What do parents report of the Education, Health and Care needs assessment process?

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Declaration

Declaration I hereby declare that, except where explicit attribution is made, the work presented in this thesis is entirely my own and has been generated as the result of my own original research. No material contained in this thesis has been used in any other submission for an academic reward.

Abstract

The relatively recent Special Educational Needs and Disability (SEND 2014) legislation called for a 'stronger voice' for parents in educational planning for their children and higher aspirations for children and young people.

This study was designed to investigate what parents report of the Education, Health and Care (EHC) needs assessment process (also 'statutory assessment') since the inception of the SEND (2014) reforms, particularly if the aims of the reforms have been met from parents' perspectives. The research is exploratory as there is currently little known about parents' experiences of statutory assessment since the SEND (2014) reforms and it is also emancipatory, where parents of children and young people with special educational needs and disability represent a traditionally marginalised group. The study further aims to improve practice for EPs who have a central role in statutory assessment, as well other professionals who may also be involved.

Semi-structured interviews were used to collect data from parents whose children were undergoing statutory assessment. Data was collected from each parent at three points in the process and data was analysed using a thematic analysis described by Braun and Clarke (2013). The findings indicate that in order for the aims of the (2014) reforms to met, this can only be realised in the social spaces created by parents and professionals working together. In order for professionals working within statutory assessment procedures to deliver the aims of the SEND (2014) reforms there needs to be a greater focus on ensuring co-construction and meaningful participation for parents in practice. It was found that this was particularly important when working with parents who have less means of creating their own conditions of empowerment.

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List of abbreviations

ASD Autistic Spectrum Disorder

CAMHS Child and Adolescent Mental Health Services

CoP Code of Practice

CYP Children and young people

EHC Education, Health and Care

EHCP Education, Health and Care Plan

EP Educational Psychologist / Educational psychology

EPS Educational Psychology Service

IEP Individual Education Plan

LA Local Authority

SEMH Social, emotional and mental health

SEN Special Educational Needs

SENCo Special Educational Needs Co-ordinator

SEND Special Educational Needs and Disability

TA Teaching Assistant

TAC Team around the child

TEP Trainee Educational Psychologist

YP Young person

Chapter 1 Introduction

1.1 The study

This research is based on the special educational needs and disability (SEND 2014) reforms and seeks to explore whether the key aims of the legislation of a stronger voice for parents and higher aspirations for children has been met from the perspectives of parents whose children are undergoing statutory assessment. The research is conducted within the social constructionist paradigm.

1.2 Rationale

The study seeks to explore parents' experiences of the Education, Health and Care (EHC) needs assessment process ('statutory assessment') in an Inner London Borough. Each parent, or parental couple, gave three interviews over the course of their child's EHC needs assessment, a process that should take 20 weeks to complete. Little is known about parents' experiences of the EHC needs assessment process, partly because the legislation for assessing children's needs in this way was introduced in the 2014 SEND Code of Practice (which formed a large part of the 2014 Children and Families Act). This research aims to generate new knowledge where there is currently a lack of an evidence base.

1.3 Researcher's position

The researcher conducted this research whilst on placement in an inner London borough. The Educational Psychology Service (EPS) had prioritised the SEND (2014) reforms in their Service Improvement Plan (SIP) and wanted to commission research that would explore the perceptions of parent service users within the EHC needs assessment process. The researcher was also interested in parents' experiences around educational psychology input and felt that researching parents' experiences would make a meaningful and relevant contribution to the profession. The researcher wanted to create an emancipatory piece of research with the participants, where parents of

children and young people (CYPs) with special educational needs (SEN) represent a traditionally marginalised group.

1.4 Current national context

Calls for reform to the statutory framework stretch back over the last decade. Most research cites **parental dissatisfaction** and **parental stress** as prominent problems during assessment and resource allocation for children with SEN. Other issues in the literature relate to fair and appropriately early distribution of resources, in order to make a positive difference in children's lives. Specifically, parents have widely reported an 'adversarial' system (Lamb 2009, Pinney 2002) where it took a long time to get the resources needed. The SEND (2014) reforms aim to remedy this. The current research is important because we need to ask parents if the reforms have achieved what was intended, albeit in this relatively early stage of delivery. If not, it will be helpful to consider why this may be.

The current reforms, of which the EHC needs assessment process is a part, are outlined in the Special Educational Needs and Disability (SEND) Code of Practice (CoP 2014), which itself is based on Part 3 of the Children and Families Act 2014. The SEND CoP (2014) must be followed by Education, Health and Social Services. Changes in law via the Children and families Act (2014) are reflected in the SEND CoP (2014) which is different to the SEN CoP (2001) in the following ways:

- The Code of Practice (2014) covers the 0-25 age range and includes guidance relating to disabled children and young people as well as those with SEN.
- There is a clearer focus on the participation of children and young people and parents in decision-making at individual and strategic levels.
- There is a stronger focus on high aspirations and on improving outcomes for children and young people.

- It includes guidance on the joint planning and commissioning of services to ensure close co-operation between Education, Health and Social Care.
- It includes guidance on publishing a Local Offer of support for children and young people with SEN or disabilities.
- There is new guidance for education and training settings on taking a
 graduated approach to identifying and supporting pupils and
 students with SEN (to replace School Action and School Action Plus).
- There is a greater focus on support that enables those with SEN to succeed in their education and make a successful transition to adulthood.

Areas in bold text are highlighted to reflect key principles of the SEND CoP (2014). These principles provide part of the theoretical basis used to generate aims and research questions within the current study.

The background to statutory assessment will now be considered in order to contextualise the current research, along with the aims of the SEND CoP (2014) outlined above. The current chapter will then conclude by stating the Research Questions.

1.5 Historic national context

Prior to the 2014 Children and Families Act, a number of reports documented issues for parents within the previous 'statementing' system. The findings discussed by these reports were influential on the intentions driving the SEND (2014) reforms, so it will be important for the current study to consider if this new legislation delivered the sought after changes. Furthermore, these reports dating before the SEND (2014) reforms will signpost the current research towards possible issues still faced by parents within the current legislation.

It has been 39 years since the influential Warnock Report (1978) which initiated the *statutory framework*, including statutory assessment and Statements of Special Educational Needs. Pinney's (2002) paper 'In need of

review?' questioned how well this statutory framework was helping to meet children and young people's (CYP's) needs. The paper highlighted the need for a national debate about options for future reform to the statutory framework. Areas identified by the paper in need of review were assessment, resource allocation and assurance that children's needs will be met.

The report claimed that, 'assessment can be an **inherently stressful process for parents** and it appears that **the length and complexity of statutory assessment are adding to this'**. The research team were struck by how negative were most of the experiences recounted to them by parents who lived in six different geographical areas. Most parents felt they 'had to fight' to have their child's needs assessed. Other concerns frequently raised by parents included the quantity and complexity of the information they received and professionals' failure to share information with one another. (Pinney 2002)

Other criticisms included in the report were that some Statements weren't useful and 'didn't say anything new'. Furthermore, the system meant that 68% of SEN funding went to the 3% of children who had statements, which raised concerns about children's early access to additional support and for children who did not meet thresholds for statementing. Another issue that the paper identified was that the proportion of children with Statements varied fivefold across local authorities (LAs) in England and Wales (in 2000). This spending pattern was identified within the report as 'incompatible' with attempts to develop early intervention.

1.5.1 Equality

Another finding in the report was that parents who were most *empowered* were able to secure a better 'deal' for their child: 'many of the parents we met described how they had been able to secure a better outcome for their child by being assertive. Examples ranged from paying for a private assessment or sending a letter threatening legal action, to storming in to the Director of Education's office and refusing to leave until he had agreed a certain package

of provision. Such tales were recounted in all the areas we visited' (Pinney 2002).

The final criticism made by the report related to *assurance*: once the statement was written, how could it be assured that the child got what they were entitled to? In cases where this failed or was 'hollow', reasons given included a lack of monitoring of resource allocation within schools by the LA. Where other agencies were concerned such as Health and Social Services, competing budgets were cited as a reason for failure of delivery. This varied however, with evidence of careful planning in Individual Education Plans (IEPs) and Annual Reviews, and where parents monitored provision.

Against these prevailing issues, which broadly centre on *inconsistency* of the quality of provision and equality issues in terms of access to resources, the Lamb Inquiry (2009) examined how **parental confidence** in the SEN system could be improved. In his covering letter, Lamb (2009) wrote 'We have heard a clear message: **parents need to be listened to more** and **the system needs to be more ambitious for their children...** we need to respond urgently if parental confidence is going to be increased and children's life chances improved... This will involve enhanced rights and a cultural shift in the way in which schools, Local Authorities (LAs) and other professionals work with parents and children'. Lamb noted that some parents were satisfied, however, 'we also met parents for whom the education system represents a **battle to get the needs of their child identified and for these to be met**'. The inquiry concluded, 'There needs to be a radical recasting of the relationship between parents, schools and LAs to ensure a clearer focus on the outcomes and life chances for children with SEN and disability'.

In summary, Lamb (2009) identified four key areas where change was needed in order to improve parental confidence and outcomes for children. These were: children's outcomes at the heart of the system, a stronger voice for parents, a system with a greater focus on children's needs and a more accountable system that delivers better services. Much of the SEND (2014) reform is based on these recommendations.

'The Special Educational Needs and Disability Review: a Statement is not enough' (Ofsted, 2010) outlined that, 'parents were... clear and indeed 'forthright' that the current system was not providing adequate assistance for their children to achieve their ambitions.' The main ambitions of young people (YP) identified by the report were successful relationships, independence and the opportunity to work.

The report also identified that many parents wanted their children to receive a Statement of SEN in order to guarantee access to additional support. This was interpreted to indicate low parental confidence in the education system's ability to meet their child's needs at the school level. At the time of the paper 'school level' support referred to 'School Action' and 'School Action Plus' which is now 'SEN Support'. The report cited inconsistency of provision and weakness in quality at this level of SEN resourcing, leading to weaknesses in the overall system.

Furthermore, 'the report found a range of different time-consuming and often inaccurate assessment methods across Education, Social Care and Health services. It was reported that inconsistency of terminology added to the confusion of multi- agency provision for statemented children, with Health services referring to 'Disabled Children', social care services referring to 'Children In Need' and Education referring to 'children with Special Educational Needs' or, post-16, 'Learning Difficulties and / or Disabilities'. The report remarked that parents and children are justified in feeling that the system is inconsistent and deeply confusing' (Ofsted, 2010).

Looking at these findings, we can see how the SEND (2014) reforms aim to address the problems outlined above. The current research aims to explore what parents report of the new legislation when it is put into practice. Will parents report they had to fight to get their child's needs assessed? Will parents' narratives reflect confidence that the new system will provide adequate assistance for their children to achieve their aspirations in life? Will parents report that they have been empowered by professionals within the

EHC needs assessment process? What findings around equality will emerge from the study? Will parents report feeling confident that what is outlined in their child's Education, Health and Care Plan (EHCP) will actually be delivered?

Ofsted (2010) judged the additional support provided to children with a Statement of SEN to be 'inadequate'. The report found that too often, agencies were concerned with whether or not a service was provided, rather than with the quality and effectiveness of the service itself. The effect of this institutional attitude on children with a statement of SEN is that, although such children often do receive the services prescribed by their Statement, they do not necessarily have their needs met by the services (Ofsted, 2010). As this is a clear theme within the literature prior to the SEND (2014) reforms, parental expectations regarding provision within the current statutory assessment system will be investigated during interviews. This links to the broader aims of the SEND reforms (2014) of higher aspirations for CYPs and greater parental confidence.

Flexibility of provision was highlighted in the report where, 'No one model of provision (e.g. special schools, full inclusion in mainstream settings, or specialist units in mainstream settings) seems to work better than any other, and the most effective forms of practice encompass a wide range of models of provision which are often based around significant flexibility' (Ofsted, 2010). This links to the new legislation in terms of greater choice and a stronger voice for parents. Will discourses of school choice and choice of provision e.g. managing personal budgets, be reflected in parents' reporting of the EHC needs assessment process?

Williams and Maloney (1998) recount some of the history and intentions around statementing, explaining how many 'good intentions' within the system failed, 'After the Act (1981) the procedures leading to a Statement were far more lengthy, and time scales of two years were not unusual'. In terms of parents' experiences, this lengthy process has widely been reported as stressful. Concern regarding less empowered parents is echoed here,

'Instead, in years of tight education budgets and a diminution of LEA powers, the systems could be squeezed, with only those children with the most articulate parents being assured that responses to their needs were unfettered by limits to funding. Recourse to the wholly adversarial complaints system was seen by many as their only course of action' (Williams & Maloney, 1998).

Williams & Maloney (1998) also describe how one of the purposes of Statements was to, 'substantiate parental rights to consultation, to have their views taken into account'. This is similar to the current reforms' stated intentions on parental involvement. It could be argued however, that 'views taken into account' is not the same as 'co-construction' of an EHCP. Will parents in the current study experience the statutory assessment process as a co-construction resulting in a positive EHCP, or will parents report feeling their views were not included?

Jones and Swain (2001) concluded, 'The experiences of these parents suggest that, while their views might be valued in principle, they can be devalued in practice'. The paper quotes the CoP (1994) in describing the purpose of an Annual Review, 'To integrate a variety of perspectives on a child's progress... to amend the Statement to reflect newly identified needs and provision.' Again, we can see that previous legislation has also called for a stronger voice for parents and this fell short in practice.

Furthermore, the paper 'Nowhere that fits' describes, 'a plethora of... laws have given parents the right not only to choose a school, but also to appeal to decisions in the best interest of their children. Yet, despite the discourse of school choice, the implementation and practice of such reforms is neither assured or simple' (Bajwa-Patel & Devecchi, 2014). This relatively more recent research also points towards well-intentioned legislation failing to be put into practice.

We can see that legislation around parental choice and parental involvement in educational planning is not new, and that it has failed to translate to practice, or parents' perceptions of practice. In hindsight, it is therefore considered that these previous reforms have failed to fully deliver the intended choice and involvement in educational planning for parents and carers. In this early stage of the implementation of the Children and Families Act (2014) this research aims to explore if these long-standing intentions will finally be realised from the perspectives of parents.

1.6 Assessment and Diagnoses

Linked to meeting threshold for an EHC needs assessment and / or EHCP, can be a diagnosis of a condition and the acknowledgement of a CYP's need being severe enough to warrant extra provision. Literature relating to parents' experiences of psychological assessment and diagnosis will be included in the literature review. It is reported, 'For families of children diagnosed with an autistic spectrum disorder (ASD) getting a diagnosis is a traumatic experience on which future care and education plans for the child depend' (Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010). This study found that, 'diagnostic and planning processes are extremely stressful for parents, that statutory diagnosis takes a long time, that care and education Plans do not include full parental participation, and that reviews of Plans do not consistently include intervention data'. It will be interesting to analyse parents' reporting of their experiences leading up to meeting threshold for the EHC needs assessment, and their journey between different services in light of the aims of the CoP (2014) outlined at the start of this chapter.

1.7 The role of the EP

EPs have a central role in statutory assessment, as they are required to provide Psychological Advice to the LA. A significant part of the role of the EP in creating Psychological Advice is engaging in consultation with parents, where the EP will seek to draw on and represent the parents' views and knowledge of the child, including their hopes for the child or young person's future. The EP is significant in ensuring that parents' views and expertise are valued within the statutory assessment process and to facilitate co-construction of the EHCP. EPs also assess CYPs directly and feedback their

findings to parents whilst seeking information from parents about the child. In this sense the EP aims to work with parents to promote shared understandings of a child's strengths and areas of need. Although each statutory assessment will have a range of different professionals and specialists involved depending upon the child's needs, every statutory assessment requires EP input.

1.8 Local context

The research was conducted with parents whose children attend primary, secondary and specialist schools in an Inner London borough. The LA is legally obliged to follow the EHC needs assessment process as set out in the SEND CoP (2014). Within the borough there are pockets of deprivation as well as significant wealth. The borough supports a population that is culturally, ethnically, religiously and linguistically diverse.

1.9 Outline of current statutory assessment processes

The following section will define a range of key terms relevant to the EHC needs assessment process. The 'EHC needs assessment request' is part of the statutory assessment process (bought into effect by the Children and Families Act 2014) through which information is gathered by the LA in order to decide if a CYP will undergo statutory assessment (an 'EHC needs assessment') in order to further decide if an EHCP will be issued. If a parent, young person, school or college asks the LA to carry out an EHC needs assessment request, the LA must respond to the request within six weeks to confirm whether or not a statutory assessment (or 'EHC needs assessment') will be carried out.

Once it is agreed that an EHC needs assessment will be carried out, the LA must seek advice and information from a number of professionals including Educational Psychologists (EPs) and this constitutes 'statutory assessment'. Based on the evidence gathered during the statutory assessment, the LA will decide if they will issue an EHCP for that CYP. If the LA declines to undertake statutory assessment of a CYP, this can be appealed at the SEND tribunal.

Similarly, if the LA undertakes statutory assessment of a CYP and decides not to issue an EHCP, this can also be appealed at the SEND tribunal.

An EHCP is for CYPs aged 0 to 25 years who need more support than is available through SEN provision offered within schools and settings (up to £6000). EHCPs identify Educational, Health and Social needs, as well as areas of strength, and set out a CYP's entitlement to the additional support they need in order for their identified needs to be met. During the EHC needs assessment process, there is the option for parents or YP to decide how the 'personal budget' will be managed. There are three ways to organise this. Firstly, direct payments can be made to the person with responsibility for the CYP, or to a YP over the age of 18, where they buy and manage services themselves. The second option is an arrangement where the LA, school or setting holds the money and the parent / carers or YP decide how to spend it. This is often called 'notional arrangements'. The third way is a 'third party arrangement' where a nominated person manages the budget. Each LA is required to publish a 'Local Offer' in order to support parents and CYPs in deciding how they would like to spend their personal budgets.

1.10 Researcher position and research aims

The researcher aims to conduct an emancipatory and exploratory study of parents' experiences of the EHC needs assessment process. This is because the researcher wishes to promote equality and to privilege the voices of parents whose children are identified as having SEND because they represent a historically marginalised group. As outlined by the literature in this chapter, more empowered parents appear to secure 'a better deal' for their children and this is also of interest to the researcher in terms of the emancipatory aim of this study. The researcher hopes to gain a greater understanding of the experiences of parents of CYP with SEND in order to enhance their own practice as an EP, and to contribute to an evidence base that will assist colleagues to better support parents through the statutory assessment process.

1.11 Research questions:

Main Research Question:

What do parents report of the Education, Health and Care Plan (EHCP) needs assessment process?

Subquestions:

- 1. What are parents' experiences of multi-agency meetings to determine outcomes?
- 2. Do parents feel properly listened to and fully included in co-constructing the EHCP?
- 3. Do parents feel empowered within the process?
- 4. What is the emotional impact of the EHC needs assessment process on parents?
- 5. Do parents view the EHCNA as resolving their children's education?

1.12 Summary

The bases for the current study and its research questions have been outlined in this chapter. The next chapter will describe a systematic literature review completed by the researcher.

Chapter 2 Literature Review

2.1 Overview

The previous chapter outlined the purpose and aims of this study, as well as the justification for the focus of the research. This chapter provides a critical review of the relevant evidence relating to parents' experiences of statutory assessment and psychological assessment (including diagnosis). Within this chapter the researcher presents a systematic and reproducible method for both identifying and evaluating the current body of work produced by researchers and professionals which aims to explore parents' experiences of statutory processes and psychological assessment of their children. This chapter is arranged in two sections. The first section outlines the systematic literature search, providing the inclusion and exclusion criteria, articles that were selected for the review and the weight of evidence for each article. The second section provides a critical review and synthesis of the selected literature, with focus on answering the following literature review questions created by the researcher.

- 1. 'What do we know about parents' experiences of statutory assessment?'
- 2. 'What do we know about parents' experiences of psychological assessment of their children?

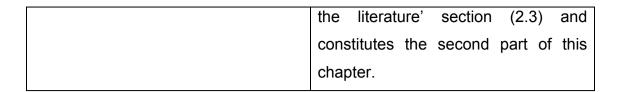
The second literature review question was included because it covers a relevant area not subsumed under the term 'statutory assessment'. This second literature review question has the potential to offer knowledge regarding parents' experience of psychological assessment, including assessment by EPs (and other professionals involved in statutory assessment processes). Furthermore, the literature review question may provide relevant information with which to answer several of the research subquestions outlined at the end of the previous chapter. For example, Subquestion 4 'What is the emotional impact of the EHC needs assessment process on parents?'

As this literature review constitutes an 'overt use of knowledge', it is possible to conduct and include an appraisal of that knowledge in terms of its ability to answer the literature review questions (Gough, 2007). Gough (2007) details several ways a literature review can synthesise forms of knowledge in order to answer literature review questions. This literature review will seek to create an 'interpretive synthesis of evidence' in order to answer the research questions. In an attempt to conduct a literature review that is transparent and of good quality, the review will follow Gough's (2007) systematic map of research activity. By doing so, this literature review is positioned as 'explicit systematic'. The stages that the research activity will comprise are: define review questions, define / apply inclusion and exclusion criteria, delineate search strategy, screening, mapping, data extraction, quality and relevance appraisal and finally, synthesis and communication. For an outline of these processes and signposting to relevant sections please see Table 1 below.

Table 1 Gough's (2007) systematic map of research activity

Define review questions	1. 'What do we know about parents' experiences of statutory assessment processes?' 2. 'What do we know about parents' experiences of psychological assessment of their children?'
Delineate search strategy	See 2.3, Figure 1 and Appendix 2.
Define and apply inclusion and exclusion criteria	See Figure 2.
Screening	Check that the evidence found meets further criteria for inclusion i.e. relevance to topic. See Appendix 1.
Mapping	Describe the evidence found and by doing so describe the research field.

	See Table 3 and Appendix 1.
Data extraction	A detailed description of each piece of evidence in order to inform judgements about quality, relevance in terms of ability to answer the review question, and synthesis. This literature review will apply the Pawson, Boaz, Grayson, Long & Barnes' (2003) 'Types and Quality of Social Care Knowledge Framework' as part of this process. See Appendix 1.
	I.
Quality and relevance appraisal	Evaluating the extent that each piece of the evidence contributes to answering the review question. (Even if a study has met the inclusion criteria and passed the screening stage, it may not meet the quality and relevance standards for the review. This is informed via the mapping and data extraction stages. The Weight of Evidence table (Table 3) will present the aggregate of this analysis.
Synthesis and Communication	Synthesis involves the integration and interpretation of the selected evidence in order to answer the review questions. Communication of the synthesis, interpretation and application of the review findings will take place under the 'critical review of



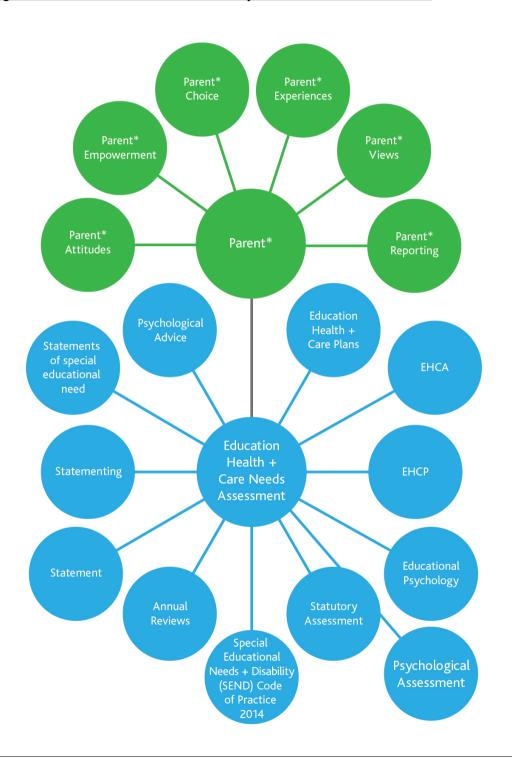
Within this research, which is positioned as social constructionist, 'We can use what we know from different sorts of knowledge collected and interpreted in different ways to develop theories, test theories, and make statements about socially constructed facts'. (Gough, 2007). By being explicit and transparent about the way evidence is selected and again by analysing how the knowledge the papers present was constructed by their author(s), we are able to support the case further that knowledge (and experience) is socially constructed. This is in opposition to presenting the evidence as though it naturally existed (Danziger, 1990) and was simply 'discovered' by the researchers who wrote the selected papers, and also by the researcher writing the literature review; who has also selected and interpreted the available evidence in a particular way. The course of constructing this literature review was explicitly mediated by applying Gough's (2007) and Pawson et al's (2003) frameworks. This does not suggest that bias has been removed from the process of selecting and interpreting the evidence used in this review, instead the researcher seeks rather to acknowledge the constructed nature of the research.

2.2 Details of systematic literature search

A systematic search of literature was carried out in August 2015 using search terms (Figure 1) within international journals hosted on the EBSCOhost search engine. Within this search engine the following databases were selected: Academic Search Complete, British Education Index, Child Development and Adolescent Studies, Education Research Complete, ERIC (Educational Research Information Centre), PsycARTICLES and PsycINFO. Limits were applied within the search criteria to exclude studies that were not written in English, were not published in peer-reviewed journals, were conducted outside of the UK and studies that were published before 1985. Search terms were applied to the title, keywords and abstracts using the 'SU' code.

The first search terms used were 'Education, Health and Care Plans' with one result, and 'Education, Health and Care Needs Assessment' with no results (see Appendix 2). In order to broaden the search, the following related terms were generated (see Figure 1).

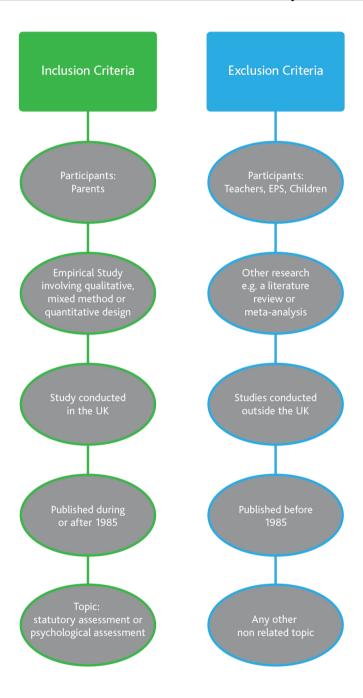
Figure 1: Search terms used in the systematic literature review



2.2.1 Selecting the literature

The systematic search returned a total of 21 papers. For these articles, abstracts were studied in order to apply the inclusion and exclusion criteria, which are illustrated in Figure 2.

Figure 2: Inclusion and exclusion criteria for the systematic literature review



Following this, 10 papers were selected as being highly relevant to the literature review questions. The 10 articles meeting the inclusion criteria are outlined below in Table 2. A detailed summary of each study including

screening (inclusion / exclusion criteria), mapping (type of research, data collection / analysis, and participant selection) and data extraction (transparency, accuracy, purposivity, utility, propriety, accessibility and specificity) can be found in Appendix 1.

Table 2: Studies selected for the literature review

Literature Review Question 1: What do we know about parents' experiences of statutory assessment?

Rehal, A. (1989). Involving Asian Parents in the Statementing Procedure- The Way Forward. Educational Psychology in Practice. Vol 4 (4) pp 189-197.

Hart, R. (2011). Paternal involvement in the statutory assessment of special educational needs. *Educational Psychology in Practice*. Vol. 27 (2) pp 155-174.

Gross, J. (1996). The weight of the evidence: parental advocacy and resource allocation to children with statements of special educational needs. Support for Learning. Vol 11 pp 3-8.

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*. Vol. 20 (3) pp 251-269.

Jones, P. & Swain, J. (2001) Parents Reviewing Annual Reviews. *British Journal of Special Education.* Vol. 28 (2) pp 60-64.

Hartas, D. (2008). Practices of Parental Participation: A Case Study. *Educational Psychology in Practice*. Vol. 24 (2) pp 139-153.

McCarthy, T. (1991). Children with special educational needs: parents' knowledge of procedures and provisions. *British Journal of Special*

education. Vol. 18 (1) pp 17-19.

Literature Review Question 2: What do we know about parents' experiences of psychological assessment of their children?

Hilton, K., Turner, C., Krebs, G., Volz, C. & Heyman, I. (2012). Parent experiences of attending a specialist clinic for assessment of their child's obsessive compulsive disorder. Child, Adolescent and Mental Health. Vol 17 (1) pp. 31-36.

Long, L. & McPolin, P. (2009). Psychological assessment and dyslexia: parents' perspectives. Irish Educational Studies. Vol 28 (1) pp 115-126.

Mansell, W. & Morris, K. (2004). A Survey of Parents' Reactions to the Diagnosis of an Autistic Spectrum Disorder by a Local Service. Access to Information and Use of Services. The International Journal of Research and practice. Vol. 8 (4) pp 387-407.

2.2.2 Mapping and Data extraction

The articles chosen for the literature review in the table above were selected by considering the quality of the presented research. In order to conduct a quality appraisal, each study was critically evaluated using Gough's (2007) Weight of Evidence Framework (See section 2.2.3 'Quality and Relevance Appraisal') and Pawson, Boaz, Grayson, Long & Barnes' (2003) Types and Quality of Social Care Knowledge Framework which will be discussed in this section. The aggregate of this analysis can be found in Appendix 1.

Pawson et al's (2003) framework proposes a set of six standards that can be applied in order to assess the quality of knowledge. These are: transparency, accuracy, purposivity, utility, propriety, accessibility and specificity (TAPUPAS). Transparency is relevant to the current study and is synergistic with Styles' (1999) evaluating qualitative research paper where, 'descriptions of data gathering procedures should be sufficiently detailed to permit

replication. Because analytic procedures are less standardised... descriptions of qualitative analytical procedures may need to be relatively more detailed'. This allows the current researcher to make judgements about the quality of the research. 'Accuracy' is also important as it reflects the current researcher's aims in the treatment of participants' data for this study. To meet the standard of 'accuracy', all knowledge claims should be supported by and faithful to the events, experiences, informants and sources used in their production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based upon relevant and appropriate information. In research that aims to study service users' experiences, for example, are the users' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? 'Specificity' relates to the method specific quality of the research in terms of its method of knowledge production and how relevant that is to the knowledgeseeker. In this literature review, qualitative studies will be considered more relevant because of the richness they can provide in thinking about parents' experiences, however, statistical data will also be considered if it helps to answer the literature review questions.

2.2.3 Quality and relevance appraisal

It is noted in Gough (2007) that Pawson et al's (2003) TAPUPAS model (outlined above) is complimentary to the Weight of Evidence Framework. Gough (2007) asserts that judgements about research evidence quality can be based on both the generic standards in execution of any given study, and also on the appropriateness of the method, combined with the focus of the review in hand (topic relevance). These three strands can be combined to give an overall weighting to each piece of evidence in terms of its ability to answer the review question. In this way, the person undertaking a review of the evidence can make judgements beyond the standard hierarchy of methodology. Following application of the Weight of Evidence Framework, the following judgements were made:

Table 3: Weight of Evidence

Study	A Methodological Quality Relates to: 'transparency', 'accuracy', 'accessibility' and 'specificity'.	B Methodological Relevance Relates to: 'purposivity' (how far the study is fit for the purpose of knowledge production in relation to the study's aims).	useful for the current knowledge-seeker and secondly the study's legal and ethical status).	D Combined Weight of Evidence
Literature Red	view Question 1:	What do we kno	w about parents'	experiences
O'Connor, U., McCaskey, R., Hartop, B. (2005)	High	High	High	High
Hart, R. (2011)	High	High	High	High
Rehal, A. (1989)	Medium-High (Due to transparency of data analysis)	High	High	High
Jones, P. & Swain, J. (2001)	High	High	High	High
Hartas, D. (2008)	Medium-High (due to methodological specificity)	High	High	High
McCarthy, T. (1991)	Medium-High (due to methodological specificity)	High	High	High
Gross, J. (1996)	Low (due to methodological	High	High	High

	specificity)			
Literature Review Question 2: What do we know about parents' experiences of psychological assessment of their children?				
Hilton, K., Turner, C., Krebs, G., Volz, C. & Heyman, I. (2012)	(due to methodological	High	High (encompasses 'assessment' well, but not within statutory processes).	High
Long, L. & McPolin, P. (2009)	Medium-High (due to methodological specificity)	were useful for this review, though much of the study's output sought to 'sell' the	'assessment' within statutory processes, though a	Medium
Mansell, W. & Morris, K. (2004)	Medium-High (due to methodological specificity)	High	High	High

2.3 Critical review of the literature: Synthesis and Communication

2.3.1 Literature Review Question 1: What do we know about parents' experiences of statutory assessment?

2.3.1.1 Overview of papers for Literature Review Question 1 relating to equality

Equality issues pervade the selected literature in terms of parents' equal access to resources via statutory processes, and also in terms of the design of the research reviewed here. Some of the research was designed in such a way as to gather the experiences of underrepresented and minority groups

within the literature, whilst other studies did not seek data from these parents. The latter group of research, whilst often possessing the largest samples and giving reliable accounts of 'trends' in parental experience, simultaneously replicated some of the inequalities present within statutory assessment by 'giving voice' to those parents who are most able to advocate for themselves. This difference between the studies presented here is useful in answering Literature Review Question 1 more comprehensively. This knowledge will also be helpful in situating the experiences of the participants of the current study within wider societal contexts in the 'Discussion'.

Two studies which *directly* generated data from historically underprivileged groups were Rehal, A. (1989) and Hart, R. (2011). Additionally, Gross (1996) looked at an underprivileged group via content analysis. Real's (1989) study examined the experiences of South Asian parents who spoke Punjabi without speaking English, where thirteen of the fourteen participants had this linguistic combination. The findings from this study are essential in answering Literature Review Question 1, and will be used to consider the experiences of parents who do not speak English either at all, or to a level that excludes them from statutory processes when high quality interpretation is not arranged. This study also has the ability to offer some insight into the experience of parents who cannot read and write in English, along with the study conducted by Gross (1996).

Gross' (1996) study is a content analysis of children's files that examines the relationship between parental written contributions and the overfunding / underfunding of children. This paper offers insights in to the experiences of empowerment and disempowerment experienced by parents with varying degrees of literacy in English.

Hart's (2011) study sought to gather the experiences of fathers within statutory processes. Fathers constitute an underrepresented group in the literature as most respondents and participants are mothers. This is mirrored in statutory assessment, where mothers are far more commonly involved in the negotiation of educational provision for their children. For example,

evidence of a discussion between an EP and the mother was found in 98% of files, whereas only 13% of files contained evidence of an EP discussion with the father. This paper examines many of the reasons for this and again has an exceptional ability to answer the review question.

2.3.1.2 Parents who do not speak English

In Rehal's (1989) study, structured interviews were carried out with fourteen Asian parents whose children had been statemented. Structured interviews were used in order to generate data where the personal experience of being a non-English speaking parent in the context of an Outer London Borough would be visible. In this matter and others, the study demonstrates high levels of purposivity. Thirteen of the fourteen participants spoke Punjabi and not English, and one parent spoke Punjabi with English as an additional language. Interviews were carried out in Punjabi by the author of the paper.

Six EPs who had been involved in the statementing were also interviewed in order to verify the procedures used in that Borough, the author purported that this increased the study's validity. The social constructionist position adopted by the current researcher means that each parent's account could only be validated by the individual offering that account. Indeed, it seems that Rehal *is* seeking the particular accounts of these participants in contrast to the dominant discourses of the LA and statutory processes. The author of the paper formulates 'methodological difficulties' within the study as the reliability and validity of *the responses*, where he proposes there is no satisfactory solution for overcoming these 'difficulties'. This suggests that the paper is written from a positivist perspective.

According to Robson's (2002) 'Classification of the Purposes of Enquiry' framework, this is an exploratory study because the design sought to generate data around a situation that is little-understood and to seek new insights by consulting with Punjabi speaking parents about their experiences of statementing. The findings of the study offer a very bleak example of the experiences of statutory assessment and educational planning with parents who do not speak English, and for whom no provision of an interpreter has

been made. Of the fourteen parents interviewed, only one knew that their child had been statemented. In this instance, it can clearly be seen that procedures outlined in the 1981 Education Act were not upheld by the LA. Apart from one parent, the other 13 parents interviewed did not know that their child had been through a formal procedure and the term 'statementing' did not mean anything to them. These findings preclude the notion that the parents had been consulted with in any meaningful form. Parents did not understand terms such as 'special education provision' and they did not fully understand their child's needs.

The significance of the formal letter proposing an assessment was not understood by parents in this study. The author reported that this led to non-attendance of parents at assessments and meetings. Although all the parents were 'invited' to contribute to the assessment, the significance of this was not understood. The parents did not understand what they could write, or what sort of contribution they could make. Similarly, the importance of receiving a 'draft' Statement was not understood. Consequently, parents did not realise they had the right to challenge the provision detailed in the document.

This paper suggests that where a parent does not speak English, they are likely to experience disempowerment and infringements on their rights, and the rights of their child. The mechanism by which this occurs is a lack of productive action on the parts of professionals, who should make reasonable adjustments so that the parents can fully participate in statutory processes. These adjustments would include the use of high quality interpretation and written materials in the correct language for the parent. This study illustrates that the model of authentic home-school partnerships where parental participation is central and active, parents build trust relationships, negotiate, challenge professional views and practices, and ultimately engage in the act of advocacy (Wolfendale 1985) was far from realised in these parents' experiences.

2.3.1.3 Fathers' involvement in statutory assessment

Paternal involvement in statutory assessment is a little-researched area. Studies will often cite 'parents', where in fact the majority of participants are mothers. Hart (2011) found that even though it was rare for there to be evidence of an EP discussion with a father (13% of files) it was much more common for EPs to refer to 'parents' in Psychological Advice. Conversely, 'parents' views' did not seem to be a replacement for 'mother's views', as explicit reference was made to these in 93% of cases.

Hart (2011) conducted a mixed-methods study, which involved contentanalysis of case files and follow-up semi-structured interviews with fathers. Data from the interviews was analysed via thematic analysis. This study can be classified as 'exploratory' (Robson, 2002) because it aims to generate insights regarding the reasons why fathers often do not take part in statutory assessment of their children.

The rationale of the study was made clear by the author who described the community psychology model and the writer's view of 'the need to empower fathers within statutory processes' discourse, as opposed to the 'burdened mothers' or 'division of labour' discourses. The study's aims were to research the degree to which fathers were involved in statutory assessment processes within a particular EPS, and to ascertain fathers' views in order to identify possible barriers to fathers' involvement during the time when their child was assessed. Files that indicated the existence of a father who could have been included in the statutory assessment (N=33) were selected. Of the original 40 files:

- Fathers signed the parental advice form in 53% of files however:
- 73% of fathers who signed the advice form lived with their child and 15% of fathers who did not live with their child signed the parental advice form.
- 98% of files contained evidence of an EP discussion with the mother and 13% contained evidence of an EP discussion with the father.

 Of the 5 cases where there was evidence of an EP discussion with the father, only one father lived separately from the child.

Explicit evidence of fathers' views in Psychological Advice was found in 8% of files, while evidence of mothers' views was found in 93%.

These descriptive statistics suggest that in terms of 'parents' experiences of statutory assessment, fathers are at risk of not being involved, or informed, that statutory assessment is taking place. This is particularly so for fathers who live separately from their children. The reasons for this will be examined by looking both at ecosystemic factors and fathers' beliefs. For the second phase of the study, the researcher utilised the Theory of Planned Behaviour (Ajzen, 1985). This theory asserts that 'planned behaviour' is influenced by three main factors. Firstly, the attitude toward the behaviour and possible outcomes. Secondly, perceived social pressure to engage in the behaviour, and lastly, perceived personal capability (or self-efficacy) regarding the behaviour.

The focus of this phase was to interview fathers who were aware of the statutory assessment and either had or not had contact with an EP, to try to ascertain reasons for involvement or non-involvement. Three groups from the files were identified. The first group were fathers who had been involved in the EP's work, with evidence of a discussion in the file. The second group were fathers who were aware of the statutory assessment and had signed the parental advice form. The final group were fathers who had not signed the parental advice form and therefore could not be assumed to be aware of the statutory assessment. One criticism of this measure is that the absence of a signature on the parental advice form does not necessarily mean that the father had been unaware of the statutory assessment. Similarly, the presence of a signature does not indicate that the father had been involved or had 'been aware' in a meaningful capacity.

Of the fathers willing to take part, four were identified as having had discussion with an EP and four had not. A range of beliefs were identified which decreased the likelihood of involvement, including fathers 'not knowing'

what to expect from Team Around the Child (TAC) meetings, fear they will find TACs upsetting, feeling the mother 'knows more' and they have 'less to offer', beliefs around 'man's role is to work; school is the mother's domain' and, 'I don't know when things are; contact is always between school and mother'. Beliefs that increased the likelihood of involvement included, 'I / we know the child best so it is useful for EPs to hear from me / us', feeling it was 'useful' to hear professionals' views, feeling they would be included in discussions, the belief that 'It is important to battle for assessment / provision' and having a relationship with their child's teachers.

Ecosystemic factors in the microsystem reported to influence fathers' involvement were division of labour within the home, including childcare responsibilities, assumptions about gender roles, practices that promote or inhibit fathers' involvement and attitudes towards fathers' roles and responsibilities. Factors within the mesosystem (e.g. school) included which parent staff make contact with, what modes of communication are used, when and how meetings are arranged, how school communicates with non-resident parents, how conflicting demands are viewed and managed, if communication between parents exists, expectations regarding fathers' involvement, and which professionals take responsibility for involving a child's family? Within the exosystem (LA) an important factor was found to be around the accepted practices regarding parental involvement, including records of non-resident parents. Findings relating to the macrosystem centred on the impact on work and the financial situation of family, and to what extent practices around statutory assessment helped or hindered fathers' involvement. And finally, whether or not there is the perception that fathers should be involved. The findings demonstrate that fathers have different experiences of statutory assessment, which may be partly influenced by their beliefs and the beliefs of others. Ecosystemic factors contribute to the creation of beliefs regarding fathers' involvement, and equally, ecosystemic beliefs such as assumptions about gender roles are likely to either sustain or change fathers' beliefs around being involved in statutory assessment.

2.3.1.4 Parents' ability to 'exert influence' on statutory assessment using literacy and communication skills

Another study that draws out the (inferred) experience of parents who are underrepresented in the wider research body, and within statutory assessment procedures, is Gross's (1996) study. This research was conducted by content analysis of children's files. An initial 100 files were included from seven secondary schools and 49 primary schools across the (county) Local Education Authority (LEA) from rural to urban settings. The sample did not include schools with high minority ethnic group populations, the majority of children and parents in the sample were white, native English speakers. This is a 'descriptive' study (Robson, 2002) because the design seeks to generate data that will portray an accurate profile of the situation. The study can also be described as 'exploratory' because it aimed to seek new insights regarding how resources may be allocated either fairly or unfairly by examining the hypothetical amount of money each child should be allocated versus the actual amount allocated and to look for discrepancies related to levels of parental advocacy. Evidence suggested that in other LEAs, 'inequitable arrangements (had been) made for children of professional middle-class parents, supported by well-organised voluntary organisations'. (Vincent, Evans, Lunt & Young, 1995). 57 files were selected for the study with substantial (over £250) gains or losses. Of these, 37 (historically overfunded) would lose resources, while 20 (historically underfunded) would gain resources.

The average number of pages of the written parental contribution for the overfunded group was 5.1 and the underfunded average number of pages was 1.4. Most significantly, the study reported that 90% of children who were overfunded by more than £1000 had a parental contribution (N=20). Of the children who were underfunded by over £1000, 0% (N=7) had a parental contribution. The author argued that the presence / absence, and the length, of such contributions appeared to have considerable face validity as an indicator of parental educational levels and parental confidence in advocating for their child. The paper concluded that 'it is possible, but unlikely, that the mere presence of lengthy written parental representations influenced

the education officers... to make more generous allocations of support when considering the case initially... A more likely explanation is that the presence and length of an initial parental contribution was linked to the capacity of the parents to exert influence in other ways- by telephone calls, requests for meetings, attendance at reviews, letters to councillors and Members of Parliament, and the appeals process itself'. (Gross, 1996)

The knowledge generated by this study presents a highly relevant point to consider regarding what we know of parents' experiences in statutory processes, and indeed how this affects outcomes for children. This study provides knowledge around differences in parents' experiences of statementing depending on their ability to exert influence on the process, and this is synonymous with experiences of empowerment or disempowerment.

2.3.1.5 Studies reviewed for Literature Review Question 1 with larger samples

The remaining four papers relating to Literature Review Question 1 will now be considered. These four studies, unlike the first three presented above, offer us less direct insight into equality issues around parental experiences of statutory processes, but do have larger samples.

'Parental views on the statutory assessment and educational planning for children with special educational needs' (O'Conner 2005) is a mixed methods study with opportunity sampling. Data collection was via a postal questionnaire and follow up telephone interviews. Thematic analysis was applied to interview data in order to generate themes around parents' views of statutory processes. The study's aim was to obtain information regarding parents' experiences of assessment and statementing procedures, to ascertain whether the process met children's perceived needs and to identify ways procedures may be improved from the parents' perspectives. All parents whose child had a current Statement had the opportunity to participate (N=7222). 2346 (32%) parents indicated a willingness to take part. This group were sent the postal questionnaire, which yielded a total of 1054 replies (15% of total). 623 parents indicated that they would agree to a follow

up telephone interview. From this sample, 122 parents were drawn at random in equal numbers from statistically identified 'overall satisfied' (N=432) and 'overall dissatisfied' (N=149) groups. Ninety-six telephone interviews were conducted.

Thematic analysis of telephone interviews produced three main themes:

- **Time taken**: the need to reduce the time taken to complete assessments and issue a final statement.
- Greater communication and involvement with parents: more contact with parents during the assessments, more feedback from professionals to parents and greater consideration being accorded to parental views.
- Clarity of information provided: examples given by parents included an explanation as to why the assessment was needed, results of assessments being presented clearly and in full, information about all services available, use of unambiguous terminology and information on parental rights.

A further six subsidiary themes emerged from the analysis:

- Earlier intervention.
- Failure to deliver required outcomes: comments centered on recommendations not being carried out, lack of professional resources in schools and therapies, Statements not reflecting all the child's needs and lack of recognition that the statement is a legal document.
- Procedures: procedures involving too much paperwork and assessment procedures not streamlined to specific learning needs.
- Professional attitudes: need for greater training and awareness of school staff, professionals not being contactable or being unhelpful, too clinical or rude, and too many professionals involved.
- Support for parents: the need for parents to have an independent person to talk to, feelings of isolation, and the process being stressful and confusing.
- Sensitivity to parents and children: a need for greater sensitivity around the impact of the process on parents and children, taking

account of family circumstances and the need for having a Statement being less stigmatised.

From the postal questionnaire, the following data were generated:

- Families living in wards with higher levels of child poverty (defined as being within the 10th percentile on indicators of child poverty) had significantly lower parental instigated requests (19%) compared to parents living in wards with less child poverty (28%).
- Whilst the study referenced 'parents' in the title and throughout the study, 80% of respondents were mothers, 10% mothers and fathers, 8% fathers and 2% a relative or foster parent. This raises questions over the knowledge claims regarding 'parents' views'.

No voices of participants were directly reported in the study, which lowered this study's 'accuracy' rating. One of the aims of the study was to recruit the largest sample possible. The limitation of the approach of sending a letter followed by a questionnaire however, is that it excludes people who can't read or write in English. This group could include people who read and write in other languages and perhaps speak English as an additional language, or English speakers who are not literate. As the previous studies suggested (Rehal, 1989 & Gross, 1996) these people represent a more vulnerable group within the statutory assessment process, where not only are they often excluded from statutory assessment processes but also from the studies seeking to improve statutory assessment for parents.

The next study looked at parents' experiences of Annual Reviews (Jones & Swain, 2001). Twelve parents from two LEAs were involved. The focus of the study was to gather parental perceptions of their involvement in Annual Reviews and the translation of principles and policy requirements into practice from the parents' viewpoints. The study was designed with two stages. The first stage involved a questionnaire and group discussion between parents regarding their perceptions of their involvement in Annual Reviews, the barriers to their involvement, and their strategies for overcoming these. An

analysis of the completed questionnaires and transcribed group discussion were used as the basis for the second stage. The second stage was an openended focus group discussion around issues arising from stage one.

Parents' views of the Annual Review process differed greatly. One parent commented, 'The review is decided before you get there. It's a simple fact.' Another parent said, 'As far as I'm concerned Reviews are not, they're not just a rubber stamp. You can make a difference'. A major theme was parents' perceptions regarding significant barriers to real involvement in decision making about their child. These barriers were formulated by the author as inherent to the position of parents in power relations and structures of educational decision-making. The paper reported that from parents' viewpoints, the starting point was school staff. These barriers were found to manifest in different ways, such as the lack of a relationship or where parents found staff to be 'oversensitive'. Some parents found that staff could be defensive in their responses and the parent-staff relationship could be one of conflict. Some parents felt that whilst they wanted to negotiate informed choices for their child at school, they were unable to because they were not kept fully 'informed' by professionals at school and within the LEA. The final barrier to decision making was reported to be the formal mechanisms and procedures of Annual Reviews, in particular the time limits. Parents also disliked that Statements were vague and lacked specificity. 'I've had reports back and looked at them and I've thought, if my child's name hadn't been at the top, this report could fit several children.' When actions had been agreed in meetings, some parents discovered that these were not reflected in the Statement. 'It comes back and it's not in the Statement. The say, oh well we've got this, but then when you dissect the wording... its something completely different.'

Many parents found the Annual Review process stressful and one parent linked this to powerlessness. 'I think the reason I found it stressful was I felt that I wasn't really getting what I wanted because I felt I had no control of the situation. I had no choice.' From the perspective of the parents, 'parental involvement' was not offered to them by the LEA or the school, but was rather

what they worked towards by negotiating decisions about their child and actively constructing parent-staff relationships. This was referred to in different ways as a 'power struggle' and links to empowerment, 'If you are more vocal, more literate and had the access to the laptop, you get more than someone else, and it's totally unjust'.

In terms of parents overseeing that promised provisions are delivered which was echoed in Pinney (2002) one parent commented, 'I try to put myself in their position and I think I would hate it if I had a pushy parent, but you've got to be pretty, kind of, intrusive to make sure that everything that's on the Statement has actually happened' (Jones & Swain, 2001). Another parent from the study commented, 'Preparation is the main key in the Review. If the staff do the groundwork with the parents and they get to know the children... and what the parents think, would like for their children.' This links to notions of co-construction and a stronger voice for parents in statutory assessment (Lamb, 2009). These findings suggest that parents value being listened to, to have adequate time to engage in decision making, to hold positive and equal relationships with staff, and for professionals involved in statutory processes to know their child. It appears that the negative aspects of parental involvement in statutory processes revolve around power struggles, stress, lack of actual resources and promised provisions being delivered, and feelings of powerlessness in decision making.

The next study continues the theme of empowerment and conflict. This is a case study (Hartas, 2008) of a parental couple's participation in negotiating their child's Statement. The case study is transparent in its methodology and triangulated information from multiple sources, including semi-structured interviews, documentation (e.g. parents' letters, professionals' reports) and classroom observations. The researcher stated the theoretical underpinnings and rationale of the study to be based on Wolfendale's (1985) authentic home-school partnerships and on strengths-based approaches to parental involvement (Powell & Batsche, 1997).

The research findings identified a range of behaviours and beliefs of the parental couple that ensured their empowerment. The parents shared knowledge and understanding about Joe's level of development / functioning by communicating information from paediatrics, SALT and Joe's social worker. The researcher reported that strategies in the classroom were developed with Joe's parent's in a 'bottom up' way. Joe's parents challenged professionals' views on many occasions, often due to a clash between what was recommended and what had worked at home. The parents challenged professional practices by raising concerns around the validity of assessment procedures, professionals' limited knowledge of Joe's linguistic and social functioning, accuracy of reports and most importantly, the process of deciding SEN provision. Joe's parents did not perceive education as a set of services delivered to their child passively in a 'top-down' manner. Rather, they exercised agency by playing an active part in their child's learning and by co-constructing educational provision.

While Joe's parents formed good partnerships with professionals, conflict and disagreement were also part of their exchanges. The author reflected that, 'Partnerships do not operate within absolute notions of agreement and disagreement but in the spaces in between.' The parents ascertained Joe's rights within the education system and rejected positioning as 'parents with a problem'. The researcher reported that deficit assumptions were evident in the practice of some professionals, who stressed the need to remedy a deficit in the parents' views, values and choices, e.g. a health visitor's interpretation of the parents' style of interaction with their child.

The parental involvement illustrated in this case study reflects empowerment and negotiating models (Wolfendale, 1985) of parents within statutory assessment. The parents exercised agency in the context of mutual responsibility and accountability, and co-constructed their child's educational provision. Parental involvement as *advocacy* requires parents to construct a social and critical space in which to engage with professional views and practices. Although this is a case study of a single parental couple's experiences, it still holds a 'medium' level of method specific quality for the

current research because of the use of semi structured interview and detailed reporting of direct quotations. It holds 'high' topic relevance in its ability to offer an example of parental empowerment, as well as the mechanisms by which parents may empower themselves within statutory processes.

McCarthy (1991) studied parents' knowledge of procedures and provisions regarding their special needs children. The postal questionnaire used in this study asked closed questions, and parents were invited to make additional comments. The study was based on the researcher's own dissatisfaction with communication from professionals to parents regarding disability and special educational needs, including a lack of communication from professionals regarding her own child's needs. Questions 1-7 concerned the statementing process, questions 8-13 were on parents' choice of school and their views on inclusion in mainstream settings. The final questions focused on communication with professionals. 203 questionnaires were sent to parents living in Sheffield. Of the 81 returned, 69 were eligible to be included in the analysis.

Table 4: McCarthy (1991) results from postal questionnaire

Question	Yes	No	Don't	No
			know	reply
'Were you in agreement with professionals	59	3	6	1
that your child needed statementing?'				
'Was the statementing procedure fully	49	15	4	1
explained to you?'				
'Was a draft statement sent to you for you to		15	6	3
make comments?'				
'Were you fully involved or informed in all		17	5	3
stages of the statementing of your child?				

Here, only 64% of parents felt 'fully involved' in the statementing of their child. All participants can be assumed to be literate in English and as such this study provides no insight into the experiences of parents who cannot read or write in English. The amount of 'don't know' and 'no response' replies may indicate an amount of passivity experienced by some parents within the statementing process.

2.3.2 Literature Review Question 2: What do we know about parents' experiences of psychological assessment of their children?

2.3.2.1 Overview of papers reviewed for Literature Review Question 2

The second literature review question examines parents' experiences of psychological assessment of their child. Three papers are reviewed. The first study (Hilton, Turner, Krebs, Volz & Heyman, 2012) gathers parents' views on attending a specialist clinic for assessment of their child's obsessive compulsive disorder. The second study is 'Psychological assessment and dyslexia: parents' perspectives' (Long & McPolin, 2009) and finally, 'A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service' (Mansell & Morris, 2004).

2.3.2.2 Parents' experiences of attending an OCD clinic, including assessment and diagnosis

Hilton et al.'s (2012) study looked at parental satisfaction with child mental health assessment by establishing parental expectations of, and satisfaction with, a specialist service for young people with OCD. The rationale of the study centred on the need to evaluate outcomes increasingly based on service users' feedback (rather than clinical outcome data) and that satisfaction with initial assessment may determine whether or not a family engage in the treatment offered. Little is known about parental satisfaction with child mental health assessment; as such this study can be classified as 'exploratory' (Robson, 2002). 40 parents completed questionnaires, which contained both closed and open questions. Data was subject to statistical and thematic analysis. Opportunity sampling was employed where parents of 51 young people assessed between May 2007 and May 2008 were invited to

complete a questionnaire. Closed questions were asked about expectations of the assessment, the experience of the assessment process, the usefulness and length of the process, relevance of the questions asked (in clinic), and satisfaction with the outcome of the assessment. Parents were invited to comment on their experiences in each of the areas examined. The most common expectations of parents regarding their child's assessment was advice or information about the treatment of OCD, a diagnosis or understanding of the child's problems, and an offer of treatment. These were also the most commonly reported parental gains from the assessment. Parents were asked specific questions about their satisfaction regarding their child's assessment, and their personal experiences. Themes that emerged from the open-ended questions were organised as 'positive' or 'negative'. Positive themes included parents feeling 'put at ease', 'feeling listened to, understood and reassured', 'being under the care of specialists / professionals', and the team being, 'optimistic about treatment'. However negative themes also emerged including the waiting time for the assessment, the limited time of assessment sessions and 'administration issues'.

Parents also completed a forced choice satisfaction rating scale for 28 questions. Some areas of the assessment had lower levels of parental satisfaction. These included 'understanding the child's strengths', again the 'waiting time for assessment', 'being given relevant written information or reading suggestions around the child's diagnosis' and, 'availability of professionals outside the appointment time'. This study had a high response rate, so it is likely that findings are representative of all the families assessed in the clinic at that time. The study demonstrated high levels of accuracy in its reporting of findings, which are clearly linked to the study's data. Each theme was presented with either one or several example quotations. Both the descriptive statistics and themes are useful findings for the current literature review. The findings from this study are also relevant to parents' views around statutory assessment considered by Research Question 1. Parents cited long waiting times, difficulty with communication with professionals, including not being provided with relevant information. Equally, parents valued being listened to and consulted with. Parents also valued having time to focus on

their child's strengths and engaging in positive talk around hopeful outcomes for their children.

2.3.2.3 Parents' experiences of attending a Dyslexia assessment service

Long & McPolin's (2009) study was carried out as part of an evaluation of the services offered by the Northern Ireland Dyslexia Centre (NIDC). Data collection was conducted via postal questionnaire, yielding both quantitative and qualitative findings. Participant selection was conducted by sending questionnaires to seventy parents of children who had had an educational psychology assessment for dyslexia through the NIDC between September 2002 and September 2006. Thirty-two questionnaires were completed. Analysis of written responses was made through 'a coding of themes and concepts'. Demographic information and responses to 13 questions on a likert scale were elicited. The opportunity for parents to make more detailed psychological assessment was also provided. comments on questionnaire focused on issues prior to, during, and after the assessment. This methodological feature has high relevance to the current research which will use three interviews, broadly focusing on before, during and after statutory assessment. The aims of the study were to explore parents' perceptions on the educational psychology services offered by the NIDC, and to provide teachers and EPs with information about parents' views of psychological assessment where their children were assessed for possible dyslexia.

In the open-ended section, all respondents expressed dissatisfaction that their views had not been listened to in school: 'I cannot stress how valuable the assessment itself was and how important it was to have my concerns validated when no-one at school had been listening to them over the years. People need to listen to parents.' Similarly to Hartas' (2008) case study this research represents relatively empowered parents, all of whom were literate in English. These parents were able to gain a private EP assessment due to dissatisfaction with school-based provision. What this study confirms for us firstly is that there are barriers to parents' involvement in statutory assessment that may centre around language and knowledge of processes. Secondly, that parents are often dissatisfied with provision at school, and crucially, that they

feel they have not been adequately listened to, including having their concerns validated.

2.3.2.4 Parents' experiences of attending an Autism diagnostic service

The final study in this literature review examines parents' reactions to their child receiving an Autistic Spectrum diagnosis (Mansell & Morris, 2004). The records of all children diagnosed by the district diagnostic service were categorised by year of diagnosis, age of child at diagnosis, sex of child with diagnosis and nature of diagnosis. The parents of those with a definite diagnosis (N100) were invited to take part. Fifty-five questionnaires were returned. The questionnaire contained questions to be answered via four-point Likert Scale ratings, with additional open-ended questions. The paper outlined four hypothesised stages in the diagnostic process for parents and families: pre-diagnosis, diagnosis, post-diagnosis and acceptance and adaptation.

The aims of the study were to:

- Obtain comments and recommendations about the service.
- Assess the use and quality of information services available to parents.
- Assess the use and perceived quality of support and treatment available to parents.
- Assess the positive and negative consequences of a diagnosis.
- Assess how parents' attitudes towards the diagnosis had changed over time.

Half of the questionnaires were completed by the mother and half were completed by both the mother and the father. Respondents were asked to rate their satisfaction with the feedback session they had had after diagnosis. Parents were then asked to rate the usefulness of different sources of support and treatment and to comment on how their attitudes to the diagnosis had changed over time. 77% of parents felt that 'diagnostic terms' had been 'moderately' or 'very' well explained. 51% felt that 'sources of support' and 46% felt that 'sources of information' were 'moderately' or 'very' well explained. 44% of parents reported that 'coping strategies' were 'moderately' or 'very' well explained, 31% reported that 'future consequences' were

'moderately' or 'very' well explained and only 28% felt that 'sources of treatment' had been 'moderately' or 'very' well explained.

The findings suggest that parents' experiences of psychological assessment often centred on receiving the diagnosis and having the diagnostic terms explained. Many parents felt that sources of support and information, coping strategies, future consequences and sources of treatment were not as well explained during the assessment period. The effect of this may be that parents feel unsupported immediately following assessment and indeed that services may be more inclined toward identification of children's needs, rather than focusing efforts towards better outcomes for children and support for parents / carers. The study also found via additional comments that many parents felt counselling should be available for parents to help deal with the diagnosis, and services should provide more information on the support and treatment options available. Parents also felt services should provide information before a diagnosis is made about how to access help, support and treatment, and during follow-up sessions professionals should provide information about further support and treatment programmes. Parents indicated that services should keep the parents informed of the likely diagnosis before the formal diagnosis is given, and services should provide help and advice on how to deal with schools including getting a place. Finally, parents felt that the service should reduce the waiting list. One parent commented, 'More time and information should be given to parents at diagnosis. I was informed of the diagnosis and told I would be seen by the family services worker in a month. That was it. No explanation. No hope. It was obvious that they knew what diagnosis they were likely to make prior to the play session but I had no prior warning. No one had the decency to tell me what might be wrong. At that point I needed to believe there was a future and I was appalled at the way I was treated. I should have had counselling there and then and lots of information given to me'. Here we can see that this parent's experience of psychological assessment of her child was very negative. It appears that there was not adequate support, or a sense of hope for the future, immediately following her child's diagnosis.

Parents were asked to rate the quality of information services. On the usefulness scale (1-4) the highest mean rated services at 3.5 were the family services worker, a local parents' support group, and academic journals. School teachers, local workshops and conferences, and the Early Years course were rated 3.4. Consultant paediatricians, meetings at the National Autistic Society, and family and friends were rated 3.2. Most parents also received information from EPs, clinical psychologists, occupational therapists, and speech and language therapists, but their usefulness ratings fell below 2.3. It was hypothesised that this may reflect the limited amount of time these professionals have with parents and that they may have more fixed ideas on 'appropriate' information to provide. Taken with the reported experience of parents immediately following assessment, this latter point has implications for EP practice where EPs should have up to date information to give to parents regarding sources of information about their child's needs, sources of support, treatment options and help with negotiating school provisions.

Regarding the quality of support and treatment, another parent commented, 'There should be more visits to schools by speech and language therapists. Education therapists should visit our children in school throughout the year in the classroom environment and give valid support to support assistants. Support assistants should have training in autism before supporting the child in the classroom; this would be very valuable for both the child and assistant and save much stress'. This quotation again suggests that many parents value being proactive in seeking information about how to support their child. This parent also indicated that their child's Teaching Assistant (TA) was not trained in Autism, and that this had caused stress for her child. This quotation also indicates that the parent experienced a lack of appropriate support of her child by 'education therapists'. In sum, these reported experiences indicate that parents feel somewhat abandoned by professionals after receiving diagnoses.

When parents were asked to indicate their reaction to diagnosis, the highest rated were: 'We were shocked / upset / devastated' (N=12), 'The diagnosis confirmed our feelings' (N=6), 'We already knew that our child had an autistic spectrum disorder' (N=6), 'The diagnosis helped explain our child's behaviour'

(N=4), 'We were angry about the diagnosis' (N=3) and 'We got the false impression that the future would be very bleak for our child' (N=3). The highest rated 'present' conclusions about the diagnosis and 'the future' were: 'We wish our child had been diagnosed earlier' (N=7), 'We have become more accepting of the diagnosis (N=6), 'The label has been a good thing' (N=5), 'We are unsure whether the diagnosis is correct' (N=5), 'We have become more aware of the lack of resources for our child' (N=4) and 'We have adapted to our child's behaviour' (N=3). One parent commented, 'Although it's been over three years since my son was diagnosed, it's still hard to come to terms with. It's an uphill struggle every day battling with the authorities for his rights'. The study does not mention that its design excludes those who cannot read and write in English. It is mentioned however that the results may not be generalisable because the sample is drawn from Bromley where general socio-economic status is high and 92% of the local population at the time of the study were white British. Methodologically, knowledge claims are well grounded in numerical data and verbatim quotations illustrated parents' views. Themes were not explicitly drawn from analysis of qualitative data; data was categorised and used in a descriptive / illustrative capacity. The study offers some useful insights regarding parents' experiences of assessment of their child, which has relevance to assessment of children within the EHC framework. Although the method specific quality was not high as no direct interviews took place, the knowledge presented by the study is useful for answering Literature Review Question 2.

2.3.3 Summary of Literature Review Question 1

Equality issues were present within the literature. Firstly, Rehal (1989) and Hart (2011) found that parents who do not speak English and fathers (particularly when not living with their children) are both at risk of not being informed, giving consent for, or contributing to the statutory assessment of their children. Further evidence suggested that higher levels of parental advocacy were associated with overfunding of children where 90% of children (N=20) overfunded by £1000 had a parental contribution, and that lower levels of parental advocacy were associated with significant underfunding of children. All children who were underfunded by £1000 or more (N=7) lacked

any sort of written parental contribution. Secondly, the inequalities described by the above studies were mirrored in the designs of the remaining studies reviewed in this chapter. The rest of the studies reviewed referred to 'parents' but were predominantly mothers, all participants spoke English and many of the studies required written responses from parents and therefore required parents to be literate in English in order to share their experiences.

O'Conner's (2003) study generated themes from interviewing parents about their experiences of statutory assessment. The time taken to issue the final statement, the need for greater communication and involvement with parents and more consideration being accorded to parents' views formed the main themes reported by the study. Parents would have liked results of assessments to be presented clearly and in full, information about available services, use of unambiguous terminology and information on parental rights. Jones and Swain's (2001) study discussed parents' experiences of Annual Reviews and focused largely on the barriers to meaningful involvement in statutory processes reported by parents. Barriers included **power relations** between parents and 'structures of educational decision making', relating to relationships with school staff, not being 'fully informed' by the LA and school staff, and finally time limits of Annual Reviews. Some parents commented on discrepancies between what was written in Statements and which provisions were actually delivered.

A case study (Hartas, 2008) described the barriers a relatively empowered couple overcame during their son's statutory assessment that led to 'authentic home-school partnership' (Hartas, 2008). These parents challenged professionals' views and practices, and resisted others' misrepresentation of them within the statutory assessment process through their powerful interpersonal and language-based skills. Whilst this case illustrated the difficulties that this parental couple overcame, it provides a useful contrast when considering the experiences of historically disempowered groups of parents described by the first three papers. Finally, McCarthy (1991) generated statistics that suggested that only 64% of parents felt properly involved in the statutory assessment of their child.

2.3.4 Summary of Literature Review Question 2

The second strand of the literature review sought to answer the question, 'What do we know of parents' experiences of psychological assessment of their children?' The first study (Hilton et al., 2012) examined parents' experiences of attending a specialist clinic for the assessment of their child's OCD. Parents reported the positive aspects of attending the assessment as feeling listened to, understood and reassured, being under the care of specialists, having separate parent and child interviews and the team's optimism toward treatment. Negative aspects of the assessment were reported as the waiting time for the assessment, the limited time during the assessment and administration issues. When parents completed a forced choice satisfaction rating scale, it was found that 'understanding the child's strengths', 'waiting time for assessment', 'relevant written information or reading suggestions' and 'availability of professionals outside of the appointment time' all had lower levels of parental satisfaction. Long and McPolin's (2009) study found that parents had not felt listened to in school and that 50% of parents were unsure about the status of their child in respect to the SEN CoP (1998). The final study explored parents' reactions to their child receiving an autistic spectrum diagnosis. Only 31% of respondents felt that the future consequences of the diagnosis were explained either 'moderately' or 'very' well and only 28% felt that the sources of treatment had been explained 'moderately' or 'very' well. Qualitative analysis suggested that parents felt a lack of hope for the future at the time of their child receiving a diagnosis.

2.4 Chapter summary

The overall issues presenting in the literature appear to be empowerment versus disempowerment, the time it takes services to react including lack of early intervention, equality of fathers and mothers and parents with varying degrees of literacy, equality of parents who do not speak English, equal access to resources, the time it takes services to react, availability of information about services, statutory processes and treatment options, communication with professionals and their perceived helpfulness, and a lack

of focus on the future or ways forward including on-going support for parents. The gap in the current evidence base relates to the recent inception of the SEND (2014) reforms; it will be useful for the current study to explore some of the issues discussed in this chapter in light of these reforms.

2.5 Aims of the current research

As outlined in Chapter 1, this research aims to explore parents' experiences of the EHC needs assessment process, bought in to law by the SEND (2014) reforms. The current study aims to build on the evidence base discussed here, which was generated before the SEND (2014) reforms, in order to explore if the key principles of the (2014) reforms have been met from the perspectives of parents. Due to the relatively recent inception of the reforms, the current study will constitute a novel addition to an evidence base focusing on the (2014) reforms, and in this sense it addresses a 'gap' in the current literature. Additionally, although an evidence base before the reforms exists, there were not many studies that directly gathered 'parents experiences' of statutory assessment, and moreover, many studies focused on parents who were literate in English. The current study aims to generate data gathered directly from parents and will seek to recruit a broad and diverse sample within an Inner London borough in order to better fulfil the emancipatory aim of the study.

3.1 Overview

This chapter is arranged in three main sections. The first section describes the ontological and epistemological position adopted by the researcher. The researcher will critically discuss social constructionism and the resulting context of a thematic analysis that utilises both latent and inductive coding of data. The second section sets out a detailed description of the procedures and methodology including data collection and analysis. The third section covers ethical considerations of the research.

3.2 Purpose and aims of research

The purpose of this study was to explore parents' experiences of the EHC needs assessment process within an Inner London borough. The research was designed to generate new knowledge where parents' views regarding the EHC needs assessment process had not been gathered due to its recent inception and to extend an evidence base where parents' views of statutory assessment had not often been gathered directly. Exploratory research is appropriate when the topic of study is new (Bobbie 2007). The political purpose of the research was to empower parents' voices and can therefore be described as 'emancipatory' (Robson, 2002). A further aim of the study was to provide rich data for EPs and other professionals around parents' experiences of the EHC needs assessment, in order to improve practice at interpersonal and organisational levels.

3.3 Ontological and Epistemological Position

The research was conducted within the social constructionist paradigm. 'Social constructionism' describes an ontological and epistemological position where there is no one fixed reality but rather multiple co-existing realities; and that 'reality' is constructed through language and group processes. This ontology is appropriate for the current 'emancipatory' research aim, because it privileges parents' accounts as 'valid' and 'as real' as any other account, for

example the account of the process contained in the CoP (2014) or the account of the process by the Inner London borough in which the research is conducted, as well as recognising the equal value of all of the parents' accounts when compared to one another. In this sense the paradigm can be used to better ensure equality, particularly because traditionally marginalised voices are of interest to the researcher. Another reason the social constructionist paradigm is appropriate is because the researcher wishes to fully acknowledge their active role in the production of this research and does not claim to 'discover' knowledge that existed independently of the research processes, as would be the case in the positivist research tradition.

A research paradigm constitutes a constellation of beliefs and values about the nature of reality and what it is 'to be human' (ontological position), the forms knowledge can take and how this knowledge may be created (epistemology) (Robson, 2002). Psychological research is conducted via the social and linguistic replication of four major paradigms: positivism, critical realism, pragmatism and social constructionism. The research purpose, research questions, design, data collection and data analysis necessarily reflect the paradigm that any research is produced within (Robson, 2002).

The social constructionist paradigm represents the researcher's values in terms of promoting equality, multiple realities and the awareness of how dominant discourses and power relations shape people's lived experiences. Dominant discourses and power relations are socially-produced phenomena and are replicated through language. Therefore, the unit of study is necessarily language, and this is reflected in the qualitative research design of this study. The reason other paradigms, for example positivist or critical realist, were rejected is because the researcher wishes to privilege the participants' accounts as holding the highest value in understanding the process from the points of view of parents. Although the critical realist paradigm is also relativist in that it recognises that knowledge and understanding are affected by the researcher within the process and the conditions of time and place, it was felt that social constructionism would provide the 'best fit' with the research aims. This is largely because the

research aim doesn't seek to 'discover' a pre-existing 'truth' about 'parents' experiences of the EHC needs assessment process as in the 'realist' position of 'critical realism', but rather seeks to draw out what is important to each of the participants in the first instance. The social constructionist paradigm has therefore driven the research aim, research questions, design, data collection and method of data analysis.

Willig (2013) writes of social constructionism, 'what we perceive and experience is never a direct reflection of environmental conditions but must be understood as a specific reading of those conditions... there are 'knowledges' rather than 'knowledge". Robson (2002) offers, 'Constructivist researchers, as heirs to the relativist tradition, have grave difficulties with the notion of an objective reality which can be known. They consider that the task of the researcher is to understand the multiple social constructions of meaning and knowledge'. Social constructionism as a research paradigm has ontological and epistemological roots in postmodernism and poststructuralism. Postmodernism is relevant to the theoretical position adopted in the current research. Postmodernism can be understood as acknowledging multiple realities and crucially, the notion of non-linear and fragmented realities rather than linear and 'coherent' realities. The researcher will seek to be alive to the concept that the way people experience themselves at different points will be non-linear and fragmented, reflecting the multiple narratives of a situation that can be held by one individual. Postmodernism is a paradigm that promotes equality, which is also reflected in the aims of the current research. Postmodernism promotes equality by acknowledging multiple truths, rather than the 'modernist' view of dominant discourses linked to 'Science' and 'progress' which privileged Western cultures and phallocentric attitudes.

Another way of describing research paradigms is by aligning them with idealist or realist theoretical positions. Idealism, like social constructionism, describes the view that 'reality' is shaped by an individual's thoughts and ideas. A key difference between social constructionism and idealism is that social constructionism also recognises that realities are co-constructed and experienced socially, rather than purely individually. The realist position, in

contrast, asserts that 'reality' has an absolute existence independent from thoughts and ideas, and is therefore aligned with positivist research traditions.

Clarke and Braun (2006) describe thematic analysis as 'theoretically flexible'. Research questions, rather than the method, provide the theoretical framework for any given thematic analysis. Thematic analysis is 'essentially independent of theory and epistemology, and can be applied across a range of theoretical and epistemological approaches' (Braun & Clarke, 2006). The paper describes that thematic analysis is often framed as realist, which is broadly in opposition to the group of philosophies called 'idealist' and constructionist (as discussed above), however, 'thematic analysis... is compatible with both essentialist (realist) and constructionist paradigms within psychology' (Braun & Clarke 2006).

Willig (2013) further illustrates how thematic analysis can take on different epistemological positions dependent on research questions, 'we see how important it is that the researcher is absolutely clear about the nature of the research question that drives their research, and about the epistemological implications of the formulation of the research question.' Similarly in regards to ontology, 'the assumptions thematic analysis makes about the world, and therefore its ontological position depends entirely upon the research question' (Willig, 2013). Willig (2013) offers that, 'most thematic analyses address research questions about subjective perceptions or social representations of one sort or another, and are therefore most likely to adopt a relativist epistemology and an idealist ontology'. This statement is compatible with the design and theoretical position of the current research.

It is therefore logical that due to the idealist ontology of the current research, that the object of study is the ideas and language produced by parents, rather than a concrete external 'thing' i.e. 'the EHC needs assessment process'. Interestingly, Willis's broad stoke of positioning thematic analysis as 'most often' relativist and idealist is disconfirming to the view in Braun and Clarke (2006) that thematic analysis is, 'often (implicitly) framed as a realist... method'. It is perhaps important to draw out here that 'implicitly framed'

relates to the potentially naïve view of researchers that they are not active in constructing knowledge, but rather somehow simply 'discovering a truth' external to themselves and naturally occurring in the world.

The selection of a semantic or latent coding of data is also linked to the research paradigm. A latent coding of data is more aligned to idealist, social constructionist and relativist positions because it explicitly acknowledges the process of *interpretation* of data, and in fact, this is seen as allowing for a deeper level of engagement with data by the researcher. On the other hand a semantic coding of data is more aligned to realist epistemology as it tends to assume that what is said by participants can be read literally, as representative of fact, and that it adequately communicates the total experience.

To summarise, the research will be conducted within the social constructionist paradigm, which describes the ontological and epistemological position of the researcher (i.e. that there is no one fixed reality but rather multiple co-existing realities; and that reality is constructed through language and group processes). This ontology privileges these parents' accounts as 'as real' as any other account, for example the account of the process contained in the Code of Practice (2014) or the account of the process by the Inner London borough in which the research is conducted, as well as the equal value of all of the parents' accounts when compared to one another. This paradigm is a mechanism by which to promote equality for the participants of this study who represent, as parents of children with SEN a marginalised group, and is therefore aligned with the emancipatory aim of the research. The researcher acknowledges their active role in the production of this research and does not claim to 'discover' knowledge that existed independently of the research activity.

3.4 Rationale for research design

The rationale for the design of the research was to best answer the main research question 'what do parents report of the EHC needs assessment

process?' from a social constructionist perspective. The ontological, epistemological and political considerations raised by working from within the social constructionist paradigm led to the adoption of data collection using semi-structured interviews, and data analysis using latent and inductive coding. This was to enable participants to give their accounts of the EHC needs assessment process with as few barriers as possible (e.g. rewording questions and promoting non-linear narratives) and later, coding that allowed themes to emerge 'bottom up' as a further empowerment of parents' voices. Thematic analysis was selected. This approach was selected over a phenomenological approach in order to produce an analysis that moved beyond particular detail to a rich data set that was representative of a larger group of parents within the borough.

The rationale for gathering interviews from each participant at three points in the EHC needs assessment process was to avoid the final outcome of the statutory assessment (the EHCP document and agreed provisions) affecting parents' accounts of their journey as it was experienced by them from within the process.

3.5 Research participants

It was decided that eight to 10 participants would yield the best sample for the thematic analysis described above due to the intention to collect three interviews from each participant (yielding 24-30 interviews). Participants needed to be parents of CYPs who had recently had their EHC needs assessment request accepted by the LA. Thirty-seven letters were sent to parents of children who had recently met this criteria, one week after the panel agreed the statutory assessment. From these letters there was one response. This parent, 'Fraser', and later his wife 'Alison' went on to take part in the research.

Due to the low response rate for the study a different opportunity sampling technique was used to recruit a further six participants. The researcher asked colleagues to take participant information letters (Appendix 3) to meetings

with parents whose children had recently had their EHC needs assessment agreed. Parents were shown the information about the study by EPs and were asked if the researcher could contact them to discuss what taking part in the study would involve, as well as the research aims. From this sampling technique eight parents agreed to a telephone call, one parent said they would not be able to spare the time to be interviewed and one parent agreed to take part but was later uncontactable.

The final sample comprised eight participants (one parental couple and six individuals) from a broad range of linguistic, ethnic and cultural backgrounds whose children also represented diversity in terms of age and special educational need. Each parent signed a consent form (Appendix 4) at the start of the first meeting, after reading the participant information letter again and asking any questions. Parents' right to withdraw without affecting their children's EHC needs assessments was highlighted.

The major limitation of the first recruitment technique was that only parents who could read English and were confident to respond independently could have taken part in the study. This would have produced a sample that was not representative of the borough, where some parents do not read and write in English, some speak English as an additional language and some speak other languages and do not speak English. As this sampling technique was replaced as described above, a more representative sample was obtained. This shift in sampling provided a more valid dataset that had greater ability to answer the research question. The diversity of participants obtained through the second recruitment phase was better aligned with the values of equality and empowerment promoted by the social constructionist paradigm and aims of the research. Please see Appendix 5 for an overview of participants and detailed descriptions of each participant.

3.6 Data collection

Data was collected at these three points in the EHC needs assessment process.

Table 4: Data collection schedule

Interview 1	1-3 weeks after hearing that their child was eligible for
	the EHC needs assessment.
Interview 2	0-3 weeks after the second TAC meeting, often referred
	to as the 'outcomes TAC'.
Interview 3	0-3 weeks after seeing either a copy of the 'draft plan'
	or final EHCP.

Data was collected via face-to-face semi-structured interviews. Telephone calls were used to arrange interviews with participants. To arrange interviews with Segal (who spoke Somali), a bilingual Somali and English speaking Teaching Assistant (TA) provided help to arrange the first interview and then the researcher and the participant arranged two further interviews by texting dates and times. Interviews were conducted mainly in participants' homes.

Semi-structured interviews have predetermined questions where the order can be modified based upon the interviewer's perception of what seems most appropriate. Question wording can be changed and particular questions that seem inappropriate with a participant can be omitted and additional questions included (Robson, 2002).

This form of data collection has resonance with the ontological and epistemological values discussed at the start of the chapter. This flexibility in how to ask questions assisted in overcoming barriers to joint understanding between the researcher and participants. This in turn promoted equality because participants were enabled to give their accounts more fully. Indeed, Braun and Clarke (2013) assert that good interviewers follow up on unanticipated issues and ask spontaneous and unplanned questions. This

model was adopted during interviews. Furthermore, this method of data collection recognises and allows for non-linear and fragmented narratives to emerge unhindered by a linear set of questions. Finally, this more 'conversational' style allowed for greater rapport-building and a more responsive interviewee-interviewer relationship. Semi-structured interviews offered this flexibility whilst enabling the researcher to ask participants about particular parts of their lives and experiences that were relevant to the research (Willig, 2008).

Potter and Wetherell (1987) advise against the use of closed questions during interviews and promote the skill of asking the same question phrased it differently in order to promote diversity of participants' responses, to avoid demand characteristics and to enable participants to answer all questions. An example of this was when one participant was asked, 'What do you think of the EHCP?' the deliberately broad question was then jointly reformulated to elicit views on the EHCP in dimensions that were significant to the participant and researcher. The participant spoke about the EHCP as a document (i.e. layout, length) and in terms of its functions (what does it do for you?)

3.7 Design of interview schedules

The interview schedules (Appendix 6) were based on the research questions and research aim of exploring if the principles outlined in the SEND CoP (2014) were being met, as well as some of the difficulties faced by parents which were identified by the literature in Chapter 1. The interview schedules were also designed to reflect the stage of the EHC needs assessment process that the parent was experiencing. Taken together, interview schedules 1-3 were designed to elicit data that reflected an evolving experience. Please refer to Appendix 7 to see earlier interview schedules prior to refinement. Interview schedules were refined by discussing interview questions with peers.

Interview one focused on the parent's journey leading up to having the EHC needs assessment agreed by the LA. Although the first question could

potentially suffice to elicit the main part interview one, subquestions were included as prompts, for example, 'What led to the identification of _____'s needs?' The first interview then looked to explore parents' expectations of the EHC needs assessment process. This question would elicit procedural knowledge as well as narratives, constructs and schema that related to the experience of the parent at that point in time.

Interview two was scheduled after the parents had attended the 'second TAC' or 'outcomes TAC' where outcomes are recorded on the EHC needs assessment form. In line with the principles of the SEND CoP (2014) these meetings were intended to empower parents and record their views, choices and aspirations for their children, as well as to detail the provision needed to meet these. Outcomes were to be co-constructed between parents and professionals, with a clear focus on parents' views and high aspirations for children and young people. Interview questions were designed to find out if parents' experiences reflected these principles at this stage in the process. Parents were asked, 'Do you feel your views have been fully gathered during this process so far?' and, 'Do you feel your views will have influence over the final EHCP?' Again procedural knowledge was examined, 'What will you do if you are not happy with the draft EHCP or the final EHCP?'

Interview three was held after the parent had seen either the draft or final EHCP. This interview sought to explore parents' experiences of the process as a whole, looking back after the Plan was complete (or near completion). Parents were asked their views on the EHCP, 'What do you think of the EHCP?' The question of whether parents felt their views were properly represented in the EHCP was explored, 'As a parent, do you think your views, aspirations and choices have been properly represented in the EHCP?' There were two questions aimed at exploring parents' feelings about their children's futures. One of the principles of the CoP (2014) is greater ambition for children with SEN. Parents were asked, 'Will the EHCP assist your child in achieving their best in the future?' and, 'Following this process, what are your feelings about your child's future?' All three interview schedules looked at

constructs of what happened in the past and parents' expectations of the future.

3.8 Interview procedure

For the six participants obtained via colleagues, the researcher telephoned them and informed them that taking part would involve three interviews over the course of the EHC needs assessment and would be arranged at a time and place convenient to them. When participants agreed to take part in the study, the date for the first interview was arranged. Some interviews had to be rescheduled due to delays in the progress of the EHC needs assessment.

Before the start of interview one, participants were made aware of the aims of the research, the researcher's position as a student conducting research (as opposed to an EP), the right to withdraw without any effect on their child's EHC needs assessment and confidentiality. Permission to use audio recording equipment was gained. All of the above points were presented verbally and in writing. Participants then signed consent forms (Appendix 4) to indicate that they had understood the information. The interviewer adopted an empathic, curious and non-judgmental position and began interviews with thanks for the time parents were giving and asking general conversational questions. Interviews were then conducted using the interview schedules as a guide.

3.9 Method of Data Analysis

Each interview was transcribed verbatim by a hired transcriber, including paralinguistic features, to a set of formatting guidelines provided by the researcher. Each transcript was read and edited by the researcher whilst listening to the corresponding interview recording in order to ensure accuracy. This editing procedure also familiarised the researcher with the dataset.

Thematic analysis is a method of identifying, analysing and reporting themes and patterns of meaning across a dataset. A theme can be understood as something important about the dataset in relation to the research question (Braun & Clarke 2013). The thematic analysis deployed in this study is

inductive; it was coded from the 'bottom up' and is therefore synergistic with 'exploratory' research within the social constructionist paradigm. Coding was *latent* rather than 'semantic' meaning that underlying ideas, assumptions and beliefs within units of language were sought, and the coding was *experiential* because the it focused on how participants made sense of the world (Braun & Clark 2006, 2013).

Braun and Clarke (2006) describe a six-stage model of thematic analysis that provided the framework for the current data analysis. The following sections provide a description of the process of data analysis for the current study at each of the six stages.

1. Familiarising yourself with your data

As the interview recordings were transcribed by another person, the researcher began the familiarisation process by listening to the recordings whilst editing each transcript for accuracy. The researcher then read each transcript twice in order to become more familiar with the data. A research diary was kept during this process in order to record initial ideas about the data.

2. Generating initial codes

The researcher studied units of data (excerpts of language) from the transcripts and coded them by cutting and pasting the extracts in to an electronic 'codebook' for each of the three interview phases. 'Complete coding' rather than 'selective coding' was employed. In complete coding, rather than looking for particular instances, the researcher aimed to identify 'anything and everything' of interest or relevance to answering the research questions, across the whole dataset (Braun & Clark 2013). This generated 411 codes. As is usually the case with this method of coding, the researcher became more selective later in the analytic process. The three electronic codebooks ensured that the researcher had an accessible record of codes and corresponding data, and this method also generated an audit trail for the purposes of transparency.

'Researcher-derived' *latent* codes were generated during the data analysis. Braun and Clark (2013) explain that latent codes are formed in the researcher's own language and are derived from an *analysis* of the unit of data that is being coded, these codes can be considered 'researcher-derived' (rather than semantic codes which mirror participants' own language). Indeed, 'The ability to generate researcher-derived codes... requires a deeper level of engagement with the data.... they assist in developing an interpretive analysis which goes beyond the obvious.'

The epistemological divide between realist and idealist paradigms is interesting when linked to coding for semantic or latent meanings, however, the divide is not absolute and necessarily depends on the positioning and intentions of the research. Braun and Clarke (2013) recognise that in practice there is overlap of these types of coding, and this is true for the current research. A thematic analysis at the latent level goes beyond the semantic content of the data and starts to identify or examine the underlying ideas, assumptions, conceptualisations, and ideologies that are theorised as shaping or informing the semantic content of the data. Thus, for latent thematic analysis, the development of the themes themselves involves interpretative work... Analysis within this... tradition tends to come from a constructionist paradigm' (Braun & Clarke, 2006). The rationale for the selection of a latent coding of data was that it would provide a richer overall analysis in order to answer the research questions, without entirely discounting the more literal reporting of the EHCP process offered by parents. The latent analysis of data is theoretically informed given the epistemological and ontological position of the researcher.

Another reason why inductive coding was more appropriate for this research is because the research is exploratory and therefore does not seek to draw out data relating to specific pre-existing theoretical frameworks, where a top-down deductive coding method would be very appropriate. Inductive coding was useful in answering the current research questions and was in-keeping with the study's aims because this method is potentially more empowering of parents' discourses. This method of coding gives greater opportunity for the

'unexpected' to be constructed by the researcher from the data. This is reminiscent of Willis's (2013) description of qualitative research as 'an adventure'. It is important, however, that the researcher acknowledges that there was a research question 'a priori' before the study was conducted and the researcher did therefore possess a pre-existing concept of the analysis in hand.

Codes were refined during the second coding, without loosing nuances that were relevant in answering the research questions. Codes that had overlap were not necessarily subsumed. 'Overlap' was used to identify pattern (i.e. candidate themes) at later stages of the analysis. Codes were a single word or brief phrase that captured the essence of why the unit of data was potentially useful. Some multifaceted units of data were coded in several ways, in order to see which codes remained useful or contributed to themes later in the analysis (Braun & Clark 2013).

3. Searching for themes

During this stage of the analysis codes were studied and organised in order to identify broader patterns. The researcher printed the contents pages of the three codebooks and cut out each code in order to arrange codes in to candidate themes. Please see Figure 3 below. At this point it was decided to create a thematic map of the whole dataset instead of creating three separate thematic maps for each data collection points, or separate maps for each of the research questions. This approach was selected in order to demonstrate links across the whole dataset. Codes were organised and reorganised in to themes that were thought to hold a **central organising concept**.

Themes were also constructed to communicate meaningful concepts related to the research questions. Themes were not simply generated by looking at frequency of codes, they were also generated by the standard of saliency (Buetow, 2010). The standard of saliency directed the researcher to look for codes and data that were *important* in answering the research questions. By the end of this stage, the researcher had constructed a set of candidate themes but had not yet fully visualised the thematic map.

Figure 3: An example of 'searching for themes'



4. Reviewing themes

This stage involved the refinement of candidate themes and had two stages.

- Reviewing coded data extracts: the researcher re-read all data (transcript extracts) and evaluated if they fitted the central organising concept and pattern described by the theme. This was achieved by collating data and codes for each theme and subtheme into a document. Please see Appendix 9 for an example of how data was collated under codes and themes.
- A final re-reading of the entire uncoded dataset was conducted whilst evaluating if the candidate themes captured a meaning of the dataset that held 'face validity' for the researcher in relation to the research questions.
- The thematic map was produced at the end of this stage.

5. Defining themes

This stage of the analysis incorporated the following:

 The first draft of the analytic narrative presented in Chapter 4 was written.

- Each theme was described by the researcher so that a reader could understand its central organising concept.
- The researcher wrote an analysis of each theme, drawing on selected quotations in order to support the concept of the theme as representative of the data. Quotations were selected from the breadth of the dataset in order to demonstrate pattern.

6. Producing the report

Here the researcher presented the analytic narrative and thematic map in Chapter 4, as well as the rest of the thesis in order to answer the research questions.

3.10 Reflexivity

Issues of reflexivity have been addressed in this chapter somewhat by outlining the researcher's ontological and epistemological position in opposition to the traditional positivist research paradigm where facts are presented as existing independently of the research process and the researcher (including their social context). Working within the social constructionist paradigm, the researcher aimed to be aware of their position as a TEP, and the preconceptions and beliefs they were bringing to the research process as an individual. It was not understood as 'problematic' that the researcher remained present as an active 'meaning-maker' within the process, and it is acknowledged that the researcher was present at every stage of the research design including the selection of the topic, the research paradigm, the data collection and data analysis. The researcher felt it was important to privilege the parents' accounts over, for example, their own experiences of the schools and the staff that participants talked about in their interviews. Moreover, the researcher aimed to adopt a non-judgmental and open-minded approach to data collection and data analysis. For a more full discussion of the researcher's position, please refer to section 5.4 in Chapter 5.

3.11 Reliability and validity

Lincoln and Guba's (1989) Evaluative Criteria (credibility, transferability, dependability and confirmability) were applied in order to check for trustworthiness.

Credibility was facilitated by 'prolonged engagement' with the research throughout the data collection and data analysis phases. 'Persistent observation' of data and reflexivity of the researcher also contributed to credibility. Further credibility was sought via academic supervision. The researcher attempted to promote transferability through 'thick description' of data, the diversity of the sample and the large amount of data (17 interviews) collected and analysed. Finally, 'confirmability' was established by creating an audit trail as described below (Halpern, 1983).

- All raw data was kept.
- Data reduction and analysis products were kept, please see Appendix 8 for an example of one of the codebook indexes, and Appendix 9 for an example of how data was collated under its corresponding codes and themes.
- Data reconstruction and synthesis products were documented, including structure of categories (themes, definitions, and relationships). Please see Figure 3. Findings were presented in the analytic narrative along with the final thematic map (Figure 4).
- The research proposal, ethical approval letter (Appendix 10) and personal notes were kept.
- Instrument development information was retained, including the preliminary interview schedules (Appendix 7).

Confirmability was also generated through systematic reflexivity. This required the acknowledgement of the researcher within the process and the effects of this on the construction of findings and the production of knowledge. Please see section 3.10 of this chapter, and 5.4 in Chapter 5. To further aid reflexivity, the researcher received regular supervision from EPs on

placement in an EPS and at university, and transparency was achieved by fully outlining the methodology and documenting the analytic process.

Ethical considerations 3.12

The University of East London Ethics Committee approved the research (Appendix 10). Approval was also sought from the Principle Educational Psychologist of the borough in which the research was conducted. The change in sampling technique was agreed with the Principle Educational Psychologist, the Placement Supervisor and the Academic Tutor.

Fox and Rendall (2002) discuss specific considerations for EP research. 'An important starting point is to recognise that ethical principles in research are socially constructed. In other words an ethical position is only meaningful within a specific context. Central to this context is the meaning and feeling that the participants have about the research'. The paper signposted the researcher to think carefully about boundarying EP practice and EP research; and planning for the beginnings and endings experienced by the participants. Beginnings and endings were verbally contracted with participants by covering what the interview aims were and looking ahead to the next interviews and the ending, including what would happen with their data. The researcher position was made clear, the researcher had to resist questions that invited advice, often by asking questions designed to deflect and generate further data, e.g. 'I'm wondering what you think / know about that? Where would you seek that information?' The importance of parents' accounts of statutory assessment was discussed with participants by the researcher.

In the British Psychological Society (BPS) Code of Human Research Ethics researchers must consider respect for the autonomy and dignity of persons, scientific value, social responsibility, and maximising benefit and minimising harm. 'Respect for the autonomy and dignity of persons' was achieved by gaining informed consent. Please see Appendix 3 and Appendix 4 for the participant information letter and consent forms. Each participant was

reminded of their right to withdraw from the study without any effect on their child's EHC needs assessment. The researcher also discussed with participants that interview data would be kept anonymous and any possible identifying information would be removed or substituted. Participants were given pseudonyms in the write up. The data for the research was stored securely using password protected software that only the researcher and transcriber had access to.

The standard of 'scientific value' was addressed by applying Lincoln and Guba's (1989) Evaluative Criteria, as discussed above. Other established frameworks were applied such as Braun and Clarke's (2006) six stage model of thematic analysis and by creating an audit trail (Halpern, 1983). Although the semantics of 'scientific' value can be debated from a social constructionist position, the researcher understood this standard as relating less to 'naturally occurring phenomena' and more about the technical quality of the execution of the research.

The researcher aimed to work with a clear focus on 'social responsibility'. This was addressed through designing research with an emancipatory as well as exploratory aim which empowered parents' voices. The output of the research was intended to enable professionals to improve the EHC needs assessment process for parents in the future, at both interpersonal and organisational levels. The research was conducted in order to highlight social inequalities present within the EHC needs assessment and to suggest ways that these can be meaningfully addressed in the future.

Issues of power are present during all social interaction, including during interviews. The researcher consciously adopted an 'active listening' posture whilst interviewing parents. During two interviews, the parent sat on a kitchen worktop whilst the researcher sat on a chair. Although this is a more extreme illustration of body language (proximity / orientation), the researcher adopted similar 'non threatening' positions in order to promote parents' empowerment during interviews. It is hoped that this supported participants to feel relaxed and in control and consequently to give their accounts more fully. The

researcher's interpersonal style was intended to address issues of equality and power, and to put participants at ease. The researcher presented as neutral and curious in the hope to lessen demand characteristics in participants.

The researcher was on placement in the borough where the research was conducted. As such, they had had professional contact with the school staff in the role of a Trainee Educational Psychologist and EPs in their EPS. The researcher had not had involvement with the participants in the study other than as a researcher.

3.13 Conclusion

This chapter described the methodology of the research. Firstly, the study's aims and the researcher's ontological and epistemological position were outlines as a way of 'grounding' further discussion within the chapter. The second section covered data collection, participants and data analysis. The chapter concluded by considering reflexivity, reliability and validity, and ethical considerations.

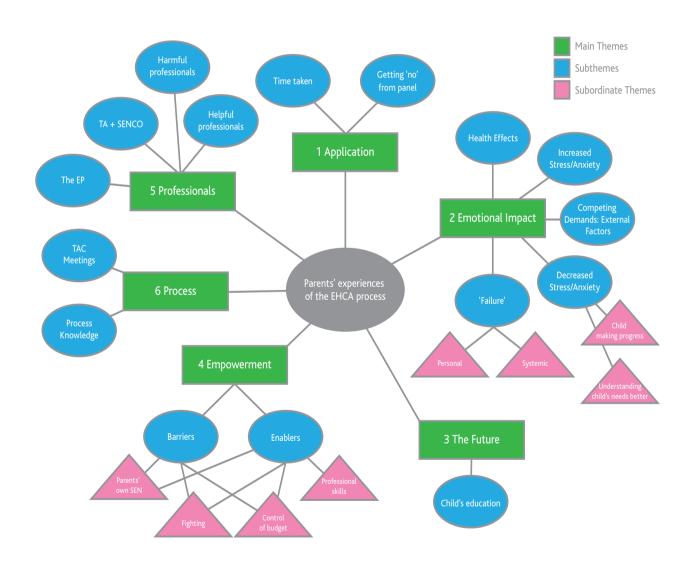
Chapter 4 Findings

'It's a fight, it's a luck. It shouldn't be'. (Kimberly 2 Line 231)

4.1 Overview of chapter

The current chapter presents a thematic map and analytic narrative in order to provide a basis for the presentation of the findings, as well as to demonstrate relationships between main themes, subthemes and subordinate themes.

<u>Figure 4: Thematic Map: 'Parents' experiences of the Education, Health and Care needs assessment process'.</u>



4.2 Thematic map

The thematic map (Figure 4) depicts six main themes in green boxes, 16 subthemes in blue ovals and eight subordinate themes in pink triangles.

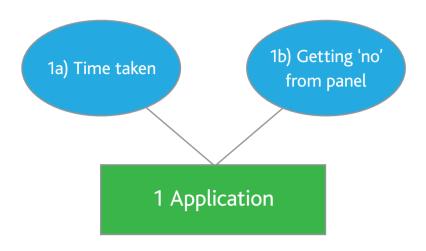
4.2.1 Inductive coding

Although an inductive coding method was employed, some of the themes directly relate to the study's research questions. This was likely due to the researcher asking questions relating to these areas in interviews. For example, 'Theme 2 Emotional Impact' relates directly to the study's research question 'Subquestion 4: What is the emotional impact of the EHC needs assessment process on parents?' The novel and unexpected findings from inductive coding organised under this main theme emerged as subthemes: 'Health effects', 'Increased stress / anxiety', 'Competing demands: External factors', 'Decreased stress / anxiety', and 'Failure'.

4.3 Theme 1 'Application'

This theme brings together data relating to parents' accounts of the EHC application process before the LA agreed to undertake Statutory Assessment. It is not surprising how much parents' accounts focused on this, particularly during the first round of interviews. This is because the first interviews were conducted shortly after the EHC needs assessment had been agreed but had not yet begun. The interview schedule for this first interview included the question, 'Can you tell me about the time leading up to getting a 'yes' from the panel?' This theme is arranged with two subthemes 'Getting 'no' from panel' and 'Time taken'. These two subthemes emerged from the data strongly, with nearly all data fitting within either subtheme.

Figure 5: 'Theme 1 Application'



4.3.1 Subtheme 1a: Time taken

All parents talked at length about the amount of time it took to complete the EHC needs assessment application. Their accounts also stretched back further, relating to bringing awareness of their child's needs to professionals' attention sufficiently to begin the EHC application process. Parents' accounts contained emotions of anger and sadness around the 'loss' of early intervention. Sometimes parents blamed themselves for not 'pushing harder' or 'going private' and at other times talked about problems in the SEN system or problems with specific professionals, services and schools. Fraser talked about how his son was self harming when he was six years old and they were discharged from child and adolescent mental health services (CAMHS), only to return to receive diagnoses when he was 15 years old and no longer attending school:

F: We took him to CAMHS when he was 6. It was round about that time or slightly earlier y'know doing that.

Fraser 1 Lines 113-114

Similarly Suzannah's son had struggled since Nursery with undiagnosed autism, only to have this recognised when he was at secondary school:

S: He's 12 now... It's been a long time.

Suzannah 1 Lines 33-35

Segal also spoke of the emotional impact of not having her child's needs recognised for a long time, and the amount of time the EHC needs assessment application took. During interviews one and two she talked about how her son had been on a reduced timetable for over a year (attending one hour a day) and was often excluded from school. This left her wondering if being in the UK was the best thing for her child:

I: This has been going on last three years. And there's not a definite information. To to pinpoint what has happened what has not happened. She said that mum feels that I feel shall I just move out of this country cos my child has not rights in this country, um, and go somewhere else.

Segal 2 Lines 428-436

4.3.2 Subtheme 1b: Getting 'no' from panel

This subtheme was carried in six of the eight participants' accounts relating to the EHC needs assessment request period. All six participants talked about the emotional impact of 'getting a 'no' from panel,' with accounts of 'bursting in to tears' by several as well as descriptions of feelings of anger and apathy. Asha was angry that her son would miss the start of the school year 'because of them' and also wondered if it was her 'fault' because she couldn't read English. She considered the impact on her son's mental health ('He would be down') due to being at home and not at school:

A: Still he will be late because of the that, couldn't get in September. **Because** of them. I don't know why they when I read it, I can't read! So I couldn't understand of them. Or maybe it's my language... Even I keep him at home

for one week. It becomes stressful. (High pitched)... **He would be down.** (Abridged)

Asha 1 Lines 780-894

Kimberly talked of her feelings of determination, anger and 'broken heartedness' when her child's needs assessment request was turned down:

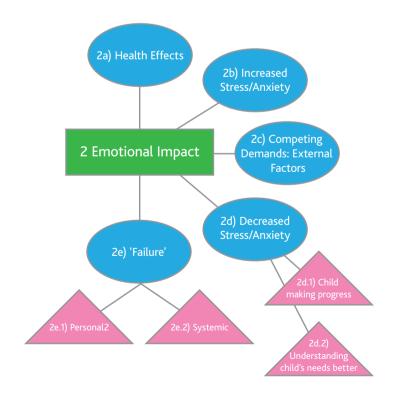
K: They knew that they had to get all of this done cos if XXX LA were to come back to me and say no again, I would have gone to Ofsted, hit the roof, the Sun newspaper, I would have shouted till somebody hear me. Just for that fact that this was the second time now. And I was broken hearted when they told me that they weren't going to do it. And I am sitting here like what? (...abridged)

K: He said "I'll handle the paperwork. I'll do it, I've got the paperwork, I'll send it off". He didn't handle the paperwork.

Kimberly 2 Lines 452-464

4.4 Theme 2: Emotional Impact

Figure 6: 'Theme 2 Emotional impact'



Throughout all parents' narratives the EHC application and assessment processes presented as highly emotional experiences. This is not surprising given some of the difficulties around having their children's needs recognised, relationships with professionals, services and schools, that their children are experiencing 'difficulty', and operating as a 'client' within a budget-constrained SEN system. One subtheme, 'Decreased stress / anxiety,' identified the positive emotional impact of the EHC needs assessment process, whilst the remaining four subthemes focused on negative emotional impact. The main theme 'Emotional Impact' was large and diverse: it yielded five subthemes and a further four subordinate themes linked to two subthemes.

Subthemes identified were 'Health effects', 'Increased stress / anxiety', 'Competing demands: external factors', 'Decreased stress / anxiety' and "Failure". Linked to 'Decreased stress / anxiety' were the subordinate themes, 'Child making progress' and 'Understanding child's needs better.' Linked to the subtheme 'Failure" were the subordinate themes, 'Personal' and, 'Systemic'.

4.4.1 Subtheme 2a: Health effects

This subtheme collated data relating to parents' attributions of the negative health effects of the EHC needs assessment process. Fraser talked about the process as causing his stroke in all three interviews, Alison talked about insomnia when she woke in the night to write her parent's statement, Fiona talked about feeling 'exhausted' and Segal talked about weight gain:

I: I couldn't even control my appetite and I put on a lot of weight during that time.

Segal 1 Lines 288-293

Fraser talked often and with a tone of sadness about his stroke, which he attributed to the stress of the EHC needs assessment process:

F: Eh well so much so that I had a stroke last month. (Laughs) So... All caused by this. Well probably caused by this, in this eye. Right side of my

brain so, went in my eye rather than my brain so I'm actually signed off work at the moment.

Fraser 1 Lines 225-330

And:

F: I'm I'm convinced after the social work thing it was my phonecalls to XXX (Connexions officer) finding out kinda what was going on with social work and school that had the big impact on my stroke. It was straight after that it happened. And I felt out of control then and it it was some of the worst phonecalls I've had to make. I wanted to know what was going on with the social work, they were phoning saying we're coming round to your house to talk about a child protection issue.

Fraser and Alison 2 Lines 301-310

'Health effects' were also implied in parents' narratives relating to the subtheme 'Increased stress / anxiety' because common discourses position stress and anxiety as having a negative effect on physical health (as well as being mentally and emotionally unpleasant). It was decided that 'Health effects' and 'Increased stress / anxiety' would be treated as separate subthemes of 'Emotional impact,' as both were prevalent in the data and viewed as equally important by the researcher in her analysis.

4.4.2 Subtheme 2b: Increased stress / anxiety

This subtheme contained a lot of related data. All parents spoke frequently of how the EHC needs request and EHC needs assessment led to increased anxiety, across all three data collection points. At the final data collection point parents also spoke about decreased stress and anxiety, though this was often tempered with recollections of more stressful and anxious times, as well the emotional 'cost' of the EHC processes. Several parents talked about a 'painful' process, for example:

L Can you ask what the impact of that has been on her?

- I/S Speak Somali
- I She said **it hurts a lot** because sometimes I think, I feel, doesn't the child have a right? Doesn't have a voice for the child?
- L Yeah yeah
- I That's what she feels
- L And he does have rights to his education
- I/S Speak Somali
- I Mum feels that the school has just closed their ears from it and if he does have a right it's just in the words they say not in the actions.

Segal 2 lines 77-87

Parents' discourses reflected their experiences of low mood as a result of the EHC processes. Fraser 'carried' a sad story 'in a carrier bag' that was all 'such a big mess' and 'should be neatly filed away'. He appeared to be experiencing guilt when he remarked, 'I'm sorry':

F: It should be neatly filed away, it's in a carrier bag! So heavy... it's just all a big mess I'm sorry. (Abridged)

Fraser 1 Lines 1018-1079

Inequalities between parents and services were raised as sources of increased stress by Kimberly, Kelly, Fraser, Alison, Suzannah, Asha and Segal. This is illustrated here when Segal reported misrepresentation by services and language inequalities:

I: She said that the only service that had contacted her is the social services and then she didn't have interpreter at the time, and the person made up something that was complete lie. That she feels, that was not accurate.

Segal 2 Lines 390-392

All participants talked about the increased stress and anxiety caused by timescales and being sent between services and professionals:

S: I don't know because that's what I said cos at the same time I was so stressed I didn't know who to go to

L: Yeah!

S: This place is sending me to go to this person, and that place is sending me to go to this.

Suzannah 1 Lines 267-270

Fiona frequently reflected that the stress relating to exceeded timescales had a negative emotional impact not only on herself, but also on her husband and their relationship:

F: It was hard because I didn't have any answers, and he (husband) was getting frustrated that I couldn't give him a timescale. The school told me they would let me know as soon as they heard but it was weeks in the end. It was very a very stressful time.

Fiona 2 Lines 321-324

Fraser and Alison experienced a 'more empowered' increased stress when they explained the emotional impact of the demands of 'building a case', 'gathering evidence' and writing the parents' statement:

A: But I do feel under an enormous amount of pressure now to produce, for us to produce a really good document to put in with the...

A: Now perhaps, perhaps we don't, but perhaps to

F: To make our case so

A: A stronger

F: Stronger case. If we didn't do it, and if, if we didn't do the parents' statement and the business case, and we didn't get the EHCP we'd be kicking ourselves so. (Abridged)

Fraser and Alison 2 Lines 1567-1589

4.4.3 Subtheme 2c: Competing demands, external factors

All eight participants talked about the 'competing demands' they had to manage whilst taking part in the EHC assessment request and EHC assessment. It is not surprising that this subtheme emerged, because parents were talking about the additional pressures of the EHC processes. This led them to reflect on the other factors that made the process more difficult to manage; or vice versa, that managing the EHC made any competing demands less easy to manage. Narratives arranged around this central organising concept included a relationship break up, bereavements, eviction, discourses of 'siblings suffering', siblings with SEN, being a single parent, having a husband who works late, 'parenting is difficult' narratives, difficulty getting to school and financial worries. Asha often talked about 'being alone' with 'no family'. In this extract she began talking about the eviction process she was facing and the recent death of her mother:

A: Yeah, I don't know where am I going... And I lost my mum in the summer. (Crying) (Abridged)

Asha 3 Lines 59-69

Kelly also lost her mother during the EHC needs assessment processes:

K: Yeah um (5) well my mum dies recently and we were close. So I don't have (4)... Yeah, she was a proper Nan to him. He went round at the weekends. (Abridged)

Kelly 3 Lines 300-303

Kimberly talked about the pressures of single parenting three children, two of whom had special needs:

K: M came home from school crying her eyes out I'm not going to school I'm not going to school I'm not going to school and it's a fight. I got the other one

that has got autism and doesn't want to get dressed or don't like change, do

you know what I mean?

Kimberly 1 Lines 531-535

Having looked at the negative emotional impact of the EHC needs

assessment process; we will now examine the positive impact in the next

section 'Decreased stress and anxiety'.

4.4.4 Subtheme 2d: Decreased stress and anxiety

Whilst the other five subthemes related to the main theme 'Emotional impact'

have negative organising concepts, several parents' accounts detailed the

positive emotional impact of the EHC needs assessment process. Linked to

this are two subordinate themes, 'Child making progress' and 'Understanding

child's needs better'. When talking about the positive emotional impact of

having the EHC needs assessment recently agreed by the LA during the first

interview, Segal's mood presented as significantly happier when compared to

later interviews where timescales had been exceeded and communication

with professionals had been poor:

I: Now everything is finish, everything is gone to where I want it to be, I am

feeling quite good, I feel better than before.

Segal 1 Lines 307-308

In her third interview Kelly talked about feeling pleased that her son's teaching

assistant 'wouldn't be taken away':

K: Um um (3) it does (2) help me to know that it helps me to know that now

XXX (TA) his teacher won't be taken away or he that he's here until Year 6

now

L: So you feel a little bit more sort of, secure?

K: Yeah

Kelly 3 Lines 232-277

78

Fiona talked about the 'relief' of finally getting the draft EHCP:

F: It's just a huge relief.

Fiona 3 Line 9

Fraser and Alison talked about the 'power' of the Plan and how having it reduced their stress:

A: But it is quite actually... now that we've got it, here sitting in the, you know, sitting in the kitchen actually, we shouldn't underestimate the power of having that because it allows as I say for that tailor-made approach to M's needs.

L Hm.

A: And if we didn't have that, the stress would still be going on. So

F: Yes.

Fraser and Alison 3 Lines 1043-1049

Asha who often talked about 'being alone' viewed the Plan to be stress reducing in that it meant she could 'share' her stress, and she was no longer alone or without solutions:

A: ... which only I used to stress, only by myself now they are sharing me. So it's better.

Asha 3 Lines 346

4.4.4.1 Subordinate theme 2d1: Child making progress

Many parents talked about the progress their child was making during their third interviews. This linked with the central organising themes of 'emotional impact' and 'reduced stress / anxiety' as parents felt that educational provision issues were finally resolved and they could see their child thriving as a result. Fiona often commented on her son's progress:

F: Um I mean he's, he's actually hitting targets that we have set for him, he's hitting them early.

Fiona 3 Lines 28-29

Fraser and Alison were similarly pleased with the progress their son was making as a result of the planning processes of the EHC needs assessment and his attending a private tuition service instead of mainstream or a specialist school in preparation for his GCSEs:

A: So he just sat his Science mock and he scraped a C... He's just started English and in one of the papers he's got a B, a higher B... And we've got Maths when he goes back actually next week... it looks as if he's going to be doing the higher paper. (Abridged)

Fraser and Alison 3 Lines 414-422

4.4.4.2 Subordinate theme 2d2: Understanding child's needs better

Parents' narratives positioned the EHC needs assessment process as helping them and others to 'understand the child's needs better'. This ranged from assessments and diagnoses clarifying situations that had been previously ill-defined and helping wider family members and school staff to understand their child better. Fiona talked about how attending TAC meetings had helped her husband to understand their son better:

F: I mean initially he was saying, "Well, I don't see the point," you know, like the two-year targets, he was saying, "This is just ridiculous." But for him, what was beneficial was going in with the professionals, with the teachers, with um, eh the, eh XXX, who worked for Early Years, who was absolutely amazing...

Fiona 3 Lines 825-831

Segal similarly found that TAC meetings had helped her sister to better understand the needs of her child (as well as her sister helping professionals):

I: [interpreting]

Yes it was, cause my sister was talking communicating with the people that was dealing with the process and she was there most of the time and they were taking down as well what my sister was saying and recording it and now she understands really well the need of H

Segal 1 Lines 395-398

Fraser and Alison explained that the SEND tribunal had raised helpful questions about their son's provision:

A: Um, and they did dual registered, at the PRU. They were quite concerned – and I can see now as well – about the social side.

F: Yeah, that was big.

A: That was a big concern that...

F: Aye and they were spot on

A: ... they had about M been removed from a kind of environment and have the potential to have quite a solitary existence.

Fraser and Alison 3 Lines 345-351

Fraser and Alison also felt that the panel validated the decision they had made to withdraw their child from school earlier on in the process, something which they found 'stress reducing' in that professionals had agreed with their view of their child's 'best interests'. This featured in their account from the macro to the micro, even when trying to decide how many GCSEs their child should take:

F: Before it's been about if we were funding it ourselves I think we would have felt he'd have to do more subjects.

F: Whereas this is a Plan from a whole bunch of professionals that says, "No, actually this is an objective thing".

F: Whereas we, we wouldn't have felt...

A: No.

F: We'd have been guilty about three subjects I think if it'd been us making the decision.

Fraser and Alison 3 Lines 1057-1065

Here Suzannah describes having a diagnosis as helping her to finally understand her child's behaviour, something which she had previously found more stressful:

S: So where is the things he was doing you don't think why you are doing these things. But now I can put an understanding to it.

Suzannah 1 Lines 311-312

Fraser was not surprised when he son received diagnoses of ASD and ADHD at the age of 15, but he felt that the staff at school who had taken a 'disciplinarian route' with his son were made more aware of his child's needs:

F: Uh huh so it came as, no surprise to us, but in school and you know the rest of the people who taken a back.

Fraser 1 Lines 603-604

4.4.5 Subtheme 2e: 'Failure'

Linked to the main theme of 'emotional impact' were discourses around 'failure'. All participants' data contained examples of this. Accounts often fitted within either two subordinate themes, where discourse of 'failure' was positioned as 'systemic' or 'personal'. The emotional impact of this was to feel 'let down' when talking about systemic failure, or when discussing personal 'failure' to feel sadness and regret that they had 'not done enough' for their child to 'get help sooner'.

4.4.5.1 Subordinate theme 2e1: Personal 'failure'

Fraser often reflected on what he would do differently in the 10 years of his son experiencing social, emotional and mental health difficulties:

F: The only regret we've got is not pushing. We couldn't have done anything now with him. Now we can't, we can't sort him out ourselves. But we, by pushing back then, perhaps even pay privately.

Fraser 1 1007-1009

Fraser felt he could have 'done more' by pushing harder or using his economic security to help his son. Asha on the other hand felt her 'personal failure' around meeting her son's needs was linked to being a single mother without any family in the country:

A: Because I'm only one here, just I can give him only mummy's love. He doesn't doesn't have anyone around him.

Asha 1 Lines 183-184

Kimberly wondered why she hadn't picked up on her daughter's hearing impairment sooner:

K: History of some family difficulty, but as I said, with all the kids, I just didn't pick it up.

Kimberly 1 Lines 96-97

Fiona described a sense of personal 'failure' when her son's EHC needs assessment request was rejected from the panel the first time:

F: Well, you just feel like you've failed.

Fiona 3 Line 1750

4.4.5.2 Subordinate theme 2e2: Systemic failure

Parents' accounts were heavily focused on systemic failures. These ranged from GPs missing symptoms of mental health difficulties, EPs and school staff suggesting a 'wait and see' approach, lack of identification of SEN within schools, lack of SEN provision in school systems, issues with individual

teachers and SENCos, promised provisions that were not delivered, 'discipline rather than care' within schools, lack of early intervention, schools not producing IEPs, and a lack of transparency within schools and services. Suzannah explained that several parents from her son's primary school had been assured by the previous SENCo that EHC request paperwork had been submitted when in fact it had not:

S: It was just a let down.

Suzannah 1 Lines 583-584

Kimberly also had experienced a lack of transparency around the EHC needs assessment request and the resulting delay in provision for her child:

K: And it's like they're they're all being slippery. They already admitted they M got slipped under the carpet. But that's not good enough.

Kimberly 2 Lines 213-214

Kelly was frustrated that she had raised issues with the GP when her son was aged two years and all throughout Nursery to Year 3 at school without any formal assessment and intervention taking place:

K: Well it was long. Quite well frustrated sometimes and not a lot I could do than what (3) But I kept saying and to them that I think. And I think it wouldn't have got so bad as like um now, it was (3) if they had tried harder for his learning back from when he was.

Kelly 2 Lines 109-111

Alison cast the professionals she had met within her 10 year journey to have her son's needs assessed as 'unhelpful' whereas Fraser thought they were 'just not interested' until their son's needs had escalated to the level where he was excluded from mainstream school, running away and taking drugs:

A: But I think because we've been going through it for a decade and the professionals we I've met have been so unhelpful

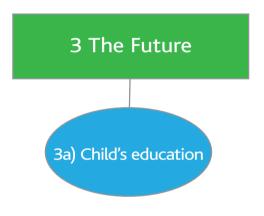
L: Mmm hum (agrees)

F: Er (2) or just not interested rather than not helpful and then we got to the stage when it got really bad and people like XXX (EP) got involved or er Dr XXX (CAMHS).

Fraser and Alison 2 Lines 542-547

4.5 Theme 3: 'The Future'

Figure 7: 'Theme 3 The Future'



Parents were asked questions about their child's future and education, so it is not surprising that this central organising concept arose from the data analysis. The theme was also important in parents' accounts because much of the focus of the EHC needs assessment process is centred around preparing for the future. Linked to this theme was the subtheme 'Child's education'. This subtheme contains data relating to the influence parents felt the EHCP would have on their child's education in the future.

During the second interview when asked about her hopes for her son's future, Segal felt that he did not have a future in the UK. This was because she felt abandoned and her son was at home with no educational provision to attend:

I: She said that mum feels that I feel shall I just move out of this country cos

my child has not rights in this country, um, and go somewhere else... Cos there's no future for us, she doesn't feel there's a future for her child here.

Segal 2 Lines 435-441

Kimberly had a clear image of what she would like her daughter's future to be like, but interestingly she commented 'I'll make sure that happens' which mirrored her narrative around how she would always have to monitor provision because 'slippery' schools would otherwise 'take the money' and not provide what was written in the EHCP:

K: So, so, yeah I think that's the desire, I just want her to be fully supported happy little girl, going to school. And having getting the most out of life experiencing everything. **Um I'll make sure that happens.**

Kimberly 2 Lines 409-412

This idea that it was ultimately the actions of the parent that would have the greatest influence on the child's future was echoed by Fraser and Alison. Like Kimberly, they saw the EHCP as a 'tool' to assist in their efforts, rather than the EHCP assuring their child's education:

A: So, first of all my feelings for M's future are hopeful and positive.

F: Yeah.

L: But, has it been the process that's done that?

F: Not necessarily, no.

A: No. I think it's us that's done that.

F: The process has helped.

A: But I suppose going back to the point I made, I think this now allows... gives us choices about, um, about finding the right, uh... this gives us the pathway for finding the right choices for M.

F: Hm.

A: That's what that does.

Fraser and Alison 3 Lines 661-671

4.5.1 Subtheme 3a: Child's education

Parents shared a wide range of views relating to the influence the EHCP would have on their child's future education. Kimberly talked about the allocation of funding as benefitting other children and not being spent where her child needs it (including in the playground) whereas Fiona talked about the school allocating a person to look after their child in the playground as soon as she requested it. Lack of monitoring of schools' SEN provision by the LA was raised, as well as lack of transparency with budgets. One parent felt that the Plan would not ensure that her child's needs were communicated adequately to staff by the school.

Little confidence was expressed by some parents that the provision detailed in the Plan would be delivered. Outcomes and targets not being ambitious enough and targets not addressing the child's real issues was raised. Another parent felt the severity of need was not reflected in the Plan. Several parents talked about the amount of exclusions their children had had, and wondered if the Plan would reduce this. One parent preferred that the Plan led to a full time TA, meaning her son was educated away from his peers as preferable to external exclusion. Several parents felt that the Plan would help in getting support in place during the secondary transfer process. Parents of an older YP felt that the Plan was not clear about how to support them into work or longer term up to age 25. Kimberly felt that her child's budget was being used to benefit several other children in the class and that the resources were not being directed where needed:

K: I don't want control of her budget but I am quite happy for them to, but I still want to know what you're spending it on... M's whole budget is being spent on this teacher and everyone else is be benefitting. I don't think that's fair. (Abridged)

Kimberly 2 Lines 169-174

Kimberly felt that the only way for her child's needs to be met was to monitor provision herself:

K: More monitoring the school books are not efficient.

L: And see how the money is spent? More monitoring that you can see how the money is being spent and also more monitoring from the council to make sure that-

K: It's being delivered

L: And I am going to skip forward to one question I know is on my final interview. Do you feel the Plan will give M what she needs? Actually on the ground?

K: Yes, as long as I carry on, overseeing everything.

Kimberly 2 Lines 393-399

Segal reported limited confidence that the Plan would ensure her child's education as she didn't feel that the Plan accurately reflected his needs:

I: What's, what's written on the documents his, his conditions, his conditions are more than what the documents are saying.

Segal 3 Lines 61-62

Kelly felt that the targets recorded in the Plan were not ambitious enough. This was a problem she felt had been present throughout her son's education and was being replicated in the Plan:

K: I was like thinking to make it harder... Well I wanted him to do more writing by his self really and they said only 3 sentences and I think it I think that is not enough really enough (2) for him

L: Oh (3) so what did they say when you?

K: They was like thinking to make it so not set him up so he can't get it and make it harder later if he gets it, reaches it then... It's just um, **they get to say really** (2) but I wish (2) I do wish he had done harder um work from when he started. (Abridged)

Kelly 2 Lines 201-212

Kelly also felt that the targets written on the Plan didn't deal with her son's underlying SEMH needs:

K: I would rather, I know that I know that he does kick off. I know that he does have meltdowns where he just refuses to do anything, but I think that if he was pushed from the very beginning that it wouldn't have got to this, he wouldn't have got to Year 5, still not being able to do certain things.

Kelly 3 Lines 166-169

Kelly (like Kimberly) was also led to feel unable to direct the school budget, or to be supported to manage the money as a personal budget:

K: Um I did ask I asked the um (3) the SENCo, if the budget could be so he had a tutor as well. But it wasn't really, she said it's not really, what you can't really do that. So it's I manage the money which I don't want to do. Or it goes to the school I think. I think that's what she said

L: Okay. And she didn't feel the school could have arranged the tutor?

K: She said that the school has a lot of stuff in place especially when it's test, when it comes up to tests. Or stuff like that where they have extra classes and things that he can go to

L: Okay. Um (3) and can I just ask you um why you didn't want to manage the money?

K: Yeah. I just feel it's such a big responsibility for me (half-laughs). And I wouldn't know what to do. (Abridged)

Kelly 3 Lines 189-206

Kimberly didn't feel that the budget was transparent. She had asked for a breakdown of money, not hours, and she also had little confidence that the provision outlined in the Plan would be delivered:

K: I don't. M hasn't got the working memory to come back and tell me every teacher that's she's done this with today, this with today, that with today. So no, I don't feel that I do. I asked for a layout and I've got it in three hours of this and four hours of that. And that wasn't what I asked for. (Abridged)

Kimberly 1405-1412

Conversely, Fiona talked about how the Plan reflected her wishes as a parent and the needs of her child, and at other times talked about the school treating the budget flexibly and transparently:

F: Um so we were quite adamant that yes, he needs a one-on-one with him in the classroom, but he needs a one-on-one more so, or not more so, just as much, in the playground. Um and they were, it was quite interesting the response to that and they picked up on it quite quickly and it was put straight into the Plan. (Abridged)

Fiona 3 Lines 903-912

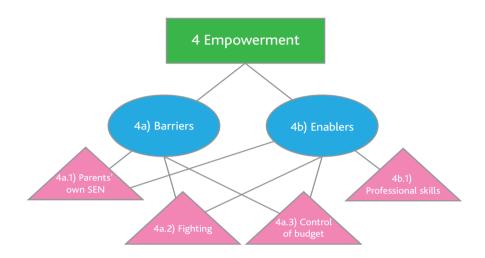
Several parents felt that the Plan would be helpful in securing support during their child's secondary transition. Here Kelly thought having the Plan would mean she wouldn't have to 'fight' to have her son's needs met:

I think it will make a big difference when he goes to secondary school. I think it'll make it easier for me when he goes to secondary, so I don't have to (2) fight the school to get what he needs.

Kelly 3 Lines 217-221

4.6 Theme 4: 'Empowerment'

Figure 8: 'Theme 4 Empowerment'



As a result of discourses and theory relating to empowerment being present in the planning of this research and indeed the SEND (2014) reforms, it was not surprising that these were reflected in parents' narratives. Of the four subordinate themes, three link to the subthemes 'Barriers' and 'Enablers'. 'Parent's SEN' was discussed as both a barrier and an enabler by Kelly and Kimberly. They felt their own experiences of having SEN motivated them to advocate for their children, whilst also talking about difficulties with pace understanding content in meetings. The only subordinate theme that did not link to both 'Barriers' and 'Enablers' was 'Professional skills' which linked to 'Enablers' only.

4.6.1 Subtheme 4a: Barriers

Present in several parents' accounts was their experiences of a 'bad parents' discourse that had disempowered them at various stages of having their child's needs assessed and provided for within the EHC processes. Alison recalled feeling her 'parenting' had been continually called in to question:

A: Every single club we tried to put him in, every single social situation that we put him in erm you know. (2) (Becomes high pitched) We had difficulties you know actually but, again, people look and think it ooh it's just discipline you know and (lowers pitch) 'That boy neeeds this and that boy needs this and that'.

Fraser and Alison 2 Lines 566-569

Fiona became aware from talking to other parents at an autism group that the parents' education level and support network could present as a barrier to parental empowerment and getting an EHCP:

F: Yeah, but it's also, you know, I'm not saying I'm a particularly well educated person, but, you know, there are people out there that, you know, that apply for, for it. And then when they get the answer no, they think that's probably the end of the road. And one of the courses I went on, that's what one of the girls said. She said she got the answer no, and when we said, "Well, what did you do about it?" she said, "Well, that was it."

Fiona 3 Lines 333-344

4.6.2 Subtheme 4b: Enablers

Many parents reported the EHC request and needs assessment processes as enabling of their empowerment. Kimberly felt that constructing the EHC documents had favourably shifted her communication with the wider professional network, rather than needing to rely on the school alone for information:

K: I don't feel that I've got to – what's the word – explain myself to them anymore. Now we've got this, they know, and it's not, they're not solely relying on the school to inform me of other people. So I think that it's got better. But I don't need to communicate as much which I shouldn't

have to communicate. I was communicating far too much because I was just not getting any answers and not really getting a lot back from the school. So now I'm not having so much to do with them, but they are all linked into the paperwork so as soon as something goes on everyone gets it, everyone's in (2) on the same page.

Kimberly 1172-1183

4.6.1.1 Subordinate theme 4a1: Parents' own SEN

Parents' own SEN was linked to two of the parents, Kelly and Kimberly. Both discussed their SEN as an enabler and as a barrier. Having SEN as a parent was empowering because they felt motivated by their own negative school experiences to make sure their children had better provision. Both also discussed having SEN as disempowering in meetings with professionals and when dealing with EHC paperwork. Kelly was more 'passive' in her discourses whilst Kimberly was relatively more empowered in terms of looking for strategies to enable her participation:

K: Yes she can accompany me to meeting, we've got a meeting on Friday, she couldn't make that, but I'm going to get someone to take minutes in the school on the meeting just so that I've got my little... Because I find that everything I find being dyslexic and having my difficulties is ah I try so hard to get everything over and they'll give me feedback and sometimes it is a little hard for me to process and log in so I like to have someone there just to say but what did she say when I said this and de de de de, you know because I'm trying so hard to fight their corners that it's a little bit sometimes difficult to take it all in.

Kimberly 1 Lines 391-399

Kelly found herself processing the content of the meeting afterwards when she was at home, and felt that aspects of the meeting had been rushed. She explained she had had a Statement when she was at school and implied that her full participation in the EHC outcomes TAC meeting had not been fully supported by professionals:

K: Well not really cos some bit **they just rushed it** and I didn't, until I got home, think really um. (4) And when I was actually (2) at school, myself, I had I had a statement too.

Kelly 2 Lines 170-171

4.6.1.2 Subordinate theme 4a2: Fighting

'Fighting' was prevalent in nearly all parents' accounts of the EHC needs assessment processes, and was positioned as both an enabler and barrier to parental empowerment. Fiona and Alison talk here about 'fighting' and 'going in for the kill':

F: ... and it takes a lot of fight. I mean if we hadn't got it this time round, you know, we would have quite happily have taken it to court...

Fiona 3 Lines 283-284

A: The last couple of months when we were basically told we wouldn't get it I think we had to go into for the kill a bit! ((Laughter))

Fraser and Alison 3 Lines 786-787

4.6.1.3 Subordinate theme 4a3: Control of budget

Parents had varying experiences of controlling their child's SEN budget, and in this sense control of budget represented a significant barrier or an enabler to parental empowerment. Fiona talked about being able to identify where the money was needed and not needed, and to work with the school to alter where money was being directed in order to meet her son's changing needs:

F: So eh it's just a case of, you know, moving things around. It's like we used to have A, and we still do at the moment, um somebody monitoring over lunch because that was one of my big fears, that he wouldn't eat. But because he appears to be doing really well with that now, um, we are hoping to move somebody away from that, because there's always someone in the dining room anyway and putting that

part of the funding into something else for him. I mean I would love him to do something like music therapy.

Fiona 3 Lines 519-53

4.6.2.1 Subordinate theme 4b1: Professional skills

This is the only subordinate theme that does not link to being a barrier and an enabler of parental empowerment. Professional skills were seen as a significantly empowering by the parents that had used them. Parents used professional skills to ensure better outcomes for their children. These discourses centred around Fiona, and Fraser and Alison's interviews. Both of these sets of parents appeared to have the most favourable outcomes, for example, reporting they had control over school held budgets (Fiona) and their child eventually attending a private education provision funded by the LA (Alison and Fraser). Interestingly, all three participants expressed 'regret', wondering about outcomes for other parents who did not have professional skills. Fraser and Alison talked at length about challenging the LA over their son's provision, as they felt sending him to the PRU or an SEMH school would be 'failing' him. They presented data to an appeals panel and at TACs on the cost of a school place in a specialist provision compared to private tutoring alongside GCSE 5*-C pass rate data:

F: One of the things would be to give them work on um, so we were told off the record to do homework on why we want XXX (private tutoring company) over the PRU. Why the PRU wouldn't be

A: Mmm yeah

F: So in simplistic terms, this is it. I looked at what M's needs were in Year 9 cos in Year 10 he was a write off there was no point and we were on course for a number of GCSEs, and he had good grades. Mmm and now he's not. So I looked at figures for the PRU to see what, what their pass rate was. Because what the council can't be doing is setting someone up to fail. You can't just say this person needs help and stick them in a PRU. So the average pass rate in XXX London Borough was about 5% higher than the national average, it's about 58% something like that. But the pass rate for bad GCSE's A-C at

the PRU was 2% last year, that's not good enough for M. We'd be failing M if we send him to the PRU. I'm not gonnae do that. (Abridged)

Fraser and Alison 2 Lines 952-969

4.7 Theme 5: Professionals

Parents' narratives focused a lot on their interactions with professionals. The accounts largely fitted within the subthemes of either 'helpful professionals or 'harmful professionals'. Teaching assistants (TAs) and Special Educational Needs Co-ordinators (SENCos) were discussed far more than any other type of professional, so this formed a subtheme. EPs were discussed much less, however, the subject was recorded as a subtheme in order to better identify data relating to EP practice as this was viewed as important by the researcher in terms of addressing the study's aims.

5b) Harmful professionals

5c) TA + SENCO

5a) Helpful professionals

5d) The EP

5 Professionals

Figure 9: 'Theme 5 Professionals'

4.7.1 Subtheme 5a: Helpful professionals

Many parents had experiences of helpful professionals (though these accounts were more scarce than 'harmful professionals' discourses). Accounts of helpful professionals ranged from those providing emotional support, to specialist advice, being helpful in TAC meetings, and supporting

their children in school. Asha and Segal often talked of the 'genuine care' that professionals had given them. Asha particularly positioned some professionals as the 'family' she otherwise lacked in the UK:

A: I thought I sent him to family's house feels like. I don't have any family in this country but when I send him, I'm happy. I thought they are his family, not only his teachers. Yes, they look after him, especially XXX (SENCo / resource base manager). (Abridged)

Asha 1 Lines 155-175

Fiona talked about an ASD specialist with high aspirations for her child making helpful contributions at TAC meetings:

F: And eh she will not take no for an answer, and, you know, she'd give very good advice and she'll make sure that people take that advice.

Fiona 3 Lines 835-836

4.7.2 Subtheme 5b: Harmful professionals

The subtheme 'harmful professionals' was present in all participants' data apart from Fiona's. Accounts of 'harmful professionals' were linked to children's needs not being identified, incorrect 'labelling' of children, and support not being provided by schools and other services. Other accounts positioned professionals as 'lazy' and 'unhelpful'. Social services professionals were spoken about as extremely harmful by Alison, Fraser, Suzannah and Segal, where Fraser linked their involvement with the onset of his stroke. Segal talked sadly of a social services professional visiting her home without an interpreter and then writing a report that she felt 'was a lie'. Suzannah recalled events leading up to phoning CAMHS and referring herself:

S: They umm well I wouldn't get involved with social services if they came to my door. They set me back. They. It's like I am begging you for help and because like. Because the first one that came out they always like closed the

case and then, there was one day where it was really bad I phoned him up in tears I think XXX other son went to get a knife for him M is there doing whatever he was doing. And I called up the social worker and said look I need help. He came out observed them and said look do you need further help I am going to talk to my manager.

L: So finally somebody...

S: No and I didn't hear from him so I phoned up said look he said he was going to go away and they said oh he's on holiday and he came back so I phoned up cos he was supposed to do a referral to CAMHS I phoned up CAMHS and said look it's been how long I haven't I heard nothing they said 'oh we refused it and we didn't get enough information from the social worker. We wrote to him to tell him we didn't have enough'. He didn't do anything. (Abridged)

Suzannah 1 Lines 174-197

Kimberly, like Suzannah's experiences of school *and* social services, had been misinformed by professionals about what paperwork had been submitted for her child's EHC needs assessment request:

K: She was there for a little while, um and then she had gone, but she had promised me the world and she was going to write this letter and do this letter and do that and... And none of it and I went to the school and I was fuming.

Kimberly 1 Lines 337-341

Fraser and Alison talked with sadness and anger at different times about how professionals at their son's secondary school had 'taken the discipline route' with him rather than planning and implementing strategies to support his SEN:

F: At school, we tried to tell them that M is we think M has some issues that need dealt with. Perhaps the SENCo should've been um involved, then the SENCo gets involved, but doesn't get involved really. She em she (2) em (5) failed us and she said I know M, dealing with M and she she'll put in place provisions for his eccentricities if that's what it was at the time without the

diagnosis. But nothing really happens in school, instead they took the discipline route with him.

Fraser 1 Lines 227-232

Suzannah similarly experienced her son's primary school using discipline, rather than supporting his SEN. She 'went along with it' but after he was diagnosed with ASD she started to 'speak up'. Suzannah linked this to her son being permanently excluded at the end of Year 6:

S: So it was like because I think I started speaking up now and no one liked it. Because before I was on their side like do this and do that. It was all fine. So um she started putting him on report he was doing things and I'm trying to explain that he's not got a relationship with the teacher so. And M if he doesn't understand things he won't put his hand up before he starts mucking about. Because he doesn't know what to do. and I'm trying to say put things in place but it was just like so. We would just go backward and forwards till

L: So it was never clear what was in place for him?

S: No

Suzannah 1 Lines 396-411

Kimberly found that despite EHC and SEN processes being followed, teachers were not always informed of her daughter's needs, which was very upsetting for her and her daughter:

K: Yeah but you're meant to read these IEPs if it's a new teacher a new class teacher or a supply teacher, they will read them. That will be it um it's not my job to make sure you read that so yeah. Mrs E didn't read it, so then M came home from school crying her eyes out I'm not going to school I'm not going to school I'm not going to school, and it's a fight.

Kimberly 1 Lines 529-523

Alison felt that her son's 'self-esteem' had been 'harmed' by the school system and teachers not recognising or supporting his SEN:

A: ... we just covered the section that said you know the reason that M's, the educational system isn't working for him is because his self-esteem has been eroded. He's got his reputation precedes. Are the teachers likely to change their ways, their attitude towards him, probably not.

Fraser and Alison 2 Lines 839-842

Kelly frequently talked of lack of early intervention having a harmful effect on her son. Here she recalled taking her son to the GP when he was two years, old and that no further assessment or help arose:

K: And I remember taking him to the doctors and saying he hits his head off the floor, he hits his head on the wall and they said 'oh it's terrible two. He is just a baby, he does not understand, ignore him'. But it went on and on and it was just never ending and then he ended up coming to Nursery here.

Kelly 2 Lines 62-65

4.7.3 Subtheme 5c: TA and SENCo

SENCos and TAs made up the greatest proportion of parents' discourses around specific professionals. This is likely because they are the people who have the most contact with them and their children at school and throughout the EHC request and needs assessment processes. Similarly to the 'helpful / harmful professionals' dichotomy, most SENCos fit within these two positions. TAs however were seen only as 'invaluable'. Segal found that the SENCo helping with her son's EHC request paperwork was emotionally intuitive:

I: Yeah and even though she don't speak my language, can we keep this between us, she is really helpful she is the one who was um um was doing the process of all this paperwork ... Yeah even though she don't speak my language. I wasn't getting the interpreting problem. She does even read my body language, if I am not well or I am upset.

Segal 1 Lines 218-225

Conversely, Fraser and Alison experienced a SENCo who 'wasn't interested':

F: So the SENCo well she hasn't been all the way through this process, she's not been interested.

Fraser and Alison 2 Lines 245-246

Kelly felt that her son's TA was a protective factor in his school life, she valued his contributions in TAC meetings and reported that the TA understood her son's needs:

K: His teacher XXX (TA's name) he works with D is, well, I was scared we was going to lose him, I don't think it could go well for D without XXX (TA's name)... He has had (2) like (3) other ones, but XXX (TA's name) really gets him and helping him a lot. And he came to the TAC meetings. (Abridged)

Kelly 2 Lines 133-143

Fiona similarly felt that the TA had a special quality in terms of the relationship with her son:

F: A lot, and there's that right person who knows him so well and she takes him out. And then gets him right, in the right place, and then can bring him back.

Fiona 3 Lines 45-48

4.7.4 Subtheme 5d: The EP

The EP was not prevalent in parents' accounts of the EHC request and needs assessment processes. Data has been separated into a subtheme in order to help identify data relevant to EP practice. When talking of the time of the EHC request paperwork being completed, Segal recalled a 'coming together' with the EP where they helped each other to understand her son:

It was really good meeting. She is really a good person as well. Helping with the paperwork, with the SENCo, because she has experience with the psychological side

L: Did XXX EP's input help Segal to understand H?

I: Yes they help each other a lot. Even when we are finish and we talked,

we were all together. (Abridged)

Segal 1 Lines 264-274

Kimberly, like other parents, felt that the EP had listened to her views:

L: Do you feel your views have been fully gathered during the process so far?

K: From XXX LA side of things the Ed Psych side of things yes, not fully from

the school.

Kimberly 2 Lines 388-391

Asha couldn't remember EP input and Kelly felt that the EP 'didn't say much'.

Although Segal had a positive initial EP experience around the time of the

EHC request, later on she had a different EP and felt 'left alone', not knowing

the name of her EP or who to contact. Here Kelly recalls earlier EP

involvement:

K: Um yeah, actually. We had a guy called XXX (EP) I think? Yeah, he was

really nice but it um (3) it um didn't really say much. And before that we had

someone else I think in Year 2? But I can't really.

L: Was there anything helpful?

K: I suppose (4) (Abridged)

Kelly 2 Lines 115-123

Asha couldn't recall any EP input:

L: Okay. Has has E seen an Educational Psychologist?

A: No

L: No, no

A: I don't think no

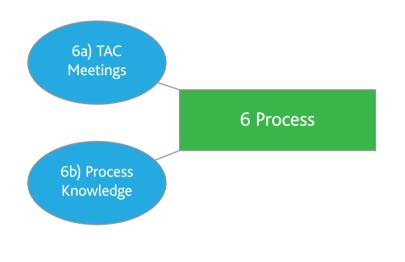
Asha 1 Lines 490-496

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4.8 Theme 6: Process

Parents talked about the processes of requesting and undertaking statutory assessment and this was arranged in two subthemes 'Team Around the Child (TAC) meetings' and 'Process knowledge'.

Figure 10: 'Theme 6 Process'



During interviews parents were asked questions like, 'What will happen next?' Their responses gave insights in to parents' knowledge and expectations of the EHC needs assessment process. This linked to empowerment. Fraser and Alison were unsure about how the LA would monitor the provision detailed in the Plan (which echoed many of Kimberly's misgivings around provision):

- A: We had no other contact with the council at all. They haven't checked to see whether the... XXX ASD worker is doing the pastoral care, um; the...
- F: None of the follow up.
- A: None, none of the follow up.

Fraser and Alison 3 Lines 1125-1129

Some parents were aware that there would be an Annual Review whilst others were not. Of those who were aware, none were sure how it would take place:

A: I was expecting a review. But how that will happen I, I maybe need to go and Google it actually to be fair to her, you know, but I'm not sure.

Fraser and Alison 3 Lines 1245-1246

4.8.1 Subtheme 6a: TAC Meetings

Parents were asked directly about their experiences of TAC meetings so it was not surprising that this emerged as a subtheme. Many parents talked about the co-construction that occurred within TACs, whilst others didn't feel their views had adequately shaped the EHC needs assessment process. Suzannah felt that everybody had contributed in the 'second' TAC meeting at her son's new secondary school (held after the needs assessment had been agreed). This was a direct contrast to the 'request TAC' held at his previous primary school:

S: Yeah actually it was actually really good because everybody put their input on what they thought he needed so, various teachers, XXX specialist service, everybody. So like, everyone together. We got a good outcome I think. (Abridged)

Suzannah 2 Lines 7-11

Kelly however felt that at various times TACs had been rushed, or that her views had not been included in target setting, or in detailing provision:

K: Well. Mostly yeah (3) but um not so not really about like what to get him I didn't feel. Cos I wanted a tutor and they said no it's no you can't do so.

Kelly 2 Lines 150-151

Kelly also talked about TACs positively at other times, which suggests that the experience of a TAC meeting can be nuanced with positive and negative elements:

K: Um I think the TAC meetings were important. You know they were really helpful, everybody knew what was happening. And so I knew what was happening at school. And you don't like you don't get that normally. I think with other children you just get told. Sometimes you just get told about that at the end of the day. But that's. With the TAC meeting you get told about everything that's happening, from home, from school. So I think it's really good. (Abridged)

Kelly 3 Lines 110-124

Fraser and Alison experienced arranging TACs themselves. They often talked of their professional skills driving the process in order to ensure a favourable outcome for their child:

A: And so for the EHP (sic) when we were trying to get everyone together. And em (2) and I was phoning around trying to get everybody to the meeting. And getting the and getting the and getting the consultants and the parent partnership at the council saying 'Why are you arranging all this? School should be doing it!' (Abridged)

Fraser and Alison 2 Lines 731-734

Suzannah was advised by the parent partnership service to think about her son's strengths and what provisions she may like to see included in the EHCP. This was important to her because the previous TAC had been 'all negative'. In this instance the parent partnership (rather than the school or EP) were helpful in prompting the parent to prepare ahead of the TAC:

S: Yeah cause they just say like this is a TAC meeting you got to now put in place what you want and then you could be thinking about things you wanted and XXX support worker lady did say something about his strengths, his strengths if I could think about his strengths.

Of all participants Fraser and Alison preferred to go to TACs well prepared, as they had a clear outcome in mind. They also felt that the purpose of each TAC was not made entirely clear beforehand, and this hindered their opportunity for preparation. They commented on a lack of an agenda for meetings. They also felt there had been several TACs and which ones were EHC related was not made clear:

A: So what are we just gonnae go and talk about the same auld thing? And who's gonna come?

Fraser and Alison 2 Lines 103-104

Kelly felt that the TAC was rushed and issues around control of a school held budget or having a personal budget were not fully explained before or during the meeting:

K: Yeah they were filling it in and I don't know what they put and then right at the end they asked me where I want the money sent and I just said school cos I was thinking for the one to one but then I got home and thought hang on what could that money be spent on? Could it be for an extra tutor? To make up. And I just didn't have time... And I think parents should be helped to know what things it can be spent on. I don't know if we spent it on something else would it mean we can't afford the teacher? (Abridged)

Kelly 2 Lines 184-193

Linking to the 'bad parents discourse', Alison felt judged at TAC meetings:

A: And I think if I'm being honest I felt judged.

F: I know.

A: I think TAC meetings, you know, when you're there and you're rightfully trying to focus on what the problems or the issues are... and then you obviously have to say you know, "This is the situation. This is what's

been done about it and this is the outcome" because you're trying to prove that the measures that they're putting in place...

L: Have been tried and they didn't work.

A: And they didn't work. But you, you I think, you're in a room with people who don't, they don't have that history, you know; they haven't been, been through the same experiences as M's been through.

F: They didn't know us as humans.

A: They didn't really know us as humans. And, you know, they have got the perception that M was a naughty kid in the school environment. So, so you try and explain to them that actually ((laughingly)) none of this is going to work; we can tell you that none of this is going to work... I think initially sort of, because, you know, that, that he'd been up in front of the governors sort of two or three times, you know, and of course you're putting that in the statement as evidence that he's... the mainstream system's not working for him. But at the same time, you know, the head, the head teachers are saying, you know, "Well..." um (3) when M was alleged to have broken into school in the middle of the night with his mates. Them saying, "Well, the fact that M was even out at that time".

F: Yeah.

A: You know, that total kind of judgement of... "Are you saying...? Well, I can assure you that we're not the kind of parents..." you know. And, and you're sitting there thinking, 'just you wait till your kids are 15, growing up in London'. (Abridged)

Fraser and Alison 3 Lines 1595-1632

4.8.2 Subtheme 6b: Process knowledge

Parents were asked questions about their expectations and knowledge relating to the process. These questions were asked in order to open dialogue relating to empowerment and parents' perceptions of their locus of control. Many parents had clear expectations around timescales, even though in reality all timescales were exceeded. Kimberly talked about the time from having the needs assessment agreed to having the final Plan being 20 weeks:

K: We, XXX EP, XXX EP come to the, we had a meeting and we went through and she explained to me that it's a shorter process this time, it's about twenty weeks.

Kimberly 1 lines 436-437

There was an imbalance between parents who knew enough about the EHC processes to be able to challenge their child's Plan and provision and those who did not know how they would go about it:

- L If she is not happy with the Plan, when it is sent out, what will she do?
- I She said I don't know
- L Ok. Cos parents have the right to appeal the Plan
- I She says she has no idea where to start that. (Abridged)

Segal 2 Lines 208-223

Conversely, Fraser and Alison understood the appeals process and used this knowledge to secure LA funding for their son to attend a private education provision:

F: And what will happen if we don't get that and what the recommendation would be. Appeals and that. And she said most mediation is successful to a large extent... So we know we knew what, we know what's happening. (Abridged)

Fraser and Alison 2 Lines 1328-1331

Kelly, like Asha, felt that if she was not happy with the draft EHCP, she would seek help from the SENCo rather than directly engaging with the LA like Fraser and Alison did:

K: If it come back and suddenly said he can't get that money and he loses his TA then I don't even know what the school would do then! But if if I wasn't happy I think I would maybe not say anything unless it was really bad, but probably I would tell XXX (SENCo) she would say.

Kelly 2 Lines 229-232

Here Asha explains that she was able to challenge the LA's decision not to carry out Statutory Assessment of her son with the help of her SENCo:

A: If it's only by myself I couldn't do anything, just, I can write, I can phone them, if they say to me no, I couldn't, even I don't know the law, I don't know what can I do, I don't have any knowledge, so I might have to accept it I don't have anything. I think I would be accept. Only me.

Asha 3 Lines 681-684

Segal had a clear outcome in mind but did not appear to be able to engage with the LA, or to have a person such as a SENCo who she could ask for help. She experienced long delays and no provision for her son to attend for around a year:

L: So you would like him to have a full-time special school?

S: Yeah.

I: Place.

S: Hm.

L: Um, how do you think that that can happen? Do you know what the next stages are?

I: She doesn't know the next stage. (Abridged)

Segal 3 Lines 34-43

Segal wasn't informed enough by professionals to be able to talk about what the Plan's function was, even during the final interview after the draft Plan had been issued:

L: Can maybe Segal tell me what the Plan gives H? What does she expect to get from it?

I: She doesn't know. All this Plan is new to her, so. (Abridged)

Segal 3 Lines 330-332

4.9 Findings summary

Parents' accounts reflected that the EHC request and assessment processes were lengthy, highly emotional and stressful. Conversely, parts of the EHC needs assessment process were reported as stress-reducing. Discourses of (dis)empowerment were present in all parents' accounts. Narratives often focused on interactions with various professionals, where professionals were positioned within a 'helpful / harmful' dichotomy. A novel finding of the analysis was that parents talked very little of EPs, however school staff (particularly SENCos and TAs were discussed at length). This may have implications for systemic EP practice. Parents' accounts reflected consideration of 'the future', with varying confidence expressed around the effect the EHCP will have on assuring their child's education.

4.10 Chapter summary

This chapter presented an outline of findings obtained from a thematic analysis whose methodology was obtained from Braun and Clarke (2013). The analysis has been used to generate findings which will be used as evidence in order to inform a discussion which aims to answer the study's research questions. In the following chapter the findings will be employed in order to allow for further interpretation by the researcher, including conclusions and implications for EP practice to be considered.

Discussion

5.1 Chapter introduction

This final chapter explored the findings outlined in Chapter 4 in relation to the existing literature in order to answer the current study's research questions. The research subquestions were explored before the main research question was answered, so that the main research question provided a summary of overall findings. A critique of the research design was included, as well as considering reflexivity and the position of the researcher. Implications for EPs and other professionals working within EHC processes was also explored, as well as implications for further research.

5.2 Overview of research purpose

The current research aims to fulfil an exploratory purpose (Robson, 2002), where little is currently known about parents' experiences of EHC statutory processes since the SEND (2014) reforms bought new statutory assessment practices in to place. The research is intended to contribute to the evidence base for EP practice and to inform EHC needs assessment procedures. The research aim is also emancipatory because it focuses on the experiences of minorities that have traditionally been marginalised (Robson, 2002) and examines inequalities caused by power relations.

5.3 Answering the research questions

5.3.1 What are parents' experiences of multi-agency meetings to determine outcomes?

'Theme 6: Process' grouped together much of the data relating to parents' experiences of TAC meetings. Parents' experiences of TAC meetings were also grouped around other themes such as 'Theme 4: Empowerment' and 'Understanding child's needs better,' which was a subordinate theme of 'Decreased stress and anxiety' under 'Theme 2: Emotional Impact'.

Parents' accounts of TAC meetings varied greatly. For example Kelly reported the positive aspects of TAC meetings in terms of sharing information,

yet the professionals involved in the TAC meetings had not enabled her full participation in co-constructing her son's EHCP. Fraser and Alison had 'felt judged' in TAC meetings and were dismayed by the lack of clarity and agendas for various TACs they had attended at school. They went on, however, to use TAC meetings to exert influence on the process. In both examples parents reported positive and negative experiences of TAC meetings. Overall, the data suggests that parents with greater 'professional skills' were able to 'exert influence' in TAC meetings, whilst other participants experienced varying degrees of empowerment or disempowerment at TACs. This ranged from Kimberly finding a strategy to manage her own learning difficulty within TACs, to Suzannah who experienced greater empowerment when she had support from a charity worker at later TACs. Segal had a very positive first 'request' TAC meeting when an interpreter had been arranged, but was then left for months with no TACs or communication at all from school, the LA or an EP. These findings will now be explored more fully in relation to the research outlined in Chapter 2.

The SEND Code of Practice (2014) called for 'clearer focus' on *parental* participation in decision making at individual and strategic levels. TAC meetings as part of the EHC needs assessment process are an important opportunity at the individual level for parents to shape decision-making regarding the content and focus of the EHCP and the resulting provisions. TAC meetings are also a mechanism by which information can be shared between parents and professionals from different services. Indeed, in Pinney's (2002) paper one of the major criticisms made by parents of the statementing process, before the SEND (2014) reforms, was around professionals' failure to share information with one another. Under 'Theme 1: Application' Suzannah and Fraser and Alison talked of their frustration at being sent between services, which arguably could have been avoided by schools arranging TACs.

Fraser and Alison talked about the purpose of TACs not being clear, including which were EHCP related, and ultimately needing to arrange TACs themselves. Fraser and Alison's reported experiences suggest that whilst the TAC was a mechanism for the home and professional network to share

information, and the parents to ensure their voices were heard, the parents often arranged and managed these rather than the professional network. The TACs didn't, however, resolve their child's EHCP and the parents enacted the appeals process. This suggests, like Gross' (1996) study that parents who have greater 'professional skills', which is a subtheme of 'Theme 4: Empowerment', are better able to 'exert influence' in a range of ways to secure better outcomes for their children, such as arranging and directing TACs and using the appeals process. The other participants' accounts, apart from Fiona's, suggested that they were relatively much less empowered in TAC meetings, and the assessment process as a whole.

Lamb (2009) called for a new system that is more ambitious for children and where parents are listened to more. Within 'Theme 4 Empowerment', Kelly talked of TAC meetings being rushed, and she identified that she needed more time to think about provision in order to have a stronger voice in planning her son's education. Kelly reported a system going back over time that was not ambitious enough for her child. She also felt that the targets recorded in her son's EHCP during the outcomes TAC were not ambitious enough.

Indeed, the SEND (2014) legislation states, 'There is a clearer focus on high aspirations.' Kelly's experience of the 'outcomes TAC' doesn't appear in this case to have answered Lamb's (2009) call for a more 'ambitious' system. The mechanism by which Kelly's higher aspirations could have been included in her son's EHCP (as she was less able to write a parental contribution due to her own learning difficulties) would have been the 'outcomes TAC', where instead she commented, 'They get to say really...'. Again, the condition of empowerment was not 'granted' by the EHC needs assessment process, or by the professionals responsible for its delivery. Within the current study the condition which made co-construction and higher aspirations possible were parents' own resources in the varying ways they were able to use professional skills to exert influence. This was reflected in Pinney's (2002) and Gross' (1996) studies.

Jones and Swain's (2001) study of statutory assessment processes (Annual Reviews) concluded that, 'The experiences of these parents suggest that while their views might be valued in principle, they can be devalued in practice'. Certainly for Kelly, her views were at times devalued in practice, by not explaining the purpose of TAC meetings beforehand, or talking about which provisions may be available, and which outcomes to co-construct and record. Her views were also devalued by not making adjustments for her learning difficulties that would have enabled her full participation. She did however also reflect on the usefulness of TACs, especially around hearing what was happening for her son at school and being able to share information about home.

Having learning difficulties (subtheme 'Parents' own SEN' under 'Theme 4: Empowerment') where adjustments are not made is likely to present a barrier to meaningful participation in TACs for some parents, as it did for Kelly. Kimberly, however, who identified with being dyslexic, asked for a person to take notes in TACs because she felt meetings would otherwise move too quickly for her to respond adequately. In this case Kimberly empowered herself by identifying a strategy and seeking support. Whilst Kimberly didn't empower herself through 'professional skills' she knew that the system was accountable and commented if she hadn't had the EHC needs assessment agreed after the second application she would have 'hit the roof', 'gone to the Sun newspaper and to Ofsted'. Disempowerment of parents with learning difficulties is especially likely where best practice is not followed, including not explaining the purpose of each TAC, not helping the parent to prepare beforehand and not actively seeking parents' views in order to co-construct provision. The new legislation itself doesn't deliver a stronger voice for parents in TACs. The mechanism by which this may be delivered is in the skill of professionals involved in the statutory assessment process. The current study found, however, that the most effective mechanism for parental empowerment and using the SEND (2014) legislation for better outcomes was enacted by the most empowered parents for their own children. In this sense, the current legislation does not protect against the 'unfair' (Pinney, 2002, Gross, 1996; Rehal, 1989) system of the past.

Suzannah felt that earlier TACs had been 'all negative' at her son's primary school, but was pleased when he started secondary school and a LA support worker suggested to her ahead of the outcomes TAC to think of her son's strengths. This links to Hilton et al.'s (2012) study of parents' experiences of an OCD assessment clinic. Parents reported lower levels of satisfaction around, 'understanding the child's strengths' and the study concluded that parents valued having time to focus on their child's strengths and to engage in positive talk around hopeful outcomes for their children. This suggests that parents' experiences of TAC meetings are effected by the balance of positive to negative talk around their children.

Hart's (2011) study found evidence of an EP discussion with fathers in only 13% of files, whilst 93% contained mothers' views. Lack of participation of fathers in TACs and statutory processes was mirrored in the current study where only one of eight participants, 'Fraser', was a father. Additionally, he was not representative of non-resident fathers, or fathers disempowered due to literacy or first language issues. These fathers represent the most likely marginalised group of parents within statutory assessment procedures.

Fiona talked about her husband's experiences of TACs and the division of labour in their home. Some of her reflections were echoed in Hart's (2011) study of fathers' involvement in statutory assessment. Beliefs that 'a man's role is to work, school is the mother's domain' was present in her discourses, particularly when she felt she was reflecting her husband's views. Fiona described that her husband had been reluctant to attend TACs and 'didn't see the point' of setting outcomes for their child. She also reported that during the 'outcome TAC' he attended, this belief changed and he began to find the process helpful, especially around hearing professionals' views. Fiona felt this helped him to understand their child better (subtheme 'Understanding child's needs better', 'Theme 2: Emotional Impact') and to have a better relationship with his child. This was reflected in Hart's (2011) study where beliefs that increased the likelihood of fathers attending TACs included feeling it was 'useful to hear professionals' views'. Also where Fiona talked about 'fighting' the LA, this reflected her and her husband's belief also identified by Hart (2011) to increase the likelihood of fathers attending TACs that it is 'important

to battle for assessment / provision'. By fostering positive beliefs about what fathers can gain from and contribute to TACs, professionals may be able to increase fathers' participation at TAC meetings which is likely to yield positive effects for the network, the father, the family and the child.

Ecosystemic factors identified by the study which affected fathers' attendance at TACs was found to be division of labour within the home, assumptions about gender roles, financial implications for fathers attending, what modes of communication are used by the school, how and when meetings are arranged, and accepted practices regarding parental involvement, including records of non-resident parents. (Hart, 2011). No non-resident fathers took part in the current study. Kimberly talked of her children's father's failure to provide financial support but she did not mention any disappointment around his non-attendance at TACs, or the possibility that he could have been included. She did however comment that he found their daughter's SEN 'upsetting' and this was identified in Hart's (2011) study as a belief held by fathers that is likely to decrease fathers' attendance at TACs. Here we can see that professionals may be able to promote fathers' attendance at TACs by helping them to better understand their child's conditions and needs, and by examining how institutions communicate with non-resident fathers to arrange TACs.

Rehal's (1989) study of parents who speak Punjabi without speaking English also gives us some insight into the experiences of TAC meetings of parents who do not speak English, and where high quality interpretation is not arranged. Of the 14 parents he interviewed, 13 did not know their child had a Statement. This was reflected in Segal's interviews where she was always unsure at what the stage the EHC needs assessment was, or whom she could contact for information. The parents in Rehal's (1989) study did not understand the significance of the letter proposing statutory assessment and this often led to non-attendance at TAC meetings. Segal reported one experience of a positive TAC meeting where an interpreter was arranged, and where all attendees including herself and her sister shared their views. This was the first 'request TAC' before a change of EP from a LA employee to a locum. Following this changeover Segal didn't attend any TACs and her child

was out of school, which may also have contributed to the lack of communication. During her second interview she was visibly experiencing low mood and felt 'abandoned'. She wondered if her son had any 'rights' or any 'future' in this country. Indeed, Social services visited Segal's home without an interpreter and for a period of around a year, she was not enabled to share her views with professionals or to ask questions. She also had very limited knowledge of the EHC process and its associated terms. When asked who she could go to for help, Segal couldn't identify a single professional or service. TAC meetings, which under the SEND (2014) legislation were supposed to enable her full participation in the process were either not held, or she was not invited to attend. The EHC needs assessment process spanned a year for Segal's son, rather than 20 weeks. Here it can be seen that without professionals diligently delivering the SEND (2014) reforms and promoting equality, the legislation in itself doesn't guarantee a more equal system or a stronger voice for parents. Indeed, just as before, the most vulnerable are also the most likely to be marginalised and their children are more likely to have poorer outcomes (Pinney, 2002; Gross, 1996).

Overall it appears that parents' experiences of TAC meetings vary greatly depending on their levels of empowerment within the process which would either enable or hinder sharing their views fully and co-constructing their child's EHCP. This itself appears to be dependent either on professionals ensuring the conditions for parental empowerment, or when parents are able to empower themselves. Being a parent who does not speak English and where interpretation is not arranged in order to invite parents to meetings and explain their importance would preclude parents from attending and / or taking part in TAC meetings. Being a non-resident parent with whom the school and LA does not communicate would also preclude parental involvement in TACs, as well as when professionals do not follow best practice or make adjustments for parents with learning difficulties.

In the current study, where parents were empowered in TACs, they needed to create these conditions themselves. This was echoed in Jones and Swain's (2001) study where 'parental involvement' was not offered to them by the LA

or the school but was worked toward by the parents by actively constructing relationships with staff and working within a 'power struggle'. This was echoed in Hartas' (2008) study where parental empowerment in TAC meetings and the educational planning process required *parents* to construct a social and critical space in which to engage with professional views and practices in order to advocate for their child, rather than this 'space' being provided by the process or the professionals.

5.3.2 Do parents feel properly listened to and fully included in coconstructing the EHCP?

The discussion above highlighted that fathers are often not included in TAC meetings, and that only 13% of files studied in content analysis contained evidence of fathers' views (Hart, 2011). Fathers therefore may not feel listened to, and non-attendance at TACs, as well as not having contact with professionals and school staff would preclude fathers from co-constructing the EHCP. In Hart's (2011) study 73% of fathers who did sign the parental advice form lived with their child, whilst only 15% of non-resident fathers signed the parental advice. McCarthy (2011) found that only 64% of parents (both mother and father) felt 'fully involved' in the statementing of their child. Within the current study only Fraser and Alison and Fiona appeared to feel 'fully involved' (in terms of the outcome) and were ultimately able to co-construct their child's EHCP and resulting provision. For example, Fiona was able to direct the school held budget and Fraser and Alison ensured the LA funded their child to attend a private education setting. The remaining five participants reported either unfavourable outcomes such as Kimberly, or expressed that the EHCP was 'good enough' but didn't fully reflect their wishes, such as Suzannah and Kelly.

As previously discussed, Segal did not feel at all 'included' in the statutory assessment process beyond the first 'request TAC'. Rehal's (1989) study suggests that parents who do not speak English are not listened to or 'included' in any way when interpretation is not arranged. This would also preclude these parents from 'feeling' involved, or to have the opportunity to co-construct their child's EHCP. The study highlighted that parents did not

understand the terms relating to statementing such as 'special education needs' or 'Statement', and they did not know that they had the right to challenge provision outlined in the draft Statement. This was echoed in the majority of Segal's experience as a parent who does not speak English. She talked about her sadness when a friend read to her a report that was generated by social services after a visit without an interpreter present. She felt the report 'was a complete lie' and it clearly did not reflect her views. When asked about the Plan she replied 'it's all new to me' after the statutory assessment period had spanned almost a year. When asked what she would do if she was not happy with the Plan, she reported that she did not know it could be appealed, and commented that she had 'no idea where to start that'. Ultimately, her son did get a specialist placement, but Segal waited a year for this with her son at home, not hearing from professionals for several months at a time. She also commented that the EHCP did not reflect the severity of her son's SEN. As a parent who does not speak English like the parents in Rehal's (1989) study, Segal was again not fully included in co-constructing her son's EHCP as her views about his level of functioning were not recorded. She and her son suffered as a result of poor communication, which manifested in greatly exceeded timescales and Segal's son being out of school for approximately a year.

As mentioned earlier, this disempowerment enacted by poor communication by professionals was however contrasted by Segal's earlier experience of a positive TAC meeting before a change over of EP when an interpreter was arranged. Segal said of this meeting 'we were all together' and reported that everyone present, including herself and her sister, were sharing views to help each other understand her child's needs. Again, feeling 'listened to' and being included in the co-construction of an EHCP (including if one is being written at all) depends for some parents solely on the standards maintained by professionals. For more empowered parents with greater means of exerting influence, they can better ensure this for themselves. This was explored more fully under 'Fighting' a subtheme of 'Theme 4: Empowerment'.

Narratives of all parents in the current study reflected times when poor communication from professionals and the LA had affected their opportunity

for involvement in the EHC needs assessment process. This included exceeding timescales, lack of contact and information regarding progress of the EHC needs assessment and lack of transparency by school staff. In terms of greater consideration being accorded to parental views, again, all parents' accounts contained examples of when their views had been devalued in varying ways. This ranged from professionals not seeking their views such as in Segal's case, not including or accommodating views that were expressed in Kelly, Kimberly and Suzannah's cases, and Fraser and Alison's recourse to 'fighting' to have their views fully considered.

These findings were reflected in O'Connor's (2005) study where parents highlighted the need for greater communication and involvement with parents in statutory assessment, including more feedback from professionals to parents and greater consideration being accorded to parental views. Because these views were obtained from resident 'parents' and parents who were literate in English and spoke English, they represent a relatively empowered group. Therefore, even parents who live at home, are literate in and speak English still experience varying levels of 'inclusion' and 'co-construction' of their child's EHCP.

Another finding of O'Connor (2005) was around 'clarity of information provided' including explanations of individual assessments, results of assessments being presented clearly, information about available services, use of unambiguous terminology and information on parental rights (O'Connor, 2005). The parents in the current study invariably did not know about a 'Local Offer' and 'clarity of information provided' was poor at times, especially relating to procedures ('Theme 6: Process'). This may have been partly due to the recent inception of the EHC needs assessment process at the time of the interviews.

'Theme 5: Professionals' collated data around parents' experiences of professionals. As discussed, it is not the 'process' that delivers a stronger voice for parents or is more ambitious for children: it is the professionals who are tasked with delivering the reforms that would make this possible, or parents with greater 'professional skills' ('Theme 4: Empowerment') would

ensure this themselves. Professionals therefore were the key factor in enabling relatively disempowered parents to 'feel fully included' and to be enabled to actively co-construct their child's EHCP. In the current study, only one relatively disempowered parent, Asha, reported being fully supported by a SENCO. Fiona, and Fraser and Alison only enacted co-construction via their 'professional skills' (Theme 4: Empowerment) and Kelly, Kimberly, Segal and Suzannah were at various times and to varying degrees excluded from the statutory assessment process by professionals' conduct and attitudes.

The current study identified discourses around 'harmful professionals' (Theme 5: Professionals). This was mirrored in O'Connor's (2005) study. 'Professional attitudes' (one of six subthemes) was highlighted by parents, including calling for greater training and awareness of school staff. Parents highlighted wider professionals not being contactable or being unhelpful, too clinical or too rude, and too many professionals involved. These factors could also be seen to effect whether or not parents in the current study felt 'listened to' and 'fully included' in co-constructing their child's EHCP. For example, Kimberly, Suzannah, Segal and Fraser and Alison all recalled times when professionals were unhelpful or rude ('Harmful professionals', 'Theme 5: Professionals), and all parents recalled times when professionals were uncontactable, or they were uncontactable due to literacy (Asha) or language (Segal) barriers. Fraser and Alison particularly talked about the stressful effect of 'too many professionals' and explained how they decided to cut the numbers down to only include 'helpful' professionals.

Another subtheme identified by O'Connor (2005) was 'procedures'. Parents highlighted that statutory assessment involved too much paperwork. This was echoed in parents' accounts in the current study in a number of ways and effected parents feeling 'listened to' and 'fully included' in constructing their child's EHCP. Asha talked about not being able to read 'all of the letters' and wondering if it was her 'fault' that her son wouldn't be able to start school in September. Segal had very limited understanding of the EHC needs assessment process and was also unable to read the paperwork.

Gross's (1996) study suggests that parents who have the strongest literacy skills and professional skills (such as requesting meetings, writing letters to councillors and enacting the appeals process) with which to 'exert influence' were more able to include themselves in statutory assessment processes and co-construct their child's Statement. This was mirrored in the current study where Fraser and Alison, although reporting the volume of paperwork to be 'stressful', used the parental statement to put their case forward and to initiate the appeals process. Similarly Fiona also reported very favourable outcomes, such as being able to direct her child's budget, where she and her husband also ensured being 'listened to', 'fully included' and able to co-construct their child's EHCP by having the ability to engage with legislation and paperwork. Fiona commented that she and her husband were prepared to instruct a lawyer after the first EHC needs assessment request was declined by the LA. Again, it appears that parents created the conditions for being 'included' and to be able to co-construct their child's EHCP. The exception to this is Asha's case, where although she could not read English, she could speak English and had a supportive relationship with a SENCo to whom she took paperwork to read, and who responded to the LA on her behalf.

5.3.3 Do parents feel empowered within the process?

In order to answer this question it is helpful to briefly consider what 'disempowerment' is, as the opposite of 'empowerment'. Disempowerment is the prevention of a person having power, authority and influence. It is a mechanism whereby a person feels less confident and less able to exert influence. Disempowerment has also been linked to a loss of 'locus of control', where a person does not feel in control of their life, and rather experiences this control located externally. In terms of the EHC needs assessment process, this would mean parents' locus of control could potentially sit with other professionals or with LA processes, rather than feeling personally in control of the statutory assessment and fully able to exert influence and to co-construct their child's EHCP and provisions. As the EHCP is conducted within a network, it is of course not possible that parents would have total control, but the aim of the SEND (2014) reforms is that their wishes and views are represented and their full participation is ensured.

For the participants in the current study, 'empowerment' is a nuanced term. In the discussion to this point some parents have been referred to as 'more empowered' or 'less empowered', due to their overall ability to exert influence on the process and the resulting favourable outcomes they reported. However, within the journeys of these parents (Fraser and Alison, and Fiona) where there were key moments they experienced significant disempowerment. Fraser felt so disempowered by a school referral to social services and the resulting contact with social services that he linked 'feeling out of control' as the cause of his stroke. Similarly, Fiona who was able to exert influence within the process overall, also experienced key moments of disempowerment. For her it was the first needs assessment request being declined by the LA, where she walked home from hearing the news 'in floods of tears' and 'felt like giving up'. And again when she experienced long periods without any communication from the LA regarding when the draft EHCP would be published. Part of the loss of control for her at this time was linked to the effect of not knowing a timescale and the pressure this caused in her relationship with her husband who considered it 'her job' to know this information. Interestingly, it appeared that moments of disempowerment for people who otherwise feel very capable of exerting influence in their lives were experienced as extremely stressful events, perhaps because they challenged the participants' perceptions and expectations. Of the remaining participants their disempowerment was more 'total', which in no way made the feeling of loss of control any 'less' for them.

A key moment of disempowerment for six out of the eight participants was having the EHC needs assessment request declined by the LA and needing to reapply. Data relating to this experience is grouped under 'Theme 1: Application', and subtheme 'Getting 'no' from panel'. The other subtheme within 'Theme 1: Application' was 'Time taken'. This was also a source of disempowerment for *all* parents in the study and related to the time leading up to having the EHC needs assessment agreed. All parents' narratives contained accounts of being sent between services, professionals not listening to their concerns and the EHC needs assessment application process itself, including being turned down and needing to reapply, all being

lengthy processes where the parents had limited ability to exert influence and to have their concerns taken seriously. One mechanism for parents' disempowerment at this stage was a lack of transparency from schools about whether or not paperwork had been completed and submitted. This disempowered parents because they were not in possession of the facts relating to their child's EHC assessment requests and applied to Kimberly, Suzannah, and Fraser and Alison.

We have seen from the discussion around parents' experiences of multiagency meetings, and matters of feeling 'listened to', being included, and having the opportunity to co-construct their child's EHCP, that fathers are often disempowered within statutory assessment and educational planning procedures due to a range of beliefs and ecosystemic factors (Hart, 2011). This was mirrored in the current study. Other factors in the literature reviewed in this study relating to empowerment were found to be power relations (Jones and Swain, 2001; Hartas, 2008), issues of literacy and having the means to exert influence (Gross, 1996) and being a parent who does not speak English (Rehal, 1989). These findings were also replicated in this research.

In the current study, data relating to parental empowerment was collated under 'Theme 4: Empowerment'. Data relating to empowerment was also arranged around 'Theme 2: Emotional Impact'. This is due to levels of empowerment and disempowerment having a direct effect on parents' emotional experiences. As discussed above, although Fraser was overall 'highly empowered' within the process, this did not remove the devastating emotional and physical impact of the times when he was disempowered. 'Theme 5: Professionals' also contains data relating to empowerment and disempowerment, particularly around the subthemes 'Harmful professionals' and 'Helpful professionals'. And finally 'Theme 6: Process' and its associated subthemes 'TAC meetings' and 'Process knowledge' also contain data relevant to considering parents' experiences of empowerment and disempowerment. As we can see from the prevalence of data relating to empowerment, it is a central finding of this study that mechanisms of empowerment and disempowerment and the impact of this on parents

requires special consideration by professionals working within EHC needs assessment processes. This further highlights that the inception of new legislation does not in itself deliver 'parental empowerment' and a 'stronger voice' for parents, nor does it remove inequalities in the statutory assessment system.

Gross (1996) found that of the children who were underfunded by over £1000 (N7), 0% had a written parental contribution. Although the feelings of parents who were unable to write parental contributions was not explored by the study, it may be reasonable to infer that these parents felt disempowered within statutory assessment processes, or if they were unaware of them, that they felt generally disempowered within educational planning processes. In concrete terms, they were disempowered. Participants in the current study had varying degrees of literacy and professional skills with which to exert influence, and this created significant differences in the outcomes for their children. Interestingly, it seems that a mitigating factor is the presence of a supportive relationship with a professional who would advocate on behalf of the parent and child. Asha was not able to read and write in English, however, she was able to ask the SENCO at her child's specialist nursery for help. Similarly Kelly commented if she 'wasn't happy' she would talk to the SENCO about it. Conversely, Segal did not appear to have any such relationship after the first interview was conducted. She was not aware of an appeals process, or who she would go to if she wasn't happy with her son's EHCP. Here it can be seen that parents who do not speak English, and non-resident parents, are the most at risk of disempowerment through pronounced lack of communication with professionals. In these cases statutory assessment may continue between the professional network, whilst removing the ability of the disempowered parent to exert influence at all.

Although Kelly, Kimberly, Suzannah and Asha could identify professionals to help them, and could in theory use these relationships as mechanisms for empowering themselves with varying degrees of success, they and parents with similar levels of literacy are also at risk of being 'less empowered' than Fiona, or Fraser and Alison. How well these parents can use a relationship with a professional to empower themselves may depend partly on how

motivated the professional is who is supporting them. That is to say, would the SENCOs the participants in this study named as 'helping' them be prepared to initiate the appeals process to enact exactly the parents wishes as Fraser and Alison had? Or would the SENCO be more likely to work to secure a 'good enough' outcome for the child? This is evidenced by Kelly reporting that her wishes for a tutor had been disregarded by the school, and that she felt the targets set for her son were not ambitious enough. Although she identified the school SENCO as the person she would go to for help if she was 'not happy' with the provision detailed in the EHCP, this same professional had at times significantly devalued her views and created barriers to the co-construction of her son's EHCP. Similarly, although Asha was very grateful for the help she had received from the SENCO and reported herself to be fully supported, the SENCO was not able to, or did not 'push' for the EHC needs assessment to be complete in time for September and Asha's son was therefore due to join the term late (something Asha identified as causing her child to 'be down'). Fraser and Alison on the other hand would arrange TAC meetings themselves if they felt the process wasn't progressing quickly enough, and they also kept in regular contact with the LA case manager to put pressure on the LA to meet timescales. Like other studies reviewed (Gross, 1996; Jones & Swain, 2001; Hartas, 2008, Lamb, 2009; Pinney, 2002) the current study's findings point to an unequal system where the most empowered parents secure a 'better deal' for their children. It is important to note however, that all parents felt disempowered at times within the process, and the resulting distress is significant despite the ultimate outcomes parents achieved.

It may also be interesting to link this to the notion of 'Fighting', a subordinate theme within 'Theme 4: Empowerment'. Kimberly, Fiona, Suzannah, and Fraser and Alison's narratives all reflected 'Fighting,' and this may be conceptualised as a response to times when they had been disempowered. For this reason 'Fighting' was linked to being both a 'barrier' and an 'enabler' of empowerment. Indeed, as much as 'Fighting' was symptomatic of disempowerment, it was also the mechanism by which parents empowered themselves. For some parents 'Fighting' involved enacting the appeals process and writing letters, whilst for others who were less literate but more

verbally assertive, this involved face-to-face confrontation with staff. For example, Suzannah and Kimberly both recalled 'fighting' in TAC meetings. This type of verbal confrontation was also documented in Pinney's (2002) study.

Jones and Swain's (2001) study contrasted parents' views relating to their empowerment within Annual Reviews. One parent commented, 'The review is decided before you get there. It's a simple fact', whilst another commented, 'As far as I'm concerned reviews are not, they're not just a rubber stamp. You can make a difference.' Parents reported a range of barriers to their empowerment within Annual Reviews. These included relationships with school staff, not being 'fully informed' and the time limits of review meetings. Many parents in Jones & Swain's (2001) study reported the review process to be stressful, and one parent attributed this to disempowerment: 'I think the reason I found it stressful was I felt that I wasn't really getting what I wanted because I felt I had no control of the situation. I had no choice.' The study highlighted that the school or the LA did not grant 'parental involvement' but parents had to negotiate this by constructing relationships with staff in what was referred to as a 'power struggle'. One parent commented, 'If you are more vocal, more literate and had access to the laptop, you get more than someone else, and it's totally unjust'. Again, this finding was replicated in the current study.

Also contained within 'Theme 4: Empowerment' were the subordinate themes of 'Parents' own SEN' and 'Control of budget'. 'Parents' own SEN' was discussed directly by Kelly and Kimberly, and more indirectly by Suzannah. This subordinate theme was linked to being both a 'barrier' and an 'enabler' of parental empowerment. This was because although Kelly and Kimberly talked of the barriers their learning difficulties presented when trying to fully participate in their child's statutory assessment, both also identified their own experiences of being at school as highly motivating in trying to secure favourable outcomes for their children. It appeared that staff did not make adjustments for parents' SEN and again, it appeared that parents needed to empower themselves. Kelly felt disappointed that she was unable to process some of the content of the 'outcomes TAC' until she had returned home, and

did not describe being able to make later changes to the EHC paperwork. Furthermore, she had some wishes dismissed outright in the second 'outcomes' TAC and did not describe how she would counteract this disempowerment. On the other hand, Kimberly empowered herself by requesting a professional to sit next to her and take notes so that she could read them before making her responses in meetings. In this way she was able to slow the pace of the meeting down and give herself the resources she needed to respond. Although Kimberly created these conditions for herself, she ultimately reported very low satisfaction with the school-based elements of the statutory assessment and the resulting provisions. Her misgivings were largely around communication with the school and assurances around her child's provision. This will be explored more fully in section 5.3.5.

5.3.4 What is the emotional impact of the EHCP needs assessment process on parents?

The largest amount of coded data in the current study related to the emotional impact of the EHC needs assessment process on parents. It could be argued that all data within the study related to 'Theme 2: Emotional Impact', because parents' emotional lives were central to their experiences. For example, 'Theme 1: Application' contained data with emotional content for parents regarding their journeys leading to the identification of their child's needs, and for six out of eight participants, having their first EHC needs assessment request declined by the LA. Similarly, 'Theme 4: Empowerment' and 'Theme 5: Professionals' contained data that was also intertwined with the emotional impact of the statutory assessment process on parents.

One subtheme of 'Theme 2: Emotional Impact', 'Decreased Stress and Anxiety' and its two subthemes 'Child making progress' and 'Understanding child's needs better' collated data that related to the *positive* emotional impact of statutory assessment. Overall, there were key moments where parents were more likely to report the positive emotional impact of the process, such as when the EHCP had been finalised, or the relief they felt when the LA agreed to undertake statutory assessment. This finding was not replicated in the literature reviewed in Chapter 2 and may tentatively suggest that at least some aspects of the EHC needs assessment are positive for parents. The

remaining four subthemes of 'Theme 2: Emotional Impact' gathered a much greater amount of data, which related to the negative emotional effects of the EHC needs assessment.

Linked to 'Theme 1: Application' was the subtheme 'Time taken'. This finding is reflected in O'Connor's (2005) study where one of the main themes was around parental dissatisfaction regarding the time taken to complete assessments and issue a final Statement. Long waiting times to have their children's needs identified and assessed lead to stress and anxiety for parents. Many parents' accounts contained data relating to 'loss of potential progress' due to long waiting times.

Linked to 'time taken' in the current study, and in reflected in O'Connor's (2005) study, was parents identifying the need for earlier intervention. The emotional impact of this within the current study was linked to feelings of 'failure'. 'Failure' was organised as a subtheme of 'Theme 2: Emotional Impact', where parents' discourses focused on further subordinate themes of 'personal' and 'systemic' failure. Feelings of 'personal failure' were associated with low mood, regret, parents feeling they had 'not done enough' and feeling like 'giving up'. Feelings of 'personal failure' however, were reported much less than 'systemic failure'. Systemic failure was often linked to professionals failing to identify children's needs or adopting a 'wait and see' approach, despite the efforts of parents to seek help. The emotional impact of this on parents was anger, sadness and feeling 'let down'. For example, Kelly talked of taking her son to the GP when he was two years old due to concerns with his social, emotional and mental health. She also felt the statutory assessment did not address his underlying needs. This was conceptualised, along with many other parents' accounts within the current study as 'systemic failure'. These findings are significant for a range of professionals working within Education, Health and Care, and call for a greater awareness from professionals regarding the on-going negative emotional impact on parents when there is a lack of early intervention and long waiting times for assessment and support.

These findings link to O'Connor's (2005) study which also indicated that statutory assessment is stressful. Within the current study the subthemes of 'Increased stress and anxiety' and 'Health effects' within 'Theme 2: Emotional Impact' were highly prevalent in the data. Indeed, all parents reported that the EHC needs assessment process was significantly stressful and anxiety provoking. Asha, Alison, Fiona and Segal reported the process 'driving them to tears', whilst Kimberly's accounts recalled experiencing anger so much that she was 'shaking'. Fraser attributed the stress of the statutory assessment process as causing a stroke immediately following a call to social services where he had felt 'out of control'. All parents reported sadness and low mood as a result of the statutory assessment process. This was linked to 'getting a no from panel' when their first assessment requests were declined, poor communication from professionals including not knowing about the progress of the EHC needs assessment, feeling disempowered by the process or by exchanges with 'harmful professionals' (Theme 5: Professionals), and discourses around 'failure' impacting on their self-image as parents, as well as feeling 'let down' by professionals in positions of responsibility.

A significant amount of data was collected under the code "bad parents" discourse,' which was organised under 'Theme 2: Emotional Impact, Increased stress/ Anxiety', (as well as 'Theme 5: Professionals, Harmful professionals' and 'Theme 6: Process, TAC meetings'). Parents often felt negatively judged by professionals, leading to feelings of anger, not being understood, or triggering self-doubt. Parents reported that at times the 'bad parents' discourse had presented as a barrier to getting help for their children earlier, and it therefore represents a significant barrier to parental empowerment. For example, Alison commented, 'And I think if I'm being honest, I felt judged.' This finding was reflected in Hartas' (2008) case study where parents enabled their own empowerment by challenging professionals' negative view of their parenting. The emotional toll of fighting negative perceptions of their parenting whilst trying to have their child's needs recognised can only be imagined to be incredibly distressing and invalidating. Indeed it can be seen that a greater need for sensitivity towards parents' emotional experience is essential, as well as highlighting the need for

professionals to reflect upon their own assumptions and the impact of these on their capacity to perform their role without causing harm to parents and children.

O'Connor (2005) further identified a need for greater sensitivity around the impact of statutory assessment on parents and children, and taking account of family circumstances. This finding was mirrored in the current study by the subtheme 'Competing demands: External Factors' as part of 'Theme 2: Emotional Impact'. Here, parents' accounts demonstrated that the emotional impact of the statutory assessment process was heightened by their family circumstances and 'competing demands' in their lives. Equally, the greater the emotional impact of the statutory assessment at any one time made coping with their competing demands more difficult. It is hypothesised that a significant amount of data emerged to constitute this subtheme because whilst parents recalled their difficult experiences around the statutory assessment process, this activated their memories of other 'difficulties' experienced at the same time. Again, within the current study the reported reciprocal nature of heightened stress between statutory assessment and other 'competing demands' highlighted the need for greater sensitivity from professionals around family circumstances.

Within the current research, 'competing demands' included bereavement (loss of their own parents) for three participants, eviction for two participants, money worries, relationship difficulties, work demands, parenting siblings with SEN and a 'siblings suffering' discourse. Also linked to 'greater sensitivity' in O'Connor's (2005) study was the need for having a Statement being 'less stigmatised'. This was reflected in Kelly's interviews where she worried about 'better' secondary schools rejecting her son because he had an EHCP (Theme 3: The Future), otherwise parents did not raise fear of stigmatisation as part of the emotional impact of statutory assessment.

5.3.5 Do parents view the EHCNA as resolving their children's education?

Parents expressed varying levels of confidence and belief that the EHC needs assessment and resulting EHCP would 'resolve' their child's education. Asha

and Fiona appeared to feel that the EHCP had broadly resolved their children's educational needs. Other parents, however, reflected concerns relating to 'assurance' that promised provisions would be delivered, and the quality of those provisions. This links to Pinney's (2002) study regarding assurance, Lamb's (2009) call for 'a more accountable system' and Ofsted's (2010) finding that often services were concerned more with whether or a not a service was provided, rather than the quality of that service. For example, Kimberly particularly did not feel the EHCP alone would 'resolve' her child's education and this would only happen if she were 'overseeing' the 'slippery' school. Moreover, Kimberly talked about her child's funding benefitting other children by paying for a TA in the classroom who helped a number of children, rather than being spent where it was needed for her child, such as in the playground and for interventions. Indeed, when she asked for a breakdown of costs from the school, she was unhappy that it came back in 'hours' rather than in monetary terms. This meant that Kimberly could not fully understand her child's budget and this prevented her participation in planning for how it could be spent to meet her child's needs. Here we can see that Kimberly's attempts to ensure the SEND (2014) legislation was delivered by the school was thwarted by the school's responses. Kimberly highlighted that her child did not 'have the working memory' to come home and tell her what extra provisions she had had that day. For Kimberly, it appeared that the 'fight' would continue, this time around ensuring provisions were delivered. This finding was echoed in O'Connor's (2005) study where parents highlighted 'failure to deliver required outcomes', including recommendations not being carried out, a lack of professional resources in schools, and a lack of available therapies.

Fraser and Alison expressed the same view as Kimberly, that the EHCP did not resolve their child's education per se, but rather that it was a 'tool' that helped them to ensure their son's education was 'resolved' at least in the short term. When asked about their son's future, Alison said she was 'hopeful' and that, 'it's us that's done that, not the Plan'. Fiona on the other hand expected to have on-going input but experienced the EHCP as resolving her

son's education because she felt she had 'the right power' to direct his school held budget where it was needed and with immediate effect.

Segal appeared to experience a particularly low mood when she was interviewed for the second time. The interpreter relayed, 'Shall I just move out of this country and go somewhere else... Cos there's no future for us'. In this sense, during the EHC needs assessment, Segal did not feel that the process was 'resolving' her child's education to the point where she wondered if she should leave the UK. During the final interview, Segal expressed that her son's education had been largely 'resolved,' as he had a full time specialist school place. The journey towards this 'resolution' had, however, been very distressing for her and her son. As mentioned earlier, Segal also didn't express total confidence that the EHCP had 'resolved' her son's education because she didn't feel that the document accurately reflected her son's special educational needs. This finding was reflected in O'Connor's (2005) and Jones & Swain's (2001) study where parents felt that Statements did not reflect their children's needs. In the current study, Kelly also voiced similar concerns that the EHCP didn't reflect or plan for her son's underlying SEMH needs (and focused on 'unambitious' learning targets instead).

Within 'Theme 6: Process', Fraser and Alison highlighted that not only did the EHC needs assessment process not make clear how the LA could support a YP up to the age of 25 in work or higher education, but also that there was 'no follow up' to check services were being provided and there was no information given about the Annual Review process. Mansell and Morris' (2004) explored parents' experiences of attending an autism diagnosis service. Their findings suggested that parents' experiences of psychological assessment often focused more on receiving the diagnosis rather than professionals focusing on sources of information and support, coping strategies, future consequences and sources of treatment. This was echoed in Alison and Fraser's experience. The emotional impact of this may be that parents feel unsupported immediately following assessment (statutory or other) and that services' efforts may be more focused on identification of needs rather than working with parents to plan for better outcomes for children. Fraser and Alison would often ask the interviewer for advice about approaching colleges and their

son's next steps, which further highlighted that beyond identification of needs, support and ways forward were not adequately planned for within the statutory assessment process. Comments from parents in O'Connor's (2005) study highlighted a need for counselling to be offered immediately following receiving a diagnosis, and help with negotiating educational provision.

5.3.6 Main Research Question:

What do parents report of the Education, Health and Care Plan (EHCP) needs assessment process?

Overall, parents reported the EHC needs assessment process as highly emotional, stressful and anxiety-provoking. This finding was echoed in O'Connor (2005), Ofsted (2010), Pinney (2002), Jones & Swain (2011) and Hart (2011). Linked to the broader emotional impact (Theme 2: Emotional Impact) of the EHC needs assessment were 'Health effects', 'Increased stress and anxiety', 'Competing demands' and discourses of "Failure". We have seen that issues of empowerment and disempowerment (Theme 4: Empowerment) are linked to the emotional impact of the EHC needs assessment process, and this links to feelings of loss of control, low confidence and any barriers that effect a person's ability to exert influence in their own life.

The mechanism by which negative emotional impact and disempowerment are enacted is the actions, beliefs and attitudes of professionals (Theme 5: Professionals), including the replication of power imbalances. Within the current study it was identified that it is professionals, rather than the legislation per se, that hold the potential to deliver a 'stronger voice' for parents (as a key aim of the SEND (2014) reforms). This was found to be especially true when parents are less able, either through 'professional skills' and to a lesser degree assertive verbal skills, to empower themselves within statutory assessment processes. Linked to empowerment and disempowerment was the construct 'Fighting' (Theme 4: Empowerment) which was understood as a symptom of disempowerment and sometimes an enabler of parental empowerment.

TAC meetings were reported very positively in some instances, especially around information sharing (Theme 6: Process). TAC meetings were significant in parents' experiences of statutory assessment and represented a space where best practice, or conversely, disempowerment of parents could take place. Within 'Theme 2: Emotional Impact' the subtheme 'Decreased stress and anxiety' highlighted the positive emotional impact of statutory assessment as 'understanding the child's needs better' and 'child making progress'. However, data relating to the positive impact of statutory assessment was significantly less prevalent than data documenting negative emotional impact.

Finally, parents reported varying levels of confidence in the ability of the EHC needs assessment to 'resolve' their child's education. Parents viewed the EHCP as a 'tool' they could use to ensure their child's positive future and to negotiate their educational provision. In some cases the EHC needs assessment did not make clear longer term support, which appeared more of a 'problem' for parents of older children than for parents whose children had many years of schooling ahead of them.

5.4 Reflexivity and researcher's position

Reflexivity, the process of the researcher acknowledging themselves within the production of research 'knowledge' derives from critical theory that developed in the 1960s (Danziger 1990), and critical qualitative research methodology (Shaw, 2010). The social constructionist paradigm adopted by the researcher in the current study is particularly relevant to the notion of reflexivity, because social constructionism positions meaning and 'knowledge' as constructed through language in specific social contexts of place and time, and between people. As such, reflexivity is concerned with the researcher's awareness of the influence of their previous life experiences (those that come to constitute 'the self' and not simply an objective 'researcher') and how this impacts on their research journey (McGhee, Marland & Atkinson, 2007). This includes the research topic selected, the selection and interpretation of the

literature reviewed, how this shaped the research process, the design of the study, the researcher in the act of interviewing participants and co-constructing meaning with them, and finally the later stages of data analysis and writing up the research. The researcher as a unique person and active meaning-maker in the current study is acknowledged as being present at each of those stages, actively constructing the 'knowledge' presented in this thesis.

The researcher was on placement as a trainee educational psychologist in the LA where the research was conducted. This meant that at times the researcher held previous beliefs about school settings and the individual staff whom participants described in their interviews, including EPs SENCOs and the special needs assessment service, for example. Shortly after concluding interviews with one participant, the researcher became an trainee EP at the school the participant's child had attended before the data analysis stage, similarly, the researcher was working as a trainee EP in a primary school where the participant's child had recently been permanently excluded, before starting at a secondary school where the researcher had also worked. The researcher aimed to be aware of the influence of this whilst listening to the parents' accounts. Due to the focus of the research, the researcher aimed to privilege parents' accounts, which were of most interest in the research, rather than privileging their own beliefs or experiences of schools or professionals referenced by participants. Working within a social constructionist paradigm, where all discourses are equally valid, the researcher was better able to privilege parents' accounts, for example, by not needing to 'triangulate' their reported experiences. Further to broader critical theory, it is 'emancipatory' to privilege accounts which may be subsumed under more dominant discourses, for example, the dominant discourse of the SEND (2014) reforms, or the Borough's discourse of statutory assessment, for example, as a process that takes 20 weeks and invites parents to 'co-construct' their child's EHCP.

When reading and beginning coding of transcripts, the researcher became highly aware of the co-constructed nature of the interviews. For example, how questions were phrased, and the possible effect on participants' responses, or

which points made by participants were followed up on by the researcher, and which were not.

When designing the study and conducting interviews, the researcher had recently become a parent and was newly interested in the experience of parenting. As the researcher was a parent of a typically developing infant, they had limited understanding of the position of a parent of a school-aged child with SEN, and the resulting demands of negotiating school provision. Prior to training as an EP, the researcher had worked as a mainstream secondary school English teacher, and later as an English teacher in a boys 11-16 SEMH school for three years. The experiences of the researcher as a teacher may have influenced her interpretation of parents' accounts, having seen schools and very pronounced inequalities 'from the inside'.

5.5 Implications for professionals working within EHC statutory processes

This section will consider implications of the current study for staff from Education, Health and Care who work within EHC statutory assessment processes. Inclusion and co-construction were formulated within the current study to rely on professionals following best practice and promoting equality. This is particularly important when parents do not have the 'professional skills' or English language skills to empower themselves as effectively as those who do. It was also observed that particular instances of disempowerment experienced by overall 'empowered' parents was very distressing, and professionals should aim to promote empowerment for all parents at all times.

Based on findings from the current study, within TAC meetings, professionals may promote inclusion and co-construction for *all* parents by adopting a non-judgmental attitude, including reflecting on what they bring to meetings in terms of assumptions and beliefs. This research also highlights the need for greater awareness of and providing practical support around making adjustments *with* parents who have learning difficulties (by asking them what would help). Additionally, best practice would involve explaining the purpose

of each TAC meeting beforehand, helping parents to prepare ahead of TACs and publishing an agenda for each TAC. Professionals should ensure high-quality interpretation arrangements for parents who speak EAL, as well as finding ways to 'keep in touch' in between meetings, establishing if non-resident parents could attend TACs and working to facilitate this inclusion. The findings also suggest that professionals need to be more ambitious in planning outcomes for children, whilst taking into account the wishes of the parents / carers and take the time to explore which hopes underlie parents' wishes. Professionals need to ensure that parents' views around their child's level of functioning are fully recorded. Professionals also need to foster the inclusion of fathers in statutory assessment by challenging beliefs around what fathers can offer and what they can gain by attending TACs. Professionals need to engage in active listening and be 'open-minded' about provision in order to promote genuine co-construction of the EHCP, and finally, to take the time to reflect on the child's strengths and a hopeful future.

Other implications which relate to statutory assessment outside TAC meetings include a greater need for transparency. Parents' reported disappointment if professionals weren't honest about which paperwork had been submitted or what stage the assessment request or statutory assessment had reached. Parents reported lack of contact in between meetings to be anxiety provoking, so professionals may wish to consider 'keeping in touch' if parents express that this would be helpful. The findings also highlighted a need for greater emotional sensitivity towards parents. This could be around family circumstances and 'competing demands', and the impact of assessments and the process itself, including timescales. The findings also highlighted a greater need for professionals to be aware of barriers to inclusion, including power relations and inequalities. Professionals need to take the time to plan and deliver strategies for individual parents which remove any barriers to their full participation. This can be achieved by fostering mutual responsibility and a greater voice for parents. Professionals need to consider adjustments to the way written materials are shared with parents when they do not read English. Parents reported long waiting times and journeys between services, meeting 'harmful' professionals along 'unhelpful' and sometimes the

Professionals need to ensure that they take parents' concerns seriously and act upon them, including promoting early intervention. Due to possible bias towards identification of needs in statutory assessment, professionals also need to ensure there is also clear focus on planning next steps, and signposting parents to sources of information and ongoing support.

Overall, professionals may wish to consider the implications and emotional impact of 'disempowerment' on parents. Disempowerment is defined as the prevention of a person having power, authority and influence. Linked to this was the notion of 'locus of control' where it is important that individuals experience a sense of control in their own lives. Professionals need to seek ways to address power imbalances, and also to remain aware of not replicating them through their actions towards parents.

5.6 Implications for EPs working within EHC statutory processes

All of the implications discussed above apply to EPs. An additional implication of the current research is concerned with EP practice at the systemic level. Parents' accounts contained much less data relating to EPs than to school-based professionals, which is likely due to the level of interaction they have with EPs compared to school-based staff. Data relating to SENCOs and TAs was particularly prevalent in the data. As such, a significant implication for EP practice is around considering how EPs can support school-based staff to consider and act upon the implications outlined above in order to promote inclusion of parents in statutory assessment and the co-construction of their child's EHCP. EPs may also be able to broaden this remit to other professionals involved in statutory processes who work in Education, Health and Care, and the voluntary sector.

5.7 Feedback to stakeholders

All participants were sent a letter in the post with the thematic map and a brief explanation of findings. Contact details were included in the letter along with an invitation to discuss the findings more fully, or to request a copy of the thesis. Findings were disseminated in the inner London Borough LA in which

the research was conducted. A summary of findings was provided to the head of schools, disability and psychology. Within the EPS, the researcher gave a 30 minute presentation covering research design, findings and implications for professional and EP practice within statutory assessment processes. A link to the complete thesis will also be provided to staff working within the EPS once it is published on the University of East London thesis database (ROAR).

5.8 Critique of research design

Despite efforts to design and carry out this study conscientiously, some shortcomings are clear and should be considered when interpreting the findings. This is largely because the research was conducting in the field and is therefore 'real world research' (Robson, 2002).

One limitation is a relatively small sample size of only eight participants. This criticism can be somewhat countered by acknowledging that each participant was interviewed either two or three times. This yielded a total of 17 interviews. For the purposes of thematic analysis this meant there was a liberal amount of data to code and organise. It could also be argued, however, that the particular sample size and the high volume of data collected from each participant would lend the study well to an interpretative phenomenological analysis (IPA) approach rather than the thematic analysis that was selected. One reason for selecting thematic analysis was to generate findings that would be 'useful' for the LA that commissioned the research, and who wanted more generalisable 'messages' rather than a collection and interpretation of several individual 'lived experiences' of parents. Having said this, the natural inclination of the researcher was towards recognising the uniqueness of each participant and their particular circumstances. The researcher would be interested in exploring IPA approaches in the future, as at times it was difficult to 'discard' items of great importance to individual participants in the study in favour of the 'broader brush stokes' that thematic analysis creates. However, the researcher did create one subtheme 'Health effects' (within 'Theme 2: Emotional Impact) even though it related explicitly to only two of the participants, because the researcher felt that it was significant and did not want to subsume it under 'Increased stress and anxiety' as they felt that a particular nuance of these parents' experiences would otherwise be lost. Additionally, another criticism of thematic analysis made by Braun and Clarke (2013) is that without grounding it in another data analysis approach e.g. discourse analysis, that it can lack analytical 'depth' that comes from a clearer focus on linguistic features which may enhance the researcher's interpretation of data and understanding of the participants' internal worlds, i.e. their constructs. Having said this, the researcher has a 'literary' background, including reading critical theory as part of their undergraduate degree and aimed to code inductively and for latent meanings in participants' narratives rather than semantic ('literal') coding alone. The researcher feels that this somewhat helped to enhance the interpretive quality of the research, with the aim of better understanding the participants' experiences. As mentioned, adopting this approach to data analysis led to ultimately discarding a lot of data in the search for themes. This was also due to the semi-structured nature of interviews, broad open questions, following the participants' leads and the inductive coding employed.

Participants were very diverse in terms of their child's needs and age, their linguistic profiles, nationalities, home circumstances, employment statuses and literacy levels, though 'thematic analysis' often calls for a 'homogenous group'. The researcher feels that the diversity of the sample added a richness to the study and it was interesting to search for themes which transcended the diversity of the sample described above. Having said this, some experiences were very particular, for example, Segal's experiences of being a parent who speaks Somali but does not speak English. This meant that her experiences were coded within the broader themes identified such as 'Theme 4: Empowerment', 'Theme 2: Emotional Impact' and 'Theme 5: professionals', rather than themes or subthemes that related specifically to being a parent who does not speak English (please see 'Implications for future research'). However, what 'homogenised' the group was that they were all parents of children who had been identified as needing additional support, and were all going through the EHC needs assessment process at approximately the same time and within the same London borough.

The initial recruitment technique was abandoned. The researcher sent approximately 50 invitation letters to parents who had just had their child's statutory assessment agreed by the LA, over an eight week period. This vielded only one reply, from Fraser and Alison. Interestingly, this couple (along with Fiona) represented the parents most able to independently 'exert influence' on the EHC needs assessment process. The researcher later reflected that she was very glad that the initial recruitment technique failed because fortuitously this led to recruiting a much more linguistically diverse sample. The remaining six participants were recruited via EPs asking parents if they would be willing for the researcher to contact them by phone to talk about the study and to see if they might be interested to take part. This removed the barrier of needing to read English that the first recruitment technique presented. Also, for parents who might not feel confident about getting in touch with the researcher, it may have been a more supportive process for the researcher to phone them (after they had agreed to this with their EP) and to reassure them and answer any questions about the study. Segal's initial consent was gained by the first EP who worked with her through a TA at the school who spoke Somali. After this, contact was made to arrange meetings between the researcher and the TA. After Segal's child was excluded from school, the researcher was able to arrange two further interviews by texting dates and times and by arriving at the participant's home with an interpreter. One limitation of the research design for Segal's interviews was that there was a different interpreter for each interview. Furthermore, the first and third interviews were conducted by male interpreters and the second by a female interpreter. The researcher noticed that Segal was better able to communicate and share her emotional experiences with the researcher and female interpreter than when interviews were conducted with male interpreters, this may have been due to individual differences but also perhaps because Segal was an observant Somali-born Muslim woman who may have experienced a culture where males and females are more segregated.

Another limitation of the design was concerning the quality of interviewing. This study represents the first time the researcher had conducted qualitative interviews, having produced a quantitative study for their MSc Psychology thesis. The researcher was also newly learning about statutory assessment, the SEND (2014) reforms and the borough specific 'pathway' for statutory assessment. This unfamiliarity was sometimes evident in transcripts, particularly at the earlier stages of the research process.

Another consideration when critiquing the research design may be the researcher's multiple roles designing the study, carrying out interviews, analysing data and interpreting findings. This is not so problematic when viewed through a social constructionist lens, but other people seeking knowledge who are more aligned to realist and critical realist epistemologies may wish to take this in to account. A level of trustworthiness (Robson, 2002) was achieved by the researcher utilising a well-established method of thematic analysis proposed by Braun and Clarke (2013). This included maintaining a clear audit trail and the researcher acknowledging themselves in the process.

5.9 Implications for future research

It would be helpful to conduct similar research focusing on children and young people's voices. It would also be useful to replicate the current study in other boroughs to see if similar or different themes emerge. Because the interviews were conducted in 2015 and 2016 soon after the inception of the SEND (2014) reforms, it may be helpful to conduct a similar study in the same borough to see the aims of the SEND (2014) reforms have been more fully realised once professionals had time to adjust to the new statutory assessment procedures. The experiences of individuals within the current study raise further questions regarding the experiences of statutory assessment of parents who do not speak or who do not read in English, of fathers and parents with learning difficulties. It would be interesting to replicate the research recruiting specifically from these groups.

5.10 Conclusion

The study fulfilled its exploratory and emancipatory aims and has contributed to the evidence base where there was a lack of research since the inception of the SEND (2014) reforms. The study further contributes to the evidence base (dating before the reforms) where there was a lack of research that directly gathered parents' views of statutory assessment, particularly from historically underprivileged groups such as parents who do not speak English or who are not literate in English. Parents' experiences in the current study suggest that whilst some aims of the SEND (2014) reforms were realised, many were not. It is concluded that the aims of the reforms can only be realised in the social spaces created by parents and professionals working together. In order for professionals working within the EHC needs assessment processes to deliver the aims of the SEND (2014) reforms, there needs to be a greater focus on ensuring co-construction and meaningful participation for parents in practice. This is particularly important when working with parents who have less means of creating their own conditions of empowerment.

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Appendix 1 Literature Review data extraction, mapping and appraisal

Literature Review Question 1

Articles:

O'Conner (2003). Parental views on the statutory assessment and educational planning for children with special educational needs.

Process	r children with special educational fleeds.
Screening: relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents as participants and the topic is parental views on statutory assessment and educational planning for children with SEN.
Mapping: describe the evidence found. Type of research, data collection / analysis, participant selection etc.	This is a mixed methods study with opportunity sampling. According to Robson's (2002) 'Classification of the Purposes of Enquiry' framework, the study is 'descriptive' because the design seeks to generate data that will portray an accurate profile of the situation. The study can also be described as 'exploratory' because it sets out to seek new insights regarding the improvements parents report could be made to the statutory assessment process. Data collection was via a postal questionnaire and follow up telephone interviews. Telephone interviews were conducted using a semi-structured interview schedule. Quantitative analysis of the postal questionnaire data was conducted using the SPSS program. Thematic analysis was applied to interview data in order to generate themes around parents' experiences of statutory processes.
Data extraction: Transparency Research should be open to outside scrutiny and make plain how knowledge was generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.	The study was commissioned by the Department of Education in Northern Ireland to inform a review of statementing procedures. The study's aims were to: 1. Obtain information on parents' experiences of assessment and statementing procedures. 2. Ascertain whether the process met children's perceived needs (from the parents' perspectives). 3. Identify ways procedures may be improved from the parents' perspectives. 4. To recruit a large a sample as possible from all parents whose child had a current statement. Sample: All parents whose child had a current statement at the time of the study had the opportunity to participate. A total of 7222 letters were issued inviting parents to take part, of which 2346 (32%) parents indicated a willingness to take part in the study. This group were sent the postal questionnaire, and a total of 1054 replied (15% of

based on the Code of Practice (2001), with four types of questions. A copy of the questionnaire was available to view as an appendix within the paper. In the questionnaire, parents were asked to indicate if they would be willing to have a telephone interview. Of the 1054 postal responses, 623 provided their telephone numbers. From this sample 122 parents were drawn at random in equal numbers from statistically identified 'overall satisfied' (N432) and 'overall dissatisfied' (N149) groups. In all, 96 telephone interviews were conducted.

From the data collection and data analysis, quantitative methods (a self-report postal questionnaire) produced knowledge presented as a set of statistics around the stated aims of the study and three main themes were reported with six subsidiary themes from the thematic analysis of the telephone interviews.

Thematic analysis of telephone interviews produced the following main themes (focusing on improvements to the process):

- Time taken: the need to reduce the time taken to complete assessments and issue a final statement.
- Greater communication and involvement with parents: more contact with parents during the assessments, more feedback from professionals to parents and greater consideration being accorded to parental views.
- Clarity of information provided: examples given by parents included an explanation as to why the assessment was needed, results of assessments being presented clearly and in full, information about all services available, use of unambiguous terminology and information on parental rights.

A further six subsidiary themes emerged from the analysis:

- · Earlier intervention
- Failure to deliver required outcomes: comments centered on recommendations not being carried out, lack of professional resources in schools and therapies, statements not reflecting all the child's needs and lack of recognition that the statement is a legal document.
- Procedures: procedures involving too much paperwork and being overly bureaucratic, the assessment procedures being neither relevant nor streamlined to specific learning needs.
- Professional attitudes: need for greater training

- and awareness of school staff, professionals not being contactable or being unhelpful, too clinical or rude, too many professionals involved, the need for greater openness among professionals.
- Support for parents: comments highlighted a need for better support for parents, the need for parents to have an independent person to talk to, feelings of isolation, and the process being stressful and confusing.
- Sensitivity to parents and children: a need for greater sensitivity around the impact of the process on parents and children, taking account of family circumstances and the need for having a statement being less stigmatised.

From the postal questionnaire, the following data were generated from a sample of 1000 parents:

- 3.8% of parents had **not** been concerned about their child's difficulties prior to the assessment, 63% of parents reported being concerned for over two years, 16% for up to two years, 12% for up to one year and 5% for up to six months.
- 48% of parents reported the school had requested the assessment, 26% of parents requested it themselves, 20% indicated that another agency had made the request, a further 8% were unsure from whom the request had come. Families living in wards with higher levels of child poverty (defined as being within the 10th percentile on indicators of child poverty) had significantly lower parental instigated requests (19%) compared to parents living in wards with less child poverty (28%). In wards with higher child poverty disproportionately more parents did not know (15%) from whom the request had been generated.
- In terms of procedures being followed, parents reported: 55% had been told the name of the Board officer overseeing their child's assessment, 35% were not and 10% replied 'don't know'. 81.4% of parents had been kept informed of progress by their Board officer, 16.6% had not and 2% answered 'don't know'.

Accuracy

Knowledge claims should be supported by and faithful to the events, experiences, informants and sources used in their production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based

A limitation discussed in the study was that a disproportionately high number of responses came from parents whose children with statements were placed in mainstream schools. Much fewer parents with children in special schools responded to take part and therefore the sample may not be representative of the whole group of parents defined by their children having a Statement. It is not clear why this skew in data occurred.

upon relevant and appropriate information. Are the participants' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative).

For the item on the questionnaire linked to parents' perception of whether procedures had been followed correctly, there was a high number of 'don't know' responses. This item does not indicate whether 'don't know' means that the participant cannot remember, or if procedures were not made clear to them.

Overall, the accuracy standard is rated as 'medium'.

Purposivity

The 'fit for purpose' standard. Has the approach met the stated objectives and aims of the study? Are the methods and approaches used to gain knowledge appropriate.

Whilst the study references 'parents' in the title and throughout the study, of the 1000 respondents 80% were mothers, 10% mothers and fathers, 8% fathers and 2% a relative or foster parent. This raises questions over the knowledge claims regarding 'parents' views'.

No voices of participants were directly reported in the study. Themes generated by the researchers were reported as derived from the telephone interview data. A validity measure for the postal questionnaire was generated by comparing withinparticipant responses from the telephone interviews. Validity of the postal questionnaire was reported to be high. Thematic analysis was performed by two raters in order to generate higher inter-rater validity.

One of the aims stated in the study was to recruit a large a sample as possible (via opportunity sampling). However, the approach of sending a letter followed by a questionnaire is that it excludes from the sample people who can't read or write in English, i.e. people who read and write in other languages and perhaps speak English as an additional language or English speakers who are not literate. Arguably, these people represent a vulnerable group within the statutory assessment process (studies have demonstrated that children with longer written responses from parents in their files have disproportionately greater funding allocated than those who do not, Gross, 1996) and therefore it is highly important to collect data from this group in order to explore levels of satisfaction and to learn how to improve the process. Generally, the study demonstrated very high levels of purposivity when linked to the aims of the study. The research is 'fit for use' for this literature review.

The 'fit for use' principle. Knowledge should be appropriate to the decision setting in which it is intended to be used, and to the information need expressed

Utility

The study gathered views from an exceptionally high number of parents regarding the statutory assessment and statementing of their child and is indicative of broad trends in parental opinion and reported experience. The study demonstrates

by the researcher(s) seeking knowledge	methodological rigor in its design (though levels of accuracy in reporting were only found to be acceptable rather than good) and is highly relevant to the current research and literature review question.
Propriety Knowledge should be created and managed legally, ethically and with due care to all relevant stakeholders.	The Education and Library boards contacted parents on behalf of the researchers to ask if their details cold be passed to researchers. For the 2346 who agreed, an information sheet was sent out by researchers which explained confidentiality and the right of parents to only answer the questions they wanted to. For those parents who indicated that they would like to take part in the second phase of the study (telephone interviews) researchers explained and assured confidentiality before participants gave interviews. All parents whose child had a Statement had the opportunity to share their views (within the bounds of being literate in English).
Accessibility Research should be presented in a way that meets the needs of the knowledge seeker, no potential user should be excluded because of the presentational style employed.	Language is highly accessible. Sets out process of statutory assessment as outlined in the Code of Practice (2001) in case the reader is unfamiliar. Use of clear headings and tables to organise information.
Specificity Method specific quality.	Highly relevant to the current study in its use of semi-structured interviews and thematic analysis. Gathering views from the largest sample possible is also considered relevant to the current knowledge seeking within this literature review.

Hart, R (2011). Paternal involvement in the statutory assessment of special educational needs.

Process	
Screening : relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents (specifically fathers) as participants and the topic is statutory assessment.
Mapping: describe the evidence found. Type of research, data collection / analysis, participant selection etc.	This is a mixed methods study employing content analysis of case files and thematic analysis of data obtained through semi-structured interviews with fathers. All case files where a child had completed statutory assessment in the last four months were analysed, and opportunity sampling was conducted from the contact information within these files to recruit fathers for interview. Findings are presented as tables of statistics representing the frequencies of e.g. mothers' views being reported in files vs

fathers' views. Findings from the thematic analysis of interview data are presented in a table showing beliefs that are likely to increase or decrease paternal involvement within statutory assessment. According to Robson's (2002) 'Classification of the Purposes of Enquiry' framework, this is a 'descriptive' study because the design seeks to generate data that will portray an accurate profile regarding the involvement of fathers within statutory assessment. The study can also be described as 'exploratory' because it sets out to seek new insights regarding reasons why fathers do or do not take part in statutory assessment procedures.

Data extraction:

Transparency
Research should be open to outside scrutiny and make plain how knowledge was generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.

The aims of the study were made clear by describing the community psychology model and the writer's view of the 'need to empower fathers within statutory processes discourse (as opposed to the 'burdened mothers' discourse or 'division of labour' discourses). The study's aims were:

- 1. To research the degree to which fathers were involved in work within a particular EPS as part of the statutory assessment process.
- To ascertain fathers' views about involvement with the EPS and to identify possible barriers to fathers' involvement during the time when their child was assessed.

The paper gives a clear account of the reasoning for the content analysis schedule. Firstly, this was to operationalise levels of paternal involvement with quantifiable objective measures and secondly to ascertain the potential for fathers' involvement. Thirdly, the author hoped that collecting this type of data would allow comparisons to be made between certain conditions and fourth, data about family context and domestic arrangements would be sought, since variables were likely to exert a major influence on fathers' involvement. The content analysis schedule is included as an appendix in the paper.

33 files were left for the content analysis after close reading: files that indicated that the father was dead, the child was looked after or lived with grandparents were excluded from the analysis. Files that indicated the existence of a father who could have been included in the statutory assessment were selected for the study.

- 95% of children (from the 40 original files) lived with their mother.
- 58% of children lived with both their father and mother.

- Parental advice forms were present in 36 files (90%) which was much higher than reported by Trier (1997) who reported that 32% of parents made written responses in the statutory assessment of their child's needs.
- Mothers signed the parental advice form in 96% of files
- Fathers signed the parental advice form in 53% of files (global score) however:
- 73% of fathers who signed the advice form lived with their child, and
- 15% of fathers who did not live with their child signed the parental advice form. (One criticism of this measure is that signing a form is not the same as contributing views)
- 98% of files contained evidence of an EP discussion with the mother and 13% contained evidence of an EP discussion with the father.
- Of the 5 cases where there was evidence of an EP discussion with the father, 1 father lived separately from the child.

Phase 2

The interview schedule was developed in order to elicit views that could be analysed using the Theory of Planned Behaviour. The theory asserts that planned behaviour is influenced by three main factors:

- Attitude toward the behaviour and possible outcomes.
- 2. Perceived social pressure to engage in the behaviour.
- 3. Perceived personal capability (or self-efficacy) regarding the behaviour.

The interview schedule is included as an appendix within the paper.

Three groups from the files were identified:

- 1. Fathers who had been involved in the EP's work, with evidence of a discussion in the file.
- Fathers who were aware of the statutory assessment and had signed the parental advice form.
- Those who had not signed the parental advice form and therefore could not be assumed to be aware of the statutory assessment.

The latter group was not interviewed as it was considered not politic to make fathers aware that their child had been assessed without their knowledge, if that had been the case.

20 fathers were selected from the first two groups.

 15 fathers who had signed the consent form but no evidence of a conversation with an EP was recorded in the file. • 5 fathers who had signed the consent form and there was evidence of a discussion with an EP in the file were also contacted to take part.

The focus of this phase was to interview fathers who were aware of the statutory assessment and either had or had not had contact with an EP to try to find out what they had felt about the process, reasons for involvement or non-involvement, and their feelings about this.

Of the 20 fathers who were identified, 8 were able to be contacted and willing to take part. Of this group, four fathers had been identified as having had discussion with an EP and four had not. All eight fathers were living with their child and their child's mother. Five of the eight fathers reported being 'made aware' of EP involvement via their partner, two fathers reported 'being made jointly aware' and one father was not sure.

Of the four fathers who had signed the Parental Advice form, three reported that they had attended meetings at the school with other professionals concerning their child's SEN and one reported that he occasionally attended parents' evenings.

Findings:

Beliefs that decreased the likelihood of involvement were:

Behavioural Beliefs

- I don't know what to expect from a meeting.
- I will find it upsetting / distressing.
- The mother knows more about the child's education so as a father I have little to offer.
- I won't be able to contribute because I'm dyslexic.
- Women are better at coping with emotional / stressful situations.
- A man's role is to work; school is the mother's domain.
- Women play a greater role in the day-to-day lives of children.
- Men are disenfranchised from the education system.
- Schools are not approachable for men.
- Employers are resistant to men taking time off work to support children's education.
- Someone needs to look after other children when meetings take place
- I don't know when things are; contact is always between school and mother.
- Being self-employed means that time is money and it costs to attend meetings.

Beliefs that increased the likelihood of involvement were reported as follows:

Behavioural / outcome Beliefs

- It is important to battle for assessment / provision.
- It is useful to hear different views / benefit from professionals' expertise.
- It is important to put our views across / have a say.
- · I will be included in meetings / discussions.
- I will be treated fairly.
- A meeting at home will give a better / different view of the child.
- I will get useful information.
- I / parents know the child best so it is useful for EPs to hear from me / us.
- I know the teachers and they are responsive.

Normative Beliefs

- It is very important for dads to be fully involved in their children's education.
- It is important to be an 'active dad'.

Control Beliefs

- Being unemployed means I have time to attend meetings.
- Being self employed / working from home means
 I have the flexibility to attend meetings.
- I could attend meetings in the evenings.
- I could attend meetings at home.
- I work shifts so am able to attend meetings in the day.
- I could take information via email.
- Social workers arrange things so that I am included.

Ecosystemic factors reported to influence fathers' involvement:

Microsystem:

- · Division of labour within the home.
- Childcare arrangements / responsibilities.
- Knowledge of education issues.
- Experiences / attitudes towards education.
- Assumptions about gender roles.
- Gender of staff
- Practices that promote / inhibit fathers' involvement.
- Flexibility of working hours.
- Attitudes towards fathers' roles and responsibilities.
- Attitudes towards parents of children with additional needs.

Mesosystem

- Who do staff have / make contact with?
- What modes of communication are used?
- When / how are meetings arranged?
- Does school communicate with non-resident parents?
- How are conflicting demands viewed / managed?
- Does communication between parents exist?
- · Are relations between parents effective?
- How are relations between child and nonresident parent?
- What are expectations regarding fathers' involvement?
- How / when / where are meeting arranged?
- Who takes responsibility for involving a child's family?

Exosystem (Local Authority)

- What are accepted practices regarding parental involvement?
- Are there records of non-resident parents?
- Are there records of all persons with parental responsibility and associated court orders?

Macrosystem

- Impact on work /financial situation of family.
- To what extent do these help / hinder fathers' involvement?
- Is there a perception that fathers should be involved?

Content analysis of files found that 98% contained evidence of an EP discussion with the child's mother, whilst 13% showed evidence of an EP discussion with the child's father. However, of cohabiting parents (N23) evidence of an EP discussion with fathers was found to be 17% whilst evidence of an EP discussion with fathers when parents were not co-habiting (N16) dropped to 6%. Evidence of mothers' views in Psychological Advice was found to be at 93% for mothers and 8% for fathers.

Accuracy

Knowledge claims should be supported by and faithful to the events, experiences, informants and sources used in their production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based upon relevant and appropriate information. Are the participants'

Four of the fathers said that they had had a meeting with an EP; these were the same four for whom there were records of an EP discussion with the father in Phase 1 of the study, indicating the validity of that measure.

Findings from the interviews were paraphrased apart from two brief direct quotations and the rest of the themes generated from the thematic analysis of the interview data were presented as themes in a table under headings 'Beliefs that increase the likelihood of involvement' and 'Beliefs that decrease the likelihood of involvement' (in EP assessment).

perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative).	These were arranged in three rows relating to 'Behavioural / outcome beliefs', 'Normative beliefs' and 'Control beliefs' (self efficacy). There was very little direct evidence from transcripts included in the paper. Overall the accuracy is 'medium' because knowledge claims are not directly linked to reported extracts of interview data. Having said this, when adopting a deductive 'top-down' view of knowledge production, the standard of accuracy can be thought of as 'high' because knowledge claims are well structured around theories used to design the research. These theories were the Ecosystemic Model (Bronfenbrenner, 1974) and the Theory of Planned Behaviour (Ajzen, 1985). Overall accuracy is medium to high.
Purposivity The 'fit for purpose' standard. Has the approach met the stated objectives and aims of the study? Are the methods and approaches used to gain knowledge appropriate?	The researcher utilised the Theory of Planned Behaviour to design the interview schedule and to analyse the subsequent data. The authors assert that this will yield more purposeful findings than by focusing on global attitudes, which may be worse predictors of behaviour. This study seeks to discover why fathers engage in the behaviour of taking part in statutory assessment of their children and as such the design of this study has high levels of purposivity by examining the beliefs that may increase or decrease paternal involvement in statutory assessment processes. The design and execution of the study meets its proposed aims.
Utility The 'fit for use' principle. Knowledge should be appropriate to the decision setting in which it is intended to be used, and to the information need expressed by the researcher(s) seeking knowledge.	The knowledge generated by the study is fit for use under the current review question. The study provides knowledge of a group of fathers' experiences presented in themes, as well as providing broader statistics on the rate of involvement of fathers in statutory assessment procedures from a larger sample. This information will help to answer the literature review question.
Propriety Knowledge should be created and managed legally, ethically and with due care to all relevant stakeholders.	The EPS has not been named in this study in order to ensure confidentiality of participants. All other ethical considerations were explained, such as not contacting fathers who had not signed the Parental Advice form in case it caused distress that they had not know that their child had undergone assessment. It appears that the study was conducted with high levels of propriety.
Accessibility Research should be presented in a way that meets the needs of the knowledge seeker, no potential user should be	The language of the paper is accessible and tables clearly display the themes generated from the thematic analysis of interview data.

excluded because of the presentational style employed.	
Specificity Method specific quality	This paper is highly relevant to the current study in its use of semi-structured interviews and thematic analysis. Content analysis of files in order to generate data on levels of paternal involvement in statutory assessment processes is also considered relevant to the current knowledge seeking within this literature review.

Jones, P. & Swain, J. (2001) Parents reviewing Annual Reviews.

Jones, P. & Swain, J. (20	01) Parents reviewing Annual Reviews.
Process	
Screening : relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents as participants and the topic is statutory assessment (specifically Annual Reviews, which were part of the ongoing statutory assessment of SEN).
Mapping: describe the evidence found. Type of research, data collection / analysis, participant selection etc.	12 parents from two Local Education Authorities (LEAs) were involved, all of whom had at least one child with a Statement of SEN. It is not made clear how participants were selected. Data analysis of questionnaires and taped conversations was carried out, though the paper gives little insight in to the type of analysis used. According to Robson's (2002) 'Classification of the Purposes of Enquiry' framework, this is an 'exploratory' study because it sets out to seek new insights regarding the improvements parents feel could be made to the Annual Review process.
Data extraction: Transparency Research should be open to outside scrutiny and make plain how knowledge was generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.	 Although the study's aims are not stated explicitly, the values underpinning the study are made clear: Parents are valued contributors to Annual Reviews and children's educational outcomes in general. The focus of the study is to gather parental perceptions of their involvement in Annual Reviews, and the translation of principles and policy requirements into practice from the parents' viewpoints. The study was designed with two stages: The first stage involved a questionnaire and group discussion. During the group discussion, parents discussed their perceptions of their involvement in the process of the Annual
	Review, the barriers to their involvement and their strategies for overcoming these barriers. The paper states that an analysis of the completed questionnaires and transcribed group discussion

was used as the basis for the second stage, however, it is not explained how this stage of the research and the analysis of data actually forms the basis for the second stage. This lower level of detail regarding the design of the research constitutes lower levels of transparency.

 The second stage was a taped open-ended discussion in the two groups around the analysis of issues arising from stage one.

Findings:

- Many parents reported that parents' views are needed in planning for the holistic education of children: 'I don't want to give away that control while he's still at school. You forget who you are sometimes, you're a teacher, you're a therapist, you're a parent you know and I think the system needs parents to do that'.
- By contrast, parents views of the Annual Review process differed greatly: 'The review is decided before you get there. It's a simple fact.' Versus, 'As far as I'm concerned Reviews are not, they're not just a rubber stamp. You can make a difference'.

Parents' perceptions about what they saw as significant barriers to real involvement in decision making about their child were reported as a 'major theme' in the paper. These barriers were reported as inherent to the position of parents in the power relations and structures of educational decision making. From parents' viewpoints, the starting point was the school staff and their relationships with, and responses to, parents. The barriers were found to manifest in different ways. One way could be the lack of a relationship and another way where parents found staff to be oversensitive. For example some parents found that staff can be defensive in their responses to parents and the parent-staff relationship could be one of conflict.

- The paper found that much of the data suggested that the professionals involved in Annual Reviews needed to reflect on the style and model of the parent-professional relationship.
- Some parents found that whilst they wanted to negotiate informed choices for their child at school they were unable to because they were not kept fully 'informed' by professionals at school and within the LEA.
- Some parents reported frustrations that

professionals within the LEA didn't know their children like they did or school staff did and would have liked them to spend more time with their child.

- The final barrier to decision making was reported to be the formal mechanisms and procedures of Annual Reviews, in particular the time limits. 'I don't think the time limits on the Annual Reviews are very good. I know it is all well and good to say you get at school a lot of people, but in an ideal world you could sit and have a nice informal chat, for a whole school morning would be more ideal, but quite often you get something to the tune of half an hour.'
- Parents reported that statements were vague and lacked specificity. 'I've had reports back and looked at them and I've thought, if my child's name hadn't been at the top, this report could fit several children.'
- When actions have been agreed in meetings, some parents reported that it was not reflected in the Statement. 'It comes back and it's not in the Statement. The say, oh well we've got this, but then when you dissect the wording... its something completely different.'
- Many parents found the Annual Review process stressful and one parent linked this to powerlessness. 'I think the reason I found it stressful was I felt that I wasn't really getting what I wanted because I felt I had no control of the situation. I had no choice.'
- The study reported that from the perspective of the parents, 'parental involvement' is not offered to them by the LEA or the school, but is rather what they work towards by negotiating decisions about their child and actively constructing parentstaff relationships. This was referred to in different ways as a 'power struggle'. 'If you are more vocal, more literate and had the access to the laptop, you get more than someone else, and it's totally unjust'. 'Normally if you do shout loud you get more than if you sit back and that is a fact, a very unfortunate fact.' 'I try to put myself in their position and I think I would hate it if I had a pushy parent, but you've got to be pretty, kind of, intrusive to make sure that everything that's on the Statement has actually happened.'
- One parent commented that preparation was

important, 'Preparation is the main key in the Review. If the staff do the groundwork with the parents and they get to know the children and how the family works and how the family thinks and how the parents are thinking and what the parents think, would like for their children.' Accuracy There is an exceptionally high level of reporting Knowledge claims should be direct quotations from the transcribed focus groups. supported by and faithful to Quotations are attributed to 'named' (anonymised) the events, experiences, participants so that the reader can gain a sense of informants and sources used the continuity and relationship between the in their production. For presented quotations. This study has high levels of knowledge to meet this standard, it should accuracy in its reporting and the knowledge claims demonstrate that all that it makes based on its well-presented data. assertions, conclusions and recommendations are based upon relevant and appropriate information. Are the participants' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative). **Purposivity** The study set out to gather parents' views on their The 'fit for purpose' perception of their involvement in Annual Reviews, standard. Has the approach barriers to their involvement and strategies for met the stated objectives overcoming such barriers. The design of the study and aims of the study? Are is appropriate and has generated knowledge that the methods and meets the aims of the study, although not all approaches used to gain knowledge appropriate? aspects of the knowledge-generation process were transparent so this is a limited judgment based more on the reported output of the study. Utility The knowledge generated is fit for use in the The 'fit for use' principle. current literature review, especially because of the Knowledge should be high level of reporting of parents' voices, which appropriate to the decision allows me to draw some of my own conclusions setting in which it is intended from the selected data and to feel confident in the to be used, and to the validity of the assertions made by the researchers. information need expressed by the researcher(s) seeking The quotations are arranged under headings, which knowledge. could broadly be described as 'themes', even though the study does not make explicit reference to themes or thematic analysis of data. These headings are of high utility in answering the current review question. The paper does not outline how participants were **Propriety** Knowledge should be selected or approached. Anonymity is ensured by created and managed not naming the two LEAs where the research took legally, ethically and with place. The verbatim quotations are ethical in that due care to all relevant although they are of course edited and selected, stakeholders.

they do show a form of regard by the researchers to

	the participants by keeping their voices 'live'.
Accessibility Research should be presented in a way that meets the needs of the knowledge seeker, no potential user should be excluded because of the presentational style employed.	The research was presented in an accessible, discursive tone, with a genuine curiosity toward parents' views and experiences. Although some details were omitted regarding sampling and data analysis, this meant that a greater focus was placed on reporting quotations from the focus group. Overall this made the paper potentially more accessible to a wider audience, including parents.
Specificity Method specific quality	The methodology is somewhat relevant to the current study in so far as data analysis generated 'trends' (if not themes) from qualitative data. This data was gathered in focus groups rather than individual interviews and so holds lower method specific quality than the previous two studies discussed where individual interviews were conducted. The previous two papers also applied thematic analysis to data. These focus groups however, were conducted face to face and so are more relevant in that aspect of design than the previous two studies which conducted interviews via telephone.

Rehal, A. (1989). Involving Asian Parents in the Statementing Procedure-The Way Forward.

Process	
Screening : relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents as participants and the topic is statutory assessment. This paper focuses specifically on Asian parents living in an Outer London Borough.
Mapping: describe the evidence found. Type of research, data collection / analysis, participant selection etc.	Structured interviews were carried out with 14 Asian parents whose children had been statemented. All interviews but one were carried out in Punjabi by the author of the paper. Six educational psychologists whom had been involved in the statementing processes were also interviewed in order to verify the procedures used in that borough. In order to gain views on how to encourage Asian parents in the procedures, self- completion questionnaires were sent out to 15 educational psychologists in four other Outer London Boroughs. This study is 'exploratory' According to Robson's (2002) 'Classification of the Purposes of Enquiry' framework because the design seeks to generate data around a situation that is little understood and to seek new insights by consulting with Punjabi speaking Asian parents.

Data extraction:

Transparency

Research should be open to outside scrutiny and make plain how knowledge was generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.

The purpose of the study was to examine attitudes of Punjabi speaking parents to the statementing procedure that they had all supposedly gone through *with* the professionals, and to find out exactly how much these parents felt involved in the procedures.

The aims of the study were:

- To explore the extent to which the general intentions of the 1981 Education Act had been met in the area of information sharing with Punjabi speaking parents in one London Borough.
- 2. To explore parental reactions to the assessment procedures and information about available special provision.
- 3. To explore parental take-up of information and opportunities for discussion.
- To explore the extent and adequacy of information to and from parents about their own views on their child's needs, their need for further information, assessment procedures and available special provisions.
- 5. To produce a suggested framework of 'good practice' in involving Asian parents in statementing procedures.

Structured interviews were carried out in Punjabi by the writer of the paper. Structured interviews were used in order to generate data where the personal experience of being a non-English speaking parent in the context of an Outer London Borough would be visible. In order to select participants, a list of Punjabi speaking parents whose children had been statemented was obtained by the researcher from the Schools Psychological Service.

Findings:

- Of 14 parents interviewed, only one knew that their child had been statemented.
- Apart from one parent, the other 13 parents interviewed did not know that their child had been through a formal procedure and the term 'statementing' did not mean anything.
- All parents were unsure of the curriculum and did not know what was being taught to their children.
- The happiest group of parents were those whose child had a physical disability. When questioned, contentment was linked to their child attending a special school and for transport.
- The parents of children attending MLD schools were least happy. The found it difficult to understand the purpose of such a school. Most of the parents in this group said it had been explained to them that the school had 'small

- groups' and this was what their child needed. Many parents in this group reported that they had been told their child would be placed in a special school 'temporarily' and had grave concerns about their child's progress. They saw no point in sending their child to an MLD school.
- The researcher reported that the term 'special educational provision' was not understood by a lot of the parents. Many of the parents thought it was for children who could not read, write or speak English adequately.
- One parent thought that 'special educational provision' meant a school for the 'mad'. It took the researcher a great deal of effort to encourage her to speak to him. This parent thought the researcher had come to take her son away and said in her interview regarding statutory assessment that she regretted 'signing any paper'.
- The significance of the formal letter proposing an assessment was not at all understood by the Asian parents in this study.
- The booklet explaining the special educational provision in the borough was not understood by the parents.
- The EP request for formal assessment was either not understood or was ignored. The author reported that the significance of this formal request is simply not understood, which leads to the non-attendance of parents at assessments.
- Although all the parents were invited to contribute to the assessment, the significance of this was not understood. The parents in this study, whose first language was Punjabi, did not understand what they could write, or what sort of contribution they could make.
- The significance of receiving a 'draft' Statement was not understood, consequently parents did not realise that they had the right to challenge the provision detailed in the document.
- As a consequence of communication difficulties between professionals and parents of this study, parents tended to go along with the proposal to assess their child. There was also evidence of the 'professionals know best' discourse in parents' responses.
- Many of the parents did not know of the Annual Review process. None of them had been invited to such a meeting in order to review provision or to share their views.

This paper moves from 'methodological considerations' including an incomplete description of how the data was categorised, to 'conclusions'.

For this reason, no quotations are included as evidence for conclusions to be drawn from. The researcher interpreted and noted in English parents' responses and views. It would have increased the paper's level of accuracy if some of these interpreted responses had been reported directly in order to show from where knowledge claims were generated.

The reader is left to trust the conclusions without being able to examine any data.

The methodology states that 'results were tabulated and results presented by categories chosen'. This indicates that the method of analysis included categorisation rather than analysis. It may be similar to deductive coding in thematic analysis, though no mention of themes or thematic analysis is made, rather the reader is presented with a list of 'conclusions' without being able to follow exactly how these were reached. Having said this, perhaps the author was required to present the work within a limited word count and felt that it was more important to focus on conclusions in order to convey their message. Overall this paper is of medium accuracy and this will effect its weighting in this area, however, the topic is highly relevant and this will in turn boost the weighting of the paper in the literature review.

Accuracy

Knowledge claims should be supported by and faithful to the events, experiences. informants and sources used in their production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based upon relevant and appropriate information. Are the participants' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative).

Two sets of parents agreed for their interview to be recorded and the remaining 12 interviews were recorded in note form during the interview, where the interviewer interpreted and recorded the responses in English during the interview. The author of the paper formulates methodological difficulties within the study as the reliability and validity of **the responses**, where he proposes that there is no satisfactory solution for overcoming these 'difficulties'. Clearly this signals that the paper is written from a positivist perspective.

In order to address reliability and validity as they are positioned in the paper, the researcher:

- Carried out structured interviews with all six non Punjabi speaking educational psychologists in the same borough as the respondents in order to verify the procedure used by the EPs. The interview schedule is included in the paper as an appendix and interviews were recorded and transcribed.
- 2. Cross-checked the respondents' children's files in order to try to verify the respondents' replies.

Additionally to these two sets of interviews, to gain views on how to encourage Asian parents in the statementing procedures, self-completion questionnaires were sent out to 15 EPs in four Outer London Boroughs, all of whom were non-Punjabi speaking. A copy of the questionnaire is included as an appendix. These EPs 'were chosen at random' by a senior psychologist in each of the other four Outer London Boroughs.

Purposivity

The 'fit for purpose' standard. Has the approach met the stated objectives and aims of the study? Are the methods and approaches used to gain knowledge appropriate?

The research method is appropriate in terms of meeting the research aims, where the author wished to examine attitudes of Punjabi speaking parents to the statementing procedure and to find out exactly how much these parents felt involved in the procedures.

If the researcher had not been able to speak Punjabi, the research would have still been possible with the use of an interpreter, however, the fact that the researcher was able to access the parents' experiences directly through shared language means that the method met the aims of the study with very high levels of purposivity.

Utility

The 'fit for use' principle. Knowledge should be appropriate to the decision setting in which it is intended to be used, and to the information need expressed by the researcher(s) seeking knowledge.

Although the transparency and accuracy of this paper could have been higher if data had been presented to the reader and the method of analysis fully explained, the knowledge the paper offers still meets the 'utility' standard for the current literature review due to the high topic relevance and ability to answer the review question. For the purpose of this evidence review, it is very important to be able to include evidence that examines the experiences of parents who do not speak English and who have a different set of cultural experiences than native English speakers.

Propriety Knowledge should be created and managed

legally, ethically and with due care to all relevant stakeholders.

The writer of the paper outlined the advantage of interviewing face to face as having personal contact with participants, the opportunity to probe and pick up on information given spontaneously, and the guaranteed high rate of return. This high rate of return may however pose some ethical considerations. The author of the paper recorded two of the interviews and the other 12 were interpreted during the interview and notes made in English. This may account for the lack of translated quotations in the paper, it does however suggest that parents were consulted about how they would feel most comfortable to give their interviews.

Accessibility Research should be	Although the procedure for contacting and obtaining consent from participants was not fully explained, participants were selected on their speaking Punjabi and having a child with a Statement. It is likely that the researcher contacted the parents themselves, so it could be thought that there may have been an amount of coercion to take part in the study. The researcher anonymises the borough where the research took place and so protects the identities of the participants. The language and presentational style is accessible.
presented in a way that meets the needs of the knowledge seeker; no potential user should be excluded because of the presentational style employed.	
Specificity Method specific quality	This study is of 'medium-high' specificity for the current study because although it involves interviews with parents about their experiences of statutory processes, the method of analysis of data is unclear and unspecified. However, the study involved face to face interviews with parents who do not speak English regarding their experiences of statutory assessment and is considered of a 'medium' level of specificity for this reason.

Hartas, D. (2008) Practices of parental participation: a case study.

Process	
Screening : relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents as participants and the topic is statutory assessment.
Mapping: describe the evidence found. Type of research, data collection / analysis, participant selection etc.	This is a case study of a parental couple's participation in negotiating their child's statement. According to Robson's (2002) 'Classification of the Purposes of Enquiry' framework, this is a 'descriptive' study because the design seeks to generate data that will portray an accurate profile of this particular situation. The study can also be described as 'exploratory' because it sets out to seek new insights regarding this parental couple's experiences of the statutory assessment process.
Data extraction:	The paper outlines the reasons why a case study
Transparency	design was appropriate: that Joe's parents
Research should be open to	represented a case unique in content and
outside scrutiny and make plain how knowledge was	character'. The case study is transparent in its
piaiii ilow kilowieuge was	methodology and outlines the use of triangulation of

generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.

information from multiple sources which includes semi-structured interviews, documentation (e.g. parents' letters, professionals' reports) and classroom observations. There were also parental tape-recordings of Joe's social and linguistic interactions, which started when Joe was three and a half years old (at the time of getting his ASD diagnosis) until the end of Joe's reception year.

The aim of the study was to build a detailed portrait of a particular parental couple's views and experiences, with a focus on their involvement in their son's SEN statementing. It is also qualified that generalisation of findings was not the goal of the study, which rather was to provide rich and contextualised descriptions of one case. Another point that strengthens the transparency of the study is the researcher's acknowledging of themselves in the process.

The researcher provided a draft copy of the paper to the parents in order to enable them to corroborate or question any of the information and assumptions that had been drawn.

The researcher also states the theoretical underpinnings and rationale of the study to be based on Wolfendale's (1985) authentic homeschool partnerships and on strengths-based approaches to parental involvement (Bernard 2006). Parental involvement practices were also explored in terms of the extent to which participation was central and active (parents building trust relationships, negotiating, and challenging professional views and practices). During parent-professional interactions parental involvement in terms of the advocacy model, which recognises parental agency coupled with a shared responsibility was also explored.

Again with high levels of transparency, the paper states that, 'threads of evidence, or patterns of consistency that emerged from the parents' accounts guide this discussion'. (Hartas, 2008). This acknowledges the privileging of the account constructed by the parents in the study, over other sources of information. The paper demonstrates high levels of transparency and allows the reader to follow the researcher's rationale in the production of knowledge.

Findings were arranged under the following headings:

 Sharing knowledge and understanding about Joe's level of development / functioning. The

- parents communicated information from paediatrics, SALT and Joe's social worker.
- Negotiating provision in the mainstream. In this case the researcher reported that strategies in the classroom were developed with Joe's parent's in a 'bottom up' way. The parents had been disappointed that some meetings with professionals focused on levels of resource allocation rather than those professionals sharing educational advice.
- Recognising good practice. Joe's parents reported that the professional support they had had during statutory assessment had been competent.
- Challenging professionals' views. Joe's parents challenged professionals' views on many occasions, often due to a clash between what was recommended and what had worked at home for them. Many of these issues were resolved by speaking with the teacher and learning support assistant. This involved refusing a SALT recommendation to hold out a cup of juice for Joe but not give it until he attempted to say 'juice' and also the teacher's reward based behavioural strategy to encourage Joe to do new things. Joe's parents had to explain that Joe needs detailed explanations of why he is being asked to do something because he will not ask questions but may be wondering about the instruction.
- Challenging professional practices. Joe's
 parents raised concerns around the validity of
 certain assessment procedures, some
 professionals' limited knowledge of Joe's
 linguistic and social functioning, accuracy of
 reports, the guidance on teaching offered and
 most importantly the process of deciding about
 SEN provision.
- Confidentiality and professional boundaries.
 Joe's parents found that the social worker's
 financial situation was inappropriate for inclusion
 in an educational statement that would be widely
 circulated. The family questioned the social
 worker's involvement in the statutory
 assessment, suggesting that she made decisions
 about educational placement based on limited
 information regarding their and their child's
 functioning, thus transcending her professional
 boundaries.
- Perceived equality and shared responsibility.
 Joe's parents did not perceive education as a set
 of services delivered to their child passively in a
 'top-down' manner. Rather, they exercised
 agency by playing an active part in their child's

- learning and by co-constructing educational provision that was right for their child as a result of dynamic dialogue. The paper's author offers an alternative perspective that parents often do not enjoy an equal relationship with professionals, they often lack the power to influence decision making and the expertise to advocate for their child's educational provision.
- Parental involvement based on trust and respect. In their collaboration with professionals, Joe's parents were accountable, kept channels of communication open, made suggestions, articulated concerns and needs and mobilised systems of support. While Joe's parents formed good partnerships with professionals, conflict and disagreement were also part of their exchanges. The author reflected that, 'Partnerships do not operate within absolute notions of agreement and disagreement but in the spaces in between.' The parents ascertained Joe's rights within the education system and rejected positioning as 'parents with a problem' to 'parents with a solution'.
- Misrecognising and misrepresenting parents. The researcher reported that deficit assumptions were evident in the practice of some professionals, who stressed the need to remedy a deficit in the parents' views, values and choices, e.g. deficit assumptions were made in the health visitor's interpretation of the parents' style of interaction with their child, summarising them along the lines of 'social isolation and peculiar use of language with their son'. This misunderstanding arose when Joe's parents used a 'template language' with which Joe was able to engage and the health visitor claimed that the parents, 'were not giving Joe a chance.'
- Parental involvement as an advocacy act. The parental involvement illustrated in this case study draw upon and extend the empowerment and negotiating models of parents within statutory assessment in that they recognise and legitimise parents' strengths and cultural capital. Parental involvement as illustrated by this case study constitutes an advocacy act: the parents exercised agency in the context of mutual responsibility and accountability, an coconstructed their child's educational provision. Parental involvement as advocacy requires parents to identify their needs, recognise their strengths, challenge practices, negotiate decision-making, express dissent, and develop resolution. The parents constructed a social and critical space to engage with professional views

	and practices, moving from a needs-based
	approach to strength-based models and finally to parental participation as an act of advocacy, where both power and responsibility are shared.
Accuracy Knowledge claims should be supported by and faithful to the events, experiences, informants and sources used in their production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based upon relevant and appropriate information. Are the participants' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative).	Each sub heading (such as 'negotiating provision in the mainstream') is evidenced with rich quotations from interviews with the parents. The assertions the parents made in the interviews often referred to tape recordings of their son's speech and social interactions, or professionals' reports. The author of the paper triangulated data from interviews with the parents with other sources of information, such as tape recordings of 'Joe', observations of him in reception class and professionals' reports.
Purposivity The 'fit for purpose' standard. Has the approach met the stated objectives and aims of the study? Are the methods and approaches used to gain knowledge appropriate?	The design meets the study's stated aims in so far as the study sought to provide a rich account of a particular parental couple's experience of advocating for their son during the statementing process. The aim of the study was not to produce generalisable findings.
Utility The 'fit for use' principle. Knowledge should be appropriate to the decision setting in which it is intended to be used, and to the information need expressed by the researcher(s) seeking knowledge.	This study meets the utility standard for the current literature review because of its high topic relevance and also its methodological rigour, accuracy and transparency.
Propriety Knowledge should be created and managed legally, ethically and with due care to all relevant stakeholders.	The researcher in this study described themselves as 'peripheral' to the statementing process that 'Joe' and his parents were engaged in. The researcher was known to the parents in their role as a parent adviser / advocate. The reporting of the parents' experiences conveys care and ethical propriety towards the parents whose experiences constitute this case study. It was outlined that the parents were given a draft form of the paper in order to corroborate or question knowledge claims that had been made by the researcher. The parents and their son are anonymised and the geographical location of the study is not known to the reader.
Accessibility Research should be presented in a way that	The findings of the study are presented in an accessible manner.

meets the needs of the knowledge seeker, no potential user should be excluded because of the presentational style employed.	
Specificity Method specific quality	Although this study does not use thematic analysis and is a case study of a single parental couple's experiences, it still holds a 'medium' level of method specific quality for the current research because of its use of semi structured interview and detailed reporting of direct quotations.

McCarthy (1991). Children with Special Educational Needs: Parents' Knowledge of Procedures and Provisions.

Process

Screening : relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents as participants and the topic is parents' knowledge of statutory assessment procedures.
Mapping : describe the evidence found. Type of research, data collection / analysis, participant selection etc.	This research was conducted by sending a postal questionnaire with closed (yes / no / don't know) answering options. Parents were also invited to make comments on any of the questions.
	According to Robson's (2002) 'Classification of the Purposes of Enquiry' framework, this is a 'descriptive' study because the design seeks to generate data that will portray an accurate profile of the situation.
Data extraction:	
Transparency Research should be open to outside scrutiny and make plain how knowledge was generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.	The study was based on the researcher's own dissatisfaction with communication from professionals to parents regarding disability and special educational needs. The researcher conducted the study because in their professional life as a nurse, they had experienced working with many parents who had not had their child's disability explained to them. The researcher had also experienced a lack of communication from professionals regarding their own child's needs. The stated position of the researcher therefore meets a high standard of transparency. The paper does not fully outline how the 208 parents who had questionnaires sent to them were selected as potential participants, other than to state that the parents who received letters had children with statements who attended six different schools. This perhaps implies that the researcher selected six schools and then contacted parents whose children had statements and attended the

schools.

The researcher describes in the paper that the first seven questions concerned statementing of special educational needs under the 1981 Education Act. The following group of questions (8-13) were on parents' choice of school placement and their views on inclusion in mainstream settings. Other questions asked were focused around communication with professionals.

203 questionnaires were sent out to parents living in Sheffield and 81 were returned. Of these, 69 were from parents whose child had a statement and 12 were from families with a child who had been assessed for special education before the 1981 Education Act came in to practice.

Findings:

Of the 69 parents whose child had a statement, the following results were obtained:

'Were you in agreement with professionals that your child needed statementing?'

Yes 59

No 3

Don't know 6

No reply 1

'Was the statementing procedure fully explained to you?'

Yes 49

No 15

Don't know 4

No reply 1

'Did you receive advice or counselling from a professional when your child was being statemented?

Yes 39

No 25

Don't know 2

No reply 3

'Was a draft Statement sent to you for you to make comments?'

Yes 45

No 15

Don't know 6

No reply 3

'Were you fully involved or informed in all stages of the statementing of your child?

Yes 44

No 17

Don't know 5

No reply 3

Here, only 64% of parents felt fully involved in the

	statementing of their child.
Accuracy Knowledge claims should be supported by and faithful to the events, experiences, informants and sources used in their production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based upon relevant and appropriate information. Are the participants' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative).	As well as presenting results clearly and unambiguously (including distinguishing between 'don't know' and 'no answer') direct quotations were also presented from the written comments that parents provided. All assertions were linked to the numerical and qualitative data. The study demonstrates high levels of accuracy.
Purposivity The 'fit for purpose' standard. Has the approach met the stated objectives and aims of the study? Are the methods and approaches used to gain knowledge appropriate?	The study demonstrates high levels of purposivity in that the design of the study meets the researcher's aim to discover parental attitudes regarding their experience of the statementing process, school choice and communication with professionals. The study does not provide much detail or seek to draw out themes relating to lived experience. The study instead generated a numerical snapshot of parental perceptions and did this via its design that allowed the researcher to gather data from 69 parents or parental couples.
Utility The 'fit for use' principle. Knowledge should be appropriate to the decision setting in which it is intended to be used, and to the information need expressed by the researcher(s) seeking knowledge.	This study is 'fit for use' within the current literature review, as it demonstrates broad trends in experiences of parents during statutory assessment and statementing. Caution will be exercised in terms of generalising findings to the current social context. All participants can be assumed to be literate in English and as such this study provides no insight into the experiences of parents who cannot read or write in English.
Propriety Knowledge should be created and managed legally, ethically and with due care to all relevant stakeholders.	Confidentiality of individual parents is maintained, and this is less challenging given that parents largely supplied 'yes / no' answers to a series of questions, rather than discussing details of their case. The research is however situated in Sheffield, which could have threatened anonymity if the data collection method was predominantly qualitative. As the participant selection process is only partly explained to the reader, it is difficult to make a judgement about the level of propriety demonstrated by the study.
Accessibility Research should be	The language and presentational style is accessible.

presented in a way that meets the needs of the knowledge seeker, no potential user should be excluded because of the presentational style employed.	
Specificity Method specific quality	Whilst this study has high levels of topic relevance to the current research, the method specific relevance is low because it is a largely quantitative study. This is quite useful however, as it provides a different (macro) view for the current researcher about trends in parents' experiences of statementing in a certain place and time.

Gross, J. (1996) The weight of the evidence: Parental advocacy and resource allocation to children with statements of special educational need.

Process	
Screening : relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents as participants and the topic is parents' level of written involvement in statutory assessment procedures for their child and the relationship between this and resource allocation.
Mapping: describe the evidence found. Type of research, data collection / analysis, participant selection etc.	This research was conducted by content analysis of children's files. An initial 100 files were included from seven secondary schools and 49 primary schools across the (county) Local Education Authority from rural settings to urban settings. The sample did not include schools with high minority ethnic group populations, the majority of children and parents in the sample were white, native English speakers. From the 100 files, 12 could not be included because appendices were inaccessible or incomplete. A further 30 files were found to have only small (under £250) differences between their actual funding allocation and their predicted tariff funding. This left 57 cases with substantial (over £250) gains or losses under the new tariff system. These cases were included in the study. According to the 'Classification of the Purposes of Enquiry' framework (Robson, 2002) this is a 'descriptive' study because the design seeks to generate data that will portray an accurate profile of the situation. The study can also be described as 'exploratory' because it sets out to seek new insights regarding how resources may be allocated either fairly or unfairly.
Data extraction:	The aim of the study (although not explicitly stated)
Transparency	was to examine under the new tariff system the LEA
Research should be open	was adopting the hypothetical amount of money

to outside scrutiny and make plain how knowledge was generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.

each child should be allocated versus the actual amount allocated under the pre tariff system, and to look for discrepancies related to levels of parental advocacy.

The author states that the research came about by chance when undertaking a secondment to pilot a new system for resourcing statements in a county authority. Evidence (Vincent, Evans, Lunt & Young, 1995) suggested that 'inequitable arrangements (had been) made for children of professional middle-class parents, supported by well-organised voluntary organisations'.

The researcher found that overall the sum funding of the files compared to the sum hypothetical new tariff funding was equal, representing the same 'pot of money'. Interestingly, when the new tariff was applied 37 (historically overfunded) would be losers under the new tariff, while 20 (historically underfunded) would gain additional resources. The study found that the number of historically overfunded children with a parental statement was 65% (N=37) and the number of historically underfunded children with a parental statement was 30% (N=20). Additionally, the average number of pages for the overfunded group was 5.1 and the underfunded average number of pages was 1.4. Whilst it could be argued that 'number of pages' is not a particularly accurate measure of length of parental contribution or indeed quality of that contribution, the study reports the difference was significant at the p>0.1 level using a Mann-Whitney U test. Power is not reported and the participant numbers are relatively small for use in statistical analysis.

The study also found that where children were overfunded by more than £1000 (under the new tariff system) 90% (N=20) had a parental contribution. Of the children who were underfunded by over £1000, 0% (N=7) had a parental contribution.

The author also studied the relationship between underfunded and overfunded disability categories and found no significant differences.

The paper concluded that 'it is possible, but unlikely, that the mere presence of lengthy written parental representations influenced the education officers and support service representatives making up... the panel under the old system to make more generous allocations of support hours when considering the case initially... A more likely explanation is that the presence and length of an initial parental contribution

	was linked to the capacity of the parents to exert influence in other ways- by telephone calls, requests for meetings, attendance at reviews, letters to councillors and Members of Parliament, and the appeals process itself.
Accuracy Knowledge claims should be supported by and faithful to the events, experiences, informants and sources used in their production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based upon relevant and appropriate information. Are the participants' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative).	The study set out to examine the relationship between a measure of parental advocacy and resource allocation and achieved this with success. A compelling argument linked with analysis of data suggested that levels of parental advocacy affected the amount of funding allocated to children, particularly in the most underfunded and most overfunded cases (by £1000) or more.
Purposivity The 'fit for purpose' standard. Has the approach met the stated objectives and aims of the study? Are the methods and approaches used to gain knowledge appropriate?	The files selected by the author did not contain indicators to examine social class relations such as free school meals or parental occupation, what they did include (in some cases but not others) was a parental contribution to the child's statutory assessment, often running to many typed pages. The author argues that the presence / absence, and the length, of such parental contributions appeared to have considerable face validity as an indicator of parental educational levels and parental confidence in advocating for their child. Indeed, it could be argued that this is a better measure of ability to advocate for one's child than free school meal or parental occupation data.
Utility The 'fit for use' principle. Knowledge should be appropriate to the decision setting in which it is intended to be used, and to the information need expressed by the researcher(s) seeking knowledge.	The knowledge generated by this study is 'fit for use' for the current literature review in that it presents a highly relevant point to consider about what we know of parents' experiences in statutory processes, and indeed how this effects outcomes for children.
Propriety Knowledge should be created and managed legally, ethically and with due care to all relevant	The study took place within a county Local Education Authority that was not named. Anonymity of parents is assured as names and locations have been removed from the write up. Two case studies

stakeholders.	were included to illustrate the quantitative data and here the children were anonymised. There may be some concern that children could be identified from the details included in the case studies, however this is unlikely as the location is not named. The paper offers little explanation of how participants' files were selected and does not mention contacting parents to ask if their child's file could be used in the study. Instead it is explained that the schools volunteered to take part. In this sense, the study does not appear to meet the highest standards of propriety.
Accessibility Research should be presented in a way that meets the needs of the knowledge seeker, no potential user should be excluded because of the presentational style employed.	The language and presentation of statistical data is highly accessible.
Specificity Method specific quality	Whilst this study has high levels of topic relevance to the current research, the method specific relevance is low because it is a largely quantitative study. This is quite useful however in answering part of the review question, as it provides knowledge around possible differences in parents' experiences of statementing depending on their ability to exert influence on the process, and this is synonymous with feelings and experiences of empowerment or disempowerment.

Literature review question 2: Parents' experiences of psychological assessment of their child.

Hilton, K., Turner, C., Krebs, G., Volz, C. & Heyman, I. (2012) Parent Experiences of attending a specialist clinic for assessment of their child's obsessive compulsive disorder.

Process	
Screening : relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents as participants and the topic is parents' experiences of assessment of their child's obsessive compulsive disorder (OCD), including parental satisfaction with child mental health assessment.
Mapping: describe the evidence found. Type of research, data collection / analysis, participant selection etc.	According to Robson's (2002) 'Classification of the Purposes of Enquiry' framework, this is an 'exploratory' study. Little is known about parental satisfaction with child mental health assessment. The study could also be classified as 'descriptive' as it seeks to convey an accurate profile of the

situation for parents around the assessment of their child's OCD. 40 parents completed questionnaires which contained both closed and open questions. Data was subject to statistical and thematic analysis.

Data extraction:

Transparency
Research should be open to outside scrutiny and make plain how knowledge was generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.

The study looked at parental satisfaction with child mental health assessment by establishing parental expectations of, and satisfaction with, a specialist service for young people with OCD. The rationale of the study centred on the need to evaluate outcomes increasingly based on service users' feedback (rather than clinical outcome data) and that satisfaction with initial assessment may determine whether or not a family engage in the treatment offered. This is important in OCD and associated disorders because there are often high levels of family accommodation of symptoms, parental distress and family dysfunction.

The aims of the study were:

- To establish parental expectations before the assessment.
- To understand parental experience of and satisfaction with the assessment.
- To determine whether the assessment process fulfilled expectation.
- To use the findings to improve the service.

Opportunity sampling was employed where parents of the 51 young people assessed between May 2007 and May 2008 were invited to complete a questionnaire. Parents were prompted to return the questionnaire by a telephone call. Forty-one questionnaires were returned, although one was filled in by a young person and was excluded from the analyses.

The questionnaire was designed to evaluate parental satisfaction in relation to key areas of the assessment. Questions included closed questions about expectations of the assessment, the experience of the assessment process, the usefulness and length of the process, relevance of the questions asked, and satisfaction with the outcome of the assessment. Open-ended questions were included, inviting parents to comment on their experiences in each of the domains examined. The questionnaire was shown to two families for verbal feedback and then piloted on a small sample. Data analysis of the questionnaire resulted in descriptive statistics and a set of themes. The

method of extracting themes from the open-ended responses was not explained and in this particular area, the study did not demonstrate the highest levels of transparency.

Findings:

Parental expectations and gains. The most common expectations of the assessment were advice or information about the treatment of OCD, a diagnosis or understanding of the child's problems, and an offer of treatment. These were also the most commonly reported parental gains from the assessment.

Parental satisfaction with the assessment service. Parents were asked specific questions about the process of the assessment and their experiences. 80% of parents chose to respond to open-ended questions about positive and / or negative aspects of the assessment. Of these, 62.5% (N20) made only positive comments, 34.4% (N11) made positive and negative comments and 3.1% (N1) made only negative comments. Themes that emerged from the open ended questions:

Positive

- · Put at ease.
- Felt listened to, understood and reassured.
- Under care of specialists / professionals.
- Separate parent / child interviews valued.
- Team optimistic about treatment.

Negative

- Waiting time for assessment.
- Limited time of assessment.
- · Administration issues.

Parents also completed a forced choice satisfaction rating scale for 28 questions. Some areas of the assessment had lower levels of parental satisfaction. These were:

- Understanding the child's strengths.
- Waiting time for assessment.
- Being given relevant written information or reading suggestions around the child's diagnosis.
- Availability of professionals outside the appointment time.

Summary: Parents valued being told about their child's strengths as well as their difficulties, being given time to explain their concerns and an opportunity to speak with clinicians without their child in the room. Parents should also be given contact details if they require support in the waiting

	time period.
Accuracy Knowledge claims should be supported by and faithful to the events, experiences, informants and sources used in their production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based upon relevant and appropriate information. Are the participants' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative).	This study had a high response rate, so it is likely that findings are representative of all the families assessed in the clinic at that time. The study has high levels of accuracy in its reporting of findings which are clearly linked to the study's data. Descriptive statistics are set out clearly in three tables and results are referenced in the discussion and knowledge claims. Although the method of extracting themes from the open-ended responses is not explained, each theme is presented with either one or several example quotations.
Purposivity The 'fit for purpose' standard. Has the approach met the stated objectives and aims of the study? Are the methods and approaches used to gain knowledge appropriate?	The study demonstrated high levels of purposivity when linked to the study aims. This is particularly because the design was such that all parents of children who were assessed in one year were invited to take part and there were 41 respondents. It might have been useful to interview parents face to face and to perform a more detailed and transparent high quality thematic analysis of transcripts in order to capture 'parents' experiences of attending a specialist clinic'.
Utility The 'fit for use' principle. Knowledge should be appropriate to the decision setting in which it is intended to be used, and to the information need expressed by the researcher(s) seeking knowledge.	This study meets the utility standard for the current literature review because it is of sound methodology, with high levels of accuracy and can offer insights about parents' experiences of assessment of their child.
Propriety Knowledge should be created and managed legally, ethically and with due care to all relevant stakeholders.	It appears that he study has good levels of propriety. The clinic where the assessments took place is named in the paper, but individual cases are not alluded to and quotations reported alongside themes are very brief and therefore would not identify participants.
Accessibility Research should be presented in a way that meets the needs of the knowledge seeker; no potential user should be excluded because of the presentational style employed.	The paper is written in an accessible style and findings are presented clearly.
Specificity Method specific quality	Both the descriptive statistics and the themes are

useful findings, though the method specific quality is lower for this study as the open ended responses were written by parents on a postal questionnaire, rather than being generated through either face tot
face or telephone interview.

Long, L. & McPolin, P. (2009) Psychological assessment and dyslexia: parents' perspectives.

parents' perspectives.	
Process	
Screening : relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents as participants and the topic is parents' perceptions of having their child assessed for dyslexia by an independent Educational Psychologist.
Mapping: describe the evidence found. Type of research, data collection / analysis, participant selection etc.	This is an 'exploratory' study according to Robson's (2002) 'Classification of the Purposes of Enquiry' framework because it seeks to understand what is happening in this particular and little-understood situation. The study was carried out as part an evaluation of the services offered by the Northern Ireland Dyslexia Centre (NIDC). Data collection was conducted via postal questionnaire yielding both quantitative and qualitative findings. Participant selection was conducted by sending questionnaires to the 70 parents of children who had had an educational psychology assessment for dyslexia through the NIDC between September 2002 and September 2006. Thirty-two questionnaires were completed. Quantitative data was analysed and presented using Excel software and analysis of written responses was made through a coding of themes and concepts.
Data extraction: Transparency Research should be open to outside scrutiny and make plain how knowledge was generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.	The questionnaire had three parts. Part One gathered demographic information and background on the pupils' educational history. Part Two presented parents with thirteen statements for response on a five-point Likert Scale. The opportunity for parents to make more detailed and personalised comments on psychological assessment was provided in Part Three. The questionnaire followed a natural chronological format and focused on issues prior to, during, and after the assessment. The aims of the study were: • To explore parents' perceptions on the educational psychology services offered by the NIDC. • To provide teachers and Educational Psychologists with information about

psychological assessment through the lens of parents who have had their children assessed for dvslexia. Findings: Over 80% of parents cited the reason for seeking an independent dyslexia assessment was the suspicion that their child was dyslexic. A further reason given by over 30% of parents was to obtain practical advice on home teaching. Approximately 50% of parents did not know the status of their child with respect to the SEN Code of Practice (1998). This suggests confusion about procedures for management of SEN and the patterns of language used by professionals may pose barriers to parental participation. In the open-ended section, all respondents expressed dissatisfaction that their views had not been listened to in school, 'I cannot stress how valuable the assessment itself was and how important it was to have my concerns validated when no-one at school had been listening to them over the years. People need to listen to parents.' 'I felt like the neurotic mummy who was always moaning... if only his teachers had listened to me'. Accuracy There was a limited amount of reporting quotations Knowledge claims should and the study mostly presented data that suggested be supported by and that the NIDC was serving parents and young people faithful to the events, well and had a place within the school system to experiences, informants support delivery of intervention and to increase and sources used in their parental participation. production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based upon relevant and appropriate information. Are the participants' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative). Purposivity The study somewhat met its aim to provide The 'fit for purpose' information to educational psychologists and standard. Has the teachers about psychological assessment through approach met the stated the lens of parents who have had their children objectives and aims of the assessed for dyslexia. It provides important study? Are the methods information, but not many points. and approaches used to gain knowledge appropriate? The knowledge provided by the paper is fit for use in Utility The 'fit for use' principle. the current literature review.

Knowledge should be appropriate to the decision setting in which it is intended to be used, and to the information need expressed by the researcher(s) seeking knowledge.	
Propriety Knowledge should be created and managed legally, ethically and with due care to all relevant stakeholders.	Propriety was given due consideration in this paper, where a letter explaining the purpose of the study and relevant information was sent out with the questionnaire. All data is anonymised.
Accessibility Research should be presented in a way that meets the needs of the knowledge seeker, no potential user should be excluded because of the presentational style employed.	The paper was written in an accessible style and statistical data was presented clearly.
Specificity Method specific quality	This study holds lower method specific quality because data was gathered via postal questionnaire rather than interviews conducted in person.

Mansell, W. & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service.

Process	
Screening : relevance to topic. NB All articles at this stage have met the inclusion criteria outlined in Figure 2.	It is an empirical study, post 1985, conducted within the UK, has parents as participants and the topic is parents' reactions to their child's diagnosis of an autistic spectrum disorder.
Mapping: describe the evidence found. Type of research, data collection / analysis, participant selection etc.	According to Robson's (2002) 'Classification of the Purposes of Enquiry' framework, this is an 'exploratory' study because it sets out to seek new insights regarding parents' reactions to their child receiving an autistic spectrum diagnosis. The study collected data via a postal questionnaire. The records of all children diagnosed by the district diagnostic service were categorised by year of diagnosis, age of child at diagnosis, sex of child with diagnosis and nature of diagnosis. The parents of those with a definite diagnosis were sent a letter outlining the purpose of the study and a questionnaire. Of the 113 children assessed between 1995-1999, 100 had a definite diagnosis and letters were sent to their parents. A reminder letter was sent after four weeks. Fifty-five questionnaires were returned. The questionnaire contained questions to be answered via four-point Likert Scale ratings with space for additional

Data extraction:

Transparency
Research should be open to outside scrutiny and make plain how knowledge was generated. This includes clarifying the aims and objectives of the study and all steps of the subsequent argument, so that readers have access to a shared understanding of the underlying reasoning of the study.

comments and also open-ended questions.

The aims of the study were:

- To assess the perceived change in quality of service provided by the district diagnostic service since changes in 1998.
- To obtain comments and recommendations about the service.
- To assess the use and quality of information services available to parents.
- To assess the use and perceived quality of support and treatment available to parents.
- To assess the positive and negative consequences of a diagnosis.
- To assess how parents' attitudes towards the diagnosis had changed over time.

The paper outlines four stages in the diagnostic process for parents and families: pre-diagnosis, diagnosis, post-diagnosis and acceptance and adaptation. The findings from the study were used to either confirm or disconfirm what is already known about these stages.

Parents were first asked to supply details regarding their child and the person filling in the form. After this parents were asked to rate their satisfaction with the feedback session they had had after diagnosis in several domains. This included a quantitative measure of the positive and negative consequences of a diagnosis. Parents were presented with a range of statements and asked to rate how much they agreed with each one with respect to their child. Parents were also asked to report which sources of information they found helpful, how they accessed them and how useful they were. Parents were then asked to rate the usefulness of different sources of support and treatment. Finally parents were asked to comment on how their attitudes to the diagnosis had changed over time. Findings:

- Half of the questionnaires were completed by the mother and half were completed by both the mother and the father.
- The most common age for diagnosis was 4-5 years and the age ranged from 2- over 10 years.
- Percentage of respondents endorsing 'moderately' or 'very' for the 1995-1999 period were as follows: How sensitive were the team giving the diagnosis?' 80%. How well were the following explained: 'diagnostic terms?' 77%, 'sources of support' 51%, 'sources of information?' 46%, 'coping strategies?' 44%,

'future consequences?' 31%, 'sources of treatment?' 28%.

The following recommendations were made by at least 4-6 parents returning questionnaires:

- Counseling should be available for parents to help deal with the diagnosis.
- Provide more information on the support and treatment options available.
- Before the diagnosis, provide information about how to access help, support and treatment.
- During a follow-up session, provide information about further support and treatment programmes.
- Keep the parents informed of the likely diagnosis before the formal diagnosis is given.
- Provide more information regarding dietary intervention.
- Provide help and advice on how to deal with schools, what is available, and getting a place.
- · Reduce the waiting list.

Qualitative comments included:

'More time and information should be given to parents at diagnosis. I was informed of the diagnosis and told I would be seen by the family services worker in a month. That was it. No explanation. No hope. It was obvious that thy knew what diagnosis they were likely to make prior to the play session but I had no prior warning. No one had the decency to tell me what might be wrong. At that point I needed to believe there was a future and I was appalled at the way I was treated. I should have had counselling there and then and lots of information given to me'. 'I believe when parents are told during diagnostic assessment that their child is autistic, they should

assessment that their child is autistic, they should be reassured that there are things they can do, e.g. Lovaas, PECS, change of diet, to make a huge difference. Obviously don't mislead them to think these things are a cure, but don't lead them to believe that the future is bleak, and doom and gloom, as I was.

The use and quality of information services:

 On the usefulness scale (1-4) the highest mean rated services at 3.5 were the family services worker, local parents' support group, and academic journals. Rated at 3.4 were school teachers, local workshops and conferences, and the Early Years course. Books were rated 3.2. Consultant paediatricians, meetings at the National Autistic Society, and family and friends were rated 3.2.

• Most parents also received information from educational psychologists, clinical psychologists, occupational therapists, and speech and language therapists but their usefulness rating fell below 2.3 and therefore were not included in the table of highest rated sources of information. It is hypothesised that this may reflect the limited amount of time these professionals have with parents and that they may have more fixed ideas on the appropriate information to provide, whereas written information can be accessed freely.

One parent commented, 'Most information was learned since the diagnosis. Bromley Autistic Trust supplied the most, although our own perseverance, research etc. has helped. Initially parents may not want to accept information so it is difficult to give it at all. However, I was desperate for a 'label' if you like, so that we could move on to a more positive outlook. Before this it was like 'no man's land'. I think a home visit early could have been useful to help with behaviour and other hints'.

The use and quality of support and treatment: One parent commented, 'As a family we have taken little parts from different therapies, books etc. and used them as and when they fit in to our daily lives. It is vital to be able to attain all these different sources and choose parts that will benefit your child the most with the least distress. There should be more visits to schools by speech and language therapists. Education therapists should visit our children in school throughout the year in the classroom environment and give valid support to support assistants. Support assistants should have training in autism before supporting the child in the classroom; this would be very valuable for both the child and assistant and save much stress'.

How parents' attitudes towards the diagnosis have changed over time: The highest rated reactions to diagnosis were: 'We were shocked / upset / devastated' (12), 'The diagnosis confirmed our feelings' (6), 'We already knew that our child had an autistic spectrum disorder' (6), 'The diagnosis helped explain our child's behaviour' (4), 'We were angry about the diagnosis' (3) and 'We got the false impression that the future would be very bleak for our child,' (3).

The highest rated changes in attitudes and experience over time were: 'Our attitudes to the diagnosis have not changed over time' (8), 'Our child has made good progress' (8), 'Other people have little understanding of autistic spectrum disorders' (6), 'Once diagnosed I was left and my child was not seen by anyone' (4), 'It takes several years to come to terms with the diagnosis' (4), 'The label has allowed us access to useful resources' (3).

The highest rated present conclusions about the diagnosis and the future were: 'We wish our child had been diagnosed earlier' (7), 'We have become more accepting of the diagnosis (6), 'The label has been a good thing' (5), 'We are unsure whether the diagnosis is correct' (5), 'We have become more aware of the lack of resources for our child' (4) and 'We have adapted to our child's behaviour' (3).

One parent commented, 'Although it's been over three years since my son was diagnosed, it's still hard to come to terms with. It's an uphill struggle every day battling with the authorities for his rights. Also, you become, or have to become, quite thick-skinned to deal with people's attitudes towards your child, because autistic children look so 'normal'. But over time some things get easier to handle and you just adapt because you have to'.

Accuracy

Knowledge claims should be supported by and faithful to the events, experiences. informants and sources used in their production. For knowledge to meet this standard, it should demonstrate that all assertions, conclusions and recommendations are based upon relevant and appropriate information. Are the participants' perspectives merely asserted or is their voice clearly reported in the data and reflected in the analysis? (Qualitative).

Just over half of parents contacted returned the survey, therefore the views may not fully represent those of all the parents diagnosed. It is possible that parents who had fewer comments to make about the services, either good or bad, were less likely to return their questionnaires and so more replies may have been received from parents who showed the strongest views about their child's condition.

The study does not mention that its design excludes those who cannot read and write in English. It is mentioned however that the results may not be generalisable because the sample is drawn from Bromley where general socioeconomic status is high, with 92% of the local population at the time of the study being white British.

Purposivity

The 'fit for purpose' standard. Has the approach met the stated objectives and aims of the study? Are the methods and approaches used to gain

Knowledge claims are well grounded in the numerical data and lengthy quotations are also included to illustrate more personal experiences from parents. Themes are not explicitly drawn from analysis of qualitative data; data is

knowledge appropriate?	categorised and used in a descriptive / illustrative capacity. The study is fit for purpose in terms of meeting its aims and data collection was possible from 51 parents, which is a relatively large sample.
Utility The 'fit for use' principle. Knowledge should be appropriate to the decision setting in which it is intended to be used, and to the information need expressed by the researcher(s) seeking knowledge.	The knowledge presented by the paper is fit for use in the current review. The study offers some useful insights regarding parents' experiences of assessment of their child, which has relevance to assessment of children within the EHCP framework.
Propriety Knowledge should be created and managed legally, ethically and with due care to all relevant stakeholders.	Although the place the study was conducted was named, there was not enough detail in qualitative responses to be able to identify participants. A letter was sent out with the questionnaire to explain the purpose and rationale of the study.
Accessibility Research should be presented in a way that meets the needs of the knowledge seeker, no potential user should be excluded because of the presentational style employed.	The paper was presented in a highly accessible manner.
Specificity Method specific quality	This study holds lower method specific quality because data was collected via postal questionnaire and a transparent and detailed thematic analysis was not used for qualitative responses. Although the method specific quality was not high, the knowledge presented by the study is still of use to the current researcher in answering the research question.

Appendix 2 Systematic Search Results

Search Terms "SU"	Results
"Education Health and Care Needs	None
Assessment"	
"Education Health and Care Plans"	None

Soarch Torme "SLI"	Results
Search Terms "SU" "Parent*" + "Education Health and	
	None
Care Needs Assessment"	None
"Parent*" + "Education Health and	None
Care Plans"	Nege
"Parent*" + "EHCA"	None
"Parent*" + "EHCP"	None
"Parent*" + "Statutory assessment"	10 Results, the following were selected: Hart, R. (2011). Paternal involvement in the statutory assessment of special educational needs. Educational Psychology in Practice. Vol. 27 (2) pp 155-174. 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. Vol. 20 (3) pp 251-269. Pinney, A. (2002). In need of review? The Audit Commission's report on statutory assessment and Statements of Special Educational Needs. British Journal of Special Education. Vol. 29 (3) pp 251-269. Norwich, B. (2007). Review of Parenting and Inclusive Education: Discovering differences, experiencing difficulties. European Journal of Special Needs Education. Vol. 22 (4) pp 484-486 Wolfendale, S. (1997). Encouraging parental views as part of statutory assessment: an analysis of local authorities special educational needs documentation produced for parents. Support for Learning. Vol. 12 (3) pp 99-103.
"Parent*" + "Special Educational	None

Needs and Disability (SEND) Code of Practice 2014"	
"Parent*" + "Statementing"	None
"Parent*" + "Statements of Special Educational Needs"	1 result, excluded as not related to parents' experiences.
"Parent*" + "Educational Psychology"	429 results. Filtered to GB, 4 results with duplicates removed. The following were selected: Day, S. (2013). "Terms of Engagement" not "hard to reach parents". Educational Psychology In Practice. Vol. 29 (1) pp 36-53. Cuckle, P. (2000). Parents' evaluation of an Educational Psychology Service. Educational Psychology in Practice. Vol. 16 (3) pp 361-371. Anthun, R. (2000). Parents' views of quality in Educational Psychology services. Educational Psychology in Practice. Vol. 16 (2) pp 141-157.
"Parent*" + Psychological Advice"	None
"Parent*" + "Statement*"	34 results, search engine unable to limit to GB and / or NI. The following were selected: Hartas, D. (2008). Practices of Parental Participation: A Case Study. Educational Psychology in Practice. Vol. 24 (2) pp 139-153. 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. Vol. 20 (3) pp 251-269. Jones, P. & Swain, J. (2001) Parents Reviewing Annual Reviews. British Journal of Special Education. Vol. 28 (2) pp 60-64. Pinney, A. (2002). In need of review? The Audit Commission's report on statutory assessment and Statements of Special Educational Needs. British Journal of Special Education. Vol. 29 (3) pp 251-269. Gross, J. (1996). The weight of the evidence: parental advocacy and resource allocation to children with

"Parent*" + "Annual Reviews"	statements of special educational needs. Support for Learning. Vol 11 pp 3-8. Rehal, A. (1989). Involving Asian parents in the statementing procedure: the way forward. Educational Psychology in Practice. Vol 4 (4) pp 189-197. McCarthy, T. (1991). Children with special educational needs: parents' knowledge of procedures and provisions. <i>British Journal of Special education</i> . Vol. 18 (1) pp 17-19. None
"Parent*" + "Psychological assessment"	90 results. The following was selected as potentially relevant from reading abstracts: Hilton, K., Turner, C., Krebs, G., Volz, C. & Heyman, I. (2012). Parent experiences of attending a specialist clinic for assessment of their child's obsessive compulsive disorder. Child and Adolescent Mental Health. Vol 17(1) pp. 31-36. (All other results were not relevant to parents' experiences).

Search Terms "SU"	Results
"Parent* experiences" + "Education	None
Health and Care Needs Assessment"	
"Parent* experiences" + "Education	None
Health and Care Plans"	
"Parent* experiences" + "EHCA"	None
(D) (1) (E) (O)	
"Parent* experiences" + "EHCP"	None
"Parent* experiences" + "Statutory	None
assessment"	None
"Parent* experiences" + "Special	None
Educational Needs and Disability	None
(SEND) Code of Practice 2014"	
"Parent* experiences" +	None
"Statementing"	
"Parent* experiences" + "Statements	None
of Special Educational Needs"	
"Parent* experiences" + "Educational	1 result:
Psychology"	Lawrence, Z. (2014). Black African
	parents' experiences of an

	Educational Psychology service. Educational Psychology in Practice. Vol. 30 (3) pp 238-254.
"Parent* experiences" + Psychological Advice"	None
"Parent* experiences" + "Statement*"	None
"Parent* experiences" + "Annual Reviews"	None
"Parent* experiences" + "Psychological assessment"	1 result: Hilton, K., Turner, C., Krebs, G., Volz, C. & Heyman, I. (2012). Parent experiences of attending a specialist clinic for assessment of their child's obsessive compulsive disorder. Child, Adolescent and Mental Health. Vol 17 (1) pp. 31-36.

Search Terms "SU"	Results
"Parent* views" + "Education Health and Care Needs Assessment"	None
"Parent* views" + "Education Health and Care Plans"	None
"Parent* views" + "EHCA"	None
"Parent* views" + "EHCP"	None
"Parent* views" + "Statutory assessment"	None
"Parent* views" + "Special Educational Needs and Disability (SEND) Code of Practice 2014"	None
"Parent* views" + "Statementing"	None
"Parent* views" + "Statements of Special Educational Needs"	None
"Parent* views" + "Educational Psychology"	None
"Parent* views" + Psychological Advice"	None
"Parent* views" + "Statement*"	None
"Parent* views" + "Annual Reviews"	None
"Parent* views" + "Psychological assessment"	None

Search Terms "SU"	Results
"Parent* reporting" + "Education	None
Health and Care Needs Assessment"	
"Parent* reporting" + "Education	None
Health and Care Plans"	
"Parent* reporting" + "EHCA"	None
"Parent* reporting" + "EHCP"	None
"Parent* reporting" + "Statutory assessment"	None
"Parent* reporting" + "Special	None
Educational Needs and Disability	
(SEND) Code of Practice 2014"	
"Parent* reporting" + "Statementing"	None
"Parent* reporting" + "Statements of Special Educational Needs"	None
"Parent* reporting" + "Educational Psychology"	None
"Parent* reporting" + Psychological Advice"	None
"Parent* reporting" + "Statement*"	None
"Parent* reporting" + "Annual	None
Reviews"	
"Parent* reporting" + "Psychological	None
assessment"	

Search Terms "SU"	Results
"Parent* attitudes" + "Education	None
Health and Care Needs Assessment"	
"Parent* attitudes" + "Education	None
Health and Care Plans"	
"Parent* attitudes" + "EHCA"	None
"Parent* attitudes" + "EHCP"	None
Taroni aunass 21161	T. G. I. G.
"Parent* attitudes" + "Statutory	None
assessment"	
"Parent* attitudes" + "Special	None
Educational Needs and Disability	
(SEND) Code of Practice 2014"	
"Parent* attitudes" + "Statementing"	None
"Parent* attitudes" + "Statements of	None
Special Educational Needs"	
"Parent* attitudes" + "Educational	36 results, the following were

Psychology"	selected:
, sychiology	Day, S. (2013). "Terms of
	Engagement" not "hard to reach
	parents". Educational Psychology In
	, ,
	Practice. Vol. 29 (1) pp 36-53.
	Lawrence, Z. (2014). Black African
	parents' experiences of an
	Educational Psychology service.
	Educational Psychology in Practice.
	Vol. 30 (3) pp 238-254.
	Lewis, V. & Miller, A. (2011).
	"Institutional talk" in the discourse
	between an educational psychologist
	and a parent: a single case study
	employing mixed research methods.
	Educational Psychology in Practice.
	Vol. 27 (3) pp 195-212.
	Hart, R. (2011). Paternal involvement
	in the statutory assessment of special
	educational needs. Educational
	Psychology in Practice. Vol. 27 (2) pp
	155-174.
	Long, L. & McPolin, P. (2009).
	Psychological assessment and
	dyslexia: parents' perspectives. Irish
	Educational Studies. Vol 28 (1) pp
	115-126.
	Mansell, W. & Morris, K. (2004). A
	Survey of Parents' Reactions to the
	Diagnosis of an Autistic Spectrum
	Disorder by a Local Service. Access
	to Information and Use of Services.
	The International Journal of Research
	and practice. Vol. 8 (4) pp 387-407.
	Hodgson, J., Mattison, S., Phillips, E.
	& Pollack, G. (2001). Consulting
	Parents to Improve a Child Guidance
	Service. Educational Psychology In
	Practice. Vol. 17 (3) pp 263-272.
	Cross, J., Kirkaldy, B. & Kennedy, H.
	(1991). Evaluating Educational
	Psychology Service delivery to
	parents of pre-school children. AEP
	Journal. Vol. 7 (1) pp 88-92.
	Anthun, R. (2000). Parents' views of
	1
	quality in Educational Psychology
	services. Educational Psychology in
"Devot* ettitudee" Devote alexis al	Practice. Vol. 16 (2) pp 141-157.
"Parent* attitudes" + Psychological	None
Advice"	

"Parent* attitudes" + "Annual	Hartas, D. (2008). Practices of Parental Participation: A Case Study. Educational Psychology in Practice. Vol. 24 (2) pp 139-153. 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. Vol. 20 (3) pp 251-269. Jones, P. & Swain, J. (2001) Parents Reviewing Annual Reviews. British Journal of Special Education. Vol. 28 (2) pp 60-64. Pinney, A. (2002). In need of review? The Audit Commission's report on statutory assessment and Statements of Special Educational Needs. British Journal of Special Education. Vol. 29 (3) pp 251-269. None
Reviews"	7 requite 1 calcated as notontially
"Parent* attitudes" + "Psychological assessment"	7 results, 1 selected as potentially relevant: Glaun, D.E., Cole, K.E. & Reddihough, D.S. (1998). Six month follow-up: the crucial test of multidisciplinary developmental assessment. Child: Care, Health and Development. Vol 24 (6) pp457-472.

Search Terms "SU"	Results
"Parent*empowerment" + "Education	None
Health and Care Needs Assessment"	
"Parent* empowerment" + "Education	None
Health and Care Plans"	
"Parent* empowerment" + "EHCA"	None
"Parent* empowerment" + "EHCP"	None
"Parent* empowerment" + "Statutory	None
assessment"	
"Parent* empowerment" + "Special	None
Educational Needs and Disability	
(SEND) Code of Practice 2014"	
"Parent* empowerment" +	None
"Statementing"	
"Parent* empowerment" +	None
"Statements of Special Educational	

Needs"	
"Parent* empowerment" +	None
"Educational Psychology"	
"Parent* empowerment" +	None
Psychological Advice"	
"Parent* empowerment" +	None
"Statement*"	
"Parent* empowerment" + "Annual	None
Reviews"	
"Parent* empowerment" +	None
"Psychological assessment"	

Search Terms "SU"	Results
"Parent* choice" + "Education Health and Care Needs Assessment"	None
"Parent* choice" + "Education Health and Care Plans"	None
"Parent* choice" + "EHCA"	None
"Parent* choice" + "EHCP"	None
"Parent* choice" + "Statutory assessment"	None
"Parent* choice" + "Special Educational Needs and Disability (SEND) Code of Practice 2014"	None
"Parent* choice" + "Statementing"	None
"Parent* choice" + "Statements of Special Educational Needs"	None
"Parent* choice" + "Educational Psychology"	None
"Parent* choice" + Psychological Advice"	None
"Parent* choice" + "Statement*"	None
"Parent* choice" + "Annual Reviews"	None
"Parent* choice" + "Psychological assessment"	None

List of articles removing duplicates:

- 1. Anthun, R. (2000). Parents' views of quality in Educational Psychology services. Educational Psychology in Practice. Vol. 16 (2) pp 141-157.
- 2. Cross, J., Kirkaldy, B. & Kennedy, H. (1991). Evaluating Educational Psychology Service delivery to parents of pre-school children. AEP Journal. Vol. 7 (1) pp 88-92.

- 3. Cuckle, P. (2000). Parents' evaluation of an Educational Psychology Service. Educational Psychology in Practice. Vol. 16 (3) pp 361-371.
- 4. Day, S. (2013). "Terms of Engagement" not "hard to reach parents". Educational Psychology In Practice. Vol. 29 (1) pp 36-53.
- 5. Glaun, D.E., Cole, K.E. & Reddihough, D.S. (1998). Six month follow-up: the crucial test of multidisciplinary developmental assessment. Child: Care, Health and Development. Vol 24 (6) pp457-472.
- 6. Gross, J. (1996). The weight of the evidence: parental advocacy and resource allocation to children with statements of special educational needs. Support for Learning. Vol 11 pp 3-8.
- 7. Hart, R. (2011). Paternal involvement in the statutory assessment of special educational needs. *Educational Psychology in Practice*. Vol. 27 (2) pp 155-174.
- 8. Hartas, D. (2008). Practices of Parental Participation: A Case Study. *Educational Psychology in Practice*. Vol. 24 (2) pp 139-153.
- 9. Hilton, K., Turner, C., Krebs, G., Volz, C. & Heyman, I. (2012). Parent experiences of attending a specialist clinic for assessment of their child's obsessive compulsive disorder. Child, Adolescent and Mental Health. Vol 17 (1) pp. 31-36.
- 10. Hodgson, J., Mattison, S., Phillips, E. & Pollack, G. (2001). Consulting Parents to Improve a Child Guidance Service. Educational Psychology In Practice. Vol. 17 (3) pp 263-272.
- 11. Jones, P. & Swain, J. (2001) Parents Reviewing Annual Reviews. British Journal of Special Education. Vol. 28 (2) pp 60-64.
- 12. Lawrence, Z. (2014). Black African parents' experiences of an Educational Psychology service. Educational Psychology in Practice. Vol. 30 (3) pp 238-254.
- 13. Lewis, V. & Miller, A. (2011). "Institutional talk" in the discourse between an educational psychologist and a parent: a single case study employing mixed research methods. Educational Psychology in Practice. Vol. 27 (3) pp 195-212.
- 14. Long, L. & McPolin, P. (2009). Psychological assessment and dyslexia: parents' perspectives. Irish Educational Studies. Vol 28 (1) pp 115-126.
- 15. Mansell, W. & Morris, K. (2004). A Survey of Parents' Reactions to the Diagnosis of an Autistic Spectrum Disorder by a Local Service. Access to Information and Use of Services. The International Journal of Research and practice. Vol. 8 (4) pp 387-407.

- 16. McCarthy, T. (1991). Children with special educational needs: parents' knowledge of procedures and provisions. *British Journal of Special education*. Vol. 18 (1) pp 17-19.
- 17. Norwich, B. (2007). Review of Parenting and Inclusive Education: Discovering differences, experiencing difficulties. *European Journal of Special Needs Education*. Vol. 22 (4) pp 484-486
- 18. 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*. Vol. 20 (3) pp 251-269.
- 19. Pinney, A. (2002). In need of review? The Audit Commission's report on statutory assessment and Statements of Special Educational Needs. *British Journal of Special Education*. Vol. 29 (3) pp 251-269.
- 20. Wolfendale, S. (1997). Encouraging parental views as part of statutory assessment: an analysis of local authorities special educational needs documentation produced for parents. *Support for Learning.* Vol. 12 (3) pp 99-103.
- 21. Rehal, A. (1989). Involving Asian parents in the statementing procedure: the way forward. Educational Psychology in Practice. Vol 4 (4) pp 189-197.

Following the application of inclusion and exclusion criteria, 10 papers from the above list were selected for the literature review. Please see Appendix 1 for detailed data extraction and screening information, and Table 2: 'Studies selected for the literature review.'

Appendix 3 Participant information letter

What do parents' report of the Education, Health and Care needs assessment process?

Project Description

The Education, Health and Care Plan (EHCP) is a new way of making sure children with Special Educational Needs get what they need. The aims of the EHC assessment process are to reduce parental stress, the length of time in getting help and to improve children and young people's life chances. This research wants to question if parents reflect these aims in the way they describe their experience of the EHC needs assessment process.

If you decide to take part and wish to remain in the study throughout, you will give 3 interviews over the 20 week EHC needs assessment period. Each interview would last for around an hour. You will also be asked to complete a questionnaire at the end of the third interview, which should take no longer than 5 - 10 minutes.

Confidentiality of the Data

All audio recordings will be transcribed and data will be anonymised by removing identities and other possible identifiers. There will be no way of tracing your data back to you.

Location

Interviews will take place in XXX Town Hall unless participants would prefer an alternative location. Interviews will be arranged at your convenience.

Disclaimer

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor Dr Mary Robinson, School of Psychology, University of East London, Water Lane, London E15 4LZ. m.robinson@uel.ac.uk

Yours sincerely, Lucy-May Bentley lbentley@wandsworth.gov.uk 07929725053

UNIVERSITY OF EAST LONDON

Consent to participate in a research study:

What do parents report of the Education Health and Care needs assessment process?

I have the read the participant invitation letter relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to ask questions about this information. I understand the procedures in which I will be involved and these have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher involved in the study will have access to identifying data, which will be anonymised within 1 week. Any identifying data will then be destroyed. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself or my child and without being obliged to give any reason. I also understand that should I withdraw after my data has been processed, that the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)		
Participant's Signature		
Researcher's Name (BLOCK CAPITALS)		
Researcher's Signature		
	Date:	

Appendix 5 Overview and detailed descriptions of participants

Overview of participants

Name	Child's	Interview	Interview	Interview	Language,	Disability	Employment
	age, need	1	2	3	culture		1
	& gender				and		Partnered?
					ethnicity		
Asha	Age 4	✓	Extended	✓	Speaks	None	Unemployed
	ASD		holiday		Amharic		Father in
	М				and EAL,		another country,
					born in		separated.
					Ethiopia.		
					(BAFR)		
Fraser	Age 16	✓	√	√	Both speak	Fraser	Both
and	SEMH				English as	had a	employed,
Alison	М				their first	stroke	married,
					language,		living
					born in UK.		together.
					(WBRI)		
Kelly	Age 8	✓	✓	✓	Speaks	Visually	Unemployed,
	SEMH				English as	impaired,	separated
	М				first	moderate	from father,
					language,	learning	single.
					born in UK.	difficulty.	
					(WBRI)		
Kimberly	Age 7	✓	✓	✓	Speaks	Dyslexia	Unemployed,
	Central				English as		separated
	processing				first		from father,
	disorder				language,		single.
	F				born in UK.		
					(MWBC)		
Fiona	Age 5	√	✓	✓	Speaks	None	Married, lives
	ASD				English as		with father of
	М				first		child,
					language,		unemployed.
					born in UK.		
					(WBRI)		

Segal	Age 7	✓	✓	✓	Speaks	Self -	Unemployed.
	Not in				Somali,	reported	Father in
	education				born in	as	another
	Needs				Somalia.	depressed	country,
	undefined				An		separated.
	М				interpreter		
					was		
					present		
					during		
					interviews.		
					(BSOM)		
Suzannah	Age 12	√	√	✓	Speaks	None	Unemployed,
	Initially				English as		separated
	SEMH				first		from father,
	diagnosis				language,		single.
	now ASD				born in UK.		
	М				(BCRB/		
					BEUR)		

Ethnicity codes key:

BAFR Black African unspecified

BCRB Black Caribbean
BEUR Black European
BSOM Black Somalian
WBRI White British

MWBC Mixed White and Black Caribbean

Asha lived at home with her two children, her son of four years and a younger daughter. Asha spoke Amharic as her first language and also spoke English as an additional language. There was no need for an interpreter during interviews. Asha was Christian. Asha and the children's father had separated and he lived in a different country, so was not able to share childcare responsibilities or to have much contact. Asha had a close friend who helped with the children and who knew about her son's ASD. Asha reported the need to keep her son's ASD private due to her experience of negative judgement from others in her community. Asha gave the first and third interviews but did

not give the second interview as she was on an extended holiday in Ethiopia visiting relatives. Shortly before the third interview, Asha was informed that she was being evicted and so opted to conduct the third interview at school.

Fraser and Alison were a relatively affluent couple who were both employed in public sector jobs. Fraser contacted the researcher to take part in the study from the letters that were sent out during the first recruitment stage. Between interview 1 and interview 2, Fraser suffered a stroke that permanently affected his vision in one eye. The family lived together with their 16 year old son and their younger daughter.

Kelly was a mother of four children who was bereaved shortly before interview 3 when her mother died. Kelly was separated from her sons' father. The children's father had little contact or care responsibilities. Kelly described that she had had a Statement of special educational needs when she was at school due to learning difficulties and a visual impairment. Kelly bought her youngest son to school where we conducted interviews because she felt more comfortable being interviewed in a private place at school than at home.

Kimberley was a mother of four children and was recently separated from the children's father. The children's father had some contact and care responsibilities. Kimberley spoke English as her first language. She had just moved in to a new flat at the time of the first interview and had moved again by the second interview. Kimberley described herself as coming from a close family and valued the support of her parents and siblings who lived near by after the second move. Kimberley's youngest child had an existing Statement for ASD and Kimberly identified with being dyslexic.

Fiona was married and living with the father of her two children: a five year old boy and an older first child. Fiona's husband was a higher earner working in the City. Fiona looked after the children day to day without family support and was unemployed. Fiona spoke English as her first language. At the time of the first and second interviews, she was having extensive building works completed in the family home. Fiona experienced one of her son's

grandfathers as interested in learning about ASD and she explained the other felt that it was something her son would 'grow out of'. By the time of the third interview, Fiona described that her son's relationship with his father was 'much closer'. Fiona often expressed that she felt 'left' to deal with the EHC needs assessment process as her husband viewed it as her 'job'.

Segal was a mother of a seven year old boy. She spoke Somali and not English, so an interpreter was included in the interviews. Segal was a practising Muslim. By the second interview, Segal's son had been out of school for several consecutive weeks. She reported that her son's school stated that they could not meet his needs, and no other school had been identified for him to attend. By the third interview, her child had been out of school for nearly a year. Additionally, she was waiting to hear from Health if her son was going to receive a diagnosis, and she was not sure what the diagnosis might be. Segal reported that she was depressed. She was separated from her son's father, who had no contact with the family. Segal and her son were living in poverty and found it very hard to leave the house. Segal wondered if there would be a better life for her son in Somalia.

Suzannah was a single mother of four children. Suzannah was employed but finding it a challenge to make ends meet. Suzannah spoke English as her first language and was born in the UK. She had faced a long journey having her son recognised as having ASD, rather than SEMH focusing on 'behavioural difficulties'. Suzannah reported that she felt shy talking in groups or at meetings, and speaking was easier on a 'one to one' basis.

Interview 1

Tell me about your journey leading up to ______'s needs assessment being agreed by the LA.

What led to the identification of ______'s needs?

What do you remember about having your child's needs assessed?

What EP involvement has there been?

What has your relationship with professionals (such as teachers, SENCos and EPs) been like leading up to now?

What effect has the identification of ______'s needs had on family life?

What effect has the identification of ______'s needs had on their school life and your relationship with the school?

What are your expectations of the process now, leading up to getting the

Plan?

Within the narrative ask questions relating to attributions e.g. 'Why do you think that was?' Ask questions relating to schemata, e.g. clarifying meanings of particular words and asking questions about expectations, 'Was that what you expected?' and 'How did that fit with your previous experience?' 'Did that meet your expectations or alter them?' 'What do you mean when you say...?'

Interview 2

You have recently had your second TAC / outcomes TAC. Can you tell me what your experience has been since we last met?

What parts of your experience stand out as important that you would like me to know about?

Do you feel your views have been fully gathered during this process so far? (Co-construction)

Do you feel your views will have influence over the final Plan?

What EP involvement has there been?

Were you happy with the outcomes?

Were you offered the choice of a Personal Budget? What is the Local Offer?

What are your expectations for the rest of the process? What will happen next?

What will you do if you're not happy with the draft or final Plan?

Within the narrative ask questions relating to attributions e.g. 'Why do you think that was?' Ask questions relating to schemata, e.g. clarifying meanings of particular words and asking questions about expectations, 'Was that what you expected?' and 'How did that fit with your previous experience?' 'Did that meet your expectations or alter them?' 'What do you mean when you say...?'

Interview 3

What do you think of the Plan / EHCP?

Now that the EHCNA is completed, what are your views looking back over that time?

What parts of your experience are important, that you would like me to know about?

Do you feel your views, aspirations and choices have been properly represented in the Plan / EHCP?

Following this process, what are your feelings about your child's future?

Will the EHCP assist your child in achieving their best in the future? (E.g. work, relationships, transition to adulthood).

What effect (if any) will the Pan / EHCP have on family life?

How will you know that provisions outlined in the Plan / EHCP are being delivered?

Do you expect to have ongoing input into the EHCP / Plan? How would this happen?

Within the narrative ask questions relating to attributions e.g. 'Why do you think that was?' Ask questions relating to schemata, e.g. clarifying meanings of particular words and asking questions about expectations, 'Was that what you expected?' and 'How did that fit with your previous experience?' 'Did that meet your expectations or alter them?' 'What do you mean when you say...?'

Appendix 7 Interview schedules prior to refinement

Interview 1

 Tell me about your journey leading up to meeting threshold for EHC needs assessment. What led to the identification of's needs? Did you initiate the assessment process for your child? What do you remember especially from the time when your child's needs were first assessed by an EP? What has your relationship with professionals (such as teachers, the
SENCo and EPs) been like leading up to now? 6. What effect has the identification of's needs had on family life? 7. What effect has the identification of's needs had on their
school life and your relationship with the school? 8. What are your expectations of the next 20 weeks until the EHCP is agreed?
Within the narrative ask questions relating to attributions e.g. 'why do you think

that was?'

Ask questions relating to schemata, e.g. clarifying meanings of particular words and asking questions about expectations, 'was that what you expected?' 'How did that fit with your previous experience?'

Interview 2

- 1. You are now (16-19) weeks in to the EHC needs assessment process. Can you tell me what your experience has been since we last met?
- 2. What communication about the EHC assessment process has there been in the time since we last met?
- 3. What part(s) of your experience stand out as important, that you would like me to know about?
- 4. What can you say of the Lead Professional?
- 5. Do you feel your views have been fully gathered during this process so far?
- 6. Do you feel your views will have influence over the final EHC Plan?
- 7. What are your expectations for the upcoming final panel meeting? Are you planning to attend? Or

How soon do you expect to be informed of the EHCP after the meeting?

8. What will you do if you are not happy with the EHCP?

Ask clarifying questions around attributions, e.g. 'Why do you think that was? And questions relating to schema, e.g. 'Was that in line with your previous experience' and 'What do you mean when you say....?'

Interview 3

- 1. The final panel meeting happened (1-14) days ago and the EHC Plan is now agreed. What do you think of the final EHCP?
- 2. Now that the 20 week EHCP process is completed, what are your views looking back over that time, from when we first met to now?
- 3. What part(s) of your experience stand out as important, that you would like me to know about?
- 4. As a parent do you think your views, aspirations and choices have been properly represented in the EHCP?
- 5. Following this process, what are your feelings about your child's future?
- 6. Will the EHCP assist your child in achieving their best in the future?
- 7. What effect if any will the EHCP have on family life?
- 8. What effect if any will the EHCP have on your relationship with _____'s school?

Prompt greater detail and clarity by asking questions that relate to attributions e.g. 'Why do you think that was?' and schemata, 'Did that meet your expectations or alter them?' and 'what do you mean when you say....?'.

Appendix 8 An example of a table of contents from one of the codebooks

Table of Contents

Time Taken	Error!	Bookmark not defined.
Problem: Child	Error!	Bookmark not defined.
Clarifying needs / Labels / Diagnoses	Error!	Bookmark not defined.
Collaborative working	Error!	Bookmark not defined.
Paperwork	Error!	Bookmark not defined.
Supportive SENCo	Error!	Bookmark not defined.
Genuine care	Error!	Bookmark not defined.
Many meetings	Error!	Bookmark not defined.
Emotional Impact	Error!	Bookmark not defined.
Needs identified	Error!	Bookmark not defined.
Helpful school	Error!	Bookmark not defined.
Pressure on child		
The EP	Error!	Bookmark not defined.
Difference?		
Co-Construction (of EHCNA)		
Interpreters / Language barriers		
Other siblings better		
Listened to	Error!	Bookmark not defined.
Family supporting		
Defending school staff		
Kept informed	Error!	Bookmark not defined.
Future: out of my control		
'Bad parents'		
Empowered / Disempowered		
Useless professionals		
Incompetent school		
We've been failed	Error!	Bookmark not defined.
System unfair	Error!	Bookmark not defined.
Health effects	Error!	Bookmark not defined.
Safety concerns	Error!	Bookmark not defined.
Criminality	Error!	Bookmark not defined.
CYP mental health	Error!	Bookmark not defined.

Main themes
Sub themes

Subordinate themes

Codes

Application

Many meetings

Segal 1 Lines 57-64

S: We had a lot of meetings with the school. School school

L: Okay I can imagine it would have been a lot of meetings. I'm interested to hear what that process was like for Segal as a *parent*

I: [interpreting]04:49

We we went through *a lot*, I am happy he got a yes in the moment

L: But it was a long time to get it?

I: [interpreting]0518

Yes it was a long time.

Co-construction in 1st TAC

Segal 1 Lines 316-323

L: Um in the TAC remember we spoke about paediatrics, XXX EP, school, the TAC meeting. Did Segal feel she was able to communicate her views?

I: [interpreting]29:24

Yes we were, everyone was sharing his view

L: Segal's views, were they included? When everyone was writing on the EHC request, did Segal feel *her* views were written down?

I: [interpreting]30:00

Yes, everything I mentioned they were writing it

Poor communication

Susannah 1 Lines 220-229

S: And so I said they refused? She said didn't the social worker get back to you? And I said *no* I've heard nothing.

L: so that's you not hearing back

S: From everybody

L: Not proper communication.

S: And you just don't know who to go to or what.

Asha 1 Lines 807-811

A: I went to XXX (resource base manager). I went every day, so I took the letter. When I show her how, I fill it the same. Why? And they she they send me forms. Even she couldn't understand the letter, she said, um even the date she fill it or something. Even not me couldn't understand.

L: Yes, even XXX (resource base manager)'s saying what is this?

Many appointments

Kimberly 1 Lines 106-111

K: So then, we kept having that done and then they decided for her to go to, ah, ah to XXX hospital, under Doctor XXX Paediatric Doctor and keep getting constant testing done every six weeks, eight weeks, constantly.

L: How did that affect you at that time?

K: It was hard, it was really, really hard because it was coming back negative, negative, negative.

Time taken

Time taken

Segal 1 lines 44-49

L: Ah okay so he got it the 29th of April. Okay so it's been a little bit of time. Okay so can Segal tell me about her journey leading up to getting that yes on the 29th of April?

I: [interpreting] This process was covering to 2 years!

- L: Wow! 2 years
- S: Mmmmmm!

Segal 1 lines 60-64

I: [interpreting]

We we went through *a lot*, I am happy he got a yes in the moment

L: But it was a long time to get it?

I: [interpreting]05:18

Yes it was a long time.

Fraser 1 Lines 111-114

F: And we were worried about that, and we took him to CAMHS at 6

L: And how old was he when he was hurting himself and you took him to CAMHS?

F: We took him to CAMHS when he was 6. It was round about that time or slightly earlier y'know doing that

(NB Year 11 child just getting EHCP)

Fraser 1 Lines 744-809

L: So you would expect them then to put a, quite a rush on getting the EHCA needs assessment so that he could get the support that they would allow in school

F: You would hope so. So so, actually, diagnosis must've come before September because we put in for the statement in September before going over to the EHC 35:08

L: Yes

F: Which then was rejected because it was the week they were changing the system.

L: Oh, so they said essentially reapply

F: Reapply

L: And what did that mean for you? Did that mean that then you had to do all of this process from the beginning?

F: Yes yeah so we had to, so we put in the statement and then had to start again. So we had to sit down with all the professionals cause he's in the midst of him 35:32 having problems at school and us having to deal with him here. I mean and both of us working full time my wife part time

L: When you'd been recently bereaved at that

- F: Recently bereaved and I've got a 9 year old daughter 35:42 doing really well at school
- L: But also has needs
- F: Ah huh
- L: As a child
- F: And she's been ignored because we're having to 35:47 concentrate on him all the time
- L: And so you've got such a lot on your plate and then you have to go through the process again essentially.
- F: So we have, so we go through the process again and that involves eh so (3) 35:59 so we got rejected because the statementing process had changed to the EHCP system so we were told to reapply. Now when did we reapply was it January?
- L: So it took quite a lot of time to reapply?
- F: Yeah. I can, I can probably get the exact dates for you
- L: I can probably look them up in the pack I have, I have M's application
- F: Right, it did take a long time for us to reapply.
- L: And that's not, when you say 'us', that's not *you* because you're, you know, the 'us' it's it's your, it's your, who? at school coordinator
- F: Well it's XXX, the Head of Inclusion 36:37 who's been just amazing support for M. And I don't know if whether she's doing it for others at the school but their their application process or the new process took so long despite us pushing pushing pushing constantly 36:54
- L: Mmmm
- F: And asking for it took months so she can see ehm (4) in fact it might have been later than January. Let me get the dates from her ehm. So XXX (Head of Inclusion)
- L: And all that time of course, M wasn't getting the one to one you all decided that he so clearly needs
- F: Yeah

Fraser 1 Lines 852-861

- F: But actually it must have been, so the process must have been started round about the time he was arrested because I remember being here when XXX EP came round to write the EP report 38:45
- L: Well that would be right. Psychological advice 38:48
- F: So and well, you know, she seemed quite taken aback about the length of time it had taken as well 38:57
- L: Yes, I'm not surprised!

Susannah 1 Lines 29-37

S: He's been having lots of problems at school from at nursery always been there

- L: So how old is he now?
- S: He's 12 now.
- L: So this has been a long time for you!
- S: It's been a long time.

Susannah 1 Lines 199-218

- L: So you *kept* finding that you weren't meeting threshold you meeting threshold. And there were these really strong incidents of behaviour here, knives, very sexualised behaviour
- S: Yeah
- L: distress
- S: So that one fell through so then in the end when I went to the doctor again she write a letter I mean social services didn't even send it to her they sent it to me, to send off back to the doctor, which the Doctor said *they* were supposed to do. And to send it to her. So then what happened I saw the doctor in the saver centre place and she said to me haven't you heard nothing and I said no and she said they refused it again saying about the sexual behaviour.
- L: And this is a CAMHS referral that just kept getting sent back
- S: Yeah and refusing
- L: again

Susannah 1 Lines 280-303

- S: was so angry and they said you write a letter and explain everything what's going and that's how we got on but.
- L: So it took *years*
- S: Mmm (agrees)
- L: And it took *years* of not proper communication, being passed from person to person, between social work, educational psychology and CAMHS all passing your case around. S: Yup.
- L: Well, I'm sorry to hear about that. It's terrible.
- S: It's alright. And then it was a nightmare and I got my first assessment and it was nine months wait to and he got assessed in April 2014.
- L: Oh oh!
- S: And they diagnosed him with ASD
- L: Finally
- S: Ahh.

Asha 1 Lines 59-74

- A: Ya, before XXX (Nursery ASD resource base). I went there, ah just they helping him. Still I didn't get anything and I asked to something help. Maybe XXX (Nursery ASD resource base) (2) but I have to know. Many times I went there. They couldn't decide what.
- L: Ah
- A: When they look at him, he's positive, he's healthy.
- L: Yeah, yeah.
- A: But, some thinks he's behind.
- L: Oh
- A: Finally, they sended him at XXX (Nursery ASD resource base). Almost I started long, it takes me long but finally November, November 26th he's start there.

Afomia 1 Line 898

A: And still now they didn't finish it (the Plan)

Kimberly 1 Lines 253-270

K: She's been under school action I think, since she has been in year one, she then went onto school action, plus what she has been on for the last two years. But the school really messed up

L: Oh?

K: last year. What happened was, we was going for this Great Ormond Street, they wanted reports and what not which they've got and the teacher that was there for that eight months, doc, ah Mr S had done everything for me, him and M really bonded with him and then he left. In that time, I had requested already for a Statement of M's needs.

L: Yeah when it was the statement

K: Back last year, not last year, the year before that.

L: So like twenty thirteen, twenty thirteen yeah then it must have been?

K: Two years ago, two years ago, I write myself. With the teacher, with Mr W, the worse SENCo, he had so many jobs, he was the head, he was a class teacher and he was also a SENCo

L: And was this the school that went into measures?

K: And that's when in went into measures, as soon as Mr W left, which I think was two years ago.

Kimberly 1 Lines 278-285

L: So you've been actually looking for M to be, for M's needs to be assessed since twenty thirteen and its now happening in the latter half of twenty fifteen.

K: Twenty fifteen, yeah

L: And how do you feel about that?

K: Oh, I'm absolutely disappointed because she is never going to get this time again.

L: Yeah

Segal 2 Lines 428-436

- This has been going on last three years. And there's not a definite information. To to pinpoint what has happened what has not happened
- L Mmm mm
- S/I Speak Somali
- I She said that mum feels that I feel shall I just move out of this country cos my child has not rights in this country, um, and go somewhere else

Susannah 2 Lines 363-367

S: I just said he was letdown, he was letdown, letdown. Because as far as I am concerned, from nursery there were like things going on and if it was the right people in that school like I was saying there's something going on, if there were the right people in that school he would have got recognised. He wouldn't have to wait till year 6 year 5 to get diagnosed

Fraser and Alison 2 Lines 569-576

Erm and we *did* have at school you know even at primary school art therapy you know tiiiiiiiiime out you know positive time out just to give him he needed some quiet space and and you know he just needed a little bit more support but not enough (2) to have full time support

L: Sure yeah

A: Erm and they did, erm at one say to us I remember actually of the the (quietly) learning erm special learning assistant said there is this thing um you know a statement you can fill out all this information but I don't know whether you know would want to do that. So

Fraser and Alison 2 Lines 622-626

A: That that (2) ah eh I haven't decided (laughs, high pitch) you know I hope we're

gonna actually do! I just cannot believe that all these highly trained professionals didn't in the 4 years stop and think (2) we need to get this boy some extra help

L: Yeah

A: I cannot believe that it took to now for them you know

Fraser and Alison 2 Lines 652-655

F: And that's because they've taken this EHC up to the wire. XXX (LA case manager) made the point that if the referral had just been done properly a year ago we would be A: In a much better position

F: Half way through

Fraser and Alison 2 Lines 1399-1403

A: I suppose it is kind of ruling out that that they have looked at everything and all been done and everything

F: Yeah

A: Yeah, but it's actually what we spent the last 10 years doing? (Laughs) Trying to rule things out and rule them in!

Kelly 2 Lines 82-90

K: And I don't think anybody really thought about it til he got to Year 3 (4:23)

L: Yeah? So quite late in a way but the signs were there

K: Yeah

L: You did keep saying

K: I look him to the GP!

L: Before he started even in the nursery (4:35)

K: Yeah

L: Yeah. So all the way up to Year 3. So nursery

K: I said it to them in Year 2

Kelly 2 Lines 107-111

L: Um (2) what was it like for you saying that you were worried but taking can I say, a long time for other people to listen?

K: Well it was long. Quite well frustrated sometimes and not a lot I could do than what (3) But I kept saying and to them that I think. And I think it wouldn't have got so bad as like um now, it was (3) if they had tried harder for his learning back from when he was

Fiona 3 Lines 354-359

R ... taken over a year and a half to get this for him.

I Yes, so long...

R And, you know, that's a year and a half of...

I ... and so much energy.

R ... you know, loss of progress as well, because even though Sh XXX Primary School did give him the one-on-one...

Kimberly 3 274-282

R She wa-, she wa- ... she has been definitely, but it's ... this is why I feel that the school's not really working for her with special needs, because she's waited so long for this. But I think if they would have given this to her ...

I Yeah.

R ... to ... when she was in such a bad, a bad patch of her learning ...

I Yeah.

R ... it could have helped that little bit more.

I So if it was sooner it would have been a lot nicer.

R Yeah, I think so. I think they've left it a little bit too long.

Segal 3 Lines 68-73

- T ((Translation)) She's saying that the doctors, when they met the doctors... the doctors say
- I Yeah.
- T ... the doctors think he's supposed to see this child earlier than that.
- I Ah yeah, yes. It took a long time, didn't it? Yeah.
- T To support this child with the sickness.

Segal 3 Lines 407-426

- I She knows what it is. So, just ask her: is there anything else I should know about parents' experiences of what it's like getting the Plan?
- T ((Translation)) She's saying... ((Translation)) The thing is she says it was difficult for her because it's not straightaway.
- I Yeah.
- T For her it was not; it was like three years away. And the school... ((Translation)) The school made her wait for three, for three years.
- I And can you ask her why she thinks that is? And that is terrible, and I want to know why she thinks.
- T ((Translation)) Because the school is... ((Translation)) The school didn't... just referred H to the doctors very early, and they were so, so many investigations.
- I Ah.
- T It made, made the plan take long. Long
- I Okay, okay. Um, so it was slow referral?
- T Yeah, slow referral, yes.
- I By the school?
- T By the school to the doctors.
- I Okay, okay. And (6) in the time when they were being slow did they just not realise how serious it was?
- T ((Translation)) I don't know, she says. Some, somehow they make it very slow.

Loss of potential progress- time taken

Fiona 3 Lines 354-359

- R ... taken over a year and a half to get this for him.
- I Yes, so long...
- R And, you know, that's a year and a half of...
- I ... and so much energy.
- R ... you know, loss of progress as well, because even though Sh XXX Primary School did give him the one-on-one...

Fiona 3 Lines 1833-1845

- I'm thinking about your first knock-back F, so the first time you had no....
- R Mm
- I ... if you'd got, if it all got done then...
- R Yeah.
- I ... what would that have been like? It would be like quite a different process.
- R Yes, it would be because I mean he, he's still, he would have had the same oneon-one. I mean Sh XXX Primary School was so good and it put that one-on-one in place...
- I Yeah.
- R ... for him, but I think it probably could have opened up more speech therapy, occupational therapy...
- I Mm.
- R ... earlier on.

Kimberly 3 274-282

- R She wa-, she wa- ... she has been definitely, but it's ... this is why I feel that the school's not really working for her with special needs, because she's waited so long for this. But I think if they would have given this to her ...
- I Yeah.
- R ... to ... when she was in such a bad, a bad patch of her learning ...
- I Yeah.
- R ... it could have helped that little bit more.
- I So if it was sooner it would have been a lot nicer.
- R Yeah, I think so. I think they've left it a little bit too long.

SEMH-no help

Fraser and Alison 2 Lines 1485-1512

L: Just staying there, and then so in transition (?) to secondary school, where did you see it, there was a particular moment where things went downhill. Starting?

A: So it started with his SATS when um, he started playing with his hair and he had a big hole in his scalp

L: Yeah?

A: Yep

L: Oh no!

A: Yeah, he, it was pick, pick, pick and that was when we did get appointment with CAMHS, and

L: And they said no nothing?

A: They were like oh, well we went through the whole interview, duh, duh, duh, we got to the end of it and I said, and what about you know, this, and they were like oh yes don't worry about it, that's fine

F: They did the test and that paediatrics, that dragon. They said it was probably hormonal

A: Yeah

L: What hair loss?

F: Yeah and so they checked his testicles, and they said, which M didn't like at all

L: No! My god

F: And then they said he's probably hormonal

A: Yes hormonal

F: Can you

A: It was, as a baby he used to do

L: Soothing?

A: Yes, he used to kind of curl, and he was just kind of the crown, rubbing actually

L: Gosh, gosh

A: So that was that. Bless him and it was just kind of stress though, SATS. And that kind of went and then um, when he went in to secondary school, yeah he was just, I think he realised quite quickly he had to kind of sink or swim.

SEMH- harder to recognise

Fraser and Alison 2 Lines 1145-1182

A: Yeah, because I think actually, whilst this is all happening, for us in our case now, I, I can see actually, I think what is quite interesting if you take it right back to the root of why you need the plan, you will have children who

L: Hmm

A: Have needs that are not behaving, adverse behavioural, they can't learn because there is a dexterity thing or

L: Yes

A: A neurological

L: And clear cut cases like this child needs a EHCP because they will be wheelchair-bound forever, and they need and they need certain

F: Yeah

L: Adjustments to access education, environment, it's not it's not so difficult A: Yeah. I think that kind of experience of filling in that plan, would be a wholly different experience to our one where M is having behavioural difficulties at school. Because they're pushing him down the discipline route, and I think actually you know, we have been at the, behind this thinking we've got to keep the school in sight, because we don't want him kicked out, while they help us get through this process

L: Gosh

A: So there's a conflict there

L: A real emotional impact

A: A real conflict in trying to kind of manage that

L: Hmm

A: But thinking (2) we need to kind of use the school to get

L: Yeah

A: To where we need to be, and if they weren't there for us, you know, we've heard all sorts of things as we've gone through this process of well if he does get expelled then he really is in the PRU then it really does show that he needs a statement

A + L: (laugh)

L: Yeah, yeah, obviously

A: But we're back to dealing with people who he doesn't know and we'd have to start our story all over again, and we'd have to

L: And you've got peer group influences there

A: And M actually has said, and you know it's quite powerful a I suppose that was the point I was getting to when I said we'd listen to his views

L: Hmm

A: Was that in these moments you know, where real engagement with him. He didn't want to go there, because he knows that he'll get into trouble much, much more trouble. So we put that in actually, he fears for his own safety if he goes there

Kelly 2 Lines 62-65

K: And I remember taking him to the doctors and saying he hits his head off the floor, he hits his head on the wall and they said oh it's terrible twos. He is just a baby, he does not understand, ignore him. But it went on and on and it was just *never* ending and then he ended up coming to nursery here

Getting no from panel

Knocked back

Susannah 1 Lines 199-218

L: So you *kept* finding that you weren't meeting threshold you meeting threshold. And there were these really strong incidents of behaviour here, knives, very sexualised behaviour

S: Yeah

L: distress

S: So that one fell through so then in the end when I went to the doctor again she write a letter I mean social services didn't even send it to her they sent it to me, to send off back to the doctor, which the Doctor said *they* were supposed to do. And to send it to her. So then what happened I saw the doctor in the saver centre place and she said to me haven't you heard nothing and I said no and she said they refused it again saying about the sexual behaviour.

- L: And this is a CAMHS referral that just kept getting sent back
- S: Yeah and refusing

L: again

Susannah 1 Lines 234-269

S: So I went to the school and said something has to be done, the doctor said this. So, in the end they got him in and he (EP) said that if he helps then CAMHS won't help or something like that.

L: Oh!

S: So that was

L: Is that like umm do you remember who it was?

S: XXX EP

L: XXX EP oh ok

S: So he was like see what they say

L: Do you remember how long roughly not precisely.

S: About 2/3 years ago.

L: So he thought if he got involved then CAMHS wouldn't

S: Yeah

L: So he sort of advised you to go back to CAMHS.

S: Yeah yeah

L: And did was that because he thought the need was very high?

S: I don't know because that's what I said cos at the same time I was so stressed I didn't know who to go to

L: Yeah!

S: this place is sending me to go to this person, and that place is sending me to go to this

Asha 1 Lines 780-894

L: And my last question is, what are your hopes and your expectations about the plan that they're making for E?

A: Normally, um they say he can speak, he doesn't need special needs. They close him. We reply, they send him to court

L: Oh, so it's going to go to tribunal?

A: Yes, well now they accepting again. We fill in the same. They asked XXX (resource base manager). She told them I feel the same with the other one. I don't know why

L: The first time it was rejected from the panel?

A: We put if before reception, they ignore it. And now I say that he's couldn't eating he's fussy eating

L: Yes

A: So if he doesn't listen, he will be with the rest of the school class. (Talks to friend) Ah yes so sorry. So they closed the thing

L: They said no! No, so you had to send it back and then it got a yes?

A: Ya

L: And then when you got a 'yes', I got your name and I asked you

A: I went to XXX (resource base manager). I went every day, so I took the letter. When I show her how, I fill it the same. Why? And they she they send me forms. Even she couldn't understand the letter, she said, um even the date she fill it or something. Even not me couldn't understand.

L: Yes, even XXX (resource base manager)'s saying what is this?

A: And she called him, mm what's wrong? You need (Inaudible). We know, we are special to her. We need why are you ignoring and she come in and I think one lady. They send him to big school.

L: Yes

A: When she see him, watch him

L: Ahh

A: She was *surprised*. Why they saying *no*

L: So they took him out of XXX (Nursery ASD resource base) base and put him into what they call big school and then they could see that he needed extra support

A: Yes when she he watch him *why*. She said why is ignore him?

L: So they added some support to the

A: Still he will be late because of the that, couldn't get in September.

L: Oh gosh.

A: Yeah yup

L: So he's not in school in September?

A: Yeah, no

L: Ahh I'm sorry that you couldn't get in

A: Because of *them*. I don't know why they when I read it, I can't read! So I couldn't understand of them. Or maybe it's my language

L: So you doubted yourself but

A: Even I keep him at home for one week. It becomes stressful.

L: Yeah

A: Did you ask yes, so I keep him at home because I don't want to (2) when they said no, I thought it's no. So what can I say? How I can't help him?

L: And how did you find out that you could re-apply?

A: I went to XXX (Resource base manager)

L: XXX. XXX helped you to say you can do it again

A: You can do it again, this is normal. Don't don't give up

L: It does happen

A: Yeah, yeah she tell me it's normal but-

L: Stressful for you

A: Ya, she said, don't worry I will call them and make sure everything is easy

L: But you felt sad

A: Yeah. I feel sad

L: Yeah

A: At the time

L: Yes at that time

A: I couldn't remember anything so. Yes and if he don't understand (2) he's sitting (2) when he do something or when. He don't know

L: Yes and they don't understand

A: He would be down.

L: He would be down

A: What I can do for him. How I can take care of him. So she say, it's okay, don't worry. I'll sort that myself. And when she talk to them, one lady she watch him with peoples with childrens she said why. He's different totally. They can't know him or why they did this? and (33:44)

Kimberly 1 Lines 307-316

K: ...he tried to give that to XXX London Borough council, Mr W and asked for a statement. Didn't take no paperwork, didn't take nothing. They wrote back to me last summer and told me no, the summer of, so we broke up on the you know July, so yeah. Sorry, is he digging at you?! cross talk 13:46-13:48)

L: I'm just going to move my feet there we go!

K: So yeah, I have a, so basically he didn't send no evidence that he was meant to, he told me that he was.

L: And this is the old head teacher?

K: Yeah, the old one. And I turned round to him and said this is a joke?

Rejected from EHCNA panel

Kimberly 2 Lines 452-464

They knew that they had to get all of this done cos if XXX LA were to come back to me and say no again, I would have gone to Ofsted, hit the roof, the Sun newspaper, I would have shouted till somebody hear me. Just for that fact that this was the second time now. And I was broken hearted when they told me that they weren't going to do it. And I am sitting here like what?

L I've had other parents saying this to me and it comes down to paperwork. Somebody not doing paper work.

K Basically. Basically.

L So sorry that happened.

K He said "I'll handle the paperwork. I'll do it, I've got the paperwork, I'll send it off". He didn't handle the paperwork.

Fraser and Alison 2 Lines 604-613

F: It was submitted wasn't it?

L: Because we're now going to EHC?

A: It was drafted

F: Ehh (disagrees) I think (2) the council refused it. The council refused it. No it was the fact and the council said

A: Oh yes that's right

F: No. The council turned it down

A: Mmm (agrees) no but that was that was em (tuts) that was the eh it was a the *new* form and they had I think used the old format. They hadn't provided enough information about how much funding the school

Fiona 2 Lines 35-44

R And I suppose from all of that it led to the school putting it the all together. Well at Sh XXX Primary School the first time.

I What? You had to do it twice? The request?

R Well yes. You know and I have to say that was, it was really hard. At that time. So they were amazing eh SENCo girls in the SENCo team but well yes. It was really new I think it was the first one they did.

I Oh.

R It was it was (sighs), well I came home and phoned S and I don't know, it was awful, I just sobbed. But he was the one who said, no, come on, we can fight it.

Fiona 2 Lines 274-281

R Yes, we did. It was eh you know, awful getting that 'no' the first time when Miss XXX phoned up to say. She was very you know, said we will just put it in again, but it was well (laughs) bleak. I eh thought 'what if it gets sent back again and A will just get lost in the school system' because he's the sort of boy who would be utterly lost.

I It sounds so tough, I don't think I've really realised what it's like for parents to get a no from the panel.

R It was it was.

Helpful school

Fiona 2 Lines 286-290

R They reassured me at the school eh they would put in the extra evidence, but it was ridiculous really. The letter explaining why he had a 'no' said he could not be assessed because he was already making good progress with his TA. But we were applying for the TA, to you know fund the TA. We were just lucky that the school had put it in place before. Thank goodness really.

Hard to proceed after knock back from panel

Fiona 3 Lines 346-357

- R You know, you have the option to go back fighting, but unless you're perhaps a good school with a good SENCO team behind you...
- I Yeah.
- R ... um and you've got, as I say, the support at home...
- I Yeah.
- R ... it's quite hard to think, "Yes, I can go back," because it's such a... I mean it's...
- I Yeah.
- R ... taken over a year and a half to get this for him.
- I Yes, so long...
- R And, you know, that's a year and a half of...
- I ... and so much energy.

EHCNA rejected- crushing

Fiona 3 Lines 645-647

I mean when we found out they initially said no, I mean it was crushing. I mean I walked from Sh XXX Primary School and St M XXX Primary School in floods of tears.

Asha 3 Lines 655-666

- R We did it, this...
- I You did it?
- R Yeah, they said he doesn't need, they say. Yeah not put him on it!
- I So you re-applied.
- R Reapplied, me and my... XXX resource base manager.
- I XXX resource base manager. Oh good, okay so you have that experience.
- R Then she call them, then they said me something. I was crying and they go, XXX resource base manager, they said no she say no worry, don't worry, I was crying, they said no. E, he need help, please. She said don't worry and she called them she met through the proper channel which E, and they sent letters and we fill it everything they tell us about E, they sent the money that they sent.

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

SUPERVISOR: Mary Robinson **REVIEWER**: Paula Magee

STUDENT: Lucy-May Bentley

Title of proposed study: What do parents report of the Education, Health and

Care needs assessment process?

Course: Professional Doctorate in Educational and Child Psychology

DECISION (Delete as necessary):

*APPROVED

*APPROVED, BUT MINOR CONDITIONS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES

*NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED

APPROVED: Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is <u>not</u> required but the student must confirm with their supervisor that all minor amendments have been made <u>before</u> the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

minor amendments required (tor reviewer):		
Major amendments required (for reviewer):		
Confirmation of making the above minor amendments (for students):		
I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.		
Student's name (Typed name to act as signature): Student number:		
Date:		
Bute.		
ASSESSMENT OF RISK TO RESEACHER (for reviewer)		
If the proposed research could expose the <u>researcher</u> to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:		
HIGH		

	MEDIUM	
	LOW	
Reviewer comments in relation to researcher risk (if any):		

Reviewer (Typed name to act as signature): Paula Magee

Date: 13/04/2015

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee (moderator of School ethics approvals)

PLEASE NOTE:

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: http://www.uel.ac.uk/gradschool/ethics/fieldwork/