"We're one side of the wall and they're the other": An Interpretative Phenomenological Analysis study exploring parents' and young people's experiences of family engagement during the Education, Health and Care needs assessment process

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Abstract

There have been a number of significant developments in the practice of Local Authorities and schools following the publication of the *Children and Families Act 2014* and the *Special Educational Needs and Disability Code of Practice: 0-25 years 2015* (Department for Education (DfE) & Department of Health (DoH), 2015). Key changes include a new co-ordinated Education, Health and Care (EHC) needs assessment process, and the introduction of EHC plans to replace Statements of Special Educational Need (SEN). Notably, the views, wishes and feelings of young people and their families are increasingly viewed as being central to decision making processes at individual and strategic levels. The present research draws a link between this emphasis in legislation and the wider notion of family engagement, which concerns families, communities and schools working together to create effective partnerships.

To date, whilst outcome focused research has suggested that family engagement can have a positive impact on a wide variety of academic, social and emotional outcomes for young people, there has been a distinct lack of research considering the experiences and perceptions of families regarding their engagement in educational processes. Consequently, this research takes an Interpretative Phenomenological Approach to consider in depth four parents' and two young people's experiences of the Education, Health and Care Needs assessment process, and specifically their experiences of family engagement within this.

Semi-structured interviews were undertaken with all six participants, and following the analysis of the resultant data using Interpretative Phenomenological Analysis, seven master themes were interpreted by the researcher. Some of the main principles of the *Children and Families Act 2014* were reflected in the interpreted themes: multi agency support, working in partnership with a keyworker, a child-focused approach, and aspects of family engagement, including family participation. However, contrary to legislation, the participants here found it difficult to understand the purpose of the EHC needs assessment process, and identified a distinct lack of knowledge about statutory assessment. In addition, families experienced a power hierarchy throughout the process, with professionals continuing to hold the dominant position. This was demonstrated through one family member describing how she felt that her and her family were on

"one side of the wall" and professionals involved in the decision making process were on "the other".

This research therefore has significant implications for practitioners working within Local Authorities and schools regarding building positive relationships with families, and how to ensure that families truly feel empowered and are able to participate in flexible ways during the EHC needs assessment process, as recent legislative changes intend.

Acknowledgements

Contents

7

Tables

Table 4-9: A table to show the frequency of super-ordinate themes within master theme seven across all participants

Figures

Figure 2-1: A figure to show the progression from family involvement to family engagement to family empowerment within research literature

Figure 2-2: A figure to show the stages of a systematic review of literature as outlined by Gough (2007)

1. Introduction to the thesis

There are two main issues at the heart of this research, firstly, family members' perceptions and experiences of the recently updated Special Educational Needs (SEN) statutory assessment process, which came into force with the publication of the *Special Educational Needs and Disability (SEND) Code of Practice: 0-25 years* (Department for Education & Department of Health, 2015), and is now known as an Educational, Health and Care (EHC) needs assessment. This is a single co-ordinated assessment process for young people aged 0-25, which identifies the educational, health and care needs of a young person, appropriate outcomes to be achieved and the provision that may be required to meet such outcomes. EHC needs assessments are the responsibility of Local Authorities (LAs), who must seek advice and information from a number of sources, including parent(s), young people themselves and an Educational Psychologist (EP) (DfE & DoH, 2015).

The second issue is family members' perceptions and experiences of engagement within the EHC needs assessment process. A range of international research studies have provided empirical support for the positive impact of the multidimensional construct of family engagement on a wide range of outcomes for young people, including academic attainment and social and emotional well-being (Dearing, Kreider, Simpkins, & Weiss, 2006; Flouri & Buchanan, 2004; Sheldon & Epstein, 2005). This has led to a recognition that parents and families have a significant influence on the holistic development of young people, and consequently to the principle within education and health that professionals and families should be working together (Department for Education and Skills & Department of Health, 2002).

An Interpretative Phenomenological Analysis approach is taken. This has proved a popular methodology in previous research within health psychology, examining lived experiences of, for example, sufferers of chronic pain (Smith & Osborn, 2007), though its application within other areas of psychology, including educational, is rather limited (Smith, 2011).

1.1 Personal and professional interest in this area of research

The author has a personal and professional interest in empowering families and young people, and ensuring that their voice is heard in the midst of professionals and school

staff, developed over a multitude of professional experiences, including working as a Trainee Educational Psychologist (TEP), but also as a SEN Teaching Assistant in an inner-city school that took pride in being at the heart of a multi-ethnic community, and that saw work with families as integral to children's learning and development.

The researcher was also driven by a desire to conduct research that would be highly relevant to practice, and felt that a detailed investigation of families' experiences and perceptions of the assessment process, as well as of their own involvement in it, could have important implications for a variety of groups and individuals, including the LA at a strategic level, and for EPs.

1.2 The interests of the Local Authority

Aside from personal values and interests, this research also came about as a result of joint thinking and working between researcher and the LA within which they were working as a TEP. When discussing the integral research component of the Doctorate with the senior leadership team within the Educational Psychology Service (EPS), the impact of the *Children and Families Act 2014* was raised as a particular potential focus. The researcher was keen to act on a unique opportunity to add to the knowledge base of the LA.

A research proposal was presented to the Acting Principal Educational Psychologist (PEP) and to the Service Manager of the SEN Service, who were both very supportive of an in-depth examination of the EHC needs assessment process for a small number of families from within the LA.

1.3 The context and unique contribution of this research

In March 2014, after having been in consultation since 2011 (DfE, 2011) the Government published a new Act called the *Children and Families Act 2014*. As part of this, the Government gave statutory guidance related to SEN called the *SEND Code of Practice: 0-25 years* (DfE & DoH, 2015). This code of practice was officially published in July 2014, came into force in September 2014 and was updated in January 2015. Chapter 9 focuses on statutory assessment, which is now known as an EHC needs assessment. This outlines how assessment should be co-ordinated between education, health and care services, with the information being gathered through assessments in these fields, and brought together into one plan by LA officers.

The principles underpinning the *SEND Code of Practice: 0-25 years* (DfE & DoH, 2015) indicate that LAs must attempt to engage families, young people and children in a variety of ways in this updated SEND system, including by involving families in decision-making, providing the necessary support and information to enable the participation of families in educational processes, and gathering the views, wishes and feelings of the family. This follows research evidence which demonstrates the significant positive impact that family engagement can have on a range of outcomes for children and young people, including academic and socio-emotional (Desforges & Abouchaar, 2003; Fan & Chen, 2001; Rimm-Faufman, Pianta, Cox, & Bradley, 2003). However, authors have found it difficult to generate a precise definition of family engagement, as it is a multi-faceted concept which can take many forms, including specific activities such as provision of learning at home by parent(s) (Goodall, Vorhaus, Carpentieri & Brooks, 2011), communication with school to share information (Epstein, 1995) and encouragement and help with homework (Desforges, 2003), as well as the communication of high achievement and aspirations (McWayne, Melzi, Schick, Kennedy, & Mundt, 2013) and working with families in order to make improvements in community-based programmes (Ferlazzo, 2011). Discussion in this area reflects a continually developing understanding of family and professional partnerships (Crozier, 1998), which historically were defined by dominant-subordinate power structures, but more recently include a model of empowerment, which allows the capacity and mastery of families and professionals to grow based on mutually desired outcomes (Turnbull, Turbiville & Turnbull, 2000; Murray, Handyside, Straka & Arton-Titus, 2013). However, little recent UK-based research is available which has investigated the experiences of families themselves in relation to family engagement, and where along this power continuum these experiences may fall.

Therefore, this research is particularly timely, coming at a point of national policy change, which has led to greater attempts by LAs, schools, and professionals working within education, health and care to facilitate more in-depth involvement of families in the statutory assessment of children's SEN. Although there has been some previous research which has gathered parents' views and experiences within SEN processes (e.g. Runswick-Cole, 2007; Truss, 2008), there is limited evidence of how families perceive and experience new statutory assessment processes. In addition, this study will offer a unique contribution in that it will utilise an Interpretative Phenomenological Approach,

14

which allows for an-depth exploration of the lived experience of the process for families, and how they have perceived and experienced family engagement within the EHC assessment process.

2. Literature review

2.1 Introduction

The purpose of this chapter is to provide the reader with an understanding of up-to-date research and practice which is most salient to the current study. The broad focus of the identified research area is on family experiences within a SEN statutory process, with a specific focus on family engagement. The chapter will begin in the area of SEN policy, in order to inform the reader about current policy and recent reform, which is of particular interest to the current research. Particular attention will be paid to the recent changes from a statementing process to the creation of EHC plans. It will then move onto family engagement, discussing the theoretical and research background of the current study, including the different ways in which family engagement has been perceived in research and therefore could be experienced by families. The review will then draw on published material that considers, and includes, family and pupil voice, before presenting a systematic review of the research which was considered most pertinent to the study, followed by a rationale for the current research.

2.2 SEN policy

The history of educational provision and legislation shows that it has been very difficult to come to an agreement within law about how best to define, educate and meet the needs of children with SEN (Squires, 2012). This has resulted in confusion for LAs and for families. As discussed by Mackenzie, Watts and Howe (2012), parents often require support in understanding and receiving the services which are relevant and appropriate for their children's needs, whilst LAs continue to differ in their practice with regards to how children with SEN are identified and educated, including the percentage of children with Statements of SEN, or an EHC plan, and the proportion of children who are placed within specialist educational provisions (Richardson, Richardson, Lamb, & Gross, 2015). The following sections will attempt to illustrate how policy and pieces of legislation have dictated the services and education that children with SEN have received over the years.

2.2.1 The meaning of Special Educational Needs: a historical perspective

The concept of SEN has come a long way in governmental policy over the last seventy years. The *Education Act 1944* stated that LAs were required to provide education for children who were 'subnormal', 'maladjusted' or physically handicapped. The Act recognised that some children may have a 'disability of mind or body' that required a different type of education from most children. This type of language reinforced a medical model of labelling children within eleven categories of 'handicap', which could be 'diagnosed' and consequently 'treated', creating categorisation and segregation of children and young people with SEN from other children and young people of the same age, which remained in legislation for many years. Reforms of policy and legislation since the *Education Act 1944* have continually referred to children and young people with SEN as segregated from other children and young people of the same age because of their greater difficulty in learning, or because of their level of disability (DfE & DoH, 2015).

The concept of segregated education however came under heavy criticism in the report of the Warnock Committee, established in 1974, which was incorporated within the *Education Act 1981*. The Committee concluded that although 20% of the school population may have SEN, only 2% needed provision and support over and beyond which a mainstream school could provide. Such recommendations were seen at the time as radical, suggesting that education should be formed on the basis of an 'integrative' (later becoming inclusive) rather than segregated approach. The system of 'statementing' was also introduced. For the first time, LAs had a legal duty to assess those children with the most complex and severe needs, and specify whether they would need special educational provision in order for their educational needs to be met. From this point onwards, statutory assessments were carried out for children whose needs could not be reasonably met with the resources typically available to a mainstream school, resulting in a statement of SEN, which formally documented SEN and any additional support which the child needs (Squires, 2012).

The Warnock Report (Warnock, 1978) marked a crucial period in history for children with SEN and their families, both in terms of the education and curriculum which was legally accessible, and the assessment of SEN and provision which the LA was required

17

to put in place by law. This change in the tide was carried forward in a broader international trend, for example UNESCO's (1994) *Salamanca Statement and Framework for Action on Special Needs Education,* which heavily promoted inclusion. The *Special Needs and Disability Act 2001* stated that mainstream schools should consider themselves capable of meeting SEN, as all young people would be placed within a mainstream setting unless parents decided otherwise, or unless such placement interfered with the education of other pupils. Disability discrimination legislation was thereby introduced into education policy. Finally, in 2004, a governmental strategy paper relating to provision for children with SEN, titled *Removing Barriers to Achievement* (Department for Education and Skills, 2004) recommended to LAs that the percentage of children placed in special schools should be falling, and that LAs should be decreasingly reliant on statements, thereby building the capacity of mainstream schools.

2.2.2 Recent SEN reform and legislation

2.2.2.1 Rationale for reform

The *Children and Families Act 2014* set out major changes in SEN. This bill ties together reform of a system which has been described as "no longer fit for purpose" (DfE, 2011, pg. 15), and "failing to meet the needs of large numbers of children with SEN" (House of Commons Educational and Skills Committee, 2006, pg 20). More specifically, criticism was made of the existing SEN framework's inability to meet a wide continuum of SEN in a flexible way, including making use of the voluntary and community sector (House of Commons Educational and Skills Committee, 2006; DfE, 2011).

Jackson (2006) claimed that the statementing process, as it stood, brought many benefits for parents, children and professionals, such as opportunities for parents to participate in regular reviews and to appeal against decisions made by LAs, as well as protecting access to resources and services external to school. However, others (Audit Commission, 2002; House of Commons Educational and Skills Committee, 2006; Warnock, 2005) expressed discontent with SEN processes as they were operating, arguing that the outdated framework was struggling to keep up with the changes of the mainstream education system, and to cope with the increasing diversity of children categorised as having SEN, leading to a bureaucratic and stressful experience for parents, and an inequitable distribution of resources. Therefore, the recent major

18

changes in SEN policy are clearly widely welcomed, and have been seen as necessary by some for a substantial period of time.

2.2.2.2 EHC needs assessments and plans

The *Children and Families Act 2014* dictated the replacement of Statements of SEN with Educational Health and Care Plans (EHCPs), which children obtain through a single assessment process, therefore enabling the co-ordination of health, education and social care services. EHCPs, as Statements of SEN historically have done, continue to apply to a small proportion of children and young people with complex SEN for whom special educational provision is required, whilst the Local Offer acts as a broader framework through which families of children with SEN can access local services (Richardson et al., 2015)

As opposed to previous Statements of SEN, which only considered the educational needs of a young person, EHCPs bring together education, health and social care needs into one single legal document. This document describes envisaged outcomes for the young person, the support which is needed to provide these outcomes and who is responsible for this support. A range of individuals and agencies have the right to request a statutory assessment for an EHCP, including parent(s), a young person over the age of 16 but under the age of 25 and health and social care professionals (DfE & DoH, 2015). Once a request is made, this initiates a 20-week timeline for the process, the conclusion of which may be the issuing of the final EHCP (see Appendix 1 for full timeline).

2.2.2.3 Local Offer

The *Children and Families Act 2014* stated that LAs are required to provide information on all potential services for a young person, and how families can access these, through a Local Offer for each regional area. The Local Offer also acts as a tool to engage directly with children, young people and parents, as it is advised that families are directly involved in its development. In this way, parents and authorities can co-construct services, and families can offer their views on exactly which services are needed (Norwich, 2014).

2.2.2.4 Summary of other changes from policy reform

The changes in legislation demonstrate a more flexible way of working with families, with the intention of enabling a greater level of choice and involvement. For example,

families now have the option of a personal budget as part of their child's EHCP, and resources which are available can be used flexibly according to the provision which is chosen by the young person and their family. In addition, families can choose to employ a keyworker approach during the EHC needs assessment process, in order to enable their understanding of the process and to make sure the views of the family are incorporated within the assessment (DfE & DoH, 2015).

2.2.3 Discussion

The transition within SEN policy from Statements of SEN to EHC plans has created many challenges for practitioners working in education, health and care who are now required to work in a joined up fashion, and to deliver coordinated input, creating relevant and appropriate provision for each young person. It has been suggested that there need to be clear routes and means to monitor and evaluate practice, including the use of Local Offers, Personal Budgets and Office for Standards in Education (OFSTED), for this to be done in an effective way (Richardson et al. 2015).

The inclusion of families is also crucial within this policy reform. In recent years, there have been improved efforts to include parents' views within the education system, and a call for LAs to make a true commitment to family engagement, rather than a tokenistic gesture of working with families (Goodall et al. 2011). There has been interest demonstrated in research literature and in inquiries carried out by the government (e.g. (Lamb, 2009; Peacey, Lindsay, Brown, & Sam, 2009) in parental confidence in the SEN system, and how this can be improved. A series of recommendations have been made, particularly by Lamb (2009), for potential improvements, including open and honest communication between parents, LAs and schools, a strategic approach within each LA to ensure that specialist advice is available to all schools for children with SEN, and demonstrating accountability of each SEN system at a national level according to feedback from young people.

Authors have illustrated the existing tensions within the SEN system which demonstrate the continual challenges faced by practitioners working in education, health and care. For example, schools are continually responsible for identifying SEN, but jointly it is the responsibility of LAs to assess and meet the needs of these children within an appropriate placement. Therefore, schools look to LAs to provide resources and funding in order to meet the needs of children with high levels of SEN (Norwich, 2014). Parents

20

continue to struggle to make their voice heard within schools and to make a difference to the support which their child is receiving, as well as experiencing poor relationships with school staff who demonstrate a lack of recognition of the needs of the young person (Peacey et al. 2009).

2.3 Family engagement

2.3.1 Theoretical framework of family engagement

The concept of family engagement in education is founded on a developmental-ecological perspective, as developed by Bronfenbrenner (1979). According to this theory, a child's development and learning does not take place in isolation, but within a series of interacting systems. Bronfenbrenner (1979) divided these systems into five different levels. Some of these systems have a less direct effect on the development of the child, for example the cultural context of the child, which would be a distal system. The most influential level of the ecological systems theory is the microsystem, which includes both home and school environment.

This perspective helps to explain the importance of family engagement, as positive interactions between systems are seen as promoting the positive development of a young person. However, over time, the relationship between home and school has been understood in different ways, and therefore it is useful to briefly illustrate the recent historical background and development of the meanings of both parent involvement and family engagement.

2.3.2 The development of the definition of family engagement

For many years, professionals working with families of children with SEN were generally perceived as experts who held a dominant role over the subordinate position of families, particularly in regard to the control of information and resources (Turnbull, Turbiville & Turnbull, 2000). However, by the early 1970s, the tide was changing. Parents, professionals, LAs and government departments were beginning to argue in favour of a greater level of parental involvement (Dale, 1996). The term 'transplant relationship' was coined as professionals shared their skills and knowledge with families, and in return parents became more confident, more actively involved and participated as 'co-educators' (Mittler & Mittler, 1983; Dale, 1996).

The 1980s saw a more thorough discussion of the concept of a partnership; however, whilst such discussion has continued to the current day, there remains no universal agreement around the concept of family engagement. Different conceptual models have been introduced over time, each with a slightly different focus, for example seeing the parent as a consumer (Cunningham & Davis, 1985), adopting a model of empowerment (Appleton & Minchin, 1991), or placing an emphasis on negotiation within partnership (Dale, 1994).

Despite this lack of clarity, there has been a notable progression within research literature from the use of the term 'parent involvement', to 'family engagement', to 'family empowerment'. This is illustrated in Figure 2-1 below, and also indicates the shift from what Turnbull, Turbiville & Turnbull (2000) called power-over, to power-with, to power-through relationships between families and professionals. Within this model, the ultimate intention is collective empowerment, whereby parents, family members, friends, community citizens and professionals cooperate in order to produce a collective effect which is greater than any individual effect. Power is consequently a resource for everyone within the group to use (Turnbull, Turbiville & Turnbull, 2000).

Figure 2-1: A figure to show the progression from family involvement to family engagement to family empowerment within research literature
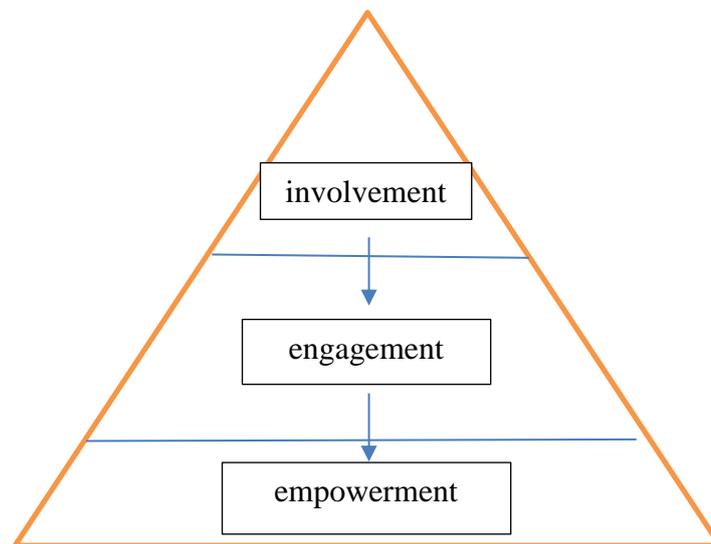
Although Figure 2-1 illustrates an ever-widening framework of family engagement, it does not suggest that there is a linear progression from involvement to engagement to empowerment, but that all three overlap (Office of the Education Ombudsman, 2012). Parent involvement, family engagement and empowerment will now be compared, including the definition and significance of each within research literature.

2.3.3 Comparison of parent involvement, family engagement and family empowerment

2.3.3.1 Defining each term

Lawson (2003) argued that much of the research on parent involvement focuses on the level of participation that parents demonstrate in activities designed by school, such as volunteering in the classroom or attending meetings at school. Ellingsen & Myers (2013) and Ferlazzo (2011) both agreed that parent involvement often refers to pre-identified projects, needs and goals, led by a school or organisation, which invite parents to contribute at a later point.

Epstein (1987), from a survey of a large sample of teachers and principals in Maryland, America, identified four types of parental involvement in schools, defined as basic obligations and providing for basic needs of children, school to home communications, parent involvement in school and parent involvement in learning at home. This was later extended to include parenting, communicating, volunteering, learning at home, decision-making and collaborating with community (Epstein, 1995). This latter version in particular raises the important role that parents play in the home as well as in their school education, but creates the danger that school staff impose their view of what parent involvement is on families rather than generating the meaning from families themselves.

The notion of family engagement, in comparison, incorporates a wider and more holistic way of working jointly and collaboratively with families, including shared decision-making informed by parents' views and wishes (Ferlazzo, 2011). Other authors have taken a family-centric approach to family engagement, for example Sheridan, Knoche, Kupzyk, Edwards and Marvin (2011), who defined family engagement as parenting practices that allow children access to experiences which promote learning, positive affective outcomes and autonomy. Family engagement can be viewed as an extension of involvement (Barton, Drake, Perez, St. Louis, & George, 2004) in the way

that it acknowledges not only what parents do but how they understand the world, the impact that this may have on their behaviour and the context within which choices are made about involvement.

Authors have referred to 'parental empowerment' as a condition of effective family engagement (Office of the Education Ombudsman, 2012). Empowerment is not only about taking part in something, but also about a feeling of ownership of that activity resulting in a sense of agency, and families having a sense of their own choice and action (Goodall & Montgomery, 2013). It has been suggested that families and communities can feel more empowered as they develop relationships with staff where they feel they are listened to, for example by being encouraged to share their concerns within their local community, so as to act on them with others with similar lines of thought (Ferlazzo, 2011).

2.3.3.2 Demonstrating the significance of family engagement within research

The range of positive outcomes correlated with parental involvement is extremely wide; from academic benefits such as higher grades (Gutman & Midgley, 2000), greater achievement in core curriculum subjects such as maths (Izzo, Weissberg, Kasprow & Fendrich, 1999) to behavioural outcomes such as improved ability to self-regulate behaviour (Brody, Flor & Gibson, 1999), and improved social skills (McWayne, Hampton, Fantuzzo, Cohen, & Sekino, 2004). However, parental involvement has been measured in a number of ways, as noted by Harris & Goodall (2007), who noted that it is the support of learning within the home environment that makes the most significant difference to attainment.

Cole (2011), in a research review carried out by the National Literacy Trust, argued that any policy which addresses literacy standards among young people needs to consider the potentially strong influence which parents can have on children's learning by perceiving parents as partners. This is supported by numerous studies (e.g. Tizard, Blatchford, Burke, Farquhar, & Plewis,1988; Gest, Freeman, Domitrovich, & Welsh, 2004) which have illustrated the importance of parents' attitudes and support for learning on literacy skills and attainment. Other studies have highlighted the importance of parent involvement for the development of positive learning and behaviour related skills; for example Fantuzzo et al. (2004) assessed the relationships between different dimensions of family involvement and various classroom competencies, and found that

home-based parent involvement activities were linked to a higher level of motivation, attention and persistence, and to significantly lower levels of classroom behaviour problems.

It has been argued by some that, regardless of the positive outcomes that have been linked within research to parent involvement, families actively being involved in decision-making is simply a right that all families should be provided with, and that all professionals within schools and service providers should consider a two-way relationship with a family as ethical practice which empowers and values families (Ferreira, Hodges & Slaton, 2013). Family engagement is therefore increasingly considered as a tool, not only to improve outcomes for students, but to enable schools to be more equitable and culturally fair, within a broader framework of social justice (Auerbach, 2009). Qualitative research carried out by Theoharis (2007) and Auerbach (2009) found that school leaders actively chose to promote family engagement because of their beliefs in community empowerment, and the positive impact which community based activities can have on families, who in the past had been marginalised, and on the wider school culture. This research has important implications for the broader impact of family engagement, beyond the widely researched positive impact on attainment.

2.3.4 Discussion

There are several areas of agreement around family engagement within the research literature. There appears to be a shared perspective that families are important for children's development, and that there is a multiplicity of benefits of parents being involved in some way (Epstein, 2001). This is heavily influenced by the theoretical concept of Bronfenbrenner (1979) that family engagement leads to a strengthening of the eco-systems within a child's development, including the mesosystem of the interaction between home and school. There has also been a recent shift from promoting parent involvement to family engagement and empowerment within communities. This suggests an acknowledgement of the active role that parents can play in education, and a sense of sharing power between schools and families.

However, family engagement remains a complex and multi-faceted concept in both research and practice. From what research can tell us about family engagement in practice, there is an emphasis on parental involvement. Families are judged on their level of involvement, and activities are dictated by those other than the family

themselves (Ferlazzo, 2011). This study is particularly interested in the perspective that family engagement should be promoted as a two-way relationship between families and professionals, developing a sense of efficacy and empowerment for families. Furthermore, recent literature has emphasised a shift away from focusing on what parents do to engage within educational provisions, to a focus on parents' understanding and experiences of family engagement (Barton et al., 2004). The current study is also interested in adding to this area of research.

2.4 Family and pupil voice

2.4.1 Defining family and pupil voice in practice

Policy initiatives have increasingly recognised the importance of hearing the family's, and specifically the child's, voice within professional practice. One landmark in the development of this area was the *United Nations Convention on the Rights of the Child* (UNCRC) (United Nations, 1989). This outlined the child's right to freedom of expression, in particular the right of all children and young people to express their views, and the necessity for these to be taken into account within decision-making. Furthermore, the *Children Act 2004* dictated that LAs must allow children and young people to have their say, particularly in the development of statutory services. The *SEND Code of Practice 2015 (*DfE & DoH, 2015) sets out guidance on how organisations should ascertain children's and young people's views, wishes and feelings, and identifies the participation of children and young people in decision-making, for example within statutory annual review processes, as a key development area for LAs.

Within educational provisions, pupil voice is often described as ensuring pupil involvement is captured in decision making, and supporting pupils in having their say in decisions within their learning environments which will have an impact on them. This is manifested in a number of strategies, including school council (Whitty & Wisby, 2007). This drive for pupil voice originates from the children's right agenda, as described above, but is also connected with democracy in schools, the school improvement perspective and the principle of inclusiveness (Fielding & Rudduck, 2006).

However, drawing attention to the views of children and young people is not a straightforward recommendation to implement in practice. Collecting the views of children and young people, and using these to improve the services available for

26

families, is complex, particularly when considering the views of young people with SEN, who may have difficulties in expressing their views verbally and therefore may require more creative approaches in order to make their voice heard (Feiler & Watson, 2010).

Despite a plethora of recommendations to enable the effective inclusion of young people's views in decision-making processes, it has been noted that there is a real need for detailed information on how this can be done, including how to genuinely incorporate young people into planning around their provision, and how to make their participation as meaningful as possible (Hayes, 2004). Recent years has seen the recommendation, introduction and evaluation of numerous processes in response to this. For example, person-centred planning has been recommended within the *SEND Code of Practice 2015* (DfE & DoH, 2015). This comprises the active involvement of individuals within the planning of their own provision and services, based on their current needs and desires (Dowling, Manthorpe & Cowley, 2007), and by communicating information in a way which is accessible to the young person, for example in a visual format (Hayes, 2004).

2.4.2 Family and pupil voice within educational research

Researchers have continually strived to demonstrate how powerful family and pupil voice can be within educational research. This has been shaped around a number of themes, including inclusion and transition.

For example, as part of an exploratory case study, Humphrey and Lewis (2008) collected data from a total of 19 pupils through a variety of methods, including semi-structured interviews and pupil diaries, with the purpose of understanding pupils' experiences of inclusion within mainstream schools. The participants described their perceptions and experiences of belonging to a school community, of the positive impact of working with a Learning Support Assistant, of little or no interaction with their class teacher and of classrooms as noisy and distressing environments.

McIntyre, Eckert, Fiese, Digennaro, and Wildenger (2007) investigated the experiences and involvement in transition to kindergarten of parents and caregivers within one city in the United States. Findings suggested that parents would have liked to have known more about the academic expectations for kindergarten, as well as about the future provision for their child, including the teacher. Parents expressed concerns about

transition, particularly about their children getting used to a new school and being able to follow directions. This study indicated that parents do want to have an active role in transition planning, but may not have sufficient information about how to do this.

2.4.3 Family and pupil voice about family engagement

A number of studies have investigated families' perceptions and experiences of family engagement, including the views of young people and parents. For example, Leeson (2007) explored the voices of a small sample of adolescent boys, with particular attention paid to their experiences of involvement in decision-making about their care within the LA. The researcher reported a series of difficulties which were experienced in gaining the participation of the sample, because of barriers put in place by adults working around the young people who viewed them as vulnerable, and as incapable of providing their own views. Participants reported feeling helpless, which was linked to not feeling involved in decision-making processes when being taken into care. Participants also described not being provided with clear information, which resulted in a diminished sense of capability to make decisions. This interestingly ran simultaneously with the perception of having been supported and listened to by key individuals, including social workers.

Russell and Granville (2005) found that the majority of parents do wish to become more actively involved in their child's education, but there are also many perceived barriers to involvement, including methods of communication between home and school which are less effective and more formalised, and inflexible forms of involvement offered by schools. Some families also faced other specific barriers, such as asylum seekers and refugees, who may lack information on the key systems and services within schools, and who may be less socially integrated within local communities. Russell & Granville (2005) concluded that parents recognised that they should be expected to meet a basic set of expectations which schools hold regarding parental involvement, including making sure their children arrive at school on time, and communicating clear boundaries for behaviour both in and out of school, but that many parents did not feel that any higher level of involvement was necessary. The researchers aimed to speak with a wide range of parents across Scotland, including those from a variety of social and cultural backgrounds, and were particularly interested in speaking with those who may be deemed hard to reach. Eighteen focus groups were held with what were described as 'silent majority parents' with children aged four to 19. These parents did

not have a high level of interest in a number of activities which take place within the school environment, such as assisting on school trips. Four focus groups were carried out with parents who were actively involved in these activities. This research has important implications for the practice of parental involvement in education, including offering advice and support for families about the different ways to become involved, and providing key messages to parents about the benefits of parental involvement.

2.4.4 Challenges to research which includes family and pupil voice

There are many powerful arguments dictating why the voice of the family should remain at the centre of research and practice, including that it improves motivation, perception of control, confidence, empowerment and autonomy of families (Hayes, 2004; Roller, 1998; Warshak, 2003).

However, professionals and practitioners also often face numerous challenges in gaining what Lewis, Newton and Vials (2008) called "effective and authentic child participation" (pg. 26). Although there is evidence of a range of ideas which have been made available (e.g. Lewis, Newton & Vials, 2008) as to how to gather the views of children and young people with severe learning or communication difficulties, including visual resources such as Cue Cards, photographs and Talking Mats, the vast majority of research studies available within peer-reviewed journals which have included the views and experiences of pupils have done so through interviews.

This limited practice with regards to the access of pupil voice is in line with authors who have challenged the concept of 'pupil voice' within practice and research (Arnot & Reay, 2007; Moore & Muller, 1999; Lundy, 2007). Lundy (2007) discusses how there is an apparent gap between the UK's commitment to the UNCRC, and practice within educational decision-making. This is supported by Kilkelly et al (2005), who demonstrated that children's views are not listened to or sought regularly in order to inform experiences of family, health, education, play and leisure, and youth justice and policing. Some participants reported only tokenistic gestures to engage with adults in decision-making, which represents a distinct contradiction to children's rights.

One must also consider the range of families' and pupils' voices which have been accessed in research. There have been concerns raised that the views of parents who are not immediately easy to access within the SEN education system are not fairly

29

represented within research, for example families of children who have been excluded from school, families of children in home education, and parents who do not participate in local education or SEN-related networks (Richardson et al., 2015).

2.5 Conclusions

This literature review has discussed past and current practice related to SEN policy, and research and theory relating to the dynamic position which families have been placed within education, as related to family engagement. As outlined at the end of *2.3.4,* there has recently been a change in focus within research concerned with family engagement, from identifying specific behaviours which define family engagement, to investigating parents' understanding and experiences of how and why they choose to engage (Barton et al. 2004). In addition, as discussed in *2.2.2,* there have been recent major changes in legislation and policy related to SEN which could potentially have a significant impact on children and families. As related to section *2.4,* the various ways in which young people and families are listened to is integral to research and practice within education.

Considering the conclusions of the previous sections of this review, a thorough and detailed evaluation of existing studies looking at how family members experience and perceive the two topics of interest here, family engagement and statutory SEN processes, is deemed useful here. These are two areas which are relevant for practice in educational psychology, and are also areas in need of clarification and updating within recent UK based published research. The details of the systematic literature review which was carried out are outlined in the following section.

2.6 Systematic review

2.6.1 Introduction

Systematic research reviews are carried out in order to investigate the breadth and depth of existing research as related to a specific research question. Therefore, they are considered useful in education, not only as a single point of reference for a wide body of research, and as a broad exploration of what is already known and of what is available, but as a way of identifying where gaps in knowledge and in research are, as well as the methodological difficulties which have been noted during the review (Evans, Harden, & Thomas, 2004).

This review will be carried out according to the stages suggested by Gough (2007), which are given below:

Figure 2-2: A figure to show the stages of a systematic review of literature as outlined by Gough (2007)

Systematic map of research activity

Formulate review question and develop protocol

↓

Define studies to be considered *(inclusion criteria)*

↓

Search for studies *(search strategy)*

↓

Screen studies *(check that meet inclusion criteria*)

↓

Describe studies *(systematic map of research)*
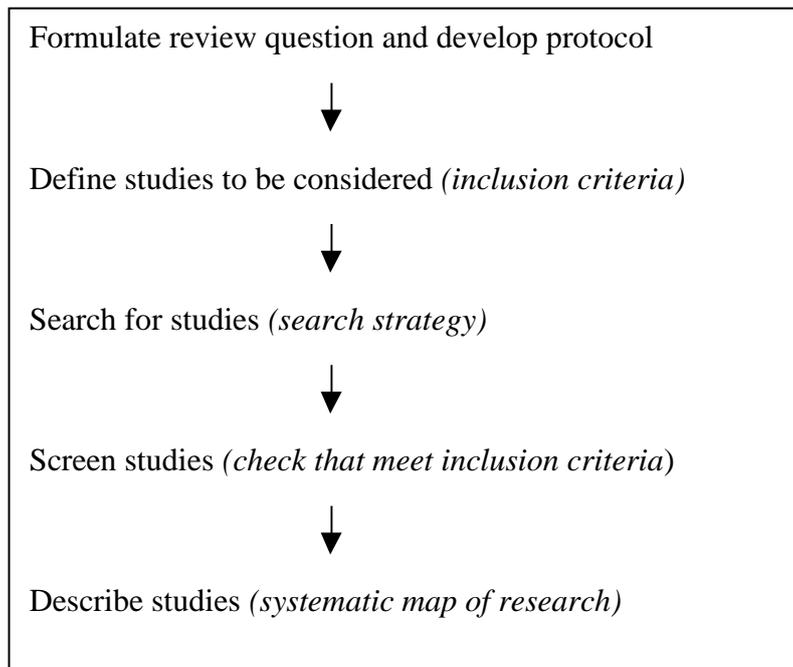
Systematic synthesis of research evidence

All the stages of a map plus:

↓

Appraise study quality and relevance

↓

Synthesise findings *(answering review question)*

↓

Communicate and engage
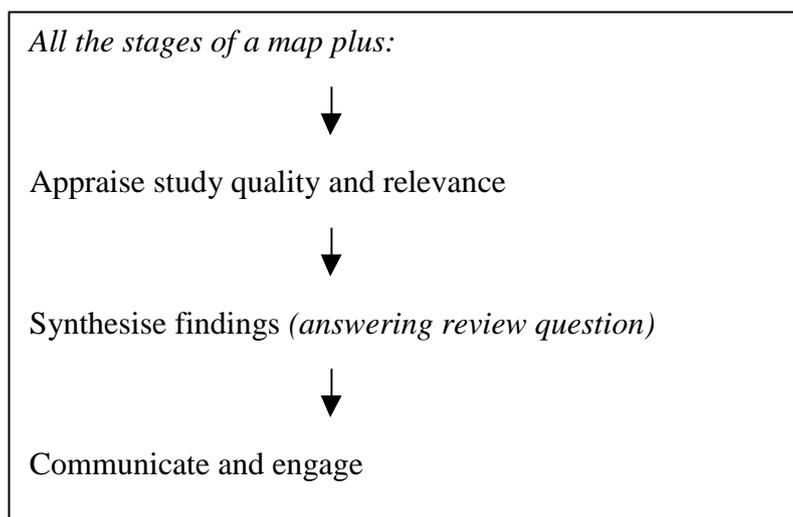
2.6.2 Formulation of review questions

The purpose of this review was to explore the opportunities which families have had within empirical research to share their understanding, views and experiences of family

31

engagement, and of SEN processes including statutory processes, and to ascertain whether further research may be warranted.

Upon reflection of these themes, the researcher decided it would be more beneficial to separate the systemic review into two areas, one in the area of family engagement (Search A) and one in the area of statutory processes (Search B). This was felt necessary in order to clarify for the reader the distinct areas of research; how families have experienced and perceived their engagement in educational contexts, and how families have experienced and perceived SEN statutory processes. Both of these areas are relevant to the current research, which offers a unique contribution to the research base by looking at family engagement within a new SEN statutory process.

Due to the separation of the systematic review into two areas, searches within databases were led by two questions:

a) **What does the research literature tell us about the experiences and perceptions of family members of children with SEN regarding family engagement within educational contexts?**

b) **What does the research literature tell us about the experiences and perceptions of family members of children with SEN regarding statutory assessment processes?**

2.6.3 Appraisal of studies

Within both of the searches, the methodological quality of each study identified was initially examined using Gough's (2007) Weight of Evidence framework (see Appendix 2 for how this framework has been used to guide ratings for this review). This framework offers an overall assessment of the extent to which a study contributes evidence to answering the review.

2.6.4 Search A: family members' experiences and perceptions of family engagement within educational contexts

2.6.4.1 Search strategy and inclusion criteria

From research question a), the following search terms were identified: 'experiences', 'perceptions', 'family', 'engagement' and 'SEN' and 'educational'.

It was next considered necessary to unpack the broad areas. 'Parent', 'pupil' and 'child' were included alongside 'family' because of the recognised numerous components of a

family structure, and in order to access relevant research which had been carried out in the area of family and pupil voice, as discussed earlier in this chapter. 'View', 'understanding', 'judgement' and' idea' were all considered in parallel with 'experience' and 'perception.' 'Involvement' was considered alongside 'engagement', in line with its multi-faceted nature discussed earlier in this chapter.

Truncations were utilised to allow for spelling variations and plurals of terms, and with the roots of the words 'involve', 'engage' and 'judge'. This was to gain access to as many relevant articles as possible, whilst limiting the search to research which examined relevant ideas.

As the research question was considered to be predominantly related to education, ERIC, British Education Index and PsycINFO, which all allow access to material which is related to education, were all consulted. Additionally, a search was carried out within Web of Knowledge and Google Scholar to ensure that any other relevant studies of a multidisciplinary nature were not missed.

To ensure consistency in searching across databases, these terms were combined in a keyword search within the advanced search option of each database, utilising the OR AND function (see Appendix 3).

2.6.4.2 Initial screen of studies

Papers meeting the search criteria for each database were initially accessed via their titles and abstracts. These studies consequently needed to be screened to check their relevance and utility as related to the research question. Duplicates also needed to be removed. This was done with the following set criteria:

Inclusion criteria

- Studies must appear in a peer reviewed journal.
- A range of research designs were included in order to allow for the range of information which may be relevant and pertinent.
- The sample in the study must relate to families of 0-25 year olds (the potential age range for EHC plans).
- The sample in the study must include a child or young person with a clear identification of SEN.
- Data must be gathered from the perspective of the family.

33

- Data must be gathered in an educational context.

- Papers must be written in English.

- The main focus of the data which has been gathered must relate to the theme of family engagement. As discussed earlier in this review, previous research has included features of family engagement which are described as parental or family involvement. The inclusion criteria here will extend to other terminology noted prior to this systematic search as relevant to this current research other than 'family engagement', namely 'involvement'.

Exclusion criteria

- Any whole books and e-learning platforms.

- Reviews of books.

- Reviews of research.

- Those articles which did not include a primary study.

- Any dissertations or unpublished theses.

- Research not focusing on families of 0-25 year olds (the potential age range for EHC plans).

- No inclusion of a child or young person with a clear identification of SEN.

- Data not gathered from the perspective of the family.

- Data gathered in a non-educational context, for example health.

2.6.4.3 Studies identified per database

PsycINFO:

The advanced search function returned 726 articles following appropriate combinations of search terms as 'key words' (i.e. identifying search terms anywhere within the text of the article). It was therefore felt necessary to necessary to narrow the search within this database further. The following terms were combined in a further keyword search within the advanced search option.

(famil*) and (involve* or engage*) and (perception* or experience* or understand* or view* or judge*) and (special* and education* and need*).

This resulted in 266 articles. After having initially screened these studies, a total of 13 remained.

34

<u>Web of Knowledge:</u>

The advanced search function returned 370 articles following appropriate combinations of search terms within the field tag of Topic (TS). After having initially screened these studies, a total of 22 remained.

<u>British Education Index:</u>

The advanced search function returned 110 articles following appropriate combinations of search terms. After having initially screened these studies, a total of eight remained.

<u>ERIC:</u>

The advanced search function returned 1478 articles following appropriate combinations of search terms. It was therefore felt necessary to necessary to narrow the search within this database further. The following terms were combined in a further keyword search within the advanced search option.

(famil*) and (involve* or engage*) and (perception* or experience* or understand* or view* or judge*) and (special* and education* and need*).

This resulted in 580 articles. After having initially screened these studies, a total of seven remained.

Studies were mainly excluded for the following reasons

- Topic connected to family engagement in education but evaluating a family engagement programme.
- Data collected from teachers' perspectives and not from the family's.
- Research did not appear in a peer review journal.
- Research focused on experiences of processes within education, such as transition, but no clear emphasis on family engagement.
- Paper demonstrated reflections on research rather than primary data gathering.
- Research reported experiences of families in areas other than education, such as health.

Seven studies both met the inclusion criteria and were accessible at the time of the systematic literature search. These studies are now reviewed in further detail.

2.6.4.4 Appraisal of studies

Table 2.1 provides an overview of the final weightings given to the included studies. The seven studies selected for inclusion in this search review were subsequently described through a keyword coding strategy. This is included in Appendix 4.

Table 2-1: A table to demonstrate Weight of Evidence framework criteria (Gough, 2007), as applied to Search A: families' experiences and perceptions of family engagement within educational contexts

	A – Methodological quality	B – Methodology appropriateness	C – Methodological relevance	D – Overall weighting
Hebel (2014)	High	High	Medium	High
Jivanjee, Kruzich, Friesen and Robinson (2007)	Medium	Low	Low	Low
Kirkbride (2014)	High	Medium	Medium	Medium
McWilliam, Maxwell and Sloper (1999)	High	Low	Low	Medium
Munn-Joseph and Gavin-Evans (2008)	High	Medium	Medium	Medium
Spann and Kohler (2003)	High	Low	Medium	Medium
Winton and Turnbull (1981)	High	Medium	Low	Medium

2.6.4.5 Comparison of studies

With reference to the Weight of Evidence framework criteria, the studies will now be compared on a range of factors in relation to methodological quality, appropriateness and relevance.

Methodological quality

The sample sizes for the identified studies ranged from four to 486. Research with a smaller sample size, such as Hebel (2014), was able to provide a range of useful descriptive characteristics of the 20 participants who made up the sample of the study, including gender, age of child, educational setting, and type of difficulty, as compared to Jivanjee et al. (2007), who perhaps did not have the scope to provide this level of information, because of the larger size of the sample. The majority of the studies clarified a clear focus for the research, and clear purposes and descriptions of data gathering measures often led to clear outcomes and descriptions of data analysis. For example, Kirkbride (2014) set out the process of thematic analysis, and illustrated her findings through visual theme maps, going on to relate these to the research questions in hand.

Methodological appropriateness

A judgement rating of 'high' was assigned to Hebel (2014) because of the qualitative phenomenological design. Kirkbride (2014), Munn-Joseph & Gavin-Evans (2008) and Winton & Turnbull (1981) all collected data through semi-structured interviews, and therefore remain highly relevant to the current study, as they focused on individual views, thus taking an idiographic approach. McWilliam et al. (1999), Jivanjee et al. (2007) and Spann & Kohler (2003) were all judged as less relevant to the present research as these authors all asked participants to give their views in a more fixed format.

Methodological relevance

The identified studies were conducted over a time span of 25 years, and consequently some studies were judged by the researcher as less relevant to the current study if carried out before 2001 when the *SEN: Code of Practice* (DfES, 2001) was published, for example McWilliam et al. (1999) and Winton & Turnbull (1981). Only one study was UK based (Kirkbride, 2014), with the remaining studies having been carried out in America, or Israel (Hebel, 2014). None of the studies included data collected from young people as well as parents.

The researcher will now present the findings of each study in more depth.

37

2.6.4.6 In-depth description of included studies

Hebel O. (2014). Parental involvement in the individual educational programme for Israeli students with disabilities. *International journal of special education,* 29, 3, 1-11

Hebel (2014) held semi-structured interviews with 20 Israeli parents, including 19 mothers and one father, whose children (aged 3-21) were eligible for an Individual Educational Plan (IEP), had been diagnosed with severe disabilities and attended special education settings. The purpose of the research was to understand the perceptions and experiences of parents about their involvement in IEPs, and also about parent-teacher collaborations in IEPs.

The two themes of the findings which were discussed within this paper, relating to parental involvement, were a child centred focus within the IEP process and a strong parental sense of self-efficacy. These were interpreted as essential components of perceived parental involvement. Perceptions of parents' self-efficacy included capacity to influence and involvement. Perceptions of a child-centred focus within the IEP process, which was described by the researcher as participants' perceptions of how the IEP process can best meet their child's needs, included parental advocacy, implementing family perspectives and understanding of a child's abilities.

Jivanjee, P., Kruzich, J. M., Friesen, B. J., & Robinson, A. (2007). Family perceptions of participation in educational planning for children receiving mental health services. *School Social Work Journal*, *32*(1), 75–92.

Jivanjee et al. (2007) collected data from 133 participants who were all primary caregivers of young people aged up to 20 who had had three months or more of mental health treatment. The researchers were particularly interested in a hypothesised significant relationship between family participation in education planning and family empowerment.

The Family Empowerment Scale, developed by Koren, DeChillo, and Friesen (1992), was used to measure family empowerment, which asks participants to state their agreement with a series of statements linked with the family, service and community domains using a Likert Scale from 1-5. Researchers developed their own questions about family perceptions of participation in educational planning, which participants again responded to on a Likert Scale from 1-5, and participants were asked to make qualitative comments about educational planning.

The researchers found that caregivers with high empowerment scores also have high levels of participation in educational planning. There were also low mean ratings of educational planning taking into account the family's needs and wishes, and staff making changes in the educational plan as a result of caregivers' suggestions.

Kirkbride, R. (2014). "They were a little family": An exploratory study of parental involvement in nurture groups - from a practitioner and parent perspective. *British Journal of Special Education*, 41(1), 82–104.

Kirkbride (2014) looked at the perceptions of parents and nurture group staff regarding parental involvement by collecting qualitative data through semi-structured interviews. Four nurture group staff and four parents or carers from four different nurture groups were interviewed, with a small number of participants allowing the researcher to focus on the individual views of the participants.

Using thematic analysis, the researcher found that the development of relationships between staff and parents, communication and sharing practice were all key to parental involvement in nurture groups. The needs of the parents which may impact on parent involvement were also described by both staff and parents, including health and emotional needs.

McWilliam, R. A., Maxwell, K. L., & Sloper, K. M (1999). Beyond "involvement": Are elementary schools ready to be family-centered? *School Psychology Review,* 28, 3, 378-394

This was United States based research, with the purpose to understand both parents' and educators' perspectives of family centred practices in the early school years, defined as a positive partnership with families. 155 staff working in education in both mainstream and specialist settings, and 121 parents of children with and without SEN were asked to complete scaled item questionnaires about family-centred practices, and about family-centred attitudes and behaviours.

This research indicated that families valued family-centred approaches, and that the features of these included responsiveness and sensitivity, atmosphere, delivery of specialised services and advocacy. The researchers also found that families of children

with SEN rate school practices as less family centred than educators, and did not feel very encouraged by school to voice their concerns and speak up for their family.

Munn-Joseph, M. S., & Gavin-Evans, K. (2008). Urban Parents of Children With Special Needs: Advocating for Their Children Through Social Networks. *Urban Education, 43*(3), 378–393

The researchers carried out qualitative semi-structured interviews with parents within three families in the United States. The sample was homogenous in that the families were all recruited from the same school, and the parents all had children of elementary school age who had been diagnosed with a disability and had been receiving special education services for more than one year. The purpose of the research was to investigate how Black and low income-parents perceive family involvement, particularly how they utilised social capital and networks to improve their sense of advocacy for their children within education.

Families spoke of reliance on family members or close neighbours for guidance in decision-making. They also accessed institutional networks such as social service centres. These networks allowed families to access necessary advice and information. The authors discussed how family involvement needs to be responsive to what individual families' perceptions and expectations of education are, and how families who are often perceived as 'hard to reach' by professionals may actually be interacting with a variety of support networks which meet their needs.

Spann, S., Kohler F. & Soenksen D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on autism and other developmental disabilities,* 18, 4, 228-237

Spann et al. (2003) designated a focus on families' experiences of participation and involvement in special education services, and was conducted in the United States. Parents of 45 children with developmental disorders were identified from a parent support group, with children ranging from 4-18 years old and attending a mixture of preschools, private programmes, and public schools. Researchers conducted interviews with parents over the phone using a 15 item questionnaire, which was divided into four topics: placement and special education services, home-school communication, the process of the Individualised Education Programme and priorities and satisfaction with school.

Over half of the parents reported that they communicated with teaching staff who worked with their child on a daily basis, and the majority of this communication was either to share information, or discuss or solve problems. Participants perceived that they were moderately involved in the IEP process, with parents of younger children (age 4-9) identifying a greater level of involvement than parents of older children.

Winton P. and Turnbull A. (1981). Parent involvement as viewed by parents of preschool handicapped children. *Topics in Early Childhood Special Education*, 1, 3, 11-19

Winton and Turnbull (1981) conducted interviews with 31 mothers of disabled children, who were either placed in a specialist or mainstream setting in the United States, about their experiences of their child's pre-school programme, with a particular focus on parent involvement type activities. This was a two phase interview drawn from an ethnographic approach: with the first phase of a semi-structured interview, and the second of a quantitative questionnaire based on categories and subcategories identified from phase one.

It was found that the presence of parent involvement activities, such as opportunities for parent groups, training and counselling, was important to parents in the selection and evaluation of pre-schools for just over half of the participants. 61% valued having satisfying parent-professional relationship (opportunities to contribute to planning and information provided about progress). The most preferred option for parent involvement was informal and frequent contact with teachers. 19% of parents also appreciated the option to have no involvement at all.

2.6.4.7 Summary and implications

Seven studies were identified from this systematic search which focused on family perceptions and experiences of family engagement. The search allowed the researcher to identify a range of pertinent studies which contribute evidence to the current research questions, but only one study could be rated as 'high' because of its methodological quality and appropriateness in its phenomenological design (Hebel, 2014). As Table 2.1 indicates, the majority of studies which were evaluated for this search contributed a 'medium' weight of evidence. The study with a phenomenological design gave the highest weight of evidence (Hebel, 2014) due to the appropriateness of the research method for the current study's review question. Jivanjee et al. (2007) offered the lowest

weight of evidence due to a lack of rigour in the study and a research design which was less applicable to the review question. The overall dearth of pupil voice incorporated into the family sample was particularly noticeable.

2.6.5 Search B: family members' experiences and perceptions of statutory assessment processes

2.6.5.1 Search strategy and inclusion criteria

From research question B, 'What does the research literature tell us about the experiences and perceptions of family members of children with SEN regarding statutory assessment processes?' the following search terms were identified: 'experiences', 'perceptions', 'family', 'statutory', 'assessment', 'process' and 'SEN'.

It was next considered necessary to "unpack" the broad areas. 'Parent', 'pupil' and 'child' were included alongside 'family', and 'view', 'understanding', 'judgement' and' idea' were all considered in parallel with 'experience' and 'perception', as discussed in *2.6.4.1*. Alongside 'assessment', the researcher wanted to include all descriptors of what may be included in statutory processes. This included 'plan', 'statement', 'process' and 'service'.

As discussed in *2.6.4.1*, truncations were utilised to allow for spelling variations and plurals of terms, and with the roots of the words 'understand', 'judge' and 'assess'.

As outlined in *2.6.4.1,* ERIC, British Education Index, PsycINFO, Web of Knowledge and Google Scholar were all consulted, in a keyword search within the advanced search option of each database, utilising the OR AND function (see Appendix 5).

2.6.5.2 Initial screen of studies

The initial screening process which has been outlined in *2.6.4.3* was followed. This was done with the replacement of the inclusion criteria 'The main focus of the data which has been gathered must relate to the theme of family engagement' with the following:

- The main focus of the data which has been gathered must relate to the theme of statutory SEN processes.

2.6.5.3 Studies identified per database

PsycINFO: The advanced search function returned ten articles following appropriate combinations of search terms as 'key words' (i.e. identifying search terms anywhere

within the text of the article). After having initially screened these studies, a total of two remained.

Web of Knowledge:

The advanced search function returned seven articles following appropriate combinations of search terms within the field tag of Topic (TS). After having initially screened these studies, a total of one remained.

British Education Index:

The advanced search function returned 14 articles following appropriate combinations of search terms. After having initially screened these studies, a total of two remained.

ERIC:

The advanced search function returned 13 articles following appropriate combinations of search terms. After having initially screened these studies, a total of one remained.

Studies were mainly excluded for the following reasons

- No evidence of data having been gathered from the family perspective.
- Research explored experiences of family, but not directly related to statutory assessment processes.
- Studies did not appear in academic journals.

Due to the small number of articles which were found for Search B through databases, it was thought necessary to hand-search for further articles through the reference lists of the articles which were found, and also through Google Scholar, looking for articles which had cited relevant research. This resulted in a further five articles.

Following this initial search, the resulting studies were compared for duplicates. Where necessary, papers were studied in greater detail, for example by methodology and findings as opposed to abstract only, to ensure that the contents met the inclusion criteria and could not be ruled out by the exclusion criteria outlined.

Six studies both met the inclusion criteria and were accessible at the time of the systematic literature search. These studies are now reviewed in further detail.

2.6.5.4 Appraisal of studies

Table 2.2 provides an overview of the final weightings given to the included studies. The six studies selected for inclusion in this search review were subsequently described through a keyword coding strategy. This is included in Appendix 6.

Table 2-2: A table to demonstrate Weight of Evidence framework criteria (Gough, 2007), as applied to Search B families' experiences and perceptions of statutory assessment processes

	A – Methodological quality	B – Methodology appropriateness	C – Methodological relevance	D – Overall weighting
Jones & Swain (2001)	Low	Medium	Medium	Medium
Keenan, Dillenburger, Doherty, Byrne, & Gallagher (2010)	High	Low	Medium	Medium
O'Connor (2008)	Medium	High	Medium	Medium
O'Connor, McConkey, & Hartop (2005)	High	Low	Medium	Medium
Runswick-Cole (2007)	Low	Medium	Medium	Medium
Truss (2008)	High	Medium	Medium	Medium

2.6.5.5 Comparison of studies

With reference to the Weight of Evidence framework criteria, the studies will now be compared on a range of factors in relation to methodological quality, appropriateness and relevance.

44

Methodological quality

The majority of the studies demonstrated a clearly identified sample, purpose, data gathering and analysis techniques. For example, Keenan et al. (2010) reported clear information regarding the sample, for example gender, mean age and employment status in percentages. Truss (2008) described the broad area of interest and applied this to the experiences of one child and his mother, with accompanying background information. The methodology for the participant observation study, including data collection methods, is clearly laid out for the reader. This is compared to Runswick-Cole (2007) who reports a brief paragraph only including the number of participants, with no other details given, and no details given about how data from the interviews carried out was transcribed, verified or analysed.

Methodological appropriateness

O'Connor (2008) was the only identified study which could be rated as 'high' within this category and therefore as highly relevant in its design to the current research, as the study used the qualitative approach of Interpretative Phenomenological Analysis in order to place the lived experience of the participants at the heart of the research. This allowed for an in-depth investigation of perceptions and experiences. Jones & Swain (2001), Runswick-Cole (2007) and Truss (2008) all made use of qualitative methodology in the form of group discussions, semi-structured interviews or case study, which all remain related to the current research and allow some exploration of the perceptions and experiences of participants, and therefore were rated as 'medium'. The two remaining studies, Keenan et al. (2010) and O'Connor et al. (2005) collected data through more structured quantitative methodology such as questionnaires and structured telephone interviews. These studies were judged as less relevant to the current research, which takes the perspective that fixed possible responses and explanations cannot provide an adequately deep, detailed or rich account of experience.

Methodological relevance

The research assigned the rating of 'medium' to all of the studies identified from this systematic search. Despite the fact that all of the studies took place within the UK, and since the publication of the *SEN Code of Practice 2001* (DfES, 2001), none of the studies accessed the sample context of the entire family perspective, including the voice

45

of the young person, and therefore could not be judged as 'high' in their methodological relevance.

2.6.5.6 In-depth description of included studies

Jones, P. and Swain, J. (2001). Parents reviewing Annual Reviews. *British Journal of Special Education*, 28(2), 60–64.

Jones and Swain (2001) examined parents' perceptions of their involvement in the process of Annual Review for pupils with Statements of SEN. The views of parents were firstly gathered through a questionnaire and group discussion, and secondly through further open ended discussion. Jones and Swain (2001) found that as parents approached the Annual Review, they maintained a holistic view of the young person, without solely focusing on education and learning. Parents felt they needed to be involved in the process in order to gain the best possible outcomes for their child.

Parents sought to work in partnership with professionals, but there were particular factors identified which acted as barriers, including lack of open communication with school staff, conflict with school staff, not feeling informed by the LA, powerlessness and the formal mechanisms and procedures of Annual Reviews, including the time limit on the meeting. Parents felt that Annual Reviews should be a compromise as a result of negotiation between themselves and others involved, but that they had to actively seek involvement in decision-making processes rather than this being offered by LA or school. Parents spoke about the importance of the preparatory work which schools do with families ahead of Annual Reviews, and also of the importance of the level of detail and specificity on a Statement of SEN, particularly with regards to the power which the Statement holds in accessing the right provision for their child.

Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*, 23(4), 390–397.

Keenan et al. (2010) focused on the parental experiences of diagnosis and forward planning for children with Autism Spectrum Disorder. Parents were recruited across Northern Ireland and the Republic of Ireland, and the Family Autism Needs Questionnaire was distributed to all parents who volunteered. A total of 95 parents and

carers took part in a mixed methods approach. All 95 provided data in their questionnaire responses and ten parents provided qualitative data in focus group discussions.

Keenan et al. (2010) found that neither the diagnosis nor the 'statementing' processes were satisfactory for parents. 44% of parents of children with a Statement of SEN did not feel it accurately described their child's needs, and 50% felt that provisions described in the statement were not appropriate to needs, showing that parental views were not routinely included within this. Parents found both the diagnostic process and the 'statementing' process difficult and lengthy. In 43% of cases the diagnosis process took 12 months or over, which contradicted policy at the time. It was concluded that parental views were not given appropriate weight when it came to their children's education, particularly when compared to the views of professionals.

O'Connor, U. (2008). Meeting in the middle? A study of parent–professional partnerships. *European Journal of Special Needs Education, 23*(3), 253–268.

O'Connor (2008) carried out a phenomenological study in order to further explore the lived experience of parenting a child with SEN, with particular focus on the concept of partnership between parent and professional. A total of 20 participants took part.

It was found that there continues to be a marked absence of the conditions which have previously been identified within research as contributing to a positive parent-professional partnership. These include reciprocal, supportive and open communication. Parents often became confused about, or were unaware of, the range of services, including voluntary agencies, which were available to them. Parents perceived that important educational decisions were made solely by professionals, and their unique ideas and knowledge base were relegated to the periphery. The researcher concluded that the study carried a powerful message, particularly for professional services, in the need to assign as much value to parental expertise as professional in order to transform the practice of SEN policy through meaningful partnership.

O'Connor, U., McConkey, R., & Hartop, B. (2005). Parental views on the statutory assessment and educational planning for children with special educational needs. *European Journal of Special Needs Education, 20*(3), 251–269.

O'Connor et al. (2005) carried out a large scale study which was commissioned by the

Department of Education in Northern Ireland as part of a wider review of the statutory assessment and statementing procedures in the country. The authors gathered information on parents' experiences of the assessment and statementing procedures, as well as whether the process met the perceived needs of the child, and how the procedures could be improved.

Data was gathered by a written questionnaire, which was supplemented by telephone interviews with a randomly selected sub-group of parents. O'Connor et al. (2005) found that the vast majority of parents were satisfied with the assessment process; 81.8% felt that the assessment gave an accurate description of their child's needs and 79.9% indicated that they were either satisfied or very satisfied with the overall assessment procedure. The authors went on to discuss three main areas which made a difference to how satisfied parents were with the process: firstly, having a named contact person, secondly, jargon free information which is clear and practical for parents, and thirdly, a clear and informed choice for parents about the educational provision which is identified on the statement.

The researchers concluded that the data suggested that the process had been designed to suit professionals rather than parents; for example parents wished for the process to be shorter in length and for there to be less paperwork involved, for professionals to be more sensitive in their interactions with families, and for there to be better coordination and information sharing between professionals.

Runswick-Cole, K. (2007). "The Tribunal was the most stressful thing: more stressful than my son's diagnosis or behaviour': the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDisT). *Disability & Society, 22*(3), 315–328.

Runswick-Cole (2007) interviewed seven fathers and seventeen mothers who had experiences with the SEND Tribunal, which is a system which enables parents to register appeals with the LA.

The author described the numerous negative aspects for the family of taking a claim to the Tribunal, including the level of emotional demand and the financial costs. Mothers described their organisational role during the process with regards to collecting and circulating information, and their perceptions of being blamed during the process for

being over-anxious, and for having reduced competence as a parent, whereas fathers were described as having a less prevalent role as they felt less confident about making knowledgeable contributions to the process. Whilst the majority of participants described the process as stressful and demanding not only for them individually, but for the family as a whole, including extended family members, a small number of participants described the process as empowering and found that it did have positive outcomes with regard to their perceptions of their own advocacy skills.

Truss, C. (2008). Peter's story: reconceptualising the UK SEN system. *European Journal of Special Needs Education,* 23, 4, 365-377

Truss (2008) set out a broad purpose of looking at whether the SEN system within the United Kingdom is working from the perspective of the parent and the child. This question was addressed through presenting the findings of a longitudinal participant observation study from the author's own experiences as a parent of a child of SEN. The author identified that the SEN system fails to take a multi-system holistic perspective, instead focusing on educational processes rather than addressing legal and medical processes which families often also experience. The study also highlighted the numerous discrepancies between the rhetoric of how the SEN system should be working for families and the reality of families' experiences, for example parent alienation from the system and breakdowns in communication. The author's role as both subject and object of the research has to be recognised, although the researcher argues that experiences are presented in an objective rather than subjective manner.

2.6.5.7 Summary and implications

The research which has been accessed as a result of this second systematic search focused on parents' perceptions of different aspects of the SEN system in the United Kingdom, including the Annual Review process, diagnosis and the statementing process, the latter of which is of particular interest to the current research. As with Search A, one study took a qualitative phenomenological approach, and many others included qualitative data of some kind in order to measure parents' perceptions and experiences.

As with Search A, none of the studies which were reviewed within this systematic search accessed the entire family perspective, including the voice of the young person, and therefore could not be judged as 'high' in their methodological relevance, as the main focus for all of the studies was on the views of the parents of the young person.

49

2.6.6 Conclusions

The systematic search illustrated here demonstrates two areas of interest and specific focus for the current study: the experiences and perceptions of families of children with SEN regarding family engagement in educational contexts, and the experiences and perceptions of families of children with SEN regarding statutory assessment processes.

Despite family engagement and statutory processes being evident in the literature over the past 25 years, an in-depth, clear and up-to-date understanding of family insights in these areas captured by high-quality research is not evident from this review. The researcher particularly noted how a greater proportion of the parents within the sample groups of the studies reviewed here were nearly always female parents. For example, Runswick-Cole (2007) interviewed ten more mothers than she did fathers within her study, and 97.7% of the sample within Jivanjee et al.'s (2007) study was female. As noted by Runswick-Cole (2007) female parents of children with SEN often take on more of an extensive caring role within the family. This may help to explain why more female than male voices have been accessed when focusing on parents' perceptions and experiences within education. The absence of the child's voice within research which was accessed within these two searches was also of interest, particularly as it has been noted that a child's understanding and experience of the world can often differ from their parents (Case, 2000).

2.7 Rationale for the current study

The significance of family engagement for schools and pupils has remained a clear area of interest in both research and policy, with frameworks of parental involvement being continually updated (Hoover-Dempsey & Sandler, 1995; Sheldon & Epstein, 2005) and current up-to-date research illustrating pivotal issues, particularly barriers and facilitators of family engagement, continually being discussed by researchers (Abel, 2014). The move from the notion of parental involvement towards the notion of family engagement and onto family empowerment is also evident (Turnbull, Turbiville, & Turnbull, 2000). Research in this area has clearly emphasised the relationship between specific and isolated parent involvement behaviours and the positive impact which this can have on development, for example through children and parents taking part in learning activities at home together (Fantuzzo et al., 2004). The impact upon academic attainment has also been demonstrated (Desforges, 2003). Such research has, though,

generally drawn on questionnaire or survey data, which is limited in terms of the depth and richness of experience which can be drawn from it, and does not appear to take account of parents' views on their own engagement. The current study aims to offer an evidence-based contribution to the definition and understanding of family engagement, focusing particularly on how this is perceived and experienced by parents and young people.

Simultaneously, the UK Government has released new legislation which dictates the latest *SEND Code of Practice* (DfE & DoH, 2015). It has been suggested that this legislation will have a significant impact on the lived experiences of families dealing with statutory SEN processes, and on all professionals working with children with SEN (Attwood, 2013), particularly as the legislation places children's and families' voices at the heart of practice and decision-making. Although previous studies have aimed to gather the views of parents of processes within education (Jones & Swain, 2001; Keenan et al., 2010; O'Connor et al. 2005; Runswick-Cole, 2007) none have yet accessed the voice of parents and young people in reaction to the recent changes in legislation.

The current study aims to present an in-depth interpretation of a perspective which is missing from the current literature: the entire family unit including the perceptions of the young person. This is with the intention of supporting the development and understanding of continually evolving processes within education, by enabling the powerful voices of individual family members, and allowing them to give their accounts of family engagement within a reformed statutory context.

2.8 Research questions

There are two main research questions for the current study which are:

1. How do family members interpret their experiences of the Education, Health and Care needs assessment process?
2. How do these same family members interpret their experiences of family engagement within the Education, Health and Care needs assessment process?

3. Methodology

3.1 Introduction

The aim of this chapter is to provide an overview of the chosen methodology for this research, Interpretative Phenomenological Analysis (IPA). This will include discussion of the theoretical and conceptual underpinnings which informed the research, as well as an explanation of the researcher's decision-making processes related to the methodology of the study. The chapter will finish by discussing quality within qualitative research, and how this is demonstrated in the current study. The intention is to demonstrate the suitability of IPA both practically and philosophically to the two stated research questions.

3.2 Methodological orientation

3.2.1 Overview

This research has the aim of providing an in-depth insight into how individuals subjectively perceive and experience a life event of interest, in this case the statutory assessment process within education which is known as the EHC needs assessment process. In order to illustrate the suitability of the qualitative approach of IPA with regard to this aim, it is important to present a clear argument of why qualitative methodology was the most appropriate way to address the research question, and to demonstrate the epistemological and ontological orientation of the research.

3.2.2 Quantitative and qualitative research: associated paradigms

3.2.2.1 Introduction to qualitative research

Although there are several different approaches to qualitative psychology, researchers who turn to qualitative methods are mostly interested in how and why a person grasps the world in the way that they do (Ashworth, 2008). Kirk and Miller (1986) suggest that qualitative research describes the presence or absence of something, its constituent properties, and what defines that thing, whereas quantitative research measures how much of an entity there is, how often it happens, or the size of associations between entities. There can often be a relatively small number of participants within a qualitative piece of research, as the emphasis is on personal and unique experiences as opposed to trying to test a preconceived hypothesis with a large sample (Smith, 2008).

3.2.2.2 Rejection of the positivist paradigm

Qualitative research is often seen as rejecting the positivist stance, which has been described as the dominant paradigm for many years within the natural and social sciences (Ashworth, 2008; Thomas, 2013). The positivist paradigm states that there is a straightforward relationship between the world, of which there is one single, unitary version, and one's perceptions and understanding of it. Consequently, positivist researchers believe that any knowledge which is produced through research should be objective (Willig, 2008). However, over time, an alternative view has developed within education and social sciences. Known as the interpretivist paradigm, this promotes the idea that the social world is constructed by each individual differently, and thus should be measured subjectively and not by objectively quantified variables. Reflective of this development of interpretivism within educational and psychological research is the emergence of qualitative methods of inquiry. Interpretivism promotes further understanding of individuals' views and behaviours through researchers attempting to give an insider perspective from that person's world (Denzin & Lincoln, 2005). This is the paradigm to which the current study subscribes.

3.2.3 Ontology

The ontology of a researcher dictates their view of the nature of reality, and asks the question 'What is there to know?' (Willig, 2008).

This research will accept the broad constructivist ontological assumption that there is not one objective reality or truth which can be discovered and measured, but that multiple realities exist according to the individual, time and place (Willig, 2008). The realist ontological belief that there is one truth which is objective, static and measurable is therefore rejected. The researcher will be particularly interested in participants' subjective experiences of a particular process rather than the objective conditions of the same process, searching for meaning rather than truth. It will assume that individuals' experiences of the same process will be shaped by a number of different factors, including their thoughts, beliefs, expectations and judgements: it isn't concerned with whether perceptions match with an external and objective reality, as each individual has their own reality which is correct. Therefore, this research is in line with relativist ontology (Denzin & Lincoln, 2005).

3.2.4 Epistemology

The epistemology of a researcher signals their perception of the nature and scope of knowledge (Lincoln & Guba, 2000).

This study will take an epistemological viewpoint in between the 'realist' and 'relativist' continuum of epistemological positions (Willig, 2008). A realist position states that data should provide us with information about an objective existence that exists outside of human perception, whilst a relativist position states that there is no such thing as reality, and therefore data collection and analysis should explore the ways in which different versions of the same experience are constructed within different contexts (Willig, 2008).

The current research adopts a phenomenological epistemological position, in acknowledging that experience must always be interpreted and is therefore constructed, but the experience remains true for the individual at the centre of it (Willig, 2008). At the core of phenomenology is the Husserlian idea that "knowledge does not exist in itself but is correlated with subjectivity and so can only be claimed in the context of a subject apprehending the world" (Langdridge, 2007, p.155). In some respects, a phenomenological position could be said to take a realist approach in that it encourages knowledge to be produced of how an individual has understood a particular phenomenon of interest. Simultaneously, this position recognises that another individual's perspective can be accessed if researched through careful and explicit interpretative methodology (Smith, 2004).

3.2.5 Reflections

The researcher has outlined above some of the distinctions between quantitative and qualitative traditions, and has in turn addressed the continuum between positivist and constructionist paradigms. However, this distinction between quantitative and qualitative research is not as simplistic as it may appear. In real world research, researchers are not driven by the research paradigm or orientation, but by their research question, and consequently the view of the world and the nature of knowledge which is best matched to what the researcher is trying to find out (Thomas, 2013). In addition, qualitative research is by no means one homogenous field, as it contains numerous methods grounded in their own epistemological stances, making different theoretical assumptions (Willig, 2008). This is particularly true of the specific research method of

IPA. A number of authors have discussed the tensions around IPA, particularly regarding the number of epistemological positions which have been adopted by IPA researchers, presented by Chamberlain (2011) as a challenge for IPA and by Larkin, Watts, & Clifton (2006) as a strength. The researcher has decided to take the perspective of Smith (2004) that phenomenology, first introduced by Husserl, represents a variation of an epistemological stance, as phenomenology is a "science which aims exclusively at establishing 'knowledge of essences'" (Husserl, 2014, pg.44) which refer to the "essential structures of subjective structures" (Gill, 2014, pg. 3).

3.3 Interpretative Phenomenological Analysis

IPA is a qualitative approach which draws on the ontological and epistemological ideas stated above, as well as the philosophical background of phenomenology, hermeneutics and idiography. Using IPA, a researcher is able to explore the personal perceptions of research participants, whilst acknowledging that their own interpretation is key to the account that is offered (Smith & Osborn, 2008). It is interested in the individual, and emphasises individual experiences and perceptions as integral to reality. IPA therefore offers the researcher the potential to collect a rich description of the person-in-context, followed by an attempt at an interpretative account to make the information meaningful for others. IPA has been noted as a flexible approach by some, as although it places the phenomenological account at the centre of the research, it makes no theoretical assumptions about the interpretation of this account, and therefore allows discursive, cognitive and affective elements to be recognised (Larkin, Watts & Clifton, 2006).

3.3.1 Phenomenology

Phenomenology originated as a philosophical school of thought regarding the study of experience. Phenomenologists on the whole are interested in thinking about what the experience of being human is like, particularly with regard to things which are important to humans and which constitute part of their lived world. However, phenomenology is not a singular concept but has developed over time. It was originally formulated by Husserl as transcendental phenomenology in the early twentieth century (Wertz, 2011). Since then, phenomenological psychology has been developed by many including Heidegger, Merleau-Ponty and Ricoeur (Moran & Mooney, 2002). It is important here to signal which aspects of phenomenology are important to the current IPA research.

55

Husserl identified two crucial aspects of phenomenology which he saw as integral to the study of experience. Firstly, a phenomenological approach asks a researcher to put aside theories, hypotheses and possible explanations about the topic under investigation to understand the lived experience of the phenomena (Mertens, 2015). In this way, phenomenology asks the researcher to go "back to the 'things themselves'" (Husserl, 2001, pg. 168) in order to experience a purer perception of the world.

Secondly, although phenomenologists acknowledge the individual as an integral part of reality, as they believe that humans actively perceive and encounter objects and experiences, they do not make any judgements regarding the existence of the experiences which take place (Wertz, 2011). Therefore, rather than being interested in the existence of the topic of interest, phenomenologists are more interested in the subjective meanings which are given. It is impossible, some have argued, to detach the human self from the world of objects and subjects, as our experience of objects and subjects at any given time is what constitutes reality (Willig, 2008).

Heidegger focused much more closely on this concept of 'being-in-the-world', arguing that meaning-making and interpretation is at the core of human experience. Rather than returning to the thing itself, Heidegger (1996) conceptualised a person-in-context, and believed it impossible to create knowledge free from interpretation. Heidegger (1988) suggested that existence takes place in an environment which is culturally and historically conditioned, and therefore it is impossible to detach assumptions and presuppositions from understanding of an experience. This challenges Husserl's idea of bracketing off assumptions about a phenomenon in order to understand purified phenomena (Gill, 2014).

The interpretative and phenomenological components of IPA are both crucial to understand here; IPA maintains a phenomenological component, in that it looks at the claims and concerns of a person, and how a phenomenon has been understood by that same person, but simultaneously it contextualises these claims by drawing on the Heideggerian ideas of a person-in-context framework, by taking into account the relationship between the person and the cultural and physical world which they find themselves in. (Larkin et al., 2006)

3.3.2 Hermeneutics

The hermeneutic tradition recognises that, in order to attempt to describe 'pure' experience, one has to interpret it, as it is impossible to gain direct access to an individual's personal world without implicating your own conceptions and views of the world (Moran & Mooney, 2002).

To explore hermeneutics further, Smith, Flowers & Larkin (2009) drew firstly on the hermeneutic circle and secondly the double hermeneutic. Firstly, the hermeneutic circle; this recognises that in order to carry out any kind of analysis a researcher has to engage in an iterative cycle. "To understand any given part you look to the whole; to understand the whole you look to parts" (Smith et al. 2009, pg. 27). As applied to this research, in order to analyse family members' experiences and perceptions of the EHC needs assessment process, it is necessary to follow this cycle; to see parts of each experience in the context of the whole experience, and to see the whole experience in the context of the parts.

Secondly, the double hermeneutic. As the researcher is making sense of the participant, the participant is in turn making sense of the phenomenon of interest. Therein lays the concept of a double interpretation, which only allows for indirect access to the phenomenon (Smith et al. 2009). Therefore, findings of any IPA study report the researcher's interpretation of the participant's attempt to express their interpretation of their own experience.

3.3.3 Idiography

An idiographic approach is also integral to IPA, as there is a strong focus on the individual, with a view that claims about the wider population can only emerge once an in-depth analysis of the individual in their unique context has been carried out (Larkin, et al., 2006). Rather than being interested in general experiences or populations, idiography focuses on particular phenomena and how they have been understood by particular people in a particular context (Smith et al. 2009). This is in strong contrast to the nomothetic research approach, popular within positivist and post-positivist research, which demands findings that can be generalised to a wider population. The approach has been strongly criticised by the proponents of IPA, such as Smith (2004), who claims that in making wider claims about human behaviour, nomothetic research loses the essence of a personal and particular account of an experience. The researcher here will

57

maintain their commitment to idiography by focusing on a detailed account of an individual experience before moving on to the next account, before illustrating convergence and divergence between individual participants. The researcher here does not aim to generate findings which are generalisable, and fully accepts that knowledge which is created will be solely applicable to the families within the study, but hopes to improve understanding about the topics of interest and therefore provider greater theoretical transferability about how families view and experience family engagement and the statutory SEN process.

3.3.4 Limitations of IPA

IPA has been criticised on four grounds by Langdridge (2007) and Willig (2008), these grounds being discussed below.

IPA makes the assumption that participants can use language to give an in-depth perspective of their experience, as studies traditionally analyse transcripts of interviews. This issue has brought about the first two areas of critique which are described here.

Firstly, that IPA excludes participants who are not able to articulately communicate their experience through language. This will be particularly pertinent to this research, which involves interviewing parents and young people with SEN. The success of the data gathering will therefore be dependent on the verbal ability, to some extent, of the participants. Some participants' accounts and understandings of their own experiences may not be suitable material for phenomenological analysis. This is acknowledged by the researcher, and extra steps were taken to shape the data gathering process around the needs of each participant, as discussed later in *3.5*.

Secondly, it has also been argued that the interpretation of language only allows for an understanding of how people talk about their experiences, rather than an understanding of the actual experience itself (Willig, 2008). How participants use language can be seen as a construction rather than a description of reality. This limitation adds an extra layer to the double hermeneutic. The researcher therefore acknowledges that any interpretative account offered will be an interpretation of the perceptions of participants, and not direct analysis of an experience.

Thirdly, as outlined earlier in this chapter, the researcher recognises that this is a small scale qualitative study, which does not aim to represent the views and ideas of the wider

population, but allows for a deeper understanding of the issue at hand. Therefore, the research is representative of a perspective and not a population.

Lastly, Willig (2008) outlines how a thorough understanding of phenomena requires identification of how and why these experiences came about. IPA does not claim to demonstrate such explanations, and instead offers an interpretation of a lived experience by asking participants to describe their understandings and experiences of a phenomenon (Smith et al., 2009).

3.4 Other approaches considered

The decision to use IPA was ultimately made in relation to the two identified research questions for this current study. However, a number of alternative methods were considered as part of the research process. Two examples of these are detailed below.

3.4.1 Grounded theory

Grounded theory seeks to generate explanatory theory of basic social processes within the environments in which they take place. Although similar to IPA in how it focuses on the perspective of a group of individuals who have experienced a phenomenon, grounded theory is interested in building inductive theories through data analysis (Charmaz, 2003), rather than understanding the lived experience of a phenomenon. Grounded theory was considered by the researcher at an early stage in the development of the current study, with the potential aim to develop understanding of how family engagement happens in the context of the EHC needs assessment process. However, ultimately it was rejected because of the lack of idiographic focus, which meant that the researcher would have been less able to focus on individual accounts and to explore individual experiences of the EHC needs assessment process.

3.4.2 Discourse analysis

Discourse analysis aims to understand how language is used to create identities and activities. Researchers in this area are therefore interested in how language produces a certain narrative of a particular topic. Discourse analysis is aligned with social constructionism, and is based on the idea that reality is negotiated through interaction with multiple discourses. The researcher decided that discourse analysis would not be an appropriate method to answer the current research questions, as it does not allow for

an in-depth focus on experience as IPA does. Discourse analysis instead focuses on how meanings are constructed through language-in-use (Starks & Trinidad, 2007).

3.5 Design

3.5.1 Sample

3.5.1.1 Context of the potential sample population

This research took place within a large urban East Midlands unitary LA. 65% of the population of the area are White British, and 35% are Black and Minority Ethnicity. It is within the most socially deprived areas in the country, as measured by the Index of Deprivation (Department for Communities and Local Government, 2015).

26% of the population of the area are either in Early Years of education, or school and training years, which is above the national level of 23.5% (Office for National Statistics, 2013). School census data indicates that the incidence of SEND within schools in the area has risen over the past decade. In 2009, 28% of all pupils had some form of SEN or disability, compared to 20.5% nationally, which is an increase of 6% from 2004. The percentage of pupils with Statements attending schools in the LA in 2009 was 1.4%, the second lowest in the East Midlands region. There has, however, been an increase over time in requests for statutory assessment and in the number of Statements issued. In the academic year of 2004/2005, there were 34 Statements issued, compared to 65 in 2009/2010 (Joint Strategic Needs Assessment, 2010).

3.5.1.2 Selection of participants

Participants were selected purposively in that they were all able to speak retrospectively about their experiences within the EHC needs assessment process within one LA. None of the sample had previously experienced statutory assessment, as none of the participants had previously had a Statement of SEN. The sample was divergent in terms of gender, and the young people who took part in the study differed with regards to their age, main areas of SEN and type of current educational setting. This contradicts guidance offered by Smith et al. (2009) to recruit as homogenous a sample as possible. However, in light of the fact that the topic of this research, the EHC needs assessment process, is only applicable to a relatively small potential sample population, the homogenous nature of the sample is seen as satisfied by the inclusion of a group of people who share and can therefore offer insight into a particular experience (Smith et al, 2009; Langdridge, 2007).

60

3.5.1.3 Recruitment of participants

The researcher was at the time of completing the study working as a Trainee Educational Psychologist, and was therefore working as part of a team of EPs who regularly visit schools and families in their professional role. She was also working collaboratively with a number of other services who come into frequent and direct contact with families involved in the statutory assessment process, including the SEN Service and the Keyworker Service.

Initially, to identify potential participants, EP colleagues and members of the SEN team were asked to identify and approach families who could share their experiences of the EHC needs assessment process. This was later widened to members of the EHCP keyworker service because of the very low number of families identified in this way. The researcher shared an initial information letter with these professionals about the proposed research in order for them to do this (see Appendix 7). This enabled the family to provide consent for their contact details to be passed to the researcher, who could then contact the family to discuss the research further. The researcher did not receive any details of the family until they had given their consent for these to be shared, and the researcher was not linked in any way in her professional capacity to the participants.

3.5.1.4 Meeting the participants

Where families had consented to initial contact details being passed onto the researcher, the researcher then contacted the family in order to provide a brief account of the research and to arrange a meeting to provide more detailed information. This was done by telephone. At this meeting a full information sheet was shared (see Appendix 8 for adult format and Appendix 9 for a format adjusted for children and young people).

The families approached by the researcher were clearly briefed on the rationale for the study, what families would be asked to do, and on the researcher's role, whereupon it was stressed that the research was separate to the assessment process itself and that declining to take part in the research would have no effect on the process for the family.

3.5.1.5 Information regarding the final sample group

The final sample group was made up of six individuals from within three families in total. In line with the idiographic commitment of IPA the richness of analysis of individual perceptions is more important than the sample size. Smith et al. (2009) argue that in order to allow for in-depth analysis of individual cases and experiences, data

collection of between four and ten transcripts is appropriate for a doctoral level study. The sample size for the present study therefore has followed this guidance.

The focus of the research designates the broad sample as family members; this included the young person and their primary carer(s), and could potentially have included other close family members, such as aunties, uncles or grandparents. The final decision regarding who should be included was made not by the researcher but by each family, as it was felt that family members were in the most appropriate position to decide who could and wanted to give their consent to provide an account of their experiences. As demonstrated in Table 3.1, the final sample, as dictated by parents with whom the researcher was initially able to meet, was made up of young people and parents, as opposed to other family members. This is depicted in the reference to the research questions in the 'Findings' and 'Discussion' chapters.

Following the guidance of Smith et al. (2009), who advise that intense data gathering sessions which could last for over an hour are not advisable for young children, only pupils in Year 4 and above were included in the research.

It was not possible to include an account from the young person in one family (David, see Table 3-1 pg. 63). The decision to exclude this young person was made after careful reflection by the researcher and also after considered discussion with the parent. There were four main issues to consider. Firstly, the best medium through which to communicate with the young person given his difficulties with verbal communication. Consideration was given to how his family members communicated with him, and how he might express his perceptions and experiences to the researcher. A variety of options were considered by the researcher, including the use of pictures, cue cards and Talking Mats, but it was thought that these would significantly constrain or pre-determine the responses available to the young person during data collection. Secondly, the capacity of the young person to consent to taking part in the research, with sufficient understanding about what this involvement entailed and of the purpose of the research. Because of the needs of the young person, it was judged that he was not able to give fully informed consent. Thirdly, the potential negative impact of the research on the wellbeing of the young person, and whether attempting to establish a relationship between the researcher and the young person may actually cause anxiety for him.

Finally, and perhaps most importantly, whether the research questions would be clear and meaningful to the young person, and whether the topics of interest were of sufficient relevance to the young person, in light of the view that "eliciting people's views rests on the assumption that the subject is one on which they have an opinion" (Lewis & Porter, 2004, pg. 194). It was decided on this basis that is was unlikely that the young person would be able to offer an interpretation of either the EHC needs assessment process or family engagement.

All participants have been allocated pseudonyms in order to protect their anonymity. Tables 3.1, 3.2 and 3.3 details information regarding each of the sample families to assist with contextualising the sample.

Table 3-1: A table to show appropriate contextual information regarding sample family one

Pseudonym	Position within family	Age at time of interview	School year group	Type of educational provision	Main areas of SEN	Sex	Ethnicity
Eve (participant in research)	Mother	N/A	N/A	N/A	N/A	Female	Black
N/A (family member but did not participate in research)	Father (divorced from mother)	N/A	N/A	N/A	N/A	Male	Black
David (family member but did not participate in research)	Son and twin brother	9 years 11 months	5	Mainstream primary school	Communication and interaction Social and emotional wellbeing Sensory, physical and health	Male	Black
James	Son and twin	9 years 11	5	Mainstream primary	Communication	Male	Black

63

	brother	months		school	and interaction		
(family member but did not participate in research)					Social and emotional wellbeing Sensory, physical and health		

Table 3-2: A table to show appropriate contextual information regarding sample family two

Pseudonym	Position within family	Age at time of interview	School year group	Type of educational provision	Main area(s) of SEN	Gender	Ethnicity
Claire (participant in research)	Mother	N/A	N/A	N/A	N/A	Female	White British
N/A (family member but did not participate in research)	(Step)father	N/A	N/A	N/A	N/A	Male	White British
Thomas (participant in research)	Son and brother	10 years 0 months	5	Mainstream primary school	Communication and Interaction Social and Emotional Wellbeing	Male	White British
N/A	(Step)son	N/A	N/A	N/A	N/A	N/A	White

64

Pseudonym	Position within family	Age at time of interview	School year group	Type of educational provision	Main area(s) of SEN	Gender	Ethnicity
(family member but did not participate in research)	and brother						British
N/A (family member but did not participate in research)	Daughter and sister	N/A	N/A	N/A	N/A	N/A	White British

Table 3-3: A table to show appropriate contextual information regarding sample family three

Pseudonym	Position within family	Age at time of interview	School year group	Type of educational provision	Main area(s) of SEN	Gender	Ethnicity
Andrew (participant in research)	Father	N/A	N/A	N/A	N/A	Male	White British
Marie (participant in research)	Mother	N/A	N/A	N/A	N/A	Female	White British
Michelle (participant in research)	Daughter and sister	16 years 9 months	12	Further Education College (having transitioned from home education)	Social, emotional well-being and mental health Communication and interaction Sensory, physical and	Female	White British

65

N/A (family member but did not participate in research)	Daughter and sister	N/A	N/A	N/A	N/A	Female	White British
					health		

3.5.2 Data collection

3.5.2.1 Choosing a suitable method

Following the guidance of Smith et al. (2009), data was gathered through semi-structured interviews. This allowed the participants the opportunity to offer a "rich, detailed first person account of their experiences" (Smith et al. 2009, pg. 56). Semi-structured interviews allow for a degree of structure, but also flexibility so that unexpected and unanticipated issues can develop and expand (Robson, 2011). It was important for questions to be open-ended, while maintaining some sort of structure in relation to the areas of interest to the research (Smith et al. 2009).

The researcher approached the current study with the understanding that other methods of data collection may have been appropriate. Some consideration was given to unstructured interviews, however, the researcher wanted to support participants as fully as possible in voicing their experiences and perceptions, and was mindful that participants either may not have been used to openly speaking about their experiences, or may have had difficulties which reduced their capacity to do so, such as speech, language and communication difficulties. The researcher felt that semi-structured interviews would support the quality of the research given that she was a novice IPA researcher.

The researcher also initially planned to carry out focus groups with participants, incorporating family units as well as individual voices. Focus groups would have allowed multiple voices within one conversation, and therefore would have allowed an insight into the experience and interactions of the family. As identified by Smith et al. (2009, pg. 71), "the presence of multiple voices, and the interactional complexity of such events does make it more difficult to infer and develop the *phenomenological*

aspects". The researcher felt that it was important to remain focused on the phenomenological and idiographic aspects of IPA, and wanted to maintain an in-depth investigation of individual voice rather than group discussion.

Consideration was also given to carrying out multiple interviews as participants experienced the process. However, after some deliberation, it was felt that it would have been difficult to establish convergent themes across participants if multiple interviews were carried out at different points in the process for different participants. Multiple interviews would also have made design and analysis more complex as a novice IPA researcher, and this may have consequentially had a negative impact on the quality of the final account.

3.5.2.2 Semi-structured interview schedule development

The researcher developed an interview schedule following the guidance of Smith et al. (2009) (see Appendix 10). The schedule was created around the broad areas of interest of experiences of the EHC needs assessment process, and perceptions of family engagement within these experiences, as well as more specific topics which may have been pertinent to families' experiences and perceptions. The final topic areas included were expectations of the process, the stages involved in the experience of the process, perceptions of family engagement both generally and within the process, and evaluation of the process. Questions were constructed in order to be as open and appropriate to the topics of interest as possible, with prompts, for example asking participants to elaborate further, or how a particular experience made them feel. The schedule began with narrative or descriptive questions, moving onto analytic or evaluative questions, allowing the participant to become more comfortable as the interview progressed (Smith et al. 2009).

The researcher wanted to develop questions which would allow for high quality data collection, whilst avoiding a style of questioning that would be either leading or presumptuous about participants' experiences. Potential questions were discussed with the supervisor of the research, and were also adapted and altered as a result of a pilot study interview with two parents. This family consented to answering questions about their EHC needs assessment process with the understanding that the data collected would not be used within the study, but could act as constructive feedback for the LA in an anonymised format. Changes were made to both the content and the sequence order

of the interview schedule following these pilot interviews. These pilot interviews also supported the researcher in developing their interviewing style, acknowledging the challenges in maintaining an open and non-leading questioning style, and in developing the kinds of prompts which may be helpful in supporting participants in giving a rich account.

3.5.2.3 Timing of interviews

Participants spoke retrospectively about their experiences, and interviews were conducted in the summer term of the academic year 2014-2015 and the autumn term of the academic year 2015-2016. The researcher aimed to interview the participants when they would be able to give as much detail as possible on their entire experience, without having had time elapse during which the participants might have forgotten details of their experiences. The researcher therefore referred to the timeline of the assessment process for each family, as referred to in Appendix 1. All families at the time of the interview were, at a minimum, 14 weeks into the EHC needs assessment process, which meant that they had had access to the EHCP for the young person, either in draft or final format.

However, the exact point at which interviews took place during the assessment process differed for each family. The researcher had to be pragmatic, in line with working in the realm of real world research, and made each decision in conjunction with participants. Consequently, this meant that some participants gave a more retrospective account than others. The researcher acknowledges here that this may have had a significant impact on each participant's interpretation of events. For example, if a participant had viewed a final EHCP, this would have included an indication of the future educational provision for the young person within the family. From the researcher's professional experience, this is often very important for families' perceptions of the process and its outcomes.

3.5.2.4 Conducting the interviews

As part of preparation for the interview, it was felt (as advised by Smith et al. 2009) to ask participants where they would like the interview to take place. All participants for this research chose their family home as the site of choice. This came with the benefit of being a comfortable familiar setting for the participant, but also bought some risks for both the researcher and the data collection itself, in terms of safety, level of noise and potential for interruptions. Some measures were taken by the researcher in accordance

with these identified risks, for example checking in with a colleague upon arrival and departure from the site of interviews, and also checking with the participant, or member of the family, the likelihood of noise or interruption. The researcher found that the majority of participants were well prepared for the interviews, and had set aside a quiet time and place ahead of the scheduled time. The researcher felt it more important for the participant to feel comfortable and at ease, and therefore in a site of their choice, than for all risks for either data collection or the researcher to be averted. This was to give the researcher the best possible chance of collecting good quality data.

The researcher met with each participant on two occasions prior to the interview taking place. The first meeting was organised once the researcher had received the contact details of the family from a colleague within the Local Authority (see 3.5.1.3), with the family's consent for the researcher to make contact. During this first meeting the researcher shared information about the research, and left an information sheet (Appendix 8) and consent form (Appendix 12) with the family to read and consider. The researcher then visited the family a second time to answer any questions which family members might be holding about the research, and to collect signed consent forms from participants. At this point a date and time for the interviews was organised. This was felt to be a positive way of establishing a relationship and some level of rapport with each participant. In this way, the researcher felt they had taken steps to ensure that participants felt comfortable enough to openly discuss the issues of interest at the time of the interview. The researcher endeavoured to ensure that each participant knew who the researcher was and what the purpose of the interview was. At the start of each interview, the researcher reminded each participant what they should expect, and what the main topics of interest were. They also reminded each participant that there were no right or wrong answers, and that the researcher was interested in each participant as an individual and what had happened to them.

3.6 Ethical concerns

This study required careful ethical consideration, firstly because the researcher was collecting data from young people, whilst also acting as a practitioner, which meant that the researcher held responsibility to both the academic institution and the placement LA to which they were linked.

It was essential during this research that the guidance of a wide range of ethical codes of practice were followed, including the Health and Care Professions Council (2009), the British Psychological Society Code of Ethics and Conduct (2009) and the British Psychological Society Professional Practice Guidelines (2002). The research also received ethical approval by the Ethics Committee at Nottingham University on 23rd February 2015 (see Appendix 11 for ethical approval letter).

Some of the key ethical considerations which formed a crucial component of the research are described below.

3.6.1 Informed consent

As outlined earlier, all potential participants received brief initial information about the research, in the form of an initial information sheet (see Appendix 7). This information was then used by the family to decide whether they were happy for the researcher to contact the family directly. On meeting the family, the researcher provided further information to the family, including the young person. This was adapted as appropriate given the needs and ages of the young people in order to enable their understanding of the research as fully as possible. This included the rationale for the study and what would be required from them. Full information sheets were provided (see Appendix 8 for adult format and Appendix 9 for format adjusted for children and young people). After this initial meeting, the researcher met with each potential participant family on a further occasion in order to discuss consent forms, and to ensure that potential participants had the option to either withdraw or continue. Consent forms were signed and collected before interviews took place (see Appendix 12).

3.6.2 Confidentiality

In order to avoid identification, individual narratives were analysed by the researcher in their original format, but any names or other unique descriptors were removed during write-up, including of family members and professionals. Participants were assured that the confidential nature of the information included in the research could be guaranteed in this way. One of the participants (Thomas) identified their own pseudonym by which they would like to be referred, which is adhered to in this research. The researcher discussed with the participants that the data would be collected with two audio-recording devices to aid analysis, consequently stored securely, transcribed, and destroyed after successful completion of the doctorate.

70

3.6.3 Reducing harm to participants

The researcher remained mindful during the research process that, although there was a minimal risk of psychological harm or discomfort, data gathering may have provoked anxiety or other negative feelings for participants. Therefore, as part of the research process, the researcher allowed for rapport building with participants both before the interview took place and during it. Additionally, clear boundaries of the discussions were set, and the researcher drew on their skills as a practitioner of sensitivity and empathy to respond to the emotional reactions of participants. The boundaries of the discussions were supported with the semi-structured interview schedule, which focused on experiences of the EHC needs assessment process and understanding of family engagement rather than an in-depth discussion of the reasons for or outcomes of EHC needs assessment. If the researcher felt that the data gathering process had been particularly difficult for the participant, or had evoked negative emotion, because of the memories attached to this distinct period of their lives, then the researcher ensured that the participant left the interview with some positive memories or thoughts about their experience. The participants were also allowed to contact the researcher afterwards in case the data gathering process did provoke any anxieties or questions.

3.6.4 Right to withdraw

Participants were informed of their right to withdraw from the study without fear of any repercussions, without having to give a reason, and at any point in the research. This was made clear to all participants before data gathering took place. Participants were also informed that should they have chosen to withdraw at the time arranged for data gathering, during or after data gathering, their information and interview transcripts would have been destroyed without any impact or consequence. Participants were also informed that they could report to the researcher if they wanted any part of their data to be excluded.

3.7 Quality within qualitative research

3.7.1 Introduction

The recent upsurge in qualitative research over recent years has led to discussion amongst authors around how the quality, credibility and value of qualitative research can be enhanced and demonstrated, as compared to quantitative research, for which there are well-established and widely used criteria by which the standard of the findings

71

are judged (Giorgi, 2002; Patton, 1999; Yardley, 2000). These criteria, including objectivity, reliability and generalisability, are often mistakenly applied to qualitative research without a deep-rooted understanding of the philosophical backgrounds of different qualitative approaches, as well as the purpose of qualitative research, which is to enable a detailed and focused exploration of a topic of interest, often incorporating particular situations and experiences of individual people (Yardley, 2000). This section will outline some of the reasons why traditional quantitative criteria are not appropriate to demonstrate the quality of qualitative research, going on to describe some of the challenges which are faced in providing definitive standards for quality control, and finishing by outlining the frameworks which the researcher has chosen to employ for the current study.

3.7.2 Rejection of quantitative research criteria

Qualitative research differs from quantitative research in significant ways, as discussed earlier in this chapter, and many qualitative researchers have asserted that if the criteria of validity and reliability, as applied to quantitative research, are drawn on to evaluate qualitative research, many of the strengths of qualitative research would be lost. For example, the sample size which is included in the present study is not large enough to be statistically representative of the target population, however it does allow for a high level of analysis, which is part of the rationale for using qualitative methods. In addition, the researcher does not aim to demonstrate reliability, as the findings of the research will offer an interpretative account of the data which is gathered, and not a replicable account. In light of the researcher's epistemological position, it is acknowledged here that the knowledge which is created by this research is subjective, and therefore objective measures such as inter-rater reliability are meaningless (Yardley, 2000).

Despite this, it was recognised by the researcher that it was absolutely necessary to adhere to certain principles to strengthen the overall quality of the research.

3.7.3 Challenges in evaluating the quality of qualitative research

Patton (1999) and Yardley (2008) both recognised that, seeing as there are multiple approaches to qualitative research, all with their own purpose, assumptions, methodologies and theoretical backgrounds, it remains a challenge to identify criteria which can be applied to all qualitative studies. This lack of unity, as well as the relative

72

novelty of qualitative research methodology, when compared with quantitative, within psychology, has led to scepticism from a range of audiences with regards to the value which qualitative research has (Yardley, 2000). This makes it all the more important that there are flexible ways of establishing quality within qualitative research which are comprehensive, legitimate and meaningful for a range of audiences, particularly stakeholders (Yardley, 2000).

3.7.4 Yardley's (2000) criteria

Having reflected on ideas around demonstrating quality in qualitative research put forward by several researchers, including Elliott, Fischer, & Rennie (1999), Patton (1999) and Tracy (2010) the researcher decided to follow the four broad principles of Yardley (2000), which also follows the guidance of Smith et al. (2009) who suggested that these criteria are highly appropriate for IPA research. These four principles will now be addressed in more depth.

3.7.4.1 Sensitivity to context

An inductive approach was taken towards the data collected, and the researcher has not offered any hypotheses predicting what participants' perceptions and experiences may have looked like. The researcher sought a definition of the topics of interest from the participants themselves, and consequently sensitivity to the participants' accounts was demonstrated by an open as opposed to closed style of questioning. The relationship between participant and researcher was also considered (this will also be elaborated on further in *3.7.5),* and sensitivity was demonstrated to this by choosing a setting for data collection familiar to the participant, and holding the interviews at times convenient for participants, as well as allowing for a series of meetings and conversations with participants as part of the research which enabled development of trust. The researcher made herself aware of the wider and more specific contexts within which the research took place by immersing herself during the research process with literature related to SEN policy, family engagement, family and pupil voice and the philosophical background and methodological issues surrounding IPA. The professional role of the researcher also meant that she had a good level of knowledge of the process and situations within which participants found themselves, and particular information regarding participants has been outlined in order to promote understanding of their specific contexts. Within data analysis, the researcher demonstrated sensitivity to the

raw data by including verbatim extracts from each participant in order to support interpretations, as suggested by Smith et al. (2009).

3.7.4.2 Commitment and rigour

As discussed within *3.6.1*, the researcher has selected a small sample of individuals, including parents and young people, because of their homogeneity in having all experienced the process of interest, the EHC needs assessment process. Interviews were tape-recorded and fully transcribed, and extracts of both raw data and data analysis will be offered to the reader in order to support the findings (see Appendices 13 and 14). Data was collected through interviewing, and details and reflections on the process are provided in *3.5.2*. The researcher maintained commitment to the idiographic focus of IPA, by carefully listening to the accounts of participants, whilst illustrating convergence and divergence between participants.

3.7.4.3 Transparency and coherence

The researcher has described in detail aspects of her decision-making process which led to the choice of the research methodology of IPA. At the core of this decision were the research questions, and which methodologies may be most appropriate and suitable in order to answer these questions. Attempts at transparency have been made by detailing aspects of the design, data collection, sample and analysis of data. Raw data is offered to enable alternative explorations and interpretations.

3.7.4.4 Impact and importance

The researcher has aimed to demonstrate throughout this study the current importance and relevance of the current research, both at a local and national level, due to recent changes in legislation contained in the *Children and Families Act 2014,* which all LAs in the United Kingdom are now working to put into practice. The perceptions and experiences of families are vital to putting children, young people and parents at the heart of practice, as the principles of the *Children and Families Act 2014* state*.* The potential impact and recommendations from the research are stated later within *5.5.*

3.7.5 Reflexivity

The researcher here acknowledges that the findings and outcomes of this research were dependent on the researcher's own standpoint, and dual role as a researcher and practitioner, and therefore demonstrates a reflexive attitude. In light of this, in order to enhance the validity and credibility of this research as much as possible, some relevant

details of the background and beliefs of the researcher will be outlined here in order to support the reader's understanding of the interpretation of the data gathered which will follow. This is following the guidance of Langdridge (2007).

3.7.5.1 Why is the researcher carrying out this study?

As outlined earlier in *1.1,* the researcher's motivation to carry out this study was influenced by her desire to carry out a piece of research which would be highly relevant to the current practice of EPs, and which also would allow for parents' and young people's voices to be accessed within research. Interest in this area, and in carrying out a qualitative piece of research, also developed from previous experience as a researcher. The researcher had previously conducted a quantitative study, looking at the contributing factors to primary school pupils' sense of school community. The researcher felt dis-satisfied that the quantitative scores excluded the subjective views and perceptions of pupils about how they felt, and what was important to them in their school community.

3.7.5.2 Relationship to the topic being investigated

Is the researcher an insider or an outsider?

The researcher is an outsider to the process under investigation as she has never been directly involved in the EHC needs assessment process, nor has she had a child who has been assessed within this process. However, in her professional capacity, the researcher has carried out assessments of EHC needs within this process for a number of young people and therefore the researcher is familiar with the details of the functioning of the process.

Does the researcher empathise with the participants and their experiences?

The researcher empathises with families who may have experienced challenging life circumstances, who may not have accessed opportunities to share their thoughts, feelings and experiences, and who may have had times of conflict with professionals and with educational provisions.

Who is the researcher, and how might the researcher influence the research?

As a 27-year-old single child-less highly educated female, the situation of the researcher is likely to be distinctively different than families going through the EHC needs assessment process. Participants may have seen the researcher as a young, highly-

qualified female representative of the LA and this therefore may have impacted on how they responded to and interacted with the researcher. Furthermore, the researcher could not assume that anything about her experience of education would be the same as participants'.

3.7.5.3 Conclusions

The researcher recognises here that the complex interaction of all of these factors may have had a significant impact on the data gathering process and on analysis of data. For example, the researcher's potentially defensive or emotive response to the data needed to be considered carefully, as participants spoke about their relationships with professionals from the LA and school staff. The researcher aimed to address this by raising her own awareness of the issues which have been discussed, avoidance of favouritism or bias towards professionals rather than families, and the illustration of an account of the data which is clear, transparent and coherent to families and practitioners.

3.8 Processing and transcribing the data

In order to create transcripts which would be suitable for IPA, the data was first audio recorded using both a laptop and a mobile telephone (in case of failure of one or the other) and then transcribed verbatim. The level of detail in the transcripts was paid attention to, and was refined through replaying of the audio and by careful listening of silences and utterances which were at first difficult to decipher. However, because the purpose of IPA is to interpret the meaning of an individual's account, unlike other potential forms of analysis, the prosodic aspects of the recordings were not recorded in detail. It was recognised here that transcription in itself is a form of interpretation.

3.9 Process of data analysis

The analysis followed the approach of IPA, which offers a systematic and structured approach to analysing phenomenological data. Although the data analysis structure is not fixed for all IPA researchers, there is some guidance offered by Smith et al. (2009) of six stages which researchers move through. These are outlined below in Table 3.4 alongside activities and reflections within each stage. Analysis was undertaken with the understanding of the researcher that these stages could be used flexibly and in a cyclical fashion rather than in a regimented and ordered way.

Table 3-4: A table to show the six data analysis stages, proposed by Smith et al. (2009), of IPA, accompanied by activities within each stage, and personal reflections of the researcher

Stage	Activities	Reflections
1: Reading and re-reading	- Close examination of the text. - Reading whilst listening to the audio recording. - Attempt at total immersion in the data and active engagement with the transcript.	- At this stage the researcher was attempting to return to the 'things themselves', the lived experiences of each participant. - It was very important for the researcher that the participant was placed at the centre, and not the initial reactions, recollections or reflections of the researcher, which were noted in an attempt to bracket these. - This also enabled the researcher to note down any initial thoughts about emergent themes in order to attempt to concentrate on the data itself. - The researcher began to reflect on where in each interview the richer data was going to be, and what the structure of each interview looked like.
2: Initial noting	- Producing wide-ranging and unfocused notes on an explanatory level. - Carried out line by line electronically with a copy of the transcript in the left hand margin and initial noting in the right. - Free textual analysis based on three areas: - Descriptive comments – describing the content,	- Different methods were employed here. The researcher found that employing free association from the text initially led to rich and detailed analysis, accompanied by underlining words, phrases and sentences which felt important to the researcher's interpretation. - The researcher then went back over each transcript several

	highlighting words, phrases and explanations which structure the participant's thoughts and experiences. • Linguistic comments – focusing on specific use of language, how the transcript reflects ways in which the content and meaning were presented. • Conceptual comments - looking at the participant's overarching understanding of the matters they are discussing, noting at a more interpretative level.	times and paid more attention to the guidance offered by Smith et al. (2009) with regards to descriptive, linguistic and conceptual comments. • The researcher found it helpful to maintain the focus on the things which mattered to the participants, the meanings of these things for participants, and why their understanding might have developed in this way.
3: Developing emergent themes	• Labelling emergent themes that characterise discrete sections of text, which may evoke more psychological terminology. • Asking what was learned through initial noting. • Searching for concise statements to capture both researcher's interpretation and the original words of the participant.	• The researcher attempted to shift her focus from the raw data to the initial notes, which at times was challenging, and sometimes meant re-visiting the initial noting stage in order to improve her understanding of initial interpretations. • The researcher's fluency within this stage improved with each participant. Initially she found it difficult to recall the whole of the interview in the development of themes, and often repeated emergent themes which were very similar in meaning to each other.
4: Finding connections amongst emergent themes	• Relating identified emergent themes to each other through charting or mapping. • Either natural clusters that share meanings of references, or clusters which have hierarchical	• At this stage the researcher wrote every emergent theme on a post-it note and laid them out on a flat surface. This enabled the researcher to immediately spot connections between some emergent themes, and also to

	• relationships with each other. • Leading to the creation of a table which summarises structured emergent themes grouped into superordinate themes, and quotations illustrating each. • Some emergent themes from Stage 3 retained, some eliminated if they did not capture quality of experience of the phenomenon under investigation.	question the meaning of others which were then re-visited. • For some accounts there were initially a huge amount of emergent themes to work with (close to 100) and this led to questioning of the quality of analysis and interpretation, which again meant earlier stages of analysis were re-visited. At this point some emergent themes were reworded or eliminated. • The researcher mainly found the processes of abstraction, subsumption, polarization and numeration most useful, as suggested by Smith et al. (2009). • The researcher then typed the groups of emergent themes into a file with transcript extracts in order to further reflect on each superordinate theme and the appropriateness of it.
5. Moving to the next case	• Stages 1-4 were then completed for each case. • Each case was seen as unique and therefore as a new and fresh analysis by the researcher – ideas from the analysis of the prior case bracketed to work on the next one.	• Tried to maintain the same process for each case, although treating each case separately was challenging, as aspects of each participant's account led to the researcher recalling details from prior accounts.
6. Looking for patterns across cases	• Connections across cases were developed by looking at the most potent and prominent themes. • Creating a way of showing connections for the group as	• The researcher at this stage created a visual representation through post-it notes of the superordinate themes created for each case, and where the connections and divergences

79

80	a whole by developing master themes across all participants.	may be. • At this point the researcher felt it important to demonstrate particular higher order concepts which were shared by participants, as well as retaining the uniqueness of each participant's account in some way.

4. Findings

4.1 Introduction

The purpose of this section is to offer an interpretative account of the phenomenological analysis that was undertaken in order to answer the research questions 'How do families' interpret their experience of the EHC needs assessment process?' and 'How do these same families interpret their experience of family engagement within the EHC needs assessment process?' It will do this by demonstrating master themes across the group, and superordinate themes subsumed within.

The researcher will be as transparent and systematic as possible within this chapter, whilst simultaneously presenting the results of the study in a full narrative account. The reader should refer to Appendix 13, where extracts of raw data for each participant are placed, alongside initial noting and emergent themes, and Appendix 14, where tables of emergent and superordinate themes for each participant can be found, organised within master themes, with accompanying extracts of raw data.

Before presenting the findings, the researcher offers a picture portrait of each of the participants. This is in order to keep in line with the idiographic nature of IPA research, and also with Yardley's (2000) criterion of transparency and coherence, by identifying key reflections from each interview.

4.1.1 Family one

4.1.1.1 Eve (mother of David)

Eve is a single parent who is divorced from the father of her two children, here given the pseudonyms of David and James, both in Year 5. David and James are twin brothers who, at the time of the interview, both attended the same mainstream primary school. David has autism spectrum disorder. School staff working with David had requested an assessment of his education, health and care needs.

Eve's interview was highly emotive, as she became upset at recalling particular aspects of the assessment process, particularly the choice she had made for her two sons to attend different secondary provisions, which she found very difficult. The development of a positive relationship with David and James' school over time was important in the

account which she gave, particularly the emotional support which school staff had offered her.

4.1.2 Family two

4.1.2.1 Claire (mother of Thomas)

Claire lives with her husband and three children, including her son Thomas. Claire works as a Teaching Assistant. Her professional experience of working in a school with children with additional needs clearly impacted on her knowledge and her assumptions of the systems involved in assessing SEN. She attempted to explain during her interview how unhappy she was with her son's educational provision at the time, and how her request for an EHC needs assessment for Thomas was a way of accessing the right support for him in the future as he moved onto secondary school.

4.1.2.2 Thomas (child of Claire)

For Thomas, the overall experience of the EHC needs assessment process was clearly very abstract, and although he referred to some elements of the terminology used within this process, such as 'EHC', he was also very hesitant and ambivalent during his account. Thomas required continual breaks during the interview, and the researcher introduced specific objects of reference for the process such as the person centred review in order to improve the richness of the account (Person Centred Review; see Appendix 1 for where this falls within the timeline of the EHC needs assessment process).

4.1.3 Family three

4.1.3.1 Marie (mother of Michelle)

Marie lives with her husband, Andrew, and their daughter, Michelle. During the interview, Marie attempted to carefully and retrospectively recall details of the assessment process. The resonant themes of Marie's account were that of before and after the process, with regards to how bleak things were for her and her family before the assessment process was initiated, and the impact which she felt the process could make in the future, and family participation as individual voices as well as a whole family unit.

4.1.3.2 Andrew (father of Michelle)

Andrew seemed to welcome an opportunity to describe his family's experiences within education, health and care up until this point. He often veered from topic to topic within one response, and his use of language such as *faceless bureaucrats* (15.481) and *computer says no* (15.482) indicated how he felt his family had been continually let down by the very professionals who were supposed to be supporting the needs of his daughter. The EHC needs assessment process therefore acted as a way of enabling change and of finally getting his daughter into an educational provision which was right for her.

4.1.3.3 Michelle (child of Marie and Andrew)

At the time of the interview, Michelle, a 16-year old with significant social, emotional and mental and physical health difficulties, was in a period of transition from accessing home tuition to attending a college. Michelle clearly had no understanding of what the Education, Health and Care needs assessment process was, when described using this terminology. Like Thomas, the researcher widened the line of questioning to include life events and topics which were more meaningful to Michelle. Although Michelle felt that the process did focus on her, particularly on her transition to college, she also found it challenging to participate in the process; the Person Centred Review (PCR) was not differentiated, for example, to her interests and preferences.

4.2 Findings regarding master themes for the whole group

Analysis of the interview data followed the process described in section *3.9*. Clear examples of the analysis undertaken in the current research are offered in Appendices 13 and 14.

A total of seven master themes emerged. Five of the seven themes were shared by all of the participants, and the remaining themes were shared by at least four out of the six participants. This analysis allowed the researcher to connect the rich and detailed accounts that the participants offered by outlining the higher order concepts that participants' accounts shared, as well as identifying the themes which remained particular to individuals, as discussed by Smith et al. (2009). The frequency of each master theme across participants' responses is presented in Table 4.1 below. The researcher used Smith et al.'s (2009) criteria of at least half of participants converging on a theme for it to become a master theme for the group.

Table 4-1: A table to show the seven master themes, and the prevalence of each master theme across all participants

Master theme	Eve	Claire	Thomas	Marie	Andrew	Michelle	Present in over half of the sample?
Filling in gaps in knowledge	✓	✓	✓	✓	✓	✓	YES
What is the purpose of this process?	✓	✓	✓	✓	✓	✓	YES
The relationship between home and school	✓	✓		✓	✓		YES
Focus on the young person		✓	✓	✓	✓	✓	YES
Now we're not alone	✓	✓	✓	✓	✓	✓	YES
Family engagement	✓	✓	✓	✓	✓	✓	YES
Not feeling engaged in the process	✓	✓	✓	✓	✓	✓	YES

These master themes were decided on in reference to the original research questions. Master themes were therefore organised into clusters according to each research question, with a number of subsumed superordinate themes. These are presented in Table 4.2 below.

Table 4-2: A table to show master themes and subsumed superordinate themes arranged according to the two research questions

Research question	Master theme	Superordinate theme
How do parents and young people interpret their experience of the EHC needs assessment process?	Filling in gaps in knowledge	Lack of understanding about the process of statutory assessment Important influences on expectations of the process
	What is the purpose of this process?	Getting it right for the future Trying to understand the purpose of the process
How do these same parents and young people interpret their experience of family engagement within the EHC needs assessment process?	The relationship between home and school	Experience of the home and school relationship Communication between home and school
	Now we're not alone	Multi agency support Working in partnership with a keyworker Things are finally getting better
	Focus on the young person	A young person centred approach Supporting the young person's involvement
	Family engagement	Family focused approach Family participation Feeling empowered
	Not feeling engaged in the process	Power imbalances between families and professionals Feeling alienated from the process Lack of whole family engagement Feeling under pressure

85

Each master and super-ordinate theme is described in turn, in clusters around each research question, with tables which demonstrate the prevalence of each super-ordinate theme across participants. This is by no means an attempt to separate out super-ordinate themes, as they are intrinsically related, as demonstrated by the interpretative account offered in this chapter.

In order to offer as much transparency within this interpretation as possible, for each superordinate theme, the researcher will offer extracts from the raw data, with accompanying page and line numbers, in order to illustrate each theme clearly for the full range of participants. Quotations have been proportionally sourced across participants in order to offer a valid reflection of individual narratives, and have been taken from at least half of the participants related to each superordinate theme in order to justify the interpretative account offered here.

4.2.1 Research question one: How do parents and young people interpret their experience of the Education, Health and Care needs assessment process?

4.2.1.1 Master theme one: Filling in gaps in knowledge

This theme identified the lack of knowledge which participants felt they had about the process, both before, during and after their experience. Consequently, this theme includes the ways in which participants' awareness of the process was shaped, including the assumptions and expectations which participants had before the process began, and the influence of support services and personal connections.

Table 4-3: A table to show the frequency of super-ordinate themes within master theme one across all participants

Super-ordinate theme	Eve	Claire	Thomas	Marie	Andrew	Michelle
Lack of understanding about the process of statutory assessment		✓	✓	✓	✓	✓
Important influences on expectations of the process	✓	✓	✓	✓	✓	✓

<u>Superordinate theme one: Lack of understanding about the process of statutory assessment</u>

Five out of the six participants expressed the difficulties they had in understanding the process. This indicated that the experience of the EHC needs assessment process was unfamiliar as opposed to their existing schema of knowledge and experience, and that families entered the experience without being clear on what was going to happen. Participants often found it difficult to articulate what their expectations were.

> *To be honest I don't know what I expected at the time, I don't think it was anything like what I expected* (Claire, 1.19-20)

> *No. All I knew was about that there was a meeting* (Thomas, 3.79)

This lack of understanding also led to confusion during the process for participants.

> *I assumed that I'd get a letter to say that yes they was going to make a full assessment or no they wasn't, but the next thing I knew..* (Claire, 4.113-114)

> *We didn't really have much time to see what it was all about* (Marie, 12.354)

When asked about the process, and their understanding of it, the young people within the families in particular found it difficult to comprehend the focus and the content of both the process and the plan.

> *We haven't done the plan yet so cos we are going to do part of the plan in a minute I don't know what, I don't know what the plan is basically mostly about* (Thomas 12.390-391)

> *I don't know, I still don't understand it* (Michelle, 4.95)

Thomas in particular demonstrated some confusion over the use of the acronym EHC (*I thought it was Centre,* Thomas, 7.231), suggesting that even the terminology used to describe the process is confusing for young people. Thomas did interpret that he had some awareness of the process and the plan itself *(Educational Health Care Plan. I knew I was gonna have one,* Thomas, 8.246).

Thomas was able to express some sense of the plan resulting in a shared perspective between himself and other people *(I think what other people and a bit what I've said,* Thomas, 13.432) and Michelle interpreted that the focus of the plan is on her education (*Uh, like my, how my education's going,* Michelle, 1.5); and also made some references to her areas of SEN as at the core of the assessment process (*Um I knew it was for my autism*, Michelle, 5.106).

Andrew was set aside from the other participants in his confusion around how to access information, and what support was available for the family with or without the necessity of the EHCP.

> *but it was all a little bit wishy-washy, and we felt there may be support out there but it, there was no clarification or direction for us to see how that would actually take effect, or happen* (Andrew, 10.316-318)

Superordinate theme two: Important influences on expectations of the process

There was a recognition expressed that the EHCP acted as a replacement of a Statement of SEN, and thus participants felt informed by their existing knowledge of statutory assessment.

> *I knew it replaced the old plan, so I knew it was coming into place* (Eve, 1.3)

88

I knew it would be the more modern up to date version of a statement so I knew it would mean any support that was in the plan would be implemented because of it being a legal document (Claire, 1.13-15)

Information was also sought through the professional contexts of participants and personal research.

being on placement at uni I did hear about it anyway so I sort of knew an idea of what it was going to be about (Eve, 1.4-5)

The only reason I knew anything about that was because I googled it (Claire, 10.277-278)

Thomas and Michelle were both reliant on being informed by other people about the process (*Because he* (referring to the EP) *told me,* Michelle, 5.108); *(But she* (referring to his mother) *said it's to help me didn't you?* Thomas, 9.270).

This sentiment was also shared by the adults within the families, as Marie and Claire described the role which professionals had in informing their knowledge of the process.

"By (pause). It was Michelle's actually, Michelle's tutor, home school tutor that gave us the website for the council" (Marie, 2.30-31)

I'd mentioned to the head-teacher where I work that I was having issues with Thomas and his behaviour and being excluded from school, and he sort of said to me straight away um if you apply for an education health care plan it's a lot harder for them to exclude him, so he sort of sown the seeds (Claire, 2.33-35)

Eve expressed her apprehension and sense of dread about the process and the impact which it may have.

Yeah I was definitely putting it off, because I knew he had to go to a different school than James, I think I sort of like delayed it, because I don't want it to be a reality for him to go to a different school (Eve, 10.281-283)

Claire expected to face barriers at each stage of the process, and was surprised to reach her ultimate goal of an EHCP for Thomas.

I was pleasantly surprised and pleasantly shocked that we didn't have to appeal (Claire, 5.124-125)

For others, their use of comparison and contrast between the assessment process and their previous experiences, or assumptions made about assessment, meant that their expectations of the process were initially low.

> *you think of an assessment as someone going away and doing it and coming back, whereas this wasn't anything like that* (Claire, 9.266-268)

> *things in Michelle's life don't happen very quickly, you know even the DLA wasn't quick, the PIP, everything's very, you have to keep ringing up people, have you got these bits, you know and we never had to do anything like that, so it was pretty plain sailing for us* (Marie, 12.330-332)

In contrast to these low expectations, Andrew and Marie expressed their eager anticipation of the process, in that it would allow the family to access further help and support which they had not previously been able to.

> *so our understanding was that there was more support available for Michelle, which is what led us, that we could get more support and more help for Michelle, that's why we started looking into it* (Andrew, 1.13-14)

> *we just knew it was a good thing to have, it would help Michelle, and that was all we were thinking, it would help Michelle get everything that she needs* (Marie, 12. 354-356)

Conclusions

There were a wide range of influences on the expectations of the process which participants held. These included statements of SEN, the personal contexts of the participants and reliance on parents and professionals. The feelings expressed by participants about what lay ahead for them in the process were also mixed, from dread to eager anticipation.

4.2.1.2 Master theme two: What is the purpose of this process?

This theme has been posed as a question as the researcher interpreted that all of the participants were continuously attempting to seek out a clear purpose of the process by addressing different areas; at times directly addressing what the purpose may be for, and elsewhere describing their perception of the impact of the process on the future.

Table 4-4: A table to show the frequency of super-ordinate themes within master theme two across all participants

Super-ordinate theme	Eve	Claire	Thomas	Marie	Andrew	Michelle
Getting it right for the future	✓	✓	✓	✓	✓	✓
Trying to understand the purpose of the process		✓	✓	✓	✓	✓

<u>Superordinate theme one: Getting it right for the future</u>

It was interpreted by the researcher that transition was an important and emotive component of the process for Eve.

> *I knew from the meetings that David was going to be suitable for a special school* (Eve, 3.59-60)

For Claire, Andrew and Marie, thinking about the future of their children's educational provision acted as a trigger point for the beginning of the assessment process, and often thinking about the future without any security of provision was linked with anxiety.

> *for me to be getting worried about his future, that's what was the turning point in me applying for one* (Claire 10.299-300)

> *having the statement or a plan would ensure that Michelle could get the support, and it went beyond school age, it went you know for college and that sort of thing, because we were so concerned about the gap, um in her so long out of school, so much missed* (Andrew, 1-2.24-27)

> *I know now that it's set in place for Michelle for the next, well until she's 24, 25 I think, so she'll get whatever help she needs, educationally, that she's never had before, you know, so that kind of helps* (Marie, 5.139-142)

91

It was apparent that Thomas did not necessarily understand the purpose of the process as securing provision for his future, as his mother Marie did. He did however describe the experience of visiting secondary schools within his perceptions of the process (*going to a few schools,* Thomas, 14.445). This was unlike Michelle who did identify that the process was intrinsically linked to her own future (*Yeah 'cos it was all about finding the right college, and I think they got the right college*, Michelle, 3.59).

<u>Superordinate theme two: trying to understand the purpose of the process</u>

Thomas, Michelle, Andrew, Marie and Claire all grappled with trying to understand what the purpose of this process was. Thomas described how he thought professionals might have met *to learn a bit more about me* (Thomas, 3.75), with the ultimate aim of helping to improve his current situation (*To help me stop those ups and downs happening*, Thomas, 10.318). Michelle struggled to understand why professionals were visiting at home *(I can't remember what it was for,* Michelle, 15.366), but she did seem to understand the process as having the purpose of providing support (*Because otherwise they wouldn't be able to help me*, Michelle, 14.325)

Andrew understood the purpose of the process as to ensure the right provision was in place for Michelle, although the exact reasons for obtaining an EHCP still remained unclear.

> *We questioned them on it, and I remember the consultant sitting there and I said well what does that do, what does that achieve, um and they were sort of saying, well as they understood it, having the statement or a plan would ensure that Michelle could get the support* (Andrew, 1.23-25)

Marie freely described her confusion about the process (*what it's for or what it does really, we don't and we applied for it,* Marie, 8. 225-226). But she clearly felt that the process would enable her daughter to catch up in some way in education that she had missed (*we then realised that she was behind on school, she struggled at school anyway, she was home schooled, so that's when we decided to ring up the council*, Marie, 1.11-13)

<u>Conclusions</u>

The true purpose of the process was expressed as a mystery. Although participants had some recognition of what was happening, it was unclear for them why. There was a

92

recognition of the process enabling some kind of extra support and help, but there was a clear lack of transparency around who the process may be more appropriate for and why.

4.2.2 Research question two: How do these same parents and young people interpret their experience of family engagement within the Education, Health and Care needs assessment process?

4.2.2.1 Master theme three: The relationship between home and school

This theme identifies the importance of the relationship between home and school, and the impact which this had on families' interpretations of experiences of family engagement, both within the EHC needs assessment and at a wider level. Participants spoke at length about several components of this relationship, including emotional support which school staff provided for parents, the lack of trust which parents felt for school staff, and the different ways in which parents and school staff communicated with each other. This theme is also poignant as it was identified by parents and not by young people.

Table 4-5: A table to show the frequency of superordinate themes within master theme three across all participants

Super-ordinate theme	Eve	Claire	Thomas	Marie	Andrew	Michelle
Experience of the home and school relationship	✓	✓		✓	✓	
Home – school communication	✓	✓			✓	

<u>Superordinate theme one: Experience of the home and school relationship</u>

Eve differed from other participants, as the account which she offered of the relationship with her son's school was very positive. She spoke of the collaboration which took place between the two parties (*work together*, Eve, 8.212), and it was clear that the interactions between Eve and school staff went further than Eve partaking in her son's education. For Eve, the school was an environment where she felt she could openly discuss traumatic events, and indeed she acknowledged that she had over time become reliant on school staff for this emotional support.

> *I mean I've always been open with them you know like talking about my divorce talking about losing my dad* (Eve, 11. 305-306)

> *I don't think if I'd had the support from school I wouldn't have coped as well* (Eve, 16.452-453)

There were several components to the development of the home-school relationship which were described as key. These included the interpretation that anything which was discussed was not shared with other people unless this had been agreed with the parent.

> *anything I told her was confidential so it was implemented, put in place where I could tell her things but it was not discussed with everyone* (Eve, 12. 322-323

Also crucial was the concept of trust. Eve believed that school staff saw her as competent in the tasks which were required of her as parent, and she also held complete confidence in school acting in the proper way in order to meet her family's needs.

94

> *I think trust as well is important, for me to trust them, and for them to trust me as well* (Eve, 8.207)

In contrast, Claire, Andrew and Marie did not feel confident about the effectiveness of school in identifying and supporting SEN. This was expressed as an assumption that school staff have neither the time nor the capacity to carry out an in depth assessment of the difficulties which their children may be experiencing in school.

> *it's easy to just stay on the surface, as opposed to digging at those layers and finding out what makes him tick if you like, because it's very hard when you've got a class of 20 odd or 30 odd kids to pay that much attention to one child* (Claire, 11.310-312).

> *there doesn't seem to be an assessment or a process, there doesn't seem to be any, I couldn't point to any time when any of Michelle's behavioural issues, or any of the, I couldn't point at any stage where you could say yes the school picked up on that* (Andrew, 3-4.89-91)

The level of knowledge which school leadership held about SEN was also doubted, and this led to a sense of mistrust about behaviour management strategies within school.

> *I think although the SENCo knew that the reason he was acting the way he was was because of his difficulties, I don't think the same thing could be said of senior leadership, cos they're not specialists in Special Educational Needs, they're specialists in managing the school, it's a different role all together* (Claire 11.314-317)

It often felt for parents like certain members of school staff were blaming the young people for the behaviour rather than identifying and supporting areas of need.

> *I think it boiled down to him getting into trouble because of his anxiety and his stress rather than him just being naughty for the sake of it* (Claire, 2.43-45)

> *she kept forgetting what class she had to be in, she couldn't cope with the timetable, she then kept getting detentions, she had detentions nearly every week because of something she'd forgotten, but that's Michelle's fault you see, and I'm thinking but it isn't because Michelle hasn't got very great memory* (Marie, 13.406-409)

Mutual respect was also core to the relationship, which Eve saw school as demonstrating by keeping her up to date and by asking for her consent when professionals were involved with her son.

> *if anyone couldn't make the meeting, then they would let me know* (Eve, 6.169)

In contrast, other parents felt that decisions which were made in school, both before and during the assessment process, were often made solely by school, with no input or evidence of joint decision-making with families, showing a distinct lack of respect for their opinions.

> *I feel that had the head, the person excluding Thomas, understood where Thomas was coming from, I don't think the punishment would have been quite so harsh* (Claire 11.316-317)

> *the school were still useless, they still never told their own autism team that Michelle was autistic so we never got any help from mainstream school in that respect* (Marie, 7.185-186)

Claire saw the process as an opportunity to express her concerns about what was happening for her child in school. This was interpreted by the researcher as having attempted to express concerns to school staff prior to the assessment process, but having seen no action taken.

> *it was my chance to say what I felt wasn't working at school, without me just saying it to school if you like, it felt a bit more official* (Claire, 4.99-100)

Superordinate theme two: Communication between home and school

As with superordinate theme one, Eve was placed in sharp contrast with the other participants in her interpretation of communication between home and school. Eve interpreted this as being open two-way positive communication, which meant that useful information was shared between herself and school staff, both having the best interests of her son at heart.

> *it was just like a going home diary so it's just a little, like a book, and it's got a picture like going home, so anything that happened at home that they needed to know like if he wasn't sleeping um or if he went to bed late or anything like that,*

96

> *I was telling school and school were telling me you know not always issues that*
> *they had, but if he had a good day what he had been doing* (Eve, 13.362-364)

This communication continued over time, including into the timeline of the process, whereby a shared perspective of the young person was created by both school staff and parent through meetings and conversations.

> *it was important that school got my view as well, and I got school's view as well*
> (Eve, 4.89-90)

Communication between Eve and school staff resulted in the two parties sharing particular aspects of the assessment process, including visits to potential future educational provisions for David.

> *It was always the SENCo, so I'd always let her know when the visit was, and um*
> *she was always, I always invited her* (Eve, 14.403)

For Claire and Andrew, although there was some interpretation of communication between parents and members of school staff which was flexible and suited to parents' preferences (*I had an email from the school SENCo*, Claire, 3.70), there also seemed to be many barriers to open two-way communication between home and school.

> *although school knew that he'd got autism and difficulties, I don't think that they*
> *took his needs as seriously as I did* (Claire, 10.296-297)

Conclusions

Participants had varied and diverse experiences of their relationships with their children's educational settings both prior to and during the assessment process. For Eve, the process acted as a continuation of what typically happened for her in her communications with school; an open, two-way and shared experience. Whereas for other parents, they were disappointed about many aspects of their child's education, and felt unable to voice their concerns in a way which would make a difference.

4.2.2.2 Master theme four: *Now we're not alone*

This theme identifies the change which participants perceived as occurring due to the assessment process, particularly compared to the experiences which families described prior to the process, during which they felt very isolated. Participants were very

welcoming of multi-agency input during the process, and the role of the keyworker was depicted as particularly important for families during the process.

Table 4-6: A table to show the frequency of super-ordinate themes within master theme four across all participants

Super-ordinate theme	Eve	Claire	Thomas	Marie	Andrew	Michelle
Multi-agency support	✓	✓	✓	✓	✓	
Working in partnership with a keyworker		✓	✓	✓	✓	
Things are finally getting better				✓	✓	✓

<u>Superordinate theme one: Multi agency support</u>

Eve, Claire, Thomas, Andrew and Marie all offered their interpretation that they did not experience the process on their own, but that it was a process which was shared with a large number of people from different backgrounds and different professions

> *his doctors, childminder, everyone was involved in it* (Eve, 1.17-18)

> *Yeah 'cos my Auntie Jenny, my Mum, My Dad, some other ladies, Katy, Mr. B***, Mr. D***. and Miss G*** and then some other ladies* (Thomas, 1.8-9)

As well as the summative effect of different professionals being involved in the process, and for Andrew new professionals being involved who could offer a fresh perspective (*the professionals are there, and it's just a blank sheet, which is great, because they've got no opinion, and are not involved,* Andrew, 8.228-229), there were also specific individuals who were perceived as having unique roles and contributions to the process. Those professionals ranged from the EP (*a lot of those points I think, have come from Laura's* (referring to the EP) *understanding of Thomas*, Claire, 11.321-322), to the transition team (*I'm sure at that point the transition team got involved, so she came with me around a few schools*, Eve, 4.105-106), to a clinical psychologist (*he was adamant*

that Michelle needed an EHCP, and he really wanted it for her, so he was always like our little vocal person in the meeting, Marie, 12.348-349). As is evident from these quotes, Claire, Eve and Marie all shared an appreciation for specific individual professionals.

As well as the unique roles and contributions which individual professionals played, Eve and Andrew both expressed a sense that professionals did far more than was required from them during the process.

> *they did so much as well out of their way* (Eve, 9.256)

> *professionals that got involved, it probably wasn't necessarily in their remit* (Andrew, 1.52)

For Marie, the contribution of professionals, more specifically CAMHs, was more important than anything else in the process (*I think they were paramount really*, Marie, 12.339). For Marie and Claire, multi-agency input allowed them to feel safe and secure that their opinions of their children were shared by another.

> *it was quite astounding for me to have another professional to have the same understanding of my son that I had always had* (Claire, 11.302-303)

> *an educational person to say yeah I've got it, yeah she needs help* (Marie, 14.410)

This discrepancy between the power held by family and professional voice perceived by participants will also be illustrated in a later master theme 'Not feeling engaged in the process.'

Superordinate theme two: Working in partnership with a keyworker

Claire, Thomas, Marie, Andrew and Eve all identified the keyworker as a particularly important part of their process.

For Thomas, the keyworker was someone who was *trying to help me* (Thomas, 14.441), and who the family jointly shared responsibility with for writing the EHCP (*yeah and we've helped her*, Thomas, 15.480).

For the adult participants, the keyworker served a range of purposes. They helped parents to feel more involved in the process by providing them with the latest information about what was happening in the process.

> *With the keyworker just emailing me, updating me, telephone calls from himself,* (Eve, 13.379-380).

> *I don't think I would have known what to do next at each stage I suppose, because she was always there to say this is what's happening, and this is what we need it for* (Claire, 13.378-379)

Importantly for Claire, the keyworker developed an understanding of her and her son as individuals during their interactions, and that she felt that she could talk openly about her current situation.

> *um I think her and Thomas hit it off really quite good at the start anyway, and I think she's an easy person to talk to, because I think if you're talking to someone you don't know about something quite intimate, like your son's needs, you've got to have a certain amount of trust in that person as well haven't you, and I think if you don't know the person and you don't feel like you're going to get to know them if you like, then you find it hard to open up I suppose* (Claire, 13.370-374)

The keyworker was also a reliable and supportive individual who spent focused time with families, acted as their advocate and enabled them to access services which were beneficial for the young person.

> *all I had to do was either text her or email her, and she was on it like you know straight away* (Claire, 13.387-388)

> *she helped us with lots of little things, to try and get in touch with people* (Marie, 6.134)

Running through Claire, Andrew and Marie's accounts was the thread that the personal qualities of the keyworker really mattered to the families.

> *Sarah seemed quite a strong-willed as a person, so I thought in a safe pair of hands, you know, someone who's going to help you to get your point of view across* (Andrew, 9.256-257)

Superordinate theme three: things are finally getting better

Family members Andrew, Marie and Michelle all interpreted that the assessment process had made some difference to their lives. Marie in particular described her continual attempts over time to access the support which her daughter needed as a persistent battle, with the assessment process eventually acting as a desperate cry for help.

> *we just keep going and we keep going and we struggle and we keep going* (Marie, 2.49)

> *Well we didn't have any help. It took Michelle to hit rock bottom before we could get any help really.* (Marie, 6.165-166)

Both Andrew and Marie expressed an intense dissatisfaction with the wider systems involved. For these parents, it was not clear why the support which was enabled by the assessment process had not been available for the family at an earlier point in time.

> *if it had happened years ago, and if she'd got the help that she'd needed, we might not be on the path that we're on now where you know she was in hospital* (Marie, 14.401-402)

The language used to describe their prior experiences was placed in direct comparison with how Marie and Andrew described the assessment process, and the eventual publishing of an EHCP for Michelle. The assessment process was described as one which brought about more change and more professional support than the family ever felt able to achieve on their own.

> *having the EHCP helped to instigate lots of things happen* (Andrew, 5.128)

In particular, compared to the lack of communication between different services which was depicted (*you've got your neurological team at the hospital and you've got the psychological team, some of the medications affect each other, but they didn't communicate*, Andrew, 5.137-138), the process for Andrew helped to promote a joined up approach whereby different services were brought together, even services who may not have been involved with the family before the process began.

> *so the EHC helped me to get people to talk about Michelle's, what she needed* (Andrew, 5.154-155)

101

Similar to her parents, Michelle felt that the assessment process had enabled some kind of change and this was clear from her description of her previous mainstream school compared to her description of her current college.

> *now we're all together we can finally have friends, and we're all the same* (Michelle, 12.277)

Michelle described the difference that finally feeling listened to had made to her.

> *you know that you're not getting put in the corner for no-one to like listen to you, and you're just going to be stuck there questioning things, and you don't really know what's going on or anything* (Michelle 13.314-316)

Conclusions

This theme has been used to describe the range of ways in which participants interpreted working jointly with a range of other people during the process. For some families this was a new concept, as they described themselves as isolated as a family unit and therefore perceived the process as having made a huge difference to enabling professional support. For others it meant the integration of a new professional, such as the keyworker, into family life, and attempting to understand their role.

4.2.2.3 Master theme five: Focus on the young person

This theme describes the young person centred approach which Claire, Thomas, Marie and Michelle all felt was taken at some point in the process, to varying degrees. It is poignant here that both of the young people included in the sample identified their needs, interests and views being taken into account at some point.

Table 4-7: A table to show the frequency of super-ordinate themes within master theme five across all participants

Super-ordinate theme	Eve	Claire	Thomas	Marie	Andrew	Michelle
A young person centred approach		✓	✓	✓	✓	✓
Supporting the young person's involvement		✓	✓			✓

<u>Superordinate theme one: A young person centred approach</u>

Claire described the process as *person orientated if you know what I mean, as in Thomas* (Claire, 8.224-225), outlining how she *felt that Thomas was included in everything, every step of the way* (Claire, 8.228). She noticed particularly that Thomas was placed at the centre of the PCR, and this was indicated by his presence for the entirety of the meeting (*it was focused around the child, whereas probably previously meetings like that you wouldn't have expected the child to stay in the whole meeting*, Claire, 1.21-22).

Thomas described the process as focusing on him on numerous occasions during his account of his experiences. He enjoyed the, perhaps novel, opportunity for a range of people to share relevant and up to date information about what was important for him. This indicated that Thomas perceived an accurate and fair perspective of him as a person was being gathered during this assessment, from both home and school.

> *so we could know all the things about me, everything all about me* (Thomas, 1.16-17)

> *they was talking about me and how I hate peas* (Thomas, 1.19)

> *Cos I'm autistic and like and some people need to know* (Thomas, 2.53)

Michelle also shared this perspective that people were using this process to get to know her as an individual person. Being in a face-to-face conversation with people who were

knowledgeable in her areas of her strength and difficulty was a particularly important part of this.

> *otherwise it wouldn't be an accurate reading, if like people are just saying it* (Michelle, 14.334)

> *people who work with autism, and yeah people who actually know about autism* (Michelle, 8.177)

For Marie and Andrew, at the core of the young person centred approach was an opportunity to place their daughter at the heart of all the multi-agency discussions which took place.

> *we were writing everything down about Michelle, so that has to put her as the most important person* (Marie, 10.284-285)

Furthermore, a young person centred approach provided an opportunity for young people to be listened to, both by professionals and parents. This was interpreted by the researcher as a rare chance for parents to step outside of their typical everyday role and to understand their children's needs. Sometimes this involved listening without the young person being required to speak, therefore demonstrating their views in a more flexible way.

> *when they're at school, or with a tutor, you don't see that, you just, they just come home and you're Mum and you know, but to listen to her, I then realised* (Marie, 5.118-119)

> *she could put what she wanted, she could write what she wanted* (Marie, 10.267)

Superordinate theme two: Supporting the young person's involvement

Michelle offered some direct advice to those who are trying to access her voice.

> *I think people should just be more quiet, and then they can hear you talk* (Michelle, 10.241)

As Michelle described her interactions with a variety of professionals during the process, it became clear that feeling listened to was a crucial component of feeling involved in the process for Michelle. When somebody was listening to her, this

indicated a degree of two-way interest in the interaction. Michelle needed this to be conveyed to her by verbal responses; any non-verbal gestures were not enough.

> *Because he was replying, like when someone isn't listening they'll either nod or just like don't say anything* (Michelle, 5.116-117)

Just as Claire described the PCR as a person-centred approach, she also identified how Thomas was supported in his involvement in the meeting.

> *one was for Thomas to sort of put down on paper some of his ideas, so I actually gave him his copy, and he was walking round and writing down relevant bits from the paper that he'd got, he was writing them on the paper on the wall, which was good for him, because I don't think he would have written anything otherwise* (Claire, 4.90-93)

Thomas himself was able to identify a number of different aspects which supported him in feeling at ease in the PCR. These included the meeting being discussed with him in advance, although this was limited to the basic logistical details of the meeting; *telling me when the time is, when we are going (*Thomas, 1.28). During the meeting, Thomas had a supportive member of staff who *walked around with me* (Thomas, 2.31). He was able to have a choice of drinks and snacks (*there was biscuits we put down and drinks*, Thomas, 2.45) at the meeting, in order to enable an informal atmosphere, which was part of the preparation of the *comfy room* (Thomas, 4.105) which Thomas did with *some kids* (Thomas, 2.39). The people who were present at the meeting were also important to Thomas (*Having my Mum, most of my family*, Thomas, 5.151) He felt this enabled him to feel able to talk about *what I like about school, what I don't like about school, what I like about home, what I don't like about home* (Thomas, 1.23-24).

It was also important to Thomas that his needs were adapted to in the process, and that people understood what his preferences in certain situations during the process were.

> *A bit happy cos no one's in there except adults but Westdale I got a biscuit.* (Thomas, 6.199)

> *No and I don't really like um long conversations* (Thomas, 5.159)

Conclusions

This theme has looked at the particular parts of the process which enabled families to perceive it as being focused on the young person. Of particular interest was that it was not only parents who perceived the process in this way, but also young people, who described being listened to, and participating, particularly in the PCR.

4.2.2.4 Master theme six: Family engagement

This theme identifies how participants described what was interpreted by the researcher as family engagement. As this concept is multi-faceted, the master theme covers a number of different superordinate themes, including a family focused approach, participating as a family, and the ideas of power and control.

Table 4-8: A table to show the frequency of super-ordinate themes within master theme six across all participants

Super-ordinate theme	Eve	Claire	Thomas	Marie	Andrew	Michelle
Family focused approach	✓	✓			✓	
Family participation		✓	✓	✓	✓	✓
Feeling empowered	✓	✓		✓	✓	

Superordinate theme one: Family focused approach

Eve, Claire and Andrew all spoke about feeling like they were at the centre of the process. Sometimes this was about professionals working to meet the needs of the entire family whilst on other occasions it was about showing interest in the family. Family members were placed at the heart of any decision-making made during the process, for example by allowing parents time to look at the plan in depth.

> *they was always oh Mum do you agree with that, or Mum, do you have anything to say, so it always came back to me* (Eve, 8.228-229)

106

> *we were given plenty of time to assess it, read it two or three times* (Andrew, 12.384-385)

A family focused approach also meant that families felt listened to. Their views were not only heard, but incorporated within the heart of the assessment, and this often meant that parents noticed professionals making a particular effort to reach out to their family.

> *I was listened to as to what was important for David* (Eve, 8.220-221)

> *she went out of her way to meet with me after that, because she wanted to go through what she had written* (Claire, 13.394-396)

Superordinate theme two: Family participation

Claire, Marie, Thomas, Andrew and Michelle all described their experience of a whole family assessment which also incorporated individual family members' voices. This was a pleasant and enjoyable part of the experience, as it assigned equal value to the voices of different family members, thus alleviating pressure from the voice of the parent.

> *quite good that we were as a family doing it* (Marie, 9.241)

> *it was not just my opinion that counted, it was Thomas's that counted as well, and we could talk about what we felt was right and what the answer should be, and I didn't feel like there was any pressure on me to answer it myself, rather than, you know I didn't feel like I was going to be coercing him into writing something that I thought was right rather than writing something that he thought was right, so it was like a joint opinion* (Claire, 9.252-256)

> *Me and Mum and Dad* (Thomas, 6.180)

This whole family participation took different formats for different families. Sometimes it was in conversation (*we did feel we got the chance to speak,* Andrew, 15.460) and sometimes it was recording their views in a written format (*make sure that I had everything written down,* Claire, 84). Preparation for contributing to the assessment process was particularly important to parents, as statutory assessment was often described as a long awaited opportunity to express their views.

> *unless you're already prepared for what they're going to ask you, you can't sometimes come up with an answer straight away* (Claire, 4.87-88)

so when I knew this was coming up we'd sat at home and thought about a few things then (Andrew, 6.173-174)

Superordinate theme three: Feeling empowered

Reflecting on their experience of the process, participants did identify that they felt in control in terms of having the ability to make something happen the way they wanted it to happen. In particular, the flexibility of the plan and the input of the voice of the parent into this written document were clearly described.

if there were any amendments to be added, or anything that I didn't agree with, there was a blue slip that I had to write, the comments on there. (Eve, 5.115-116)

I'm now having the opportunity to say whether I think this is right so it was, I'm trying to find the right word, um (pause) felt a bit more in control (Claire, 7.203-205)

Autonomous decision-making was also important for parents. Eve identified that she was able to dictate her choice in terms of looking at and deciding about a secondary school (*I narrowed my decision down to a school that I chose*, Eve, 1.10), and felt that she dictated the organisation of events during the process (*with meetings I made sure everyone was aware when they was taking place*, Eve, 1.18-19). Claire and Marie both acknowledged applying for the assessment themselves, and making the decision independently to do this (*I did have quite a long think about it, I didn't apply for it until April*, Claire, 2.36-37; *decided to ring up the council, or the city council, and to ask about it*, Marie, 1.13)

Feeling empowered during the process was important for parents as it also meant that they felt more confident in their own beliefs about their children. Parents also perceived that they could claim the right support for their children, as professionals were held accountable to the provision stated on the EHCP.

validates it for me that it's not just all, that I'm not just seeing things, or I'm not making it up (Marie, 4.108)

these people seem to be taking it very seriously what they have to be doing, and I could pick up they were being scrutinised (Andrew, 12.379-380)

This theme has described the experience of family engagement which participants perceived during the process in three ways. Firstly, the experience of a process which firmly puts the family at the heart of everything going on. Secondly, participating as a whole family. Thirdly, feeling in control of the process and empowered by events during it.

4.2.2.5 Master theme seven: Not feeling engaged in the process

Table 4-9: A table to show the frequency of super-ordinate themes within master theme seven across all participants

Super-ordinate theme	Eve	Claire	Thomas	Marie	Andrew	Michelle
Power imbalances between families and professionals	✓	✓		✓	✓	✓
Feeling alienated from the process		✓		✓	✓	✓
Lack of whole family engagement		✓		✓	✓	✓
Feeling under pressure	✓	✓	✓	✓	✓	

Superordinate theme one: Power imbalances between families and professionals

Families often felt under the influence of professionals, and this resulted in what was interpreted by the researcher as passive involvement. Eve, Claire, Marie and Andrew all described their experience of accepting the process as it was defined and dictated by others, without any true resistance or objection.

> *I just went along with it* (Eve, 2.25-26)

> *so if for some reason someone wants to come round and do something, we're like yeah come round and do it, it was, maybe it was being accommodating* (Marie, 11.303-305)

109

During the process, participants also perceived themselves as reliant on professionals to make certain decisions or complete certain actions during the process.

> *maybe in the second year whether I needed to get a statement for David, at that time it was called a statement, and they said oh because we're meeting his needs, I'm not sure whether he needs a statement* (Eve, 7.96-198)

> *she'd took that away, she was going to send that off to the SEN team* (Claire, 7.197-198)

Professionals were described using the rather vague term of 'they', as 'they' retained the power in deciding whether to continue with the assessment for the young person or not. There was a lack of knowledge identified by parents about these professionals, consequently leading to a deeply rooted lack of inclusion of families in decision-making.

> *we're one side of the wall and they're the other side of the wall if you like, just because they're invisible because we've not had no contact* (Claire, 12.356-357)

> *It was when they were talking about my schooling and all how I think and stuff.* (Michelle, 1.17)

For Marie and Andrew, it was very important to access a professional third party perspective on their daughter's need, incorporating expert knowledge and power which parents didn't have.

> *I mean I'm just an old hairdresser, I haven't got the first clue about autism* (Marie, 6.72)

> *you've suddenly got the EHCP people, who are able to have the clout to ask questions* (Andrew, 5-6.157-158)

Superordinate theme two: Feeling alienated from the process

During the process, participants often felt isolated from assessment and decision-making. Parents often had to leave events to chance, and decision-making was perceived as invisible to all but a select few. This created a sense of uncertainty, as participants did not have safe and secure knowledge of what would happen next.

110

everybody discusses Michelle and discusses the plan, and then say yes or no to it, and then Sarah said, you will be notified two days, maybe later, whether you've got the plan or not (Marie, 11.320-321)

it was just that initial wait between us submitting the details to it going to panel, and even at this stage we didn't know whether we was going to get a plan or not (Claire, 7.184-185)

I don't know whether they've got a points system or whether they discuss it and decide, was it a clear case, or was it a marginal (Andrew, 16.512-513)

Michelle described how distant from and uninterested in the process she felt, which was interpreted by the researcher as a lack of connection with the process as a way of having control and direction over her own life, and the lack of choice she had in the format and activities during the PCR.

I didn't really think about it I guess I just left and went out with my friends (Michelle, 82).

There was a lot of people and how they were doing it was really boring (Michelle, 39).

<u>Superordinate theme three: Lack of whole family engagement</u>

Despite the aspects of family participation which were described within the prior master theme, participants also identified a clear lack of whole family engagement, and furthermore a lack of engagement of other family members aside from parents and young people.

it didn't include the other siblings I don't suppose, very much, cos I don't know, they were never really aware of Thomas's issues, um to, I was never actually asked I don't think if either of the other two wanted to have any input to be honest (Claire, 8.221-224)

The young person supposedly at the core of the assessment process was often perceived as excluded from it, either in terms of not being physically present at points, or not participating in the conversation taking place around them.

Then Sarah came round on the Wednesday, last Wednesday I think it was, Thomas was away, and talked through the actual plan (Claire, 7.192-193)

the stuff that she thought we were talking absolute gobbledy-gook about really (Marie, 9.262)

This idea was supported by Michelle's description of the PCR, which captured how difficult she found it to engage in this particular meeting.

Because it was really boring. (Michelle, 2.34)

I had no energy to, and I was just like, my legs were aching and I got tired (Michelle, 3.55)

Superordinate theme four: Feeling under pressure

Families felt that they faced particularly anxiety-provoking parts of the process. Parents in particular felt that there were pre-conceived roles for them in the process, such as acting as an advocate for the young person.

Um initially I thought my role was to um, I don't know, be there for Thomas, and sort of stick up for him if you like (Claire, 4.97-98)

there are times when I feel I need to, even though she's 17, I need to say, or I need to be more vocal for her because she's not actually saying how it is. (Marie, 5.127-128)

Parents also felt they needed to say and do what was perceived as the 'right' thing during the process. Typically, this involved painting a negative and bleak picture of the difficulties which their child was facing, rather than celebrating their strengths and what was going well. Parents felt that they had access to a one off opportunity during the PCR when as much information as possible needed to be translated to ensure the assessment process would be carried forward.

I was a bit apprehensive because I'm thinking at this stage, um you know right at the beginning of the meeting, I'm thinking um it started on a positive but I really need them to see his difficulties (Claire, 3.80-82)

have to think of everything, that everything is down there, or else maybe you'll jeopardise the outcome (Marie, 4.92-93)

I must admit nervous, because you almost feel like this is your one chance and panicking (Andrew, 7.207-208)

Furthermore, participants felt under pressure to participate in the process in a certain way, more specifically writing on poster paper during the PCR, and meeting with professionals, depicting a significant lack of choice or power over how the process unfolded.

> *we had to write things down on walls, cos they had paper - big pieces of paper*
> (Thomas, 1.12)

Conclusions

Put in purposeful direct comparison to the previous master theme 'family engagement', this theme outlines the range of difficulties and challenges which families faced in engaging in the process. It feels extremely poignant how families perceived that there were particular moments in the process which acted as sole opportunities to record their views and concerns. It is also very interesting how families identified a significant lack of choice in how to participate in the process, with fixed formats of family participation being offered, such as the PCR and booklets for parents and young people to fill out.

5. Discussion

5.1 Introduction

The purpose of this chapter is to link the analysis to both the overarching research questions, and the relevant literature discussed in the literature review. A small amount of new literature that the researcher felt was highly relevant, given the analysis of data, will also be introduced through this chapter. Specifically, this chapter will discuss and critique key elements of each master theme in relation to relevant psychological and sociological theory, and in relation to the research questions. Consideration of methodological issues, possible implications for practice and potential areas for future research will also be identified.

When considering the relevant psychological and theoretical frameworks the researcher looked once again to the eco-systemic approach of Bronfenbrenner (1979), which was introduced in the literature review as a way of understanding family engagement. Bronfenbrenner (1979) is particularly useful in considering systems at the wider societal level, termed the macro-level, which impact on the micro-level of individual experiences. Family members' perceptions and experiences of the EHC needs assessment process within this research, at the micro-level, were impacted on by a wide range of interactions with the LA and with school staff, at the macro-level. Parents, and in particular Claire, Andrew and Marie, perceived that the LA and school were under pressures which impacted on their capacity to assess and meet the needs of children with SEN, and to allocate resources and funding in an effective way.

As stated, in order to improve understanding of the analysis carried out, the researcher here considers literature which was not introduced in the Literature Review, but which was particularly resonant with the themes that emerged through data analysis. This literature specifically relates to the factors which shaped and influenced the experiences of participants during the EHC needs assessment process, especially their experiences of relationships and interactions with professionals during the process. The researcher found the socio-cultural discussion of the evolution of the family-professional partnership, with a focus on power, empowerment and community participation, by Vincent (1996) and Turnbull, Turbiville & Turnbull (2000), particularly interesting and relevant to the research objectives.

5.2 How do parents and young people interpret their experience of the Education, Health and Care needs assessment process?

5.2.1 Filling in gaps in knowledge

The interpretations of accounts offered within this study denote that family members did not feel that they had a satisfactory level of knowledge about the EHC needs assessment process, either before or during their experience. This finding is particularly powerful as it is one which was shared by young people, Thomas and Michelle, as well as by parents.

The researcher interpreted that participants did not choose to be deliberately ignorant about what was happening for themselves and their families during the process, but this was simply a symptom of the process in itself. This was due to the perceived lack of transparency and clarity with regards to what the assessment process could and couldn't enable. Andrew in particular described his significant level of confusion with regards to the support and resources that were or weren't available for his family, and which of these services and resources may be ring-fenced by having an EHCP.

This lies in direct comparison to statutory guidance published by the government, in the form of the SEND code of practice: 0-25 years, which states the following:

> "The LA **must** ensure children, young people and parents are provided with information and advice on matters relating to SEN and disability" (DfE & DoH, pg. 33)

In light of the researcher's interpretation that some of the experiences of the families within this research lie in stark contrast to the advice given in legislation, it is suggested that the LA within which this study was carried out is not making use of the tools and methods which are available as a way of supporting families to feel informed about the EHC needs assessment process, and what it would mean for them. This also has implications for participation in the process, as identified by Delgado-Gaitan (1991) who stated "To actively participate in schools parents must become informed about the school system and how it functions" (pg. 25).

As related to previous research, Epstein & Dauber (1991) found that parents expressed a desire for better advice and information to be provided by school programmes and teacher practices. Whilst the current research is not directly related to the work undertaken by teaching staff to inform and involve parents in education, it remains poignant that, a number of years on from Epstein and Dauber's (1991) study, families still perceive that they are poorly informed about statutory processes within education.

This raises the question as to whether there is still much to be done to promote the principles of the new legislation within LAs. This development in practice may in turn have an impact on parents', and perhaps the wider community's, expectations of the process, and may enable families to feel informed about the options, including services, that they can expect within the Local Offer. This will be discussed further in the later section *5.5.3.*

From what young people could tell the researcher within this study, the EHC needs assessment process simply did not hold an important place in their lives. Both young people within this research demonstrated confusion and ambivalence about the process. For the researcher, this raises the question as to whether professionals and parents currently feel that young people do always *need* to be involved in the process. There is a distinct lack of published research available to refer to which has investigated the perceptions of young people with regard to their own involvement and engagement in statutory assessment within education, and also the perceptions of parents and professionals with regard to the extent of the involvement of young people in this area. This may be an important area for future researchers in this area to consider. This will be considered in the later section *5.6.*

The accounts given by family members within this theme also suggest that there are many factors that help to shape the expectations of families of the EHC needs assessment process. This is an area that is not covered in depth within existing literature. This study clearly demonstrates that there are divergences between individual family members, as to the factors which impact on expectations, ranging from knowledge about prior statutory assessment processes, to the personal and professional contexts of different families, to information gathered from professionals. These factors have an important impact on how families may approach the process, particularly with regards to the emotions which families may experience in the lead up to the process,

whether they wait for it in eager anticipation, as Andrew and Marie did, or approach the process with a sense of dread about what may lie ahead for the family, as Eve did.

5.2.2 What is the purpose of this process?

Guidance published consistently states that the purpose of statutory assessment, to which there has been little change despite the reform in policy, is to clarify and assess in detail the SEN of a child or young person, and to set out what specialist provision the child or young person needs (DfES, 2007). However, these findings indicate that families who took part in this research perceived the purpose of the EHC needs assessment process as ensuring some kind of safety net for their children with regards to their future and to transitions to future educational provisions. The accounts given by parents in this research indicate that a parental application for an EHC needs assessment was made because of concerns about their children's future education, learning and wellbeing, and that parents understood the assessment process as a way of ensuring support for their children until they were 25 years old.

This in turn led to the interpretation by the researcher that parental confidence in wider SEN systems remains key to the experience of parents of the statutory assessment process; parents do not have enough confidence in the wider systems which are in place within education, outside of the statutory assessment process, in order to meet the needs of children with SEN. Thus parents are dependent on statutory assessment in order to feel confident that the right support will be put in place. Parents expressed a sense of discontent about their children's current or previous experiences within educational provisions, and this led to parents seeking support and help which they did not feel had been or was widely available within the educational systems which they had experienced.

Over ten years ago, Norwich, Beek, Richardson and Gray (2004) highlighted tensions within the education system in a response to the findings of the Audit Commission (2002), and of a report carried out jointly between the Audit Commission and OFSTED (2002). This research indicates that these tensions remain relevant to the current statutory assessment process. Both of these reports recognised how parents often feel that they have to fight for a statement, as they are not confident that without it, and the protection which it provides, the right provision will be made for their children. Norwich et al. (2004) discuss how LAs and schools can work to assure parents in order

for them to feel confident in the education of their children, and how this work may have previously been neglected in order for LAs to meet their statutory duties.

In relation to the present study, LAs are once again under a large amount of pressure with regards to their statutory duties, particularly as the timeline for statutory assessment has been shortened from 26 to 20 weeks. However, a focus on meeting statutory timelines should not detract attention from other key issues as related to meeting the needs of children with SEN, as outlined in previous literature (Audit Commission & OFSTED, 2002).

5.3 How do these same parents and young people interpret their experience of family engagement within the Education, Health and Care needs assessment process?

5.3.1 The relationship between home and school

There was a significant divergence noted in the accounts of the relationship between parents and school. Some parents, particularly Marie, Andrew and Claire, perceived that they were in direct confrontation with school staff about particular issues with their children's education, and others, particularly Eve, developed a much more positive relationship with school staff. The divergence between the families within this theme may be better understood when drawing on literature which discusses the potential barriers and facilitators to family engagement, including Abel (2014) who identified how existing disconnects between teachers and families, for example differences in culture, and misconceptions about the role which parents may have in their child's education, for example the assumption that parents of children from low-income communities do not care, may have an impact on the development of relationships between families and professionals. The findings of this research suggest that some families do develop a sense of true partnership with their children's schools. Key to this partnership, as Bailey (1994) suggests, is dialogue, honest and open sharing of ideas and opinions, respect, trust and the perception of the parent(s) that school really care about the wellbeing of their child and family. However, this study also indicates that other families find it difficult to forge an effective relationship and style of communication with schools. This highlights issues which have been noted in previous research (e.g. Truss, 2008) within the experiences of parents, such as school staff who fail to act

appropriately on their concerns about a young person, and difficulties in accessing effective support for the young person at the right time.

It appears from the findings of the current study, as also suggested by Truss (2008), that there is a high level of variability between schools, regarding levels of support, engagement with support services and attitudes towards the family. This research also indicates that two-way communication between home and school is extremely important in order to develop a positive relationship; Eve described her perceptions of feeling listened to and feeling that information which was shared by both herself and school staff really mattered to her son's development. This is in line with the definition of family engagement offered by Ferlazzo (2011), who referred to 'active listening' to the thoughts and ideas which parents bring, and shared decision-making.

5.3.2 Now we're not alone

The findings of the current research highlight two themes within the literature; the sense of isolation that families can encounter, and the difference that developing positive relationships with professionals can make.

The interpretative accounts that families have given in this study resonate strongly with parental accounts of experiences of alienation from schools and support services (Truss, 2008), of the "inherent need for children to fail over an extended period of time before any help can be secured" (Truss, 2008, pg. 372), and of frustrating, distressing and time consuming experiences of diagnosis and forward planning (Keenan et al., 2010).

Cunningham and Davis (1985), Appleton and Minchom (1991), and Dale (1994) all discuss the potential benefits of professionals working in partnership with families. These were particularly apparent when families spoke of their experiences of working with the keyworker. This is in line with both legislation and prior research. Statutory guidance (DfE & DoH, 2015) states that the main functions of key working support should include emotional and practical support as part of a trusting relationship, enabling and empowering the family for decision-making and the use of Personal Budgets, co-ordinating practitioners and services around the child or young person and their family, being a single point of regular and consistent contact and providing information and signposting. The keyworker in the assessment process fulfilled many of these functions for the families interviewed here. O'Connor et al. (2005) also demonstrated the importance of a personal keyworker approach, and the difference that

this can make with the level of satisfaction parents have with the statutory assessment process. This was described by O'Connor et al. (2005) as "the importance of having a named contact person whom parents can meet face-to-face to discuss the outcomes of the assessments and the proposed statements, who will listen to their insights and suggestions and who will update them on progress" (pg.266). This is also in line with the most important features of the keyworker, which were outlined by participants in the current study. The researcher interpreted the accounts of Claire, Marie and Andrew in particular as depicting a keyworker who shared their power with the family. Families within this research felt in partnership with the keyworker, who actively involved the family in decision-making and met the needs of the family and the child (Turnbull, Turbiville & Turnbull, 2000). It was particularly important that the keyworker listened to what families had to say and collaborated with families through sharing information and solving problems.

This research also suggests that the EHC needs assessment process does go some way to ensuring collaboration between support services. This insight into families' experiences of multi-agency working has not been discussed at length within previous research literature. There has been previous discussion about best practice in multi-agency working and what this includes, for example by Carter, Cummings & Cooper (2007). However, the importance of multi-agency working within families' experiences was surprising for the researcher, particularly the different areas of impact which were noted as a result of the process, with regards to bringing professionals together and ensuring discussions between different services.

5.3.3 Focus on the young person

Five out of the six participants in this research described the process as focused on the young person in some way. This is in accord with the core principles of the SEND Code of Practice (DfE & DoH, 2015), which include 'supporting children, young people and parents to participate in decisions about their support' (pg. 21). O'Connor et al. (2005) also found within their research that parents generally felt that the statutory assessment process fairly and accurately reflected their child's needs.

This theme highlights findings from other research that identified a child centred focus within the experiences of parents of educational processes (Hebel, 2014), and reinforces previous literature which puts a focus on the young person as core to family

120

engagement (Ingber & Dromi, 2010). However, the accounts of pupil participation within this theme led the researcher to reflect on what was really meant by the concepts of 'pupil voice' and 'pupil participation' within the context of this research.

According to Matthews, Limb and Taylor (1999), within the field of children's participation, there appears "a divergence of views on the nature, purpose and form that participation should take" (pg. 137). The interpretation of families' accounts here agrees with this, as participants Thomas and Michelle both experienced participation in the process in different ways. For Thomas, his participation was interpreted as recording his views with his mother and the keyworker, and attending the PCR. Michelle interpreted her participation as feeling listened to, being in conversation with adults during the process and being involved in decision-making. This has important implications for both practice and research in the future.

Despite the perceptions expressed by participants within this theme, it remains questionable whether the young people were truly active in the process. Reynaert, Bouverne-de-Bie, & Vandevelde (2009) have previously discussed concepts of independence and autonomy within children's rights literature, including young people constructing and directing educational processes in their own way. The researcher suggests in light of this literature that the involvement of the young people in the process within this research was fairly limited, predominantly to attendance at a multi-agency meeting, and engagement in conversation with professionals, with no interpretations offered of linking the involvement of the young people to their interests or aspirations. It is also suggested that one reason for this fairly limited involvement was that the child was expected to know about their own life, needs and interests in order to become autonomous, as suggested by Benporath (2003).

5.3.4 Family engagement

The findings within this theme suggest that families experienced aspects of both family engagement, in terms of a collaborative two-way relationship with professionals which enabled families to feel listened to, and family empowerment, in terms of the sense of agency and control which families developed, during the assessment process. This brings to the forefront the definition of family engagement offered by Ferlazzo (2011) of working jointly and collaboratively with families, including active listening of the thoughts and ideas which parents bring, and shared decision-making.

121

Whole family participation appeared particularly important to parents and young people within their perceptions of family engagement. Thomas and Michelle described themselves and their parents as holding joint importance in decision-making about their futures and education. The work undertaken by professionals to incorporate individual family members' voices during assessment was particularly significant for participants, and especially so for Eve and Marie. Eve, Claire, Marie and Andrew's descriptions of being put at the heart of decision-making, and of developing positive relationships with professionals who expressed a genuine interest in what was important to the family, supported them in feeling valued and important during the process.

The researcher found Claire's interpretation of family engagement within the EHC needs assessment process particularly interesting; she described herself and Thomas, her son, jointly engaging in a task provided by the family's keyworker. Claire clearly felt more engaged in this process because of herself and Thomas working together without the support of any third party. This is a concept which has not previously been explored within previous literature, but suggests that the family-centred and strengths-based approach to family engagement could be considered on a wider basis than merely in terms of engagement with professionals; the capacity of family members to work together appears a potentially important notion.

Choice was also an important aspect of family engagement, particularly for Eve. Her experience of being offered a choice for her son's secondary school was highly significant, which suggests that choice of provision remains an important way for parents to feel engaged in their children's education. This is in line with legislation: "we will give parents the right to express a preference for any state-funded school, including Academies and Free Schools" (DfE, 2011, pg. 8). This research indicates that parents welcome this opportunity and feel that it is an important part of parent voice. It was particularly interesting that all three families in this sample were considering transition in educational setting at the time of the interviews. The accounts indicate that if family members were involved in the transition then it was perceived as a more positive experience by the family.

Families within this research felt throughout the process that they had more ability to take greater control and develop autonomy over aspects of their lives, which was interpreted by the researcher as feeling empowered. Parts of the process allowed

122

families to create greater freedom and control in their lives, for example adjustments made to the draft plan. This is in line with what Wolfendale (1992) described as enabling individuals, or individual empowerment.

5.3.5 Not feeling engaged in the process

Oppressive power relations were very important within this theme. Natiello (1990) suggested that authoritarian power historically has been most common within human relationships, where an individual human or group of humans hold control and power over the will of another or others, as opposed to individual freedom. Authoritarian power can lead to feelings of distrust, a lack of control, and dependency from those in a subordinate position on those in a more dominant position. Often those in a subordinate position feel disconnected from those in a more dominant position, and they can develop feelings of low self-esteem.

Parent and professional relationships in particular have been described in this way, with parents in a subordinate position, and professionals in a more dominant one (Turnbull & Turnbull, 1997), particularly when describing the partnership between parents and professionals involved in the education of a young person (Dale, 1996). This is referred to as a 'power-over relationship', and is often due to the fact that professionals hold control over information and resources which parents need in order to make decisions regarding support for their children. There are many features of the power-over relationship, including professionals holding control in decision-making, parents perceiving professionals as having a higher level of competence and communication in a professional-friendly rather than parent-friendly style (Turnbull, Turbiville & Turnbull, 2000). These features were all identified by participants in the current study. This construct of a power struggle between parents and professionals has been referred to elsewhere within research, for example by Jones and Swain (2001), who made a link between parent involvement and a power struggle between parents and professionals, and Hodge and Runswick-Cole (2008), who discussed how parents continually feel disempowered in their relationships with professionals. O'Connor (2008) also made reference to an inequity in the relationship between professional and parent, with reference to professional gate-keeping which led to parents being on the periphery of decision-making. Despite the high level of understanding conveyed of power imbalances between families and professionals within literature, this research indicates

123

that families still do perceive that power is unequally shared between themselves and education professionals within education processes.

With regard to the reasons for this sense of inequality, as Vincent (1996) recognises, there is a perceived discrepancy between the professional knowledge of practitioners, and families, as well as a language barrier in terms of parents perceiving that they need to use the 'right' kind of language for their points to be clearly understood. Todd and Higgins (1998) discuss the different positions which parents and professionals occupy in relation to the systems of education and care that young people are involved in, and the varying perspectives of both parties which occur as a result. This encapsulates the experience of parents in the current study of being on 'the other side of the wall' from professionals.

Neo-Marxist theory can also help to shed light on the issues which are being explored here. Gramsci, for example (cited in Vincent, 1996) described the hierarchical structure of power, with some social groups holding more economic, social and cultural power than others. Subordinate groups are not completely powerless, as identified by the families in this research, who describe feeling empowered to a certain degree by this process, but an imbalance in power remains. Families in this study have found themselves positioned within the EHC needs assessment process, which requires "forms of knowledge, institutional structures and social relationships" (Giroux, 1994, p. 157). The LA has dictated a structure and agenda for the process which families have to follow. Consequently, for some participants, this has led to the perception of constraints within the process, particularly linked to agency and choice. Families were forced into submission with regards to their experience, for example patterns of social interactions with unfamiliar people who were not chosen or defined by families.

Meaningful participation of the whole family, including the young person, in any educational process is complex and challenging for any professionals working with or around the family, as indicated by the numerous discussions held by researchers around how to measure family involvement, and the multidimensional components of this (e.g. (Fantuzzo, Tighe, & Childs, 2000). This research also highlights the viewpoint that the child is not able to participate, or that they are "ignorant, innocent and needy" (Cordero Arce, 2012, pg. 365) is still in existence. For example, Michelle remained in her room during some home visits from professionals during the process, and therefore remained

124

an outsider to discussions held around her EHC needs assessment. This also aligns with discourse around children's rights which has been in existence since the adoption of the UNCRC, with reference to highlighting "the childhood image of the competent child" (Reynaert et al., 2009, pg. 520). The image some adults have of children as vulnerable and in need of protection is also depicted within this theme as parents feeling under pressure to act as an advocate for their child because they are unable to speak for themselves.

5.4 Consideration of methodological issues

IPA is an extremely powerful research methodology in that it offers an insight into the perceptions and experiences of a group of individuals, with an idiographic and phenomenological focus. However, the strengths of IPA are also in some ways its weaknesses. It is acknowledged here that the research methodology only allows for a small sample group, in this case six participants. Therefore, this research cannot be taken as representative of all families who experience the EHC needs assessment process.

The family members who have been interviewed within this research are of course strongly interlinked with the contexts within which they find themselves, and these contextual factors will have an important impact on the accounts which have been offered. Although the researcher has taken steps to enhance the potential transferability of these findings to other contexts, for example providing information about the LA context and the families who participated, the skewed sample should be considered when discussing methodological issues linked with this research, as it comes from one singular LA and within a certain timeframe.

The findings of this research come from interpretations of the researcher. This again is strength as well as a weakness, as whilst the research is able to offer a layer of analysis as well as description, inevitably, the research will include some of the researcher's own beliefs and biases, as the interpretation is subjective. As noted throughout this study, the researcher has made continual attempts to counter this, by describing in detail how the data has been gathered and analysed, and by attempting to maintain transparency and rigour within the methodology.

Issues experienced by the researcher during data gathering through semi-structured interviews should also be considered here. Following the guidance of Smith et al.

125

(2009), the interview schedule was used in a flexible manner. The researcher referred to the guide of the schedule in order to phrase questions to each participant, and to move from narrative accounts to analytic questions. However, the researcher reflected during the course of the interviews that it was important to avoid sticking rigidly to this structure, and to allow for flexibility and for ebbs and flows in conversation.

A particular point of interest and reflection here was the joint role of the researcher as researcher-practitioner. There were some skills which the researcher had developed over the course of their training as an EP which proved useful and which the researcher was able to draw on in the course of interviewing. These included taking a role as an active listener, listening attentively, noticing and probing certain points, being sensitive to the participant's view point and phrasing questions in a comprehensible way. However, there were also some habits which the researcher had developed, for example sharing experience and knowledge, which although useful in a professional context, were less helpful in a research context.

The researcher recognises here that there were many challenges within the course of the interviews that the researcher continually grappled with. These are issues which have been recognised by others as continual challenges within semi-structured interviewing (Smith et al. 2009), such as remembering issues to return to, asking closed questions, asking multiple questions at the same time, accidentally leading the participant, accidentally making and communicating assumptions about the world view of the participant, interpreting information which is being received whilst in the course of the interview, and not probing enough to provoke an appropriate level of depth and detail. However, the researcher simultaneously recognises that their interview technique improved as time went on, and there were some challenges faced which the researcher dealt with more fluently as they experienced conducting more interviews. These included learning to take time in an interview and listening carefully to what is being said by the participant (and sometimes to silence), and maintaining the semi-structure of the interview whilst being attentive to the concerns and interests of the participant. The researcher was also particularly attentive to the rhythm of the interview process, and noted changes in the dynamic of the interaction between the researcher and the practitioner, depending on how comfortable the participant seemed, for example, with reporting affective perceptions rather than descriptive accounts.

126

It is also important to acknowledge what IPA as a methodology expects from participants during data collection. Interviews require participants, including young people, to have a certain level of verbal ability in order to engage with the researcher in conversation. Although both young people who took part in the research could communicate through language, because of their additional needs (both were diagnosed on the Autism Spectrum Disorder, and therefore found social communication, social interaction, and imagination and flexibility of thought difficult), they found it difficult to talk openly, abstractly and at length about their emotions and experiences. They were a lot more comfortable referring to their concrete observations about the world. From the experience of having carried out this research, the reflexive and articulate qualities which were demanded did impact on the data which was collected from the young people, but didn't stop them from participating.

5.5 Possible implications for practice

The aim of this section is to illustrate the possible implications for practice that have been highlighted by the previous findings and discussion.

The issues which have been highlighted by six family members, including parents and young people, highlight the complexity of the experiences which families may have during SEN statutory assessment. This research also highlights the facilitators and barriers to family engagement which families may experience on a wider basis than only during statutory assessment. Caution should be advised whilst considering these implications, as recommendations for practice are tentative due to the small and limited participant sample size.

5.5.1 Possible implications for Local Authorities

This research suggests that there should be widely available and easily accessible information for families which promotes a better understanding of the process, including its purpose. In light of the finding that participants in this research often experienced confusion before, during and after the EHC needs assessment process, this information should be made available to families who are considering a request for an assessment of EHC needs, to the families of the young person for whom an EHC needs assessment has been initiated and at regular points during the process.

Widely available and easily accessible information should also be available about the Local Offer within LAs, leading to an open discussion with families about which aspects of the Local Offer may be relevant to them, and how the Local Offer could be developed further, in a format which is clear and easy to understand. This should include transparency around what different support services are able to offer with and without an EHCP.

This research indicates that LAs should view each family who experiences the EHC needs assessment process as unique, and should work with them accordingly. This may include gathering information about what may impact on families' approaches and experiences within the process, including prior relationships and experiences with educational provisions and personal and professional circumstances. As such, support should be offered to make the EHC needs assessment process meaningful and relevant for each individual family, for example by adapting to their circumstances and working conditions, which may include single parent families and working parents who may be unable to attend meetings and visits during the day. In addition, LAs should carefully consider the potential benefits of the relationship between keyworkers and families and the importance of this with regards to access to services and resources for families.

It is likely that LA officers do not see themselves as agents of oppression, or as promoting imbalances in power in their everyday work. The findings of this study, however, suggest that there are components of the EHC needs assessment process as experienced by families which places families as the subordinate group in relation to employees of the LA. This is occurring despite the fact that the government has published clear guidance, as part of their transformation of the system for young people with SEN, stating that LAs should put the participation of young people and their families at the centre of the system, as well as ensuring choice and control for families over the support they receive. LAs should view family engagement within the EHC needs assessment process as not only activities which are demanded of or done with families, but as encompassing the attitudes, beliefs and interactions of the whole education community. With regards to the EHC needs assessment, LAs should aim to truly involve families in any decision-making which is relevant to them during the process, therefore offering greater empowerment to children and parents. Families should feel able to understand any decision which is made by LA officers, with

128

transparency around who makes the decisions within the EHC process, and how these are made, including whether to make an assessment, or to issue an EHCP. Collaboration with families during decision-making should be made more transparent, so that their voice and presence is clear, ensuring that the very nature of the EHCP is shaped by families from the beginning of the assessment process. LAs should consider introducing elements of choice, as part of family engagement, with regards to what happens during the process for families, for example the format of the PCR or how families and young people choose to offer their views and wishes.

LAs need to consider the nature of the relationship between family members, inclusive of young people, and professionals during the EHC needs assessment process. They need to make a firm commitment to moving away from a model which defines professionals as experts, who act as gate-keepers to resources and interventions, to one which is flexible to the needs of the family, acknowledges the expertise which families can bring, and promotes a shared ownership of the EHC needs assessment process. This echoes previous research which has also reported the negative perceptions of parents of educational processes (Jones & Swain, 2001).

LAs should make a firm commitment to ensuring that families, professionals and the wider community as a whole become knowledgeable about the resources which would make the most difference to families' lives, and enabling families' participation in decision-making about the nature and extent of resources which are allocated to them. These components were suggested by Turnbull, Turbiville and Turnbull (2000) as key to collective empowerment. As part of this, LAs should look at improving confidence in SEN provision as an alternative to the demand for statutory assessment. This may include ensuring an easy point of contact with a school or LA for parents of children with SEN.

5.5.2 Possible implications for schools

In line with the above possible implications, schools should consider the different ways in which the participation of young people in the process could be supported by school staff, alongside the development of ideas around what is constraining and facilitating the successful participation of young people in the process currently. This may include

the consideration of when and how parents act as advocates for their children's views, and whether this is always appropriate, how else young people could participate aside from written and verbal contributions and how much attention is paid to the degree to which each young person wishes to participate.

Schools should incorporate person-centred planning within regular practice, with the participation of children and young people as suited to their needs and interests, as opposed to a fixed format which is presumed to suit every child and young person.

Schools should maintain flexible and open lines of communication with families about their concerns and needs, including how children's needs are met with a graduated response within the school's SEN budget. This should include regular opportunities for parents to express their concerns, and meaningful participation of families within plan-do-review cycles. Support should be offered to families to rebuild trust in teachers and schools when it has been lost, particularly by demystifying the work that schools and professionals do to ensure additional needs of young people of being met.

5.5.3 Possible implications for Educational Psychologists

This research highlights that EPs, within their regular practice, should take into account families' previous experiences of support and education, as this may have an important influence on how families interact and respond to support services. Professional and personal contexts of families should also be taken account of, for example if a parent is working in education, EPs should be aware that this may influence their perceptions of educational processes and systems.

EPs should consider their vision of working in partnership with families, particularly whether this includes decision-making and influence. This may include reflection on the perceived role of the parent and also of the young person in the statutory assessment process, and how this impacts on interactions between EPs and families within the EHC needs assessment process. EPs may also reflect on the power imbalance between professionals and families in the EHC needs assessment highlighted by this research, including the assumption that decision-making power during the process does not lie with the family, but with professionals who then decide on the best course of action on behalf of the family. This may also include clear guidelines for EPs on how and when to feedback assessment information gathered within the EHC needs assessment process to each family, thus enabling co-construction of EHCPs with families.

EPs should consider the role which they may play in supporting families' understanding of the process, particularly in line with promoting equality and diversity for families and young people by sharing information which is widely available and easily accessible at regular and early points in the timeline of the process.

5.6 Future research

The aim of the current study was to enhance understanding of families' experiences of statutory assessment, with particular attention paid to family engagement within this. This research also set out to demonstrate how important it is to carry out phenomenological qualitative research with families, including with young people, something not widely undertaken previously.

The interviews that took place followed the general guidance offered by Smith (2004), which concedes that the opening questioning style generally recommended within IPA may not always be appropriate for children, and that the researcher may have to incorporate gentle probing and guiding of the participant through the interview. It is important that future research in this area incorporates the perspectives of young people in order to ensure that their voices, perceptions and experiences are incorporated within practice and research.

Future researchers could also consider deeper explorations of particular areas or events of interest to young people, for example specific relationships with members of school staff. Because of the challenges faced by the researcher as discussed in *5.4,* future researchers could develop a variety of meaningful tools to elicit the voice of the child, including visual methods.

It would be interesting to consider the transferability of these findings to other settings in order to see how well the accounts given by the families within this research are supported by families elsewhere, particularly given the variability between LAs in interpretation of new legislation and what this looks like in practice. This research was conducted in a relatively deprived East Midlands City, and therefore similar research could be conducted in other LAs with different demographics and differences in practice which may influence the experiences of families.

Future researchers in this area could also consider other possibilities for data collection which were beyond the scope of the present research, including written personal

accounts, or diaries, of participants, and conducting focus groups in order to establish the themes or discourses present in a group, including in a family. Research with professionals involved in the EHC assessment process would make an interesting comparison to this research, and would provide a deeper understanding of their perceptions and experiences of the process. This could include an analysis of power of the participants in individual EHC needs assessment processes, including SENCOs, class teachers, specialist teachers and EPs, as carried out within the previous statementing process by Todd & Higgins (1998).

As outlined earlier in this chapter, future researchers may wish to investigate further, and in a greater level of detail, the experiences and perceptions of young people with regard to their own involvement and engagement in statutory assessment within education, and also the perceptions of parents and professionals with regard to the extent of the involvement of young people in this area. Of particular interest would be the various positions of young people within statutory assessment from the perspective of different individuals, including professionals and parents.

6. Conclusions

6.1 Unique contribution of the current research

This thesis has offered an interpretative account of six individual family members' experiences of the recently updated statutory assessment process in education, capturing the voices of four parents and two young people across three families. The unique focus of the research has been how these families made sense of their experiences of the EHC needs assessment process. It has illustrated some gaps between the rhetoric of how the system should be working, according to government legislation, and the lived experience of parents and young people, related to both their experience of the assessment process, and their experience of family engagement within this. In this way, an in-depth insight into experiences of the statutory assessment process is here viewed as "a lens through which to view parent-school relations" (Todd & Higgins, 1998, pg. 228)

This research has particularly demonstrated the importance of family and pupil voice within research. It has attempted to empower parents and young people by providing an interpretation of their view of the EHC needs assessment process, and of family engagement. The inclusion of the voices of two young people is particularly powerful, although it did not come without its challenges, as discussed earlier in *5.4.* Parent and young person voice is seen as poignant here, informing understanding of the *SEND Code of Practice 2015* (DfE & DoH, 2015), and the implications of this legislation for the life-worlds and experiences of families.

By offering a detailed analysis of the accounts of six individuals, IPA has allowed for a rich insight into six particular circumstances and situations. Warnock (1987) (cited in Smith, 2004, p. 42) suggested that by delving into the particular, we can become closer to the universal. By carrying out this study, the researcher hopes therefore that a greater understanding of how the EHC needs assessment process may be experienced by a wide range of people has been achieved.

The researcher aimed to demonstrate how there may be some similarities in how different parents and young people experience the same process, as well as important divergences in how particular individuals experience the same process. This is the link

between idiography and phenomenology, and part of the unique contribution of IPA research (Smith, 2004).

6.2 Summary of findings

The *Children and Families Act 2014* outlined major changes to the support which is offered for children and young people with SEN. The legislation states that LAs should involve the family in any decision-making that relates to them, by paying particular attention to their views, wishes and feelings, supporting their participation in decision-making, and offering more choice and control over local provision.

This research has found that for some families, the action of initiating an EHC needs assessment for their child is an act of empowerment in itself. It allows families to take action to get what they feel their child wants and needs, including services and resources which perhaps their family may have not been able to access prior to the assessment process taking place. Families can also perceive a family focused approach during the process, as well as the participation of the whole family, for example through engagement at the PCR and contributing their views, often with the support of a keyworker.

This research indicates, however, that integral to families' experiences of the newly introduced EHC needs assessment process was their lack of awareness of the systems involved in it. It seems difficult for LAs to place families and their views at the heart of this process without promoting a better understanding of the process for them. Despite parents remaining dependent on statutory assessment to feel confident that the right support will be put in place for their children, depicting a lack of parental confidence in the SEN systems and processes outside of statutory assessment process, it is not fully clear for them what the specific purpose of statutory assessment is and who it may be more appropriate for.

This research has also shown that participants' perceptions and experiences of family engagement, and of power relations within this, were complex and not at all unitary. Participants experienced feelings of empowerment and powerlessness in different ways. Although the EHC needs assessment process did bring about positive change for families, their perceptions of interactions and relationships with professionals indicate that a power imbalance exists, as it did 50 years ago, with families perceiving that professionals maintain control in decision-making. Although families experienced some

aspects of family engagement, there was often no choice for families around how they are involved. Professionals also retained control over communication and resources within the process, and families found it difficult to even access information about the process so that they can understand what was going on during it. Often families found, during the process, that certain activities were expected of them, for example visiting educational provisions, which parents were consequently expected to fit in around their personal and professional circumstances.

There was a distinct lack of opportunities for families to participate in the key decisions which were made during the EHC needs assessment process, including whether the request for an assessment got accepted or turned down, and whether to issue an EHCP or not. This creates a continual hierarchy of power with professionals being placed in a more dominant position. Ultimately, the panel of professionals who met to decide whether to carry out an assessment of EHC needs for the young person was perceived by parents as holding the most decision-making power.

This research has highlighted that although many principles of the *Children and Families Act 2014*, for example the assumption of the centrality of the family in the process, family choices being key to decision-making, and open access to resources, may be perceived positively by many, their full integration into practice remains a significant challenge.

7. References

Abel, Y. (2014). Process Into Products: Supporting Teachers to Engage Parents. *Education and Urban Society*, *46*(2), 181–191.

Appleton, P. & Minchom, P. (1991). Models of parent partnership and child development centres. *Child: Care, Health and Development, 17*(1), 27-38.

Arnot, M., & Reay, D. (2007). A Sociology of Pedagogic Voice: Power, inequality and pupil consultation. *Discourse: Studies in the Cultural Politics of Education*, *28*(3), 311–325.

Ashworth, P. (2008). Conceptual foundations of qualitative psychology. In J. A. Smith (Ed.). *Qualitative psychology: A practical guide to research methods* (pp. 4-26). London. Sage Publications.

Attwood, L. (2013). The real implications of "benevolent" SEN reform. *Support for Learning*, *28*(4), 181–187.

Audit Commission. (2002). *Policy Focus - Statutory assessment and statements of SEN: in need of review?* Wetherby: Audit Commission Publications.

Audit Commission & Office for Standards in Education. (2002). *Local Education Authority Support for School Improvement. London: HMSO.*

Auerbach, S. (2009). Walking the Walk: Portraits in Leadership for Family Engagement in Urban Schools. *School Community Journal*, *19*(1), 9–32.

Bailey, D. (1994). Organizational empowerment: From self to interbeing. In L. Gutierrez & P. Nurius (Eds.), *Education and research for empowerment practice* (pp. 37-44). Seattle: University of Washington, School of Social Work, Center for Policy and Practice Research.

Barton, A., Drake, C., Perez, J. G., St. Louis, K., & George, M. (2004). Ecologies of Parental Engagement in Urban Education. *Educational Researcher*, *33*(4), 3–12.

Benporath S. (2003). Autonomy and vulnerability: on just relations between adults and children. *Journal of Philosophy of Education, 37*(1), 127-145.

British Psychological Society: Division of Educational and Child Psychology (2002). *Professional Practice Guidelines.* Leicester: The British Psychological Society.

British Psychological Society (2009). *Code of Ethics and Conduct.* Leicester: The British Psychological Society.

Brody, G. H., Flor, D. L., & Gibson, N. M. (1999). Linking maternal efficacy beliefs, developmental goals, parenting practices and child competence in rural single-parent African American families. *Child Development*, *70,* 1197-1208.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments in nature and design*. Cambridge, MA: Harvard University Press.

Carter B., Cummings J. & Cooper L. (2007). An exploration of best practice in multi-agency working and the experiences of families of children with complex health needs. What works well and what needs to be done to improve practice for the future? *Journal of clinical nursing*, *16*(3), 527-539.

Case, S. (2000). Refocusing on the parent: What are the social issues of concern for parents of disabled children? *Disability & Society*, *15*(2), 271–292.

Chamberlain, K. (2011). Troubling methodology. *Health Psychology Review*, *5*(1), 48–54.

Cole, J. (2011). *A research review: The importance of families and the home environment.* London, England: National Literacy Trust.

Cordero Arce, M. (2012). Towards an Emancipatory Discourse of Children's Rights *. *The International Journal of Children's Rights*, *20,* 365-421.

Crozier, G. (1998). Parents and schools : partnership or surveillance ? *Journal of Education Policy*, *13*(1), 125–136.

Cunningham, C., & Davis, H. (1985). *Working with parents: Frameworks for collaboration.* Milton Keynes, UK: Open University Press.

Dale, N. (1996). *Working with families of children with special needs: Partnership and practice.* London: Routledge.

137

Dearing, E., Kreider, H., Simpkins, S., & Weiss, H. B. (2006). Family involvement in school and low-income children's literacy: Longitudinal associations between and within families. *Journal of Educational Psychology*, *98*(4), 653–664.

Delgado-Gaitan, C. (1991). Involving Parents in the Schools: A Process of Empowerment. *American Journal of Education*, *100*(1), 20-46 .

Denzin, N.K., & Lincoln, Y.S. (2005). Introduction: The discipline and practice of qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.). *The SAGE Handbook of Qualitative Research* (2nd ed.) (pp. 1-143). London: Sage Publications Ltd.

Department for Communities and Local Government. (2015). *The English Indices of Deprivation 2015.* London: Office for National Statistics. Accessed online from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/4 65791/English_Indices_of_Deprivation_2015_-_Statistical_Release.pdf

Department for Education. (2011). *Support and Aspiration: A new approach to Special Educational Needs and Disability.* London: HMSO.

Department for Education and Skills. (2002). *Together from The Start – Practical guidance for professionals working with disabled children (birth to 2) and their families.* Nottingham: DfES Publications.

Department for Education and Skills. (2004). *Removing Barriers to Achievement.* Nottingham: DfES Publications.

Department for Education and Skills. (2007). *Background information: Statutory Assessment – Education.* Nottingham: DfES Publications.

Department for Education and Department of Health. (2015). *Special Educational Needs and Disability Code of Practice: 0 to 25 years.* London: HMSO.

Desforges, C., & Abouchaar, A. (2003). *The Impact of Parental Involvement , Parental Support and Family Education on Pupil Achievements and Adjustment: A Literature Review.* Nottingham: DfES Publications.

Ellingsen, K., & Myers, L. (2013). Measuring Parent Engagement in Early Childhood Intervention Programs. Proceedings from *National Conference on Family Literacy April 28-30, 2013 – Louisville, KY.*

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *The British Journal of Clinical Psychology*, *38*, 215–229.

Epstein, J. (1987). Toward a Theory of Family-School Connections: Teacher Practices and Parent Involvement. In K. Hurrelmann, F. Kaufmann & F. Lösel (Eds). *Social Intervention: Potential and Constraints* (pp. 121-137). New York: Walter de Gruyter.

Epstein, J., & Dauber, S. (1991). School programs and teacher practices of parent involvement in inner-city elementary and middle schools. *The Elementary School Journal*, *91*(3), 289–305.

Evans, J. M., Harden, A., & Thomas, J. (2004). What are effective strategies to support pupils with emotional and behavioural difficulties (EBD) in mainstream primary schools? Findings from a systematic review of research, *Journal of Research in Special Educational Needs, 4*(1), 2-16.

Fan, X., & Chen, M. (2001). Parental involvement and students' academic achievement: A meta-analysis. *Educational Psychology Review*, *13*(1), 1–22.

Fantuzzo, J., McWayne, C., Perry, M., & Childs S. (2004). Multiple Dimensions of Family Involvement and Their Relations to Behavioral and Learning Compentencies for Urban, Low-Income Children. *School Psychology Review*, *33*(4), 467–480.

Fantuzzo, J., Tighe, E., & Childs, S. (2000). Family Involvement Questionnaire: A multivariate assessment of family participation in early childhood education. *Journal of Educational Psychology*, *92*(2), 367–376.

Feiler, A. & Watson, D. (2010). Involving children with learning and communication difficulties: the perspectives of teachers, speech and language therapists and teaching assistants. *British Journal of Learning Disabilities, 39*, 113-120

Ferlazzo, L. (2011). Involvement or Engagement? S*chools, Families, Communities, 68*, 8, 10-14.

Ferreira, K., Hodges, S. and Slaton, E. (2013). The promise of family engagement: an action plan for system-level policy and advocacy. In A. McDonald Culp (Ed.),

Child and Family Advocacy: Bridging the Gaps Between Research, Practice and Policy (p. 253-268). New York: Springer.

Fielding M. & Rudduck J. (2006). Student voice and the perils of popularity. *Educational Review,* 58 (2), 219-231

Flouri, E., & Buchanan, A. (2004). Early father's and mother's involvement and child's later educational outcomes. *The British Journal of Educational Psychology*, *74*(2), 141–153.

Gest, S. D., Freeman, N. R., Domitrovich, C. E., & Welsh, J. a. (2004). Shared book reading and children's language comprehension skills: The moderating role of parental discipline practices. *Early Childhood Research Quarterly*, *19*(2), 319–336.

Gill, M. J. (2014). The Possibilities of Phenomenology for Organizational Research. *Organizational Research Methods*, *17*(2), 118–137.

Giorgi, A. (2002). The Question of Validity in Qualitative Research. *Journal of Phenomenological Psychology, 33(1),* 1–18.

Giroux, H. (1994). *Disturbing Pleasures.* London: Routledge.

Goodall, J. & Montgomery, C., 2013. Parental involvement to parental engagement:A continuum. Educational Review, 66 (4), 399-410.

Goodall J., Vorhaus, J., Carpentieri J., Brooks G., Akerman R. & Harris A. (2011). *Review of best practice in parental engagement.* London: Department for Education.

Gough D. (2007) Weight of Evidence: A framework for the appraisal of the quality and relevance of evidence. *Research Papers in Education*, 22 (2), 213-228.

Great Britain. *Special Educational Needs and Disability Act: Elizabeth II. Chapter 10. (2001)* London: The Stationery Office.

Great Britain. *Children Act: Elizabeth II. Chapter 31. (2004).* London: The Stationery Office.

Great Britain. *Children and Families Act: Elizabeth II. Chapter 36. (2014).* London: The Stationery Office.

140

Gutman, L. M., & Midgley, C. (2000). The role of protective factors in supporting the academic achievement of poor African American students during the middle school transition. *Journal of Youth and Adolescence, 20,* 223–248.

Harris, A. & Goodall, J. (2007). *Engaging parents in raising achievement: do parents know they matter.* Department for Schools, Children and Families Research Report DCSF-RW004.

Hayes, J. (2004). Visual annual reviews : how to include pupils with learning difficulties in their educational reviews. *Support for Learning*, *19*(4), 175–180.

Health and Care Professions Council (2009). *Standards of conduct, performance and ethics.* London: Health and Care Professions Council.

Hebel O. (2014). Parental involvement in the individual educational programme for Israeli students with disabilities. *International journal of special education,* 29, 3, 1-11.

Hodge, N., Runswick-Cole, K., Runswick-Cole, K., & Cdso, F. (2008). Problematising parent–professional partnerships in education. *Disability & Society*, *23*(6), 637–647.

Hoover-Dempsey, K. V., & Sandler, H. M. (1995). Parental involvement in children's education: Why does it make a difference? *Teachers College Record*, *97*(2), 310-331.

House of Commons Education and Skills Committee. (2006). *Special Educational Needs Third Report for Session 2005-2006 Volume I.* London: HMSO.

Humphrey, N., & Lewis, S. (2008). "Make me normal": the views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism : The International Journal of Research and Practice*, *12*(1), 23–46.

Husserl, E. (2014) *Ideas: General Introduction to Pure Phenomenology.* London: Routledge.

Husserl, E. (2001). Logical *Investigations Volume 2*. London: Routledge.

141

Ingber, S., & Dromi, E. (2010). Actual versus desired family-centered practice in early intervention for children with hearing loss. *Journal of Deaf Studies and Deaf Education*, *15*(1), 59–71.

Izzo, C. V., Weissberg, R. P., Kasprow, W. J., & Fendrich, M. (1999) A longitudinal assessment of teacher perceptions of parent involvement in children's education and school performance. *American Journal of Community Psychology*, 27(6), 817-839.

Jackson, R. (2006). Book Reviews Special Educational Needs: A New Look. *The British Journal of Developmental Disabilities, 52*(102), 65–71.

Jivanjee, P., Kruzich, J. M., Friesen, B. J., & Robinson, A. (2007). Family perceptions of participation in educational planning for children receiving mental health services. *School Social Work Journal*, *32*(1), 75–92.

Joint Strategic Needs Assessment (2010). *Children and Young People with learning difficulties and disabilities.* Accessed online from https://xxxinsight.org.uk/insight/jsna/children/jsna-disability-and-learning-difficulties-children.aspx

Jones, P., & Swain, J. (2001). Parents reviewing Annual Reviews. *British Journal of Special Education*, *28*(2), 60–64.

Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*, *23*(4), 390–397.

Kilkelly, U., Kilpatrick, R., Lundy, L., Moore L., Scraton P., Davey C.,…McAlister C. (2005) *Children's rights in Northern Ireland*. Belfast: Northern Ireland Commissioner for Children and Young People.

Kirk, J., & Miller, M. L. (1986). *Reliability and validity in qualitative research.* Beverly Hills: Sage Publications.

Kirkbride, R. (2014). "They were a little family": An exploratory study of parental involvement in nurture groups - from a practitioner and parent perspective. *British Journal of Special Education*, *41*(1), 82–104.

142

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, *37*(4), 305–321.

Lamb, B. (2009). *Report to the Secretary of State on the Lamb Inquiry Review of SEN and Disability Information*. London: DCSF Publications.

Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method.* Harlow: Pearson Education.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102–120.

Lawson, M. (2003). School-Family Relations In Context: Parent and Teacher Perceptions of Parent Involvement. *Urban Education*, *38*(1), 77–133.

Leeson, C. (2007). My life in care: experiences of non-participation in decision-making processes. *Child & Family Social Work*, *12*, 10.

Lewis, A., Newton, H., & Vials, S. (2008). Realising child voice: The development of Cue Cards. *Support for Learning*, *23*(1), 26–31.

Lewis, A., & Porter, J. (2004). Interviewing children and young people with learning disabilities: Guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities, 32* 191–197.

Lincoln, Yvonna S. & Guba, Egon G. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.). *The handbook of qualitative research*, (pp.163-188). London: Sage.

Lundy, L. (2007). "Voice" is not enough: conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *British Educational Research Journal*, *33*(6), 927–942.

Mackenzie, R. Watts, J. & Howe, L. (2012). Supporting aspirations – or not? Recent reforms on equality, the green paper on Special Educational Needs and the potential of a neurodiversity spectrum statement. *Tizard Learning Disability Review, 17*(1), 36-48.

Matthews, H., Limb, M., & Taylor, M. (1999). Young people's participation and representation in society. *Geoforum*, *30*, 135–144.

McIntyre, L. L., Eckert, T. L., Fiese, B. H., Digennaro, F. D., & Wildenger, L. K. (2007). Transition to kindergarten: Family experiences and involvement. *Early Childhood Education Journal*, *35*(1), 83–88.

McWayne, C., Hampton, V., Fantuzzo, J., Cohen, H. L., & Sekino, Y. (2004). A multivariate examination of parent involvement and the social and academic competencies of urban kindergarten children. *Psychology in the Schools*, *41*(3), 363–377.

McWayne, C. M., Melzi, G., Schick, A. R., Kennedy, J. L., & Mundt, K. (2013). Defining family engagement among Latino Head Start parents: A mixed-methods measurement development study. *Early Childhood Research Quarterly*, *28*(3), 593–607.

McWilliam, R. A., Maxwell, K. L., & Sloper, K. M (1999). Beyond "involvement": Are elementary schools ready to be family-centered? *School Psychology Review,* 28, 3, 378-394.

Mertens, D. (2015). *Research and Evaluation in Education and Psychology.* London: SAGE Publications.

Mittler, P. & Mittler, H. (1983). Partnership with parents: an overview. In P. Mittler and H. McConachie (Eds.) *Parents, Professionals and Mentally Handicapped People: Approaches to Partnership.* Beckenham: Croom Helm.

Moran D. & Mooney T. (2002). *The Phenomenology Reader.* Oxon: Routledge.

Munn-Joseph, M. S., & Gavin-Evans, K. (2008). Urban Parents of Children With Special Needs: Advocating for Their Children Through Social Networks. *Urban Education*, *43*(3), 378–393.

Murray, M., Handyside L., Straka L. & Arton-Titus T. (2013). Parent empowerment: connecting with preservice special education teachers. *School Community Journal, 23*(1), 145-168.

Natiello, P. (1990). The person-centered approach, collaborative power, and cultural transformation. *Person Centered Review, 5*(3), 268-86.

144

Norwich, B. (2014). Changing policy and legislation and its effects on inclusive and special education: a perspective from England. *British Journal of Special Education*, *41(*4), 403-425.

Norwich, B., Beek, C., Richardson, P., & Gray, P. (2004). Examining key issues underlying the Audit Commission Reports on SEN Policy Paper 1 (5th series), *Journal of Research in Special Educational Needs, 4*(2), 98-112.

O'Connor, U. (2008). Meeting in the middle? A study of parent–professional partnerships. *European Journal of Special Needs Education*, *23*(3), 253–268.

O'Connor, U., McConkey, R., & Hartop, B. (2005). Parental views on the statutory assessment and educational planning for children with special educational needs. *European Journal of Special Needs Education*, *20*(3), 251–269.

Office for National Statistics (2013). *Births by area of usual residence of mother, UK*. London: Office for National Statistics. Accessed online from http://jsna.nottinghamcity.gov.uk/insight/Strategic-Framework/Nottinghamshire-JSNA/Summaries-and-overviews/The-people-of-Nottinghamshire.aspx#pl_lifestg

The Office of the Education Ombudsman (2012). *Engaged Parents Successful Students: An overview of the local and national parent engagement in education efforts*. Office of the Education Ombudsman for the Community Center for Education Results.

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research* (*34),* 1189–1208.

Peacey, N., Lindsay, G., Brown, P., & Sam, A. (2009). *Increasing parents' confidence in the special educational needs system : studies commissioned to inform the Lamb Inquiry - final report*. Coventy: University of Warwick.

Reynaert, D., Bouverne-de-Bie, M., & Vandevelde, S. (2009). A Review of Children's Rights Literature Since the Adoption of the United Nations Convention on the Rights of the Child. *Childhood*, *16*(4), 518–534.

145

Richardson, P., Richardson, P., Lamb, B., & Gross, J. (2015). How will accountability work in the new SEND legislative system? *Journal of Research in Special Educational Needs*, *15*(1), 57–57.

Rimm-Kaufman, S. E., Pianta, R. C., Cox, M. J., & Bradley, R. H. (2003). Teacher-Rated Family Involvement and Children's Social and Academic Outcomes in Kindergarten, Early Education and Development *(14)* 2, 37–41.

Robson, C. (2011). *Real World Research.* Oxford: Blackwell Publishers Ltd.

Roller, J. (1998). Facilitating Pupil Involvement in Assessment, Planning and Review Processes. *Educational Psychology in Practice*, *13*(4), 266–273.

Runswick-Cole, K. (2007). "The Tribunal was the most stressful thing: more stressful than my son"s diagnosis or behaviour': the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDisT). *Disability & Society*, *22*(3), 315–328.

Sam, K., & Granville, S. (2005). *Parents' views on improving parental involvement in children's education.* Edinburgh: Thomasish Executive.

Sheldon, S. B., & Epstein, J. L. (2005). Involvement Counts: Family and Community Partnerships and Mathematics Achievement. *The Journal of Educational Research*, *98*(4), 196–207.

Sheridan, S. M., Knoche, L., Kupzyk, K., Edwards, C., & Marvin, C. (2011). A Randomized Trial Examining the Effects of Parent Engagement on Early Language and Literacy: The Getting Ready Intervention. *Journal of School Psychology*, *49*(3), 361–383.

Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative psychology. *Qualitative Research in Psychology*, *1*, 39–54.

Smith J. (2008). *Qualitative psychology: a practical guide to research methods.* London: SAGE Publications.

Smith, J.A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, *5*(1), 9–27.

Smith J., Flowers P. and Larkin M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research.* London: SAGE Publications.

Smith, J.A. & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic back pain. *Psychology and Health, 22,* 517–534.

Smith, J. a, & Osborn, M. (2008). Interpretative Phenomenological Analysis. *Qualitative Psychology: A Practical Guide to Research Methods*, 53–80.

Spann, S. J., Kohler, F. W., & D., S. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities*, *18*(4), 228–237.

Squires, G. (2012). Historical and socio-political agendas around defining and including children with special educational needs. In Armstrong, D., & Squires, G. (Eds.), *Contemporary issues in special educational needs: Considering the whole child* (pp. 469–481). Maidenhead: McGraw-Hill.

Starks, H., & Trinidad, S. B. (2007). Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, *17*(10), 1372–1380.

Theoharis, G. (2007). Social justice educational leaders and resistance: Toward a theory of social justice leadership. *Educational Administration Quarterly, 43*(2), 221-258.

Thomas G. (2013). *How to do your research project.* London: SAGE Publications.

Tizard, B., Blatchford, P., Burke, J., Farquhar, C. and Plewis, I. (1988). *Young children at school in the inner city*. London: Lawrence Erlbaum Associates.

Todd, E. S., & Higgins, S. (1998). Powerlessness in Professional and Parent Partnerships. *British Journal of Sociology of Education*, *19*(2), 227–236.

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837–851.

147

Truss, C. (2008). Peter's story: reconceptualising the UK SEN system. *European Journal of Special Needs Education,* 23, 4, 365-377.

Turnbull, A. P, & Turnbull, H. R. (1997). *Families, professionals, and exceptionality: A special partnership* (3rd Ed.). Upper Saddle River, NJ: Merrill/Prentice-Hall.

Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2000). Evolution of Family-Professional Partnerships: Collective Empowerment as the Model for the Early Twenty-First Century. In J.P. Shonkoff & S.J. Meisels (Eds). *Handbook of Early Childhood Intervention* (pp. 630–650). Cambridge: Cambridge University Press.

United Nations. (1989). *United Nations Convention on the Rights of the Child (UNCRC)*, Geneva: United Nations.

United Nations Educational, Scientific and Cultural Organisation. *The Salamanca Statement and Framework for Action on Special Needs Education.* UNESCO: Paris, France.

Vincent C. (1996). *Parents and Teachers Power and Participation.* London: Falmer Press.

Warnock, M. (1978). *Special Educational Needs. Report of the Committee of Enquiry into the Education of Handicapped Children and Young People.* London: HMSO

Warnock. M. (2005) *Special Educational needs: a new look.* London: Philosophy of Education Society of Great Britain.

Warshak, R. (2003). Payoffs and Pitfalls of Listening to Children. *Family Relations*, *52*(4), 373–384.

Wertz, F. J. (2011). A phenomenological psychological approach to trauma and resilience. In F. J. Wertz, K. Charmaz, L. M. McMullen, R. Josselson,, R. Anderson, & E. McSpadden (Eds.) *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry* (pp. 124-164). New York, NY: The Guilford Press.

Whitty G. & Wisby E. (2007). *Real decision making? School councils in action.* Nottingham: DfES Publications.

Willig, C. (2008). *Introducing qualitative research in psychology.* Maidenhead: Open University Press.

Winton P. and Turnbull A. (1981). Parent involvement as viewed by parents of preschool handicapped children. *Topics in Early Childhood Special Education*, 1, 3, 11-19.

Wolfendale, S. (1992) *Empowering Parents and Teachers: Working for Children*. London: Cassell.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J.A. Smith (Ed.) *Qualitative psychology: A practical guide to methods* (2nd ed., pp.235–251). London: Sage.

Appendices

Appendix 1: Timeline of EHC needs assessment process within sample LA

Statutory Assessment Process

Total Timeline 20 weeks
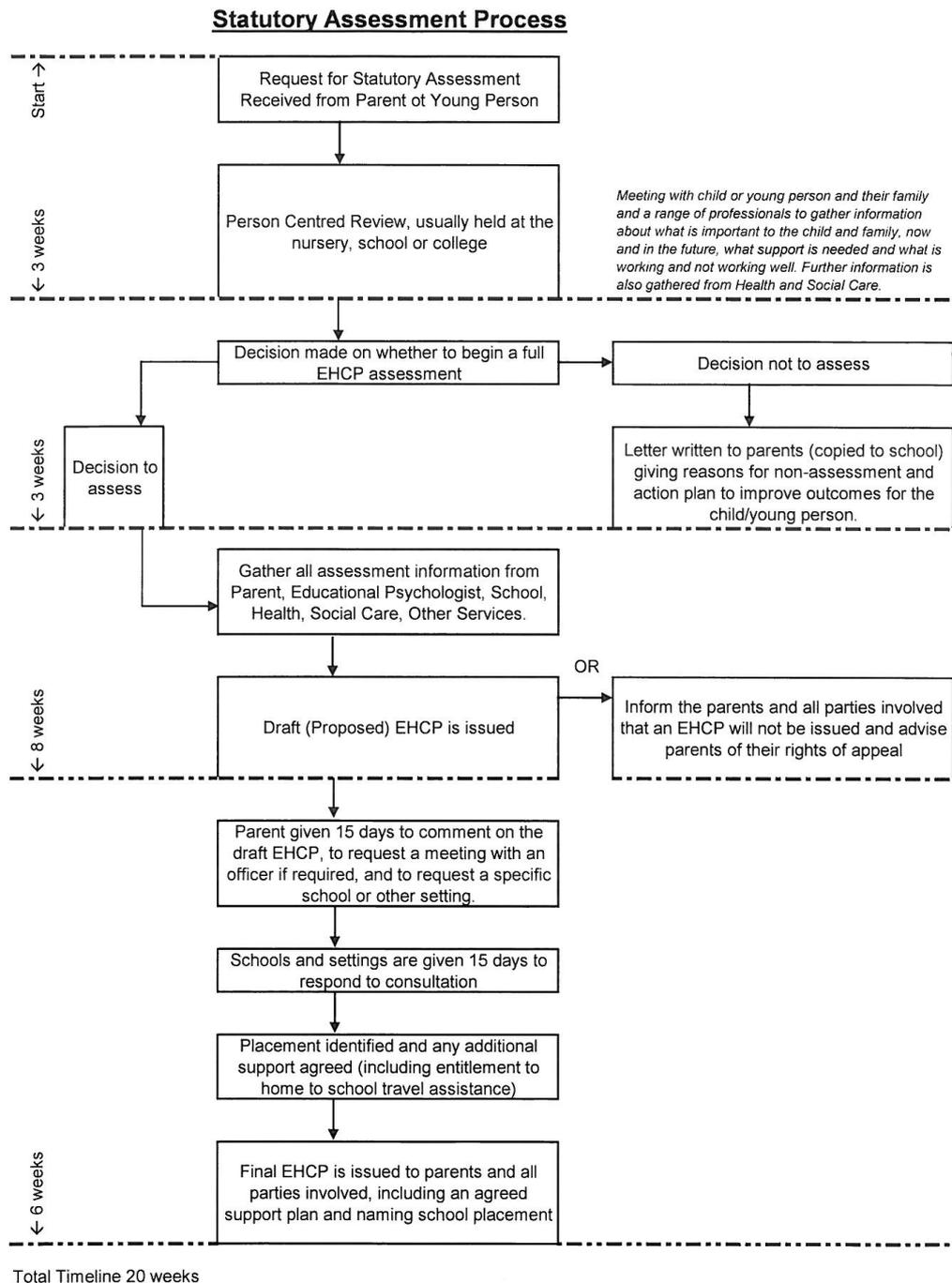
Appendix 2: Gough (2007's Weight of Evidence framework criteria as applied to the systematic searches of literature for this study

	A	B	C	D
	Methodological quality – generic judgement about the coherence and integrity of the evidence	Methodological appropriateness - of the evidence and design for the research question	Methodological relevance - of the topic and context for the research question	Overall assessment of the extent that a study contributes evidence for the research question (overall weight of evidence which is either the average of A, B and C, or the most frequently occurring rating if an average is not possible)
High	Purpose of research is clear Clearly defined participant sample Clearly defined and described data gathering strategies, outcomes and how these led to conclusions	Phenomenological method	UK based Includes all of family including young person with SEN Time context considered highly relevant to current research (carried out from 2011 when *Support and Aspiration: A new approach to Special Educational Needs and Disability* (DfE, 2011) *w*as published to	

			current day)	
Medium	Purpose of research is partially clear Some elements of participant sample described Partially defined and described data gathering strategies, outcomes and how these led to conclusions	Qualitative method, with data gathering including semi-structured interviews or participant observation	Europe based Includes family members but not young person with SEN Time context considered relevant to current research (carried out between publications of *SEN Code of Practice* (DfES, 2001) and *Support and Aspiration: A new approach to Special Educational Needs and Disability* (DfE, 2011))	
Low	Purpose of research is not clear Participant sample poorly described Partially defined and described data gathering strategies, outcomes and how these led to conclusions	Surveys Quantitative method	Non Europe-based Time context considered less relevant to current research (pre-2001) Includes wider family members but not parents or young people e.g. grandparents	

Appendix 3: Summary of keyword search for Search A

Database searched	Date	Keywords employed	No of hits

152

British Education Index	June 2015	(famil* or parent* or child* or pupil*) and (involve* or engage*) and (perception* or experience* or understand* or view* or judge*) and (special* and education* and need*)	110
ERIC	June 2015	(famil* or parent* or child* or pupil*) and (involve* or engage*) and (perception* or experience* or understand* or view* or judge*) and (special* and education* and need*)	1478
Web of Knowledge	June 2015	(famil* or parent* or child* or pupil*) and (involve* or engage*) and (perception* or experience* or understand* or view* or judge*) and (special* and education* and need*)	370
PsycInfo	June 2015	(famil* or parent* or child* or pupil*) and (involve* or engage*) and (perception* or experience* or understand* or view* or judge*) and (special* and education* and need*)	726

Appendix 4: Keyword summary of studies identified from Search A

Citation	Sample	Research methodology	How was the data gathered and analysed?	Specific topic of interest	Main findings
Hebel (2014)	20 Israeli parents, 19 mothers and 1 father, whose children (aged 3-21) were eligible for an IEP and had been diagnosed with severe disabilities, members of non-profit organisations supporting families	Semi structured interviews	IPA	Understanding the perceptions and experiences of parents about their involvement in IEPs	A child centred focus within the IEP process and strong parental sense of self-efficacy were essential components of parental involvement.

Perceptions of child-centred focus included parental advocacy, implementing family perspectives in IEP process and understanding of child's abilities.

Perceptions of parents' self-efficacy included capacity to influence and to be involved.

Parents wanted children to realise their potential and thought that parental involvement would help them to do this.

Parents felt that teachers do not always consider children's potentials and do not always initiate IEPs which are responsive to this. |
| Jivanjee, Kruzich, Friesen & Robinson (2007) | Parents or other primary caregivers of young people aged up to 20 who had received mental health treatment | Questionnaires: The Family Empowerment Scale. Family perceptions of participation | Statistical analysis plus verbatim quotations of individual experiences | Participation in educational planning and the mediating factors of this | Mixed ratings of participation in educational planning.

Low mean ratings on educational planning taking into account family's needs and circumstances, and their values and culture, and on staff making changes in planning as a result of caregivers' |

	133 screened surveys returned out of 867 who indicated willingness to take part. Recruited via support organisations US based	in educational planning measured on Likert Scale			suggestions. Caregivers with high empowerment scores perceived high levels of participation in educational planning. Experienced difficulties in securing services for children with emotional disorders – average 16.8 month lag between time that children began experiencing difficulties.
Kirkbride (2014)	Four female parents/carers of children from four different nurture groups in the UK	Qualitative semi-structured interviews (constructivist, inductive paradigm)	Thematic analysis	Parental involvement in nurture groups	Three main themes to emerge from parents: forms of parental involvement (keeping parents informed, parents receiving practical and emotional support, developing knowledge and understanding), barriers to parental involvement (lack of parental voice, feeling blamed, poor communication, knowledge and understanding), other factors affecting parental involvement (concerns and difficulties around need, parent/school relationships, seeing changes in their child, parental needs/family context). Overall experiences within nurture groups reported as positive, including collaboration with nurture group staff.
McWilliam, Maxwell & Sloper (1999)	Educators and families of children with disabilities	Questionnaires – family-centred elementary	Statistical analysis	Understanding perspectives of family-centred practices in the	Indicates that families value family-centred approaches. These include responsiveness and sensitivity, atmosphere,

155

	recruited from kindergarten to third grade in 88 public elementary schools across North Carolina, one from each school 75 families completed data, 97% mothers Matched with 46 families of typically developing child	school practices scale (20 item scale looking at family-centred practices) Helpgiving Practices Scale (25 item scale measuring family centred attitudes and behaviours) Context Questionnaire		early elementary school grades	delivery of specialised services and advocacy. Families of children with disabilities rate school practices as less family centred then do educators. Families who had experienced early intervention viewed school practices similarly to those who hadn't (had been hypothesised that these families may have higher expectations of school practice). Indicates that higher SES families of typically developing children are experiencing higher level of involvement. Families of children with disabilities did not feel very encouraged by school to voice their concerns and speak up for their family.
Munn-Joseph & Gavin-Evans (2008)	Three families living in an urban area in the Midwest of USA with elementary-age children diagnosed with disabilities attending one school Received special education services for	Qualitative semi-structured interviews	Constant comparative method – transcripts analysed and compared for emergent themes	Family involvement in special education programming and intervention Use of social networks in parent advocacy How parents advocate for children in parent-school relationship	Family involvement with school ranged from proactive to reactive depending on family characteristics. Range of experiences regarding communication with school staff. Each family maintained expectations around primary goal of educating the whole child. Family involvement therefore related to academia as well as behaviour and social interactions. Families did not operate in

156

					isolation but in conjunction with social and institutional agents.
	more than one year Designed to capture involvement perspectives of Black and low-income families Three families highlighted for discussion from total of 8 parents interviewed				Families spoke of reliance on family members or close neighbours for guidance in decision-making. Also accessed institutional networks such as social service centres. These networks allowed families to get advice and information which was needed. Suggests that involvement practices should be developed unique to each family.
Spann, Kohler & Soenksen (2003)	Parents of 45 children (aged 4-18) with autism or related pervasive developmental disabilities Enrolled at pre-school or public school From six different counties of mideastern state in USA Recruited through the assistance of a parent support group	15 item questionnaire administered by telephone interviews – structured interviews	Summary of responses and comments	Involvement and perception of special education services	Many families reported regular communication with schools – 80% expressed moderate to high satisfaction with communication with school. This interaction focused on variety of topics – most common was exchanging information related to child's needs and performance. Also communicated to brainstorm around problems which arose at home or at school. Majority of families believed they were moderately to highly knowledgeable about and involved in their child's IEP process. Parents of older children reported lower levels of satisfaction with home-school communication, involvement

157

					in the IEP process.
Winton & Turnbull (1981)	31 mothers of preschool children with mild or moderate difficulties enrolled in 15 different preschools (mixture of specialised and mainstream) across North Carolina, USA	Two phase interview drawn from ethnographic approach: first phase of semi-structured interview, first phase of developing a quantitative questionnaire based on categories and subcategories identified from phase one	Coding of first phase into major categories and subcategories (similar to IPA but not identified as this by researcher) Descriptive analysis used to analyse interviews and questionnaires	How do parents describe and experience their experience with their child's pre-school programme, focusing on parent involvement activities	Presence of parent involvement activities e.g. opportunities for parent groups, training and counselling was important to parents in selection and evaluation of pre-schools (52%). 61% valued having satisfying parent-professional relationship (opportunities to contribute to planning and information provided about progress). Range of opportunities for parental involvement identified, including volunteering in and out of class and opportunities to help others understand their child. Most preferred option was informal and frequent contact with teachers. 19% of parents also appreciated option to have no involvement at all. Distinction made between parent involvement with the child and involvement with the programme.

Appendix 5: Summary of keyword search for Search B

Database searched	Date	Keywords employed	No of hits
British Education Index)	June 2015	(famil* or parent*) and (perception* or experience* or understanding* or view* or judge*) and (special* and education* and need*) and	14

158

			(statutory) and (assess* or plan* or statement* or service* or process*)	
ERIC	June 2015	(famil* or parent*) and (perception* or experience* or understanding* or view* or judge*) and (special* and education* and need*) and (statutory) and (assess* or plan* or statement* or service* or process*)	13
Web of Knowledge	June 2015	(famil* or parent*) and (involve* or engage* or participat*) and (perception* or experience* or understanding* or view* or judge*) and (special* and education* and need*) and (statutory) and (assess* or plan* or statement* or service* or process*)	7
PsycInfo	June 2015	(famil* or parent*) and (involve* or engage* or participat*) and (perception* or experience* or understanding* or view* or judge*) and (special* and education* and need*) and (statutory) and (assess* or plan* or statement* or service* or process*)	10

Appendix 6: Keyword summary of studies identified from Search B

Citation	Sample	Research methodology	How was the data gathered and analysed?	Specific topic of interest	Main findings
Jones &	Twelve parents	Stage one:	Data	Involvement	Parents view Annual Review

159

Swain (2001)	from two different LEAs	Questionnaire Group discussion Stage two: Open-ended discussion Mixed methods	concluded into themes illustrated with quotations	in process of annual review for statements of pupils with SEN	through a lens of holistic development of their child. Parents want to be involved in the Review process. Lack of consistency in Review processes: variation in experiences around how much support parents received to prepare for the Review, and in the say that they felt that they had in decision-making. Relationship with school staff could act as barrier to involvement in process. Formal mechanisms and procedures could also impede parent involvement. Parents found statements to be too vague and not state specifically enough the support which a child should be given. Felt that Annual Review should be a compromise as a result of negotiation between themselves and others. Preparation before the Review is essential. Parents feel like they have to actively seek involvement in decision-making processes rather than this being offered by LA or school.
Keenan, Dillenburger, Doherty, Byrne & Gallagher (2010)	95 parents and carers reporting on a total of 100 children aged 1-6 diagnosed with ASD in Northern Ireland and Republic of	Questionnaire (Family Autism Needs questionnaire) followed by focus group Mixed methods	Statistical analysis using SPSS supplemented with quotations reported from	Diagnosis and forward planning for children with ASD	44% of parents of children with Statement did not feel it accurately described their child's needs. 50% felt that provisions described in statement were not appropriate to needs.

	Ireland (questionnaires) Ten parents (focus groups)		focus groups		Statement timeline often exceeded regulations. Parents found diagnostic process of ASD difficult and lengthy. In 43% of cases diagnosis process took 12 months or over. Parental views not included sufficiently in forward plans in 50% of cases. 85% of parents had been invited to participate in review of child's forward plan.
O'Connor (2008)	20 parents, Northern Ireland selected from earlier phase of research, 10 having expressed overall satisfaction with the statutory assessment process and 10 having not	IPA – semi structured interviews	NVIVO Qualitative Analysis Programme	Parent-professional partnerships	Parents do not consider themselves as partners in the "business" of education. Inequitable relationship perceived by parents with professionals: professional gate-keeping, limited communication. Parents resistant to language of education marketization. The protocol for statutory assessment, and the publishing of a statement was often their first encounter with the systemic bureaucracy of SEN policy. Series of bureaucratic constraints that thwarted access to support and communication, and that unnecessarily protracted the assessment and statementing processes. Non-identification of a named Board officer or inadequate and unsuccessful communication with a designated contact. Parents were not predisposed to seek out alternative support.

O'Connor, McConkey & Hartop (2005)	1054 responded to questionnaires sent out to parents in Northern Ireland with a child with a current statement who had indicated a willingness to take part 122 families chosen at random for telephone interviews	Self-completed postal questionnaire supplemented by telephone interviews with smaller subsample	SPSS used for questionnaires, telephone interviews analysed by thematic content	Experience of the assessment and statementing procedures	Majority of parents appear to be satisfied with both the assessment and statementing process (80%). Parents that the process did fairly and accurately reflect their child's needs (82%) and how needs would be met (80%). The main contributor to parental satisfaction was having an assessment and statement that fully and accurately reflected the child's needs as seen by the parents. Findings reflected the importance of having a named contact person whom parents can meet face-to-face to discuss the outcomes of the assessments and the proposed statements, who will listen to their insights and suggestions and who will update them on progress. Parents require jargon-free information that is clear, unambiguous and careful attention should be paid to schools named in the statements. Parents need to be aware of the range of options that were considered in recommending a school placement and for their concerns to be addressed. Starting the process when the child is younger; reducing the time taken and the amount of paperwork involved; professionals being more sensitive in their dealings with parents and children; better coordination and information

					sharing among professionals; and access to support for parents would all improve the process for parents.
Runswick-Cole (2007)	Seven father and seventeen mothers who had registered an appeal with Tribunal	Interviews	Data organised into themes of findings	Experience of families who go to the SEN and Disability Tribunal	Tribunal's decisions described as life-changing. Experienced difficulties in getting LEAs to implement Tribunal's orders in part or in full. The lack of monitoring and the very limited right to appeal against a SENDisT decision is seen by parents as a major weakness of the system. Parents, then, incur the costs of going to SENDisT in a context where disabled families are already likely to be amongst the most financially disadvantaged (legal costs, cost of independent reports, costs of going to the Tribunal). The stress parents faced as a result of preparing for and attending the Tribunal had an impact on parents' emotional well-being and health. The mothers' stories about going to the Tribunal illustrate the extent of their caring roles and the construction of their vulnerability. The process of going to the Tribunal acts on mothers and fathers individually but also collectively, as their relationship is changed by the experience. Within the Tribunal children's views are not often heard

					directly.
					A small minority of parents described the process of going to SENDisT as empowering.
Truss (2008)	Self-selected sample of one participant as author reports on her own experiences of accessing help and support for her son, focusing on the period from September 2005, when his needs first became severe, to March 2007, when a statement of special needs was finally agreed with the LA	Longitudinal participant observation study – single case study	Ethnographic narrative account drawing on copies of correspondence and a diary with records of discussions and observations	Whether or not the UK SEN system works From the perspective of the parent and the child, at the moment when a need first becomes apparent.	Highlights a discourse of parents having to fight for their child within the SEN system, experiencing alienation from schools and professionals. Also describes SEN systems breaking down – a gap in the rhetoric of how the SEN system should be working compared to the lived experience of families and young people. Experienced school staff who did not act appropriately about their concerns about the young person, nor act collaboratively with the family. Series of experiences with medical and educational professionals who failed to identify and diagnose SEN correctly. Parents not provided with the correct range of information in order to understand fully the SEN system. SEN system operating in three domains: educational, medical and legal.

Appendix 7: Initial information letter for families

To …….

I am writing to you as a student from the University of Nottingham who is currently working as a Trainee Educational Psychologist for XXX. As part of my training to become an Educational Psychologist I am required to complete a research project. I understand that you and your family have recently become involved in the Education, Health and Care needs assessment process, and I am very interested in your experiences and ideas during this process as part of my research study.

The research would involve meeting with you and your family both as a group and as individuals. The whole procedure will last 3 hours, allowing 90 minutes for the group discussion and 90 minutes for the individual interview. It is unlikely that the group discussion and interview will last for the full 3 hours, and would take part on two separate occasions. None of the information which you give me would be shared with the Special Educational Needs support service as part of the Education, Health and Care needs assessment process.

Please sign below if you are happy for your contact details to be passed to myself in order for me to discuss further details about the research with you. Your decision to not wish to take part or be contacted will have no implications for the Education, Health and Care plan process.

This research is fully supported by both XXX Community Educational Psychology Service (contact Educational Psychologist XXX (XXX@XXX.gov.uk) and the University of Nottingham (contact Academic Tutor Nathan Lambert nathan.lambert@nottingham.ac.uk). I can be contacted on email or lpxse1@nottingham.ac.uk, and by telephone XXX
Signature of researcher:

I understand that by signing this form I am agreeing for Sally Eccleston, acting as a researcher, to contact me. This will involve the release of my contact details to her.

Signature of family representative:

Appendix 8: Full information letter for adults

<table>
<tr><td>

School of Psychology

Full information Sheet

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The University of
Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

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Title of Project Experiences and perceptions of family engagement during the
Education, Health and Care needs assessment process: An Interpretative
Phenomenological Approach

Researchers: Sally Eccleston

Supervisors: Nathan Lambert

Contact Details This research is fully supported by both XXX Community Educational
Psychology Service (contact Educational Psychologist XXX XXX@XXX.gov.uk) and
the University of Nottingham (contact Academic Tutor Nathan Lambert
nathan.lambert@nottingham.ac.uk). I can be contacted on email
sally.eccleston@XXX.gov.uk or lpxse1@nottingham.ac.uk, and by telephone.

This is an invitation to take part in a research study on the experiences of families
during the Education, Health and Care needs assessment process. Before you decide if
you wish to take part, it is important for you to understand why the research is being
done and what it will involve. Please take time to read the following information
carefully.

I think it is important to include the ideas of families in current research. Families have
lots of different experiences with individuals, services and the LA. This research would
allow me to share with others these experiences, and would help people to think
differently when working with families. With this research, I am looking to improve
understanding of individual experiences within the EHC needs assessment process,
whilst allowing families' voices to be heard within research. I hope to have some impact
on the practice of education, health and care professionals.

As you will know, a request has been raised for an Education, Health and Care plan for your child, or a child in your family. It is at, or near, the end of the process that you would be taking part in the research, although you would be agreeing to take part now. I am looking for a number of families to take part who will all be going through this process. This research is being carried out as part of a doctorate training programme, and therefore is expected to come to an end by August 2016.

If you agree to take part, I would be meeting with you and your family both as a family group and as individuals. We would arrange a time to meet as a group to discuss different things to do with your Education, Health and Care Assessment process. These would include relevant background information, your communication with support services, your expectations, your involvement in the process as a family and any factors which were helpful or not helpful.

I would then meet with everyone on a one-to-one basis to carry out an interview around individual experiences. This would be to get in-depth individual ideas about the impact that the process had, any involvement in the process and any difficulties or barriers faced.

The whole procedure will last 3 hours, allowing 90 minutes for the group discussion and 90 minutes for the individual interview, although it is likely that I would be meeting with you for less than this. Both the group and individual discussions will be recorded using an audio recording device. These recordings will be stored electronically in a secure and confidential manner.

I will also ask at the end of the research if it is OK to meet on a further occasion in order to share how I have written up what you have said. I want to make sure that you are happy for this to be reported, and to see what you think about how I have analysed what you have said. You will have a chance to say 'yes' or 'no' to this meeting.

Everybody taking part in group and individual discussions will need to sign a consent form, which will be shared at the same time as this information sheet.

Participation in this study is totally voluntary and you are under no obligation to take part. You are free to withdraw at any point before or during the study. At no point will any of your information be shared with the Special Educational Needs support service.

All data collected will be kept confidential and used for research purposes only. It will be stored in compliance with the Data Protection Act.

 If you have any questions or concerns, please don't hesitate to ask now. We can also be contacted before, during and after your participation through the above contact details. Please feel free to take your time to decide whether or not you wish to take part, and please discuss your decision with other people if you wish.

<div align="center">

If you have any complaints about the study, please contact:

Stephen Jackson (Chair of Ethics Committee)

stephen.jackson@nottingham.ac.uk

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Appendix 9: Full information letter for children and young people

<table>
<tr><td>

School of Psychology

Full information Sheet for young people

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The University of **Nottingham**

UNITED KINGDOM · CHINA · MALAYSIA

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</table>

Title of Project Experiences and perceptions of family engagement during the Education, Health and Care needs assessment process: An Interpretative Phenomenological Approach

Researchers: Sally Eccleston

Supervisors: Nathan Lambert

Contact Details This research is fully supported by both XXX Community Educational Psychology Service (contact Educational Psychologist XXX XXX@XXX.gov.uk) and the University of Nottingham (contact Academic Tutor Nathan Lambert nathan.lambert@nottingham.ac.uk). I can be contacted on email sally.eccleston@XXX.gov.uk or lpxse1@nottingham.ac.uk, and by telephone.

This sheet serves as an agenda for discussion with the young person which will take place one-to-one with the researcher. It is likely that this information will have to be adapted to take into account, for example, profound learning difficulties. The mode of presentation will be carefully considered, for example whether visual stimuli are necessary, and it may be that an adult is present who knows the young person well to promote understanding.

My name is Sally, and I am learning how to become an educational psychologist. Educational psychologists help schools and teachers to help pupils. I don't work in your school, but I work in other schools. As part of my learning, I have to do a research

study, and I would really like you to take part. I think it is really important that people listen to what pupils and families say and that they get to find out what happens to them.

To help you in and out of school, there are lots of people working together who talk about what you need and who can do this. To help you, your teachers/parents (delete as applicable) have asked for an assessment of what you need and what will help you. This is called an Education, Health and Care needs assessment. (At this point the young person may require further explanation of this process if they don't already know about it).

As part of this, there will be some meetings so people can talk about your needs and education. You will be invited. I am interested in how this process felt for you when it has reached its end. To find this out, I would like to talk to you and ask you some questions, both when you are in a group with your family and when you are on your own. So there would be two separate meetings, which would both last for 1-1 ½ hours. I will be recording what we both say during these meetings.

If you would like, we can now talk about the kinds of questions which I might ask you. I will use what you say in my research, but no-one will be able to know that it is you that has said it. I will be writing about what you tell me.

You do not have to say 'yes' to taking part. No-one will be angry if you say no. You will be able to leave the research at any point, even half-way through, and if you do not want to speak to me, you can tell an adult who you know and you will not have to speak to me again.

Do you have any questions? You can talk to your mum/dad/family before you decide.

If you do want to take part, you will need to sign the attached consent form so I know you are happy about the research.

Appendix 10: Semi-structured interview schedule

<u>Introduction and preparing to start</u>

- Thank participant for taking part
- Discuss anonymity and confidentiality
- Discuss audio recording of interview
- Discuss purpose of interview
- Interested in you and your experience; no right or wrong answers
- Like one-sided conversation; I may say very little
- Some questions may seem self-evident but that's because I am trying to get to grips with how you understand things

<u>Discussion 1: Expectations</u>

1. What did you understand about the EHC needs assessment process before it began?
   a. What did you expect to happen?
   b. What did you think the plan would mean for you?
2. What was the source of those expectations? What led you to think that?

<u>Discussion 2: Experience</u>

1. Please could you describe how the EHC process began for you and your family? What led to that?
2. What happened next? What was your role in that? What did you do?
3. Can you describe all the stages involved? What happened next?
4. Can you describe how the EHC process affected your everyday life?
5. Can you tell me about what has happened since a copy of the plan has been issued? How has that made you feel?

<u>Discussion 3: Family engagement</u>

1. Can you tell me what family engagement means to you?
2. What does it mean to you within the EHC process?

3. Where would I have seen family engagement in your process? How did that make you feel? What do you think other people thought about your engagement in the process?

4. What supported or inhibited your engagement in the process? Were there any barriers? How did you overcome these?

5. Can you tell me about your communication and relationships with anyone who you felt was involved in the EHC process?

6. What else would promote family engagement in the process?

Discussion 4: Evaluation

Can you imagine how the process could be even better for families?

Why do you think that?

Appendix 11: Ethical approval letter

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

School of Psychology

The University of Nottingham

University Park

Nottingham

NG7 2RD

T: +44 (0)115 8467403 or (0)115 9514344

SJ/wb

Ref: 621R

Monday, 23 February 2015

Dear Sally Eccleston & Nathan Lambert,

Ethics Committee Review

Thank you for submitting an account of your proposed research 'Experiences and perceptions of family engagement during the Education, Health and Care needs assessment process: An Interpretative Phenomenological Approach'.

That proposal has now been reviewed by the Ethics Committee and I am pleased to tell you that your submission has met with the committee's approval.

Final responsibility for ethical conduct of your research rests with you or your supervisor. The Codes of Practice setting out these responsibilities have been published by the British Psychological

174

Society and the University Research Ethics Committee. If you have any concerns whatever during the conduct of your research then you should consult those Codes of Practice. The Committee should be informed immediately should any participant complaints or adverse events arise during the study.

Independently of the Ethics Committee procedures, supervisors also have responsibilities for the risk assessment of projects as detailed in the safety pages of the University web site. Ethics Committee approval does not alter, replace, or remove those responsibilities, nor does it certify that they have been met.

Yours sincerely
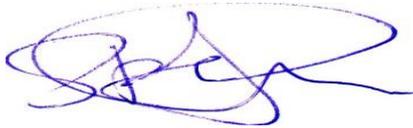
Professor Stephen Jackson

Chair, Ethics Committee

Appendix 12: Consent form

School of Psychology	The University of Nottingham
Consent Form	UNITED KINGDOM · CHINA · MALAYSIA

Title of Project Experiences and perceptions of family engagement during the Education, Health and Care needs assessment process: An Interpretative Phenomenological Approach

Researcher(s): Sally Eccleston lpxse1@nottingham.ac.uk

Supervisor(s): Nathan Lambert lpnal@nottingham.ac.uk

The participant should answer these questions independently:

- Have you read and understood the Information Sheet?   YES/NO

- Have you had the opportunity to ask questions about the study?   YES/NO

- Have all your questions been answered satisfactorily?   YES/NO

- Do you understand that you are free to withdraw from the study?   YES/NO
  (at any time and without giving a reason)

- I give permission for the data from this study to be recorded using an audio recording device.
  YES/NO

- I give permission for my data from this study to be shared with other researchers provided that my anonymity is completely protected.   YES/NO

- Do you agree to take part in the study?   YES/NO

"This study has been explained to me to my satisfaction, and I agree to take part. I understand that I am free to withdraw at any time."

Signature of the Participant: Date:

Name (in block capitals)

I have explained the study to the above participant and he/she has agreed to take part.

Signature of researcher: Date:

Appendix 13.1: Example of an annotated page from Eve's transcript

Emergent themes	Original transcript	Initial noting
	I - Could I ask you to describe your understanding of the EHC assessment process before it began for you? Y - Um...I guess sort of like I knew, **I knew it replaced the old plan**, so I knew it was coming into place, and **being on placement at uni I did hear about it anyway** so I sort of knew an idea of what it was going to be about. Um so I knew what the process will intake anyway and **at school they're really good at updating me like about meetings and stuff and when they were going to take place**. I - So it sounds like your understanding was a mixture of personal knowledge and knowledge given to you by school as well. Y - yeah, yeah it was, and placement.	Looking at expectations of the process Participant is hesitant here. Still establishing how comfortable she is in the interview context and how comfortable she is with me as an interviewer. Interesting repetition of the word 'knew'. What is the sense that she is making of this word? Is she trying to convince herself that she knew something? Or are we just getting into the rhythm of the interview? Replaced the old plan - sense of the old plan stopping and the new one starting. She knew that it was coming, but did she know what it was that was coming? Doesn't really seem to have been informed about key differences between statement and EHCP Feels important to her – being on placement at uni, introducing her personal experience as a source of information for the process Different sources of information for creation of expectations of the process – what did these mean for her and did she mould all sources of information into one coherent model? Going into the process with clear expectations or not? And what were they? Willing to acknowledge even at this early point that she *knew* but was also supported by her placement and by school Use of word 'updating' – defined as giving someone the latest information School here are enabling the parent to participate by telling her when the meetings are, but they are still holding the power. The agenda is still set by them. Me summarising what she's just said to get a handle on it. I felt like she needed a bit of input from me even at this early stage because she

Replacement of the statement

Exploring personal and professional experience

Becoming informed

School to home communication

Power sharing

Appendix 13.2: Example of an annotated page from Claire's transcript

Emergent themes	Transcript	Initial noting
Seeking advice from outside of the process Exclusion as a way of managing behaviour EHCP as solution to problems Being influenced by others Taking control of making a decision Feeling dissatisfied with current support Social categorisation of in-group (us) and out-group (them) Lack of confidence in school provision	personal professional experience that contributed. Y - Yeah, yeah I - Was there anything else that contributed to your understanding of the process before it began for you? Y - Um, not really no. I'd mentioned to the head-teacher where I work that I was having issues with Thomas and his behaviour and being excluded from school, and he sort of said to me straight away um if you apply for an education health care plan it's a lot harder for them to exclude him, so he sort of sown the seeds and that was at Christmas, just before Christmas. Um so I did have quite a long think about it, I didn't apply for it until April. I - So what were your reasons for applying for the EHC plan for Thomas then?	Contradicting herself here. Saying that nothing else really contributed to her understanding of the process but then goes on to talk about the impact that the headteacher within her place of work had. She is claiming here that she 'mentioned' having 'issues'. Described as behaviour and consequent exclusions – seem core to her understanding of YP's needs and difficulties. I have experience with difficult relationships between families and schools – participant here is describing going elsewhere for advice and support about what she should do as a parent. Letting things off her chest or seeking a professional opinion? What was the nature prior to this of her relationship with the headteacher? Professional boundaries. Did she need to validate her own opinions on what was going on? Seeking support from elsewhere other than family and school. Systemic context. Automatic reaction of head was to advise application for EHC plan. Almost like a knee jerk reaction – you're having problems – solution is to apply for the plan and this will lower potential risk of exclusion. My interpretation here is impacted by my personal and professional knowledge of what an EHC plan is and what it is for. Use of metaphor 'sown the seeds' – planted the idea in her head, discussion which caused parent to apply for the plan in the future. Parent's reaction was not as knee-jerk. Indicating that she still felt it was her own decision to make. That she knew what was best as a parent. Any discussion with Thomas at this point? 4 month timeframe between 'seeds being sown' and application being put in. What other sources of information or advice was she receiving during this time?

Appendix 13.3: Example of an annotated page from Thomas's transcript

Being included in the process	Y And writing on, so written on, so <u>we could know all the things about me, everything all about me</u>.	Range of ways to record information and not just through language. 'We' – so he was included in the activity of writing things down.
Lack of choice during the process	I OK, and what else happened at the meeting?	Was the process explained to the YP?
All about me	Y Um, <u>they was talking about me and how I hate peas</u>.	He perceives that the PCR was all about him. It was important that people there knew everything about him. So we could know – because we didn't know already? New information being shared? The process was shared between a number of people.
Sharing information about the young person	I Yeah.	This fact which may seem irrelevant to other people is very important to YP. Did he get to choose what people did and didn't find out about him? What was the agenda and did he have a say in it? Like a pen portrait – what I really like and really don't like. What is important for YP to share? What would he rather remain private? What is important to know?
Verbal communication	Y And most everything about me.	
	I OK.	
Agenda of the meeting	Y <u>What I like about school, what I don't like about school. What I like about home, what I don't like about home</u>.	
Influence of home and school		Again two environments of home and school – showing influence of both on development. Could he express himself openly? Discussing with strangers. How was this facilitated? Was his view being advocated anywhere else?
Focusing on positives as well as negatives	I And can you tell me who helped you to get ready for that meeting?	Important to provide information about what he likes but also doesn't like. Described in a fairly simple format. They were talking about it – was he talking about it too? Included in the conversation?
Preparation before the PCR	Y Um, I don't think anyone – just Mr. B.	
	I Mr B and how did he help you to get ready for it?	Did he feel informed about the meeting? Did he want to be informed? Trusted support person?
Some explanation for YP of what to expect at the PCR		Some degree of participation here. But is the meeting 'real and relevant' to the YP? His day to day experience is home and school. Meeting took place in school.
Trusted and supportive member of staff in school		

Appendix 13.4: Example of an annotated page from Marie's transcript

Emergent themes	Original transcript	Exploratory comments
	I - Was there anything that particularly supported your involvement in the process overall?	
Role of the keyworker to support family involvement	Y - What as a person? I'd say Sarah, our keyworker.	Keyworker's role - to support involvement. To help? This is the only thing she picks out when I ask her about anything in particular.
	I - In what way?	
Keyworker as always available when needed	Y - She was just always there really. You just knew she was always at the end of the line if you wanted her. She would do her visits, I think it was every 3 or 4 weeks she would come and visit, just	Like earlier - always made herself available. Parent felt more involved because she always had someone to turn to. Really appreciated the link of a person between herself and the process? What is the importance of a professional making herself easily accessible to a family?
Frequent contact with the keyworker	talk, the majority of the time we don't have a lot to say, because it's just like we've got on with this, we've got on with that, you know so she's going that's great, that's brilliant, you know we don't really ask for her help really, because we've just been used to getting on with it ourselves. But yeah	She would do them - was there any choice? How were these organised? Family welcomed the visits? Liked having her to regularly visit? Every 3 or 4 weeks would have been at least 5 times throughout the process. Sustaining regular face to face contact.
Building relationship with keyworker		Just talk' - sometimes talking makes the most difference? Keyworker is talking but family don't have much to say? No perception of important things that they want to say? Family doing things in the way they prefer? Behaving in an independent way?
Building relationship with keyworker	Sarah was always at the end of the line, but we didn't, it went quite smoothly, the whole process went quite smoothly, we know where we were, we knew what we	So the keyworker is praising the family, recognising what they are already doing. Recognising strengths, building relationship. Talking about what is already going well and what the family are already doing on their own.
Coping as a family without support	were doing, we knew when we	Pattern of family behaviour, sign of family dynamics- not to ask for help, to get on with things. Why is it so difficult to ask for help? Do they find it difficult to do this?
Keyworker as always available when needed		Again - she was always readily available. No perception of any particular diffficulty or stumbling point during the process. Did the keyworker help with this? What would have happened without the keyworker?

Appendix 13.5: Example of an annotated page from Andrew's transcript

Emergent themes	Transcript	Initial noting
the ehcp holding professionals accountable	Y - I feel because they're under more scrutiny, I feel that as professionals they've got targets to	under scrutiny because professionals are held accountable due to the legality and the pressure of maintaining what is in the ehcp? Local authority is held accountable for the right things being done. Who is accountable to who? Ultimately to central government - is this who is setting the target? professionals are accountable to the children and their family. Promoting a blame culture? Seeing education as a targets driven system - but this is a good thing. Where does the pressure come from?
the ehcp holding professionals accountable	meet. I've worked in sales and in marketing, most of my life, I worked in London for years, and um	relating to his own experience of sales and marketing, and of meeting targets, applies this to professionals in education
the ehcp holding professionals accountable	you're under very tight expectations, business is like that, and you had your daily what you need to	relating education, health and care to business. Education has become more market like - more choices and opportunities available and therefore professionals have to show their worth and meet targets being set. So that the individual is able to choose. Consequently raising standards? Is this the purpose of education?
the ehcp holding professionals accountable	do, and I feel that these people seem to be taking it very seriously what they have to be doing, and I	Repetition of the phrase 'taking it seriously' - seeing it as important
the ehcp holding professionals accountable	could pick up they were being scrutinised, you know maybe everybody is nowadays, you know	so professionals being under scrutiny for the parent is a good thing - it has made a difference.
the ehcp holding professionals accountable	everything's got to be, but I felt there was extra, they're being scrutinised in specific areas of what	it wasn't just the everyday scrutiny - when something is looked at really closely - it was something more than this.
	Michelle needs, and I feel it's because of what's in the plan, they have to meet that plan, you know,	it is up to the council to arrange and maintain the specified provision. If this is not done parents have leverage, they have grounds to complain, and this makes a difference. There is a basic legal duty for LA to meet what is in the plan, and the parent picks up on this.
Including the family in reviewing the draft ehcp	and the plan to me, you know we had time to review it, Sarah said read through it, if there's	given the space and time to look at the draft - this is important. Being told to read it and to come back with any comments. Encouraging family to be involved and to have an input.

Appendix 13.6: Example of an annotated page from Michelle's transcript

Emergent themes	Transcript	Initial noting
	I - And what kinds of things were you thinking during that meeting?	
Feeling overwhelmed during the PCR process	Y - I wanna go home.	She would rather be at home rather than in the meeting. Suggesting again that she had not been adequately prepared for the meeting, that it was not meaningful or relevant for her? The kind of language she is using is aligned with a YP of a much younger age, a toddler. Symbolising that she is feeling overwhelmed and needed something more familiar or more comfortable? in the context of her life - does this mean that most everyday activities take place at home and that it takes time for her to become familiar with a different setting?
	I - I wanna go home.. because?	
Not feeling engaged in the PCR process	Y - Because it was really boring.	Why would it have been really boring? Because she didn't find out anything new? Did she find out what people liked about her? Did she feel listened to? Did she find out what she was getting better at? What she is finding difficult? Did she know what would happen after the meeting? Did she feel that there would be positive change as a result? What would she have liked to talk about? Could she have created a video? Based on her interests/hobbies? A presentation? Could she have chaired the meeting with support?
	I - OK. What was boring about it?	
Finding it difficult to participate in the PCR	Y - Well you just have to go round in circles writing stuff about yourself, and that was it.	Go round in circles' - this is interesting. Does she mean literally walking round in circles in the room adding items continually to the pieces of paper? Moving round again and again in a circular way? This also makes me think of the idiom 'going round in circles' as in acting in a very confused way, to continually go over the same ideas, resulting in confusion, without reaching a satisfactory decision. This indicates to me that she did not clearly see the purpose of the PCR and there was no clear action plan as a result. 'You just have' - again no choice in how things were done. 'Writing stuff about yourself' - maintaining the focus on the YP. She felt part of it and was participating - but it wasn't meaningful. 'About yourself' - not about help and support. 'That was it' - indicating that modifications were needed in order to make the process interesting to YP? Did she not want to be involved and was this a barrier? Shows that the method of expression impacts on the experience of YP, and perhaps more creative ways of expressing this could communicate the message more clearly. She had difficulty communicating and participating - so use art, music, photos instead?

Appendix 14.1: Table of emergent and superordinate themes for Eve

Master theme one: Filling in gaps in knowledge

Superordinate theme: important influences on expectations of the process

Emergent theme	Quote	Line number
Assumption of being child and need focused	So obviously I knew it was going to be about James and about his needs	16
Replacement of the statement	I knew it replaced the old plan	3
	at that time it was called a statement	195
Exploring personal and professional experience	being on placement at uni I did hear about it anyway so I sort of knew an idea of what it was going to be about	4-5
	you hear all these horror stories	179
	speaking from personal experience, when I've been at uni, I've been with some of the mums and dads,	257-259
	I think just speaking from experience of being on placement, I'm using placement because you know I've been working with other families	338-339
Apprehension	I knew they would be going to different schools.. I just went along with it if that makes sense	25-26
	I think I just left it as late as possible before actually going round special schools, again because of my anxiety	60-61
	Yeah I was definitely putting it off, because I knew he had to go to a different school than James, I think I sort of like delayed it, because I don't want it to be a reality for him to go to a different school	281-282
	That was the hardest part, and I think that's why I put it off for so long, not going to have a look around schools, because I didn't want to make it a reality.	468-469
	I think it was more anxiety about both my boys because I knew from personal experience what was going to be in the plan	23-24
	again because of my anxiety, and David's anxiety	61
	obviously a lot of anxiety about why is	

	his twin brother going to a different school	440-441

Master theme two – what is the purpose of this process?

Superordinate theme: Getting it right for the future

Emergent theme	Quote	Line number
The relationship with transition to a new school	I think it was more me actually going around schools for visits, I felt like it was moving forward	58-59
	I knew from the meetings that James was going to be suitable for a special school	59-60
	I'm sure at that point the transition team got involved, so she came with me around a few schools	105-106
	the only difference was on my days off I had to go round and look at schools	147-148
	Well I'm hoping because I've only named one school, I've only put one school down, that he does get into that school	388-389
	I suppose when I know he's got into school I suppose I'll start making plans around that	393
	I suppose there was a link, because obviously they need to know what school was going to be in the plan	427-428

Master theme three: the relationship between home and school

Superordinate theme: Experience of the home and school relationship

Respect	if you had a professional go into school, school would let me know or ask me if that was ok	380-381
	if anyone couldn't make the meeting, then they would let me know	169
Trust	so I've built that trust with them	192
	I think trust as well is important, for me to trust them, and for them to trust me as well	207
	I mean I've always been open with them you know like talking about my divorce talking about losing my dad	305-306
	that trust, so I could talk to the SENCo like a	

	friend, I could tell her things	321-322
	because I'm his mum, so they, not that they had to trust me, but they had to take my word for it	210-211
Emotional support from school	people say oh I can't believe how you're coping but I just think I've coped well with it, so but um yeah I don't think if I'd had the support from school I wouldn't have coped as well.	450-452
	so I could talk to the SENCo like a friend, I could tell her things	321-322
Collaboration	work together	211
Consent	if you had a professional go into school, school would let me know or ask me if that was ok	380-381
Confidentiality	anything I told her was confidential so it was implemented, put in place where I could tell her things but it was not discussed with everyone	322-323
History of relationship	we've always had a really close relationship, me and school that is, so right from Reception up to now I've just built that bond with them,	181-183
	Um I mean school have always been fantastic,	57
	school has always been involved with everything	143
	I mean I can't praise school enough, from James being in Reception year, um when there's always been any issues, always been discussed with me	177-178

Superordinate theme – Communication between home and school

Emergent theme	Quote	Line number
A mirror image between home and school	everything was mirrored at school, that was really important so that James was having that same routine	186-187
	making sure that everything was like I was doing at home, Social Stories that was being mirrored at school	308-309
Points of contact in school	It was always the SENCo, so I'd always let her know when the visit was, and um she was always, I always invited her	403
	so it was always the named TA, i don't know if he was the named TA, but I always feel like he works more with James, so um he came with me to two	434-435

	schools	
Home to school communications	I always kept school updated	103
	I know school weren't aware of James's keyworker, so I did say James's keyworker is involved now	170-171
	anything I was using at home, so you know the visual timetable his routine you know anything, if I was doing a Social Story at home I would tell school that was what I was doing	184-186
	I did put in his home diary, his going home book, just to say oh I'm going to visit this school, or what happened when I visited this school, so it was me updating them, or letting them know when the visit was	423-425
	I did feel that obviously it was important that they knew the schools I was going to as well	426-427
School to home communications	at school they're really good at updating me like about meetings and stuff and when they were going to take place	5-6
	always involved in keeping me updated	57-58
	if anyone couldn't make the meeting, then they would let me know	169
	just school explaining to me, making sure I understood it	439
Shared modes of communication	whether it was by email or by James's home diary	103-104
	it was just like a going home diary so it's just a little, like a book, and it's got a picture like going home, so anything that happened at home that they needed to know like if he wasn't sleeping um or if he went to bed late or anything like that, I was telling school and school were telling me you know not always issues that they had, but if he had a good day what he had been doing	362-364
	that book was important so they did read the book and see oh yeah he's had a bad night	369-370
Creating a shared perspective	obviously the TA was with me at that point and she said No I agree	308-309
	things the school found difficult, things that I found difficult at home	79-80

	it was important that school got my view as well, and I got school's view as well	89-90
	I suppose also if there were any difficulties they were having at school or at home as well	106-107
	if I had any issues at home I would let school know and vice versa	144
	it was important that both sides was discussed	91-92
	So even before I'd said anything they said Oh I'm not sure about this and I said I agree	297-298
	so any new information was passed, was always important to be passed on by myself and from school as well,	173-174

Master theme four: now we're not alone

Superordinate theme: Multi agency support

Emergent theme	Quote	Line number
Shared experience with professionals	Just when everything started being put together and um we had like meetings at school	51
	Just so we knew what was going to go in his plan and um we got his plan right.	95
	so a copy was sent to everyone who was in the meeting as well	114-115
Multi agency input	his doctors, childminder, everyone was involved in it	17-18
	That's really bad, because everyone was like so involved	249
	me and the keyworker or any of the professionals	260-261
	it would be the link keyworker or the transition team	425-426
	they did help me	261
	they did so much as well out of their way	256
Specific roles of individual professionals	I'm sure at that point the transition team got involved, so she came with me around a few schools	105-106
	the lady involved in the plan, she's rang me and explained that what I thought	124-125

	was an error was not an error	
	so yeah that was part of his role I think,	
	but especially with having the transition team, I mean she came to pick me up and take me to the school	254-255
		262-263
Information give by professionals	With the keyworker just emailing me, updating me, telephone calls from himself, transition team just keeping me up to date	379-380
	So she explained that to me	126-127
	updating me, when the plan was going to be ready, when the draft was going to be ready	252-253
	the keyworker has explained to me because we're classed as city and that is county	391-392

Master theme six: family engagement

Superordinate theme: Family focused approach

Emergent theme	Quote	Line number
Family involvement	I guess for me it's just involving the family	153
	I did take David as well, going to have a look	459-460
Parent in the centre	when the meetings suited me, working around me.	160-161
	whether I could attend the meeting as well, school asked me which dates suited me, or a time,	167-168
	they was always oh Mum do you agree with that, or Mum, do you have anything to say, so it always came back to me.	228-229
Feeling listened to	I've said oh can you just explain that to me, and it was always explained.	345-346
	I was listened to as to what was important for James	220-221
	how they listened to me, um given me the opportunity	223
	Just having, hearing our views, our points, you know, what matters. Any problems we rise.	156

189

Focus on the whole family	they explained just to fit around David's needs as well because obviously he plays a big part being a twin brother,	438-440
	He did get upset, yeah so they did say going forward they would have to do some work with him as well	457-458
	because obviously David got upset in the meeting, so saying they needed to like say they needed to work with David as well, like doing the Social Stories thing, different things to work with both boys, supportive things around James's needs, around David, how he was going to be struggling with both transitions.	82-84

Superordinate theme: *Feeling empowered*

Emergent theme	Quote	Line number
Flexibility of the process and of the plan	I suppose also if there were any difficulties they were having at school or at home as well, that could be added into the plan, that was an important part as well.	106-107
	if there were any amendments to be added, or anything that I didn't agree with, there was a blue slip that I had to write, the comments on there	115-116
Power sharing	at school they're really good at updating me like about meetings and stuff and when they were going to take place.	5-6
	Just so we knew what was going to go in his plan and um we got his plan right.	95
	given me the opportunity, you know I was always asked if there was anything I needed to be added, and again any issues or worries I had, that was discussed there	223-224
	yeah any new ideas they had they were telling me which I felt helped me to use at home	311-312
	it was just discussed in the meetings like for me to start looking around schools	422-423
Choice	But I had to put my chosen schools down, but I only had one so I think I put that down	118-119
	I always wanted James to carry on with a mainstream, so the first school was a	

	mainstream with a unit	400-401
	I just wanted him to mix with other mainstream in a mainstream school, and I wanted to go, so I narrowed my decision down to a school that I chose	
	I didn't want him to go to an all autism school, I wanted him to mix	409-410
		416
Parent setting the agenda for meetings	if I wanted to invite anyone else to the meeting	168-170
	with meetings I made sure everyone was aware when they was taking place	18-19
Parent acting autonomously	I felt like I've always just said it even if it sounded stupid	403-404
	I started thinking oh I'll have a look at another mainstream school with a special unit	58
	I think it was more me actually going around schools for visits	80-81
	schools that I had an idea to have a look around	104-105
	and invited TAs to come with me if they could come with me	291
	I made sure that someone came with me	432-433
	I always invited her, so if she could make it to any visit	
	because I felt he had AHD, so I requested a test for that as well	447-448

Master theme seven: Not feeling engaged in the process

Superordinate theme – Power imbalances

Emergent theme	Quote	Line number
Domination of power	maybe in the second year whether I needed to get a statement for James, at that time it was called a statement, and they said oh because we're meeting his needs, I'm not sure whether he needs a statement	195-197
	I said oh I don't know so I mentioned it to the school and she said oh we are looking into it so I think it might have been them actually that put forward the	199-201

191

	plan	251-252
	when the plan was going to be ready, when the draft was going to be ready, so he did update me with that	
		393
	they said it could be sometime next year before they could let me know	117-118
	I mean I thought there was an error, which I wrote, but it was explained that it wasn't an error	127-128
	obviously it's a year until he starts school they can't give me the school I want, they can't put that school down because they have to go through the process and everything,	
		390-391
	we're classed as city and that is county, so I've put a county school down	
Passive involvement	in the meeting it was discussed what different, what was the targets to meet and the benefit for James as well	69-70
	I just went along with it	25-26
	we had like meetings at school, it was discussed	51-52
	James was in the meeting, and David as well in the meeting, yeah so it was discussed what the plan was about, and what the targets were to meet	78-79

Superordinate theme: Feeling under pressure

Emergent theme	Quote	Line number
Responsibility	I think I thought I need to start looking round schools so I know which school to put down in the plan what would be suitable for him as well	70-72
	so the only difference was on my days off I had to go round and look at schools	148-149
	when the plan actually started, I thought I actually need to be, I do need to name a school in this plan so I do need to start looking around schools	283-285
	I needed to name the school	429
	he just felt like I should choose the school, I thought that was a big decision to make on my own	473-474

Parent acting as the voice of the child	I think it was important for me I felt like I was James's voice, because he does have limited speech and he can't express his needs so much	87-88
	I couldn't see James in that school if that makes sense because I was trying to picture him how he would be around the school	413-414
	just by looking I was already I was thinking this doesn't suit James	402-403
Being a single parent	I don't think Dad attended	77
	it was important I was there, no, it was important that Dad was there, but Dad couldn't make it	88-89
	obviously Dad's not, he's not, well he is involved with the boys, he sees the boys quite regularly when he can, but um with regards to going to school visits he couldn't come with me to any school visits	291-293
	not that Dad didn't want to be involved, but just that the boys are with me more	472-473

193

Appendix 14.2: Table of emergent and superordinate themes for Claire

Master theme one: filling in gaps in knowledge

Superordinate theme: Lack of understanding about the process of statutory assessment

Emergent theme	Quote	Line number
Feeling uninformed about criteria to assess	they decide from the information that you've already given, yes he needs to be assessed for a plan or no he doesn't	126-127
Feeling lost in the process	the covering information was quite vague and quite I wouldn't say family friendly if you like	437-437
No existing schema for EHCP	I don't think I understood at the time how detailed it would be, and I certainly didn't know what it was going to look like,	462-463
Lack of understanding of the process	I assumed that I'd get a letter to say that yes they was going to make a full assessment or no they wasn't, but the next thing I knew I got an email from the facilitator who happened to have then been assigned as our keyworker, it was a pure coincidence apparently,	113-115
	Before I got the paperwork I didn't really understand very much of um the process	2

Superordinate theme: Important influences on expectations of the process

Emergent theme	Quote	Line number
Life and professional context of the parent shaping experience	I work in a school so I already knew	**27**
	I work in a school and it's very hard for me to get time off during school time,	**136**
	I work in a school and I sort of already understand the educational system better than a lot of parents would do, and I already knew about the statement process, I work with children whose got statements	**442-444**
Replacement of a statement	it would be the more modern up to date version of a statement so I knew it would mean any support that was in the plan would be implemented because of it being a legal document	**3-15**
Personal research	I googled it. I googled the process	**24**

	at the Person Centred Review the only reason I knew anything about that was because I googled it	**279-280**
Understanding of the process shaped by other people (4)	because I think I've heard that many stories from other people that it's really hard to actually get the initial assessment started	125-126
	I'd mentioned to the head-teacher where I work that I was having issues with Thomas and his behaviour and being excluded from school, and he sort of said to me straight away um if you apply for an education health care plan it's a lot harder for them to exclude him	33-35
Preparing for battle	and I think I was ready to have to appeal my thoughts as to why he does need assessing, and I didn't need to	127-128
Low expectation for inclusion of YP	previously meetings like that you wouldn't have expected the child to stay in the whole meeting.	21-22
Expecting family not to be involved	I knew it would mean an assessment of Thomas, but I didn't know what part we would play in that	278-279
	you think of an assessment as someone going away and doing it and coming back, whereas this wasn't anything like that	285-287

Master theme two: What is the purpose of this process?

Superordinate theme: Getting it right for the future

Emergent theme	Quote	Line number
Transition	I'm thinking basically if he's not coping in a standard primary school in Year 5, you know what's he going to be like in Year 6, and there's no way he's going to cope with transition and the general expectation in a secondary school	48-51
	course taking Thomas with me to the secondary schools was um wasn't something I would have normally done, not until sort of when he's already in Year 6	212-213
Long term thinking	it set the cogs going thinking about the future	46
	I was worried about his future, for me to be getting worried about his future, that's what was the turning point in me	297-299

195

| | applying for one | |

Superordinate theme: Trying to understand the purpose of the process

Emergent theme	Quote	Line number
The light at the end of the tunnel	it's almost like all this hard work and all the meetings and, not form filling, but information gathering and things like that <u>actually did mean something</u>	204-206
	<u>it's not just like having an educational psychologist go into school</u>, it was more, you know it was for a reason.	403-404
	.. as long as that's put into place and it works as it should do, as it's supposed to do, because that's what it's there for, then I'm sort of thinking I'm not going to be so worried now, do you know what I mean.	339-341
Sense of success and achievement by getting the EHCP	<u>if he was successful</u> in getting the education health and care plan	12-13
PCR as an info gathering tool	I just knew it was sort of like an information gathering exercise sort of thing	20-21
Tension in perceptions of purpose of the PCR	it started on a positive but I really need them to see his difficulties	80-81

Master theme three: The relationship between home and school

Superordinate theme: Experience of the home and school relationship

Emergent theme	**Quote**	**Line number**
School seeing the behaviour and not the need	um I think it boiled down to him getting into trouble because of his anxiety and his stress rather than him just being naughty for the sake of it.	43-45
	and I think although the SENCo knew that the reason he was acting the way he was was because of his difficulties, I don't think the same thing could be said of senior leadership, cos they're not specialists in Special Educational Needs, they're specialists in managing the school, it's a different role all together	313-316
	to understand somebody like Thomas, he's quite an in-depth person, and he's got lots of layers of his difficulty	309-310
	and I felt quite strongly at the time that there were several adults at the school who didn't understand	40-42

	the depths of Thomas's anxious behaviour, of course because all that some of the adults at school see is the anger outbursts it results for, and I felt that he was quite often misunderstood because of his anger	
Exclusion as a way of managing behaviour	I feel that had the head.. the person excluding Thomas.. understood where Thomas was coming from, I don't think the punishment would have been quite so harsh	316-317
	because he'd been excluded several times	312-313
Lack of trust in school	it was my chance to say what I felt wasn't working at school, without me just saying it to school if you like, it felt a bit more official	98-99
Lack of confidence in school provision	it was probably more bigger things that weren't working	109-110
	Mainly because I didn't feel he was getting the support that he um needed	39
	I think in the educational system, I think it's easy just to.. you've got a child in the class, and they've got difficulties, and then you just manage it on a day to day basis	307-308

Superordinate theme: *Communication between home and school*

Emergent theme	Quote	Line number
Breakdown in communication between school and home (5)	<u>although school knew that he'd got autism and difficulties, I don't think that they took his needs as seriously as I did</u>,	**296-297**
Communication between home and school	I had an email from the school SENCo with the proposed time and date of the Person Centred Review,	70-71

Master theme four: Now we're not alone

Superordinate theme: *Multi agency input*

Emergent theme	Quote	Line number
Unique EP input	And a lot of those points I think, have come from Laura's understanding of Thomas	321-322
Multi agency input (5)	<u>there was a chance for everyone at the meeting</u>, because I think I mentioned that my sister came, um and there was the lady from the Autism team, there was Thomas's 1:1 TA present, the Special Needs Teaching Assistant that sort of generally oversees the special needs at the school, his teacher as well, and ..	**74-76**

	I can't remember who else.. of course you've got the facilitator	
	that would be nice to do with the people that's actually going to implement it,	**454**
Validation of opinion	I think talking like to the lady from the autism team and to the educational psychologist, I felt like they were confirming what I already knew	299-300
	it was quite astounding for me to have another professional to have the same understanding of my son that I had always had	302-303

Superordinate theme: Working in partnership with the keyworker

Emergent theme	Quote	Line number
Parent trusting keyworker	so I think I found her help invaluable, especially considering she got a really good understanding of Thomas really quickly,	**140-142**
Role of the keyworker to help	the email said that she was going to be our keyworker and to get in touch if I wanted help,	**116-117**
	Sarah arranged a couple of visits for me for different secondary schools,	**138**
Role of the keyworker to work with the family	the keyworker came several times, she did some work with Thomas, she did some work with me	**113-134**
Role of the keyworker to pass on information	I got a text from Sarah on the day to say that Thomas had been issued with a plan,	**183**
	she knew exactly what she was talking about all the time, and if she didn't know the answer to a question, she would get back to me in quite a timely manner	**345-346**
	anything we needed to know the question to, she had the answers for, you know all I had to do was either text her or email her, and she was on it like you know straight away,	**384-386**
Role of keyworker to gather opinions of family	um Sarah had given Thomas and me a book to fill in, I think it was called My Plan or something	235-236
Positive relationship between family and keyworker	she was very professional, um I think she's got, as a whole as a person, she's got a good understanding of special needs	368-369
	her and Thomas hit it off really quite good at the start anyway, and I think she's an easy person to talk to, because I think if you're	370-375

	talking to someone you don't know about something quite intimate, like your son's needs, <u>you've got to have a certain amount of trust in that person</u> as well haven't you, and I think if you don't know the person and you don't feel like you're going to get to know them if you like, then you find it hard to open up I suppose, she just gave out that sort of professional friendlyness if you know what I mean.	

Master theme five: Focus on the young person

Superordinate theme: A young person centred approach

Emergent theme	Quote	Line number
Process orientated around YP	person orientated if you know what I mean, as in Thomas	223-224
	<u>I knew it would mean an assessment of Thomas</u>	278-279
	I felt that Thomas was included in everything, every step of the way	
	, it was just as much about Thomas as it was about the paperwork,	

Superordinate theme: Supporting the young person's involvement

Emergent theme	Quote	Line number
Inclusion of YP voice	of course then Thomas got his own chance to write things on there as well	**85-86**
	one was for Thomas to sort of put down on paper some of his ideas, so I actually gave him his copy, and he was walking round and writing down relevant bits from the paper that he'd got, he was writing them on the paper on the wall, which was good for him, because I don't think he would have written anything otherwise	**89-93**
	<u>she was talking to Thomas about things which he felt he needed</u>	**151-152**
Opportunities for YP voice	he was given an opportunity to say something if he wanted to, at any of those times that we had any contact.	229-230

Master theme six: Family engagement

Superordinate theme: Family focused approach:

Emergent theme	Quote	Line number
Feeling valued	she went out of her way after that, after she'd seen Thomas, she went out of her way to meet with me after that, because she wanted to go through what she had written,	394-396
Collaborative approach with parent	the educational psychologist came around with her report the day before it was due to be submitted, and um we talked about it,	166-167
	so she would come round and go through it with me, and she did,	189
	she'd written a report and she wanted to make sure that things in it were correct, so she came here after I'd finished work, so basically out of hours if you like, to talk through the report, which I thought was good.	396-399

Superordinate theme: Family participation

Emergent theme	Quote	Line number
Opportunity for parent voice	I sort of more felt it was my chance to put my views across as well,	97-98
Preparing to participate	They had sent me a booklet to fill in, which helped massively because unless you're already prepared for what they're going to ask you, you can't sometimes come up with an answer straight away,	86-88
Inclusion of family voice	we, you know, put our supporting plan together	**155-156**
	a space for family to write, and of course then Thomas got his own chance to write things on there as well as me and my sister, um and my husband was there,	85-86
Parent and YP working together	because it's hard sometimes with somebody like Thomas to get him to sit and do anything with anybody, so it did feel like we were working as a bit of a team rather than a bit like battleships	244-246
A balanced perspective between parent and YP	and it was very much centred around different opinions from me and Thomas, it wasn't just about how I felt, or just about how Thomas felt, so that book was something that me and Thomas did together	236-238
	, Thomas would tell me what he'd think and I'd tell him what I thought and then we'd decide between us what we were going to write down	248-250

Superordinate theme: Feeling empowered

Emergent theme	Quote	Line number
<u>Taking control</u>	actually thinking I'm now having the opportunity to say whether I think this is right so it was, I'm trying to find the right word, um.. <u>felt a bit more in control</u> if you like	202-204
	I applied for it, and I know exactly what it was, what's it for	426-427
Autonomous decision making	so I did have quite a long think about it, I didn't apply for it until April.	36-37
	I need to put something in place now, ready for when he goes to secondary school	54
	I applied for the plan myself as opposed to school.	57
Flexibility	like I say there were a couple of things which still weren't right, um but we get a blue form to fill in with anything which is inconsistent or anything we didn't agree with	193-194
	it's only a draft plan, that's not a problem, it can be altered	173-174
	The form, it's quite a long detailed form, and I didn't fill it in on just one occasion, I filled it in over a period of about 6 weeks, um where I was adding bits and going back and reading it again,	58-60

Master theme seven: Not feeling engaged in the process

Superordinate theme: Lack of whole family engagement

Emergent theme	Quote	Line number
Mum more involved than Dad	he was, he didn't, he's not very forthcoming, he doesn't understand the educational processes like I do	425-426
	in a nutshell <u>he knows it's going to help Thomas, with his education and hopefully to keep him better behaved at school</u>, and <u>that's probably the most he would think about it</u>, because it's, you know, <u>it's not something he feels he can get involved in</u>	428-430
	<u>I think he doesn't understand how important it is to me and Thomas,</u>	431-432
Lack of inclusion of siblings	if Aaron had been included a bit more in the process, he might be a bit more understanding of things like that.	419-421
	it didn't include the other siblings I don't suppose, very much,	220-221
Lack of whole family	not probably like I've already mentioned for the	407-408

engagement	whole family,	
Lack of inclusion of YP voice	Then Sarah came round on the Wednesday, last Wednesday I think it was, Thomas was away, and talked through the actual plan,	191-192

Superordinate theme: Feeling alienated from the process

Emergent theme	Quote	Line number
Not being listened to	there were a couple of really big mistakes in it, I don't think it was purposeful mistakes, it was just some misunderstandings,	169-171
Not feeling involved in decision making	I knew that they decided with that information from the person centred review, they took that away and they decide whether to make a full assessment or not,	4-6
Passive involvement	she was coming to see us, you know not every week, but she was seeing us at different stages,	150-151
Communication which is not transparent	it wasn't clear that the assessment was going to take place.	117-118
	actually I didn't receive a letter until I queried it with her and they got it sent out.	121-122
Social categorisation of in group and out group	Now there's a waiting stage between now and when they decide whether he'll get a draft plan or not	**157-158**
	there's an invisible party doing everything behind in the background	**350-351**
	it's the SEN team that meet and decide whether he needs the plan, but you know we've had no contact with the SEN team,	**351-352**
	we're one side of the wall and they're the other side of the wall if you like, just because they're invisible because we've not had no contact	**355-356**
Feeling an outsider to the process	it seemed a lot longer than it was, because that's it there's nothing we can do.	**164**
	even at this stage we didn't know whether we was going to get a plan or not	**185**

Superordinate theme: Feeling under pressure

Emergent theme	Quote	Line number
Being worried about putting across views	, I was a bit apprehensive because I'm thinking at this stage, um you know right at the beginning of the meeting, I'm thinking um it started on a positive but I really need them to see his	79-81

202

	difficulties, so <u>I wasn't sure at that stage whether I'd be able to correctly put across my, my concerns</u>	
Responsibility as a parent (2)	one of the action points from the Person Centred Review was for me to take Thomas and look around some secondary schools	
	, I need to put something in place now	
Parent perceiving herself as an advocate for child (3)	Um initially I thought my role was to um, I don't know, be there for Thomas, and sort of stick up for him	
Getting it right (7)	<u>it was getting my head round what each one meant so I could answer it properly and just as in-depthly</u>	
	. I was quite anxious that I had forgotten to say something which was important, because <u>I knew this meeting was make or break</u>	
	I was then conscious that this had already gone to the panel with the mistakes in	
	I didn't want to come across as being really negative, so I think that was probably one of my main reasons for being anxious	

Appendix 14.3: Table of emergent and superordinate themes for Thomas

Master theme one: Filling in gaps in knowledge

Superordinate theme: Lack of understanding about the process of statutory assessment

Emergent theme	Line number	Quote
Lack of understanding of the PCR	79	No. J All I knew was about that there was a meeting,
Awareness of the process	229	Educational Health Care
Awareness of the process	239	No only EHC
Lack of child friendly terminology	231	I thought it was Centre.
Lack of understanding of the process	272	Two different things like, but I've got hypermobility, so I can act.…when I was 5, 6 and 7, I
EHCP as abstract	248	But I don't know when.
EHCP as abstract	390	We haven't done the plan yet so cos we are going to do part of the plan in a minute I don't
Lack of knowledge about the plan	424	I think ….Maybe
Lack of knowledge about the plan	391	know what ….I don't know what the plan is basically mostly about

Superordinate theme: Important influences on expectations of the process

Emergent theme	Line number	Quote
Perceptions of the plan influenced by parent	270	But she said it's to help me didn't you?
Perceptions of the plan influenced by parent	342	Mum has

Master theme two: What is the purpose of this process?

Superordinate theme: Getting it right for the future

Emergent theme	Line number	Quote

Choosing between secondary schools	178	It's *** or ***
Choosing between secondary schools	186	Um, by liking them and not liking them.
Choosing between secondary schools	190	And we're not going ***, too big, but we may be going *** or ***
Visiting schools as part of the process	188	Just like, thinking that, we had like a tour… Mum, what were the 3 schools?
Visiting schools as part of the process	445	Mmmh going to a few schools

Superordinate theme: *Trying to understand the purpose of the process*

Emergent theme	Line number	Quote
Lack of understanding of the purpose of the PCR	75	To learn a bit more about me. I don't know.
Purpose of the EHCP to enable access to services and resources	266	She didn't feel – she said, My Mum said it was to help me get things yeah but Um – not –
Purpose of the EHCP to enable access to services and resources	267	she said it – what did you say – that it's for my help me get better things. She said it was to
Purpose of the EHCP to enable access to services and resources	268	help me but she didn't say to help me but other things, different things.
Purpose of the EHCP to help	262	Help me
Purpose of the EHCP to make progress	264	Get better at things
Purpose of the plan to improve the current situation	318	To help me stop those ups and downs happening
Envisaging change in behaviour	320	I get a bit gooder and nicer at school.
Envisaging change in behaviour	322	Not that much tantrums
Understanding the purpose of the assessment	474	Cos she needed to know more about me

Master theme four: Now we're not alone

Superordinate theme: *Multi agency support*

Emergent theme	Line number	Quote
Experience of PCR shared with teachers and family members	8	Yeah 'cos my Auntie ***, my Mum, My Dad, some other ladies, Katy, Mr. B, Mr.
Experience of PCR shared with teachers and family members	9	D and Miss G and then some other ladies.
Shared process with other people	244	I knew we were going to have an Educat..

Emergent theme	Line number	Quote
Developing relationship with keyworker	441	<u>The lady who is trying to help me</u>
Answering the keyworker's questions	471	Cos she wanted to know
Keyworker responsible for EHCP	478	Making a plan
Sharing responsibility for EHCP	480	Yeah and we've helped her

Master theme five: focus on the young person

Superordinate theme: Supporting the young person's involvement

Emergent theme	Line number	Quote
Receiving support to participate in the PCR	31	No, oh walked around with me.
Receiving support to participate in the PCR	112	I needed a bit of help what to think of, didn't I?
Setting up a comfortable atmosphere with refreshments	45	Cos there was biscuits we put down and drinks.
Setting up a comfortable atmosphere with refreshments	101	Um. Getting things they like, like biscuits and drinks.
Helping the YP to feel comfortable in the PCR	105	In a comfy room
Helping the YP to feel comfortable in the PCR	119	So you don't get that thirsty. You don't have to go out of the room to get a drink, or to get
Helping the YP to feel comfortable in the PCR	120	biscuits.
Having family present at the PCR	151	Um, yeah. Having my Mum, most of my family.
Feeling prepared for the PCR	28	Um, <u>telling me when the time is, when we are going</u>, telling me, that um, '<u>cos he's going</u>
Feeling prepared for the PCR	29	<u>with me, he's taking me</u>.
Feeling prepared for the PCR	33	Eh? Oh laid on his lap.
Preparing for the PCR with friends	39	Some kids.
I want to feel prepared	212	Yeah, because basically um, that means I know where I'm going and it helps me get
I want to feel prepared	213	prepared.
I want to feel prepared	370	<u>It's important because I need to know about</u>

		most things that are gonna to happen.

Superordinate theme: A young person centred approach

Emergent theme	Line number	Quote
Expression of YP view in the PCR	23	What I like about school, what I don't like about school. What I like about home, what I
Expression of YP view in the PCR	24	don't like about home.
Gathering of views through conversation with the keyworker	469	And I thought that school was a bit OK and a bit good, a bit bad.
People finding out about me	16	And writing on, so written on, so we could know all the things about me, everything all
People finding out about me	17	about me.
People finding out about me	51	Cos basically it's um, it's all about me and things people know, need to know about me.
People finding out about me	63	Cos everyone was talking about me.
People finding out what happens in school	161	About things that are happening in school
People finding out what helps me at school	67	But they talk about how Mr. B helps me.
People finding out what helps me at school	69	Always with me.
People finding out what helps me at school	71	But, like…he sometimes when he needs to go get a drink I have to make, look after, be
People finding out what helps me at school	72	good.
Finding out what is important to me	19	Um, they was talking about me and how I hate peas.
All about me	21	And most everything about me.
All about me	59	Cos it's all about me.
All about me	387	Cos it's mostly about me.
All about me	430	Cos It's about me
Sharing important information about me	53	Cos I'm autistic and like and some people need to know.
Enjoying the process	57	And a bit happy.
Adapting to the needs of the child	199	A bit happy cos no one's in there except adults but Bluecoat I got a biscuit.
Understanding the needs of the young person	459	No and I don't really like um long conversations

207

Master theme six: family engagement

Superordinate theme: family participation

Emergent theme	Line number	Quote
Shared family decision making	180	Me and Mum and Dad
Shared family decision making	182	Cos Dad may be taking me
Parents holding the power in decision making	205	Mum, Dad and sometimes me.

Master theme seven: Not feeling engaged in the process

Superordinate theme: Feeling under pressure

Emergent theme	Line number	Quote
Lack of choice of format of the PCR	12	Um, we had to write things down on walls, cos they had paper - big pieces of paper.

Appendix 14.4: Table of emergent and superordinate themes for Marie

Master theme one: filling in gaps in knowledge

Superordinate theme: Lack of understanding about the process of statutory assessment

Emergent theme	Line number	Quote
Unaware of the process before it begins	5	Y - We didn't know anything about the EHC process at all, um it wasn't, cos Michelle wasn't even at
Unaware of the process before it begins	34	Y - Um, like I said we didn't really know what an Education Health and Care plan did, we were just
Unaware of the process before it begins	351	of, as just the parent, maybe because we never really heard much about an EHC, and maybe
Lack of understanding of the process	225	think Michelle even understands what it is, or what it's for or what it does really, we don't and we
Lack of understanding of the process	226	applied for it (laughs).
Lack of understanding of the process	354	really, we didn't really have much time to see what it was all about, we just knew it was a good thing

Superordinate theme: Important influences on expectations of the process

Emergent theme	Line number	Quote
Replacement of a statement	7	we thought yes Michelle needs a statement, it had changed to an EHCP plan so we had to
Expectations and beliefs about the process shaped by professionals	20	Y - Someone at CAMHs I think.
Expectations and beliefs about the process shaped by professionals	30	Y - By.. It was Michelle's actually, Michelle's tutor, home school tutor, that gave us the website for the
Expectations and beliefs about the process shaped by professionals	364	Y - Became vocal once it began I think. It was the tutor.
Favourable comparison to past experience	330	things in Michelle' life don't happen very quickly, you know even the DLA wasn't quick, the PIP,
Favourable comparison to past experience	331	everything's very, you have to keep ringing up people, have you got these bits, you know and we
Favourable comparison to past experience	332	never had to do anything like that, so it was pretty plain sailing for us.
Focus on getting help	355	to have, it would help Michelle, and that was all we were thinking, it would help Michelle get everything

Master theme two: what is the purpose of this process?

Superordinate theme: Getting it right for the future

Emergent theme	Line number	Quote
Thinking about the future	38	something for the next, just to get her through college and maybe university if that's where she
Thinking about the future	35	hoping it would help Michelle because she was getting up to college years. We realised that Michelle
Protecting future provision	140	you a little bit, because I know now that it's set in place for Michelle for the next, well until she's 24,
Protecting future provision	141	25 I think, so she'll get whatever help she needs, educationally, that she's never had before, you
Protecting future provision	142	know, so that kind of helps, plus also if you think where she is now at college, if they're not doing
Protecting future provision	143	anything, you've got a bit of back up, a bit of help and support, to say well this isn't happening for
Protecting future provision	144	Michelle, let's try and sort this out, so you will like they will, so that's really good.
Protecting future provision	200	we're hoping that she gets all the help in this next year, that she maybe might get back into the

Superordinate theme: trying to understand the purpose of the process

Emergent theme	Line number	Quote
Focus on getting help	197	Y - Yeah I feel it can do, yeah. Because I think she's in college now but she's in the special unit
Focus on getting help	202	EHCP will help more.
Focus on getting help	355	to have, it would help Michelle, and that was all we were thinking, it would help Michelle get everything
No immediate impact	195	Y - Not yet.
Purpose of the EHCP to enable YP to catch up	12	was behind on school, she struggled at school anyway, she was home schooled, so that's when we
Purpose of the EHCP to enable positive change	224	really, because she needs to move onwards and upwards, and even having that, even though I don't

Master theme three: The relationship between home and school

Superordinate theme: Experience of the home and school relationship

Emergent theme	Line number	Quote
School not understanding YP's needs	408	detentions nearly every week because of something she'd forgotten, but that's Michelle's fault you
School not understanding YP's needs	409	see, and I'm thinking but it isn't because Michelle hasn't got very great memory. So when he's come in
Difficult experience in mainstream	36	struggles in a mainstream school, that's why she was no longer in one, but she'd never had any help,
Poor relationship with mainstream setting	170	attempts, all those sort of things. The school were no help really, I felt, or they just didn't pick up on
Poor relationship with mainstream setting	185	changed, well the school were still useless, they still never told their own autism team that Michelle
Poor relationship with mainstream setting	186	was autistic so we never got any help from mainstream school in that respect, but everybody else,
Poor relationship with mainstream setting	399	that, but for someone to actually, you know, I had such a fight with the school for so long that for,
Poor relationship with mainstream setting	404	empathy really from school, and I think I found that the hardest, it was always your child's doing this,
Poor relationship with mainstream setting	405	your child's doing that, we can't be having this in the school, she's scaring the Year 7s, she's bleeding
Poor relationship with mainstream setting	406	everywhere, and it was almost like it was all her fault you know, she kept forgetting what class she
Poor relationship with mainstream setting	417	fault, and you're just sitting there thinking well it wasn't you know. So for *** to then come in
Low expectations for involvement of mainstream setting	61	didn't surprise me that they didn't turn up, but Michelle's tutor was there, Michelle's psychiatrist was
Low expectations for involvement of mainstream setting	82	in Michelle's life at that time, apart from the school, were there.

Master theme four: Now we're not alone

Superordinate theme: Multi agency support

Emergent theme	Line number	Quote
The role of the EP as assessor of needs	96	the assessment guy, and he paid us a few visits, first on our own, and then introduced Michelle to him

The role of the EP as assessor of needs	98	3 visits, where they sat on their own and he asked her questions, and they did tasks and you know,
The role of the EP as assessor of needs	387	Well for someone to come in and assess your child, and to go away and say yep she needs help or
The role of the EP as assessor of needs	395	know, so for someone to come into your house, and twice to assess them, and say yes you do, it just
The role of the EP as assessor of needs	410	as an educational person to say yeah I've got it, yeah she needs help, it just, yeah, it's upsetting, but
YP engaging with the EP	97	a couple of times, which, once she'd got to know him a little bit, he came back for I think about 2 or
EP showing interest in the family	131	educational visit, the home tutoring group, which Sam said oh I'd like to sit in on that which was
EP showing interest in the family	132	quite nice, so he came to that, I think then he spoke to Michelle's psychologist privately as well. So I
Family and professional partnerships	357	psychologist, he just asked, he just made it more clear for us, because he was asking things and we
Family and professional partnerships	361	Yeah, so with him, it was really good.
Family and professional partnerships	367	Yeah, Margaret had been Michelle's tutor since about December, before she got discharged from
The importance of professional involvement in the process	339	think they were paramount really.
Clinical psychologist acting as advocate for the family	348	the whole meeting really, but for the education, he was adamant that Michelle needed an EHCP, and
Clinical psychologist acting as advocate for the family	349	he really wanted it for her, so he was always like our little vocal person in the meeting, because me
Clinical psychologist acting as advocate for the family	343	Michelle had a 6 weekly educational meeting, her psychologist, he would always be there, see how
Clinical psychologist acting as advocate for the family	344	she's getting on, because I think Michelle's on so much medication, and the way Michelle thinks
Clinical psychologist acting as advocate for the family	345	because of her anorexia, he's always interested to see how it's affecting school, or whether she's
PCR as an opportunity for a multi agency perspective	54	which was done at CAMHs where we all met together. They gave us booklets on writing, how
PCR as an opportunity for a multi agency perspective	60	Because Michelle's, because everyone was there, all except Michelle's mainstream school, which
PCR as an opportunity for a multi agency perspective	62	there, family therapist was there, Michelle, myself and my husband were there, and we all had to
PCR as an opportunity for a multi agency perspective	81	her psychiatrist was there, you know, so it was important that everybody who was quite influential

Emergent theme	Line number	Quote
PCR as an opportunity for a multi agency perspective	258	Well it was quite interesting to see their views, how they saw Michelle, well it was probably more
PCR as an opportunity for a multi agency perspective	270	lady who was there, so it was quite interesting to see how the psychiatrist or a family therapist

Superordinate theme: Working in partnership with the keyworker

Emergent theme	Line number	Quote
Building a relationship with keyworker	293	talk, the majority of the time we don't have a lot to say, because it's just like we've got on with this,
Building a relationship with keyworker	294	we've got on with that, you know so she's going that's great, that's brilliant, you know we don't
Frequent contact with the keyworker	292	wanted her. She would do her visits, I think it was every 3 or 4 weeks she would come and visit, just
Keyworker as always available when needed	152	but she was always there if we needed her, not that we really felt we did, you know she helped us
Keyworker as always available when needed	291	She was just always there really. You just knew she was always at the end of the line if you
Keyworker as always available when needed	296	Sarah was always at the end of the line, but we didn't, it went quite smoothly, the whole process
Role of the keyworker to identify and help with sources of stress	153	on other things, like getting Michelle to stay on at the farm, which she was doing once a
Role of the keyworker to identify and help with sources of stress	154	week, um so she rang him up, because we were getting a little bit confused about it all, so you know
Role of the keyworker to identify and help with sources of stress	155	when we got a bit confused about it, she kind of stepped in and took over a little bit, kind of well
Role of the keyworker to identify and help with sources of stress	156	don't worry about that I'll deal with it, I'll get back to you, so it was nice to have someone to do that, for a change, yeah
Role of the keyworker to keep the family informed	317	Sarah said she knew, they gave us a date, sort of like 3 or 4 weeks before.
Role of the keyworker to keep the family informed	319	Yeah, I'm sure it was Sarah, yeah, who would give us the date, of somewhere in the middle of
Role of the keyworker to make the process easier	134	good, because she helped us with lots of little things, to try and get in touch with people, or you

Superordinate theme: Things are finally getting better

Emergent theme	Line	Quote

	number	
A constant battle	91	struggle with, so then you have to re-appeal all the time, which is what I've had to do, so I was, you're always conscious that you
A constant battle	392	hasn't got a disability, so you've got to be constantly fighting that, and sometimes you're thinking
A cry for help	37	never had anything from the autism team, nothing, and we just thought that you know she needed
A cry for help	50	help for us was, is a major thing, it doesn't matter how big it is or how little it is, so an educational
A cry for help	51	health care plan for us was very important because she'd never had any help.
A cry for help	104	so really to go through a time, to sit there and say my child needs help, you know we need help we
A cry for help	105	need help she needs help, um sometimes I just think if someone else from the outside comes in and
Coping as a family without support	47	because we struggled ourselves as a family on our own, through most of Michelle's life, through not
Coping as a family without support	165	Yeah, I think it's, god! Well we didn't have any help. It took Michelle to hit rock bottom before we
Coping as a family without support	166	could get any help really.
Coping as a family without support	180	that's the way it is, but because of not really having the help there and not having the help with
Coping as a family without support	352	because we never had anything from an autism team saying this is what your child needs in the first
Coping as a family without support	295	really ask for her help really, because we've just been used to getting on with it ourselves. But yeah
Perception of support as ineffective	171	it. She had a mentor to go and see if she wanted to, but it didn't really help, and even when she was
Perseverance	49	don't get it we just keep going and we keep going and we struggle and we keep going, so any little
Traumatic event acting as trigger point for the process	187	CAMHs and the home tutoring, have been excellent since then. It just seems a shame that, you
Traumatic event acting as trigger point for the process	189	but you know you have to hit rock bottom before you can even start to get any help.

214

Master theme five: Focus on the young person

Superordinate theme: A young person centred approach

Emergent theme	Line number	Quote
Understanding my child's difficulties	115	things, so I just say them in Layman's terms, you know because that's easier, but when he was doing
Understanding my child's difficulties	116	little tests with her, I realised that you know, there were certain areas that she was particularly
Understanding my child's difficulties	117	struggling with, you know, which kind of opened my eyes a little bit, so I was like OK. Because I think
An opportunity for parents to listen to YP	112	actually sat and listened to some of the questions that he was asking and listening to her answers, then I
An opportunity for parents to listen to YP	118	when they're at school, or with a tutor, you don't see that, you just, they just come home and you're
An opportunity for parents to listen to YP	119	Mum and you know, but to listen to her, I then realised, yeah how far behind she is a little bit, you
An opportunity for parents to listen to YP	244	many things, it was funny to see what she would write, and how she saw her life, and how she saw
An opportunity for parents to listen to YP	259	interesting for us to see how Michelle reacted to other people's views of her, that's what we found
An opportunity for parents to listen to YP	64	just interesting to see her, how she saw and thought about things, you know it was quite interesting.
A person centred approach	239	what we like about Michelle, what do we think of Michelle, where would we like Michelle to be, what
A person centred approach	281	Michelle, followed by us.
A person centred approach	284	thinks, and I suppose we were writing everything down about Michelle, so that has to put her as the
A person centred approach	285	most important person in the room. We weren't writing anything down about myself, about how I
A person centred approach	286	feel or what a crappy day I've had with her, or how hard it's been, it's just about Michelle and what
A person centred approach	287	she needs.
Inclusion of YP voice	261	what we wrote she put a tick, and if she didn't like it she put a cross, and that was quite interesting
Inclusion of YP voice	264	love the way Michelle looks, and then she'd just cross it, so then you understand her more, because
Inclusion of YP voice	266	what she's thinking, so without having to speak she could just go around and I think she found that
Inclusion of YP voice	267	quite easy, because she could put what she wanted, she could write what she wanted, she didn't

215

Inclusion of YP voice	268	have to speak to anybody or you know, which is what she normally finds quite hard you know,
Inclusion of YP voice	272	would go round and cross it out (laughs). It was quite funny. So that was quite good.
Inclusion of YP voice	283	Because I think we just, having Michelle be able to write things down of how she feels, or what she

Master theme six: Family engagement

Superordinate theme: Family participation

Emergent theme	Line number	Quote
Whole family assessment	253	Um, not really, apart from when we had the assessment with Sam, you know the first couple of
Whole family assessment	254	meetings it was me and Andrew. Um, and then he met Michelle with me and Andrew, so that was the only
Participating as a family	241	spot that one, so, and it was just, it was quite good that we were as a family doing it, but almost
Participating as a family	246	kind of done separately and together.
Capturing individual views	236	Um, I think because like doing this, sometimes it was quite individual, I think that's quite good
Capturing individual views	237	because what I see Andrew doesn't always see, and what Andrew sees or hears or thinks is a new guy area.
Capturing individual views	240	does Michelle have difficulties with, you know, he would put things and I would think oh yeah didn't
Capturing individual views	242	separate if you know what I mean, because he sees these things differently to me, and I cope better
Capturing individual views	243	than he does, and then he copes with things better than I do, you know Michelle doesn't cope with
Capturing individual views	312	and I think that can sometimes make it hard, because sometimes he sees and hears things that I
Capturing individual views	313	don't actually recognise as a problem, or vice versa, and I think having both your parents there is a
Capturing individual views	314	good thing, because you don't miss out on anything.
Inclusion of family voice	260	quite interesting, where we could all write something, and then she could go round, and if she liked
Appreciation of planning and preparation for the PCR	56	could write down, it would give us similar questions to what we are going to be asked later that day,
Appreciation of planning and preparation for the PCR	57	so we could kind of think about, and gave us plenty of time to actually think about it which was

Superordinate theme: Feeling empowered

Emergent theme	Line number	Quote
Alignment of EHCP with parent's views	217	read it, no but it was alright, it was totally what I thought was right, so I didn't have any qualms with
Feeling informed during the process	297	went quite smoothly, we know where we were, we knew what we were doing, we knew when we
Feeling informed during the process	298	would hear about the outcome of the EHC, whether we could get it or we wouldn't, and it all
Feeling informed during the process	299	happened on that day, you know it all went smooth.
Feeling informed during the process	322	did, it did happen like that.
Parent feeling listened to	276	Yep. Definitely listened to.
Feeling in control	13	decided to ring up the council, or the city council, and to ask about it, and we were told it was better
Feeling in control	31	Council, that's how we looked into it ourselves, um and then my husband phoned up.
Feeling in control	353	place, so it was all, by telling us about an EHC, we just phoned up and it started to go, and we hadn't

Master theme seven: Not feeling engaged in the process

Superordinate theme: Power imbalances

Emergent theme	Line number	Quote
Parent searching for validation of opinion	101	Because it justified what I always thought. I've never had, you know Michelle never got diagnosed
Parent searching for validation of opinion	106	actually sits with her for a couple of hours and does things, and then comes away and says 'yeah she
Parent searching for validation of opinion	107	does need help' it kind of justifies everything that I think, well I think, yeah validates it I suppose,
Parent searching for validation of opinion	108	validates it for me that it's not just all, that I'm not just seeing things, or I'm not making it up or, that
Parent searching for validation of opinion	388	she needs support just validates it for you, because sometimes you're just bouncing off all the time,
Parent searching for validation of opinion	396	kind of validates for you that you're not kind of spouting rubbish.
Parent searching for validation of opinion	418	and say yes she needs support and help, then I just think thank you! (laughs)

217

Lack of knowledge about areas of need	172	at CAMHs. I mean I'm just an old hairdresser, I haven't got the first clue about autism or, all these
Self-doubt	393	well is it all, am I making such a big thing out of this, is it me, am I, you know, does she deserve an
Self doubt	178	forms about it, not forms, but an assessment form, and they never got back to me, so I just thought
Self doubt	179	OK well maybe we're just barking up the wrong tree there with Michelle, and she's just quirky, and
Professionals knowing more than parents	341	I don't know whether it was their knowledge, when you're there thinking I should be asking those
Feeling reliant on CAMHs to diagnose	173	sorts of things that go on. So I was thinking when she was at CAMHs, if there was something wrong, I
Feeling reliant on CAMHs to diagnose	174	was thinking surely they would have picked up on it, so I thought years ago that Michelle was
Feeling reliant on CAMHs to diagnose	176	and I always thought she was, but obviously because she was at CAMHs I thought, well surely they
Feeling reliant on CAMHs to diagnose	177	would know and say, so they didn't. I did put it to them and they, I did fill in a form, we did fill in

Superordinate theme: Feeling alienated from the process

Emergent theme	Line number	Quote
Family as outsiders to decision making	320	June where everybody discuss Michelle and discuss the plan, and then say yes or no to it, and then
Family as outsiders to decision making	321	Sarah said, you will be notified two days, maybe later, whether you've got the plan or not, and we
Lack of choice within the process	301	I think probably that we were told what to do!
Process not in our control	135	know, so I think we just waited until we heard the EHC plan fall through the letterbox with a thud

Superordinate theme: Lack of whole family engagement

Emergent theme	Line number	Quote
Process as meaningless to YP	262	to see the stuff that she thought we were talking absolute gobbledy-gook about really, which was

Superordinate theme: Feeling under pressure

Emergent theme	Line	Quote

218

	number	
Parent acting as an advocate for the young person	122	Just to put Michelle's side, because I know Michelle doesn't.
Parent acting as an advocate for the young person	124	Because I think Michelle's not very vocal, you know she doesn't find it easy to talk to people, and
Parent acting as an advocate for the young person	125	she tends to go in her shell, so you tend to speak for her, well I've always done that I think, and I'm
Parent acting as an advocate for the young person	127	she can do it, so I'm trying to, you know, but there are times when I feel I need to, even though she's
Parent acting as an advocate for the young person	128	17, I need to say, or I need to be more vocal for her because she's not actually saying how it is.
PCR as a one off opportunity	87	Because I think, it's almost like if you forget something, it gets missed and then, you don't get the, I'd hate it if I
PCR as a one off opportunity	88	thought, oh I forgot to put that down, and then didn't get the help for it. So for me it was a little bit
Feeling under pressure in the PCR	69	Not so much assessment, but trying to um, I mean we were told to think of everything, and to
Feeling under pressure in the PCR	70	write everything down that we could possibly think of, which is quite hard, but it was quite good
Feeling under pressure in the PCR	72	then I would get back up and write something else, because you cant always, Michelle is so complex,
Feeling under pressure in the PCR	73	you can't always remember everything that's going on, or everything that you think she needs help
Feeling under pressure in the PCR	84	Y - To make sure that I had everything written down that Michelle struggles with so people, they can see,
Feeling under pressure in the PCR	85	what help we needed, and to try and not forget anything.
Feeling under pressure in the PCR	92	have to think of everything, that everything is down there, or else maybe you'll jeopardise the
Feeling under pressure in the PCR	93	outcome.

Appendix 14.5: Table of emergent and superordinate themes for Andrew

Master theme one: filling in gaps in knowledge

Superordinate theme: Lack of understanding about the process of statutory assessment

Emergent theme	Line number	Quote
lack of understanding of the process	511	No, even now I'm not even sure how many people, who is involved, and how the assessment, I
knowing who is and isn't responsible for the process	52	professionals that got involved, it probably wasn't necessarily in their remit if you like, it wasn't,
finding the process by chance	566	out there at all that this is available, for us to find out by chance, I feel that schools, I don't feel that,
Lack of understanding about statutory assessment	10	comments about this, that there's either a statement or a health care plan, or some help that you can get, um and this
Lack of understanding about access to support	8 9	statements, this sort of thing, because we were concerned about what support and help we could get for Michelle, you know and her experience, um and we had sort of heard a couple of little
Lack of understanding about access to support	11	had come up a couple of times on odd occasions, and we sort of thought what is this what is this,
Lack of understanding about access to support	27 28	gap, um in her so long out of school, so much missed, we thought how do we get this support, because it seemed to be all a bit of a mish mash, and they said this would be one of the ways to
Lack of understanding about access to support	577 578	of little signals going on there. We didn't know there were options, opportunities available, and that could have been solved earlier, so I sort of feel that's something that could be looked at.
barriers to support	322	a team at Futures which helps with career, but you've got to have an EHCP to access that team, so
Barriers to support	323	when this lady said oh you can come to us, I sort of said but you said she couldn't get that extra help
barriers to support	410 411 412	know, that's the other worry we had, if Michelle wasn't didn't have a plan, that, there's always support, or there's bits and pieces for kids at that age, 16, 17, 18, what happens if that 21, 22 year old, still trying to get their education that they need, they're going to struggle, you know, so with

accessing support without an ehcp	328	got it, again you sort of think, although they say if Michelle didn't get this, no-one's 100% clear on
	329	what they could or would get, and we knew that, in the back of my mind as well was, if she doesn't
	330	get this, I think we get one more meeting with Sarah, your support's gone, and I would be worried
unclear communication of information	317	was all a little bit wishy-washy, and we felt there may be support out there but it, there was no
	318	clarification or direction for us to see how that would actually take effect, or happen, and, so for us if
	319	you like, although they were saying, if you like, in the assessment, there was other factors that
	320	weren't very clear, and even one of the questions in the meeting by some of the professionals "but
offering clear, comprehensible, relevant and accessible information	333 334 335	and saying that to someone, I would say here's clear support that you could access, and I know they
		point to a number of websites or organisations, I know I've tried ringing a few, and it was all a bit of
		a mire if you like, that might be where they say, oh if you don't get it, your keyworker's not stopping

Superordinate theme: important influences on expectations of the process

Emergent theme	Line number	Quote
Using the EHC needs assessment as a way of getting more support	13	think, so our understanding was that there was more support available for Michelle, which is what led
Using the EHC needs assessment as a way of getting more support	14	us, that we could get more support and more help for Michelle, that's why we started looking into it, if
Using the EHC needs assessment to enable change	29	ensure it, and when they sort of said oh it can make things happen, we thought well this is

Master theme two: What is the purpose of this process?

Superordinate theme: Getting it right for the future

Emergent theme	Line number	Quote
anxiety about transition	57	Michelle's future, how we were going to deal with this, I don't feel that it would have necessarily been
anxiety about transition	113	everything else, because we knew as it would come up to summer, what would happen for this year,

anxiety about transition	114	applying for colleges and stuff like that, what our options were. So we had a bit of a panic because
ensuring support for years to come	409	were making, um and um to know you have that for so many years is just great really, because you
ensuring support for years to come	413	that plan and the many years it has, it's given her a real opportunity to get the need, because that
ensuring support for years to come	414	was our worry later in life you know, for Michelle, you know so yeah, it was great.
ensuring support for years to come	26	age, it went you know for college and that sort of thing, because we were so concerned about the
anxiety about transition	6	discussing her leaving full time medical care, and we were talking about the future, about her

Superordinate theme: *Trying to understand the purpose of the process*

Trying to understand the purpose of the EHCP	24	that do, what does that achieve, um and they were sort of saying, well as they understood it, having
Using the EHC needs assessment as a way of getting more support	25	the statement or a plan would ensure that Michelle could get the support, and it went beyond school

Master theme three: The relationship between home and school

Superordinate theme: *Communication between home and school*

Emergent theme	Line number	Quote
lack of joined up approach between home and school	102	were noticing with Michelle's education, if one year she was off the Richter scale and very high in
lack of joined up approach between home and school	103	Science, and then a new teacher came in the next term and Michelle's Science went down, I would say
lack of joined up approach between home and school	104	well hold on why is that why is her education gone from really really great to.. either it's a teacher
lack of joined up approach between home and school	105	change or she was in this case being affected by the social aspect or the people. So there had been
Trying to involve school in request for assessment	35	educational future, so the doctor at CAMHs, health professional, wrote to the school, on our, from
Mainstream setting doing the bare minimum	66	you like, had supplied some school work to ***, and came along to some of the meetings at
Mainstream setting doing the bare minimum	67	***, more or less to say there was funding for her, her minimum educational needs if you like,
poor communication between parents, school and support	74	she was diagnosed, but they were never involved in the whole process, which one doesn't speak too good,

222

services		
poor communication between parents, school and support services	76	engaged with the autism team, to me I felt it wasn't on their agenda if you like, I felt there's a
poor communication between parents, school and support services	83	experience, and it highlights it when the autism team didn't know about it, who was linked with the
poor communication between parents, school and support services	84	school et cetera et cetera so we were quite miffed about that.

Superordinate theme: Experience of the home and school relationship

Emergent theme	Line number	Quote
negative relationship between home and school	65	Well we felt that the school hadn't acted in any regard to her autism, the school, the year head if
negative relationship between home and school	68	but they weren't pro-active in any way. We always felt a little bit that the school didn't react, and we
Conflict over resource allocation and funding	325	needs, organisations, want funding to do what they've got to do, they want funding, it's easier for
feeling dissatisfied with the sen support system	89	structure, there doesn't seem to be an assessment or a process, there doesn't seem to be any, I
feeling dissatisfied with the sen support system	90	couldn't point to any time when any of Michelle's behavioural issues, or any of the, I couldn't point at
feeling dissatisfied with the sen support system	91	any stage where you could say yes the school picked up on that, um but I understand the nature of
feeling dissatisfied with the sen support system	99	think the process is good, EHCP, but I think the schools possibly, there's training issues there, picking
feeling dissatisfied with the sen support system	100	up on behaviour patterns, or, and it might be because they've got budgets, curriculums to get
feeling dissatisfied with the sen support system	101	through, and teachers who are under pressure, all the stuff that we picked up on at the school, we
feeling dissatisfied with the sen support system	106	issues with Michelle almost from when she first went to the school, but at no time was there any tests
feeling dissatisfied with the sen support system	107	for her behaviour or assessments or anything like that.
feeling dissatisfied with the sen support system	297	educational people money, probably costs schools money, and unfortunately budgets, and
feeling dissatisfied with the sen support system	298	demands, and pressures on educational needs may, although they would never say it, but I could
feeling dissatisfied with the	299	feel that that could be a factor somewhere in how, why

sen support system		schools don't pick up, and why this doesn't
feeling dissatisfied with the sen support system	567	whether it's because a Church of England school and they've got a different agenda, but I feel it's not
feeling dissatisfied with the sen support system	571	know, but I feel it was so clear that the professionals, that there's a lot of training needed, and
not getting the right support at the right time	572	before Michelle, you know there was a chance early on, before Michelle did self-harm and went to
not getting the right support at the right time	573	hospital and all of this blew up a few years, there was a point where there was bullying at school and
not getting the right support at the right time	574	Michelle was struggling, she was met by CAMHs, and we went to the school, and I remember the lady
not getting the right support at the right time	575	from CAMHs saying to school there is caution and CAMHs could help the school, but it was sort of
not getting the right support at the right time	576	politely oh we could look at that, but nothing was really, and you do feel that there were some sort

Master theme four: Now we're not alone

Superordinate theme: Working in partnership with the keyworker

Emergent theme	Line number	Quote
feeling informed by the keyworker	233	then you see, the next process was the keyworker, and talked about that other professionals may
feeling informed by the keyworker	236	so the process was explained, forgotten her name, keyworker come and see us..
feeling informed by the keyworker	244	understand the process a little bit. So Sarah had come round, talked to us both about what was
feeling informed by the keyworker	245	going to happen, um and I think yeah that's so important.
feeling informed by the keyworker	306	at, we got notified, or Sarah did say, oh there will be, we got a date, we know when things were
feeling informed by the keyworker	356	Sarah said we would get a letter, you know get notified in so many weeks, so we know we've
feeling informed by the keyworker	360	where Sarah sort of explained how, what that gives you, how it gives you a 3 month review, or you
keyworker as an advocate for the family	254	that sort of relationship building if you like a little bit, yeah and um quite a strong character, take no
keyworker as an advocate for the family	255	nonsense sort of thing, I felt that, I know how that relates to us as parents, but I thought I know
keyworker as an advocate for the family	256	Sarah seemed quite a strong-willed as a person, so I thought in a safe pair of hands, you know

224

keyworker as an advocate for the family	257	someone who's going to help you to get your point of view across, explain to you what to do, and
keyworker as an advocate for the family	258	um, no that worked really well, and I felt that she was quite instrumental, yeah it was good.
keyworker as an advocate for the family	540	one where they just sit and chat, which is sort of what Sarah did at times, filling in things and that, I
caring nature of the keyworker	251	on your level if you like talking about stuff, she, you could tell there was a little bit of care in there,
caring nature of the keyworker	252	she seemed quite genuine, that's quite important I would say, because you know she's in a role
caring nature of the keyworker	253	where she's meeting people for the first time, OK with people, a people person, able to chat fairly,
a keyworker with experience	248	Great because she's um, you can tell she's got a lot of experience with different types of
a keyworker with experience	249	situations, um yeah, because I felt that she'd dealt with kids in and out of care and stuff like that,
a keyworker with experience	250	and was quite wise if you like, wise to the world if you like sort of thing, so you felt that she was very
keyworker contributing to decision making	496	of the contact, like I say if everyone makes sure there is lots of chats with the keyworker, lots of
keyworker contributing to decision making	497	meetings, and that the keyworker's feedback is very much taken on board by any professional,

Superordinate theme: multi agency support

Emergent theme	Line number	Quote
joining up different services in assessment	261	because we said we had an educational meeting at CAMHs, and the doctors and the professionals
bringing people together	176	consultant there, and some other professionals in the room, that really worked, you know, that
non-judgemental atmosphere	228	that the professionals are there, and it's just a blank sheet, which is great, because they've got no
non-judgemental atmosphere	229	opinion, and are not involved, and that's great, because it's a blank canvas, so you can just start to

Superordinate theme: things are finally getting better

Emergent theme	Line number	Quote

assessment process as change agent	128	having the EHCP helped to instigate lots of things happen, because we were able then to push
assessment process as change agent	129	through, it engaged more of the professionals than we were able to do, for other aspects, so I think
assessment process as change agent	156	consultant at the epilepsy unit, um and things progressed, that was an aside thing if you like from
assessment process as change agent	179	meeting was actually a catalyst for that happening, so the keyworkers just put things up on the wall,
assessment process as change agent	180	um but it actually instigated Michelle getting better assessment and treatment at her epilepsy unit,
assessment process enabling communication	130	it helped with the epilepsy people, um because there had been some issues at the hospital, and we
assessment process enabling communication	131	had a lot of trouble communicating, even via a doctor we couldn't get through, and it was another
assessment process enabling communication	132	area of stress if you like, trying to get the right follow up help and support for Michelle's epilepsy, and
assessment process enabling communication	133	strange enough the EHC actually helped to get that moving. But it also helped because, this was all
assessment process enabling communication	144	with the CAMHs, and I feel as a result of that the consultant wrote a letter to the epilepsy team,
assessment process enabling communication	150	her epilepsy, so they wrote a letter then to the hospital, the hospital then, I then followed it up, and
assessment process enabling communication	151	the phone system seemed to work, first time in a year and a half! I managed to get hold of someone,
joining up different services	137	you've got your neurological team at the hospital and you've got the psychological team, some of
joining up different services	138	the medications affect each other, but they didn't communicate, so the people dealing with the
joining up different services	139	neurological issues and the epilepsy team didn't deal with mental health, mental health, they didn't
joining up different services	140	communicate, so we, it was left to us to try and get this going, as soon as this assessment process
joining up different services	154	months, so Michelle had missed almost a year of appointments about her epilepsy, so the EHC helped
joining up different services	155	me to get people to talk about Michelle's, what she needed. We then got an appointment with.. The
joining up different services	165	the educational, so for me that was a big important um step forward if you like, just in the
joining up different services	201	parents, because Michelle has two different areas of medical needs, her mental health and her
joining up different	202	neurological health, that's what EHCP helped, if you like, in a

services		small way, but if anything that's
joining up different services	241	spent a lot of time treating the anorexia and talking about that, and the health professionals at
joining up different services	242	CAMHs were very focused on anorexia and less on her autism, or, um various issues like that, so I

Master theme five: A focus on the young person

Superordinate theme: A young person centred approach

Emergent theme	Line number	Quote
tailoring support to the needs of the young person	400	they'll adjust and adapt accordingly, but they talked about her self-harm, they talked about her
person centred approach	364	seriously, um putting in what support Michelle needs, but help she needs, all this stuff and you're

Master theme six: Family engagement

Superordinate theme: Family focused approach

Emergent theme	Line number	Quote
showing interest in the family	269	manner, which I felt was really really useful, but it was great that he was able to take the time to go
showing interest in the family	270	that meeting, because some people might say oh I've got something else, professional. He then
showing interest in the family	275	I felt, yeah it was good, he took a lot of time, you could see, I was quite surprised at the depth, he
showing interest in the family	276	did really go through, you know they're trying to cover all the angles here and really go through it,
working with a professional who is listening	466	just specific points, they're actually going to give you the chance to take on board what you're trying
working with a professional who is listening	467	to say.
feeling important during the process	120	it was fine, doing that, it felt like they were taking it seriously, if that makes sense.
feeling important during the process	142	said what sort of things as a parent do you want to happen, and the first thing I said was for them to
Involving the family in reviewing the draft ehcp	383	and the plan to me, you know we had time to review it, Sarah said read through it, if there's
Involving the family in reviewing the draft ehcp	384	anything you feel, come back, so we were given plenty of time to assess it, read it two or three

227

	385	times, we were over the moon, but then we sat and went through what the plan is, what's written
Involving the family in reviewing the draft ehcp		

Superordinate theme: Family participation

Emergent theme	Line number	Quote
Parental request as a way of enabling parent to express their views	432	opportunity to put your piece in there, then you felt it at the actual, that room bit was really great,
the voice of the parents	460	EHCP process, you know, that's what, we did feel we got the chance to speak, and we'd probably
the voice of the parents	426	process. We felt engaged enough to open up and talk, for me I'd be happy to talk more and more
the voice of the parents in the pcr	433	that was really good, because you could see that you could get the opportunity to put your, what
the voice of the parents in the pcr	434	you felt, because obviously you're protective and you want your daughter to get that help, so you
the voice of the parents in the pcr	435	were being given the opportunity, you felt I'm getting the opportunity to do that. I'd probably want
the voice of the parents in the pcr	450	this, and you go in a room, and someone says here you go write on the wall, and you can talk about,
gathering the views of the family	424	who came to see us, it was apparent because they were asking us as a family, as well as doing stuff
lack of prior opportunity to express thoughts and feelings	439	haven't had that, you haven't had that opportunity, and you haven't been able to do that, so you've
lack of prior opportunity to express thoughts and feelings	440	probably got all this built up, and you go 'boof'. We have had some of that in her treatment at
lack of prior opportunity to express thoughts and feelings	461	want to talk more, but everybody needs that, parents need it, because they don't get listened
lack of prior opportunity to express thoughts and feelings	462	to enough out there, or schools and systems haven't got the time, so yeah that's..
preparing for the pcr	173	everyone could write down, so when I knew this was coming up we'd sat at home and thought about
preparing for the pcr	174	a few things then, and I thought where is there a clot, where is there a blockage, where are we
preparing for the pcr	175	struggling to get you know, so I felt if we highlight this at this, you know, and having the CAMHs
family alongside professionals	172	What would you like to see, and Michelle could write down, the professionals could write down,
family alongside professionals	420	It was apparent in the very first meeting, in the room where everyone's got a pen, so you're

| | 421 | engaging with, not just Michelle, but everyone. Um, it was apparent to me in that. It was apparent in the |

(continued from previous page)

Emergent theme		
family alongside professionals	421	engaging with, not just Michelle, but everyone. Um, it was apparent to me in that. It was apparent in the

Master theme seven: Not feeling engaged in the process

Superordinate theme: Power imbalances

Emergent theme	Line number	Quote
the power of the professional's voice	157	the assessment which you might not think well, but because you've suddenly got the EHCP people,
the power of the professional's voice	158	who are able to have the clout to ask questions and also to raise our, so it was working even in
the power of the professional's voice	282	professionals able to put forward assessments and stuff like that. I feel, I feel for other people out
the power of the professional's voice	337	what was amazing was the power that people have, and the people who are doing the assessment
the power of the professional's voice	338	and setting this up, and the power EHCP has, for those people who either get it or don't get it, um I
the power of the professional's voice	343	about Michelle going herself as a volunteer. Well Sarah phoned up, and just said who she was duh
the power of the professional's voice	344	duh duh, the minute you say who you are, keyworker for duh duh duh *** City Council duh
the power of the professional's voice	345	duh duh duh, the ears prick up and they say yeah yeah course Michelle can come down, and um, just a
the power of the professional's voice	346	phone call, just a couple of little things like that from someone in authority, not necessarily a
the power of the professional's voice	347	massive authority, but a professional can so help, because that's nothing really to do with um her
the power of the professional's voice	348	assessment or her future educational needs, but Sarah just made that one phone call, and that
bridging the gap in style of language	220	the right language, or the professional language to express her needs as eloquently or as
bridging the gap in style of language	221	professionally as a lot of people in the room, the consultant or somebody might put it in a really
bridging the gap in style of language	222	professional way, I'd say as a parent sometimes, or with my background, I wouldn't necessarily
bridging the gap in style of language	223	convey the right wording or, so for us it was a little bit of a struggle in some ways, some aspects it's
hierarchy of knowledge	530	knowing their own, but the public, people like us, we don't understand how that works, or what the

Superordinate theme: Feeling alienated from the process

Emergent theme	Line number	Quote
not feeling involved in decision making	123	notification that they were going to go for assessment, um, CAMHs were informed then, and they
not feeling involved in decision making	307	happening, and we knew that were would be a team that would meet, a council team, an
not feeling involved in decision making	308	assessment team would meet, and they would look at this and decide whether..During the process
not feeling involved in decision making	357	got that date if you like, a date set, when you're going to know, what you're going to know we don't know
not feeling involved in decision making	472	psychologist guy came here, I would say, I remember them saying they were having this meeting and I'm sort of thinking in
not feeling involved in decision making	473	my head, oh who are these people and why can't I go and say my bit? Or, why haven't they all asked
not feeling involved in decision making	475	will it get across to these unknown people making this decision about your daughter's future, so you sort of
not feeling involved in decision making	480	where you're like who are these people sitting in a room. I remember initially when you hear about
not feeling involved in decision making	481	the process you're thinking oh bloody hell faceless bureaucrats, going to make the decision, are
not feeling involved in decision making	482	we back to you know, computer says no, sort of thing, you've got that little bit about bureaucracy,
not feeling involved in decision making	483	the system, do I need to go in there and slam on the table, sort this out! Do you know what I mean?
not feeling involved in decision making	521	out of ten, how do I know, alright you've got this information, but how do I know our point's got
not feeling involved in decision making	522	across effectively, I don't know that, so if it was a no, you'd be saying did it? I'd have to appeal it. So
not feeling involved in decision making	305	Well I understand that they would get all their evidence together, then there would be meetings
not feeling involved in decision making	517	no, I would be very wondering did my message get across, did, how do I know, is the keyworker's.
wanting to know more about who is making the decisions	487	Yeah, or even if they said, these are the type of people, or these are, there's going to be, and they
wanting to know more about who is making the decisions	488	may have, I can't remember that, or there's going to be someone from duh duh duh, and this is what
wanting to know more about who is making the	489	their background is, this is what they do. I think just trying to

230

		get a little handle on who these people
wanting to know more about who is making the decisions	490	are, they might say oh we can't Skype call everybody! But you sort of think, but I would say because
wanting to know more about who is making the decisions	515	understanding. I'm picking a little bit, but you could say understanding who those people who make
wanting to know more about who is making the decisions	516	those decisions and how they work, how that affects um, I would feel if you get a no, if we'd got a
wanting to know more about who is making the decisions	523	I'd say if that was more clarified if you like , people say, these are the people, this is what they do,
wanting to know more about who is making the decisions	534	hindsight I feel, if it had been a no, I feel I would have liked to have known who was making those
Understanding eligibility for the assessment	512	know they got all the assessments from different professionals, I don't know whether they've got a
Understanding eligibility for the assessment	513	points system or whether they discuss it and decide, was it a clear case, or was it a marginal or was it
not trusting the process	499	complicated, professionals don't always get it right, and different personalities, different people,
not trusting the process	500	different opinions, you know so you sort of feel. So that's what I would say, you know it's the sources
Not feeling involved in the assessment	193	there, which we're not party to, the only time we've ever seen was in that very first assessment

Superordinate theme: Lack of whole family participation

Emergent theme	Line number	Quote
YP finding it difficult to participate	271	came round here and did uh, we were quite nervous about that, because he came round to sit with
YP finding it difficult to participate	272	Michelle and you're sort of thinking oh how many of these people are going to come in and what's
YP finding it difficult to participate	273	Michelle going to have to go through, and she did struggle quite a bit I think with the assessment, and
YP finding it difficult to participate	260	There was this guy who came round, he wanted to do his assessment, that was useful too
YP finding it difficult to participate	277	um I know it's quite tough for Michelle, and he had a little photo book, and he was going through

Superordinate theme: Feeling under pressure

Emergent theme	Line number	Quote
feeling under pressure at the PCR	207	Y - Mixed really, I must admit nervous, because you almost feel like this is your one chance and
feeling under pressure at the PCR	208	panicking thinking oh god, there's so many things going through your head, what Michelle does this,
feeling under pressure at the PCR	209	Michelle does that, and then you're thinking I can't think of any, so you go through the whole um and
feeling under pressure at the PCR	218	try and convey as much as possible Michelle's needs, and um if you like so as a parent, I thought I
feeling under pressure at the PCR	219	need to get this across, and I feel to be honest in some ways I would struggle or not necessarily use
feeling under pressure at the PCR	226	what I'm trying to say, what I need to say, how you put it, so you're looking at the questions, and
feeling under pressure at the PCR	230	express what you feel Michelle's needs are, but yeah that's what I felt was my responsibility.
needing support during the pcr	214	know for me anyway, you're sort of looking at it wide-eyed, what am I going to say next, what am I
needing support during the pcr	215	going to put here, I don't know, um and dependent on your personality, what you're like, so
needing support during the pcr	216	sometimes you take a little while and I was still standing with the pen thinking have I put enough
needing support during the pcr	217	down, you know have I put.. so I think, yeah it's a tough one that, 'cos I think for me I felt I needed to

Appendix 14.6: Table of emergent and superordinate themes for Michelle

Master theme one: filling in gaps in knowledge

Superordinate theme: Lack of understanding about the process of statutory assessment

Emergent theme	Line number	Quote
Narrow focus of assessment visit	106	Um I knew it was for my autism.
Feeling uncertain about the EHC needs assessment process	3	I think so yeah.
Measuring progress through summative assessment	7	Um, they look at my percentages that I've done at school.
Focus on education	5	Uh, like my, how my education's going.
Lack of understanding of the assessment	332	He was, I think he was doing some documents or something on me, writing percentages.

Superordinate theme: Important influences on expectations of the process

Emergent theme	Line number	Quote
Impact of professionals	108	Because he told me.
Impact of professionals	123	Yeah I have, Becky came round again to talk about college.

Master theme two: What is the purpose of this process?

Superordinate theme: Getting it right for the future

Emergent theme	Line number	Quote
Getting the transition to college right	59	Y - Yeah 'cos it was all about finding the right college, and I think they got the right college.
Getting the transition to college right	78	me then they won't be able to find the right college.
Deciding by visiting	264	Looking around the place.
Deciding by visiting	266	The teachers seemed really nice, and how everything was laid out was easy to understand. Some

Emergent theme	Line number	Quote
Lack of understanding of the purpose of assessment	95	I don't know, I still don't understand it.
Lack of understanding of the purpose of assessment	97	Like why they have to do it. I did at the time but now I've just forgotten.
Lack of understanding of the purpose of assessment	103	That a man was coming round to do the test that I did in hospital.
Lack of understanding of the purpose of assessment	110	Um, can't remember but he did say like, told me like why he was doing it, and stuff but I can't
Lack of understanding of the purpose of assessment	366	I can't remember what it was for but it was just exactly the same test, and I knew that was for my
Lack of understanding of the purpose of assessment	376	to do and the reason why but I can't remember.

Master theme four: Now we're not alone

Superordinate theme: Things are finally getting better

Emergent theme	Line number	Quote
Discrimination	276	school if you have a disability you'll be left out, and we were all them kids who were left out and had
The same yet different	278	the same because everyone's different, but we're all understanding. Some of them don't understand
Feeling like I belong	127	college I'm in it's got a lot of, it's mainly all for people who have disabilities in that part of the
Feeling like I belong	128	college, which is the one I'm in, so it's very accepted.
Feeling like I belong	277	no friends, and now we're all together we can finally have friends, and we're all the same, well not

Master theme five: Focus on the young person

Superordinate theme: Supporting the young person's involvement

Emergent theme	Line number	Quote
You can listen to me if you can hear me	241	Um just, I think people should just be more quiet, and then they can hear you talk, and don't be
You can listen to me if you can hear me	242	rude because otherwise whoever you're with won't be able to understand or hear you.

Making changes by listening	285	They actually like listen to you and if you're finding things stressful they know how to deal with it.
Making changes by listening	288	Um it means that they're actually trying to do something and they're actually trying to help.
Feeling listened to	330	but he was listening to me.
Understanding verbal response as listening	116	Because he was replying, like when someone isn't listening they'll either nod or just like don't say
Understanding verbal response as listening	117	anything, or just come out with a completely different thing than you said, but he replied.
Understanding verbal response as listening	306	Because they're talking to me about it.
Understanding verbal response as listening	358	Like she was listening, but she wasn't there, it was like, most of the time it was just quiet.
Understanding verbal response as listening	419	Um by talking to me really.
Being listened to	314	Because you know that you're not getting put in the corner for no-one to like listen to you, and
Being listened to	315	you're just going to be stuck there questioning things, and you don't really know what's going on or

Superordinate theme: A young person centred approach

Emergent theme	Line number	Quote
Only a valid assessment if someone meets me	334	Because otherwise it wouldn't be an accurate reading, if like people are just saying it.
understanding what I need as a person	281	They bought me clay, so when I get stressed I can make clay things.
understanding what I need as a person	283	They let me, if I find things too stressful they let me out of the college.
understanding what I need as a person	325	Because otherwise they wouldn't be able to help me.
Getting to know me as a person	184	Who know me as well.
Understanding me through my behaviour	423	Um by watching how I am as well.
Showing interest in the young person	187	Asked me questions.
Showing interest in the young person	189	What I find difficult and what helps me, and things like that.

235

Master theme six: Family engagement

Superordinate theme: Family participation

Emergent theme	Line number	Quote
Parents' involvement in decision making	251	Because when things happen, like the college, my parents have to be involved, because I'm their
Parents' involvement in decision making	252	kid and they, I don't really know how to say it.
Being involved as a family	245	that me and my family are involved in something.
Being involved as a family	249	Yeah, as a family.

Master theme seven: Not feeling engaged

Superordinate theme: Lack of whole family engagement

Emergent theme	Line number	Quote
Feeling overwhelmed during the PCR process	32	I wanna go home.
Feeling overwhelmed during the PCR process	46	A bit scared.
Feeling overwhelmed during the PCR process	61	They were nice, but I was just scared.
Not feeling engaged in the PCR process	34	Because it was really boring.
Not feeling engaged in the PCR process	44	Tired.
Not feeling engaged in the PCR process	55	I had no energy to, and I was just like, my legs were aching and I got tired, I sort of left for a bit.
Finding it difficult to participate in the PCR	42	questions, but then you have to do more than one, and I couldn't think of any, so it was a challenge.
Not feeling able to contribute	73	It would still be really boring but I would be more awake.

Superordinate theme: Feeling alienated from the process

Emergent theme	Line number	Quote

Not feeling interested in the process	82	I didn't really think about it I guess I just left and went out with my friends.
No choice in involvement of professionals	87	A guy came round the house and he wanted to do lots of tests on me and like hold up lots of
No choice in involvement of professionals	88	pictures and I have to say what I saw, and he was there for about an hour.
Not taking account of my wishes and needs	50	Not as much moving around. I like moving around but when they wake me up at like ten in the
Not taking account of my wishes and needs	51	morning it's not that great.
Unfamiliar adults being part of the process	23	No, there was another person but I can't remember who they were.
No choice in the format of the PCR	36	Well you just have to go round in circles writing stuff about yourself, and that was it.
No choice in the format of the PCR	41	Um.. well there was , you have to like, it was just like all you do is walk around and like answer
No choice in the format of the PCR	39	There was a lot of people and how they were doing it was really boring.
No choice in the format of the PCR	50	Not as much moving around. I like moving around but when they wake me up at like ten in the
No choice in the format of the PCR	70	I was like OK cool and then they told me the time and I was like well this is going to be boring
No choice in the format of the PCR	27	They stuck loads of posters around the room saying what do you find difficult, and I had to write
Being left out of the conversation	138	I was in my bedroom.
Being left out of the conversation	203	Um probably to my parents.
Being left out of the conversation	210	No, I just keep myself to myself.
Adults meeting to talk about me	17	It was when they were talking about my schooling and all how I think and stuff.
Adults meeting to talk about me	30	They were just talking about my personality.

Superordinate theme: *Supporting the young person's involvement*

Listening to the young person		
You can listen to me if you	24	Y - Um just, I think people should just be more quiet, and then they

can hear me	1	can hear you talk, and don't be
You can listen to me if you can hear me	242	rude because otherwise whoever you're with won't be able to understand or hear you.
Making changes by listening	285	Y - They actually like listen to you and if you're finding things stressful they know how to deal with it.
Making changes by listening	288	Y - Um it means that they're actually trying to do something and they're actually trying to help.
Feeling listened to	330	but he was listening to me.
Understanding verbal response as listening	116	Y - Because he was replying, like when someone isn't listening they'll either nod or just like don't say
Understanding verbal response as listening	117	anything, or just come out with a completely different thing than you said, but he replied.
Understanding verbal response as listening	306	Y - Because they're talking to me about it.
Understanding verbal response as listening	358	Y - Like she was listening, but she wasn't there, it was like, most of the time it was just quiet.
Understanding verbal response as listening	419	Y - Um by talking to me really.

Master theme six: Family engagement

Superordinate theme: Family participation

Family involvement		
Feeling informed	257	know people there, my tutor took me around Horizons College and I really liked it, we spoke about
Feeling informed	258	what they would do and it seemed really nice.
Involvement through attendance	254	Y - Because I go there!
Parents' involvement in decision making	251	Y - Because when things happen, like the college, my parents have to be involved, because I'm their

Parents' involvement in decision making	252	kid and they, I don't really know how to say it.
Being involved as a family	245	Y - That me and my family are involved in something.
Being involved as a family	249	Y - Yeah, as a family.
Preparation for assessment	369	Y - Um my counsellor at the hospital told me.
Preparation for assessment	371	Y - Just that they were going to do a few tests, like game tests on me, because of my autism, and
Preparation for assessment	375	Y - Yeah, pretty much, well no he just told me, he sat me down and he told me about what he's going
Giving my consent	372	they said the day it was going to happen, and then I was like OK.

Master theme seven: Not feeling engaged

Superordinate theme: Power imbalances between families and professionals

Emergent theme	Line number	Quote
No choice in involvement of professionals	87	A guy came round the house and he wanted to do lots of tests on me and like hold up lots of
No choice in involvement of professionals	88	pictures and I have to say what I saw, and he was there for about an hour.
Adults meeting to talk about me	17	It was when they were talking about my schooling and all how I think and stuff.
Adults meeting to talk about me	30	They were just talking about my personality.

Superordinate theme: Lack of whole family engagement

Emergent theme	Line number	Quote
Feeling overwhelmed during the PCR process	32	I wanna go home.
Feeling overwhelmed during the PCR process	46	A bit scared.
Feeling overwhelmed	61	They were nice, but I was just scared.

239

during the PCR process		
Not feeling engaged in the PCR process	34	Because it was really boring.
Not feeling engaged in the PCR process	44	Tired.
Not feeling engaged in the PCR process	55	I had no energy to, and I was just like, my legs were aching and I got tired, I sort of left for a bit.
Finding it difficult to participate in the PCR	42	questions, but then you have to do more than one, and I couldn't think of any, so it was a challenge.
Not feeling able to contribute	73	It would still be really boring but I would be more awake.

Superordinate theme: Feeling alienated from the process

Lack of *choice*		
Not feeling interested in the process	82	Y - I didn't really think about it I guess I just left and went out with my friends.
No choice in involvement of professionals	87	Y - A guy came round the house and he wanted to do lots of tests on me and like hold up lots of
No choice in involvement of professionals	88	pictures and I have to say what I saw, and he was there for about an hour.
Not taking account of my wishes and needs	50	Y - Not as much moving around. I like moving around but when they wake me up at like ten in the
Not taking account of my wishes and needs	51	morning it's not that great.
Unfamiliar adults being part of the process	19	Y - I think her name was Becky or something.
Unfamiliar adults being part of the process	23	Y - No, there was another person but I can't remember who they were.
No choice in the format of the PCR	36	Y - Well you just have to go round in circles writing stuff about yourself, and that was it.
No choice in the format of the PCR	41	Y - Um.. well there was , you have to like, it was just like all you do is walk around and like answer
No choice in the format of the PCR	39	Y - There was a lot of people and how they were doing it was really boring.
No choice in the format of the PCR	50	Y - Not as much moving around. I like moving around but when they wake me up at like ten in the
No choice in the format of the PCR	70	Y - I was like OK cool and then they told me the time and I was like well this is going to be boring
No choice in the format of the PCR	27	Y - They stuck loads of posters around the room saying what do you find difficult, and I had to write

240