The power dynamics that are essentially discussed in relation to the social oppression of this group I now emphasise as the social injustice these practices represent (Freire, 1970). It can be said that there are strong links between the challenging of practice within partnerships in SEND and disability studies (Barnes & Mercer, 2004), which can be observed in my discussion on models of disability and the politics surrounding the legislative changes related to partnership working (see Section 2).

Furthermore, my theoretical framework of pragmatism situates this study at the heart of reflection on actions that should lead to transformation of practice (Goldkhul, 2004). In line with this transformation lays the Deweyan creed of democratic and inclusive education, where individuals should be given freedom to realise their aspirations and be able to act with agency to convey their wishes and stances, whether they are related to their own individual lives or social and political matters (Striano, 2019; Nussbaum, 2011 as cited in Striano, 2019). This notion of agency and freedom is prominent in the capability approach discussed earlier, that centralises the value of individuals' agency at the same time recognising that it is operationalised in the complexities of society (Sen, 1989, as cited in Striano, 2019). The concepts of democracy, inclusion and agency are therefore in strong correlation with the principles of co-production, the application of which encompasses my argument for a change in partnership working practice.

In light of these connections and discoveries, as a researcher, I have realised that my initial intentions to explore parental views were transformed into a more activist stance, where I call for practitioners' consideration of how their

practice enables or prevents the democratic, inclusive, reciprocal and equal approaches to partnerships with families with a view of developing egalitarian practices. In the hope that the framework of co-production can be explored further in these partnerships and examined for its potential to challenge mentioned inequalities in power and agency of parents and carers, the completion of this research has contributed to my, even more emphasised, advocacy for the value of humanity and equality as central to all human pursuits (Freire, 1994).

In the next sub-section, I outline the aims and research questions that I designed to investigate the subject of parent-practitioner partnership in detail.

### **7.3. Research limitations**

This section presents the limitations to my study. I outline these limitations with consideration for how these shortfalls could have been addressed.

If I were to plan and conduct this research again, I would consider a range of possible adaptations.

Firstly, I would extend the timeframe for the survey and repeat its announcement on social media at least three more times to gain a higher statistical significance for this stage of the research. Although it appears that the regular members of different forums attend them frequently, I could have considered wider implications for parental caring responsibilities (e.g., a child's illness, which could have meant the potential parent might have been out of touch with regular activities for a prolonged period of time).

Secondly, by employing non-random convenience sampling scheme in this research (see Section 3.2.5.), I did not specify any particular preferences for participants' characteristics, e.g., their age, gender, geographical position or the needs of their C/YP. Although this open-ended approach enabled me to reach as many participants as possible, if I wished to make this research more representative, I could have extended the timeframe of the study and addressed the announcement to reflect the diversity of participants I was

inviting to take part. Increasing the time the survey was active would also potentially have gained more participants, and therefore a larger sample size.

Thirdly, to ensure the research remained inclusive of a diverse community of parents, I could have translated the survey into other languages, and ensured participants who were not able to use written means of communication could have used verbal dictation. This limitation has potentially resulted in exclusion of certain aspects of experience that might have been pertinent to some parents. For example, through analysis I came to the conclusion that the data gathered from the interviews appears to include many more accounts of challenging circumstances, whereas the data from the survey presents a more mixed depiction. I reflected that, potentially, during the interviews participants could have been more inclined to recall the instances that they found challenging as, we tend to remember negative memories more vividly than those with positive connotations.

Fourthly, as an early-career researcher I felt obliged to not impose my study on anyone and did not request confirmation from administrators of the platforms to ensure the link to my survey was posted as agreed. This meant I could have relied on announcements that might not have been made by the administrators of these platforms. In the future, I would pre-empt the structure of reminders in my initial communication to ensure these do not come as a surprise to a collaborator.

Fifthly, I could have relied only on the qualitative approaches and simply interviewed parents or used any other available qualitative methods, for example narrative enquiries. Although this would have enabled me to potentially gain more individual perspective on the subject of partnerships, I felt it would have been limited to the smaller locality participants lived in. I acknowledge here that my questions directed the thinking and parental responses; however, by giving participants the opportunity to elaborate on their answers in the open questions of the survey, I gained more information than I would if I only included closed-ended questions. To address the limitation of locality, with increasingly accessible and widely utilised video conferences and meetings, I could have given parents an opportunity to join the live discussion online, or I could have

organised an online focus group. This option would have enabled participants from further afield to take part in the interviews, as distance was one of the obstacles to face-to-face participation for parents.

To conclude, I found the journey through two opposing paradigms a great challenge. Not only did I have to acquire substantial knowledge of both worldviews, but I also had to continually adapt my thinking and understanding while working within different methods in analysis and interpretation. To ensure clarity in my approaches, I learned about each worldview separately, and when I felt I understood the philosophical and practical foundations for each, I knew I was ready to undertake the task of mixing of methods. Exploring each paradigm in depth enabled me to depict the mixed methods research foundations with a greater ease, too. Through this challenge, I became more open-minded to engaging with and appreciating a multi-disciplinary approach to research in the future.

Despite the limitations of this study, I remain assured that the choice of methods and approaches has yielded valuable data in the context of this project. By gaining insights into parental views, preferences and lived experiences, my understanding of parental perspective has been enriched immensely. Therefore, I intend to continue the journey of this study further to explore the potential of enabling a two-way dialogue between parents and practitioners in the EHC services, with the intention of sharing what co-production can offer to inclusive partnerships between parents and practitioners. I elaborate on this intention in more detail in Section 7.5.3.1.

#### **7.4. Contributions to knowledge**

This section describes how this thesis builds on the existent body of knowledge discussed in section 2. It does this in three main ways:

1. It provides new insights into a broad range of parental experiences of partnerships with various practitioners in EHC sectors since the implementation of the Code in 2014. It draws on parental narratives to

argue that inequalities of expertise and power imbalances within partnerships have not been addressed in the majority of practices.

2. It presents a framework (p. 241, Table 16) for using co-production as a more inclusive model for partnerships with parents of C/YP categorised as having SEND. This brings together the principles of co-production and inclusion with those of effective partnerships, as prescribed by the Code, to demonstrate the potential that co-production has to offer to these partnerships. Importantly this alternative model for partnerships is situated within the rights-based model of disabilities, which builds on the assumption that equal value should be given to participation, belonging, decision-making and societal inclusion for all. I suggest that this framework provides an important new model for partnerships through its clear links between inclusion, equality, empathy, two-way dialogue and the rights-based model.
3. This study argues that the Code missed an opportunity to strengthen the partnerships within SEND practice by failing to consider the principles of co-production as a driver for inclusive, equal and effective partnerships with parents and carers.

## **7.5. Implications for practice, policy and research**

This section provides an overview of the implications this study has for practice, policy and research. I consider each of these implications in turn, followed by an outline of a proposal for my post-doctoral research that would build on the findings from this study.

### **7.5.1. Practice**

This study indicates that changes in practice and policy could be enriched by adoption of the co-productive framework within partnerships between parents and practitioners.

Within practice in EHC sectors, co-production is perceived by participants in this study as an enabler of inclusive partnerships due to its reciprocal, contributory and equitable nature. Although not without faults, and certainly requiring further research into practical implications, co-production could transform attitudes, approaches and cultures of working together. The findings of this research could serve as a basis for reflection on practice for all practitioners within the EHC sectors, including 'front-of-house' workers. The framework for co-production in partnerships with parents presented in this thesis could provide the starting point for these reflections (see Table 16, p. 241).

It is important to include all the voices involved in the formation of partnerships, those of a diverse representation of parents, the voices of C/YP's, and the voices of divergent practitioners in the SEND field.

As explored in Chapter 2, partnerships pose many challenges and rely on many factors that require consideration to ensure that effective communication, respectful approaches or equality of expertise are maintained. Therefore, prior to implementation of this framework, underlying values of partnerships need to be evaluated by both sides, in relation to the context in which they work together and in order to frame an equitable and inclusive starting point with clear expectations for negotiation of the inevitable differences.

Despite the imperfect nature of co-production, this study shows that reflective practitioners are essential within the EHC sectors in order to minimise 'professional dominance' rhetoric. To further raise the awareness of practitioners' own assumptions and beliefs about disability and SEN, it becomes imperative that all practitioners devote some of that reflection to questioning and developing understanding of the systems and models they operate within. By adopting co-productive practice, these reflections would become a part of everyday practice.

In light of the findings in this study, I propose that co-production in parent-practitioner partnerships in the context of SEND would entail ensuring that equal, reciprocal, and participatory partnerships are formed; where parents and all practitioners learn from stories about lived experiences, work through possible differences in a dialogic manner, build on principles of inclusion by being open and empathetic to others' standpoints, and where parents and carers are recognised and acknowledged as another 'agency' with a wealth of expertise and knowledge about their children and young people.

I acknowledge that these partnerships will be contextualised to some degree depending on settings, therefore, I argue that a value-based approach, as presented in Table 16 (p. 241) would serve as a starting point for equal, reciprocal and participatory partnerships. This value-based approach would be particularly pertinent in assessment and creation of EHCPs, as well as early identification, transition to adulthood or between settings circumstances. By adopting the values of reciprocity, everyone being recognised and acknowledged as an asset, collective contribution to community capital, parents and practitioners will enable a change in embedded practices where parental 'voice' currently remains on the periphery of decision-making.

### **7.5.2. Policy**

Given the alignment of the principles of co-production within partnerships, and those prescribed by the Code for partnerships with parents, it seems appropriate to suggest that it would be beneficial for co-productive partnerships to be more explicitly interwoven into the wording of this guidance. This explicit reference to co-production as a model for partnerships could be supported by further references to inclusion, equality, and the rights-based models of disability, all of which underpin the co-productive model of partnerships. As inclusive practice, whether in the context of education or on a societal level, refers to equality, participation and belonging to those it aims to include, co-productive partnerships would be fulfilling a wider purpose than engaging

families in decision-making – they would pave a path to transforming the ways of working together.

It could also be of interest to policy makers to establish links between co-productive practices in forming partnerships with families in all contexts, thus unifying approaches across public services and enabling exchange of expertise to be shared between professionals and families alike. Practical examples of what the co-productive model could look like in practice, and how successful practices have already implemented the ethos of co-production in their organisations, could be included within the Code and could empower the transformation of embedded cultures.

Parents in this study have also identified a range of practitioners and approaches that, in their opinion, deserve recognition for their inclusive work with families. Therefore, it could be in policy makers' interest to design a system where these organisations are celebrated in an official manner.

Finally, a platform to share parental lived experiences and expertise could be incorporated into the training of workforces within EHC services by co-designing training with parents for all practitioners, including 'front-of-house' staff.

### **7.5.3. Directions for future research.**

Throughout this thesis, I emphasise the role and importance of parental perspectives within the practices of partnerships in the field of SEND. A parental lens is at the forefront of this research and the practice I hope to affect for a myriad of reasons explored here. However, it is undeniable that partnerships are formed between parents and practitioners in the field; practitioners whose work, dedication and understanding has also been brought to focus by this study. It has never been my intention to exclude practitioners from the scene of partnerships, rather to begin this research journey with the marginalised voice of a group that, historically, has been perceived as inferior in knowledge and expertise of C/YP categorised as having SEND. With the desire to establish approaches to inclusive partnerships that are meaningful to families, I hope



practitioners and researchers in the field will value the potential of co-production and examine its application in their practice.

It is essential that the application of the co-productive partnerships model is trialled and evaluated in practice by both sides of the partnership.

Consequently, I believe it would be beneficial to gather shared views between practitioners and parents on the meanings and practical representation of co-production in various contexts. Shared perspectives would also strengthen the implications for practice where the expertise of both sides of the partnership can be appraised. By sharing the space to discuss the implications from different standpoints, I believe practitioners and parents will grow closer in understanding and empathy. With these premises in mind, I present my mini proposal for post-doctoral study that will build on the findings of this thesis. The proposal is illustrated in detail in the sub-section below.

#### ***7.5.3.1. Mini proposal for post-doctoral study***

This research project has transformed my thinking and ideology as a teacher, educator, and researcher. The reflections I engaged in when working with parents have furthered and deepened my knowledge and understanding of their point of view, but most of all, made me realise the importance of seeking and utilising parental expertise in my own practice. As a practitioner I sought the recognition of my knowledge and years of academic training before I engaged in inclusive partnerships with parents. I empathise with the effort and dedication that is channelled into practice by many practitioners, but I also empathise with parents who continually face discrimination and dismissal of their efforts and dedication.

To recognise and value both, I will undoubtedly encounter many obstacles on the way; however, my intention remains strong and unshaken to explore this dual perspective of how partnerships might be enabled through co-production. As a result of engagement in various activities, including relational pedagogies,

I would like to facilitate the exploration of the representations and meanings of co-productive partnerships through co-produced research with parents and practitioners. I propose to utilise the approach of the community of philosophical inquiry (Lipman, 2003) as the main method driving the multi-modal data collection. Through participation in the inquiries, participants would build an array of meanings and representations of co-production within partnerships. These representations will then be collated and available to all participants as a shared collection to draw from. This shared collection could potentially contribute to the development of shared identity of the collective, where co-producers will share the same values and work towards the same outcomes (Bovaird, Flemig, Loeffler & Osborne, 2019). Participants will be able to utilise this collection in their networks/institutions to explore the implications of co-productive partnerships in practice in various contexts, as the implementation of the framework will take different turns depending on the context it will be applied in (Bovaird, Flemig, Loeffler & Osborne, 2019).

I hope to build a group of researchers who would be available to support participants in implementation, evaluation, and report generation of these investigations. Participants would also be recognised as co-researchers in these processes and invited as speakers to the annual symposiums. A short overview of the study is illustrated below:

*Table 17 Mini proposal for future research*

Study	<p>'Community of philosophical inquiry (CoPI) into meanings of co-productive practices in parent-practitioner partnerships'.</p> <p>Potential research question: How can CoPI enable effective dialogue between parents and practitioners to create a shared meaning of co-production, its principles and representations in practice?</p>
Rationale	<p>The main premise of co-production is equal and reciprocal dialogue that informs practice. To enable this dialogue, I propose to initiate a conversation between parents and carers that is intended to provide participants with a platform to express their differences in standpoints and listen to the differences others might express; to grow through, at times, challenging conversations, in a safe and creative space; to contribute to a shared meaning of what co-production means for both sides of the partnership; and to establish a shared ethos of how co-production could be implemented into practice. This conversation would be facilitated by the community of philosophical inquiry approach, where participants would consider deeper philosophical</p>

	underpinnings of their experiences and perspectives in the hope of igniting reflection that will affect their actions/practice.	
Participants	Parents and carers of C/YP categorised as having SEND.  Practitioners in the EHC sectors.	
Method	Community of philosophical inquiry.  Approach: Philosophy for Children, creative methods of expression (collage, poetry, photographs), focus groups.	
Desired outcome	A shared vision for the representations of co-production from both sides of the partnerships.  Participants' readiness to apply co-production in practice and reflect on its application with others.	
Pilot study	Recruit a group of maximum 20 participants, 10 parents and 10 practitioners from EHC services (some of whom might be able to trial the first framework in their contexts).  Deliver three sessions:  <div><div>1.</div><div>Introduction to CoPI (including resources that participants can explore at home), establish group rules, encourage participants to express what co-production means to them (in words, drawing, pictures or any other form). Share between the group.</div></div> <div><div>2.</div><div>Facilitate CoPI with a stimulus, group discussion, philosophical games.</div></div> <div><div>3.</div><div>Participants to review their 'definitions' of co-production form the first session. As a group, negotiate shared meaning of what co-production-encompasses in relation to principles, practical considerations and how it can be implemented and evaluated. Participants to evaluate their learning and contribution to shared framework.</div></div>	
Timeframe		
Year 1	Year 2	Year 3
<p><b>Activities:</b> building networks (twitter, academics/students within and outside of local universities, local EHC services, local employers, parent/carer forums; Rotherham Charter, local councils; P4C introductory sessions for all members; creative representations of the meanings of co-production).</p> <p>Pilot study. Outcomes analysed and distributed via network base.</p>	<p><b>Activities:</b> development of plans for co-production across services through P4C sessions; first annual symposium; identification of potential post-graduate research paths/students/participatory groups.</p>	<p><b>Activities:</b> gathering participants' reflection on their practice of co-production; 2nd annual symposium open to international delegates; continually building the network; working towards outputs (e.g., co-creating book/film/learning material with participants).</p>

<b>Outcomes:</b> establishing a mission/ethos statement and interest areas; interdisciplinary network base; knowledge of what is wanted/needed from a range of perspectives.	<b>Outcomes:</b> established network of a range of stakeholders; established ethos of philosophical thinking in a safe space; sharing practice.	<b>Outcomes:</b> developing wider network; identification of further research; publication on the process.
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#### 7.5.4. Summary

Working with families in a genuinely co-productive manner would demand a shift in currently embedded traditions of practitioner driven exchanges where, most of the time, parents are positioned as supporters, information givers or assistants extending the specific support within the domain of the home environment (see Section 2). Only through inclusion of parents in the design of services and ways of developing partnerships with families, can this shift be achieved. The experiences of the parents within this study suggest that it will require considerable preparation through joint reflection and offering of platforms to share stories by both sides of the partnership to enable development of understanding and empathy towards each other. This forces the onus of responsibility on professionals. One way to facilitate opportunities for such joint reflection could be achieved by finding ways of enabling parents to drive considerable parts of the informal contemplation of what co-production means to particular communities of practice.

Further research is needed to explore how such collaborations might work and to explore these from both sides of the partnership. It is possible, however, that such an approach would provide the scaffolding that parents say they need for building effective communication and work collaboratively with practitioners who play such prominent roles in theirs and their C/YP's lives.



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## List of Appendices

### Appendix 1 Audit trail for Survey - codebook for survey (extract)

Following the coding process of the data to the first open question in the survey, I realised that I have identified many codes that were overlapping with each other. For example, I used three different codes for communication: effective communication, ineffective communication, and lack of communication. Through the process of further reflection, I combined all codes related to communication into one code. Assigning a definition to that code further supported the clarity of further coding and analysis processes for the remaining questions in the survey. To illustrate these changes, an example below is presented.

Initial Codes	Final code and definition
Effective communication	<b>New Code: Communication</b>  <b>Definition:</b> Any representations of effective or ineffective communication with, from and in between services. This also includes lack of adequate or fractional communication. <b>Exclusions:</b> this code does not include inadequate access to information or content included in the EHCPs. Access to information data is assigned to Theory v Practice code, and data related to content of the plans is assigned to Meaningful Content code.
Ineffective communication	
Multi-agency communication	

### Codes and Themes for survey (qualitative data)

Code	Definition
Person-centred approach	All mentions of the need for person centred approach, including the recognition of the broader family context. Approaches enabling individualisation and differentiation of resources, approaches, and additional provision. <b>Latent:</b> Individualisation, inclusion.
C/YP's views and needs in present and future	This code is specifically dedicated to all mentions of how C/YPs views, needs and aspirations change through time and different circumstances. Although it links to person centredness, it is separated from that code as its focus is related to the recognition by practitioners that the plans require thorough reviews, even when, on the surface, changes might not be easily visible. <b>Latent:</b> individualisation, trust.
Theory v practice	All references to the discrepancies between the Code's guidance and parental experiences in practice. These include official deadlines for EHCPs not met, feedback from parents that is not acted upon, inadequate access to essential information or advice, or failure to gain parental confidence.

	<b>Latent:</b> trust, performativity, accountability, cultural challenges, transparency.
Extended age limit and legal strength of the EHCP	All instances where parents have reported that the legality of the Code has enabled them to negotiate appropriate support for their C/YP; references to the extended age limit as an opportunity to plan a more structured provision beyond the obligatory education age. <b>Latent:</b> empowerment, accountability.
Communication	Any representations of effective or ineffective communication with, from and in between services. This also includes lack of adequate or fractional communication. <b>Exclusions:</b> this code does not include inadequate access to information or content included in the EHCPs. Access to information data is assigned to Theory v Practice code, and data related to content of the plans is assigned to Meaningful Content code. <b>Latent:</b> inclusion.
Meaningful content	Instances where the content of the EHC, or any other documentation related to decision-making has not been accurate, or accurately reflective of the C/YP's needs, wishes or aspirations. <b>Latent:</b> Accountability, trust, inclusion.
Practicalities of EHCPs	Aspects that impact on the effectiveness of the collaborations between families and services when plans and decisions are made. These include flexibility in approaches to time and means of collaborations, availability of all practitioners involved and their ability to read all the essential notes prior to the meeting. <b>Latent:</b> systemic challenges, cultural challenges.
Seeking parental 'voice'	Instances where practitioners actively seek parental input, not only through feedback, but also through proactive engagements in order to enhance the service. <b>Latent:</b> collaboration, inclusion, empowerment.
Enabling co-production	Instances where parents recognise that they are treated as partners, their 'voice' is valid equally to the 'voice' of practitioners. References to the diminishing culture of 'us and them' and where parental expertise of their C/YP and professional expertise are acknowledged and valued. <b>Latent:</b> inclusion, empowerment, humility.
Change in practitioners' approaches.	References to examples when practitioners adapted their ways of working and thinking in order to maximise the effectiveness of their service/provision. <b>Latent:</b> reflection, inclusion, openness.
Empathy	All instances where parents felt the information about their C/YP were misunderstood, where misconceptions were formed by practitioners, where assumptions about families were made based on insufficient information or on personal attitudes of practitioners. <b>Latent:</b> social inclusion, prejudice, stigma, humility.
Required cultural change	References to the existence of the 'professional dominance' discourse. Elaborations on the need for the shift in attitudes of practitioners as the only experts. <b>Latent:</b> power, cultural challenges, humanity.
Accountability	Instances of the lack of accountability when services do not meet the needs or legal obligations of the C/YP. A dilemma between some practitioners having to meet targets/responsibilities imposed on them by the system, which prevents them from developing effective partnerships with families. <b>Latent:</b> systemic challenges, accountability, performativity.
Trust in public services	References to all instances when parental trust has been broken by actions or inactions from practitioners involved in decision-making about their C/YP. Some instances of the differences between public and private services are included in this code. <b>Latent:</b> accountability, integrity.



Implications for policy changes	Examples of practices where the system prevents partnership working. These include waiting lists, the continuous power struggles between LAs, particular provisions/services and families. <b>Latent:</b> accountability, inclusion.	
Theme	Definition	Codes included
EHCP process	This theme includes all aspects related to the collaborations during the initiation or review of the EHCPs. It also illustrates the discrepancies between the Code's guidance and the realities parents have been experiencing in practice.	<ul style="list-style-type: none"> <li>• Person-centred approach</li> <li>• C/YP's views and needs in present and future.</li> <li>• Theory v practice</li> <li>• Extended age limit and legal strength of the EHCP</li> <li>• Communication</li> <li>• Meaningful content</li> <li>• Practicalities of EHCPs</li> </ul>
Practices enabling parental 'voice'	This theme encompasses all approaches, attitudes and practice that participants reported to be 'positive' and effective in collaborative working in their view.	<ul style="list-style-type: none"> <li>• Seeking parental 'voice'</li> <li>• Enabling co-production</li> <li>• Change in practitioners' approaches.</li> </ul>
Practitioners' attributes, knowledge, and attitudes	This theme reflects the dispositions and knowledge that practitioners from across the services that are often missing in partnership working, affecting its effectiveness, and, sometimes, its existence.	<ul style="list-style-type: none"> <li>• Empathy</li> <li>• Required cultural change</li> </ul>
Required systemic changes	Examples of factors that impact the partnership working are included in this theme. It also illustrates how some of the guidance included in the system hinders the collaborative and inclusive practice in parent-practitioner partnerships.	<ul style="list-style-type: none"> <li>• Accountability</li> <li>• Trust in public services</li> <li>• Implications for policy changes</li> </ul>

## Appendix 2 Audit trail for Interviews - final codebook for interviews

Code	Definition
<b>Pilot interview</b>	
Meaningful provisions	All aspects contributing to meaningful provisions or their lack; EHCPs, targets, outcomes, curriculum. Instances of when C/YP are recognised or not as individuals and not only through the labels of their SEND. It also includes all references to the dichotomy between academic and social/emotional/mental health progress and its place in forming meaningful provision for C/YP. <b>Latent:</b> Labels, individualisation, inclusion
Systemic barriers	All factors resulting in unmet deadlines, insufficient collaborations bound by inadequate time for information/advice exchange, and lack of investment in building relationships with individuals and families resulting in practitioners not knowing the service users. Any mentions of how the budget influences partnerships or indirect factors that influence partnerships working. Examples of the impact bureaucratic tasks have on parent-practitioner relationships, on the effectiveness of the role of professionals from EHC services and on the lives and ability to receive support by families. Mentions of the shortage of time, resources or staff and their knowledge to fulfil their responsibilities and duties as prescribed by the Code and ineffective assessment procedures. <b>Latent:</b> Performativity, moral dilemma, empathy
'Listened to but not heard'	Instances of parents being enabled to express their wishes with their views being disregarded and not implemented in practice. <b>Latent:</b> Empowerment
Left unsupported in crisis	Experiences where parents/carers had to resort to act without support because the support from services failed, including encounters where lack of answers/solutions led to families' prolonged crisis. <b>Latent:</b> Neoliberalism
Blame	Directed at parents/carers by practitioners, self-inflicted by parents/carers and instances of blame towards services or systems directed EHC services by parents/carers. <b>Latent:</b> Accountability
Invisible disabilities or their manifestations	Instances where practitioners do not recognise or believe in 'hidden' conditions, their level of severity or their impact on individuals' mental health, which sometimes does not manifest itself in common symptoms. Any misconceptions practitioners' might have about particular disabilities or their symptoms. <b>Latent:</b> Misconceptions and stigmatisation
Parental expertise	References to acknowledgements (or their lack) of parental expertise in their children and the professional knowledge they bring to the collaborations. This code also includes parental expertise in the system and their growing knowledge of the law surrounding the Code. <b>Latent:</b> Empowerment
Practices enabling effective partnerships	All aspects that parents/carers identified as working well in practice, including professionals' ability to create inclusive environments. <b>Latent:</b> Empowerment
Need for flexibility in approach	Experiences where embedded practices prevent ensuring equitable provision was created for C/YP. <b>Latent:</b> Performativity

Special v Mainstream schools	Any direct comparisons between the two settings, including instances where academic results are deemed more valid than life skills development or vocational training achievements. <b>Latent:</b> Inclusion
Ineffective Communication	Instances of when the communication channels were ineffective, including verbal, non-verbal, written, and interpersonal communication. <b>Latent:</b> Communication
The overarching 'power' of practitioners' expertise	Examples of how individual professionals can influence relationships, provisions, decisions and ethos of interactions and collaborations in a detrimental manner. Any references to positive influences are included in the code 'Practices enabling effective partnerships'. Instances where parents/carers have been disempowered to make decisions or influence provisions as the decision-making processes were solely influenced by professionals. <b>Latent:</b> Power, empathy
Trust	Instances of when parents/carers experienced trusting or mistrusting relationships with practitioners involved in care for their C/YP. <b>Latent:</b> Humility
Multi-agency collaboration	Experiences of effective and ineffective collaborations with multi-agency teams or between the multi-agency members. <b>Latent:</b> Systemic barriers, power, collaboration
Practitioners' competencies	References to practitioners' understanding of systems, SEND and their attitudes and approaches towards working collaboratively with families. This includes leaders of EHC services and their role in implementing ethos of inclusion. <b>Latent:</b> Performativity, empathy, inclusion, equality
Support networks	Evidence of parental support networks where they can seek answers, advice and reassurance from others who have similar experiences. <b>Latent:</b> Empowerment
Practitioners' attitudes	Instances where parents/carers experienced professional's defensiveness in relation to being challenged, to accountability, or being asked for clarifications or evidence of taken actions as described in the plans or agreed at review meetings. Experiences where parents/carers dealt with superiority of practitioners' knowledge and expertise. <b>Latent:</b> Accountability, performativity
Plans agreed, but not followed	Instances of when agreements between professionals and families was reached, but not fulfilled in practice. <b>Latent:</b> Trust, accountability
Implications for Inclusion	Situations referring to practices fostering or preventing inclusive ethos, whether in individual organisations or society as a whole; these include parental conclusions or perceptions of what they have experienced. <b>Latent:</b> Inclusion, humanity
Fear	Instances where parents engaged in additional roles/responsibilities, as they feared the support for their C/YP would not be provided otherwise; instances where parents/carers recognised that professionals acted upon the fear of being held accountable. <b>Latent:</b> Accountability, neoliberalism
Having the 'insider' power (Being the 'insider' merged with Knowledge is power)	Recounts of situations where parents/carers assigned a superior power to the role of professionals and undertook employment or voluntary work in the system to gain the 'status' of a professional, and as a result the 'power' to affect the manner in which they were perceived by other professionals in the system; Instances where

	<p>parents/carers used their knowledge to their advantage to negotiate appropriate provision for their C/YP.</p> <p><b>Latent:</b> Empowerment, collaboration</p>
Everyone is different	<p>Any mentions of individualisation or its lack, whether that applies to individual C/YP or individual families.</p> <p><b>Latent:</b> Individualisation, humility</p>
Honesty	<p>Instances where parents/carers felt they could not be honest in their interactions or when they felt professionals were not honest with them.</p> <p><b>Latent:</b> Integrity</p>
Emotional journey of a parent/carer	<p>Examples of how parents/carers negotiate the emotional impact of the advocacy for their C/YP, including carrying parental guilt of any sort. Experiences where parents/carers recount their perceptions of preparations for review meetings, multi-agency meetings or visits to healthcare providers. Responsibilities that parents/carers perceived as valid or those that are imposed on parents/carers by systems and society.</p> <p><b>Latent:</b> Advocacy, emotional labour, power, empathy, stigmatisation</p>
Family context	<p>Instances of the effects that family context has on the C/YP with SEND, including impact of the demands of caring for a C/YP with SEND on the rest of the family unit.</p> <p><b>Latent:</b> Individualisation, collaboration</p>
Chasing things up	<p>Examples of when parents/carers are exposed to prolonged and continuous situations of having to chase up documents, appointments and or responses from professionals in order to make informed decisions or receive adequate support.</p> <p><b>Latent:</b> Systemic barriers</p>
Transitions	<p>Experiences of transitions between provisions, including to adulthood settings.</p> <p><b>Latent:</b> Collaboration, empowerment, systemic barriers, inclusion</p>
The power of words	<p>Instances where wording was ambiguous or not empathetic and caused the communication channels to be broken or disrupted.</p> <p><b>Latent:</b> Communication, empathy, humility</p>
Notes on changes/adaptations	<ul style="list-style-type: none"> <li>Initially, the codes 'time constraint', 'budgetary constraints' and 'bureaucratic overload' were separate codes, but upon reflection they were put together into one code: 'The Systemic barriers'.</li> <li>The code 'Bracing myself for negotiations' and Parental responsibilities were engulfed by the 'Emotional journey of a parent/carer' code.</li> <li>The code 'Unrecognised barriers to learning' was engulfed into the 'Invisible disabilities or their manifestations' code.</li> <li>The code 'Helplessness' was renamed to 'Left unsupported in crisis' as situations described by parents/carers that were assigned to that code illustrated parental resourcefulness in helpless situations, rather than their helplessness.</li> <li>The code 'The Power of individual practitioners' and the code 'At the mercy of practitioners' were combined in a new code 'The overarching power of practitioners' expertise'.</li> <li>The code 'Ability to influence provisions' was divided into Practices enabling effective partnerships if they were positive examples or into the code 'Listened to but not heard' if they were negative examples.</li> <li>The codes 'Practitioners' defensiveness' and 'Practitioners' arrogance' were combined into a code 'Practitioners' attitudes'.</li> </ul>

Interview 1	
Parental understanding of practitioners' challenges in the system	Expressions of understanding and empathy from parents/carers towards practitioners in the system-bound practice that the professionals are not always able to affect due to systemic barriers. <b>Latent:</b> Co-production, communication, collaboration, empathy
Acknowledgement of effective practice	Mentions of the need for or instances where effective practice is shared and acknowledged, either on personal, local, or national level. <b>Latent:</b> Inclusion, collaboration, co-production
Notes on changes/adaptations	<ul style="list-style-type: none"> <li>Initially, the code 'Practitioners' competencies' included the structural barriers to the abilities of practitioners enabling them to fulfil their responsibilities. This code was then split into the 'Practitioners' capacity' code, where all competencies including knowledge and approaches were assigned to Practitioners' competencies, and all structural or systemic arrangements, like assessment deadlines or follow-up procedures, were assigned to 'Practitioners' capacity' code. This code was later engulfed by the 'Systemic barriers' code.</li> </ul>
Interview 2 (no additional codes were identified)	
Individual interview 1- Chloe (no additional codes were identified)	
Individual interview 2 - Val	
Respect	Instances where parents refer to being respected or respecting practitioners when working together. It includes instances of perceived lack of respect, too. <b>Latent:</b> Co-production, collaboration, humility.
Notes on changes/adaptations	<ul style="list-style-type: none"> <li>On reflection, the aspect of the code 'Being an insider' was taken away to form a new code 'Knowledge is power' to reflect parental perception that having knowledge allows them to gain more power in negotiations and collaborations with practitioners, not only by becoming an insider in the institutions, but through other means, e.g. possessing high academic qualifications and being articulate about the law.</li> </ul>
Individual interview 3 - Rory (no additional codes were identified)	
Individual interview 4 - Mimi	
Everyday impact of caring for a C/YP on parents/carers	All instances of the effect of caring for a C/YP with SEND might have on a family regarding physical impact (e.g. inability to physically support YP who might be larger or stronger than the carer or any adaptations that the family had to undergo in order to provide their C/YP with adequate support, e.g. bed-sharing, sleeping rotas). <b>Latent:</b> Lived experience, empathy
Individual interview 5 - Annie	
Notes on changes/adaptations	<ul style="list-style-type: none"> <li>Misconceptions about any particular disabilities or their manifestations have been added as an additional description to the code 'Invisible disabilities or their manifestations'.</li> </ul>
Individual interview 6 - Holly	
Individual interview 7 - Lily	
Individual interview 8 - Sally	
Notes on changes/adaptations	<p>Following further review of themes and codes the following codes were merged and themes identified:</p> <ul style="list-style-type: none"> <li>Codes merged: 'Knowledge is power' and 'Being the insider' into 'Having an insider knowledge'; 'The power of words', 'Listened to but not heard' and 'Ineffective communication' into 'Communication'; 'Everyone is</li> </ul>

	<p>'different' was engulfed into 'Meaningful provision'; the code 'Systemic barriers' became a theme 'Systemic barriers affecting attitudinal and cultural shift towards co-productive ways of partnership working'; the code 'Acknowledgement of effective practice' was assigned to the 'Systemic barriers' theme as it reflected practices that parents/carers experienced lacking in the systems.</p>
<b>Themes identified:</b>	
1. Parental lived experiences of caring for a child or young person with SEND: the importance of sharing stories	<p><b>Definition:</b> The stories shared by parents/carers are an essential component of raising practitioners' awareness of the complexities of everyday impact SEND can have on family and individuals. Beyond the everyday stories, this theme also illustrates the dynamics between parental expertise of their C/YP and the expertise they hold in relation to systems and systemic demands placed on them as a result of being parents/carers of C/YP with SEND. These challenges pose a critical barrier in partnerships with practitioners who are unaware or not sensitive to these aspects of parental experiences.</p>
2. The effects of practitioners' attributes, attitudes, approaches and knowledge on the formation and maintenance of effective partnerships with parent/carers	<p><b>Definition:</b> This theme encompasses four main aspects of the impact practitioners have on the partnerships working: their knowledge (which includes misconceptions based on incomplete knowledge of SEND), their attitudes (including traditional ways of professional-the expert ways of working with families), their approaches (those that reflect personalisation, empathy and equity and those that are fuelled by blame, fear of accountability, sense of responsibility to fulfil assigned duties regardless of the effects they might have on affected families), and the embedded differences of working between mainstream and special schools (these settings affect the attributes, attitudes and approaches practitioners often inherit while undertaking roles in particular settings).</p>
3. Discrepancies between the principles of the Code and parental experiences in practice	<p><b>Definition:</b> This theme reflects the particular elements of partnership working that the Code aimed at addressing; these include: multiagency collaborations, transparency of services (including the co-produced Local Offer within Local Authorities), parental raised confidence that their views are valued and considered when decisions are made with their family context taken into account, adequate information and advice available for parents/carers to make informed decisions about their C/YP' future (whether that is related to Education, Health or Care provisions), and more robust and adequate transitions to adulthood and meaningful outcomes for C/YP in their EHCPs.</p>
4. Practices enabling effective partnerships	<p><b>Definition:</b> A range of practices that parents/carers have found effective in enabling partnerships with practitioners across the EHC services are represented by this theme. The aim of this theme was to capture all the experiences and practices that are already taking place, rather than what parents/carers envisage as desired practices. These examples were intended to build a picture of what is happening, albeit inconsistently, and what is possible to achieve as some practices and practitioners are able to implement practices that support families and illustrate some possible changes in culture and attitudes.</p>
5. Systemic barriers affecting attitudinal and cultural shifts towards co-productive ways of partnership working	<p><b>Definition:</b> This theme comprises a plethora of aspects that are bound by systemic regulations and procedures which contribute towards challenges that families experience when entering or maintaining partnerships with practitioners who work with their C/YP. These barriers include budgetary constraints, bureaucratic overloads for both parents/carers and practitioners (e.g. SENCOs who play a vital role in engaging with families, or social workers), assessment procedures, time constraints, and</p>

	<p>shortages in resources (including adequately trained staff in EHC services). This theme also includes implications for inclusive practices affecting parental confidence in systems surrounding SEND; and in a broader sense, the societal effect the understanding of inclusion or its lack has on enabling the shift towards more co-productive ways of working together.</p>
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## Appendix 3 Information sheet for survey

### Information sheet

Date: \_\_\_\_\_

#### **Title of the study: Has the New SEN Code of Practice (2015) influenced the nature of parent/practitioner partnership?**

Dear Parent/Carer,

You have been invited to take part in this study, as you are a parent or a carer of a secondary-aged student in a Special Educational setting. I would be most grateful for your participation as this project aims at exploring parental views on the effects of the new SEND Code of Practice and the Education, Health and Care plan reviews and their individual experiences.

In this first stage of the study you will be required to complete a questionnaire, which should take you approximately 5 minutes. This questionnaire is anonymous and it's available in hard copy as well as in an online version, which can be accessed at: \_\_\_\_\_ . The results of both versions of the questionnaire will only be available to myself and Sheffield Hallam University. The final findings will be shared with the schools, but only as a general report, without any information which could potentially indicate participation of any parents in particular.

In the pack delivered to your child's school there are two separate unsealed envelopes, one of them is designed for the completed questionnaire and the other one is designed for your contact details should you wish to take part in the second stage of the study. The answers in your questionnaire **WILL NOT** be attached to your contact details at any point of the study.

The second stage of this project will take place at Sheffield Hallam University and it will be arranged for the beginning of 2018. You will be informed about the time and place in advance and there will be a form for travel expenses reimbursement available. It will be conducted in the form of a focus group, where all involved parents/carers will be able to discuss their views and share their opinions with me and other participants. The group conversation will be recorded and saved on an audio file available to myself and Sheffield Hallam University for transcript purposes. These, however, will not be shared with anybody else, and therefore your participation will not affect your personal or professional relationships with the school your child attends. Any sensitive matters raised will be guarded with confidentiality and there will be a contact provided should you wish to discuss it further at the particular school.

All the data collected will be kept under strict guidance at Sheffield Hallam University for up to 10 years for other publications purposes.

Your participation is totally voluntary and you have the right to withdraw all of your contributions within a month from the date the questionnaire has been issued (please see the date at the top of the information sheet).

The information gathered in the questionnaire will inform the direction of the focus group in the second stage of the study, and a summary of outcomes from both parts of the project will be offered in a form of presentation at some point in the academic year of 2018-19. You will be informed about the exact details of the presentation via your preferred means of communication and there will be an opportunity to discuss the contributions/outcomes at the time.

One of the aims of this research is to convey parental voice regarding their collaboration with professionals in SEN settings, therefore the outcomes of this study might be used to further explore those relationships and share the results with a group of professionals in SEN settings in the future.

If you have any questions, please contact me at the details provided below.

Thank you for your time and contribution.



Best Wishes,  
Katarzyna Fleming  
Email: [Katarzyna.z.fleming@student.shu.ac.uk](mailto:Katarzyna.z.fleming@student.shu.ac.uk)

## Appendix 4 Consent Form for survey

**TITLE OF RESEARCH STUDY: Has the NEW SEND Code of Practice (2015) influenced the nature of parent/practitioner partnership?**

*Please answer the following questions by ticking the response that applies*

- |   | YES                      | NO                       |
|---|--------------------------|--------------------------|
| 1. I have read the Information Sheet for this study and have had details of the study explained to me.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any point.   | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I understand that I am free to withdraw from the study within the time limits outlined in the Information Sheet, without giving a reason for my withdrawal, or to decline to answer any particular questions in the study without any consequences to my future treatment by the researcher. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I agree to provide information to the researchers under the conditions of confidentiality set out in the Information Sheet.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I wish to participate in the study under the conditions set out in the Information Sheet.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other research purposes.  | <input type="checkbox"/> | <input type="checkbox"/> |

**Participant's Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Participant's Name (Printed):** \_\_\_\_\_

**Contact details:** \_\_\_\_\_

**Researcher's Name (Printed):** Katarzyna Fleming

**Researcher's Signature:** \_\_\_\_\_

**Researcher's contact details:**

Katarzyna Fleming

Email: [Katarzyna.z.fleming@student.shu.ac.uk](mailto:Katarzyna.z.fleming@student.shu.ac.uk)

**Please keep your copy of the consent form and the information sheet together.**

## Appendix 5 Information sheet and consent form for online survey

Dear Parent/Carer,

You have been invited to take part in this first stage of a study which aims at exploring parental views on the effects of the new SEND Code of Practice and the Education, Health and Care plans reviews and their individual experiences.

In this first stage of the study you will be required to complete a questionnaire, which should take you approximately 5 minutes. This questionnaire is anonymous and the results will only be available to myself and Sheffield Hallam University, and kept under strict guidance for up to 10 years for publication purposes. The findings will be shared as a general report, without any information which could potentially indicate participation of any parents in particular. Your participation is totally voluntary and you have the right to withdraw all of your contributions within a month from the date the questionnaire has been completed.

The information gathered in the questionnaire will inform the direction of the focus group in the second stage of the study, and a summary of outcomes from both parts of the project will be offered in a form of presentation at some point in the academic year of 2018-19. You can express your willingness to take part in the second stage via email or at the end of this survey.

One of the aims of this research is to convey parental voice regarding their collaboration with professionals in the SEND field, therefore the outcomes of this study might be used to further explore those relationships and share the results with a group of professionals involved in the SEND field in the future.

I have been working in SEN schools for the last 13 years and working with parents who have children with Special Educational Needs is very close to my heart. Being a teacher allows me to support families and young people on a daily basis and learn to understand the world from your perspectives. My passion for SEN has led me to begin a doctoral study exploring parental views on relationships with professionals. I commenced the project in the hope of sharing those views with various organisations and help professionals, who work or will work with your children, to understand your experiences and point of view.

If you have any questions, please contact me  
at: [Katarzyna.Z.Fleming@student.shu.co.uk](mailto:Katarzyna.Z.Fleming@student.shu.co.uk) or my Director of Studies Prof. Tim Jay  
at: [t.jay@shu.ac.uk](mailto:t.jay@shu.ac.uk).

My intention is not only to establish what does not work, but also what would make a great difference to your lives if you were given an opportunity to design the provision yourselves.

I cannot express enough how important your views are and how privileged I feel to work or have worked with you as you have taught me patience, gratitude and perseverance on a different level. Thank you for your time and contributions.

Best Wishes,

Katarzyna Fleming



PhD Student at Sheffield Hallam University  
Sheffield Institute of Education  
Department of Development and Society

If you agree for me to use your answers in my study in accordance with the terms stated above please tick the box below.

## Appendix 6 Ethical application

### APPLICATION FOR RESEARCH ETHICS APPROVAL (SHUREC2A)

#### SECTION A: Research Protocol

**Important Note-** If you have already written a research proposal (e.g. for a funder) that answers the methodology questions in this section please include a copy of the proposal and leave those questions blank. You **MUST** however complete **ALL** of Section B and C (risk assessment).

1. **Name of principal investigator:** Katarzyna Fleming

**Faculty:** Development and Society

**Email address:** b4550808@my.shu.ac.uk

2. **Title of research:** "Has the new SEN Code of Practice (2014) influenced the nature of parent/practitioner partnership in SEN setting?"

3. **Supervisor (if applicable):** Prof Tim Jay

**Email address:** t.jay@shu.ac.uk

4. **CONVERIS number (applicable for externally funded research):** N/A

5. **Other investigators (within or outside SHU):** N/A

Title	Name	Post	Division	Organisation

6. **Proposed duration of project:**

**Start date:** October 2015

**End Date:** July 2020

7. **Location of research if outside SHU:** Surveys distributed in three secondary SEN schools: Talbot Specialist School, Seven Hills School and Bents Green School; focus group to take place in SHU.

8. **Main purpose of research:**

- ☒ Educational qualification  
☐ Publicly funded research  
☐ Staff research project  
☐ Other (Please supply details)

9. **Background to the study and scientific rationale** (500- 750 words approx.)

It is evident that the dilemma of parent/practitioner relationships stretches its problematic nature to partnerships with parents of mainstream students as well as parents of students with disabilities. In mainstream schools it involves a range of difficulties in parental engagement (Goodall and Montgomery, 2014) and parental involvement (Hornby and Lafaele, 2011); however, this study will particularly explore how/if the proposed changes in the New SEND Code of Practice, in regards to parent/professional partnerships in SEN settings, have positively impacted on the groups of parents participating in the research.

The numerous studies conducted to explore the parent-practitioner partnership in SEN settings describe it as continually difficult. "The value of, and need for, parent/professional partnerships is an unchallenged mantra within policy relating to 'special educational needs'. In spite of this, partnerships continue to be experienced as problematic by both parents and professionals." (Runswick-Cole and Hodge, 2008, p.637). In a study investigating the levels of empathy in pre-serviced SEN teachers in North West England, participating parents identified teachers as unable to sympathise with their disabled children if they didn't have disabled children themselves (Broomhead, 2013). Another inquiry, conducted via structured interviews in Lancaster University with 15 practitioners and 22 parents of children with various SEN addressed the blame parents struggle with and the need for labelling of their disabled children, and urged professionals to consider parental blame as a major emotional factor influencing their experiences as parents of children with SEN (Broomhead, 2013a). In her research at Sheffield University evaluating parental experiences with practitioners in SEN institutions through the years, Murray (2000) significantly criticised the central role of 'professional experts' in decision making through 'partnership', which rules are often still being defined one-sidedly by the professionals.

The literature portrays clear barriers to parent/practitioner partnership, some of which have been addressed by the government initiatives. The first major scheme, implemented between 2009 and 2011, was the Achievement for All pilot project aimed at increasing positive outcomes for learners with SEND. It proved to be

successful at improving parental and professional relationships through 'structured conversations' (Lendrum, Barlow and Humphrey, 2015). However it was concluded, the transfer between the learning from this pilot and national implementation would require some modifying and the inevitable need to adapt certain aspects of the project in different schools where it would be embedded in the future (Humphrey and Squires, 2011). Up to date, it is not evident that any formal implementation of the AfA projects in SEN settings has taken place.

The most recent and prominent changes in enabling and constructing parent/professional partnership have been outlined in the New SEND Code of Practice implemented by all schools and SEN provisions across the country in September 2014. Newly enacted legislation promises a pupil centred approach to gain best outcomes and for parents' voice to be heard and centrally regarded during the decision-making process for those pupils (Norwich and Eaton, 2015). It also imposes the responsibility on local authorities, Early Years providers and schools to enable parents to share their knowledge about their child and to provide them with confidence that their views and contributions are valued and will be acted upon (DfE, DoH, 2015). Therefore, the recent changes in legislation should have given parents opportunities to express their views and desires more openly, which this study aims to explore.

**10. Has the scientific / scholarly basis of this research been approved?** (For example by Research Degrees Subcommittee or an external funding body)

- ☐ Yes  
☐ No - to be submitted  
☒ Currently undergoing an approval process  
☐ Irrelevant (e.g. there is no relevant committee governing this work)

**11. Main research questions**

- 1) Has the new SEND Code of Practice affected parents/practitioner partnership in SEN settings?
- 2) Has the New SEND Code of Practice implemented in 2014 changed the nature of the parent/practitioner partnership?

3) What do parents envisage as further improvements to the principles of the New SEND Code of Practice from 2014 in regards to the parent/professional relationship?

## 12. Summary of methods including proposed data analyses

### **Survey**

The initial method, interchangeably used with focus groups in a later stage of the study, will be a survey, the aim of which will be to partially inform the content of the focus group. It will be delivered in a paper copy and electronic version at the same time to all three schools chosen for the research.

Analysed data from the surveys will be presented to the participants during a focus group discussion and as part of a summary of all findings at the later stage to all three schools and participants should they wish to be informed.

### **Focus Groups**

The survey will be followed by a focus group. This method will enable gathering of more in-depth information in regards to how the participants perceive the subject in investigation (Bell and Waters, 2014). The content of the discussions will be recorded on audio files and analysed directly from them.

### **Appreciative Inquiry**

The inherent features of the focus group will be derived from the first two components of the Appreciative Inquiry method, the stage of “discovery”, closely followed by the stage of “dream” (Kessler, 2013). Cooperrider, Whitney and Stavros (2008) believe that appreciative inquiry enables to create a “deliberately supportive context for dialogue” as it focuses on exploration of positive aspects of collaboration, rather than concentrating on “what is not working well”, which has been a subject of many earlier mentioned studies around parent/practitioner partnerships. This could contribute to the creation of a future dialogue between professionals and parents of SEN children, for which this study will create a comprehensive base.

The purpose of the implementation of the strategies in appreciative inquiry is designed to encourage the group to explore possible changes in a positive



structure and contribute to a collaborative appreciation of shared values and practices present within their school's environment. In creating this positive approach to the subject, the stage of "dream" will be designed to involve the participants in joint thinking about what their desired and preferred future partnerships with schools might resemble.

At the end of the data collection process, I'm intending to be able to clearly compare the core principles of parent and professionals' collaboration implemented in the new SEN Code of Practice with individual parents' experiences and opinions of the process.

## SECTION B

1. **Describe the arrangements for selecting/sampling and briefing potential participants.** This should include copies of any advertisements for volunteers, letters to individuals/organisations inviting participation and participant information sheets. The sample sizes with power calculations if appropriate should be included.

At the initial meeting with the head teachers of each school a pilot survey will be presented for discussion, together with the consent form for each head agreeing for the survey to be distributed amongst parents of the students in their school.

The introductory letter to the head teachers is attached.

The actual survey will be distributed in all three schools with two unsealed envelopes with labels enabling the return process. Both envelopes will be sealable and the contact details of parents will not be attached to their answers at any point.

The second part of the study will take place at SHU and will involve parents participating in a group discussion. Due to potential conflict of interest with parents from the school I currently work at (and which is taking part in the research), the focus group will only be open to parents of the two remaining schools. Therefore, their information sheet will not include information about it.

2. **What is the potential for participants to benefit from participation in the research?**

Parents/carers of students in secondary SEN settings will be able to express their views and opinions openly and potentially further influence the nature of parent/practitioner partnerships on a bigger scale.

**3. Describe any possible negative consequences of participation in the research along with the ways in which these consequences will be limited.**

The nature of information parents/carers might disclose can be very sensitive and therefore it has to be conducted with the upmost confidentiality and careful consideration. I will be asking the head teachers of each school for a contact number to someone who could be designated to deal with individual cases should those occur. This contact will be available for the parents when required.

As mentioned before, due to the potential of conflict of interest and potential inhibition in openness by parents from the school I currently work at, the focus group will only be open to parents from the other two establishments.

**4. Describe the arrangements for obtaining participants' consent.** This should include copies of the information that they will receive & written consent forms where appropriate. If children or young people are to be participants in the study details of the arrangements for obtaining consent from parents or those acting in *loco parentis* or as advocates should be provided.

All participants will be required to sign and date a consent form, which will be included in the pack together with the questionnaire and information sheet. All three copies are attached.

**5. Describe how participants will be made aware of their right to withdraw from the research.** This should also include information about participants' right to withhold information and a reasonable time span for withdrawal should be specified.

The right to withdrawal will be included in the information sheet provided with each survey and separately for the focus group.

**6. If your project requires that you work with vulnerable participants describe how you will implement safeguarding procedures during data collection.**

N/A

**7. If Disclosure and Barring Service (DBS) checks are required, please supply details**

N/A

**8. Describe the arrangements for debriefing the participants.** This should include copies of the information that participants will receive where appropriate.

All the outputs of the study (should this be a part of a publication, report or another study) will be available to participating schools.

In the academic year of 2018-19 there will be a presentation describing outcomes of the study at SHU, to which all participating schools and parents will be invited.

**9. Describe the arrangements for ensuring participant confidentiality.** This should include details of:

- how data will be stored to ensure compliance with data protection legislation

- how results will be presented
- exceptional circumstances where confidentiality may not be preserved
- how and when confidential data will be disposed of

All online data will be stored under the secure SHU online portal, all files will be saved on the SHU Q drive and all hard copies of surveys will be stored in a locked place at my home address.

All results will be presented anonymously.

All data will be disposed off when the study is completed or stored in the Research Archives as stated in the Data Management Plan.

- 10. Are there any conflicts of interest in you undertaking this research? (E.g. are you undertaking research on work colleagues or in an organisation where you are a consultant?) Please supply details of how this will be addressed.**

One of the participating schools is my current place of work; therefore the focus group will not be open to participants from that school.

- 11. What are the expected outcomes, impacts and benefits of the research?**

The results of the surveys and focus group outcomes aim at contributing to developments towards improving partnership principles and practices within EHC services as a long-term goal. One of the main principles of the New SEN Code of Practice is to enable parental voice in the decision-making process for their children. Therefore, this study, if shared in the future with SEN establishments, could build a foundation for research involving practitioners working with children with SEND. This could potentially be influential towards further positive changes in collaborative relationships between parents and practitioners and enable broader understanding of what parents of children with SEND require to establish effective and positive partnerships with services.

- 12. Please give details of any plans for dissemination of the results of the research. This includes your plans for preserving and sharing your data. You may refer to your attached Data Management Plan.**

Please see the data management plan attached.

## SECTION C

### HEALTH AND SAFETY RISK ASSESSMENT FOR THE RESEARCHER

**1. Will the proposed data collection take place on campus?**

- ☐ Yes (Please answer questions 4, 6 and 7)  
☒ No (Please complete all questions)

**2. Where will the data collection take place?**

(Tick as many as apply if data collection will take place in multiple venues)

- | <b>Location</b>   | <b>Please specify</b>                   |
|---|---|
| <input type="checkbox"/> Researcher's Residence                                 |   |
| <input type="checkbox"/> Participant's Residence                                |   |
| <input checked="" type="checkbox"/> Education Establishment                     | Each school participating in the study. |
| <input type="checkbox"/> Other eg business/voluntary organisation, public venue |   |
| <input type="checkbox"/> Outside UK   |   |

**3. How will you travel to and from the data collection venue?**

- ☐ On foot      ☒ By car      ☐ Public Transport  
☐ Other (Please specify)

Please outline how you will ensure your personal safety when travelling to and from the data collection venue

Driving by car at day time in Sheffield is regarded as low risk.

**4. How will you ensure your own personal safety whilst at the research venue?**

I will make sure I wear a badge at all times and am introduced to school behaviour policy as well as fire safety.

**5. If you are carrying out research off-campus, you must ensure that each time you go out to collect data you ensure that someone you trust knows where you are going (without breaching the confidentiality of your participants), how you are getting there (preferably including your travel route), when you expect to get back, and what to do should you not return at the specified time. (See Lone Working Guidelines). Please outline here the procedure you propose using to do this.**

I will design a rota with times of data collection and let a member of my family know the timings of each outing.

**6. Are there any potential risks to your health and wellbeing associated with either (a) the venue where the research will take place and/or (b) the research topic itself?**

- ☒ None that I am aware of  
☐ Yes (Please outline below including steps taken to minimise risk)

7. **Does this research project require a health and safety risk analysis for the procedures to be used?**

- ☐ Yes  
☒ No

(If **YES** the completed Health and Safety Project Safety Plan for Procedures should be attached)

**Adherence to SHU policy and procedures**

<b>Personal statement</b>	
I confirm that:	
<ul style="list-style-type: none"> <li>this research will conform to the principles outlined in the Sheffield Hallam University Research Ethics policy</li> <li>this application is accurate to the best of my knowledge</li> </ul>	
<b>Principal Investigator</b>	
Signature	Katarzyna Fleming
Date	04.07.2017

<b>Supervisor (if applicable)</b>	
Signature	
Date	

<b>Other signature</b>	
Signature	
Date	

**Please ensure the following are included with this form if applicable, tick box to indicate:**

	Yes	No	N/A
Research proposal if prepared previously	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any recruitment materials (e.g. posters, letters, etc.)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participant information sheet	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participant consent form	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Details of measures to be used (e.g. questionnaires, etc.)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outline interview schedule / focus group schedule	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Debriefing materials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health and Safety Project Safety Plan for Procedures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Data Management Plan*	<input checked="" type="checkbox"/>	<input type="checkbox"/>	

If you have not already done so, please send a copy of your Data management Plan to [rdm@shu.ac.uk](mailto:rdm@shu.ac.uk)  
It will be used to tailor support and make sure enough data storage will be available for your data.

## **Appendix 7 Review of Ethical application for online survey (copy of an email from the Ethics Committee)**

**! DS Research Ethics** <ds-researchethics@shu.ac.uk>

**To:** 'KATARZYNA BOJARSKA', '! DS Research Ethics'

Tue, 9 Jan 2018 at 16:34

Dear Katarzyna

Your application for an amendment to your research ethics approval has been granted.

Good luck with your study.

Kind Regards

Samm Wharam

Faculty Ethics Committee Secretary

Faculty of Development & Society

Direct line +44 (0)114 225 3308

For ethical approvals or policy questions, please email [DS Research Ethics](mailto:ds-researchethics@shu.ac.uk)

Further details about the Ethics Committee can be found at: <https://staff.shu.ac.uk/fds/meetings/committee/>

## Appendix 8 Redundant quotes from interviews (extract)

All references to practice from before the implementation of the Code have been removed from data analysis, unless they had a direct impact on experiences since the Code has been implemented. Two examples of these instances are presented below:

Barbara: 'he did not understand what was happening to him. The education did not either. I went to the head of LEA because I just felt I was speaking to people who did not see it or understand it. The head of SEN kept saying 'it is just him, he is just like that' ...My daughter, three years younger sat beside him said I will help you to do this. He just burst into tears; he did not have a clue. And that was the first time when we realistically had seen the problem he had. Because he did not bring a lot of homework home as he had a problem with homework – we kept saying he cannot start it, he cannot sit, he cannot function, no matter what piece of equipment we brought in to assist that – it did not work. Whatever strategies we tried to help, for him schoolwork was at school, home was home'.

Carrie: 'I have been annoyed and this is years ago when he first started school. He had gone to private nursery and then he was going straight into school. And I had then, the headteacher said come and talk to me. So, I did and had about three meetings with him. But at that time, thinking about the EHCP and the statements – the funding came with the statement for any additional support and the head teacher was really keen to know whether he was getting a statement. And I didn't know the system then. So, people came to our house to see my son and then the process had begun. Apparently, he had an ed psych coming see him and I didn't even know that's who she was. But it wasn't till he had been in for two days and I remember picking him up from after school club. And I was called in by his teacher who told me that the ed psych had seen my son and she asked me as they were having a few issues: "do you think he could start in January instead of this September?" She asked me if I could keep him at home but I worked full time. She said they needed to get the statement so he could get the right support. So that I did get and that's the first time I cried, and he was only 4.5 and I cried in a meeting because what was I going to do. He thinks he has left the nursery, well we could not go back to the nursery. But I gathered myself, got cross with myself, I was a teacher at that time, so I spoke to a SENCO at my workplace which was a secondary school. She gave me somebody's number in the LEA. So, I phoned and I said "I am not taking him home but he has to have the support". They knew he had to have the support, but that person said "of course you don't take him home. School needs to put support in place". That is where the trust went and that's where you would imagine the crisis could have happened. You know it might'.

## Appendix 9 Coding for interviews (extract)

Pilot interview	Codes
<p><b>Q1 Whole School SEND Framework</b></p> <p><b>Green (have been implemented)</b></p> <p><b>Orange (on the way)</b></p> <p><b>Red (not addressed)</b></p> <p><b>Q2 Do schools promote system to help parents support maximising of outcomes?</b></p> <p>Veronica: well, I do work at home with my daughter to keep on top of her skills and help her reach her targets. I discussed them at the reviews</p> <p>Janet: I supposed that works because that is what we do, isn't it? The outcomes on the EHCP. We do all we can at home.</p> <p>Ally: my son's outcomes are not entirely focused on education as such. He is in a special school and his targets are like how to make a sandwich and things. So, they can help with that sort of thing when he goes to respite. But I assume some of those things are quite tricky as they do not fit in a curriculum, you know, teaching a child to put appropriate clothes on for the weather in a correct way around.</p> <p>Adam: that exactly what our son's targets are. And it would be good if all the curriculum was this meaningful</p> <p>Ally: the school is on board with the agreement that his outcomes have to have some form of independence later on. And they facilitate that.</p> <p>Adam: things like life skills as opposed to academic skills. That is what it is all about.</p> <p>Janet: I would not put them on green. It is just that some of the EHCP outcomes are unrealistic. One for my son is: "to let the teacher know if he doesn't understand something". But he does not understand that he does not understand something, ha ha! So, it is not something that he can achieve. So, I am waiting for another review to ask for it to be changed. I would not leave it for a year if I realised that it is not achievable. Because the gap between him starting college and the next review was not that long, I just thought I would wait. Otherwise I would have asked for it to be changed.</p> <p>Veronica: normally it is only annual, isn't it?</p> <p>Janet: yes, he had his a week after starting college which was absolutely ridiculous.</p>	<p>Emotional journey of a parent/carer</p> <p>Meaningful provisions</p> <p>Meaningful provisions</p> <p>Practices enabling effective partnerships</p> <p>Meaningful provisions</p> <p>Systemic barriers</p>



Veronica: yeah, because they would have only got to know him, if.	
<p>Bev: the schools give the opportunities for parents to come and talk but whether they listen is another issue. They are good at letting us talk but I've necessarily always seem them adhering to my wishes. I am still on the statement and I was wrong to have it converted in January. In 5 min instead of the meeting being confirmed, we received a letter stating that "we are providing inadequate provision, we have been reported". And now we have a massive dispute going on because I have started a complaint procedure. My child is not home educated by virtue of the fact that he was so traumatised that he would not step into any educational setting at all once for all. We are fine, it is just the way it is. We do not need answers because there are no answers, and it is as simple as that. And I do not think we will make a decision about this, we submitted information during the meeting and I don't think they will do anything and if they will it will be court proceedings and then we would show them off for what they have done to our child and that the provision has been so inadequate and that we have not been heard. And that they have blatantly discriminated against my child and we've always opted not to sue. But this time round they have broken something inside me, and I am sick and tired of being treated like a criminal. We do not have him at school because I am a paranoid mother that does not want him there.</p> <p>Veronica: I am absolutely shocked and amazed with your story...I just cannot believe it.</p> <p>Janet: I have heard a few stories about mainstream school and therefore I never thought it could be an option.</p> <p>Bev: the problem is he is too normal when he is not stressed out. If most people do not recognise him as being autistic on the first account, then...Well, some can see it, but they are very far and few between. Even CAHMS. We were told when he was diagnosed at the age of 5, the neurologist said he is so smart at covering his disability that you will have massive problems. And so, we did and so we have. It is only the highly experienced and the ones that really understand autism who get his problems. We had three full time members of staff over the years that have immediately understood where he was coming from and then it worked like a dream. Bu the rest of it just total nightmare.</p> <p>Bev: I think it is a mental attitude of professionals of "I know best". And if people come with that attitude and I am a smart cookie and I am going to sort that kid out and I am going to prove the parents wrong, they seriously traumatise our children. It is the ones that come in without experience, might have done some theory at the university, e.g. we had one who started seriously traumatising him in Y5 so my son started to bail out. We had slightly better experience with the Y6 teacher who has experience. And I appreciate that it is difficult. And I am sick of hearing you are the expert on your child, yes actually I know my child best. Even my son says he thinks we really understand his needs. But then teachers go and do the opposite of what we say. That is why I would not go anywhere near mainstream, my son actually would not. He still has a few years to finish his education but at the moment he can't even process any academic learning now, he is so stressed just by doing it. We had him tested the other day, when he had to do English and maths and he was non-verbal</p>	<p>Listened to but not heard</p> <p>Left unsupported in crisis</p> <p>Blame</p> <p>Invisible disabilities or their manifestations</p> <p>Practitioners' attitude</p> <p>Parental expertise</p> <p>Invisible disabilities or</p>

<p>for the rest of the day and by the end of it he said: " mummy, if I had to do that again, day in and day out I would be where I was two years ago". And that was when he was starting to engage with the thought of suicide. And this is a child who is happy, who always brought happiness to others.</p> <p>Veronica: that is something that definitely should change, it's not right.</p> <p>Bev: This is why I also think SENCOs should not be allowed to practice without qualifications, without experience and take over people's jobs, people who were highly experienced and understood the whole thing. We had an amazing woman who practiced inclusion the way it is supposed to be in practice – look at barriers and take them down so the child can work. She knew how to get those kids to do their jobs.</p>	<p>their manifestations</p> <p>Practices enabling effective partnerships</p>
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## Appendix 10 Codes and raw data excerpts- interviews (extract containing two codes)

Code	Definition	Extracts
<b>All interviews</b>		
<b>Meaningful provisions</b>	<p>All aspects contributing to meaningful provisions or their lack; EHCPs, targets, outcomes, curriculum. Instances of when C/YP are recognised or not as individuals and not only through the labels of their SEND. It also includes all references to the dichotomy between academic and social/emotional/mental health progress and its place in forming meaningful provision for C/YP.</p> <p><b>Latent:</b> Labels, individualisation, inclusion</p>	<p>Amanda: my son's outcomes are not entirely focused on education as such. He is in a special school and his targets are like how to make a sandwich and things. So, they can help with that sort of thing when he goes to respite. But I assume some of those things are quite tricky as they do not fit in a curriculum, you know, teaching a child to put appropriate clothes on for the weather in a correct way around.</p> <p>Adam: And it would be good if all the curriculum was this meaningful</p> <p>Janet: It is just that some of the EHCP outcomes are unrealistic. One for my son is: "to let the teacher know if he does not understand something". But he does not understand that he does not understand something, ha ha! So, it is not something that he can achieve.</p> <p>Ally: yeah, so I have put things under his outcomes that are not smart, even though they are the outcomes we have agreed on with the school. They are not differentiated down of how he is going to move through each step. I only put things down like: "he needs to have access to a sensory space". But that is not a smart target, it does not say how long, it is only to do with an outcome.</p> <p>Veronica: And then when they took her to the Botanical Gardens, prepared her for it with pictures and pre-empted what was going to happen – she was absolutely fine,</p> <p>Ally: I get general stuff written. My son has a home-school book and it is the same TA who writes in it every day. She writes what he has eaten in fairness, so I know what he had had for his lunch but the rest of it is very generic. He was calm and the list of things he has done. But it does not give me the sense of what he has enjoyed and what he has not.</p> <p>Bev: Education and all the services in the city need to stop treating parents' input like tokenism ticking boxes exercise. It needs to become more meaningful.</p> <p>Dannie: when we got the PA for our daughter, they took him into account saying that we are already getting one day a week holiday club money through SNIPS(special needs inclusion play care service) so they decided she did not need a PA in the school holidays. So, in the 6-week holidays she will get 6 days holiday club 10-3 and that is it, no other support.</p>

		<p>Janet: But when college drops down to three days next year, if one of those days does not fall on the days when I work, then...he will just be with me.</p> <p>Ally: My son's DLA form was filled so he was, for years, only on the middle band for care. And he wakes in the night, he is nonverbal, he cannot cut his food up, could not feed himself at that point, cannot dress himself. People say at school to us why is he not getting a high rate because that then clicks you into other things.</p> <p>Mary: obviously, the timescales with the transfers. I have got two children who both have been transferred and neither of them had any up-to-date assessments done. So, it was just basically like a copy and paste from the existing statement into the EHCP and maybe added a little bit from the school, like the school's comments. Which I appreciate they are the view from the education side, but then in terms of special educational needs, they cannot be every practitioner's that would ever be involved in EHCP. So, it is missing things. You know, my son, my elder one, his statement was revised when he went to a secondary school and when they transferred him to EHCP it was the end of secondary school age. But the information in it was largely based on the profile that was created when he was 11. And he is a lot of different now. Some of it was not meaningful at all, some things needed to be added.</p> <p>Linda: And I have nobody working with my daughter at all so there is no current information at all. My daughter has just had an EHCP review and they have based everything on an educational psychologist report from over 2.5 years ago and for some reason they said that they were going to commission an educational psychologist report and that did not happen. And I just got a letter saying that things have not changed much for my daughter, so she does not need fresh ed psychologist report.</p> <p>Linda: And I do not think it was a cost saving exercise and it did have an update in it although the update was incorrect. And I am, like, where has this information come from in the update and, it was actually a conversation between two practitioners, a person from post 16 department and the ed psych. So, the updated information had actually come from someone who does not know my daughter. She met her once for about half an hour. The information was incorrect.</p> <p>Julia: I was at a meeting in college last week with my 18-year-old son, he has had an EHC plan since he was 2. He had no language till he was 6. He has done fantastically well. Gone through mainstream and gone onto college. And this review for his EHC was in November, none of that has been implemented, not one thing.</p> <p>Julia: He has sensory processing difficulties and it is all over. There is no progression at all, he is getting 8 hours of formal</p>
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		<p>education, he should be getting 15. So, the other stuff has just not been put in place.</p> <p>Kathy: yeah and because it is an academy, it is all about achievement, attainment, bums on seats. It is not about child's needs; it is not about keeping the children emotionally stable. It is about what they can achieve academically. Whereas to me it is much more important that his mental health is being cared for, not if he is achieving.</p> <p>Linda: and the pressure on the teachers to perform and to show that their children are performing is absolutely through the roof. So how they then have time to look after the SEN, taking that time away from all that?</p> <p>Linda: they should measure progression, rather than academic achievement. If they did that some of the schools that might appear not to do too well, suddenly would be right up there.</p> <p>Mary: when I was going through the EHCP conversion, my son's took 54 weeks. I threatened juridical review to finalise it and they have not even done any assessment so why it took that long I do not know. And as he did not have his ASD diagnosis yet, his primary need was his anxiety and SLT. And there were no reports from either of those because they just did not bother responding – CAMHS or SLT.</p> <p>Mary: I agree, my daughter was under CAMHS for many years and it was pointless. She already had three assessments for ADHD, which they could not decide if she had ADHD or ASD. They finally medicated her when she was 17. Verbally they said she had ADHD diagnosis, she then transitioned into adult services and then we were told that she has not got official ADHD diagnosis. Despite of the fact that she had been on Ritalin for 18 months.</p> <p>Anna: My son's EHCP – and to be fair he does not really talk to many people and does not really give out views and things. So, they are working on old documents and old feelings rather than the here and now.</p> <p>Anna: He went to a couple of PRUs but PRUs were not what he needed. He needed a specialist provision but again it was overlooked.</p> <p>Anna: there was not much in it, he did not have SLT assessment, CAMHS did not put in a report for his EHCP, social workers again are not there because he has turned 18 and said: "what? Why do I need a support?!"</p>
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<p><b>Systemic barriers</b></p>	<p>All factors resulting in unmet deadlines, insufficient collaborations bound by inadequate time for information/ advice exchange and lack of investment in building relationships with individuals and families resulting in practitioners not knowing the service users. Any mentions of how the budget influences partnerships or indirect factors that influence partnerships working. Examples of the impact bureaucratic tasks have on parent – practitioner relationships, on the effectiveness of the role of professionals from EHC services and on the lives and ability to receive support by families. Mentions of the shortage of time, resources or staff and their knowledge to fulfil their responsibilities and duties as prescribed by the Code and</p>	<p>Janet: yes, he had his a week after starting college which was absolutely ridiculous.</p> <p>Veronica: yeah, because they would have only got to know him, if.</p> <p>Ally: it depends on the school. I have a son who is dyslexic and has got anxiety issues, so he has got my plan. That is when the school was on action plus. But it is down to the school. The advice is that it is advised to do it termly, the wording is that you do not have to, but it is advisable. It is good practice.</p> <p>Bev: it is manpower and therefore it is money.</p> <p>Dannie: in secondary school it is probably two days for those SENCOs doing these meetings with parents. It is a lot of work they are having to do. And then instead of advising teachers and doing their work in the classrooms. It is that juggling act again.</p> <p>Ally: I think it is all the manpower again. They have so much on. They do not do the reviews the way they should do them. I know my son goes to a Saturday club on alternate Saturdays, which he has been doing since he was 8, and he is 14 now. We have never had reassessment through that. And they are supposed to reassess it every year in order to check that it is still meeting his needs and it is still appropriate.</p> <p>Veronica: So, 7 weeks we have been without a blue badge, we have had so many issues in that time. We have been sitting in car parks, lodging around, running in front of the taxi because we did not have a blue badge. We had to cancel some of the trips out with the PA.</p> <p>Kathy: I think people who pay for it, should not be involved in assessing for it. Because there is a conflict of interest straight away. There is a financial incentive not to assess properly and while you do not identify needs you save money.</p> <p>Linda: there have to be some links. The problem is if you have the budget and you have to pay for all the SEN needs then obviously you are going to try to keep cost as low as possible. And, like, if you have a fine amount of money and you have to juggle it and you have to allocate and every time, you are going to go for the cheapest option, are you not? I am pretty sure this is what has happened with my daughter's EHCP and that is why we have not seen the ed psych. It is cheaper for the SEND department not to pay for it. A quick update will be much cheaper than a full report. But that is not the ed psych's fault and that is not the manager's fault, that is to do with the budgetary constraints.</p>
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	<p>ineffective assessment procedures.</p> <p><b>Latent:</b></p> <p>Performativity, moral dilemma, empathy</p>	<p>Kathy: she is a full-time class teacher in a very high SEN school. So, her capacity just does not allow time to look at a child in a classroom.</p> <p>Mary: It depends how they spend their SEN funds as well. So in my son's school they put TAs in every single class in the school, which meant that because he needed something that was not part of the main provision, there was no money to provide what he needed. Because they spent it to meet the majority of the school's needs. Which I can understand completely. So again, it can be about what the school have left when your child's need is identified and that might not fit in it. When he had a statement before the EHCP, they did not actually do anything on his statement. It might as well have just not existed.</p> <p>Linda: and the pressure on the teachers to perform and to show that their children are performing is absolutely through the roof. So how they then have time to look after the SEN, taking that time away from all that?</p> <p>Julia: Ofsted framework has absolutely nothing, nothing fits into that in terms of the principles of the code or the actual code.</p> <p>Kathy: our SENCO has been a SENCO for 20 plus years and she has not done much training because she is a full-time teacher. So, I think that has an impact.</p> <p>Julia: our head teacher was too, and it really did not work.</p> <p>Mary: I do not think it is a good practice either.</p> <p>Julia: no, there is nowhere else to go really when things go wrong.</p> <p>Sam: I think it should be someone designated but not a head.</p> <p>Linda: it should be a clearly identified role, but it is down to staff and budget constraints. A person that would do this and nothing else.</p> <p>Linda: my daughter's school, where my daughter should have been at should I say, as she is out of school now. Their SEND department has 2 staff and one of them was a teaching assistant who was pulled out here, there and everywhere. And SENCO. For a thousand children!! So...</p>
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		<p>to transfer it to an EHCP, and it was totally wrong. They were just four gaps of nothing.</p> <p>Anna: it still feels as though it is a very reactive service, reactive system, the evidence has to be there to some degree before they can make the referral. Because that is how the criteria are. And it is not like we know there can be an issue, they might have seen a little of it now, why do we not refer that child to this provision, e.g. CAMHS, ed psych and then we can make plans so these people can come and work with that child before the family is in crisis. But no, they wait until the child is in crisis.</p> <p>Carrie: I think it is that playing with the system and trying. So you have practitioners that are on the side of the parents/families.</p> <p>Chloe: Ha ha, hopefully the teacher will tell you about those things. But the whole process of the EHCP is negative, from the diagnosis all the way through. I feel it is not, they have to look for the negative to gain the diagnosis to justify the provisions. If you are not bad enough you will not get the plan. So, in a way you have to emphasise all the negative traits about your child to get some kind of provision in writing to give you that legal backup. And without that there is nothing!</p> <p>Chloe: I trust in what they report they see; I am worried about things that they do not see. If you know what I mean. It is difficult to see certain things. There are so many children in every class. There is not time to spin around, let alone give that child the attention that they need. I think they do their best to know what is going on, but they do not see the full picture.</p> <p>Chloe: So, I am happy that he is comfortable but it is not meeting his education. And I do not really want to say anything as it would be very offensive to her, she is trying to do her job and without her he might not even have been in school. But it is still not what he deserves.</p> <p>Chloe: She was not employed in her role by choice, she was employed in that role as it provided her with a full-time permanent contract. You do not always get a SENCO who wants or understands that role, it is an add-on. She was qualified, but she did not want it and she was not paid for it. And she has two hours a week to deal with the workload so she is also facing huge battles as how can you do it in two hours a week.</p> <p>Chloe: There needs to be a general consensus of who is responsible for what and what is going to happen. Almost like a structure of where they can access resources to support them as they might not have any resources to support their work and if they have not got any support, they are not able to bring it to you. It is also difficult and different between different authorities as there is no consistency between them. And what one accepts, the other does not. They need to agree</p>
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		<p>Chloe: Because we live in one authority and my son goes to a school in a different authority there is no understanding between health and education as they are run by different authorities. And there is no communication between them, and it is like "aw, no, we cannot help you, it is not our area, we do not want to take anything extra". There is fear of getting things wrong and being exposed by another authority.</p> <p>Chloe: They do not want to be held responsible, no one wants to be held accountable, so it is always pushed. It is perception...There is a general fear of SEND and disability: we have done something wrong and we are going to be in trouble. So, it is best we do not do anything, just in case we make a mistake.</p> <p>Val: The GP was very helpful and did a referral to CAMHS. But CAMHS declined it without even seeing us claiming it was because of ASD. It is the inflexibility of the system.</p> <p>Rory: It is evident that health services for physical health have much more funding than mental health and disabilities like autism. And this is a battle wherever you go.</p> <p>Rory: The resources there are disadvantageous. It feels like a post code lottery, you do not get what you need, you get what is prescribed for the region where you live. Because of the structure the organisations are run. Often, you will find one organisation that will provide far beyond their remits because of the gap in services. Those people feel bad for the situations families are in. I have experienced it and it was not official, as you can imagine.</p> <p>Rory: The reason why we are suffering is because of the way the services are structured. When my son was diagnosed the main focus was whether he met the criteria of the spectrum. The difficulty we had while he was being assessed nobody else wanted to know that we were having problems. E.g. health visitors could not come as the services could not be duplicated. Their duty was not fulfilled. It felt as though if you are under one department another department does not want to hear about you. Some of the health visitors, while they still were there, would not attend the visits or come unannounced.</p> <p>Rory: Bureaucracy is the reason for the problematic relationships between parents and practitioners. The communication is often broken.</p> <p>Rory: But he had a very disturbed sleep as he was placed next to the nurse's station which was very busy, and the monitor did not read anything. The sister however told us that was not accurate, and she admitted that we should have stayed for another night however the consultant did not even come to see us. After looking at the monitor he declared that there was nothing wrong. We were leaving the hospital in tears until another doctor saw us and asked us what was wrong and he</p>
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		<p>asked us to wait. He got the consultant to come and see us and he was admitted for further observation. It was decided that he should have both tonsils removed, both at the same time as that was the best practice.</p> <p>Rory: My blame is to do with funding and the way the GP commissioning groups organise their work. There is not enough follow up with newest research and techniques that could be used by clinicians.</p> <p>Rory: We are also concerned that because of his intelligence perhaps he might require different input educationally. But because of the cuts in funding we do not have access to an educational psychologist to make those changes upon their report.</p> <p>Rory: There are so many services that you are not able to be self-referred. So, we are often knocking on the wrong doors because somebody referred us wrongly.</p> <p>Rory: They referred him to Autism specialist team who told us that he received so much support that they cannot do it anymore, even though it was supposed to be continuous. We are constantly advised to give up and forget fighting for things that are extra.</p> <p>Mimi: And unfortunately, it is very difficult to get as it is such an expensive provision to get. You have to tick enough boxes for it, you do not automatically get it.</p> <p>Mimi: Until he left school at the age of 19, at the end of June last year and they suddenly decided "why do you need all this respite and we are going to review it". And it is difficult, this is nearly a year on, and they are still reviewing it!</p> <p>Mimi: And not every family have that luxury. I worry for families and for people who do not have the education to be able to...you know, people who think what doctor says is law, 'the doctors are Gods'. But you know, I have worked with consultants; they do not scare me. But other people, they go to hospitals and are not comfortable in that environment. They do not listen to what they are saying, they panic and they do not know how to use the words that trigger things. And I do worry for those because they are the people that get failed by the system.</p> <p>Mimi: So, it costs less money effectively at the end. And the other thing is that you do not get help until you are in crisis! You have to scream and shout for the help. The system is more reactive than proactive. Because the services do not have the resources to be proactive, whereas if they were proactive they would actually spend more money if they were proactive than they are spending by being reactive.</p> <p>Mimi: I know all about deprivation of liberty and that sort of thing. That is what his life is about and that is what services will</p>
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		<p>have to be delivered. But there are so many forms to fill in, it is simply crazy.</p> <p>Holly: Before he went to 6th form, there were some issues around funding for the resource unit, which culminated in the meeting with the head and we were reassured that we would get a TA that would support our children. Unfortunately, there were more cuts and I just found out there were none. I do not actually think they have enough resources to support those children.</p> <p>Holly: The problem is the funding, but also the communication as I experienced.</p> <p>Holly: In fact, the payments have not gone up in a very long time and I did manage to find through various means by phoning so many people (even if there was one person allocated to this particular service, the changeover in social services is so vast, you would not be able to trace them).</p> <p>Holly: So, they referred him to regional eating disorders services, but they deferred us saying it was not within their remit. Then CAMHS referred us there again and they offered some counselling sessions; (+Chasing things up)</p> <p>Sally: but the SALT team came with such a backlog that it took them two years to do the assessment on him. Because so much time passed and even though there were things that needed to be done, now it is only time to be discharged because if he is referred again it is quicker to get back in the system than stay there and wait.</p> <p>Sally: Even when you are going to (the name of the assessment centre), you go: "somebody just give me some information, I need some information!" I need someone to understand my child, but it is not there. Because they are so busy, their workload is so big, they prioritise.</p> <p>Sally: And when school queried why all the things they asked for were not addressed, the council person said it was because of the back log because of all the transitions from the statements to EHCP. They were just sending the current plans out and they were going to review them again.</p> <p>Sally: It is almost as if until you say I am walking out, I cannot cope, that someone is going to listen. It is as if only if you are in a total crisis, something will be done. I cannot guarantee, when I am on my own, I can go out, I can look after them.</p> <p>Sally: The referral had to happen, (the name of the assessment centre) said it was a GP who should refer us, but the GP said their budget did not cover that.</p> <p>Sally: It is very hard to be their voice when you are had been fighting the system. We want our child to be happy, how do we get there, what needs to be put into place? Get all the</p>
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		<p>professionals together and talk with you! But that is not what has been happening. It is lovely that the outcomes are far reaching but they need to be reflective of the near future in detail first!</p> <p>Sally: They [LA] do not respond to email; the communication is atrocious. They ignore phone calls and I believe they are encouraged to do this because they have not enough time.</p> <p>Sally: E.g. I have to pay for a letter from a GP to say my child cannot queue when I have to take them to do a social activity, so he does not end up having a meltdown.</p>
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## Appendix 11 Coding for Survey (extract)

	Parent/carers statements	Codes for analysis
1.	In my son's school we work together with school and other practitioners where applicable. It would be nice if this always happens. Sometimes (due to budget constraints I feel) where a child's needs have changed then there is not necessarily a reassessment carried out by the relevant practitioner to inform changes to the plan. This could also be the case if new needs are identified in some way (but have not been fully assessed).	*Consistent collaboration between school and home  *Budget constraints
2.	Parents are taken seriously. The child's disability is taken more seriously.	*Acknowledge parents' views as valid. *Practitioners' understanding
3.	As a parent of a special needs child I would like to be heard. I am an OT working in special schools with kids with ADS. The most frequent statements of blame I hear from staff are directed towards parents. There needs to be more opportunity to be heard. Video footage and other media can be useful in pin-pointing difficulties, as different contexts will often present different issues.	*Parents/carers being "heard".  *Practitioners' understanding  * Person-centred approach
4.	The EHCP is ignored once written - it is just a paper exercise. Greater respect for the parent's understanding of the child and less blaming the parent. Greater understanding of the strains placed on parents. At primary level I would like to see more respect for the child's viewpoint – actually listening to him/her. My son was moved to an integrated resource when he was nine and for the first time he was actually asked about situations that were distressing to him and included in meetings between me and the member of staff when I raised concerns. Significantly improved communication systems to ensure parents are able to monitor what homework needs to be done and ensure letters home are received.	*Theory v practice  *Blame  *Acknowledge parental expertise of their child  *Practitioners' understanding  *Person-centred approach  *Effective communication
5.	Trust me more, and my knowledge of my child.	*Acknowledge parental expertise of their child
6.	Better communication at school and between professionals Working in partnership Follow the law Caring about the child I have x3 Sen children with ASD and other differences, schools seem unable to see us as a	*Multi-agency communication  *Adhere to the law (SEND CofP)  *Person-centred approach *Family context



	struggling family unit and ignore this complexity when planning or arranging communications. Supporting parents' disabilities.	*Practitioners' understanding
7.	More home school liaison. I get very little information about my child's day, other than what lessons he has had and if he has had any behavioural episodes. I would like more information about the strategies they are using with him, SLT input and any good moments, interactions with peers and staff.	*Effective communication
8.	We never see anyone apart from a paediatrician once or twice a year. With regards to the ASD side, we were given a folder with leaflets and that was it. No one turns up to school meetings apart from teachers. There's no communication from autism team so school haven't had any support at all. Not enough staff.	*Lack of information enabling decision process.  *EHC staff attendance
9.	To be seen more often with if possible, the same person. To see things being done or steps towards things being done.	*Frequent changes in staffing  *Effective communication
10.	I think the level is about right; it's just the review stage which could be done in better partnership though this is discussed thoroughly once it is done.	*Parents' involvement in decision-making processes
11.	The chance to have a representative with u. I'm OK – I'm a social worker, but I know many people struggle to speak to and don't know what to say or what they are entitled to for their child.	*Adequate support at the reviews

## Appendix 12 LLS Whole School SEND statements (card game)

The cards include statements derived from the Whole School SEND Framework, indicating desired approaches mainstream and special schools should demonstrate while working with parents of pupils with SEND.

Participants were asked to grade each statement with the following criteria:

Green: the provision your child attends meet this criterion,

Orange: the provision is working towards meeting this criterion,

Red: the provision does not demonstrate any signs that this is considered.

\*Some statements vary between special and mainstream schools and therefore are included on one card.

School systems promote parent/carer contributions to maximise outcomes for pupils with SEND	School leaders have created a culture and ethos that actively welcomes and engages parents/carers of pupils with SEND
Teachers ( <b>all staff in special schools</b> ) have a clear understanding of pupil need and personalised strategies are informed by parent and carer partnership. These are consistently applied throughout the school.	<b>Special Schools:</b> The school asks for feedback from parents and carers on the quality of support and provision.
Pupils, parents and carers are made aware of local and national services that provide impartial advice and support such as the SEND Information, Advice and Support Service (IASS).	Systems are in place to allow parents and carers to meaningfully contribute to shaping the quality of support and provision.
<b>Special Schools:</b> The school recognises the role pupils, parents, carers, and advocates have in co-production and can demonstrate this. <b>Mainstream Schools:</b> The school and parents work in partnership to achieve genuine co-production, for example parent/carer forums and workshops, and structured conversations for pupils with SEND with EHC plans.	<b>Special Schools:</b> Pupils have personalised plans that are reviewed with parents and carers at least termly.  <b>Mainstream Schools:</b> Pupils with SEND have personalised plans that are reviewed with parents and carers at least termly. Interventions follow a cycle of Assess, Plan, Do, Review.
Parents and carers are fully involved in discussions with the school on identification and assessment.	

## Appendix 13 Group interview plan

1. Informal greetings, offered refreshments, casual introduction, invitation to take a seat, arrange belongings and outer wear. **(15 min)**

**2. PERSONAL INTRODUCTION:** I have worked in special needs settings for nearly 13 years and have witnessed many different journeys parents of pupils with SEND go through. This has led me to commence the doctoral study, which this group interview is a part of. I would like to thank you for taking your time out to participate in this research, as without your input it would not mean anything. **(1min)**

**-Introduction** of the purpose and layout of the interviews, distribute consent forms to be signed, provide explanation for the use of recording devices **(5min)**. "The aim of this group exercise is to gather as many opinions and views on the topic of parent/carer relationships as possible. We will spend 2 hours divided into 2 parts and there will be a break half way through for about 10-15 min. It is essential that all participants sign the consent forms and are aware of the confidentiality remits. Please ask me any questions you might have in regards to the consent forms. I will be using two recording devices in case one stops working. If, for any reason, you would like to add anything that you feel you wouldn't like to be recorded, please let me know during the break or at the end. Can I ask everyone to read and sign their consent forms?". Distribute the vouchers.

**-Effective group discussion** (on a flip chart or a poster) – say that I would appreciate it if all participants kept those points in mind throughout our meeting. **(4min)**

### 3. INTERVIEW QUESTIONS

#### Part 1

**a) (50 min)** As some of you might know, I conducted a survey in the first part of my study. It allowed me to gather information, which I would like to expand on today. The SEND Code of Practice sets a legal obligation for all practitioners to engage and include parents/carers in the decision-making process. To start with I would like to expand on some of the questions from the survey.

The results from the survey suggest that more parents/carers agree that the outcomes of the EHC plans are clear to them, however some are unsure and there are many who strongly disagree.

- Why might the outcomes not be well understood by parents/carers? (Probing Questions: "Who sets the outcomes?" "What language are the outcomes written in?", "Do you contribute to the outcomes?", "How do the outcomes relate to current needs of your child?" "Are the outcomes broad or specific?" "Some parents said that the review facilitators have never met their child and therefore couldn't understand his needs – have you had or heard about similar instances?)

Comparable amounts of participants agreed and disagreed that they can plan their children's education with the support of other practitioners during EHCP reviews, but almost 60% disagreed that there is enough information and professional advice available for them to make informed decisions about their child's future.

- Do you feel you can rely on the expertise and advice of all practitioners when planning your child's education? (Probing Questions: Who, other than school practitioners, are

attending your reviews?", "Do you feel those practitioners can effectively contribute to the reviews?", "Do you feel their impact has a positive significance in your child's future?", "How would like those practitioners to support planning of your child's future?")

A very large proportion of parents/carers strongly agreed that they feel confident to ask practitioners for support if they don't understand something and are encouraged to express their views.

- How could practitioners ensure that parents/carers feel confident in asking for their support if they don't understand something about the review? (Probing Questions: "Is it important that you are familiar with the practitioners leading the review?", "Would reassuring questions from the practitioners be helpful?"-e.g. "Do you understand how this might look in practice?" Or "Have you come through an activity like this in the past?" "What did the practitioners do to encourage your confidence in expressing your views at the last meeting?" "Is there a particular structure to the meetings that makes you feel comfortable?" "Can you think of any occasions or parents who told you that they struggled to express their views – what do you think might help them?" "Who and how did you ask for advice when the EHCP were introduced?" "Do you feel there is an assumption that you know/understand more than you do?" "Do you feel you can express your opinions towards all practitioners equally?", "Are there some practitioners that you feel more comfortable than with others and is there a pattern, e.g. all health practitioners are receptive/all school practitioners aren't?" "What makes those practitioners more approachable and welcoming?")

The same number of parents/carers agreed and disagreed that their opinions were taken into account when outcomes for the reviews were created and nearly 60% disagreed that their opinions have equal value to those of professionals.

- What do you think are the reasons for dismissing parents/carers' opinions when the outcomes for the reviews are being created? (Probing Questions: "Can you think of a time when you suggested something, and it wasn't taken into account by practitioners?" "How do you know your opinions aren't being taken into account?" "In what context have your opinions not been valued at the same level as practitioners'?" "Can you think of an example when your opinion was dismissed, and practitioner didn't take it into account?" "Can you think about a time when you were disagreed with and a practitioner made a decision for your child instead of you?")

Almost 57% of parents/carers stated that they aren't regularly informed about the progress agreed at the review.

- How often and in what form would like to receive the update on progress in relation to reviewed outcomes? (Probing Questions: "What is a reasonable time for your child to meet the outcomes?", "Are the outcomes timely and appropriate to be reviewed e.g. termly?", "Would it be useful to know small targets contributing to the outcome and know how those little steps can be supported at home?")

**b) (10 min)** Our next set of questions will involve the Whole School SEND Framework. This document was created by the London Leadership Strategy with support of practitioners, parents and pupils. It is supposed to help schools assess their provision in different areas, some of which involve working with parents. I compiled all statements regarding parent/carer-practitioner relationship guidance and would like you to think about and discuss:

- Where, in your opinion, does each statement belong? Is it:

GREEN – the statement is demonstrated in practice by the provision my child attends

ORANGE – the provision demonstrates willingness and consideration for working towards these criteria

RED – the provision doesn't demonstrate any signs this approach is considered.

### Break (10-15 min)

### Part 2)

**(35 min)** For the first time in the history of Special Educational Needs and Disability legislation, parents are given the legal right to have their voices heard. There are many practitioners who already work with your children and who are required to change their ways of thinking and their practice to adhere to this legal requirement. There will also be new practitioners who are or will be trained to work with your children. I believe it is important for all of those practitioners to be aware of your thoughts, opinions, experiences and needs. My intention is to share the outcomes of this study with as many practitioners as possible in the future and therefore I would like you to think about:

I would like us to concentrate on positive aspects of all relationships between you and practitioners working with your children.

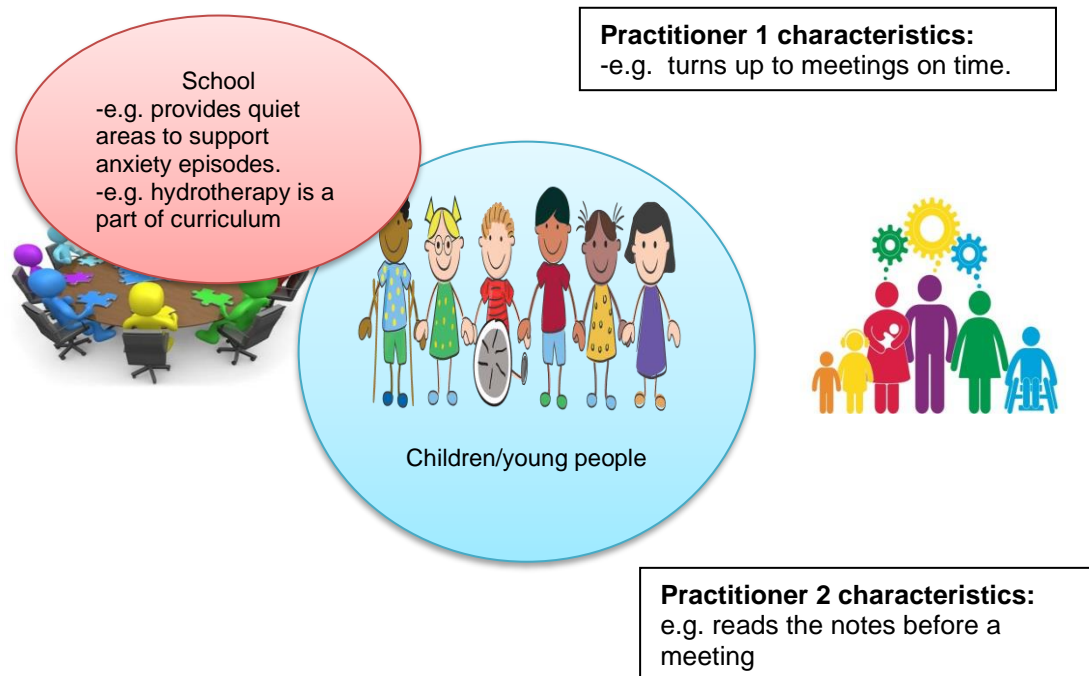
- Can you give examples of positive situations, communications, interventions or any other positive aspects you have experienced when interacting with practitioners working with your child? (Probing Questions: "Was there a time when you felt reassured by a practitioner?", "Can you give an example of a positive situation when you felt the practitioner addressed your worry?" "Can you give an example of a positive situation when you felt included in decision-making about provision for your child?")

Now, I would like us to imagine an ideal provision for SEND children/young adults. The SEND Code of Practice draws on strengths of the Multi-agency team collaboration in order to centralise the needs of the child and the family unit.

- What would be the characteristics of the provision you would like to design for your children? What would you like to communicate to anyone working with your child? I would like you to consider practitioners who have experience working with SEND students and those who are just embarking on their career paths.

Probing Questions: "When you felt misunderstood or not listened to, what advice you would like to give to the practitioner you dealt with?", "How would you like to be told that your child had a behavioural episode at school today?" "What do you think might improve the communication between practitioners and parents/carers?" "Can you think of ways of completing the statement: "I would like the practitioner to... when they write in my child's home-school diary, ... when they call me on the phone, ...when I ask the them for information, etc", "What would you like the practitioners to consider before they meet with you for a review?", "If it was your niece or a cousin starting a career in education, what would you like them to be mindful of when working with parents/carers like you?" "Think about a 20 year old you and imagine what might be the things you wouldn't, but really should consider when approaching a parent/carer of a pupil with SEND" "Do you think people are aware and sympathetic to what challenges you might face as a family unit on a day to day basis?", "What would you like them to consider?" "What are the day-to-day difficulties you might face?" "What do you expect practitioners to understand/sympathise with?"

\*I will use a big piece of paper and poster notes and encourage the group to complete the mind map in this process. I will use a picture of a child, family, school and other practitioners to be placed accordingly on the mind map (Probing Questions: "Do we agree to put the child in the centre?", "Will the family be next to the child or regarded as a separate unit?", "What other crucial practitioners should be included in our 'dream provision'?" "What would the characteristics of service/attitudes/approaches of each part look like?", "What would you like the practitioners to be like or behave like?", "What knowledge would you like them to have?", "How would you expect the communication to run?", "Parents expressed in the survey that they want to be perceived as experts on their child, but not to be expected to be an expert on the disability, teaching strategies or education at the same time – how do you position yourself within this statement?")



At the end of this session, we should have a clear picture of what the provision would include, what attitudes and approaches parents expect from practitioners and how all of those aspects can be interrelated.

### 3. Analysis of the recording

\*was any question of a sensitive matter?

\*were all the questions clear and understood in the same way?

\*were any of the questions leading?

\*is there sufficient time given to each part of the interview? \*were probing questions leading?

\*did the interview run according to time schedule? \*did the recording equipment work effectively?

\*did the resources management impact on the timing of the interview and can this be managed more efficiently?

## **Appendix 14 Individual interview plan**

1. Consent form signature.
2. Short reminder of what the interview will entail, reassurance to ask questions.
3. Ask if the participant had any questions.
4. Present one finding from the survey at a time:
  - Equal value of opinion between parents/cares and practitioners
  - Regularity of feedback on progress
  - Accessibility of information and advice
  - Practitioners' understanding of SEND and processes involved
  - Possible barriers to open, trusting and effective collaboration
  - What improvements would allow for the relationships between parent/carers and practitioners from all services to become co-productive?

## **Appendix 15 Reflective journal extract: reflecting on emotions.**

January 2018

As a fairly inexperienced researcher, I was advised to consider the emotional aspects that may affect the success of interviews. Following my experience in working with parents I felt somewhat comfortable to facilitate the interviews. However, I learned that, as a researcher, I need to be more reflexive and reflective when it comes to conducting research, as opposed to holding meetings with parents in my practitioner capacity. I will need to pay attention to the power dynamics during the interview, ensuring that everyone has an opportunity to voice their opinions and talk about their experiences. At the same time, I will respect participants right to not share anything, should they feel inclined to do that. I will provide clear guidance on expectations and will display these to encourage participants to refer to these throughout the interview. I will also introduce a 'safe word' so if anyone experiences unexpected emotions and wishes to stop the interview, they can easily signal that to the rest of the group.

April 2018

In reflection on the pilot interview, I realised that I could not possibly foresee how the dynamic of the group would unwrap during the interview. I did not know all the participants, did not know their stories and could not predict how each of them would interact within the group. Therefore, I became less precious about gathering data that would necessarily fit with all my objectives and answer the research questions directly; instead I allowed more time for participants to tell their stories.

I also did not dedicate enough time to consider the effects the stories shared could have had on me. I learned that I needed the support of my supervisory team to depict these emotions and acknowledge their impact on me as a researcher. This realisation contributed to me feeling more prepared for the following interviews.



## Appendix 16 Email to interview participants introducing details of the interviews

Dear (Name of a parent/carer),

I hope you are well. Thank you for expressing your interest in the second stage of my study.

My next group discussion is taking place on the 19th of April and I would love you to take part. It will start at 10:30 and last for two hours. Refreshments, cake and nibbles will be provided and each parent will also receive a £5 high street voucher for their participation. We will be based in Cantor Building in Room 9223, that's on the 2nd floor.

The questions we will explore will include:

1. Do parents feel their views/opinions are valued equally to those of professionals?
2. What can the professionals do/behaviour like to encourage parents to express their views or ask for clarifications (in the process of EHCP reviews and general interactions)?
3. Are the outcomes of EHCP clear to parents, timely/appropriate for their children and created with family in mind?
4. How often would you like to be informed about your child's progress in relation to the outcomes?
5. What information/access to advice is essential for you to make informed decisions about your child's future?
6. What would an "ideal" partnership between parents/carers and professionals look like?
7. What would you like to communicate to anyone working or being trained to work with your child?

I'm including the Information sheet and a consent form, which I will require everyone to sign, so if you have any questions, please contact me beforehand. Please be reassured that I will always wait for your consent to include your opinions in my project, should you change your mind.

There is also a map with directions and car parks available close to the venue.

I'm extremely excited to work with you and am looking forward to exploring your views.

Please let me know if there is anything you may need in terms of access. I will be available via email at all times, so please contact me if, for any reason, you are struggling to get to the venue.

Best Wishes,

*Katarzyna Fleming*

PhD Researcher  
Sheffield Institute of Education  
Sheffield Hallam University  
Charles Street  
S1 1BW Sheffield

### 3 Attachments

## Appendix 17 Information sheet for interviews

### Information sheet

**Date:** \_\_\_\_\_

**Title of the study: Has the New SEND Code of Practice (2015) influenced the nature of parent/practitioner partnership?**

Dear Parent/Carer,

You have been invited to take part in this second stage of the study, which started with a questionnaire you have filled in previously.

We will discuss and share your views and opinions about working with professionals at the school your children go or went to.

The group conversation will be recorded and saved on an audio file available to myself and Sheffield Hallam University for transcript purposes. This will not be shared with anybody else and will not affect your personal or professional relationships with the school your child attends. Any sensitive matters raised will be guarded with confidentiality and there will be a contact provided should you wish to discuss it further at the particular school.

I will present you with the answers from the questionnaires, which we will be able to discuss. There will be plenty of opportunities to talk about other aspects related to the study, as your personal views matter the most. I am hoping to find out about all your experiences, those positive and those less so. My aim is to listen to how you would see the future relationships with professionals working with your children improve.

You will not be obliged to introduce yourself by surname or say the name of the school your child/ren attend, however, because this will be a group discussion some parents might know you already.

Similarly to the survey, the findings from the group discussion will be provided to each school as a general report, but it will not disclose any particular comments from individuals, which could be traced back to them.

All the data collected will be kept securely on a Sheffield Hallam University server for up to 10 years for other publication purposes.

Your participation is totally voluntary and you have the right to withdraw all of your contributions within two weeks from the date this discussion has taken place (please see the date at the top of the information sheet).

If you have any questions, please contact me on the details provided below.

Thank you for your time and contribution.

Best Wishes,

Katarzyna Fleming

Email: [Katarzyna.Z.Fleming@student.shu.ac.uk](mailto:Katarzyna.Z.Fleming@student.shu.ac.uk)

Address: Sheffield Institute of Education

Charles Street,

S1 1WB Sheffield.

Director of studies: Prof Tim Jay, email: [t.jay@shu.ac.uk](mailto:t.jay@shu.ac.uk)

## Appendix 18 Consent form for interviews

### STUDY: Has the NEW SEND Code of Practice (2015) influenced the nature of parent/practitioner partnership?

*Please answer the following questions by ticking the response that applies*

	YES	NO
1. I have read the Information Sheet for this study and have had details of the study explained to me.	<input type="checkbox"/>	<input type="checkbox"/>
2. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any point.	<input type="checkbox"/>	<input type="checkbox"/>
3. I understand that I am free to withdraw from the study within the time limits outlined on the Information Sheet, without giving a reason for my withdrawal or to decline to answer any particular questions in the study without any consequences to my future treatment by the researcher.	<input type="checkbox"/>	<input type="checkbox"/>
4. I agree to provide information to the researchers under the conditions of confidentiality set out on the Information Sheet.	<input type="checkbox"/>	<input type="checkbox"/>
5. I wish to participate in the study under the conditions set out on the Information Sheet.	<input type="checkbox"/>	<input type="checkbox"/>
6. I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other research purposes.	<input type="checkbox"/>	<input type="checkbox"/>

**Participant's Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Participant's Name (Printed):** \_\_\_\_\_

**Contact details:** \_\_\_\_\_

**Researcher's Name (Printed):** Katarzyna Fleming

**Researcher's Signature:** \_\_\_\_\_

**Researcher's contact details:**

Katarzyna Fleming  
Sheffield Institute of Education  
Sheffield Hallam University  
S1 1BW Sheffield

**Please keep your copy of the consent form and the information sheet together.**

## **Appendix 19 Reflective journal (excerpt from reflections on the pilot group interview)**

5<sup>th</sup> of May 2018.

Following the first two group interviews, I realised how important it is for me as a facilitator to allow time for participants to discuss the issues they find important. This has to take place, even if these matters might not necessarily relate to the research questions. As I listened to the stories shared and grew to understand the enormity of parental challenges in the system, I realised how some of them perhaps opened up about those issues for the first time. It was therefore imperative for me to acknowledge the importance of their lived experiences and allow the platform for their stories to be heard. It would have stood against the aims of this project if, I, as a researcher and practitioner, yet again imposed the direction of these discussions in accordance with my own agenda.

This, of course, meant that within the time frame that we initially agreed, the discussions were inclusive of some topics that were not a part of the research questions. However, I allowed the discussions to take this, more organic, direction and decided not to be too precious about the potential for more stories that would cover my questions. I was grateful that these parents/carers contributed their time to my project and as I analysed the interviews, it transpired that the topics I aimed to explore were reflected on more than I had expected.

As a reflection, I will focus on 5 main questions in the individual interviews and allow participants a greater autonomy to tell their story as they see it.