

**Choosing and securing secondary provision for their child on the autistic spectrum – an action research project investigating parental motivations, experiences and suggestions for improvement to practice**

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## **Abstract**

Previous research has shown that choosing a secondary school for a child with a diagnosis of Autism Spectrum Disorder (ASD) is very difficult for parents, with parents emphasising the weight and anxiety of the decision-making process. The Children and Families Act (2014), more than any legislation before it, has embedded the right to parental choice and voice when choosing a secondary school. However, there is scant research into parental experiences of securing appropriate secondary placements for their child with an ASD; additionally, no research to date considered how the statutory processes and practices triggered by the 2014 legislation, and accompanying Special Educational Needs and Disability Code of Practice, have impacted parental perception, experiences, and decision-making. To extend the evidence base, this action research project set out with two aims - firstly to explore, via semi-structured interviews, the experiences and motivations of parent participants (n=7) when choosing and securing secondary provision for their autistic child; secondly, via a focus group (n=5), to actively seek suggestions from parents about how practices and support could be improved, thereby developing their sphere of influence.

The interviews were analysed using Interpretative Phenomenological Analysis, focusing on both parents' idiographic accounts and patterns across cases. Three key patterns, or 'Master Themes' emerged from the cross-case analysis: A difficult journey; Those who prevail and those who become lost; and The factors that influenced choice and decision making. All participants set their school choice experiences within a long and convoluted process, and all described personal, relational and systemic obstacles – often using language and metaphor related to journeys and battles to describe their experiences. They felt helped by allies but hindered by wider systems. There was a sense, both conscious and unconscious, of personal metamorphosis and growth, of the educational journey with their child changing them, or forcing them to change and acquire personal power, sometimes knowingly subverting processes. The findings were contextualised with reference to a theoretical and conceptual framework developed by the researcher, which includes relevant paradigms such as Bronfenbrenner's Ecological Systems Theory and Bourdieuan Cultural Capital.

Provocative propositions developed during the focus group's Appreciative Inquiry, encapsulated suggestions for improvement to practice relating to: i) improving clarity of communication/information sharing; ii) ensuring meaningful collaboration; and iii) improving outcomes for autistic children.

Implications for practice and possibilities for future research were also considered.

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Lastly, Geoff, always my rock. Thank you for all that you do, for us all.

## **List of abbreviations**

- AR – Action Research
- CASP – Critical Appraisal Skills Programme
- CoP – Code of Practice (2015)
- CYP – Children and Young People CoP
- DSM - The Diagnostic and Statistical Manual of Mental Disorders
- EP – Educational Psychologist
- EHCP – Education and Health Care Plan
- FG – Focus Group
- ICD - International Classification of Diseases
- IPA – Interpretive Phenomenological Analysis
- LA – Local Authority
- MMAT – The Mixed Methods Appraisal Tool
- SaLT – Speech and Language Therapist
- SCP – School Choice Process
- SEMH – Social, Emotional and Mental Health
- SEND or SEN – Special Educational Needs and Disabilities
- SENCO – Special Educational Needs and Disability Coordinator
- SRB – Specialist Resource Base
- WHO - World Health Organisation

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# **1. Introduction**

## **1.1 Overview**

This chapter aims to contextualise, explore and discuss areas related to the phenomenon of parents choosing and securing secondary provision for their autistic child. It begins with an outline of the research, before locating it in a regional and national context. Additionally, as the author of this study, I reflect on how my own experiences and positioning serve to both elicit and inform the trajectory of the research. Key concepts and theories relating to the research topic are also explored. Finally, a theoretical and conceptual framework is presented which draws together the key ideas presented - a flexible referential schema through which to frame and consider my findings.

## **1.2 Research outline**

Previous research has shown that choosing a secondary school for a child with a diagnosis of ASD is very difficult for parents, with parents emphasising the weight and anxiety of the decision-making process (McNerney et al, 2015; Reed et al., 2012). The Children and Families Act (2014), more than any legislation before it, has embedded the right to parental choice and voice when choosing a secondary school. However, there is scant research into parental experiences of securing appropriate secondary placements for their child with an ASD and no research considering how the statutory processes and practices triggered by the 2014 legislation, and accompanying Special Educational Needs and Disability (SEND) Code of Practice (CoP), have impacted parental perception, experiences, and decision-making (see Somner, 2021).

## **1.3 Placing research into context**

### **1.3.1 Key concepts**

#### **1.3.1.1 Autism Spectrum Disorder**

##### **1.3.1.1.1 Definition and changes in diagnosis**

The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association [APA], 2013) diagnostic criteria for autism highlights needs related to “social communication and social interaction”, with individuals also displaying “restricted, repetitive patterns of behaviour or interests” (p. 50). Previous to DSM-5, four separate sub-categories of autism were consolidated into one umbrella diagnosis of ASD, these were Autistic Disorder, Asperger Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder (PDD). However, due to concerns around inconsistencies in diagnosis of the different subtypes (see APA fact sheet, 2013), the DSM-5 stated that “individuals with a well-established DSM-IV diagnoses of autistic disorder, Asperger’s disorder or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder” (p. 51). In addition, the three previous categories of autism symptoms – social impairment, language/communication impairment, and repetitive/restrictive behaviours - were consolidated into two, these being persistent deficits in social communication/interaction and restricted, repetitive patterns of behaviour. Incorporated into the latter category was an acknowledgement of ‘sensory issues’, which covered hyper- or hypo- reactivity to stimuli or unusual interests in stimuli. Similar changes were mirrored by the latest draft of the World Health Organisation’s (WHO) International Classification of Diseases (ICD-11, 2019), however unlike the DSM-5, the ICD-11 does not specify a certain number or combination of features to meet the threshold for autism, instead it lists a range of key features to enable clinicians to make their own informed decisions.

While Autism Spectrum Disorder is currently the preferred diagnostic term the present study chooses hereafter to use the term, ‘condition’ rather than ‘disorder’ to recognise autism as a ‘difference’ rather than a ‘deficit’ (Baron-Cohen, 2012).

### **1.3.1.1.2 Autism Spectrum Condition and school experience**

Autism Spectrum Condition (ASC) is a lifelong neurodevelopmental condition that affects an individual's ability to interact and engage with other individuals and the wider world around them. Children and young people (CYP) with an ASC can, amongst other things, misread nonverbal interactions, have difficulty building friendships appropriate for their age, be highly sensitive to changes in their environment, or be overwhelmed by sensory stimulus (Maiano et al., 2016; Licence et al., 2020). It is therefore unsurprising that previous research has highlighted the struggles and high levels of anxiety that they face within educational contexts, as their intrinsic autistic characteristics clash with factors within the school environment (Eldar et al., 2010; Ambler et al, 2015; Goodall, 2018).

Transition to secondary school can present a particular challenge to CYP with an ASC. Secondary schools are often physically larger, transitions between classes more frequent, and support reduced while demands on academic achievement increase. The social milieu also becomes harder to navigate upon reaching adolescence, with autistic CYP reporting anxieties related to feeling marginalised (Calder et al., 2013), alongside pressures to 'fit in' and 'act normal' (Carrington and Graham, 2010; Ackerley, 2017).

Research exploring parental experiences and perspectives related to school choice and transition acknowledges the emotive impact of their child's ASC diagnosis, highlighting anxieties related to potential lack of ASC specific provision (Tissot, 2006 & 2011; McNerney, 2015), lack of appropriate support for their child (Parsons et al, 2009), or their child not being able to cope/feeling distressed (Tissot, 2011; McNerney, 2015; Tobin et al, 2012). Noteworthy however, is the fact that child-level factors such as autistic features were commonly not perceived by parents as the main reason behind successful or unsuccessful experiences. Instead school and system-related factors - including hold-ups to placement decisions and perceived lack of preparation, planning, and information transfer between schools or between parents and the LA, were seen as the main determinants of transition success, or lack of it (Hoy et al 2018; Makin et al 2017; Tobin et al, 2012).

### **1.3.1.1.3 Prevalence**

A recent large scale study (Roman-Urrestarazu et al., 2021), drawing on data from the School Census on the National Pupil Database, reported that around 1.76% of CYP in the UK is on the autistic spectrum, an increase from previous estimates of 1.57%. Recent Department for Education (DfE) SEN data indicates that it is the most common primary need for an Education, Health and Care Plan (DfE, 2021).

Local data from my LA, concurs with this increase in prevalence, with autism logged as the primary need in the county on the register for disabled children 2019 (Norfolk SEN Strategy, 2019). This increase could be indicative of an increase in the number of individuals with autism and / or due to increased awareness and diagnosis of the condition. Whatever the reason, it seems likely to have an impact in terms of the availability and suitability of appropriate educational provisions (see Somner, 2021).

### **1.3.1.2 Theoretical perspectives**

#### **1.3.1.2.1 School choice and decision making**

Previous ASC-specific research focusing on school choice has identified that parents were given and sought advice from a range of professional and non-professional people (McNerney et al 2015). McNerney et al's study also found that parents who valued a social model of disability – i.e. who believe that people are disadvantaged by barriers in society, not their difference – tended to prefer inclusive mainstream provision, believing that it would provide better social integration, particularly with other children in the same neighbourhood.

Conversely, those parents who implicitly leaned towards a medical model –where the child is labelled as needing special support – tended to enrol their children in specialist provisions. Interesting to note was that some parents with a 'social' view, who had originally chosen a mainstream provision, then moved their children due to a perceived lack of support or worries about their children's anxiety and unhappiness (Byrne, 2013; McNerney et al, 2015).



While there is no ASC-specific literature relating to relevant decision-making theories, Booth (2017) presented a range of theoretical models of decision making which she believed are pertinent to parental choice-making when choosing secondary placement for their children with special educational needs (SEN). Many of the theories presented, such as the Information Processing Approach, derived from cognitive psychology and economics, focusing on decision making situated within the individual. However, one could hypothesise that a parent's experience of the decision-making process when choosing secondary provision for their child on the autistic spectrum is likely to be influenced by an array of factors. These factors may include their models of disability and attitudes to their child's SEN, their constructs related to the merits of different types of provision, previous social interactions, and social interactions during the school choice process (SCP). Therefore, a natural extension of this hypothesis is that a model founded on a social constructivist premise that decision-making is interactional and socially situated, rather than wholly individual, such as the Social Constructivism Model of Ethical Decision Making (SCMEDM, Cottone, 2001), would be well suited to illuminate their experiences. Constructivism will be considered in more detail in the methodology chapter.

Whilst the SCMEDM has its merits, it does not however account for the role of emotions. In their review of research related to the effect of emotions on decision making, Lerner et al. (2015) concluded that "emotions constitute potent, pervasive, predictable, sometimes harmful and sometimes beneficial drivers of decision making" (Lerner et al., 2015, p. 799). One could appreciate for example how a parent's perceptions may be influenced by their own negative experiences of particular settings, with associated emotions affecting decision making and potentially acting to reduce the depth of thought given and amount of information sought. Research has suggested that emotional reactions which generate positive affective states can lead to an overestimation of the probability of positive outcomes while underestimating the likelihood of negative outcomes; conversely, emotions that incite negative affective states have the opposite effect (Svenson, 2003; Lerner et al., 2015).

### **1.3.1.2.2 Bronfenbrenner and Bourdieu**

Bronfenbrenner's Bio-ecological Systems Theory (Bronfenbrenner, 1979, 1992; Bronfenbrenner and Morris, 2006), presents concentric micro-, meso-, exo-, and macro- systems, which interact and influence the development of the child at the centre. In the context of school choice and transition, it is useful in explaining how the microsystem of family and school is influenced both by macrosystem level cultural contexts and social ideologies (i.e. attitudes to disability) and exosystem level government/local authority policy, practice, and funding.

It is at these wider levels that one can appreciate the impact of familial disadvantage or selective school admissions on both the SCP and the CYP. Research has shown that schools that are oversubscribed are more likely to admit children who will put less pressure on teaching resources and have less impact on academic results (Tomlinson, 2005; Lu, 2020). Additionally, parents who have had lower levels of education and experience higher levels of disadvantage tend to exercise less choice, due to difficulties both with accessing resources and information and then gauging that information to make informed decisions (Hastings et al., 2005).

Bourdieu's (1986) theory of cultural capital also offers a useful lens through which to frame a multisystemic understanding of the SCP. Capital is defined as not only economic but social and cultural – an accumulation of resources, knowledge, and behaviours that people can tap into and which work together to form 'in groups' and 'out groups' – a source of power for some and inequality and powerlessness for others (Gioia, 2017). Yoon (2020), in his assessment of the contributions of Pierre Bourdieu's theories and concepts to school choice research, concluded that the Bourdieusian perspective sheds critical light on how school choice can lead to a stratified system of schools – a system of school choice that, "encourages everyone, including educators, to play their part in keeping it competitive, creating the best versus the worst, or the 'winners and losers'" (Yoon, 2020, p. 206).

### **1.3.2 Researcher context**

The current study sought to investigate the experiences of the SCP from the perspective of parents whose children have an ASC (see Somner, 2021). My interest in this area stems from my previous role as lead teacher of a primary ASC Specialist Resource Base (SRB) where I witnessed how frustrating and emotive securing 'appropriate' secondary provision could be for parents. The role involved supporting parents informally and via annual reviews to research, consider and choose potential secondary educational placements, as their child neared transition. All parents were concerned about how their ASC child would fit and thrive in a mainstream secondary environment and discussions of what was appropriate often centred around notions of a nurturing and flexible approach. While some parents wanted the best available mainstream fit with access to support, others wanted only dedicated specialist ASC provision which they saw as the gold standard.

Significantly, with relevance to previous research, it was noted that parents were often left feeling confused, exasperated, and often highly anxious about the process of choosing and securing appropriate provision, despite and sometimes because of input (or perceived lack of it) from the local authority (LA) SEN Team. I was also struck by the difference between parents in terms of knowledge, self-advocacy, and confidence in the process, and the impact this seemed to have on outcomes in terms of securing provision.

### **1.3.3 National context**

Legislation in the last 40 years has steadily increased and endorsed the central role of families and parents in decision-making. Fundamental to this had been the 1981 Education Act, which paved the way for the integration of children with SEND into mainstream provision via the introduction of child-specific legally binding documents, in the form of statements of SEN (Norwich, 2014).

The 1981 Education Act and subsequent legislation have incrementally enshrined inclusion into the educational landscape, requiring schools to make reasonable adjustments to enable children with SEND to be challenged and supported

appropriately, and be an active part of the school community (DfE, 2014). This seems to have had an impact in terms of equity of educational provision with Ofsted's 2010 SEND Review concluding that, "no one model – such as special schools, full inclusion in a mainstream setting, or specialist units co-located within mainstream settings, worked better than any other" (p. 7). However, the review also concluded that "children and young people with similar needs are not being treated equitably and appropriately: the parental perception of inconsistency in this respect is well-founded" (p. 7). A delay to a long-awaited update to this review has recently been called "inexcusable" by the All-Party Parliamentary Group for SEND ("Cross-party group of MPs criticise 'inexcusable delay'", 2021)

Most recently the Children and Families Act (2014) set out, more than any legislation before it, to embed a more holistic approach to SEN assessment and give CYP and their families more agency within the SCP, able to identify and select their preferred provision, supported and guided by key professionals (McNerney, 2015). Part 3 of the 2014 legislation formed the basis of a new SEND CoP and introduced Education, Health and Care Plans (EHCPs) to replace statements of special educational needs. These were created to bring together education, health, and social care services and provision to secure the best outcomes for children with SEND - embedding partnership and co-production with CYP and parents, clearly presenting needs and outlining how local services should work to meet them.

However, subsequent to the updated legislation, demand for EHCPs have placed huge logistical and financial stress on local authorities, with a recent survey by the County Council Network (CCN) finding that high-needs deficits in 40 county authorities have ballooned from £134m in 2018/19 to a projected £1.3bn in 2022/23 ("Councils call for urgent action in Spending Review to address £1.3bn special educational needs deficit", 2021).

According to the DfE (2018), 72% of children with an ASC are currently educated in mainstream settings, with two-thirds expected to access the mainstream academic curriculum without statutory support in the form of an EHCP.

Accounting for 30% of the total number of EHCPs, ASC is the most common primary type of need among pupils with an EHCP, an increase from 29% in

January 2020 (DfE, 2021). Recent data revealed that there were 132,345 pupils with autism in primary, secondary, and special schools in January 2019, compared to 119, 909 the year before - a rise of over 12,000 (DfE, 2019). In response to this, the Chief Executive of charity Ambitious about Autism stated that "the number of pupils with autism in our schools continues to increase but sadly the support they need from our education system is not keeping pace. Autistic pupils are much more at risk of exclusion than their peers and we know parents face a much harder battle to get their children the education they deserve" (Parkes, 2019).

#### **1.3.4 Local context**

With regards to ASC, data from the LA in which this study is situated indicates that, in line with national trends, there has been increasing numbers of EHCP applications and also a significant growth of parental requests for non-mainstream specialist provision (Norfolk SEN Strategy, 2019). The county has one maintained special school for children with an ASC and ten ASC (SRBs) attached to maintained schools (six primary and four secondary) – all of which have occupancy rates of 100% and many children waiting for spaces. Colleagues within the LA acknowledge that in some circumstances, this restricted number of specialist places has led to parents lodging tribunal appeals, pursuing out-of-county placements, or home educating their child with an ASC. To address the demand for specialist provision, the county recently committed £120m to a SEND Transformation Programme (which has included the establishment of a further four SRBs and one ASC Special School). Trends in local data suggest that this demand for EHCPs will continue to rise, along with associated demands for special school places. One can therefore appreciate the value of research that unpicks the factors that drive and influence parental decision making regarding school choice, at both a local and national level.

#### **1.4 Research rationale**

My own experience, anecdotal conversations with LA professionals, and previous research have all highlighted the difficulties faced by parents when choosing and securing secondary provision for their child with an ASC. However, the previous

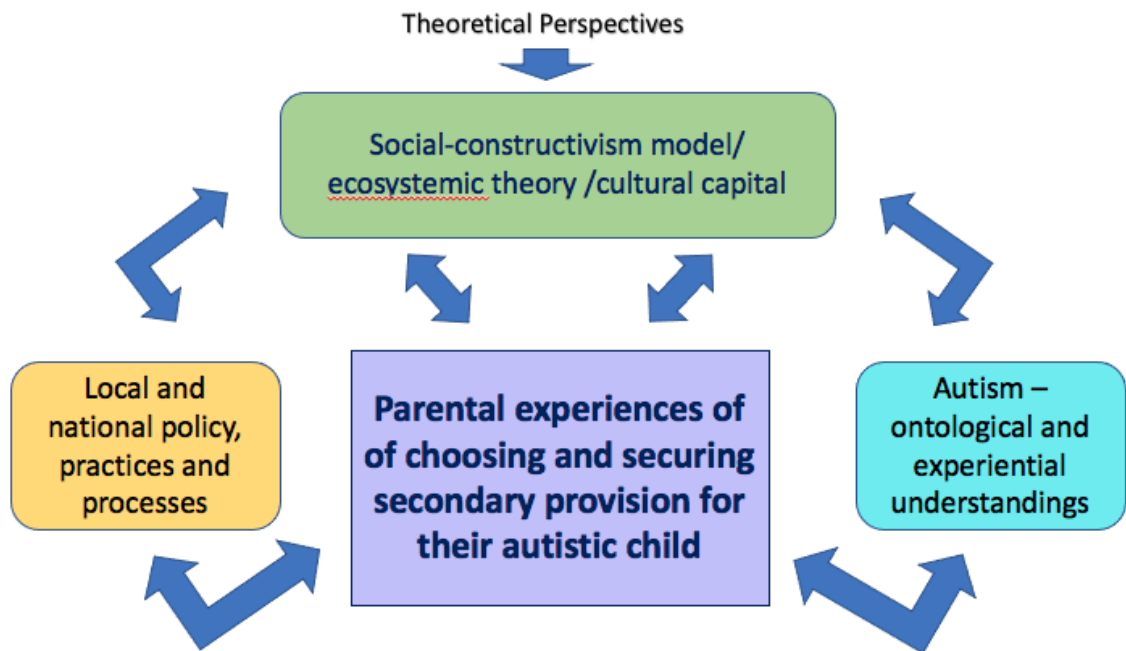
research pool is tiny and outdated, not accounting for the potential impact of the last changes to SEND legislation. Recent research considering parental narratives around decision-making regarding secondary educational provision for children with an EHCP (Smith, 2020), has highlighted how parents can struggle with the increased autonomy to make decisions without support and guidance. It is hoped that the current research will enable further exploration from the perspectives of parents with children with an ASC.

The qualitative phenomenological nature of this research served to give a rich and nuanced picture of parental experiences. Additionally, to increase the potential impact of the research, I sought to actively seek suggestions from parents about how practices and support could be improved, with suggestions for improvement to practice to be shared with key LA personnel at a future workshop.

It is intended that the outcomes of this research will serve to inform and improve future practice with regard to how parents experience both the SCP and wider statutory processes.

### **1.5 Theoretical and conceptual framework**

Osanloo & Grant (2016) use the metaphor of a blueprint of a house to emphasise the importance of a theoretical framework, arguing that, “it is the foundation from which all knowledge is constructed (metaphorically and literally) for a research study” (p. 12). They go on to argue that information gathered for a dissertation should always be interpreted through a theoretical framework to ensure clarity of explanations and avoid, “limited uselessness of findings and conclusions” (Sarter, 2006, p. 494). This introduction has set out selected theories and key themes which the author – due to her context, values, and previous experience – feels are pertinent to the phenomena of choosing and securing appropriate secondary educational provision for a child on the autistic spectrum. Key theories and concepts discussed earlier in the chapter are summarised below as a visual framework, this framework will be used as a flexible lens through which to analyse and discuss my data and underpin my conclusions.



*Figure 1: Theoretical and conceptual framework*

## 1.6 Summary

This introduction has outlined the key concepts pertaining to the present research. In the following chapter I undertake Cycle 1 of the action research (AR), where I seek to:

1. Explore, via a review of relevant literature, the 'situation at present' (McAteer, 2013) regarding how parents of children with additional needs have experienced choosing and securing educational provision for their child and the factors that have influenced their decisions.
2. Clarify research questions.

## **2. Literature review**

### **2.1 Overview**

This chapter outlines the process of searching for, synthesising, and critiquing literature related to my literature review question, presented below. The synthesis of the literature and acknowledgment of potential gaps in research will lead to the formation of my research question.

### **2.2 Purpose and literature research question**

The purpose of this literature review was to systematically search and synthesise the research evidence relating to the parents' experiences of choosing and securing educational provision for children with autism. However, an initial scoping search quickly revealed a dearth of studies relating particularly to the parents of autistic children. Therefore, the literature search question was widened to include the experiences of parents of children with special educational needs (SEN) in general:

*How have parents experienced choosing and securing educational provision for their child with special educational needs and what factors have influenced their decisions?*

'Provision' was chosen as a wide-ranging term to include all educational facilities in which children can be placed.

### **2.3 Literature review process**

To facilitate a relevant, clear, and systematic search I established some aims related to the literature research question above. Then, guided by Booth et al (2016), developed a three-phase process to fulfil these aims.

Aims:

- To identify studies focusing on parental experiences of choosing and securing educational provision for their child with special educational needs.



- To identify studies focusing on the factors that may influence parental decision-making relating to educational provision for their child with special educational needs.
- To identify insights that the studies provide into both factors influencing the choice of educational provision and the process of securing that provision.
- To evaluate the strengths and limitations of these studies.
- To reflect on and synthesise findings from these studies and identify gaps relevant to the research area.

Three-phase review process:

- Phase 1: Systematic search of literature using clear inclusion and exclusion criteria.
- Phase 2: Critical evaluation of literature using the Critical Appraisal Skills Programme (CASP, 2018) for qualitative research and systematic reviews and the Mixed Methods Appraisal Tool (MMAT, Hong et al., 2018) for mixed methods research. The CASP and MMAT tools are designed to allow for the systematic assessment of the trustworthiness, relevance, and results of research papers.
- Phase 3: Synthesise information from selected studies to answer the literature review question, assessing and thematically analysing what is already known and identifying potential gaps in literature in order to develop my research question.

## **2.4 Phase 1: Systematic literature review**

In accordance with the description of a systematic review presented by Grant and Booth (2009), I seek to, “systematically search for, appraise and synthesise research evidence” (p. 95), utilising inclusion and exclusion and reporting on “what is known” (p. 95). Later, in the discussion chapter, I will present implications for practice and future research.

### 2.4.1 Inclusion and exclusion criteria

Included	Excluded	Reasons
Studies published in English	Studies not published in English	As an English speaker it is not possible for me to access studies in other languages and I do not have the financial means to organise translations
Studies that make use of UK context and /or population	International studies (unless they referred to UK context)	In order to reflect current educational context
Studies that focus primarily on parents or carers of children with special educational needs (all types) and their consideration of school choice or decision making with regards to the educational placement of their child with special educational needs	Studies with a focus on information from other sources (e.g. CYP, teachers)	To increase validity and relevance with regards to exploratory and experiential research aims
Studies that focus on securing all educational provision within compulsory schooling age*  <i>* It was initially decided to focus only on securing secondary provision, but initial searching revealed a dearth of studies. Therefore, the search was widened</i>	Studies that focus on securing 16+ provision or studies that focus on transition rather than school choice process	To increase validity and relevance with regards to research aims
Studies published in peer-reviewed journals and thesis with high validity (judged using CASP and MMAT)	Studies that are not peer reviewed or theses with low validity	To increase the trustworthiness of the literature review
The search criterion was set to include studies from 1981 until the present date	Studies before 1981	So that all relevant studies post the 1981 Education Act, when parents of children with statements of SEN were able to express preferences regarding schools to be named in statements, would be included

Table 1: Table outlining inclusion and exclusion criteria

### 2.4.2 The search process

A literature search was conducted in May 2021 and reviewed in July 2021. The databases within EBSCO services and Scopus were used for the search. The EBSCO services database search included Academic Search Complete, British Education Index, Child Development and Adolescent Studies, CINHALL Plus with Full Text, Education Research Complete, ERIC, and PsychINFO.

The table below outlines parameters and search terms used.

Search date	June 2021
Databases	The EBSCO services database search included Academic Search Complete, British Education Index, Child Development and Adolescent Studies, CINHALL Plus with Full Text, Education Research Complete, ERIC, and PsychINFO.  Scopus database was also searched.
Search Terms	Parent* AND choice OR 'decision making' AND (choice OR 'decision making') AND ('special needs' OR 'special education*' OR autism* OR ASD OR ASC) AND (School* OR Education*)
Inclusion and exclusion criteria	Outlined above
Parameters	Peer-Reviewed  English language  UK/England/GB/Ireland/Scotland  1981-2021
Results	8 papers from database search and 5 additional papers from citation search and personal contact = 13 in total
Articles selected after final review (revisiting inclusion/exclusion criteria and utilising first 2 questions of the CASP)	9

*Table 2: Summary of the literature review strategy*

The EBSCO databases generated 51 papers and Scopus generated 79 papers. Removing duplicate entries within each database left a total of 37 papers from EBSCO and 9 papers from Scopus. Titles and abstracts of the 46 papers were then reviewed for relevance to the literature search criteria and duplicates between the two databases removed, which left a total of 8 papers. These papers, alongside five more that came from in-paper citation (i.e. ‘snowballing’) and the E-Theses Online Service (EThOS), were then subjected to a more detailed review, to ensure only relevant literature was included in the final literature review, this involved:

1. considering them against the inclusion and exclusion criteria,
2. utilising the first two questions of the relevant CASP or MMAT to screen each paper and ensure their research aims were clear, and check that the methodology used in each of the papers was an appropriate way of addressing the research goal.

This process removed three papers from the initial total of 13, leaving 10 papers. However, one of the papers was an updated version of a previous paper, the previous paper was therefore removed, leaving a final total of nine papers to be included in the literature review.

## **2.5 Phase 2: Critical evaluation of the literature**

### **2.5.1 Critical appraisal overview**

The nine identified papers were read multiple times and systematically appraised using the appropriate appraisal tool, as explained above.

The table below lists the papers included in the literature review alongside decisions regarding the quality of each study following critical appraisal.

<b>No.</b>	<b>Research paper title</b>	<b>Author(s) and publication year</b>	<b>Decision regarding quality of study following critical appraisal using CASP &amp; MMAT tools</b>

1	Parental narratives around decision-making regarding secondary educational provision for children with an Education, Health and Care Plan  Doctoral dissertation, University of East London	Smith (2020)	High
2	Factors influencing parents' selection of schools for children with disabilities: A systematic review of the literature –	Mawene & Aydin, (2018)	Medium
3	Parents' perceptions and experiences of the decision-making process when choosing secondary school placement for children with statements of special educational needs: an interpretative phenomenological analysis  Doctoral dissertation, University of Nottingham	Booth, 2017	High
4	Choosing a secondary school for young people with autism: A multi-informant study	McNerney, Hill & Pellicano (2015)	Medium
5	'Nowhere that fits': the dilemmas of school choice for parents of children with statements of special educational needs (SEN) in England	Bajwa-Patel & Devecchi, (2014)	Medium
6	Working together? Parent and local authority views on the process of obtaining appropriate educational provision for children with autism spectrum disorders	Tissot (2011)	Medium
7	Where do children with a statement of special educational needs transfer to at change of phase from primary to secondary school and how do parents choose which provision is most suitable for their child  Doctoral dissertation, University of Birmingham.	Byrne (2011)	High

8	Securing provision for children with autistic spectrum disorders: the views of parents	Tissot (2006)	Medium
9	Implementation of School Choice Policy: Interpretation and Response by Parents of Students with Special Educational Needs	Bagley, Woods & Woods (2001)	Medium

*Table 3: Studies included in literature review and critical decisions*

## **2.5.2 Critical evaluation of each paper**

All papers were deemed to be of high or medium quality and were therefore considered robust enough to be included in the final thematic literature synthesis. Before presenting the literature themes, there follows a critical evaluation of the nine selected papers, explaining the reasoning behind each appraisal decision. A detailed descriptive overview of each of the papers, including details relating to purpose, aims, context, participants and main findings can be found in Appendix 1.

### **2.5.2.1 Paper 1: Smith (2020)**

While the results of the idiographic small scale (N=4) narrative doctoral study were not generalisable, the aims of the research were clearly stated as was the gap in knowledge that the study sought to address. The narrative qualitative methodology was clearly presented and appropriately chosen to allow for an in-depth consideration of participant stories and meaning-making. The researcher displayed good reflexivity throughout, acknowledging their influence on the research despite measures to “out” researcher presence. The recruitment strategy was purposefully limited to two selection criteria to allow a broader range of potential parents to contribute. Some basic demographic information was collected. Researcher bias was limited by using voluntary participation in the study. Methods of data collection and analysis were selected, justified and clearly shared based on the study’s narrative orientation. Due to the narrative positioning of the research, deeper social and ideological factors were only considered if they were part of participant stories, and given the fairly homogenous sample (i.e. all white British, all in partnerships, all employed), factors such as culture, race, ethnicity, language, socioeconomic status, etc, that may have been relevant to

the SCP, were not considered. Relative positioning, potential biases and the reciprocal relationship between researcher and participants were considered in detail.

Data analysis was rigorous and findings were clearly presented but not generalisable, therefore a detailed comparison with other studies was not possible. Limitations of the study were mindfully explored, as were ethical concerns and implications for practice.

Whilst lacking in terms of access to a diverse range of voices, close ties to nuanced and complex narratives provided rich experiential data and contributed to an updated understanding of decision making regarding secondary educational provision (SEP) for children with SEN in the current context. This, combined with the other factors shared above, lead to it being deemed of high quality.

#### **2.5.2.2 Paper 2: Mawene & Aydin (2018)**

This systematic review focused on 15 studies (both randomised controlled trials and qualitative) which considered, “the factors influencing the decisions of parents of children with disabilities when selecting schools” (p. 313). Research questions were focused and well-crafted and a five-level sequence of search terms was mindfully and systematically designed to thoroughly search literature in order to find relevant studies.

Results were combined into a framework set out by Glenn-Applegate et al. (2011) which considered structural, process-related and familial factors – to which they added child-related factors. This worked well to structure and group findings and the studies were comprehensively critiqued for quality and rigour. Results were clearly organised in two parts, the first reporting descriptive information and the second presenting findings to address the research questions. Conclusions were critical and detailed. Some recommendations for improvement to practice were made but these were fairly limited. Limitations of the review were briefly considered but lacked detail.

On balance, given strengths relating to the search process and presentation of findings, the study was considered of high quality and valuable in illuminating factors influencing parents' selection of schools for children with disabilities.

#### **2.5.2.3 Paper 3: Booth (2017)**

Research aims and questions were clearly presented in this small-scale (n=8) idiographic study and the researcher made a robust and detailed case for the appropriateness of using interpretative phenomenological analysis (IPA) to explore parents' perceptions and experiences when choosing secondary school placement for their child with SEN, based on critical realist epistemological underpinnings. Methods for data collection and analysis were in line with those advocated by Smith, Flowers and Larkin, (2009) and were clear, explicit, and well justified. Reflexivity was transparent throughout and the relationship between researcher and participants, and the impact of potential biases was mindfully reflected upon. Data analysis was rigorous and the stages of analysis were shared. Findings were organised and detailed, and discussed in relation to original research aims and questions.

The recruitment strategy was purposefully chosen, focusing on children who had an EP attend the Year Five change of phase review (as EPs were only required to attend change of phase reviews where questions had been raised about the type of placement for secondary school), however conversely one could argue that it may have created sampling bias weighted towards more complex cases. As advocated by Smith et al (2009) the study aimed for a homogeneous sample of participants, however the homogeneity of the group may have been influenced by the fact that demographic factors such as social-economic status, learning needs of parents, and ethnicity, were not controlled for within the inclusion criteria.

Ethical concerns were considered, as were limitations of study and implications for practice.

Whilst the idiographic nature of the study meant that findings were not generalisable the study was of high quality, addressing a gap in the research and



contributing to an updated understanding of parents' experiences and perceptions of the decision-making process post the SEN CoP (2015).

#### **2.5.2.4 Paper 4: McNerney, Hill & Pellicano (2015)**

The aims of this qualitative small-scale multi-informant study (parents n=7, CYP n=6, parent advisors n=5, secondary school professionals n=5) were clearly presented, but no research questions were shared. Studies included in the literature section were relevant but there were no details of search parameters or procedures. Although the main themes of relevant literature were discussed and some comparisons/contrasts between studies drawn, there was very little critical review of the chosen studies, lessening the overall validity of the commentary.

The recruitment strategy was appropriate but limited to one borough, which introduced geographical bias. The study contained no critical reflexivity regarding researcher role and potential bias/influence during interviews/analysis/selection of data.

The qualitative multiple informant research design was appropriate and worked well to provide a fuller picture by accessing a range of voices in the secondary SCP for autistic children - eliciting the views and perspectives of not only parents but key professionals, and autistic young people themselves. Data collection and methodology were briefly shared but lacked detail, i.e. interview procedure/questions were not shared but readers were told that they were adapted for the different types of participants and there was a very short overview of the thematic analysis process.

Some demographic information was provided revealing potential geographical bias (i.e. 100% participants were from one London borough) and potential gender bias (e.g. 100% child participants were male, 86% parent participants were female, 100% local authority staff were female).

Themes and findings were concisely presented but the credibility of findings was not discussed e.g. via triangulation/respondent validation. Findings related back to research aims and addressed a gap relating to securing secondary provision for children with autism, they were discussed in relation to current legislation and

contributions made to existing knowledge. However, the authors did not consider the role of deeper social and ideological factors in shaping the underlying preferences of informants. Potential limitations and suggestions for future research focuses were very briefly noted.

While the study did contribute to a very scant research base regarding school choice for autistic youngsters and the findings were clearly presented and linked back to research aims, the lack of transparency with regards to methodological and analytical approaches, and a lack of reflexivity, lead to a decision to rate the study as medium quality.

#### **2.5.2.5 Paper 5: Bajwa-Patel & Devecchi (2014)**

No clear aims or research questions were presented for this survey-based study (n=380), instead findings were presented relative to an initial assertion that 'nowhere fits', introducing the potential for confirmation bias from outset. The survey-based data used was taken from previous doctoral research, which was mentioned but not named or referenced, there was no reference to criteria for selecting participants and no details of the analytical procedure were shared. All of these factors are likely to impact the validity of the study. Data was presented qualitatively and graphically. All participants were from one geographical area, introducing potential geographical bias. Sampling bias was noted (i.e. 66% in specialist provision compared to 34% in mainstream), as was age bias (i.e. majority of sample related to children of 12-13 years). Respondent bias was acknowledged, with a higher response rate expected from dissatisfied parents.

The study contained no reflexive critical examination of researcher role. Findings were clearly presented and considered in relation to existing legislation/relevant research-based literature. The role of demographic factors was considered, but not in great detail. Discussion of study limitations was included but very brief. There were no suggestions for future research focuses but some for educational practice, i.e. schools providing a comprehensive package of services to meet the needs of children.

Overall the study, despite its inherent biases, was considered to be of medium quality due to its generalisable nature and value in terms of illuminating the dilemmas of school choice for parents of children with SEN.

#### **2.5.2.6 Paper 6: Tissot (2011)**

While the aims of this mixed-methods paper were clear from the outset, no research question was presented. Literature relevant to the study was discussed but lacked a depth of critical review and comparison.

The mixed-method design at first seemed appropriate (due to a large cohort size) but there are several points of critique that need highlighting. The first relates to the fact that parent participants, accessed via postal survey, numbered 738, while local authority staff numbered only 5 - their views accessed via semi-structured interviews. This difference in numbers and methodological/analytical approach arguably results in a lack of parity between the different voices accessed via the study, i.e. findings for parent participants are more generalisable but lack depth, and findings for local authority staff are detailed but lack generalisability. Additionally, the data used for parents was 5 years old, collected for a previous study (considered later), which could have affected validity. Sampling bias was well countered by participant recruitment strategies, with participants purposefully recruited from a wide range of locations. Justification was given with regards to the data collection methods used but there was no information about how the quantitative and qualitative data was analysed (making it impossible to ascertain whether data analysis was sufficiently rigorous). Ethical permissions were briefly touched upon but there was a lack of reflexivity.

There were definite strengths in terms of how findings were synthesised and organised into themes, the clarity with which they were presented, and how they linked back to research aims.

While there was no in-depth consideration of demographic factors apart from the type of school and no real consideration of deeper social and ideological factors, it was noted by the researcher that these would be important to attend to in future work.

The discussion gave a good overview of the research and difficulties faced by both parents and local authorities around inclusion and inclusive practice. While not offering suggestions for improvement to practice it did instead raise two questions that the author felt needed answering by local authorities in order to improve collaborative ways of working.

The research was valuable and addressed a significant gap in school choice literature (concerning ASC), and additionally shone a light onto local authority views/involvement.

On balance, considering strengths in terms of clearly presented and illuminating findings which considered viewpoints of both parents and local authority staff and which related to research aims, and weaknesses pertaining largely to lack of methodological and analytical insight, this study was deemed to be of medium quality.

#### **2.5.2.7 Paper 7: Byrne (2011)**

The study employed a qualitative multiple case study design (n=5), underpinned by a theoretical framework arising from a review of literature and the theoretical interests of socio-cultural and activity theory. Research aims were clear and the methodology/research design was appropriate for the research question and focus, however, the thesis was confusing to navigate.

The multiple case study design required reflexivity to be central and it was – researcher influence and bias were considered in detail.

The recruitment strategy was purposefully designed and followed, however 80% of participants were of one cultural background, introducing cultural bias (which was reflected upon). The study's idiographic design meant that findings were not generalisable, however there was an implicit acknowledgement of this.

Methods of data collection and analysis selected were rigorous and clearly presented – based on case study protocol and theoretical propositions derived from the research literature that were well justified and made explicit.

The use of socio-cultural and activity theory was utilised as a framework to reflect on how individual actions and decisions are located within and influenced by much wider social, cultural and historical contexts. However, the application of this framework during the analytic stage seemed to have a narrowing effect, i.e. via the use of prescriptive matrices to classify information according to activity theory, which at times seemed reductive and open to confirmation bias.

Therefore, while the theoretical frameworks seemed at first well-chosen to illuminate research aims, they may not have resulted in illuminating findings of depth and nuance. Findings were presented and were clearly related to research questions and aims but felt limited relative to the extensive consideration given to methodology and theoretical frameworks – the process seemed to outweigh the outcomes.

Ethical concerns were considered and confidentiality/right to withdraw was shared with participants. Limitations of study and implications for practice were also considered in some depth.

The research contributed an updated understanding of where children with special needs transfer to post their primary phase of education.

Despite misgivings related to overfocus on methodology and theoretical framework the study was robust and was deemed to be of high quality.

#### **2.5.2.8 Paper 8: Tissot (2006)**

This survey-based study preceded the subsequent study by Dr. Catherine Tissot (outlined above, 2.5.2.6). However, it focused only on parent participants. The same survey-based data was used as in the 2011 study. While it gave a good critique of potential weaknesses in sampling strategy, the present critique echoes that of the previous Tissot paper regarding weaknesses related to lack of methodological and analytical transparency. However, as with the previous paper, there are also strengths relating to how findings were synthesised and organised, the clarity with which they were presented, and how they linked back to research aims.

Despite the weaknesses discussed, this was a pioneer study and had value in addressing the significant gap in literature previously mentioned. Findings were clear and additionally shone a light onto local authority views/involvement. It was therefore decided to be of high enough quality to consider for the literature review (i.e. medium).

#### **2.5.2.9 Paper 9: Bagley, Woods & Woods (2001)**

The study drew on analyses of quantitative and qualitative data generated by a large-scale research study on secondary school choice, funded by the UK Economic and Social Research Council. Research aims were clear from the outset, however no research questions were presented. Recruiting via a large study enabled access to readily available data but invited responder bias, i.e. parents were recruited if they had stipulated on the survey that their child was special needs, all were self-selecting and subjective. Of note is the fact that SEN accounted for only 5.9-7.0% of the overall survey sample, compared to the national average of 20%.

Research design and methodology were appropriate for generating both generalisable insights and exploring parental experience, however there was no explanation of methodology or analytic procedures. One should also note that data was collected in the mid-nineties and is over 25 years old, leading to inevitable data degradation. The use of postal questionnaires, supplemented by personal interviews enabled triangulation of data. Unlike other survey-based studies in the current selection, the survey template was shared. However, it was noted that some of the terminology used was vague and open to a range of interpretations. Additionally, parents were often asked to choose responses from a list, which was leading and would have imposed survey bias. Three contrasting case study areas were selected to counter geographical bias, with the response rate comparable in each area.

There was some brief consideration of demographic factors but no real consideration of deeper social and ideological factors, despite one geographical area having a large ethnic minority community.

The paper contained no mention of ethics or ethical procedures and there was no evidence of reflexivity.

The findings and discussion were clearly organised, related back to aims, and gave a good overview of the research. Dominant discourses, the tension between policy and practice, and the difficulties faced by parents were also considered. However, suggestions for improvement to practice and future research were not offered.

The findings answered the research aims, revealing both the range of factors considered by parents when choosing schools, and the barriers they encountered as they attempted to navigate competitive school choice markets - both of which contributed to an updated understanding in the field. However, transparency of methodology and the analytic procedure was absent, the study was therefore considered of medium quality.

Consideration of the above study concludes the critique for each of the nine papers included in the literature search, we will therefore proceed to Phase 3 of the review process.

## **2.6 Phase 3: Synthesis and thematic analysis of selected literature related to the literature research question**

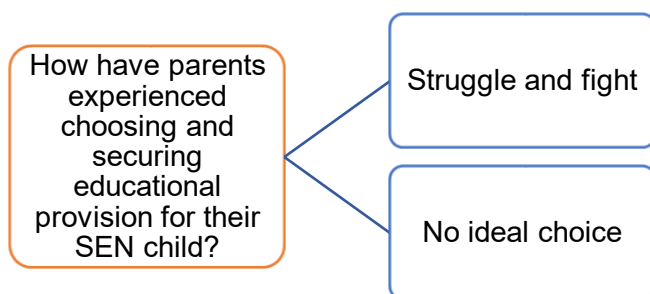
When analysing the studies' findings and building my research questions, I attempted to address the two different elements of my literature search question, namely:

- 1) How have parents/caregivers experienced choosing and securing educational provision for their child with special educational needs?
- 2) What factors have influenced their decisions?

This was underpinned by consideration of key theories and areas of relevance shared in the introductory chapter. It should be noted that a synthesis of much of the literature was initially done for my research proposal, submitted previously (Somner, 2021).

### 2.6.1 How have parents/caregivers experienced choosing and securing educational provision for their child with special educational needs?

Framed by the first element of my literature search question, a synthesis of the findings of the studies considered for the literature review fell broadly into two areas (presented in the diagram below) – the first relates to the negative experiences faced by parents, and the second to a perceived lack of choice.



*Figure 2 – Areas identified in literature relating to element one of literature search question*

#### 2.6.1.1 Struggle and fight

Many of the 738 parents of autistic children surveyed by Tissot (2011) gained the placement of their choice (79%, n=584), however the majority of them viewed the experience of gaining their chosen provision negatively, with the process noted by many as being “bureaucratic, stressful and time-consuming” (Tissot, 2011, p. 1). This situation was also experienced by parents in the McNerney et al. (2015) study who described the process as ‘terrifying’, emphasising that the process was very different for parents of children with autism, “just like normal parents get anxious, but you get *really* anxious about it” (p. 12). Similarly, parents in both Byrne’s (2011) and Smith’s (2020) studies described the process as a ‘battle’ in which they often felt unsupported, unheard, and powerless, summed up powerfully by a parent in Smith’s research stating, “it’s by your bloodied fingers that you get support” (p.71). Smith’s (2020) small-scale study additionally highlights frequently occurring narratives associated with a sense of ‘them and us’, with regards to their relationship with the local authority. This positioning is associated with both the EHCP and the SCP and paints a picture of battling parents pitted against an uncaring and rigid system.



In all the studies above, the cause of the stress is attributed primarily to failings in local authority practices and information sharing. Additionally, difficulties with securing specialist provision were attributed to local authorities' significant lack of funding (Tissot 2006 & 2011; McNerney et al., 2014; Booth, 2017), while difficulties accessing mainstream were attributed to the pressures of league tables and competitive choice markets leading to mainstream schools not wanting to take on children with autism and SEN, for fear of them affecting results (Tissot 2011; Byrne, 2011; Booth, 2017). Parents' narratives in Smith's (2020) study also suggest a reluctance for mainstream schools to meet needs, the opposite of a traditional market structure where the customer comes first, "it's the opposite of the kind, of a customer relationship [sic]" (p. 69). There is a sense in parental discourses that the marketisation of education, with an emphasis on budgets and league tables, may come at the cost of inclusivity and social justice (Smith, 2020; Tissot, 2011).

#### **2.6.1.2 No ideal choice and marginalisation**

Despite government literature stating that parents should be given a 'real choice of school' (DfE, 2011, p. 5) many parents felt that, in reality, with special school places in high demand and some mainstreams resistant to taking SEN, the range of choice was limited (Byrne, 2011; McNerney et al., 2014; Bagwa-Patel & Devecchi, 2014). In Booth's (2017) qualitative study, parents attributed a lack of choice to both the lack of specialist provision available and a lack of specialist SEN support in mainstream, with one parent commenting that "if every school had resourced provision for SEN then the choice would be increased" (p. 128).

Additionally, several studies (McNerney et al., 2014, Booth, 2017; Byrne, 2011 2013) noted that some parents, particularly those from lower socioeconomic or minority cultural backgrounds may struggle to have their voices heard in professionally-dominated discussions around SEN and school placement.

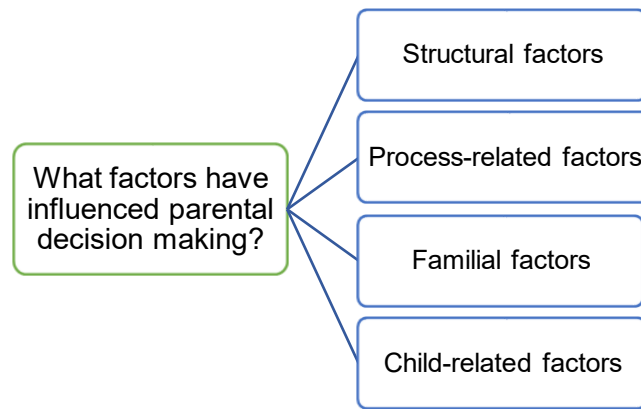
Local authority participants in McNerney et al's (2014) mixed informant study conceded that some parents may have been less equipped to make fully informed decisions because support systems did not always account well for differences in linguistic, cultural, and social needs. What is notable in the papers

considered in this review, is that while many studies flagged the importance of accessing the voices of these groups in future research, none actively sought them.

Studies conducted after the changes to legislation introduced by the Children and Families Act 2014, suggest diverse parental experiences and perceptions relating to support. Interestingly, Booth's (2017) research highlighted very different parental perceptions linked to the same local authority caseworker, with one parent commenting positively and one commenting that "it's always been us trying to squeeze information out rather than it being offered so it doesn't feel like we've been supported. We're kind of supported only if we ask the right questions" (p.108). This sense of some parents being compromised by a lack of knowledge of systems and processes was echoed by parent participants in Smith's (2020) narrative research, with one parent sharing perceptions around struggles some parents face in gaining appropriate educational provision for their child, "they don't have the ability or knowledge, the understanding about how to go about it, so, they're never going to be able to access those schools, which is so sad because their child probably desperately needs to" (p. 93). There seems to be an acknowledgement of inequalities in the system, and a marginalisation of certain individuals who lack knowledge, impacting their active participation in the SCP.

### **2.6.2 What factors have influenced parental decision-making?**

Framed by the second element of my literature search question, a synthesis of the findings of the studies considered for the literature review led to a choice to utilise the four-category framework used in Mawene and Bal's (2018) systemic literature review, these are shown in the diagram below:



*Figure 3 – Areas identified in literature relating to element two of literature search question*

### **2.6.2.1 Structural factors**

In all studies parents wanted staff in secondary provision to have knowledge and expertise of SEN (e.g. Booth, 2017; Byrne, 2011; Bagley et al., 2001). In fact, the availability of specialist staff and education programmes was identified by Mawene and Bal's (2018) systematic review as the primary factor parents consider when thinking about where to place their child (noted in 93% of included studies). Parents of children with ASC stated a preference for autism-specific education programs and specified a desire for lower class sizes and individualised attention (Tissot, 2006 & 2011; McNerney et al., 2014), also stressing the importance of relationships and an adaptable learning environment which could flex to meet their child's social and educational needs (McNerney et al., 2014). Distance from available provisions loomed large in all parents' minds, for both SEN and specifically ASC, as specialists placements were often out of area, adding more complexity and stress to choice making (Tissot, 2006 & 2011; McNerney et al., 2014; Byrne; 2011; Bagwa-Patel & Devecchi, 2014; Booth 2017).

### **2.6.2.2 Process-related factors**

Mawene and Bal's (2018) review found that teacher's interpersonal characteristics were important to parents, who wished their children to be taught by individuals who were stable, caring, and responded to their children's individual needs – echoed by several other studies in this review (e.g. Smith, 2020; Bagley et al, 2001).

Effective communication was highlighted by several studies, whether it be between parents and teachers (McNerney et al 2014; Booth, 2017) or parents and LA staff (Smith 2020; Tissot, 2006 & 2011; Booth, 2017), with parents appreciating a two-way process within which they felt listened to and their perspectives valued (Finn et al, 2006 (in Mawene and Bal's review); Booth, 2017).

On a wider level, parental decisions were influenced, in both positive and negative ways by access to support and information. For example, parents in McNerney et al.'s small scale qualitative study felt that they hadn't received the help or information they needed from the LA to make an informed decision when choosing an appropriate school placement, stating that they 'felt a bit lost' and consequently seeking support from family, friends and ASC parent support groups instead. Conversely, Tissot's (2006 & 2011) large ASC-specific study revealed that while some parents were dissatisfied with the support they received, others felt well supported, particularly if the person supporting them was consistent and they had built a relationship with them.

Byrne's (2011) small scale multiple case study found that parents who had elected for their child to go to their local mainstream secondary school felt that they had been free to make their own choice with the support of family and friends only. However, those who had elected to go to special school felt that professionals had advised them to choose this provision, with friends and family tending to question this choice. The latter group felt that they did not have true autonomy in their choice.

### **2.6.2.3 Familial factors**

Parents' worldview of disability was noted to influence their choice of educational provision. Bagwa-Patel & Devecchi (2014) and McNerney et al (2014) found that parents who valued a social model of disability – i.e. who believe that people are disadvantaged by barriers in society, not their difference – tended to prefer inclusive mainstream provision, believing that it would provide better social integration, particularly with other children in the same neighbourhood. Conversely, those parents who implicitly tended towards a medical model – i.e.

where the child is labelled as needing special support – were more inclined to enrol their children in specialist provisions. Noted in particular relation to ASC was that some parents with a ‘social’ view, who originally chose mainstream provision, then moved their children due to a perceived lack of support or worries about their children’s anxiety and unhappiness (Byrne, 2013; McNerney et al, 2014).

Interestingly, Mawene and Bal’s (2018) systemic review found that socio-economic status had minimal impact on factors influencing school choice, meaning that parents from low-income backgrounds employed similar rationales to those from more affluent backgrounds when considering the most appropriate provision for their children.

#### **2.6.2.4 Child-related factors**

Unsurprisingly, the literature showed that parents were very mindful of their children’s individual needs, and how these could best be supported was often a prime concern (Bagley et al., 2001; Tissot, 2006 & 2011; McNerney et al., 2014; Byrne; 2011; Bagwa-Patel & Devecchi, 2014; Byrne, 2011; Booth 2017).

The desire for their child to be happy and develop good self-esteem greatly influenced school choice decisions. Many papers, including two ASC-specific ones, concurred with a large study by Bagley and Woods (1998) in proposing that parents tended to favour provisions where their children would feel safe, secure, and nurtured, often placing greater emphasis and importance on this than academic attainment (Tissot, 2006 & 2011; McNerney et al., 2014; Byrne; 2011; Bagwa-Patel & Devecchi, 2014; Booth 2017). Bagley et al. (2001) additionally noted that parents who reported negative experiences at primary school demonstrated an increased desire to find a secondary placement which recognised and mindfully supported their child’s needs.

With regards specifically to children on the autistic spectrum, Tissot (2006) found that the variability in how autistic traits were acknowledged and perceived led to differences of opinion in terms of how to best meet the educational needs.

### 2.6.3 Summary, gaps identified, and research questions

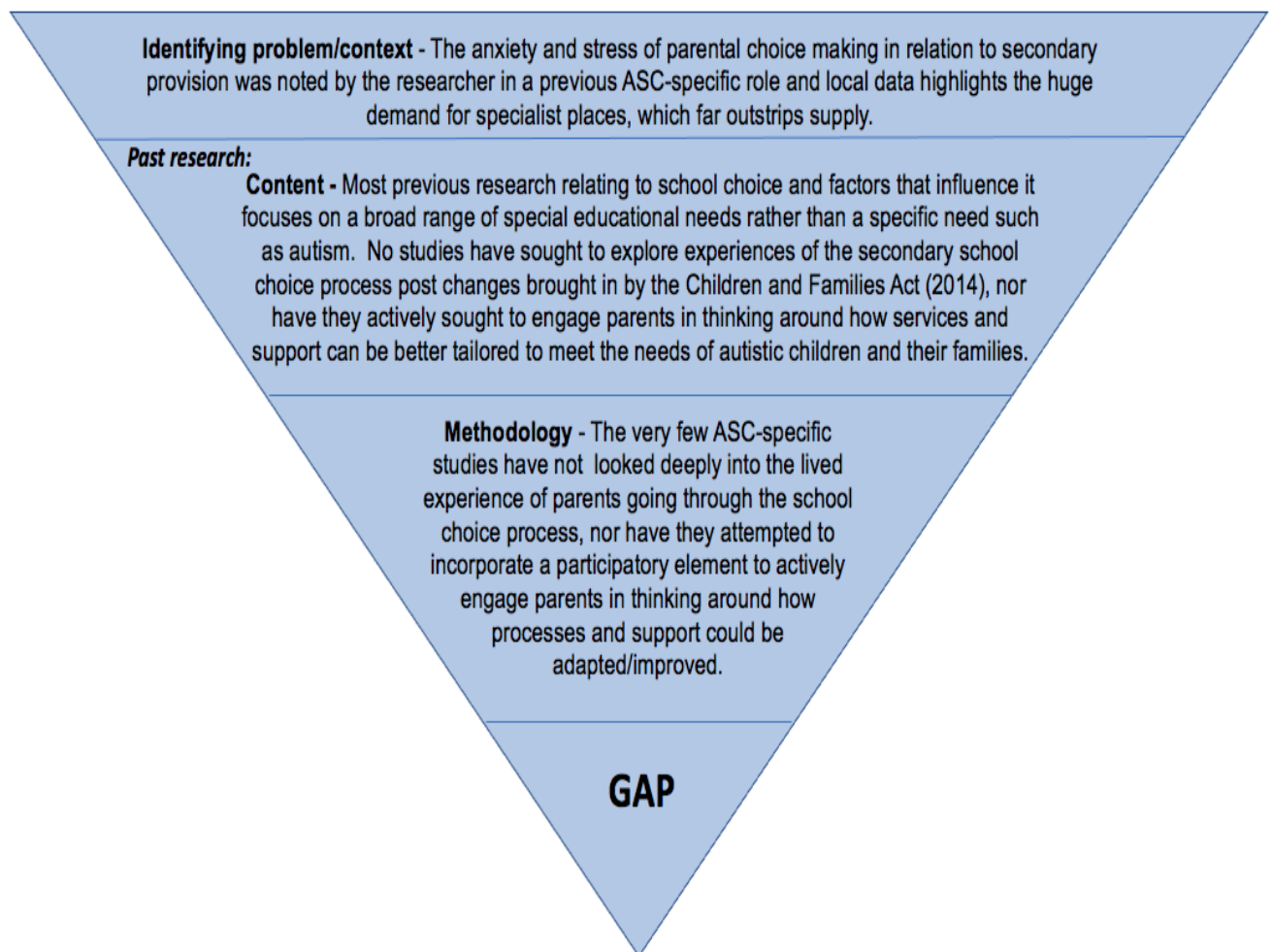
The studies considered for the literature review were deemed of high or medium quality, addressing gaps in knowledge and illuminating parental experience to enable the answering of the literature search question, *“How have parents experienced choosing and securing educational provision for their child with special educational needs and what factors have influenced their decisions?”*. However, several of the studies were over ten years’ old (e.g. Tissot, 2011 & 2006; Bagley, Woods & Woods, 2001), and some lacked methodological transparency (e.g. McNerney et al., 2015; Bagwa-Patel & Devecchi, 2014).

Key themes were noted related to parents experiencing SCPs as stressful, bureaucratic, and lacking in support, with local authorities positioned as primarily concerned with budgets and mainstreams positioned as non-inclusive. Perceptions regarding this lack of mainstream inclusivity/their resistance to SEN, plus a lack of specialist places, contributed to a sense of school choices being limited. Factors influencing choice were varied and related to structural factors such as the preference for small class sizes, process-related factors such as effective communication, familial factors such as world-views of disability, and child-related factors relating to CYPs’ individual needs.

In terms of the rationale for the proposed study, the review of literature highlighted negative perceptions and experiences of parents of the SCP which would benefit from further exploration. While there has been research in the English context, there have been very few studies subsequent to changes to policy and practices brought about by the 2014 Children and Families Act, and the handful of research that exists relates broadly to all types of SEN. McNerney et al. (2014) advocated for the urgency of research considering specific needs, such as autism, in order to illuminate different perspectives regarding the SCP. A focus on secondary SCP for parents with autistic children has only been considered in one study (McNerney et al., 2014), and this was prior to changes brought by the Children and Families Act. There has been no participatory research that actively seeks to engage parents, as key stakeholders, to contribute to thinking around how services and support can be better tailored to meet the needs of autistic children and their families.

Figure 4 below shares the progression of my thinking when identifying a ‘gap’ for the present study. Ideas were refined with reference to both the influence of past roles and local context (discussed in the introductory chapter) and studies considered in the literature review.

*Figure 4: Identification of gap for the present research*



My study, therefore, aimed to answer the following research questions:

*Main research question - What are the lived experiences of parents when choosing and securing secondary provision for their child on the autistic spectrum?*

*Sub-question - What factors influence the choices of parents of children on the autistic spectrum with regards to secondary provision?*

A participatory element to the research introduced via a focus group:

*Focus Group main question – How can practices and support be enhanced and adapted to improve the experience of the secondary school choice?*

In the following chapter I will elaborate further on the methodology employed to answer these questions.



### **3. Methodology and data collection**

#### **3.1 Overview**

This chapter aims firstly to consider action research (AR) and the philosophical assumptions underlying the current research. Attention is then given to how I collected and analysed data within my three AR cycles. Finally, there is consideration of research quality, researcher positioning, reflexivity and ethics.

#### **3.2 Research position**

This study is primarily exploratory, examining the lived experiences of parents when choosing and securing secondary provision for their child on the autistic spectrum. It is also emancipatory in its facilitation of parental voice and the active involvement of parents in the potential shaping of future practice. These two different positions, i.e. to explore/understand and to emancipate, require philosophical underpinnings that are both interpretative and critical.

Cresswell (2012) asserted that a researcher must understand, engage with and make transparent underlying philosophical assumptions as they strongly influence the interpretation of data, arguing that philosophical standpoints should be clear from the outset to enable better perspective and self-awareness to guide theoretical thinking.

Consideration will now briefly be given to the underlying characteristics of AR before considering the philosophical orientations of the current study.

#### **3.3 Action Research**

Pioneered by Kurt Lewin in the 1940s, AR emphasises participation as a strategy of enquiry. In contrast to the experiential distance required for objectivity in scientific enquiry, it values the embodied knowledge of its participants. More recently, Reason & Bradbury (2001) describe AR as follows:

“Action research is a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes,

grounded in a participatory world view which we believe is emerging at this historical moment. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities.” (p. 1)

The aims of AR are proposed as two-fold, relating both to the personal aim of the researcher – who seeks to improve her knowledge and behaviours – and a wider social aim of enabling research participants to develop their knowledge and sphere of influence (McNiff, 2016).

McAteer (2013) explains that AR is not associated with a particular methodology but is instead an orientation to enquiry, involving collaboration with research participants with the aim of improving practices. While AR studies differ widely in approach, McAteer proposes that they incorporate some basic characteristics. These include 1) the need for critical reflection, 2) the desire to improve practice and contribute to the development of professional knowledge and 3) a research process that is iterative, with each cycle being subject to review and reflection (McAteer, 2013).

### **3.4 Philosophical orientation of current research**

#### **3.4.1 Ontology – what is the nature of reality? What there is to know?**

In considering the nature of reality there is a continuum of thought ranging from realist to relativist. Realism argues for the independence of reality from human thought, to be discovered and perceived objectively (Burr, 1995). Relativism questions this, instead arguing for the existence of multiple, subjective realities with no universal objective truth, appreciating that experiences are context-bound and recognising the influence of history and culture (Mason, 1996), e.g. one person may hold a belief about the educational legitimacy of hitting a child, while another would consider it child abuse.

The present study recognises that reality can and does exist independently from human thought in the world, but that engaging with and interpreting this reality is

socially and culturally mediated. This position between realism and relativism is recognised as a critical realist ontological assumption.

Roy Bhaskar, a pioneer of critical realism, argues that as an ontological position Critical Realism (CR) enables consideration of how actors shape their social worlds but, in turn, are constrained by social structures embedded in the fabric of social life, as well as illuminating the presence of oppressive mechanisms operating at the causal level of reality (which the social scientist is morally obligated to negate/expose for what they are) (Bhaskar, 2008). With this 'obligation' in mind, I attempted to apply Bhaskar's (1975) CR framework to the current study. It describes social reality as having three layers – the real domain, the actual domain, and the empirical domain. In brief, the *real domain* contains social structures and mechanisms. These structures distribute resources and authority to different people within a social setting, and this in turn enables or constrains the actions they can take. These actions (or lack of action) create events (or non-events) in the *actual domain*. The actions people take tend to either reproduce structures back in the real domain or change those structures. Sometimes an event happens, and no one notices. If an event is observed, however, that observation and/or experience occurs in the *empirical domain*. Appendix 3 presents my attempt at applying a critical realist framework to the current study, one can see for example how the 120m SEND Transformation Programme in the real domain, enables more ASC specific provisions to be built in the actual domain, which results in greater school choice in the empirical domain. This exercise, in illuminating the mechanisms which influence wider society and individual experience, made me appreciate CR's utility in providing a firm philosophical foundation for AR.

Taking this ontological position into account, and mindful of the current study's need for philosophical underpinnings that are both interpretative and critical, I have situated my research methodology within a phenomenological framework. Developed largely by the German philosophers Edmund Husserl and Martin Heidegger, it attempts as far as possible to interpret experience, based on the premise that reality consists of objects and events ('phenomena') as they are perceived or understood in the human consciousness. Phenomenology sets out

to understand and interpret the emotive, social and behavioural meanings bestowed on these perceptions, “to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place” (Giorgio & Giorgi, 2003, p. 27), i.e. it assumes that what is known is understood through individual experience and seeks to interpret these experiences. CR, in acknowledging both realism and relativism, provides an ideal philosophical framework for phenomenology, i.e. as a researcher I will be eliciting and exploring participants' experiences or phenomena (ontological realism) while recognising that they can be interpreted in manifold ways (epistemological relativism).

### **3.4.2 Epistemology – how we can know?**

Foucault defined epistemology as a system of possibilities for knowledge (Foucault, 1977), with Cresswell (2009) describing it as “a general orientation about the world and the nature of research that the researcher holds” (p. 6).

In modern social science, two of the main epistemological stances are postpositivism and social constructivism. These differ in their approach to how human behaviour can be ‘known’, and how knowledge is gathered and from which sources.

Postpositivism generally refers to an attempt to adapt and apply approaches from natural science to social science research. With the paradigm-shift towards postmodern philosophy, postpositivists recognise that their values, biases and hypothesis have an influence on what is observed, yet remain committed to a pursuit of objective reality. As such they tend to draw on quantitative methods of examining phenomena, testing theories to reach a generalisable ‘truth’.

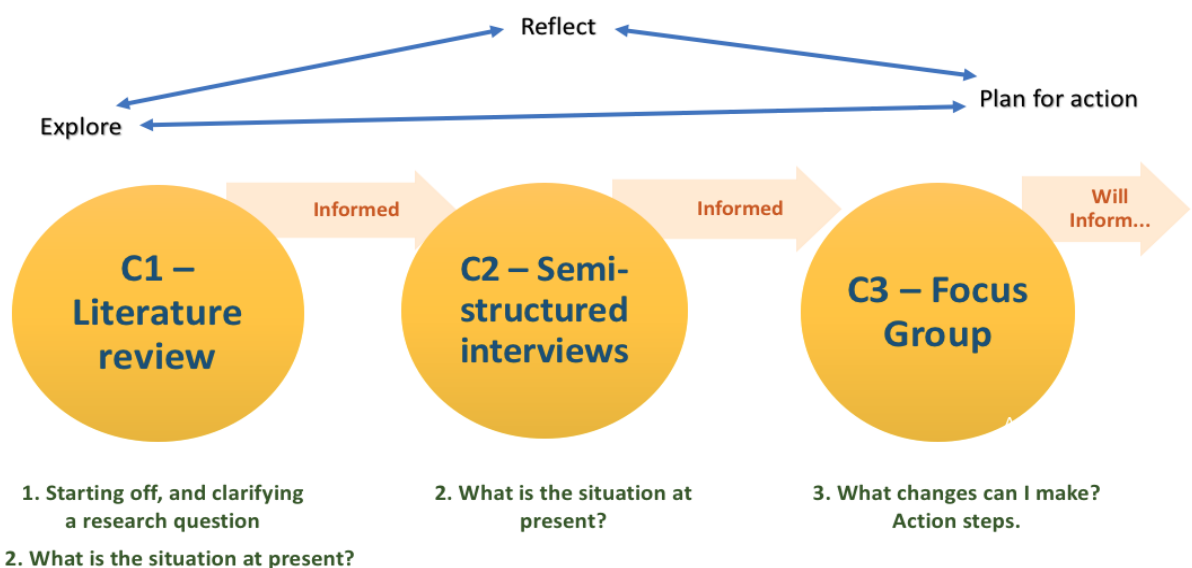
In contrast, social constructivists take a subjective stance, viewing social phenomena as constructed through interactions between people, and acknowledging that individuals' world views are shaped by the contexts in which they work and live. This viewpoint rejects the idea of an objective reality to be known, and actively acknowledges that a researcher will interpret phenomena through their own value sets and experiences. Therefore, constructivist

researchers are more likely to utilise qualitative methods, which allow them to garner and acknowledge multiple perspectives (Robson, 2011).

When reflecting on my personal context and developing experiences as a practicing psychologist I am cognisant of how the same event can be experienced in multiple ways, influenced by upbringing, culture, power and the personal schemas that develop from them. I realise that I cannot view a situation with complete objectivity, that my worldview and experiences influence and affect all of my interpretations and interactions. AR requires the researcher to build a collaborative picture with participants to “seek understanding of the world in which they live and work” and “develop subjective meaning of their experiences” (Cresswell, 2012, p. 24). As such, I believe social constructivism best reflects both my own epistemological beliefs and the epistemological stance of the current AR study. The ways in which this epistemological position influenced data collection and interpretation will be explored within the remainder of this chapter.

### 3.5 Study design and implementation

McAteer’s AR framework (2013) and Carr and Kemmis’s (1986) cyclical AR model were utilised and combined as a pragmatic model for engaging with my research. Throughout the process I endeavoured to explore the current situation, reflect on findings and use these reflections to plan for action, shown pictorially below:



**Figure 5 – The three cycles of the present research, informed by Carr and Kemmis’s (1986) cyclical AR model and McAteer’s AR steps.**

Each cycle, and the methodological and analytical processes within it, will now be considered in turn.

### **3.5.1 Cycle 1 – The literature review**

In Cycle 1 I conducted a review of relevant literature, seeking to satisfy Stages 1 and 2 of McAteer's framework by beginning an exploration of the 'situation at present' (McAteer, 2013) regarding how parents of children with additional needs have experienced choosing and securing educational provision for their child and what factors have influenced their decisions, whilst also enabling the clarification of research questions. This review of literature and research questions resulting from it are presented in chapter two of this thesis.

#### **3.5.1.1 Action steps**

The findings from the literature review and associated research questions then informed decisions concerning Cycle 2. For example, many of the studies relating to parental experience of school choice focused on a broad range of SEN rather than a specific need, and given that autism is the most common primary need for an EHCP (DfE, 2019), I chose to focus on recruiting parents of children with a diagnosis of autism. Additionally, I noted that no studies had sought to actively engage parents in thinking around how systems, services and support could be better tailored, after gathering more information about 'the situation at present' via semi-structured interviews. The exploratory nature of the research question I had developed led me to seek methodological approaches congruent with my epistemological position, which allowed reflexive consideration and acknowledged the complexities of individual experience. Discussion with my Director of Studies and personal experience of employing both semi-structured interviews and IPA during my master's degree made me mindful of their potential utility in the current study.

### **3.5.2 Cycle 2 – Semi-structured interviews**

#### **3.5.2.1 Approach to interviews, how data was collected**

The use of semi-structured interviews as a means of collecting data for my MSc research demonstrated their utility as an adaptable method of enquiry, allowing for the researcher to flex the order of questions to follow the flow of the interviewees' narrative and use open prompts to encourage elaboration around pertinent comments. It facilitated, "the gathering of richer and more insightful data, while facilitating comparison between interviews conducted with different interviewees" (Rowley et al, 2012, p. 95) and I judged it to be a good method to allow parent participants to share their experiences while allowing the space for new insights. Semi-structured interviews were considered an ideal vehicle to access more information about the 'situation at present', allowing for both flexibility and a level of control over the interview structure, to better answer the research questions.

The interview schedule (see Appendix 4) was designed to access information relating to the research questions while allowing space for the participants to share relevant wider experiences, with open-ended questions lessening the influence of the researcher in leading participants toward preconceived answers; instead eliciting a sharing of views and experiences and revealing issues of importance, in keeping with the study's epistemological position.

An inductive/deductive approach was taken to the design of the interview schedule, with questions informed by my findings in Cycle 1 and my previous experiences. For example, questions relating to the personal strengths the participants felt they possessed which helped them through the secondary choice process related to my experience as an SRB lead teacher and discussions with parents, where they shared the need for determination and resilience. Consideration was given to making questions accessible for all participants and therefore I avoided the use of jargonistic language.

Robson's (2011) proposed sequence of questions (adapted version below) guided the development of a flexible interview schedule:

1. *Introduction.* Interviewer introduces herself, explains purpose of the interview, assures confidentiality, and asks for electronic signature on consent form (Appendix 5). Permission sought to record. Participants invited to optional FG.
2. *Warm-up.* Easy, non-threatening questions to contain and settle participants.
3. *Main body of interview.* Open questions aimed at gathering information to answer research questions, but allowing for wider sharing of experience, in what the researcher considers a logical progression.
4. *Cool-off.* Wind down conversation, share debrief sheet (Appendix 6), answer questions to defuse any tension. Explain next steps with regards to FG (to those participants who express an interest).
5. *Closure.* Thank you and goodbye.

Reflection after the first interview led me to change the order of the questions to improve the flow of the question set. In addition, I realised that I needed to be more explicit in encouraging parental reflections around factors that influenced their decision-making and the processes they needed to go through to secure their chosen school place. While the amount of data gathered during the research process was significant enough for me to allow for this adjustment to approach, I reflected on the utility of a pilot interview, which would have allowed me to gain objective feedback from the pilot participant and hone my interview order and skills.

My literature review illuminated parents' experiences of power imbalances in their interactions with professionals and schools. To counter this I decided to hold the interviews online. As well as providing a more neutral space, the fact that parent participants were interviewed in their own homes, with a lack of visible recording device, may arguably also have helped to make the interviews more relaxed and naturalistic than they would have been if held in schools or offices of the county council. Mindful of a virtual environment's potential effect on attunement, I endeavoured to create a relaxed space and took time at the beginning of the interviews to build personal rapport. Time limits were not fixed but I attempted to contain the interviews to between 60 and 90 minutes. The online platform where



the interviews took place had recently added a live transcription service, which captured our conversation in real-time. However, the transcription required considerable 'cleaning up', while listening again to the live recording, in order to transcribe verbatim what was said.

### **3.5.2.2 Participant recruitment**

Attentive of the philosophical phenomenological underpinnings of the research, I choose Interpretative Phenomenological Analysis (IPA) as an appropriate analytical methodology, which will be considered later in further detail.

Smith, Flowers & Larkin (2009) suggest that between four and ten interviews is a reasonable sized sample for a qualitative doctoral research study, due to the depth of analysis required for each case. In line with Smith et al's recommendations, I endeavoured to be mindful of homogeneity to ensure insight into the phenomena being studied (i.e. all participants will be parents of secondary aged children with a diagnosis of autism, with an EHCP, who have gone through the SCP). While this study cannot claim absolute homogeneity of sample characteristics, it can claim purposive shared understanding of the secondary SCP. Inclusion and exclusion criteria for participants and associated rationales can be found in Appendix 7. Of note is the fact that parents were eventually found from a wider range of school year groups than originally intended due to difficulties related to recruiting sufficient participants.

The literature review indicated a gap regarding the experiences of parent participants whose children went to a range of educational settings, it was therefore my initial intention to recruit nine participants for the semi-structured interviews, three each from a) mainstream secondary schools, b) SRBs and c), special schools for children with ASC. However, this was not ultimately possible, as outlined in recruitment explanation below.

Most participants were accessed via initial emails with attached participant information sheet (see Appendix 8) to fellow EPs/SEN team members who then acted as gatekeepers to school SENCOs. SENCOs then made contact with parents who fitted the recruitment criteria, and those parents who indicated they

were interested in taking part were provided with the participant information sheet, detailing the purpose of the study and how they would be involved. While this process was frustrating at times (I was low on a busy SENCO's priority list), six participants were accessed – one from a mainstream school, two from an SRB, and three from ASC specialist schools. However, one of the three participants from an ASC specialist school did not meet the inclusion criteria as the child had not transitioned to the school from a primary setting in Year 6. My final two participants were recruited internally, via SEN team and EP colleagues. Both had children in mainstream settings, one was a specialist teacher with the EPS team and one was an advisor for the youth offending team. Please see table below for an overview of the participants.

<b>Participants</b>			
<b>Participant pseudonym (gender/ethnicity)</b>	<b>Job</b>	<b>Child pseudonym and age</b>	<b>Type of setting</b>
Rose <i>(female/white British)</i>	Teaching Assistant (TA) in a special school	Sam – 12 years <i>(male)</i>	Mainstream
Sarah <i>(female/white British)</i>	Specialist teacher	Ted - 14 years <i>(male)</i>	Mainstream
Kate <i>(female/white British)</i>	Advisor for youth offending team	Felix – 15 years <i>(male)</i>	Mainstream
Denise <i>(female/white British)</i>	TA at an alternative provision	Jake – 12 years <i>(male)</i>	Newly opened SRB
Fiona <i>(female/white British)</i>	TA	George – 11 years <i>(male)</i>	Established SRB
Ellie <i>(female/white British)</i>	Works for a charity supporting families of children with SEN	Archie – 12 years <i>(male)</i>	A free school for pupils with ASC
Natalie <i>(female/white British)</i>	Supports her children as a single parent	Peter – 15 years <i>(male)</i>	An independent school for pupils with ASC

**Table 4 – Description of Participants**

For a comprehensive overview of the phases of recruitment see Appendix 9. Notable is the fact that all participants who responded were mothers, and all were White British (six of whom either worked in educational provisions or supported families of children with additional needs). However, the lack of cultural diversity was arguably to be expected as the 'White British' demographic constitutes 92.4% of the rural county in which the research was situated (ONS Census 2011).

### **3.5.2.3 Data analysis – IPA**

IPA is informed by concepts and debates from three branches of philosophy: phenomenology, hermeneutics, and idiography. Each will be briefly considered, mindful of their compatibility with the current research.

#### **3.5.2.3.1 Phenomenology, hermeneutics, and idiography**

Phenomenology – The compatibility of phenomenology with critical realism, the ontological foundation of this study, has already been considered.

Phenomenology refers to the study of conscious subjective experience and as such IPA was an ideal method for hearing the lived experiences of parents and the factors that influenced their choices as they progressed through SCPs for their autistic child, allowing them to frame and elaborate on these subjectively. This “rich source of ideas about how to examine and comprehend lived experience” (Smith et al., 2009, p. 11) provided the solid base of the study.

Hermeneutics – Hermeneutics is the theory of interpretation, the 'I' in IPA. Interpretation is acknowledged as central to the analytical process, with its proponent Heidegger stating “whenever something is interpreted as something, the interpretation will be founded essentially upon the... fore-conception. An interpretation is never a pre-suppositionless apprehending of something presented to us” (Heidegger, 1962, p, 191–192). The researcher will always bring their 'fore-conceptions' and cannot help but interpret in the light of their own experience. This bias needs to be acknowledged and the interpretive lens then shone on the participants' meaning-making. IPA involves a double hermeneutic

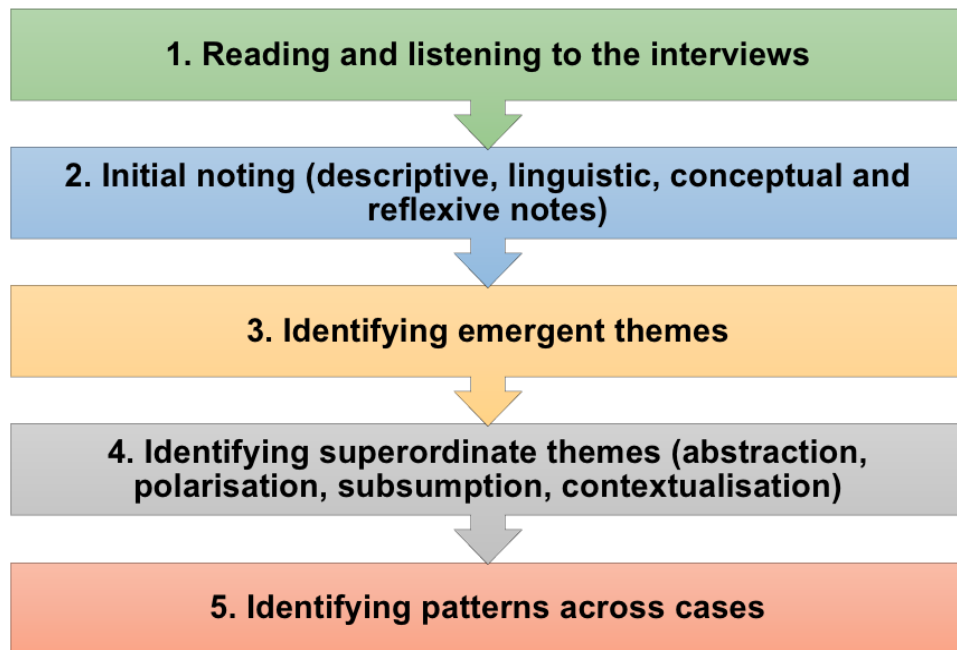
process, one in which, “the researcher is making sense of the participant, who is making sense of x” (Smith et al., 2009, p. 35). This acknowledges both first and second-order meaning-making, as the researcher attempts to understand experienced phenomena through both the participant's interpretation and their own experiential lens. Reflexivity is an essential part of the IPA process, as such, throughout my engagement with participants and the analytical process I attempted to engage with how my knowledge, experience, and assumptions may have influenced the research process. I additionally tried also to ask questions of myself such as, ‘what am I/ the participant trying to achieve here?’, ‘do I have a sense of something going on here that maybe I/the participants are less conscious of?’.

Idiography – IPA is an idiographic methodology, concerned with depth and detail rather than generalisable laws (a nomothetic approach). There is a commitment to valuing individual meaning-making, to analyse in detail the experiences of participants and the sense they make of their experience within a particular context, therefore claims about incidence and the wider population cannot be made. However, IPA can demonstrate the existence of phenomena and can focus on the transferability of findings from group to group rather than generalisation (Hefferon & Gil-Rodriguez, 2011). Thus in multi-case studies, the researcher can explore similarities and differences via cross-case analysis. Smith et al. (2009) argue that this kind of analysis can take us closer to the universal and allow us to consider concepts that are shared across humanity, there is an acknowledgement that specifics are unique, but that they connect to something mutually experienced.

In summary, I have chosen IPA as a methodology due to its dual focus on the unique characteristics of individual participants (an idiographic focus) and patterning of meaning across participants. This was considered ideal, allowing for both a ‘deep dive’ into the individual motivations and experiences of parents going through the SCP and a wider consideration of similar and contrasting experiences. Consideration will now be given to the data analysis process.

### 3.5.2.3.2 The data analysis process

Data analysis followed the process for IPA research recommended by Smith et al. (2009). Figure 6 below presents the staged overview of the process I followed, examples of my analysis are presented in Appendix 10 (a. to c.)



*Figure 6 – Data analysis 5-stage process*

Analysis stages:

1. Reading and listening to the interviews.  
Cleaning up the transcriptions provided the first step in terms of familiarisation. Following this I read the transcript two times and also listened to audio recordings on walks out, I endeavoured to keep participants meaning-making as the central focus and noted points of salience and prevalence.
2. Initial noting (including descriptive, linguistic and conceptual). This step required a deep and time-consuming dive into the data. Smith et al. (2009) outline three forms of noting.
  - a) Descriptive comments consider the content of the text.

- b) Linguistic comments consider how participants convey meaning, e.g. pauses, exaggeration, laughter/smiles, repetition, hesitancy etc.
- c) Conceptual comments engage with the text at an interpretive and interrogatory level, exploring the implicit meaning behind comments, aiming to move beyond superficial understanding towards something deeper and more sophisticated.

Additionally, I occasionally made reflexive comments to acknowledge my 'fore-conceptions'.

### 3. Identifying and developing emergent themes.

Here I focused on initial notes rather than corpus as a whole, aiming to reduce volume whilst mindful of maintaining nuance and complexity. Smith et al., (2009) share that, "themes are usually expressed as phrases which speak to the psychological essence of the piece and contain enough particularity to be grounded and enough abstraction to be conceptual" (p.87).

### 4. Identifying superordinate themes.

This stage involved searching for connections across emergent themes and clustering them into superordinate themes for each participant. I found using coloured post-it helpful for this, which enabled me to arrange and re-arrange emergent themes – the kinaesthetic and visual element allowing a deeper connection with the data and its associations. It was a fairly lengthy process, during which I remained mindful of and utilised the four techniques for clustering emergent themes/identifying superordinate themes suggested by Smith et al., (2009), namely:

- a) Abstraction – Use of an abstract label that encapsulates meaning-making captured within emergent themes, i.e. 'metamorphosis of self' can capture emergent themes do with personal change and growth.
- b) Subsumption – use of an existing emergent theme as a superordinate theme.
- c) Contextualisation – use of temporal, narrative and cultural aspects of narratives.

- d) Polarisation – noting of seemingly opposing but connected themes, e.g. ‘belonging’ could portray a participant's sense of feeling like they belong or the opposite.

Each case was analysed using steps 1–4 above. In line with idiographic philosophy, I attempted to analyse each case in its own right. Due to the significantly large amount of emergent themes, I found it useful to cluster them in subordinate themes which then clustered into a superordinate theme. While not a stage identified by Smith et al.,(2009) I found this approach useful to categorise the data into more manageable units – whilst also facilitating further identification of similarities and discrepancies between participant narratives during cross-case analysis. At the end of each individual analysis, a table of superordinate and subordinate themes and a graphic representation of superordinate themes were developed.

## 5. Identifying patterns across cases.

Once the analysis of all cases was completed tables of superordinate and subordinate themes and associated graphic representation were laid across a large surface and considered. As advocated by Smith et al (2009) connections and patterns were searched for between participants’ superordinate and subordinate themes, while remaining mindful of individual idiosyncrasies. Due to the individual nature of each analysis and its idiographic interpretation, themes did not map precisely onto each other and instead provided standpoints from which to consider, compare and, at times, contrast each voice. The cross-case analysis for each group – mainstream and specialist provision – was tabulated (see section 4.3.2). To enhance clarity, and the easy identification of individual voices in the cross-case analysis, each participant was assigned a colour.

### **3.5.2.3.3 Limitations of IPA and personal reflection of engaging with it**

Willig (2008) presented a range of conceptual and practical limitations of IPA. The first criticism was that IPA does not account enough for the integral role of language and the fact that there are multiple ways of describing an event, dependent on prevalent social discourse and context. However, in their rebuttal

of this Smith et al. (2009) argued that IPA accepts that language is context and discourse bound and is flexible enough to acknowledge this within the interpretation. A second criticism related to how the linguistic and communicative limitations of both participants and researchers precede and influence their ability to both conceptualise and share experiences, i.e. can IPA adequately capture the experiences and meanings of experiences rather than just opinions of them? However, this is a potentially elitist viewpoint which proposes that only individuals with the right level of fluency can describe their experiences. Smith et al. (2009) suggest that IPA researchers should note Willig's criticism and be mindful of collecting rich and attentive and comprehensive data from participants. Additionally, Willig voiced concerns regarding the descriptive nature of IPA, arguing that phenomenological inquiry allows only limited scope for deeper interpretation and theorising, seeking to explore meaning-making and lived experience but not why phenomena occur. However, Smith et al. (2009) contend that IPA's philosophical foundation of hermeneutics, idiography and contextual analysis allows for the understanding of how culture and context have shaped experience.

When engaging with the methodology, I attempted to be attentive to these criticisms and counter them by collecting rich data and using IPA's flexibility to remain mindful of the cultural and contextual situatedness of both my participants and myself. I was very aware during analysis of my own imperative to find links (and shortcuts) between data sets, and how this could lead to a biased analysis. Consequently, I attempted to keep very close to the data and the individual 'idiosyncratic' stories of each participant while exploring wider patterns of meaning-making across the corpus. Salience of themes was given the same weight as prevalence to account for and reflect the intensity and impact of some of the parental experiences. I hoped that, by approaching analysis in this way, I could adequately communicate the complexity and nuance of both individual and collective idiographic experience in my findings.

#### **3.5.2.4 Action steps**

After analysis of individual cases, participants were contacted to ask if they would like feedback on my findings and asked if they were still interested in being part



of the FG. A range of dates was suggested and one chosen (which the largest number of participants were able to attend).

The superordinate themes uncovered during individual case analysis fell into two camps relating to, 1) internal processes, e.g. metamorphosis of self, and 2) external factors, i.e. communication and information exchange. It is the latter that were considered for the FG, informed by relevant findings from the literature review, i.e. the findings from Cycle 1 and Cycle 2 were taken into Cycle 3. Cycle 3 will now be considered.

### **3.5.3 Cycle 3 – The Focus Group**

Cycle 1 and 2 were concerned with an exploration of the ‘situation present’ (McAteer, 2013). To explore ‘what changes could be made and action steps’ (McAteer, 2013) a FG was held. My intent was to create a collaborative space in which parent participants could “influence each other by responding to ideas and comments in the discussion” (Krueger, 1994, p. 6), and work together to discuss and identify suggestions for how practices and support could be improved – acknowledging them as key shareholders in the SCP. An overview of the structure and stages of the FG can be found in Appendix 11.

Participants who had agreed to take part in the FG were sent an information sheet (Appendix 12), which outlined the FG’s purpose, my role within the group and the FG ground rules. The FG, like the semi-structured interviews, took place online.

Mindful that a united and well attuned group was likely to be more successful and motivating than a disparate group in the achievement of group goals, I aimed to quickly establish cohesiveness. While I knew this was likely to be already partially achieved by the participants shared social identity (i.e., of having an autistic child and going through the secondary SCP), I attempted to further establish affiliation by first sharing cross-case findings from individual interviews and then allowing the participants share their school choice process experiences in an open discussion (described in more detail in section 3.5.3.1).

I was also aware of the need to manage group dynamics and power differentials. Having met most of the participants online twice (during brief pre-interview orientation chats and the interviews themselves) I was mindful that some were more vocal and confident than others, so I was determined from the outset to moderate in a way that would allow all participants to contribute. While being online significantly reduced opportunities for non-verbal communication, it did allow for greater facilitation of turn-taking as all the participants, like myself, had grown used to operating in an online environment where turn-taking is necessary for people to contribute affectively and be heard. This was enhanced by making explicit at the start of the FG that I would like everyone to contribute, and I also feel that being in their own environments rather than a new environment may have allowed participants to settle more quickly and feel less daunted and able to contribute.

Particular attention was given to building cohesiveness, facilitating rich exploration, and ensuring that all participants - regardless of personal confidence/differences in acquired power and personal circumstance – had a chance to speak and collaborate, all of which contributed to a group dynamic which worked well to service the participatory goals of the research.

### **3.5.3.1 Use of Appreciative Inquiry**

Appreciative Inquiry (AI), “a group process that enquires into, identifies and further develops the best of ‘what is’ in practice and processes in order to create a better future” (Preskill & Catsambas, 2006, p. 2), was selected as a strengths-based tool to facilitate the session. It enabled an exploration of positive steps forward by the use of positively phrased questions, while not preventing participants from sharing negative aspects of their experience. I have always felt that there is a paradox in traditional problem solving/change-based methods, where to improve a situation the default position is to ask what is not working, leading to potential deficit-based entrenchment (and associated sapping of energy, motivation, and goodwill). For parents who were already worn down by SCPs, I instead wanted a more empowered positive approach, where participants, in keeping with the participatory drive of the research, were co-

creators. I was also mindful that too much deficit-based talk may have prevented forward movement in the finite time we had for the FG.

The chosen AI process involves four stages – Discovery, Dreaming, Designing and Destiny (see Figure 7). The first phase involves appreciating or 'discovering' the best of what is – within the context of the research I wanted this to be an exploration of what was working in terms of the processes associated with secondary school choice. The next stage, the 'dream' involves thinking about how to build on what is working by blue sky imagining about what processes and practices could become. This 'dream' stage then facilitates the third stage, a co-constructive 'designing' of positive and possible steps forward – known as 'provocative propositions'. Cycle 3 of the research was not concerned with the 'destiny' (stage 4) element of AI, i.e. 'creating and committing to what will be' (Cooperrider & Whitney, 2005). This is hoped to be achieved in Cycle 4 – a follow-up workshop of key local authority special educational need (SEN) partners (including parental representation) to be held in my first year of qualified practice.

One can appreciate how AI (which recognises that knowledge and reality are constantly being shaped through discourse, and that attempts to explore wished-for realities are constructed via participants aspirations, experiences, and core beliefs) relies on the philosophical framework of social constructivism. However, one needs also to acknowledge the potentially restrictive lens AI brings in terms of seeking only positives and strengths. To counter this I decided to allow some time at the start of the focus group to enrich the 'discovery' element of the AI, while also allowing time for participants to build rapport and collaboratively explore shared and contrasting experiences in a safe environment. While this part of the focus group was only brief due to time constraints (approximately 20 minutes), this 'sharing of school choice process experiences' element of the focus group was an opportunity for participants to explore each other's sometimes difficult and traumatic personal accounts, as well as allowing them to actively compare, interpret and co-construct new levels of understanding together, further illuminating social constructivism as the ideal philosophical base for AI. Overall, I found the principles of AI fitted well with my epistemology, being

both constructionist and acknowledging post-modern perspectives on narrative and discourse.

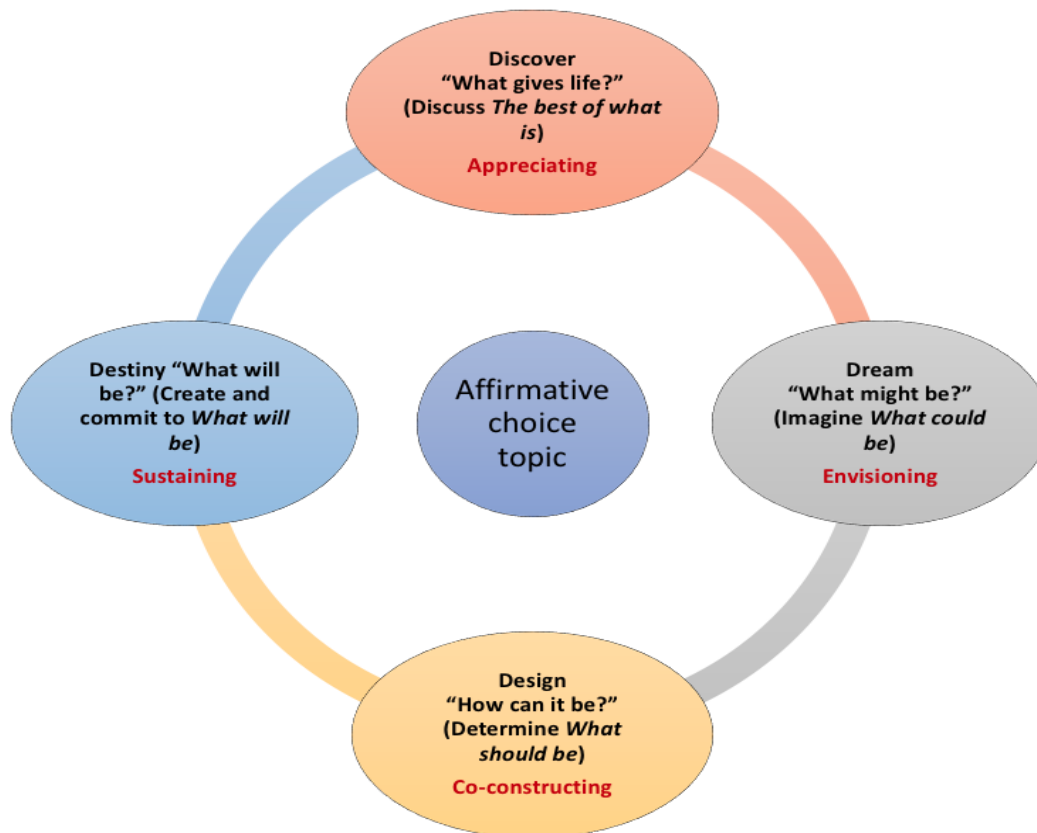


Figure 7 – The 4D Cycle of AI (Cooperrider & Whitney, 2005)

AI was a useful strengths-based approach to highlight some of the positive elements of the SCP, e.g. participants shared examples of professionals who went beyond tokenistic involvement and guided them, with empathy and understanding, through processes and practice. I also noted the collaborative strength of taking participants engaging in ‘discovering’, ‘dreaming’ and ‘designing’, it enabled recognition of shared experiences and introduced a sense of hopeful forward movement, something I feel wouldn’t have been achieved in the same way via a traditional ‘problem-solving’ approach.

### 3.5.3.2 Reflections on limitations of AI

Before doing AI, given the very negative nature of some personal experiences, I was concerned that participants may feel their experiences were being negated by a shift to focusing on the positive. To counter this I wanted to first

acknowledge personal experience by sharing and discussing cross-case findings (in the first part of the FG) and be as transparent as possible about why I was using AI and its pragmatic strength as a tool within our time-limited session. This worked well to frame the session, but I recognise that some important and meaningful conversations, with regards to difficult shared experiences, did not take place (although they were acknowledged in the cross-case feedback).

### **3.5.3.3 Action steps**

The provocative propositions generated during FG and the wider implications for practice developed as a result of Cycles 1 and 2 will be taken to key local authority staff in Cycle 4 – a workshop of key local professionals including, 1) those involved making decisions with regards to the SCP, e.g. the Head of High Needs SEN and Disability and the Principal Educational Psychologist and 2) those who liaise directly with families during the SCP, e.g. EHCP coordinators, SENCOs and educational psychologists. There will hopefully also be representation from parents involved in the research and/or parent support group representatives. It is hoped that this workshop will fulfil the ‘destiny’ part of the AI cycle – using the positive and possible parameters developed collaboratively as part of the AR cycles to improve and develop practice with regards to school choice, and providing a forum to “create and commit to what will be” (Cooperrider & Whitney, 2005).

## **3.6 Trustworthiness and reflexivity**

Qualitative research, by its nature, is not concerned (as quantitative research is) with the generalisability of findings, but by how people make sense of the world. This can lead to accusations of lack of rigour. Trustworthiness works to counter this by posing the question, “can the (qualitative) findings be trusted?” (Lincoln & Guba, 1985). The best-known criteria to judge the trustworthiness of qualitative research are credibility, transferability, dependability and confirmability.

Credibility – the equivalent to internal validity in quantitative research – relates to “the defensibility and plausibility of claims made by research” (Spencer and Ritchie, 2012, p. 230), i.e. is my study measuring what it is supposed to be

measuring? Within the current research an objective truth was not sought, instead the findings aimed to reflect the meaning-making of my parent participants and I was concerned with how congruent my findings were with their lived experiences. To preserve credibility I provide detailed examples of my different methods of data analysis, from raw data and coding to thematic diagrams, tables and maps. Additionally, during the three cycles, analysis and generation of findings/discussions, I constantly triangulated my qualitative data with other sources. I shared examples of my coded transcripts with my director of study and other TEPs and discussed/agreed themes with them. Mindful of Mertens (2010), who described member checks as being pivotal in establishing the credibility of qualitative research, individual and cross-case findings were fed back to participants. “Tactics to help ensure honesty in informants” (Shenton, 2004, p. 66) were also employed, i.e. I took time to develop attunement and rapport with participants, making interviews as relaxed as possible and reassuring parents that confidentiality was assured. As discussed previously, I felt that holding interviews online (and therefore participants being in their own homes) contributed to a sense of connection and settlement.

Transferability is concerned with applicability, i.e. can the findings of the study be applied to other situations? To ensure greater transferability it is the responsibility of the researcher to provide a ‘thick description’ of participants/the research process, thereby enabling the reader – in this case other parents/EPs/SENCOs etc. – to judge whether your findings are applicable to themselves and their particular context. In terms of the current research I have attempted to provide rich descriptions during Cycle 1 and 2, however Cycle 3 is arguably more concerned with actions and possible future outcomes (i.e. the ‘action’ in the action research). It is ultimately hoped that both themes and recommended action steps will be seen as transferable and useful to a range of stakeholders.

Dependability is important to trustworthiness because it establishes the research study’s findings as consistent and repeatable, i.e. that findings are consistent with original transcripts and coding. Merriam (2005) asserts that in phenomenological studies dependability relates to “consistency in data [interpretation]” (p.331) and suggests that researchers take care to ensure consistency in the way that they

conduct interviews and transcribe, analyse and interpret data. When reflecting on data collection and interpretation during the current research I felt that despite mindfulness of consistency, the sharing of individual stories required flexibility from the interview process in terms of how and when questions were presented (however, the same questions were ultimately asked of all participants). The member checking and transparent sharing of data collection and analytical procedure already mentioned served to embed dependability, as did adhering to Smith et al.'s 5 stage process when doing IPA. I sought to give equal time and attention to each data item in the coding process and frequently compared themes to the original data set and the data set to themes (the hermeneutic circle).

Confirmability concerns neutrality, that where possible, "findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher" (Shenton, 2004, p. 72). Within this qualitative study, particularly within the philosophical groundings of IPA, I cannot claim to have completely ringfenced my assumptions, beliefs and 'fore-knowledge' from the research. However, I feel that my in-depth methodological description has allowed for an increased level of research integrity. I have also been mindful of and attempted to employ reflexivity throughout.

Reflexivity – as a qualitative researcher I had to acknowledge my presence in the research process and the potential influence this had on collecting, analysing and interpreting the data. Critical realism's core characteristic is the notion that the world exists independently of our knowledge of it and that theories of the world are socially constructed (Johnson & Duberley, 2000; Sayer, 2000). With this in mind, I appreciate that my knowledge of the world is fallible and that no matter how much I strive to understand the subjects of my research, my findings typify my own theories and beliefs, but other people may construe the data differently due to their diverse life experiences and frames of reference. Finlay (2002) describes reflexivity as the defining feature of qualitative research, cognisant of this I attempted throughout the research process to consider and make explicit my views, assumptions and beliefs. I utilised Burnham's Social GRACES reflexive model (Burnham, 1993) to further consider and reflect upon my privilege

and associated prejudices and assumptions that could implicitly influence and affect both my interactions and the way I engaged with data. The pen portrait below shows the ‘graces’ that could be of particular influence (in ***bold italics***):

I am a white (***ethnicity***), British (***geography***) middle-aged (***age***) woman (***gender identity***). I am educated to a post-graduate degree level and am currently undertaking a professional doctorate (***education, class, ability***), financially comfortable (***economics***) and heterosexual (***sexuality***). I live with my partner and our three teenage children, one of whom identifies as non-binary (***gender awareness***). While tolerant of other people’s beliefs I have no religion (***religion***). I have a good network of social support.

In my professional life, I have worked as a mainstream teacher, a teacher trainer, a head of education in a school for looked after children with social and emotional difficulties, an ASC specialist resource base lead teacher, and a TEP in the Local Authority in which the research was conducted (***employment***).

Reflexivity was discussed in supervision meetings with both my director of studies and placement supervisor; it was also recorded throughout the research process in a reflexive diary, e.g. reflexive notes were made after each interview noting the feel of the interview, my relationship with the interviewees, and my subjective responses to participant experiences and meaning-making.

### **3.7 Ethical considerations**

All aspects of the current research adhered to the British Psychological Society ‘Code of Ethics and Conduct’ (BPS, 2018) and the Health Care Professional Council ‘Guidance on conduct and ethics for students’ (HCPC, 2012). A research ethics application was submitted to the Research Ethics Committee of the School of Psychology, University of East London, in February 2021, with approval received in March 2021 (see Appendix 13).

While the protection of human subjects through the robust application of appropriate ethical principles is important in all research, I was mindful of staying particularly attuned in this participatory qualitative study, due to both the deep



dive into personal experiences and the fact that participants were involved in the shaping and direction of ‘action steps’.

Key ethical issues are considered below.

### **3.7.1 Competence**

The BPS *Code of Ethics and Conduct* (2018) were followed. During supervisor and peer supervision sessions I valued drawing upon the experiences and observations of colleagues to reflect on both the ethical standards and wider ethical issues. Ethical considerations related to my research were noted in my research diary.

### **3.7.2 Respect and responsibility**

The risk assessment conducted in preparation for the research did not identify any significant risks of harm, be it psychological or physical. However, throughout my engagement with parent participants, I was mindful of my duty of care, and remained aware that emotive and impactful experiences were being shared – to this end I sought to make the participants feel as supported and contained as possible, and provided a debrief sheet with details about how to seek follow-up support. There was transparency and assurances throughout – in initial information/invitation letters, consent forms, debrief sheets, and verbally within interviews and FG – regarding anonymity, confidentiality, informed consent, and the right to withdraw.

### **3.7.3 Integrity**

I aimed to make all information shared with participants a clear and honest reflection of the nature of the research and how the participants would be involved. Additionally, participants were invited to ask questions and seek clarification before, during and after interviews and the FG. The recruitment process used gatekeepers to access parents and therefore no undue pressure was placed on them to participate.

### **3.8 Summary and conclusions**

In summary, the cyclical AR approach of the current study has required the utilisation of a range of different frameworks and methodological approaches, with a larger aim of influencing processes and practices. Cycle 1 and 2 aimed to achieve a detailed understanding of 'the situation at present', developed via a comprehensive literature review and Interpretative Phenomenological Analysis of data from seven semi-structured interviews. The conclusions drawn from these were subsequently used to inform Cycle 3 – a FG which enabled the collaborative co-creation of positive 'action steps' via a process of Appreciative Inquiry. These action steps will be shared with key professionals and parent representatives at a future workshop (stage 4 of the AR cycle).

The following Findings chapter initially explores 'the situation present' through the presentation of themes and superordinate themes developed from the semi-structured interview data. Provocative proposition 'action steps' from the FG are then presented.

## **4. Findings**

### **4.1 Overview**

This chapter starts with a brief consideration of research participants. This is followed by a comprehensive account of the cross-case IPA analysed interview findings resulting from Cycle 2 of the action research. Last, findings from Cycle 3, the focus group, which used AI to co-construct positive and possible improvements to practice, will conclude the chapter.

### **4.2 The participants**

I have compiled brief bullet-pointed pen portraits and diagrammatic representations of individual participant's superordinate themes to encourage a circularity of interpretive understanding. These should support the reader to consider findings of the cross-case analysis within the context and individual experiences of each parent participant, and can be found in Appendix 14. It should be noted that the superordinate themes presented by parent participants were often interrelated and overlapping, e.g. themes relating to fight and transformation were closely linked with themes relating to lack of support and/or perceptions of broken and inefficient systems. The reader should note that Kate refers to her child Felix using the pronouns they/them.

### **4.3 The quest narrative and patterns across cases – Cycle 2**

#### **4.3.1 The Quest**

Analysis of participant experiences and meaning-making consistently elucidated a quest narrative, which framed the profoundness of lived experiences with their autistic child. Within the interviews, discourse relating to difficult journeys and battles was unanimously referred to. Participants faced obstacles – personal, relational, and systemic. They were helped by allies but often felt hindered by oppositional forces. There was a sense, both conscious and unconscious, of personal metamorphosis and growth, of the educational journey with their child changing them, or forcing them to change and acquire personal power. For some there is a sense of a 'warrior' status being initiated, but it is generally a

mantle they would have rather not have assumed. Participants also reflected on those who get left behind on the quest to find appropriate educational provision.

### 4.3.2 Patterns: master themes across cases

With this bigger 'quest' narrative in mind, and as advocated by Smith et al (2011), connections and patterns were searched for between participants' themes, while remaining mindful of individual idiosyncrasies. Three key patterns, or cross-case 'master themes' emerged from this analysis:

- A difficult journey
- Those who prevail and those who become lost
- The factors that influenced choice and decision making

Table 5 below shows the superordinate themes identified in each participant's account, grouped into these master themes.

	Participants						
<i>Patterns, 'Master Themes' Across Cases</i>	Denise	Ellie	Fiona	Natalie	Rose	Sarah	Kate
<b>A difficult journey</b>	<p>My autistic child</p> <p>Barriers to the process</p> <p>What it takes</p>	<p>The journey has taught me and shaped me</p> <p>It's complicated</p>	<p>The impacts of my autistic child's educational journey</p> <p>Snakes and ladders</p> <p>It's not what I'd hoped</p>	<p>Learning from my autistic children</p> <p>Power and suffering</p> <p>The new system is broken</p>	<p>Autism and its impacts</p> <p>Fight and trans-Formation</p> <p>What we need and what we get</p>	<p>Judgement, loneliness and self-doubt</p> <p>What helps and what hinders</p> <p>The long term impacts of short term decisions</p> <p>The bigger picture</p>	<p>Atypical in a typical world</p> <p>Trauma and healing</p> <p>Power Play</p> <p>The bigger picture</p>

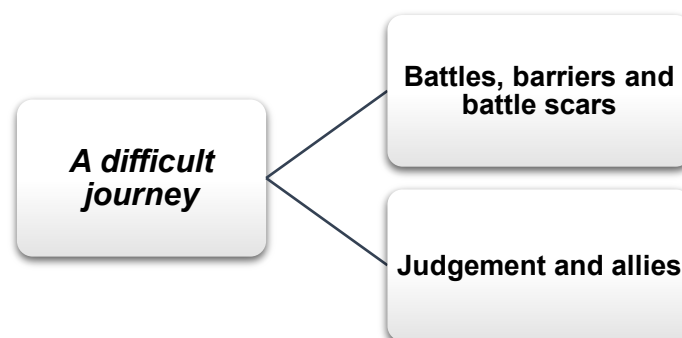
Those who prevail and those who become lost	What it takes	Change is possible	The impacts of my autistic child's educational journey	Power and suffering	Fight and trans-Formation	The bigger picture	Trauma and healing
	My autistic child	Winners and losers	Snakes and ladders	Learning from my autistic child	The system is broken	What helps and what hinders	Power Play
The factors that influenced choice and decision making	The possibility of a positive experience	The journey has taught me and shaped me		Power and suffering	What we need and what we get		
	Factors that influence choice	Factors that influence choice	Factors that influence choice	Factors that influence choice	Factors that influence choice	Judgement, loneliness and self-doubt	Factors that influence choice
	What it takes		The impacts of my autistic child's educational journey	Learning from my autistic children	What we need and what we get	Factors that influence choice	Trauma and healing
					Autism and its impacts	What helps and what hinders	

*Table 5 – Participants' superordinate themes grouped into master themes across cases*

These master themes provide standpoints from which to consider, compare and, at times, contrast individual accounts. Further subdivisions of master themes were utilised to aid clarity and allow for a more coherent and systematic reporting, presented below. Each master theme is summarised first as an overview paragraph and then diagrammatically, followed by a descriptive account of the findings for each, trustworthiness is maximised by use of credible examples. Colour is used throughout the presentation of the cross-case findings to bed them in the ideographic, and to enhance clarity.

#### 4.3.2.1 A difficult journey

The major, most prevalent and salient theme, emerging from parental narratives relates to the difficult journey all participants have had to face to ensure that their autistic child is appropriately supported. While the main research question related to parental experiences of choosing and securing secondary provision for their child on the autistic spectrum, all parental narratives revealed a journey towards this stage, often involving experiences in previous educational settings and attempts to secure an EHCP. There was often a pervading sense of ‘them and us’, of having to stand up and fight against systems positioned against them. Strong and recurring themes throughout the corpus relate to the significant impacts – both on their child, and themselves – of a lack of understanding, the judgement of others, and system inefficiencies. Participants have had to overcome many barriers and often felt alone in the process. However, most, to greater and lesser extents, were joined at different points by professional allies.



*Figure 8: Master theme: A difficult journey*

##### 4.3.2.1.1 Battles, barriers, and battle scars

All participants set their school choice experiences within a long and convoluted process. Choosing and securing a secondary school place did not begin in Year Six by simply expressing options on a school admission form. All participants used language and metaphor related to journey and battle when describing their experiences, with images and descriptions conveying barriers to progress and the, sometimes profound, emotional impacts of the journey with their autistic child.<sup>1</sup>

<sup>1</sup>During the interviews I asked participants to sum up their experience of the school choice and wider processes in three words, these have been compiled into a word cloud which can be found in Appendix 15a.

For example, whilst the diagnostic process for her son Jake was early and straightforward, Denise spent years “battling” (p. 5) for him to be adequately supported in his nursery and primary school, ultimately entering a legal dispute with the local authority after he was refused an EHCP and receiving several “notes in lieu” (p. 5). She also describes being “batted back” (p. 19) several times by decision-makers when seeking an SRB place. When reflecting on this, Denise used the metaphor of three fights:

*(...) some [autistic children] have got the diagnostic fight, then you've potentially got the EHCP fight, and then you've got the fight to find the correct placement, especially if you're going for specialist. Yeah, it's like, well it's exhausting, it's exhausting. There were times when we could have quite easily said we've got enough going on in our life at the moment, do we really have to keep fighting this out? And the answer was always yes, we do have to fight it out because it's important for our little boy. (p. 23)*

Denise's multiple uses of the fight metaphor and repetition of the word 'exhausting' give an impression of the impact these processes have had on her. The journey feels unrelenting, but questions of whether to keep fighting are countered by a sense of responsibility to her son, which gives her the impetus and strength to continue. This sentiment was echoed by all mothers, with Natalie summing it up in an impassioned way when talking about her youngest son's recent diagnosis:

*I'm completely comfortable with my child having ASD, it's just another way of the brain working and being human, but because I know what torture it is to go through the system, and what I'm gonna have to do I'm like, I haven't I even got an ounce of strength left. I'm still fighting for my older two and I've gotta do it all again, the thought is torture. (p. 10)*

Natalie uses torture and similar metaphors throughout her narrative to powerfully illustrate her struggles and suffering during the educational journey with her children with autism and additional needs, where she has often felt forced into corners and negatively positioned as a single mother. This 'torture' refers not only to debilitating impacts on herself but to the impacts on her children, shown in her description of her son Peter's self-harm in a previous mainstream school placement because of his high levels of anxiety, “... he started pulling handfuls of hair out, he had big bald patches, he'd start pulling out his hair literally at the idea of going to school” (p. 6).

The impact of previous and current school placements permeated the corpus as a strong and recurrent theme, of difficulties and trauma associated with 'atypical' minds attempting to navigate interactions, procedures, and systems set up for a 'typical' majority. Kate attempts to speak from her child Felix's point of view in exemplifying this:

*Felix will tell you it isn't the autism that causes problems in school, it's because other people don't say what they mean or mean what they say, but if everybody did their life would be a million times easier and autism wouldn't cause any problems, but because people aren't clear that causes problems. I remember a teacher getting very angry with Felix because she'd said, 'would you like to come in now?', and Felix said, 'no thank you' and continued to play. Felix could not understand why they'd been told off and lost a privilege. It was like, 'I was polite, I said no thank you, if she wanted me to come in, why didn't she just tell me so?' (p. 2)*

This viewpoint echoes Natalie's comment that autism is, "...just another way of being a human", and resonates with a social model of disability, positioning autism not as a 'problem' but as a part of the human spectrum, around which systems have a moral imperative to adapt. However, contrary to this, parents such as Natalie and Kate felt their children were often punished by a systemic lack of adaptability and understanding. Examples relating to this lack of understanding with regard to autistic profiles saturated narratives, further illustrated here by Ellie and Fiona:

*(...) she said, "oh that's ok we'll catch him up", and it was like no, I don't think you quite heard actually 'cause if it was just a case of catching him up, then yes, absolutely, you know if you've got that magic wand, but they were just so far in the dark ages, you know in terms of understanding his needs, they just didn't get it at all. (p. 5)*

*(...) if he's with staff who don't understand his struggles and his needs then they can see him as just being naughty or just not wanting to do it, rather than he can't do it. He can't, you know, he literally cannot remember what you've just told him to do. (p. 1-2)*

Fiona's son George struggles with poor working memory, anxiety, and mental health problems, which have caused significant upheaval in his current placement. Anxiety and mental health issues were constantly identified as a barrier to learning, settlement and progress for autistic youngsters, with experiences strongly evidencing the negative impacts of a lack of understanding



about the condition, alongside withdrawal of support or short-term injudicious decision making. Sarah describes the fall-out from a decision to remove her son Ted from Larkin's, a nurture unit within his mainstream secondary provision. The struggles her son had to process the changes are clear, as are his feelings of rejection and the impact on his sense of self. The lasting impact on Sarah is also evident, and she is one of many parents who have reflectively questioned their secondary school choices:

*He hit the ground running in Larkin's, the staff knew who he was and they were brilliant with him, but then he got to year eight and the powers that be took all the support away and he was just left in a classroom, and he just couldn't cope. I mean as soon as they recognised that they did start to put it back, but the damage had been done really, he saw it as those teachers didn't like him anymore. Yeah, it just completely shattered his hope and his confidence in everything. It was...oh I get a bit emotional thinking about it, it's just awful watching that child who was so happy, go to point-blank refusing [to go to school], and that's when I started to question if I had done the right thing. (p. 3-4)*

The impact of blinkered decision making and a system failing to adapt to individual needs is reinforced by Kate:

*(...) what pushed it over the edge was Felix doing one of the SATs. Felix says that the TA was trying to help him cheat by making encouraging noises, so Felix went and sat in a different part of the room and sat on the floor with his hands clamped over his ears. Rather than leaving them alone, which was in the EHCP and in the care plans, she started trying to cajole... and there were no ear defenders and no chewy gems and no nothing. So to drown her out Felix started a lot of rocking backwards and forwards hands over ears and going 'lalala'. I imagine that behaviour is probably saying quite a lot, but they decided that Felix was perfectly in charge of what they were doing and were doing it deliberately... so they decided to ban him from the Year Six residential. (p. 18)*

Felix is physically and metaphorically backed into a corner, with his anxieties leading to stimming behaviours which, rather than being met with strategies to support, are positioned as defiance and sanctions delivered, despite provision being clearly outlined in his EHCP. Kate, alongside other participants, feels Felix's academic strengths have consistently masked his greater difficulties, acting as a barrier to appropriate understanding and support and making her feel judged and gaslighted – made to feel like she is 'mad' and fabricating his

difficulties, “*They think that Felix is bright and very clever and hasn't got a disability, instead it's 'the mother is a lunatic' [makes speech signs]*” (p. 19)

A feeling of being judged and positioned as unreasonable or ‘pushy’ is a salient theme running throughout the corpus. Sarah’s previous use of the term ‘powers that be’ and Kate’s generic unnamed ‘they’ imbue a sense of polarisation, of ‘them and us’. There was a sense from all participants of having to stand up against forces with a different agenda to their own.

Rose for example used folders worth of banked and collated reports (shown to me during the interview process) to challenge the local authority’s decision not to award an EHCP. The capital of professional evidence and opinion is used to challenge the power of the local authority. While Sam was well supported and relatively settled in his rural primary school setting, Rose was aware of how his ongoing additional needs could impact his secondary experience:

*I think the thing is, the school thought he doesn't need an EHCP because he's fine at school, and maybe he was fine in that setting, but it's all the other things he struggles with A LOT, which I knew would need support at secondary level... so in the end I applied myself, but they came back and said no. I didn't accept no, I went back to them and said, “I want to know how you've come to that decision when I've got 10 years' worth of professional reports telling them about all the social issues and difficulties that he has”, and they couldn't advise me why they said no, so it then went back to panel and they agreed to agree to give us this EHCP (p. 10)*

There is a paradox here, with effective inclusive practice in the primary setting being a barrier to accessing an EHCP which participants feel will ensure support in secondary – something noted by other mothers such as Denise:

*I think the problem with the process is that if things are being managed well in primary you're less likely to be hitting those criteria to get one [an EHCP], but I knew it was needed to get the right support. (p. 5)*

There was a sense from all participants that an EHCP was needed as a stepping-stone, either to ensure that their children received adequate support in a mainstream secondary setting or to access a specialist setting:

*(...) choosing the right school or getting the right provision in school for your child, there's so many layers to it isn't there, like the whole EHCP process is absolutely part of the school choice process, 'specially if you*

*want to access additional provision, then you have to suddenly take on board this other stuff, that as a parent you don't really want. I mean for lots of places you arguably shouldn't need a plan but it helps, it definitely helps. (p. 42)*

Ellie, who works in a charity supporting parents of children with additional needs is well versed in the EHCP and SCPs. Her experience has made her mindful of how the two processes are interlinked. She recognises that while EHCPs should not officially be needed to access a range of secondary provisions, having one provides a stepping-stone, especially into specialist settings. Her comment, about having to *“take on board this other stuff”*, highlights opinions expressed by the majority of parents participants when talking about trying to access specialist provision, of there being another layer of complexity related to a lack of specialist places, which she later describes as like *“like trying to get into the Chocolate Factory or something” (p. 43)* – a golden ticket for which you have to fight.

Parents also felt up against a polarising barrier related to local authority budget constraints:

*In those meetings about the EHCP or getting a special school place, I have my scripts of getting what my son needs and they have their script of saving money, we have two opposing scripts. I literally had to practice in the mirror before to not look emotional. I'd come up with potential scenarios and practice in the mirror so I don't cry 'cause any emotional reaction in these meetings and you've lost completely. (p. 9-10)*

The emotional impact of these meetings on Natalie is clear, but previous experiences have made her feel that any signs of emotion will position her as weak, and she worries that her voice will not be heard. The professionals overseeing these processes are positioned as callous and uncaring opponents, interested only in the balancing of spreadsheets. Effort has gone into building her defences and preparing herself to face her perceived foe. She has also gone to lengths to educate herself and arm herself with knowledge, something she has felt compelled to do with the advent of the 'new' ECHP process, here she compares it with the statementing process that her oldest child went through:

*I think the idea was that parents had more say about decisions about their child, like school placement, but I don't know if it's that different, in fact I feel*

*like now they're expecting us to do highly academic stuff, they're expecting parents that may have additional needs themselves, that have children that are likely to have sleep issues, other medical conditions, possibly learning difficulties on top of ASD, expecting those parents to find the time to research, understand, fill out forms... but you know there is no support, none whatsoever, and so they made it worse, not better. (p. 41)*

Natalie's use of the word 'us' indicates that she is one of the parents who have struggled with the EHCP process, she herself is autistic and has dyslexia, and has found the amount of paperwork daunting and difficult. Her narrative again highlights her sense of isolation, of being alone and unsupported in a sea of complexity.

Sarah, a specialist teacher and previously a SENCO, with a good knowledge of both the EHCP and statementing process, also perceives the old system as more straightforward, for both parents and schools:

*I think in a lot of ways it's [the EHCP process] a lot harder, I felt that the statementing process was sort of relatively simple, you just had a tick sheet with three different levels and you just highlighted off the areas of need and where they were in each level. These statements came with attached hours and money was funded for that many hours. So you knew exactly how much you had to play with to get the support. (p. 11)*

This sense of clarity conflicts with all participants' narratives about both the present EHCP system and SCPs, which are saturated with a sense of feeling underinformed and out of the information loop. Ellie's analogy below, which refers to both her own experience and that of parents she has supported, emphasises this disconnect, evidencing a sense of isolation and incomprehension when navigating the alien world of the specialist SCP:

*(...) it's almost like you've been dumped in Japan, that you're expected to find your way around by speaking Japanese... You know, like the panel, that's such a cloak and dagger type thing. I mean, who is "the panel" [stresses and makes parenthesis sign]? Who are these people that make these decisions? Nobody knows... you know nothing. Your child could have actually gone to four panels and you don't actually know about it because it's not communicated with you. (p. 22)*

The use of the term, "cloak and dagger", implies that processes are purposely concealed and there is a sense of her frustration with inadequate communication. It is this inadequate communication that has led Ellie to

question the role of EHCP coordinators (known by different names in other local authorities, e.g. SEND caseworker or EHCP caseworker), who are assigned to help parents navigate the EHCP process and guide them during their search for appropriate provision:

*(...) we called her 'the cornflake', you would ask her questions and she'd say, "well I'll have to go find out about that" and never get back to you, or tell us like, "it's really not my place to discuss that". Well then why is it that you are the person at the forefront of the local authority for parents? You're the local authority representative who is supposed to be coordinating things and supporting us to find the right place. (p. 17)*

The term 'cornflake' illustrates Ellie's perception of coordinators as unreliable and never good for their word. With a reticence on their part about giving too much away, worried perhaps about accountability or constrained by a bigger system. Ellie's later metaphorical description of them as, *"voice pieces of the big bad local authority"*, sees her positioning them as puppets of a malevolent oppositional force rather than parental advocates. At the end of our interview however, Ellie reflects on their potential workload, mindful of a significant backlog of EHCP requests and the multiple families that each coordinator supports, commenting, *"you really couldn't pay me enough money to be an EHCP coordinator. I would feel like I needed to go to work in armour every day! The amount of people that must be trying to get hold of you, and physically probably trying to get hold of you! What an awful role."* (p. 40).

Ellie's comments are indicative of frustration in all parental narratives about lack of support and communication, but also echo an appreciation of the bigger picture regarding a growing backlog of assessments and plans across the country, and of systems struggling to meet a growing backlog of unmet needs.

However, an understanding of the workings of the school choice system was less evident, confusion reigned with regards to what provision was available or whether their child would fit confusing and seemingly shifting criteria. This confusion was highlighted by Fiona as part of a wider narrative about parents countering their sense of isolation by seeking information and support from each other on social media sites:

*I went on there [Facebook parent support group] and heard like, 'we went and looked at so and so school and what a waste of time that was because they won't accept him because of this and this'... I mean why are they even letting you through the door and getting your hopes up, 'cause you don't fit their criteria anyway. And they change [the criteria], parents are told different things by the same school, it's just a complete minefield. (p. 23)*

Sarah describes being given, “a great big thick wad of booklets of the special schools' admissions” at her son's annual review in Year Five, “and then basically left to get on with it” (p. 14). She describes multiple criteria based barriers to specialist provision during her secondary school decision-making process, and now lives with guilt that she made the wrong decision, as her son's mainstream placement has never adequately addressed his needs:

*I should have looked more for special schools, but at the time I was told he didn't fit the SRBs for autism, 'cause he was too severe and they wouldn't take him and his learning wasn't what they wanted and he didn't fit a complex needs school because he was too able, so he was like right in middle. He's falling between the criteria which isn't uncommon and it's a shame that they can't be more flexible. It's kind of you're either this or this. If you don't fit into this box or this box, then actually you end up in mainstream. (p. 4)*

Five out of the seven participants described their children as ‘in-between’ or ‘in the middle’. Sarah's personal and professional experience makes her aware of how difficult it can be to secure an appropriate place for them. However, parents such as Natalie and Ellie challenged these criteria, particularly those which relied on previous screening of learning abilities, highlighting how standardised ways of measuring intelligence fall short when applied to an atypical presentation, and how an over-reliance on them can lock up potential if not considered within a wider context:

*That new one that opened [ASC specialist school] turned him down because they only took children that worked at the correct academic level. So I fought his case and said look, he's got the IQ to work above his academic level, it's just because of previous schooling, it's not because he's not able. (p. 25)*

*(...) so we then reapplied and I put in a piece to say, you know, just because he doesn't access these tests in the right way, these tests aren't made for children with additional needs actually, they are very standard tests for standard children. (p. 15)*



If these challenges to criteria-based decisions didn't work, parents resorted to different tactics to try and secure what they felt was appropriate provision. Denise refused to place her son in the mainstream school offered and home-educated him until a place at a newly built SRB came up. Several parents knew of other parents who chose to home educate rather than sending them to the mainstream offered. Natalie herself considered it before getting a last-minute placement at an independent provision for ASC, sharing the pressure she was put under to take the mainstream place:

*They [EHCP coordinator] said to put him in his catchment school and I said no, I'm not doing that 'cause he can't go to mainstream. They then said if you don't put down a mainstream high school he'll end up out of education because he won't find a specialist secondary one in time and then you won't get any help, so you won't be able to get him back into education for years, he might not even get back at all... but that's all lies, they tell that to every parent when the parent doesn't want to put down a mainstream, I wasn't going to fall for it this time (p. 28-29)*

There is a sense of coordinators trying to influence decision-making by tapping into parental fear, something that Natalie implies has happened to her before and that she now has the knowledge to stand up against. Ellie chose a different route to challenge a decision not to offer her son a place at a newly opened ASC provision:

*(...) they said that they were full, so then I said that's fine I'll lodge a tribunal because they've said they're full, but that's not reason for them not to take him actually, and obviously you're suitable 'cause you only turned him down because you're 'full'. (p. 15)*

As is often the case, Ellie's son was offered a place during mediation, before the tribunal happened. Ellie's innate confidence and knowledge of the tribunal process meant that this decision didn't seem to faze her, most other parent participants felt more intimidated by it, but were prepared to utilise the process if necessary, Rose for example:

*I didn't relish it but I was completely willing to take them to tribunal. I rang the SEN partnership, and they were on the phone with me for a long time talking to me about what I needed to do, it was so reassuring. (p. 20)*

Rose has found an ally within the process, one of the many cited throughout the corpus. The stress and isolation of years of battling, cited by all participants when

reflecting on their educational 'quest', was punctuated with reflections on those who had helped them. In the following section, before turning our attention to these allies, we shall briefly return to a prevalent theme, which had, and continues to have, an insidious effect on many of the participants – judgement.

#### 4.3.2.1.2 Judgement and allies

The combative nature of the process of seeking appropriate support and provision for their child left participants feeling vulnerable and isolated, faced not only with daunting systems and power imbalances, but the judgement of others. For Kate this was felt both at Felix's school, where she was, *"made to feel like I was an overbearing, hysterical, demanding, unrealistic parent"* (p. 5), later recalling an incident of trying to get her son into school during a period of schooling in which things were spiralling out of control and he was refusing to attend:

*I was physically dragging Felix into school and we were doing fairy steps across the playground with everyone staring at you. The judgy mum brigade are out, the teachers are standing at the door just sighing. (p. 16)*

It appears that this judgement is sensed not just from school staff but parents too, with a misinterpretation of autistic reactions as 'naughty' as Fiona mentioned earlier and the positioning of a parent as unreasonable. In fact, there were multiple references, both specific and implied of parents being positioned as almost wanting the label, of fabricating the autism, something that was noted previously as felt by Kate, with school professionals going so far as naming it, *"it was even suggested [by the previous Head] that I was making up Felix's issues, Felix is fine at school, it's when he sees you that it goes wrong". (p. 5)*

Some mothers have felt positioned as embellishing their child's autistic symptomology or using it as an excuse for poor parenting:

*(...) "no such thing as autism" I've been told, "autism is just another word for badly behaved", I've had loads of comments like that. And from your own family, they don't accept things and they question your style of parenting. (p. 19)*



Central to Sarah's account is a sense of blame and judgement associated with a lack of understanding of this 'invisible' condition; of parents having to push for some understanding that the behaviours or anxiety their children are presenting are manifested from autism rather than being contrived by them as a product of their own 'hysteria' or failings as a parent.

As a researcher, I was surprised to find that the majority of the participants felt judged by their families. For example, Natalie felt accused by her family of wanting to label her children for financial gain, *"so my family turned their back on me because as far as they're concerned I'm sitting around and making things up about my children to get free money off the government"*. (p. 13)

Lack of support from family members was countered in many cases by the support of 'knowledgeable others', those who understood processes and/or the challenges faced by autistic children and their families.

*The key person was the speech and language therapist (SaLT), she worked with Ted for quite a long time and she was the one who sat with me when I didn't know what to do, she put a plan in place for me and said, 'I'm going to do this for you, you've got just to do this', and she just helped my confidence grow.* (p. 22)

Sarah had previously felt totally alone and judged, there is a sense that the SaLT saw her distress and need for support and nurture, a calm yet commanding influence who worked alongside her and provided comfort, enabling a shift in Sarah's confidence to navigate the journey with Ted.

The SaLT was involved with Ted for some years, concurring with other narratives regarding the positive impact, for both children and their families, of consistent support (and conversely, the negative effects of a constant churn of professionals). Kate, whose educational journey with her child has been hugely traumatic for both of them, developed long-standing professional allies who, *"stuck their head above the parapet for me"* (p. 14). Penny, for example, a well-respected specialist SEN advisor, played a significant role in countering the entrenched positioning of the school against her:

*Penny has an amazing deferential way of taking people with her, it was easier for them to hear it coming from her because it's less personal, there's no hint*

*that mum's being hysterical or wants too much. She understands what can happen in the boundaries of a school. Quite often Penny and I already agreed what's gonna happen, it would be the same thing that I would be saying, but I think it's easier for schools when it comes from a professional. It cuts out a lot of the bullshit in the middle, rather than everyone worrying about motivations (p. 4)*

Penny's title and kudos positioned her as an objective 'knowledgeable other' by both school and parent. There is a sense of the value placed on a professional who guides rather than imposing opinions or directives. Interesting to note is the parallel narrative to Natalie's, of a mother's voice stifled and her efficacy diminished because emotionality is being reductively equated with lack of judgement. We see a clear advocate role being played here, with professional voices positioned as carrying more weight and power than that of 'over emotional' parents.

It is worth noting here that Kate had high regard for her EHCP co-ordinator who she describes as, "*awesome*" (p. 29). Denise also valued her coordinator, although like Kate and other participants she commented on a lack of consistency, with coordinators often changing:

*Well, the issue we had was they kept changing the EHCP coordinator... but actually in the end she [the coordinator] was great, she said I'm gonna stick with you through your story and I'll make sure that we're really honest with you about panel meetings and about what happens in them'. She guided me through that process and stopped me stressing. She was really honest about if there was no space, and then guided me to the new SRB. You know I think if she hadn't done that I think we'd still be in the process of somebody just batting us back and saying "we haven't got space" (p. 20-21)*

Here we have a professional inside the school choice system who is willing to stick their head above the parapet, who informed the family that she would see them through the process, and whose guidance had a containing effect. Honesty and good communication are valued and there is a sense of a relationship being formed which moves beyond the tokenistic.

EPs were noted by participants as useful but short-lived allies. Kate appreciated how her assigned EP synthesised evidence and information and gave an objective overview of Felix which she could present to future provisions and reflected that "*she drew things together and really got down to the bottom of who*

*he was” (p. 31).* However, as with other participants, EP involvement was fleeting and connected only to the EHCP process, with needs often not being reviewed again:

*Felix is a different person now with a lot less needs, but some different ones that weren't there then, because hormones and age kick in. But yeah, everything is still based on when Felix was in Year Five, nothing has been reviewed. (p. 31)*

Statutory reports were often cited as providing valuable insights into children's needs and useful suggestions for provision, both of which armed participants during their journey – used both to push for inclusive provision and to challenge special school selection decisions. However, this seemed the extent of EP involvement in the SCP.

School-based professionals were also commonly cited as allies. After a tempestuous journey with a hostile primary head, Kate found an understanding ally in the SENCO at Felix's mainstream secondary school, a relationship she described as *“healing”* for both herself and Felix, sharing how, *“she told Felix she would never force him to do anything and slowly built up trust with both of us” (p. 22).*

Fiona had always had a good relationship with her primary SENCO, who had collaborated with her to plan in-school support for her child. The SENCO recognised the need for a positive transition and involved herself in the SCP:

*(...) she was brilliant, and when we were considering schools she helped us look at options and signposted us to a lot of places and support groups and everything, she was just there, I knew I could go to her. (p. 16)*

A person 'being there' is important, a safe containing base to go to, with a wider knowledge that enables effective support and understanding. One of the most striking aspects of all narratives was the power attributed to a professional lending a compassionate ear, of participants feeling like they were being heard. This is touchingly communicated by Sarah, who became tearful when describing a meeting with a key worker from a charity offering support for families of SEN children:

*(...) she just came and just sat in my house, she came every week and she just talked to me. It was those people, the people who are kind who... [starts to become tearful]... I'm so sorry, I don't normally get like this, but it's just bringing it all back. I was barely coping you know, but this lady came in and just listened and people don't realise how much listening helps... I'd felt so judged but she just listened. (p. 22)*

For Sarah kindness and feeling heard helped to counter her sense of judgement and isolation, still powerfully felt. Her tearful reaction to the memory evidences both the depth of her emotional wounds and the power of a compassionate ally.

#### 4.3.2.2 Those who prevail and those who become lost

The journey to secure appropriate secondary provision for their autistic child was, in different ways, difficult for all mothers. While professional allies, to greater and lesser extents, assisted in the navigation of educational journeys and helped to counter both barriers and isolation, there remained a sense from all participants that they were central to advocating for their child and driving processes forward. Narratives revealed how participants attained more personal influence and strength by educating themselves and proactively developing both a greater knowledge of systems and processes, and personal qualities such as tenacity and resilience.

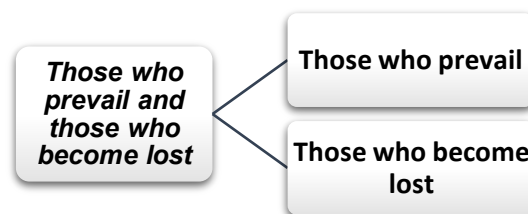


Figure 9: Master theme: Those who prevail and those who become lost

##### 4.3.2.2.1 Those who prevail

When reflecting on advocating for her child throughout his educational journey Rose stated, *"I've been the main driver for years" (p. 18)*. This driving analogy indicates a sense of Rose proactively maintaining forward motion and momentum, of ensuring things are heading in the right direction, of paying attention and making adjustments when faced with obstacles in her path. This need for proactivity was ubiquitously felt, neatly summed up by Denise, *"I realised it was down to me to be proactive, you can't just sit within the process, you have to keep pushing within it" (p. 20)*.

Proactivity and other personal qualities such as determination and resilience were cited frequently by participants as crucial attributes to help them within the wider 'quest'<sup>2</sup>, and were often part of wider reflections relating to personal transformation. These transformations often involved parents having to overcome fears and inhibitions, develop self-belief and metamorphose into more outwardly confident and better-informed versions of themselves. Fiona and Natalie both reflect on this:

*I mean, I didn't think I was that type of person, but over the years you turn into that person, you have to. I mean like going into that meeting a few months with my ring binder and my highlighter, Danny [her husband] said he could see them thinking "oh here we go, we're not gonna be able to push this one over". But inside I was shaking and I felt sick. (p. 33)*

*Another painful and difficult lesson that I have had to learn over the years is that you have to kind of almost reinvent yourself... to learn to be hard (p. 9)*

Fiona's use of the *"that type of person"* label was contextualised within a wider discussion about mothers labelled as 'warriors' by educational professionals, something Fiona had experienced in her professional role as a TA, where the label came with negative connotations of being blinkered and unreasonable – experiences that have already been touched upon. However, while assuming an assertive role has not come naturally to her (like Natalie in the mirror, it is something she has had to practice and prepare for) there is an inevitability in her narrative about having to become *"that person"* to advocate for her child.

Both extracts, particularly Natalie's reference to, *"painful and difficult"* lessons are indicative of the impact of this personal metamorphosis into the 'warrior'.

All participants commented on their need to acquire knowledge – about autism, autism-friendly practices, and wider statutory and legislative processes – with Rose commenting, *"you have to get very clued up, I've been going through this process since Sam was two and I've read and read and read, and I work in a special school, so I almost live and breathe it"* (p. 8). Like Ellie, Denise, and Sarah, her experience of having a child with additional needs has led her towards

<sup>2</sup> Personal qualities named by participants as required during the SCP and wider educational journey have been compiled into a word cloud which can be found in Appendix 15b.

a career within special education, which has further developed a sense of personal efficacy. Natalie, a full-time single mother, has worked hard to educate herself – a response to feeling marginalised and underinformed on the journey with her first son:

*I jigsawed it together and did the research to kind of figure it all out, and then I got myself qualifications, so when they would come out with these kind of statements I would throw it all back at them... 'cause actually, now I do know what I'm talking about. (p. 9)*

There is a sense of the power of this acquired knowledge for Natalie, giving her confidence to challenge her positioned oppressors. She also employed other, arguably more subversive ways, to ensure the outcomes she wanted for her son, naming and acknowledging the power that she felt was gained through nepotism:

*I got a role as a parent governor at the school because I knew if I got the role I could move things along for my son and use my position to get him what he needed, so I purposely did that and it worked so I was completely right. I basically got myself power, I got power to get around the system. (p. 8)*

Kate, an advisor with the Looked After Children Service, and her husband, took processes into their own hands after the relationship with Felix's primary school broke down. She, Felix, and her family have had a very difficult and traumatic experience of the educational journey, particularly at primary school, and much of her narrative related to the trauma they faced and continue to manage – with Felix first voicing ongoing suicidal ideation at the age of nine years old. Driven by a desire to counter the significant damage done and ensure that provision would be put in place to support and *“heal”* (p. 22) Felix in their mainstream secondary provision, Kate applied for an EHCP herself and kept a close eye on timelines. Chris her husband enrolled in training with the Independent Provider of Special Education Advice (known as IPSEA), to increase his knowledge and understanding of the SEN legal framework and learn how to write EHCPs himself:

*I applied for an EHCP because I didn't trust the school to do it (p. 14)*

*Chris did all this IPSEA training so that he wrote Felix's EHCP. The (primary) school hated it, they went nuts, 'you can't do this!', well we can (p. 29)*

Again there is a sense of acquired knowledge as power against a larger system, of resistance against a tyrannical foe. Kate also employed other ways to push for support including successfully seeking the support of a prominent local MP, who called a meeting with the LA, “*selling a kidney*” (p. 14) and using personal capital to get a private autism diagnosis, and taking the primary school to court after they banned Felix from the Year Six residential. Here she and Chris (who entered the room during the interview) name a potential reason for the improved collaborative support Felix has received in secondary school:

*My husband is just pointing out one of the main reasons he firmly believes that schools ever since have been very willing to work with us is that we have, unfortunately, now got a reputation as the parents who went to court and that they think that we are gung ho... he's convinced that the reason that everyone worked with us ever since is a fear we could take them to court.*  
(p. 26)

In response to a request to sum up, in a phrase, the educational journey with his child, Chris answers, “*war of attrition*” (p. 26). This analogy suggests a long-term battle where guerrilla tactics are used to undermine the enemy. Kate’s narrative is indicative of meaning-making throughout the corpus, where participants challenged “*powers that be*” (Sarah, p. 3), with their own acquired power, in diverse and sometimes subversive ways. Ellie and Natalie both use their knowledge of wider systems to help other parents subvert them:

*(...) I always tell parents that if their child needs an EP to come in, then absolutely go for a statutory assessment ‘cause legally they’re entitled to it, it’s a faster way to get an EP in if they need one. It shouldn’t be like that, but it is, and you have to work the system. I do realise it’s a vicious circle you know, I know it means that’s there’s more requests for assessment so they’re not catching up on the backlog and children are waiting, my god you get lost in it, it’s just TOO big an issue.* (p. 31)

*I gave her a phone number and with that phone number she got the ball rolling with the threat of making a complaint, and I told her who to complain to. This September he finally found a secondary place in a specialist school.*  
(p. 22)

The layers of complexity involved in SEN practices and processes are strongly felt in Ellie’s last sentence. She acknowledges how these guerrilla tactics could be impacting an already overloaded system, but like Natalie (and other



participants) there is a sense that such tactics are used in response to practices and processes positioned as unfair, unclear and isolating.

Parent-to-parent support was commonly cited as crucial to navigating the wider quest and improving outcomes, however there were also many mentions of parents who remain marginalised, voiceless, and lost.

#### **4.3.2.2.2 Those who become lost**

Each participant made some mention of the marginalisation of more vulnerable individuals and families, who were perceived as falling through gaps in systems and processes. These lost individuals were encountered in both personal and professional capacities and their plight sympathetically framed by an understanding of the systemic and societal challenges faced on a journey with an autistic child. Ellie and Natalie's actions highlight the solidarity felt between parents and an attempt to aid those who need assistance.

Many participants reflected that marginalised voices may not have the *“energy, self-belief or confidence”* (Rose, p. 22) to challenge systems and secure their preferred provision. There was a sense that without these qualities, and with no one to advocate for them, some parents were railroaded into accepting a mainstream place for their child, with Ellie stating, *“if you spoke to those parents whose children were in mainstream but need specialist, I think a lot of it is because they haven't battled, for whatever reason they didn't battle”* (p. 42).

Denise further sums this up and reflects on the barriers some parents faced:

*The parents who haven't got the skills, or confidence, or maybe they've got special needs themselves, you know they could also be on the spectrum or have learning disabilities, or have struggles with mental health... They watch their children struggle in mainstream secondary schools and their experience is just awful, and there's nobody fighting their corner for them, there's nobody saying, 'let me help you'. Where is the system of support for the parents who need support? (p.17)*

There is a sense of a special needs system that isn't inclusive and doesn't account for or support parental additional needs. Denise, who supports children with social, emotional and mental health (SEMH) needs and their parents, went on to mentalise the inner voice of one of these parents before



going into an EHCP needs assessment meeting, *“they're gonna ask me fancy questions and I'm not gonna be able to answer them or not gonna be able to do this, let's just withdraw from the whole system and not face it”* (p. 18).

Here we can see an opinion of a system entrenched in professional jargon and inaccessible without mindful support and advocacy. In fact, many participants voiced beliefs about the existence of entrenched systemic inequality, leading to 'have and have nots' in terms of who was able to access autism-friendly practice and/or specialist provision. Kate sums this up articulately and powerfully:

*Whoever shouts the loudest gets the most, that's the bottom line. There are so many children whose parents either aren't capable or willing, or who are too worried about upsetting people or just don't have the knowledge or the cognitive ability to be able to have this fight.* (p. 29)

Navigating the difficult journey with an autistic child is seen as requiring both the energy, resilience, and dogged determinism to do battle and a nuanced knowledge and understanding of complex processes, legislation and service agencies. These layered skill sets are acquired along the way by some, who emerge battle-worn and sometimes scarred, but with a sense of having reached their desired goal in terms of securing inclusive autism-friendly support within secondary provision. Those unwilling or unable to access these tools for survival are viewed as lost and ignored, and their children left to suffer in inflexible systems that don't account for an atypical mind.

#### **4.3.2.3 The factors that influenced choice and decision making**

In accordance with the secondary research question, views were sought about the factors that influenced the research participants' decision-making regarding secondary school choice. However, their direct answers only accounted for some of the responses, others were shared more implicitly and often related to the impact of previous experiences or lessons learnt on the educational journey with their autistic child.

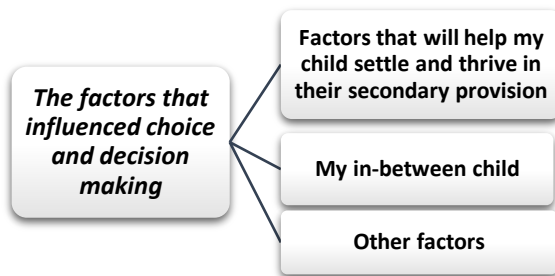


Figure 10: Master theme: The factors that influenced choice and decision making

#### 4.3.2.3.1 Factors that will help my child settle and thrive in their secondary provision – size, support, routines, and good communication

In common with other participants, one of the major considerations for Fiona when contemplating secondary provisions was size, as she wanted to ensure that her son George wasn't overwhelmed by *"hundreds of children"* (p. 13). Small class sizes were commonly named as an important factor when weighing up the pros and cons of various provisions, and as with Fiona, this often related to previous experiences of having to deal with the fall-out from their children struggling in busy mainstream junior classes. Three out of the four participants whose children went to specialist provision named it as a major factor in informing their decision making, including Denise:

*Because of previous difficulties we knew that he was not gonna manage a huge environment, so the kind of big factor was where can he go that's got a small environment with the right people who are gonna support him and understand him. That was kind of key for me. And that was when I thought oh, you know, we need to start looking at specialist ASD provisions. (p. 18)*

All participants, regardless of whether their children were in mainstream provision, SRBs, or specialist schools, cited 'support' as an important factor in their decision making, viewing it as pivotal for successful transition. This support was defined in different ways. Some narratives framed it humanistically, placing importance on lessening their child's anxieties via a nurturing approach where they felt *"safe and boundaried"* (Ellie, p. 10). Denise for example wanted to ensure that her son Jake had the reassurance of a *"safe space to go to, where there was a person that could reassure him or give him structure"* (p. 15).

Denise's comments relating to the availability of people who would *"understand"* Jake and *"give him structure"* are indicative of narratives throughout the corpus

which highlighted autism-friendly practice and support as major influencers of decision making, however, there was also often a caveat that autism is a huge spectrum, where one size doesn't fit all. A need for provisions to recognise their children as individuals and not just 'autistic', while still offering support from professionals who were mindful of neurodiversity, were commonly cited as reasons against choosing mainstream. Ellie for example, whose son Archie attends a specialist ASC school, wanted him to be seen, *"as an individual, with an individual set of needs"*, and felt this would be impossible in a mainstream school, stating, *"if there's one teacher and 30 children, as much as they might like to meet everybody's needs, they can't"* (p. 13).

Structure, clarity, and routine (commonly linked to their child's atypicality), were also cited as important considerations by many. Fiona for example shared:

*For George, that consistency was key, he likes to know what's happening and what might change. I was looking for somewhere that was flexible to his needs but also would help him through the day with clear expectations and routines. I also really wanted somewhere that would tell me "so and so isn't in for this lesson", so I can discuss it with him and get him ready for it. (p. 10)*

The need for good communication, implied by Fiona at the end of the extract, was positioned by all participants, both explicitly and implicitly, as a powerful factor influencing school choice. Several participants described engaging with SENCOs during school visits to establish ground rules regarding the need for open and honest reciprocal communication. In the following extract Denise describes meeting the SENCO at her son's SRB for the first time. Open and honest communication is framed as fundamental to ensuring clarity of expectations, building meaningful working relationships:

*I said to the school that you need to be really open and honest with me, we need to work together and be as consistent as we can with him, otherwise we're gonna get have a big problem. I have to make really difficult conversations with parents in the setting that I work, I build the relationships with them and then we can talk about things really openly, and I think that is what I then expect from other people. Because if you can't have that communication, the barriers can't then get knocked down (p. 12)*

Fiona, Denise and other participants reference the transformative power of meaningful communication and good relationships, both in terms of enabling a

‘knocking down of the barriers’ which may potentially prevent settlement and forward movement for their child and in addressing potential pitfalls before they happen. For Kate, who is left damaged by many years spent feeling marginalised and gaslighted as “*hysterical*” by Felix’s primary school, communication was framed within wider factors of acceptance and appreciation of the “*whole child*”, all of which needed to be in place to heal trauma:

*We decided that it had to be a school that we could communicate with us and that actually wanted Felix and was willing to see Felix as a whole child, with all the good bits and all the bad bits. Felix needed to be healed and to get over what had happened. (p. 22)*

#### 4.3.2.3.2 My in-between child

This need to heal both herself and Felix further complicated the decision making process for Kate, she realised that a specialist place may bring more support, flexibility, and acceptance of his autism, but this was countered by a sense of wanting him to learn about “*real life*” so that he had the potential to better navigate independent life in the future:

*I was really second-guessing because if Felix got into a specialist, then all of the social stuff and stuff that was lacking would have been there. Felix would have been accepted for exactly who they were. If Felix was having a bad day they could have gone in later, all of those things would have been there. But it isn't real life. Felix has every opportunity of getting a job and living independently, and Felix wasn't going to learn how to do that if they go to secondary school thinking that if you're having a bad day, you haven't got go today, because that isn't real life. (p. 28)*

Ellie, one of several of the parents who described their children as “*in-between*” (p. 6) or sitting “*in the middle*” (Denise, p. 6), also voiced concerns about her son living, “*in a world specially made for people with autism*” (p. 13), but previous experiences of the educational journey swayed her decision, “*he never really coped in the junior school, so he wouldn't have coped in mainstream high school*” (p. 6).

Description of children as ‘in-between’ emphasises the difficulty of decision making around secondary placement, parents have the historical knowledge of fighting for and supporting their autistic children as they have attempted to navigate a ‘typical’ world – yet they are also aware of the need to prepare their

children for their future independent lives within this world. This paradox often seemed at the crux of parental decision-making around whether their 'in-between' child should experience the 'real-life' of mainstream or a more autism aware and inclusive special placement. Although Kate's primary driving factor when choosing a secondary placement was for Felix to be 'healed', she was among other participants who framed special school as having lower academic expectations. Rose, whose son Sam attends a small mainstream secondary school, emphasised this viewpoint and the fact that decisions need to be based on individual children, she chose her son's placement after meeting the SENCO who assured her that Sam would be well supported. Sam's subsequent settlement embedded her belief that mainstreams can be inclusive and work with parents, however, concurring with other parents of children in mainstream she reserves that right to pursue a specialist placement if her son starts to struggle:

*Our decision to put him in mainstream over a specialist was because we thought that he would get a better education at a mainstream. I know that sounds awful because I'm working at a specialist school and they are amazing, but for us, we wanted to try mainstream... and so far so good, he knows what's expected of him, and he gets himself 100% involved. Maybe in a year's time, if it doesn't work, we might need to look at that [special] (p. 7)*

Rose later went on to reflect:

*I think there needs to be more schools that will support academic achievement but also autistic needs, there needs to be more of them because I'm sure there's a lot of people like us. (p. 21)*

Both Fiona and Denise felt an SRB could be the solution. Denise described her thought process after looking around both an SRB and The Arc, a specialist ASC provision, with the SRB seeming to solve the paradoxical problem of supporting both academic achievement and autistic needs, *"I thought The Arc might be a step too far, whereas at the SRB he could sit in the middle and have the best of both worlds" (p. 7).*

Throughout parental narratives, there was often an inevitable acceptance that their autistic child would have to learn to fit in the 'real world', to *"keep low and blend in"* (Rose, p. 2), and operate within a world set up for the 'neurotypical' majority. However, there was also a sense that systems needed to be responsive

and flexible in their support of additional needs. This 'social model' of disability has already been noted in Kate's comment that, "*it isn't the autism that causes problems in school*" (p. 2). Natalie, whose son Peter attends an independent specialist ASC provision, uses a powerful analogy when sharing her thinking about the impact of "forcing" autistic children to conform to neurotypical norms:

*I once had a schoolteacher in Jason's original school, say to me, "well, they've got to learn to cope with the real world". We were coming back from an event on a minibus and I said, "yeah, you're right, we need to get rid of all these ramps then, 'cause they should just get up and walk". It's no different for Peter, yes, he's gotta cope in the real world, but the real world's got to learn to deal with him. It's a two-way thing. If an individual is expected to be a certain way and not be themselves, they will be severely mentally harmed. It will be those that are forcing them to do that who are guilty, not the individual who's tried and tried to cope, tried to conform (p. 33)*

Natalie, like Kate, was influenced in her decision-making by a belief that many of the problems faced by her child are the result of a lack of understanding and adaptability, of social oppression and exclusion. This has made both mothers push for acceptance and inclusion – despite coming from either side of the mainstream/special fence. All parents indirectly rejected a medical model which looks at what is 'wrong' with the person, instead of what that person needs. However, as has already been discussed, there was a sense that it still exerts influence on wider perceptions and leads to judgement.

#### **4.3.2.3.3 Other factors**

Other factors considered when choosing secondary provisions related to practical considerations such as availability, proximity, and travel time. Sarah sums this up when explaining her reasoning behind choosing a mainstream provision:

*(...) location played a big part in it and just the lack of [specialist] provision nearby, he would have had to travel so far. Had that new school been up and running, I would have definitely considered him to go there. (p. 10)*

There is a sense that Sarah would have been open to the idea of a specialist placement if one was nearer. The sparsity of specialist placements means that reaching them often involves an extended journey in a taxi, while not always a deal-breaker it was a factor considered by many participants. For Fiona, who is considering moving her son from his current SRB to a new specialist provision, it

remains a concern, *“he wouldn't need supervising in a car or anything like that, but it's just so far and it just makes it such a very long day, doesn't it?”* (p. 23).

Fiona also hoped that the new provision would teach life skills, seeing them as part of a broader autism-friendly curriculum, *“I think a lot of autistic kids need that broader life skills curriculum, to develop their understanding of day-to-day stuff you know”* (p. 14).

Decisions, especially those made by parents who opted for mainstream, were also influenced by wanting to maintain some familiar social continuity for their child. Sarah for example shared that her decision to place Ted at mainstream was based partly on his sibling and friends going there, *“Ted's elder brother had gone to that school so he felt a bit more reassured, and two children he grew up with who've got similar disabilities to him, they both were going”* (p. 5).

Ellie's decision to pursue a specialist secondary placement was in part influenced by wanting access to professionals whose thinking and approaches were contextualised by ASC specific knowledge:

*(...) from my point of view, having access to the clinical team within The Arc is a massive thing because I find that difficulties and needs are put down to autism, so say if you've got a speech and language difficulty, if you're autistic it's much more difficult to get support because you're autistic. If you've got SEMH difficulties, it's much more difficult to get support because you've got autism. You know often when kids are labelled in one way then they can't access other things, and I think that's a problem when accessing services in mainstream.* (p. 23)

The autistic label is seen by Ellie as a blocker to appropriate support, shutting down thinking about the wider needs of an individual.

Natalie summed up the feeling of many participants by saying that a placement should be like a *“working family”*, going on to clarify that *“the ethos has to be a family, but the expectations should be high”* (p. 31).

Parents wanted their children to be both accepted and challenged, for autistic needs to be flexed and accounted for within a nurturing environment which also had high expectations.



#### 4.4 The Focus Group – Cycle 3

Cycle 3 of my AR project, the focus group, used Appreciative Inquiry (AI) to facilitate a collaborative exploration of, ‘what changes could be made and action steps [taken]’ (McAteer, 2013).

Participants had already begun to share their views about how practices and processes could be improved during the semi-structured interviews. Ellie for example shared thoughts on how mainstream inclusivity could be improved and demand for specialist places consequently driven down a greater focus on SEND in teacher training:

*(...) proper inclusion, that's really the only thing that will stop the amount of people who want specialist places. I mean it should be a much bigger part of teacher training, ALL teachers should do a decent amount of SEND training, why should it be only those teachers that are interested? (p. 44)*

Kate again returns to the social model of disability as a way forward in terms of mending a ‘broken’ system and reducing the EHCP backlog. For her the answer potentially lies with school systems not seeing special needs and autism as something that needs ‘fixing’ with the “golden ticket” of an EHCP, suggesting instead that they should embed universal practices to remove barriers for all young people:

*The EHCPs are seen as the golden ticket to things working. But actually, if a school can meet needs, you don't need the EHCP. But because it's all been so f\*\*\*\*\* people insist on the EHCP, which kind of means the whole system is broken. I mean I don't know how you fix it, but like where Felix is now, Felix doesn't need the EHCP because they're meeting the need. A lot of what's needed isn't complicated, like doing things visually, I mean it should be what they are doing for all children. So how can we get away from having to have an EHCP to meet the basic needs of children? Isn't the answer a universal approach to special needs? Then you wouldn't need the EHCP and the system wouldn't be broken, and then more kids would benefit, even the ones without the diagnosis. (p. 32-33)*

The FG enabled participants to revisit and share some of these reflections during the ‘Discovery’ stage of the AI process, where we also collaboratively explored what we felt was working (with regards to practices and processes associated with secondary school choice). During the ‘Dream’ phase we used ‘what was



working' as a springboard to positively imagine what processes/practices could become. This 'dream' stage then facilitated the third stage, a con-constructive 'Designing' of positive and possible steps forward called provocative propositions, i.e. the changes that could be made and possible action steps advocated by McAteer (2013).

Below, presented diagrammatically are both 'what is working' and our provocative propositions, grouped under the areas that we collaboratively identified as most salient:

- Improving clarity of communication and information sharing
- Ensuring meaningful collaboration
- Improving outcomes for autistic children

#### 4.4.1 What is working

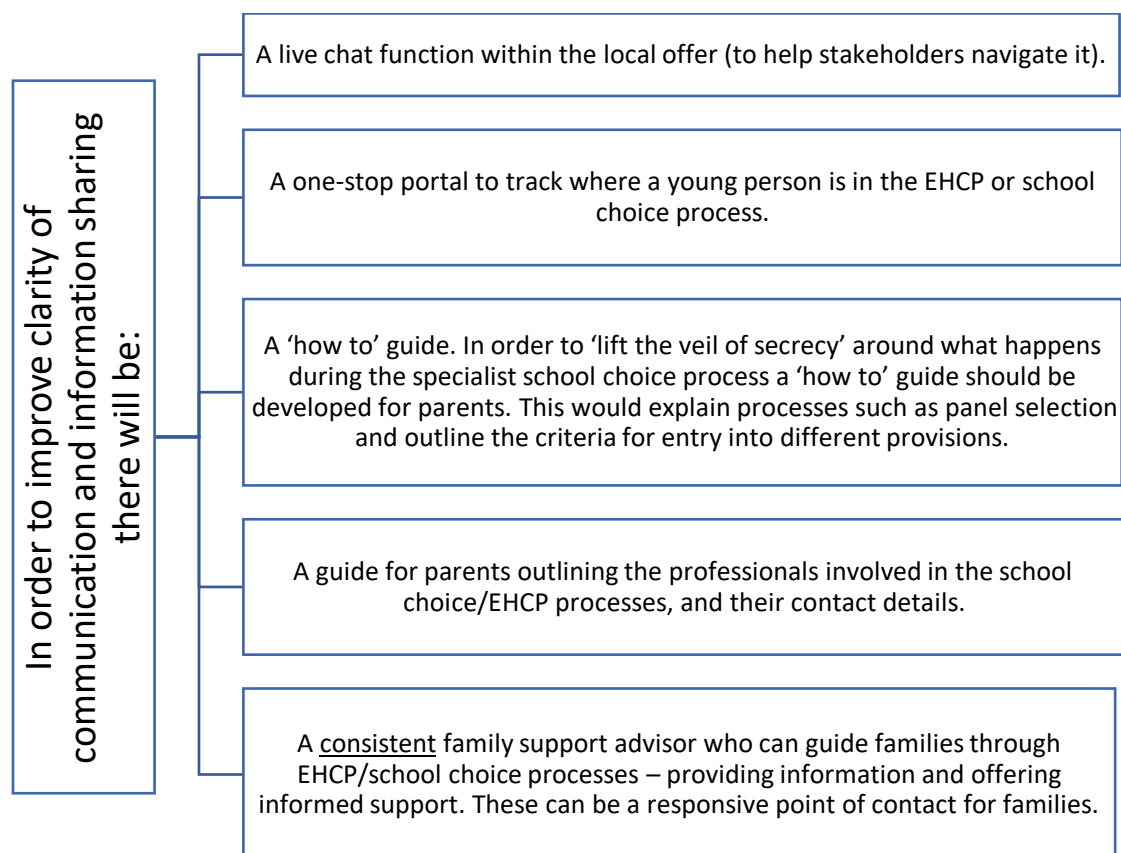


Figure 11 – 'What is working' explored during the discovery phase of AI (Cooperrider & Whitney, 2005)

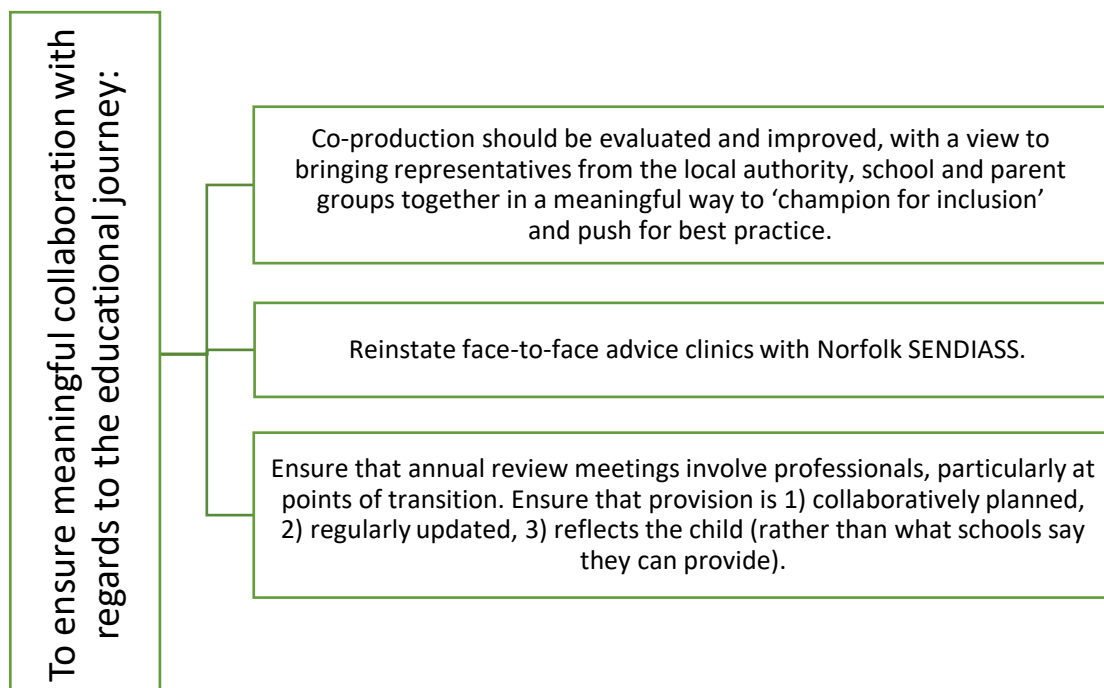
#### 4.4.2 Provocative propositions

Time was given before collaborating on the provocative propositions to consider how to construct them. We discussed the use of active voice and a couple of exemplars were compiled on a visualiser. I had asked each participant to have a pen and paper available during the focus group, and suggested that they use them to jot down ideas for each area before coming back together to discuss and refine them. Ideas were scribed and edited in real time on the visualiser – I

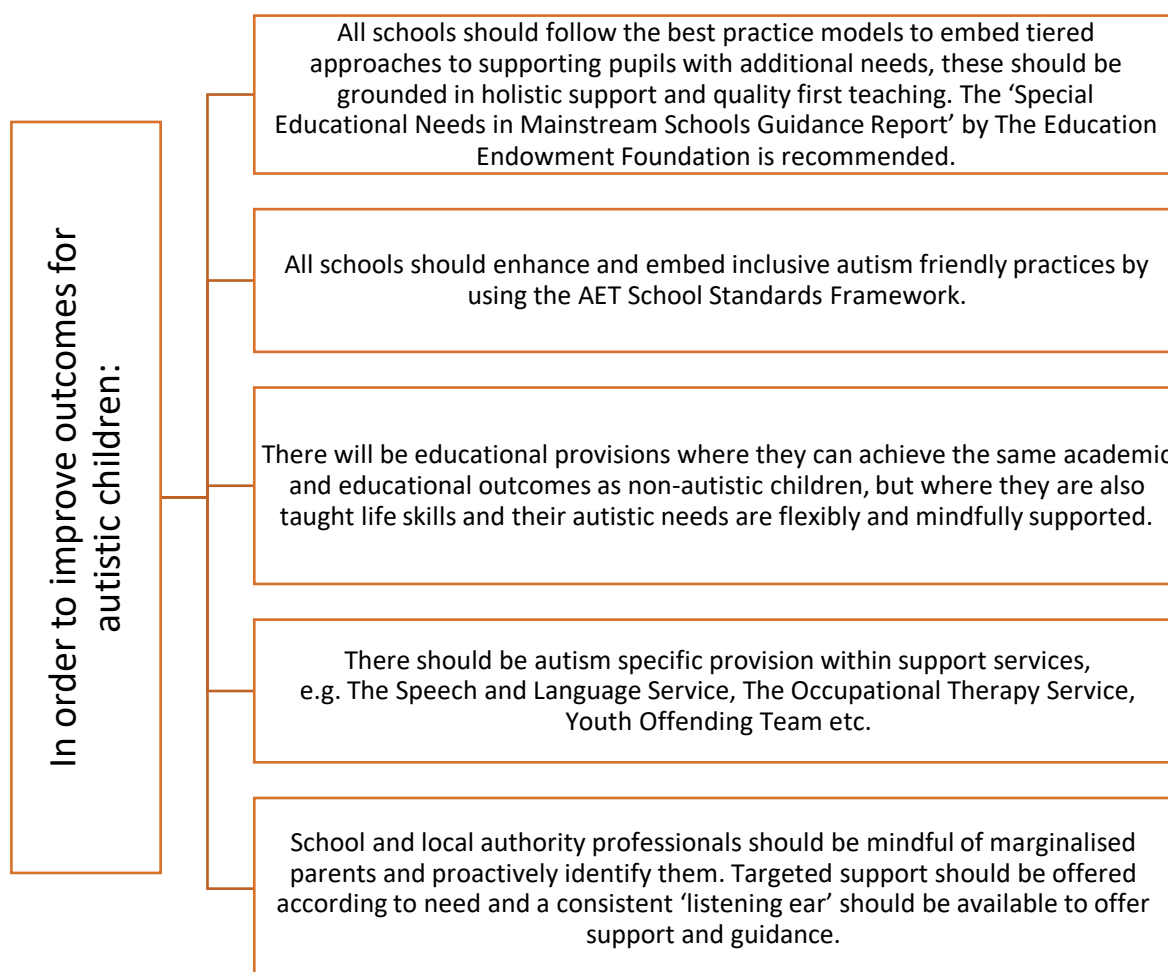
checked in with the participants frequently to make sure they were happy with the contents and wording, with some amendments made in accordance with their feedback. I also attempted to ensure that everyone had contributed. Participants were respectful and supportive of each other throughout the process and while collaboration was to some extent restricted by the online context of the focus group I noted them independently checking in with each other regarding the emphasis and direction of individual propositions. The visualiser was very helpful allowing participants to be very closely involved with their construction.



**Figure 12 – Provocative propositions relating to clarity of communication and information sharing**



**Figure 13 – Provocative propositions relating to meaningful collaboration**



**Figure 14 – Provocative propositions relating to improving outcomes for autistic children**

As previously shared, a workshop of key LA SEN partners and parents will comprise Cycle 4 of my research. It is here that the provocative propositions will be shared and developed to fulfil the 'Destiny' (stage 4) element of AI, 'creating and committing to what will be'.

#### **4.5 Summary**

This chapter provides an account of parental experience, presented through the lens of my IPA. From the broad research questions I developed a thematic account of individual parent experiences and synthesised these to consider the patterns, similarities, and differences, which I presented as three broad master themes. I then ran a focus group, where I worked collaboratively with five of my seven original participants to generate a range of provocative propositions suggesting ways in which processes and practices, related to SCPs and wider support, could be improved. The following chapter contextualises findings within current research literature, my conceptual and theoretical framework, current legislation and local authority practices, and wider relevant psychological paradigms.

## 5. Discussion

### 5.1 Overview

This chapter is presented in two parts:

Part 1 – The three master themes reported in Chapter 4 will be discussed, contextualised and critiqued with reference to relevant parts of my conceptual and theoretical framework (Figure 1, found in introductory chapter).

Subdivisions will then be contextualised within existing research, particularly that considered in Cycle 1 of the AR. Wider relevant psychological paradigms will also be noted.

Part 2 – A critical evaluation of the study, which will include consideration of personal reflexivity, study strengths and limitations, and implications for future practice and research.

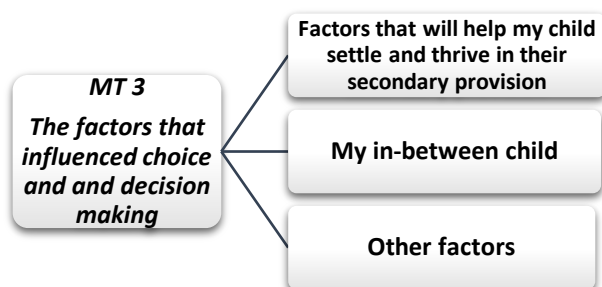
Consideration will also be given to Cycle 3 of the AR, the focus group.

### 5.2 Relating research questions to findings

The findings of this study were encapsulated in three overarching patterns, or master themes (MT), identified during cross-case analysis of participants' themes and superordinate themes. Master themes 1 and 2 (Figures 8 & 9, shown again below with associated subdivisions) relate directly to the main research question (namely, *What are the lived experiences of parents when choosing and securing secondary provision for their child on the autistic spectrum?*), with parental experiences framed within the wider pervasive 'quest' narrative explained in section 4.3.1



Master theme 3 relates to the sub-question (*What factors influence the choices of parents of children on the autistic spectrum with regards to secondary provision?*), presenting factors which parents named, directly and indirectly, as influencing their choices and decision making regarding secondary provision (Figure 10, shown again below).



While research questions and associated interview questions related primarily to parental experiences of choosing and securing secondary provision for their child on the autistic spectrum, it was notable that all parental accounts revealed a journey towards this stage (i.e. often involving experiences in previous educational settings and attempts to secure an EHCP). To honour their narratives, I decided to incorporate some of these experiences and the emotions associated with them into the findings and henceforth into this chapter, where I discuss and critique the study.

### 5.3 Part 1 – Linking findings to theories and literature

#### 5.3.1 Theme 1 – A difficult journey

This theme captured the central and salient theme throughout parental narratives, one of a journey that embattled them and left them feeling “*exhausted*” (*Denise, p. 23*), isolated, and judged. Barriers were faced, often attributed to inefficient processes, lack of communication/support from LA and school professionals, and a lack of understanding of their child’s autism.

##### 5.3.1.1 Autism – impacts and interpretation

The handful of school choice research that exists relates broadly to all types of SEN – the present study filled a gap by looking specifically at the lived

experiences of parents of children with autism, addressing a further gap by looking deeply at their lived experiences. This phenomenological stance enabled meaning-making and views to be captured which revealed the impacts of having a child with autism, personal positioning with regards to the condition, and how parents felt it is positioned by wider society.

While parental experiences substantively differed, throughout the corpus there was the sense that autism, as an 'invisible' disability, could beget judgement and a lack of understanding. Sarah for example felt judged by other parents and her family, who questioned her parenting and told her that, *"autism is just another word for badly behaved"* (p. 19). Kate experienced an extreme sense of judgement from the staff at her son's primary school and was made to feel like a *"hysterical, demanding, unrealistic parent"* (p. 5) – accused by the previous head of, *"making up Felix's issues"* (p. 5). Like other parents in the study her high achieving child was labelled as 'naughty' and accused of becoming dysregulated *"deliberately"* (p.18), despite his diagnosis. Meanwhile, Natalie's family accused her of wanting to label her children for financial gain. These experiences concur with my personal experience while working in an SRB, of supporting a mother whom medical professionals suspected of manufacturing and exaggerating her autistic child's difficulties. The online newspaper Autism Eye (Autism Eye, 2018) reported being contacted by increasing numbers of parents under investigation for 'Fabricated and Induced Illness' (FII), accused of embellishing their child's symptoms because of their own anxieties, or need for attention or financial gain. While the condition does exist, it is very rare, and a discussion paper (Gullon-Scott et al, 2020) has suggested that up to 97% of cases identified using NHS 'warning signs' (NHS website, 2019) may be false positives. While FII is an extreme form of judgement it is evidence of the type of challenges faced by parents of children with autism, including those of the present study, where doubt is cast on their honesty, or where pushing for support for their child stigmatises them as being, *"that type of person"* (Fiona, p. 33).

Previous definitions of autism equated it solely with impairment, with this 'medical model' ignoring the involvement of social, cultural, and environmental factors in the construction of autism as a disability (Chown & Beardon, 2017). This view

began to be countered in the late 1970s by critical movements such as the Disability Rights Movement who defined disability as a form of social oppression – based on constructions of ‘normalcy’ which limits or excludes (i.e. disables) people perceived to have an impairment, rather than recognising the wide spectrum of “being human” (*Natalie, p. 10*). The current study identified parental opinion regarding the cognitive, social and sensory differences and difficulties associated with autism, while also unanimously acknowledging the barriers the participants and their children had encountered due to rigid and labelling systems. This positioning, which recognises both the biological and psychological/social disadvantaging effects of the condition is defined by the World Health Organisation (WHO) as the biopsychosocial model of disability, one that “synthesizes what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects” (WHO, 2002, p. 9). There was a sense from the participants, that the social and sensory difficulties associated with autism have disabling effects to which society adds a layer of attitudinal and process-based barriers that further disable – often attributed to causing the ‘difficult journey’.

Previous studies looking at parental school choice for children with SEN/ASC, (Bagwa-Patel & Devecchi, 2014; McNerney et al, 2015; Jenkinson, 1998), tended to separate parents into two camps – those who valued a social model of disability (who were reported as preferring inclusive mainstream provision), and those who tended towards a medical model (and were more inclined to enrol their children in specialist provisions). The phenomenological framework of the current study has allowed an insight into a more nuanced and complex interpretation of parental decision-making. It is not a case of two camps but rather for a shared biopsychosocial model of disability view, regardless of what the school choice has been – for example Natalie’s comment that “*the ethos has to be a family, but the expectations should be high*” (p. 31), resonates with Kate’s comment that, “*It’s got to be real-life but nurturing*” (p. 28). While Kate explicitly named her desire for Felix to learn about “*real life*” in a mainstream provision to prepare for their future. Natalie, along with other ‘specialist school’ participants, such as Denise and Fiona, also wanted to prepare their children for independence. Both ‘specialist’ and ‘mainstream’ parents seemed keen to move away from



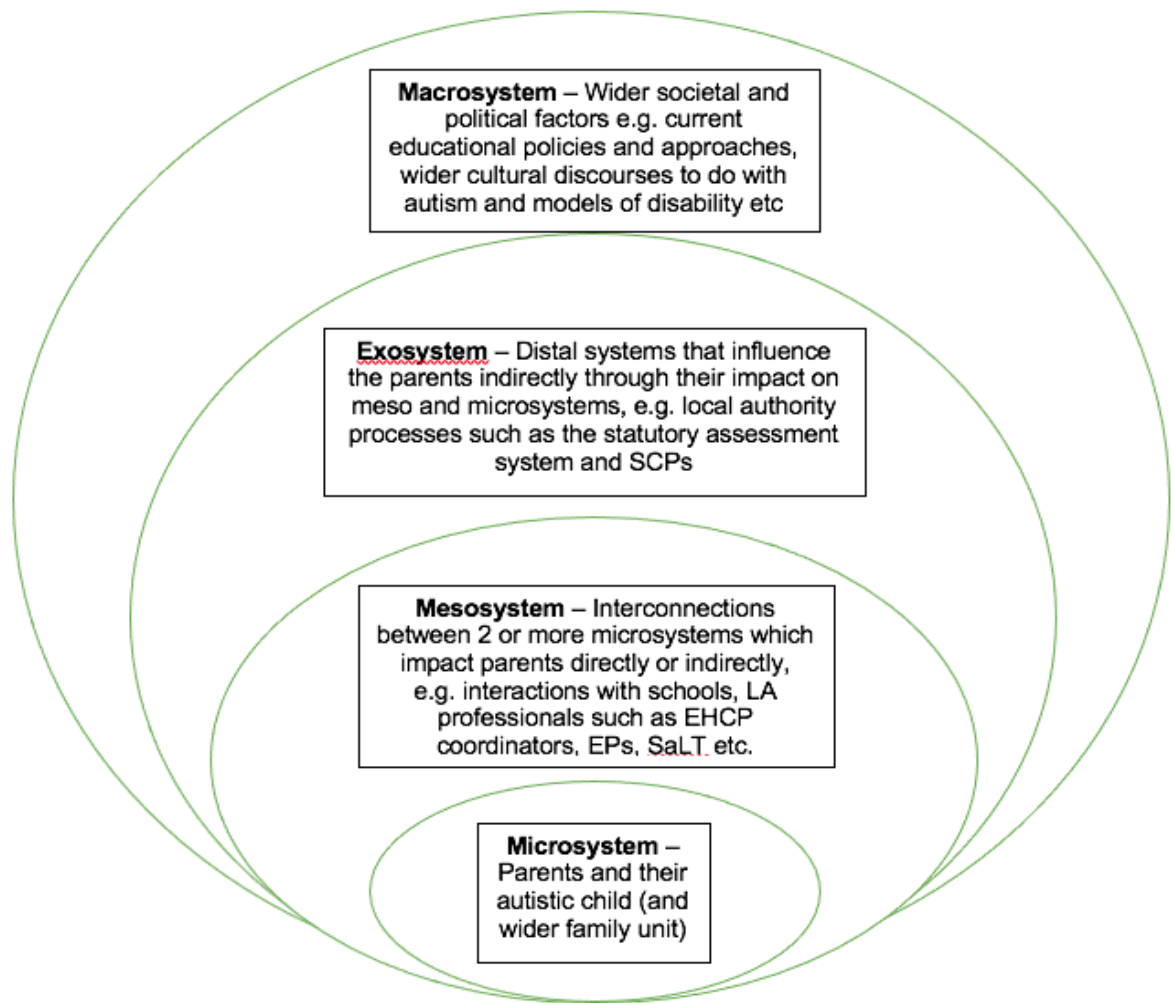
paternalism and dependency and to encourage self-efficacy, and this was factored into wider decision-making.

Perhaps this more holistic biopsychosocial view is indicative of a wider societal change in the way SEN and ASC are framed and understood – with the adoption of social models of disability more noticeable in recent years. However, the narratives of the present study suggest that there remains attitudes and structures that disable, and there is still some way to go to move beyond rhetoric towards real understanding and genuine inclusive practice.

### **5.3.1.2 Theoretical perspectives**

#### **5.3.1.2.1 Bronfenbrenner – interacting systems**

The social constructivist underpinnings of this research are interactionist by nature and have illuminated the interfaces and exchanges between different systems within the educational journey and SCP. Previous studies relating to parental experiences of school transition have adopted Bronfenbrenner's (1979) Ecological Systems Theory (Gioia, 2017; Gayton, 2021) to frame and consider their key findings concerning the layered systems that interact during school transition processes. I have likewise utilised the model to illuminate and consider interactions between systems within the present research. Figure 15 below is a summary of the interacting systems described in the data, framed and contextualised by Bronfenbrenner's model:



*Figure 15: The interacting systems described in the data, framed and contextualised by Bronfenbrenner's Ecosystemic Model (1979)*

In subtheme 1, 'Battles, barriers and battle scars', the impact of factors at the higher **meso-**, **exo-** and **macrosystem** levels on the parent/child **microsystem** are apparent. These external factors are positioned as exerting a negative and traumatic effect. Parents often 'other' and feel 'othered' by those at **mesosystem** level, and hindered by processes at **exosystem** level. **Macrosystem** factors such as parental models of disability influence the way the parents engage with professionals at **mesosystem** level and processes at **exosystem** level – as well as influencing school decision making.

In subtheme 2, 'Judgement and allies', the impacts of a lack of empathy and understanding at **meso-** and **microsystem** level (from family) is illuminated, this is commonly attributed to attitudinal barriers relating to the understanding of autism. However, this is offset by examples of allies at the **mesosystem** level

who *“stuck their head above the parapet”* (Kate, p. 14), and helped to counter feelings of rejection and isolation.

#### 5.3.1.2.2 Broader theoretical context of note

Rooted repeatedly in parental narratives was a sense of ‘them and us’ with regard to school and LA systems and personnel. Several theories are useful to reflect on this. First, Positioning Theory explores the discourse used by individuals and groups to locate themselves and others in society, and within this discourse personal perspectives are assumed, rights are claimed and judgements/expectations are placed on others (Moghaddam & Harr , 2010; Harr , 2012). The way that the parents in this study felt positioned and themselves positioned others was frequently illuminated in the findings, Natalie for example felt negatively positioned as a single mother in meetings with LA and school professionals and in turn positioned ‘them’ as being motivated by balancing budgets rather than considering what was best for her son. Sarah also positioned mesosystem and exosystem professionals and systems as the *“powers that be”* (p. 3). Throughout parental narratives there was a sense of these professionals being assigned as trusted or distrusted, ‘with-us’ or ‘against-us’ (concurring with Moghaddam & Harr , 2010).

The ‘difficult journey’ with their autistic child shaped parents, along the way they developed affiliations with other parents of autistic children, sometimes helping each other to subvert systems. Social Identity Theory (Tajfel et al., 1979) can helpfully frame these associations, enabling one to hypothesise that parents who feel judged, alone, and lost in complexity are drawn to finding others facing similar challenges – with ensuing interactions further defining them, both individually and as a group, as the ‘parents of autistic children’. A social identity which could lead help to counter isolation and bolster a sense of belonging, but which could also lead to the ‘othering’ of those perceived to be obstructing the accessing of suitable provision for their children – this sense of ‘them and us’ potentially leading to discourse such as Ellie’s in her description of, *“the big bad local authority”* (p. 17).

Final relevant theories to note relate to subtheme 2, which reflected parental perceptions around the strength of trust, cooperation, openness and feeling listened to by professional allies (in contrast to the judgement that parents had all experienced). There was a sense from all participants that these relationships were powerful and facilitated greater personal confidence and self-efficacy, a fundamentally humanistic Rogerian perspective, i.e. once we receive positive regard from others, we form positive regards for ourselves. The concept of containment (Bion, 1962), is also useful, allowing us to understand the value attributed by parents to ‘allies’ who offered warmth and attunement, ‘holding’ their distress and supporting their anxieties until they had the strength and knowledge to find their own ways forward. This was powerfully shown in Sarah’s comment that, *“I was barely coping you know, but this lady came in and just listened and people don’t realise how much listening helps” (p. 22).*

### **5.3.1.3 Context within existing research**

#### **5.2.1.3.1 Subtheme 1 – Battles, barriers, and battle scars**

Consistent with previous research (Bagley et al., 2001; Tissot, 2011; Bagwa-Patel & Devecchi, 2014; McNerney et al., 2015; Booth, 2017; Smith, 2020) the findings of this study illuminated the stress and uncertainty felt by parents during the SCP and wider educational journey. Metaphor and discourse related to ‘fights’ and ‘battles’ were similarly noted in the parental narratives of previous studies (Byrne, 2011; Bagwa-Patel & Devecchi, 2014; Booth, 2017) – powerfully exemplified by a parent in Smith’s (2020) narrative research who stated that, “it’s by your bloodied fingers that you get support” (p.71). This depth of feeling was also apparent in the narratives of the present study, with Natalie describing her experiences as, *“torture” (p. 10).*

In line with previous studies, parents primarily attributed their stress to failings in LA practices and information sharing (Tissot 2006 & 2011; McNerney et al., 2014; Booth, 2017; Smith 2020) – with LAs positioned as being more concerned about, *“saving money” (Natalie, p. 9),* than ensuring appropriate provision and support for their child (Tissot 2006 & 2011; McNerney et al., 2014; Booth, 2017).

During Kate's search for an appropriate secondary place, an 'academic' mainstream *"made it clear they didn't want Felix"* (p. 20). This experience corresponds with those of other parents in previous studies when attempting to secure mainstream provision, and in all cases was attributed to the pressures of league tables and competitive choice markets and how this potentially leads to mainstream resistance to enrolling children with autism and SEN, for fear of them affecting results (Tissot 2011; Byrne, 2011; Booth, 2017; Smith, 2020).

With regards to previous studies relating specifically to ASC, there was parity in parental narratives regarding views about the additional anxiety they felt compared to other parents when choosing suitable secondary provision. Fiona's comment that *"there's just so much more besides [as a parent of an autistic child]... you have all these worries and anxious thoughts"* (p. 16), for example, echoes a parent in McNerney et al.'s study who stated, "just like normal parents get anxious, but you get *really* anxious" (McNerney et al, 2015, p. 12). In both cases, this anxiety is attributed to the burden of decision-making for an 'in-between' child with an invisible disability and doubts about whether they were doing the *"right thing"* (Sarah, p. 4).

Another common finding within the limited ASC parental choice research has been what McNerney et al., termed "grasping at straws for information" (McNerney et al., p. 12). This sense of uncertainty, doubt, and confusion was felt previously by the participants in Tissot's studies (Tissot, 2006 & 2011) and was echoed by all parents in the current study – elegantly captured by Ellie's analogy about feeling lost, *"in Japan"* and her description of panel meetings (where decisions are made regarding allocation of specialist places) as, *"cloak and dagger"* (both p. 22). Parents felt unsupported during the SCP, left alone with, *"a great big thick wad of booklets"* (Sarah, p. 14). However, the phenomenological underpinnings of the current study, in contrast to previous studies, illuminated parental understanding of the pressures on the LA and school systems, they were able to appreciate the bigger picture and wanted to work collaboratively with the system to find solutions and ways forward, this was summed up by Ellie, *"it should be a team effort, less 'them and us', you know the co-production they [the local authority] talk about... the parents, the local authorities and the schools"*

should all [stressed] be a team. Almost a team of superheroes that are there to help that child” (p. 41). Interesting to note with respect to the improved co-production that was promised by the latest SEN CoP, is a recent article in the online newspaper Special Needs Jungle, which described co-production as an “illusion”, with both parents and SENCOs feeling excluded from processes and/or co-production as tokenistic (Tirraoro, T. & Boddison, A., 2021). This accords with a previous comment by Ellie that “it’s all just a tick-box exercise... dressed up in a co-production bow” (p. 19).

Other new insights, not found in previous ASC-related literature, communicate the impact of blinkered decision making on ASC profiles and the shifting admission criteria experienced by those who were attempting to access specialist provision.

#### **5.2.1.3.2 Subtheme 2 - Judgement and allies**

The judgement encountered by parents during the educational journey with their autistic child was not illuminated by literature considered for the literature review. The current study however gave an insight into both its saliency amongst these parents of children with autism, and its impacts, particularly on parental sense of self and confidence. Judgement came from many places – other parents, school, LA professionals – and, to my surprise, from family members (n=5 out of 7). Further literature searches relating to familial acceptance of/stigma related to autism led me to a recent report which summarised a symposium on autism in UK ethnic minority groups in 2018 (Kandeh et al., 2020). The report also synthesised previous research and concluded that cultural, religious and familial beliefs can lead to judgement and stigma around autism in minority communities (Nwokolo, 2010; Alqahtani et al, 2012). The findings of the present study are notable in suggesting that this stigmatisation of the condition occurs in the white British population too – a change to discourse may therefore be required.

The present study echoed previous SEN and ASC-specific research (Byrne, 2013; McNerney et al., 2015; Smith, 2020) in highlighting differences of parental experience with regard to interactions with LA professionals. While some had had negative experiences of EHCP coordinators, finding them unavailable and

unsupportive, others had positive experiences – with good communication, honesty, and consistency being cited as valued factors in an effective working relationship. Also in line with earlier studies, parents found allies from a range of professions (Tissot, 2011; Booth, 2017; Smith 2020), with trust, communication and positive relationships noted as more valuable and impactful than practical support (Booth, 2017; Bradbury et al., 2004). The need for consistent and collaborative support for parents of children with a SEN is documented in literature (Turnbull et al., 2000; Turnbull et al., 2006), as well as being enshrined in The Children and Families Act (2014) part 3 and SEN CoP (2015). However, a recent research ‘Supporting SEND’ survey conducted by Ofsted (Ofsted, 2021) found that although LAs had “strong ambitions” for improved collaboration and support, it “did not always translate into improved practice and positive experiences for schools and families’ (p. 52).

### **5.3.2 Theme 2 – Those who prevail and those who become lost**

#### **5.3.2.1 Theoretical perspectives - Bronfenbrenner and Bourdieu and the consideration of power**

The interactionist framing of Bronfenbrenner’s (1979) Ecological Systems Theory enabled reflection on parental narratives relating to personal transformation and growth during the educational journey and SCP. Allowing, for example, an appreciation of how metamorphosis at the individual microsystem level was constructed and sculpted by interactions and experiences at meso-, macro-, and exo-systemic levels. The theory additionally enabled an understanding of how personal transformation had the potential to reciprocally influence wider meso- and macro- levels, i.e. through a deepened understanding of processes, and an increase in personal power.

Differences in acquired power (and associated differences in levels of systemic influence), were acknowledged by participants, as were differences in outcomes for some parents compared to others – framed via interpretation as those who prevail and those who become lost. Kate’s description of “*selling a kidney*” (p. 14) to get a private autism diagnosis evidences the embedded power of personal capital during the navigation of the educational journey. However, her accessing

of support from a prominent MP and her earned, “*reputation as the parents who went to court*” (p. 26) can be understood in the context of Bourdieu’s (1986) cultural capital. The idea of cultural capital allows us to appreciate the relative power of some parents compared to others – a result of better education and better knowledge of systems and processes, of better social and professional connections. Some parents like Kate, start the journey with more monetary and cultural capital than others, and while it couldn’t prevent trauma and battle scars, it did bring the power to influence outcomes and break down barriers to provision. Other participants, like Natalie, Rose, Ellie and Fiona needed to acquire power, through educating themselves, and building connections with parent groups and key professionals. Differences in cultural capital and power were perceived by participants to affect parental confidence and self-efficacy and either increase or diminish their capacity to achieve influential interactions with meso- and exosystems. ‘Those who become lost’ are positioned as lacking capital, their voices and power diminished – potentially due to their own additional needs – struggling within a macrosystem where cultural narratives privilege ‘normalcy’.

Rose’s folders of evidence, Kate’s husband enrolling himself on IPSEA training, and other participants establishing jobs within the SEN world made me reflect on knowledge as power – “*scientia potestas est*” (Bacon, 1597). With participants’ discourses illuminating the power associated with both knowledge acquisition and social connections with knowledgeable others. Michael Foucault, who examined the knowledge/power binomial within the context of psychiatry, submitted that power and knowledge are central to subjectifying people, to producing the haves and the have nots (Roberts, 2005) – a position from which we can appreciate the narratives of the present study. In response to this subjectification, Foucault conceptualised discourses related to resistance and subversion (Heller, 1996). These concepts worked well to frame the actions of Natalie, in securing the post of school governor to influence decision making, and Ellie, in recommending ways for parents to sabotage ‘due process’ to secure desired outcomes. We see resistance in the form of guerrilla tactics, employed to subvert aspects of social systems judged unfair and detrimental to the welfare of their children.



### **5.3.2.2 Context within existing research**

#### **5.3.2.2.1 Subtheme 1 – Those who prevail**

In accordance with this research, previous research illuminated parental views about the qualities needed to navigate school choice systems. In Smith's (2020) narrative study for example, a parent participant shared the need to be self-determined and "pushy" (p. 79). Likewise, Booth's (2017) IPA study revealed parental opinions about the need to proactively chase support and information, as well as a need to build resilience to weather protracted EHCP and SCPs – all of which concur with my findings. However, personal change and growth, a salient theme in the current research, was not shared in the findings of the literature considered for the review. That said, a wider literature search identified a study mapping the experiences of mothers of children with autism (Ryan, 2009) – noted in their narratives was a sense of growing individual advocacy, which then metamorphosised (for some mothers) into collective activism alongside other parents. These findings resonate with that of the present study, where parents transformed into better informed, better connected, and more (outwardly) confident versions of themselves in order to navigate the wider educational journey and SCP. Moreover, the present study provides examples of personal activism and subversion, parental characteristics which have not previously been represented in parental school choice research.

With reference to the 'warrior' parent label, it is interesting to note its 'official' use in the Lamb Inquiry report – which considered how parental confidence in the SEND system could be improved – where Brian Lamb stated that, "as the system stands it often creates 'warrior parents' (...) feeling they have to fight for what should be their children's by right; conflict in place of trust" (Lamb, 2009, p. 2). As already discussed 'fight' and 'conflict' describe the central and most prevalent theme running throughout the corpus – despite the commitments of the SEN CoP to better support and collaborate with parents to improve outcomes. Indeed, in line with the present study, a recent Ofsted report considering the experiences of CYP with SEND and their families in the context of the SEND reforms over the last 10 years, found that many parents felt that systems were still not offering enough support, that they still had to "fight for the rights of their children" (Ofsted,

2021, p. 33), and that “the last 10 years had done very little to ease the need for ‘warrior parents’” (Ofsted, 2021, p. 15). This shall be returned to later.

As an ex-teacher, I, like Fiona, had heard the ‘warrior’ label attributed to parents perceived as difficult, blinkered, and ‘pushy’. However, narratives of parents in the present study challenged this thinking and revealed that parents – who often felt tired, beaten down, and battle-scarred by processes – would far rather have meaningful reciprocal dialogue than fight and subvert. The ‘warrior’ appeared to be worn as armour, helping them to navigate the educational journey and enabling them to keep pushing against real and perceived barriers to ensure the best support for their autistic child. Underneath the armour however, as shown in the narratives of Kate, Fiona, Natalie, Rose and Sarah, there was vulnerability and a need to feel heard.

#### **5.3.2.2.2 Subtheme 2 – Those who become lost**

Within the present study, all participants mentioned parents who they thought were marginalised and fell between the gaps of educational processes and support. While previous research has noted the fundamental need for parents to proactively engage with processes to access educational opportunities for their children (e.g. Mawene et al., 2018; Bryne, 2011; Bagley et al., 2001), there has been very little mention of those parents who *“haven’t got the skills, or confidence, or maybe they’ve got special needs themselves” (Denise, p. 17).*

However, two exceptions to this were found in studies considered for the literature review. Booth’s (2017) IPA study, for example, identified parental concerns similar to those in the present study regarding parents who may not be able to advocate for their child, and how this may result in the child being ill-supported in a mainstream provision. For example, Ellie’s comment that, *“if you spoke to those parents whose children were in mainstream but need specialist, I think a lot of it is because they haven’t battled, for whatever reason” (p. 42),* resonates with a comment from one of Booth’s participants that parents who aren’t proactive and don’t advocate for their child, “just end up there [at local mainstream] and that’s it” (p. 107). In Smith’s (2020) narrative study, one of the participants also acknowledged parents who, “don’t have the ability or knowledge, the understanding about how to go about it [i.e. accessing suitable

educational provision and support]” (p. 93). There is a sense in these previous studies, and the present study, of entrenched systems inequalities, and the marginalisation of certain individuals. Mindful of Bourdieu and Foucault one can appreciate that while processes and provision may be theoretically available to all, there is not equal chances to access them, with some individuals hindered by a lack of power and capital. Within the wider frame of social justice, there is arguably an imperative to address these inequalities and provide equitable opportunities for all – however, an online search into how marginalised groups of parents (i.e. those with additional needs, those from disadvantaged backgrounds, those with English as a second language) are supported to navigate SEN and school choice systems drew a blank, indicating that there is still some way to go to acknowledge both their presence, and the difficulties they face.

### **5.3.3 Theme 3 – The factors that influenced choice and decision making**

#### **5.3.3.1 Context within existing research**

The factors influencing parental decision making in this study demonstrated the complexity associated with navigating SCPs and the wider educational journey with an ‘in-between’ child with an ‘invisible’ disability – a child who would benefit from both the more nurturing and inclusive approaches offered by specialist provisions, and the more academic and ‘real-world’ experiences offered by mainstream.

Findings corresponded strongly with previous studies where parents placed higher value on finding somewhere their child would feel secure and mindfully supported, rather than provisions that were highly academic (Bagley et al., 1998; Tissot, 2006 & 2011; McNerney et al., 2014; Byrne, 2011; Bagwa-Patel & Devecchi, 2014; Booth 2017). This desire for mindful support, as with previous research, often involved parents pursuing places which had, 1) smaller class sizes and higher staff-child ratios (e.g. Tissot, 2006 & 2011; McNerney et al., 2014); 2) ASC specific knowledge and expertise (e.g. Booth, 2017; Byrne, 2011; Bagley et al., 2001), and 3) staff/learning environments which could flex to meet individual social and educational needs (McNerney et al., 2014; Smith, 2020; Booth, 2017). Also in line with previous studies (e.g. McNerney et al 2014;

Bagwa-Patel & Devicchi, 2014), much weight was placed on the need for good communication, and the potential to build positive reciprocal relationships with school staff. Distance from school was important for some mothers and less so for others, generally dependent on how well they felt their child would cope on a long taxi ride. Concurring with other studies, parents of children in special school settings placed proximity to home below the need for specialist support (Bajwa-Patel & Devecchi, 2014; Bagley et al., 2001).

This study's findings both corroborate (seen in Ellie's, Fiona's, and Denise's narratives) and counter (seen in Kate's and Rose's narratives) the findings of previous studies where negative experiences of mainstream primary schooling resulted in an increased desire to secure specialist secondary provisions, which parents felt would better support and adapt to their children's needs (Bagley et al., 2001; Booth, 2017). And all findings cited above contrast those of Byrne's multiple case study (2011), which found that, "the one factor which did not appear to consistently have an influence on parents' decisions to choose either a mainstream school or special school was the child's experience in their mainstream primary school" (p. 97). Indeed, primary experiences were returned to in all parents narratives and cited as a factor which informed the decision making process.

For both Kate and Rose, mainstream was positioned as offering a greater potential for academic achievement and a more 'real world' experience that would better prepare their children for their future lives. However, decisions were not taken lightly – options were purposefully considered and assurances from school professionals sought – the need for flex and inclusivity remained paramount, and both mothers reserved the right to explore specialist options should their children need them. Rose's comment that, *"there needs to be more schools that will support academic achievement but also autistic needs"* (p. 21), sums up the sentiment felt by participants from both sides of the mainstream/special fence who all wanted their children to be challenged and achieve their best, and for there to be high expectations – this resonated with previous literature (e.g. Bajwa-Patel & Devecchi, 2014). The present study additionally revealed how this viewpoint factored into decision making regarding

the pursuit of SRB places, where parents feel their child could potentially have, *“the best of both worlds”* (Denise, p. 7).

With the judgement from her family in mind, Natalie's comment about finding a placement that is like a *“working family”* (p. 31) seems paradoxical. However, framed by her intent and contextualised by wider narratives in the corpus, it works well to sum up the salient factors that parents both, directly and indirectly, shared relating to secondary school choice – that their children be both accepted and challenged, within a nurturing, non-judgemental, flexible environment, which accounted for individual differences.

### **5.3.3.2 Theoretical perspectives**

As already discussed, the parents in this study, contrary to the findings of previous research, were not influenced in their decision making according to whether they fell into a social model of disability camp (favouring mainstream) or a medical model camp (favouring specialist placements). Instead, perhaps indicative of wider systemic shifts in the way that SEN/ASC is framed and understood, a mixed biopsychosocial view better framed their narratives, where all parents were keen to find provisions that both supported and flexed for individual need and had high expectations. However, while parents on both sides of the mainstream/special fence noted difficulties as being, to some extent, attributable to their child's autism, there was a stronger sense of the harm caused by a lack of understanding and adaptability – offering potential insight into why many parents of children with autism often choose to seek specialist places, resulting in demand far outstripping supply.

The information processing approach to decision making (Bettman, 1979), introduced in chapter one, helped to illuminate how participants construct choice parameters based on experience, internally weighing up the pros and cons of each option. However, these previous experiences didn't occur in a vacuum and were contextualised within existing constructs (including those related to autism and disability), and previous social interactions. Emotions – the “potent, pervasive, predictable, sometimes harmful and sometimes beneficial drivers of

decision making” (Lerner, Li, Valdesolo and Kassam, 2015, p. 799) – also played a significant role.

Therefore the current study, like previous parental choice research (e.g. Booth, 2017; Smith, 2020), found that parental choice-making spanned a range of different choice-making models, e.g. information processing and the Social Constructivism Model of Ethical Decision Making (SCMEDM, Cottone, 2001), and couldn’t easily be defined by one. What was clear however, despite parental choice being incrementally embedded into legislation since the 1981 Education Act, was that parents continue to perceive choice as limited and their educational and school choice journeys as stressful and lonely, often feeling unsupported, judged, and not listened to.

#### **5.3.4 Conclusions from discussion of findings**

Figure 16, below, attempts to summarise parental experience and meaning-making, which divided broadly into what helped and what hindered during the SCP and wider educational journey. Before this, I summarise new insights garnered from the present study, i.e. not found in the previous research considered:

- An insight into how SCPs were framed within bigger narratives regarding the wider educational and life journeys with their autistic children.
- An insight regarding parental growth and change associated with navigating SCPs and wider educational journey.
- An insight that parents did not fall neatly into 'medical' or 'social' models of disability camps dependent on the schools they choose – instead both 'mainstream' and 'specialist' parents conformed more to a biopsychosocial model.
- An insight into how difficult previous experiences sometimes led to parental beliefs that their autistic child’s problems were the result of inflexible systems/environments which privileged 'normalcy', and for some this was a driver for pursuing a specialist placement.

- An insight that all parents desired a placement that would *"support academic achievement but also autistic needs"* (Rose, p. 21), and that this was used by some as a justification for choosing an SRB.
- Insights regarding the interplay of personal attributes, cultural capital and the acquisition of knowledge, and how these combine to increase personal power and potentially improve outcomes.
- Insights regarding how parents had to embolden themselves and step outside their comfort zones to 'fight', of reluctantly assuming the mantle of the warrior, but wishing they didn't have to.
- An insight into parental activism and subversion of systems in order to access support and influence outcomes.
- An insight into parents reserving the right to home educate their child if they couldn't secure their desired placement, and a recognition that this practice was not uncommon for families of children with autism.
- An insight into parents' appreciation of the bigger picture and the difficulties faced by LAs. This was underpinned by a desire to work with wider systems, rather than against them, to counter the sense of 'them and us'.
- An insight into judgement from families (in white British context).
- An insight into how parents experience and share information about the shifting criteria of special schools.

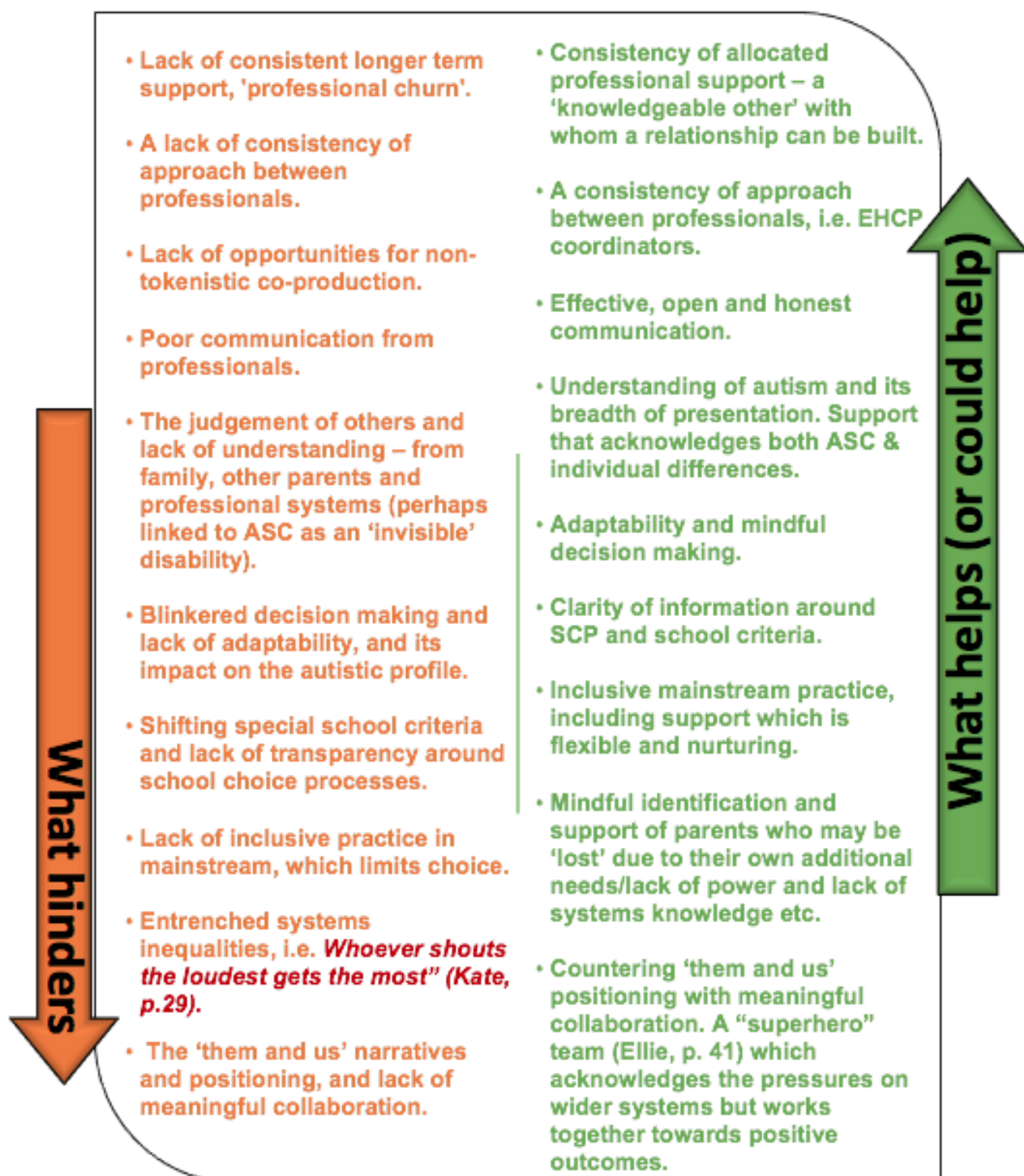


Figure 16 – Conclusions from discussion of findings – what helps and what hinders



## **5.4 Part 2 - Critical evaluation and implications**

### **5.4.1 – Methodological critique**

#### **5.4.1.1 IPA**

The limitations of IPA and my reflections on engaging with it have already been presented in section 3.5.2.3.2. In general, I found it to be a solid base from which to explore and address the phenomenological aims of my study, enabling me to gather rich, detailed, first-person accounts of parental experiences. However, limitations noted in critiques of the methodology (e.g. Willig, 2008) were duly experienced in the present research. Firstly, there must be an acknowledgement of the study's small sample size, preventing generalisable claims to be made about the findings. However, while not generalisable in the nomothetic sense there are robust thematic patterns, which corresponded strongly with the limited amount of previous research in the field – with further depth and relevance achieved by contextualising findings in the context of relevant psychological theory. Secondly, I noted, like Willig (2008), that while all participants had the capacity to share their experiences, some were better at communicating in a nuanced way and reflecting on what they had said, resulting in some narratives having more depth than others.

Problems with recruitment – often associated with the high workload of SENCO and SEN team gatekeepers – led to some changes to my intended study design which should also be noted. Firstly, my original intent to cross-analyse data in three discrete groups – mainstream, specialist, and SRB – was waylaid by difficulties recruiting specialist participants, leading to a decision to conduct cross-case analysis as one large group. While these participants were homogeneous in the sense that they were all parents of secondary aged children, with a diagnosis of autism and an EHCP, who had gone through the SCP, a more detailed and nuanced exploration of the experiences relating to securing different types of secondary provision may have been achieved if my initial plan had been possible. Secondly, I had hoped to access more marginalised and diverse voices, achieved through purposeful sampling via gatekeepers. However, this diversity wasn't achieved to the level I had hoped – while there was some diversity in

terms of marital status and socioeconomic situation, all participants were white British and female, and each had been able to effectively advocate and push for their child during the SCP, and the majority (all but one) worked in educated/SEN. I reflected that while the inclusion criteria of having an EHCP may have improved homogeneity, it may have also increased the likelihood of recruiting more ‘embattled’ participants (who had had to jump through more process-based hoops) as well as being a barrier to recruiting more marginalised voices, as the families without plans may have not had the knowledge or fight to *“keep pushing within it [the EHCP process]” (Denise, p. 20)*. As a researcher I need to acknowledge the fact that diversity tends to provide greater perspective and innovation (Levine et al, 1998), and that the lack of diversity within my participant group is likely to have narrowed and skewed my findings towards parents who had the ability to navigate various processes and who have ‘battled’.

#### **5.4.1.2 Focus group and AI**

The focus group was efficient in exploring ‘what changes could be made and action steps’ (McAteer, 2013). I mindfully prepared for the group by pre-sharing information about the structure and aims and invested time at the start of the process to build rapport, using my consultation and Video Enhanced Reflective Practice (VERP) skills to facilitate group exchanges and the collaborative generation of ground rules. The subsequent sharing of key findings allowed the group to quickly connect and acknowledge commonality of experience. This social identity and rapport were very useful within the tight timeframe available, helping to facilitate honest reciprocal exchanges during the AI cycle.

When preparing the AI, a strength-based technique, I had some reservations about how my embattled participants would react and contribute to the ‘discovery’ phase of the process, where they were asked to explore what was working in terms of the processes associated with secondary school choice. However, while contributions were few (and sometimes immediately countered by negative exceptions) participants didn’t resist this stage as I thought they might. Instead they helped each other to think around positive experiences, which related

primarily to constructive relationships and effective communication with key professionals.

Participants reacted positively and constructively to the idea of ‘bold’ provocative propositions, which they collaboratively discussed and suggested the wording for (recorded, and edited when prompted, on a visualiser). The process was very much owned by the participants, and although I was officially a participatory member of the group I purposefully took a step back and allowed them to lead in the generation of propositions, involving myself mainly in a facilitative capacity. As hoped, AI enabled a meaningful, non-tokenistic generation of possible steps forward in areas identified as most pertinent by FG members – communication and information sharing, meaningful collaboration, and improving outcomes for autistic children – all of which concurred with their individual experiences and the cross-case findings (see section 4.4.2).

Overall the strengths-based aspect of AI worked well to create energy, motivation and momentum, but that this may have been diminished without the initial rapport that was built by acknowledging and briefly discussing difficult shared experiences.

#### **5.4.1.3 Reflexive critique**

*The pot carries its maker's thoughts, feelings, and spirit. To overlook this fact is to miss a crucial truth, whether in clay, story, or science. (Krieger, 1991, p. 89)*

The quote above acknowledges the relationship between the research and researcher and highlights the importance of reflexivity, where the researcher engages in, “explicit, self-aware analysis of their own role” (Finlay, 2002, p. 1).

Reflexive consideration has made me mindful of how previous roles have affected my intersubjectivity with participants. For example, my work in an SRB for ASC and a therapeutic school made me mindful of the vulnerability and powerlessness I sometimes felt when dealing with young people’s anxiety and associated dysregulated behaviours, allowing me to appreciate how my participants have felt at times. However, the double hermeneutic and ideographic

focus of IPA has also made me mindful that similarity of experience is countered by the multifarious ways in which it is experienced, due to our diversity of biographical, social and cultural contexts. Furthermore, my previous experience of supporting parents of autistic children through secondary SCPs, made me aware of the anxieties associated with it. I had experienced first-hand the uncertainty associated with accessing specialist provisions, and had heard anxieties about whether mainstream schools would be supportive enough, or if special provision would provide enough 'real life' experiences. My interactions with a parent who felt accused of fabricating her daughter's autistic symptomology, and previous experience as a teacher listening to the sometimes disparaging professional narratives relating to 'pushy' 'warrior' parents, have also influenced my constructs regarding the lived experiences of SEN parents and the mantles they assume. In fact, an implicit, and previously unacknowledged, negative personal construct about 'warrior' parents sharing misinformation on social media, led to an early decision not to recruit via parents support groups. It was only later when engaging with parents and listening to how they supported each other on these forums that I acknowledged this negative bias and the barrier it had created – realising that it had potentially led me away from accessing more marginalised voices.

As the study progressed, I became increasingly aware of the potential for bias. Whilst the "I" of IPA recognises the subjectivity of the researcher, there is still an expectation to 'bracket-off' preconceptions and 'fore-knowledge' as much as possible. However, as a novice with the methodology, and despite my best efforts to attune to parents and remain close to experiential meaning-making, I acknowledge the likely impact of my interpretations on the hermeneutic cycle, and wider findings.

While I am confident of my strengths in relationship building and facilitating positive rapport during the individual interviews and focus group, the responsibility of data analysis sometimes felt challenging. IPA's clear protocols set out by Smith, Flowers & Larkin (2009) leant themselves well to my 'rookie' researcher status, leaving me assured that I conducted individual analysis in a thorough and systemic way (moving beyond simple description to more nuanced

linguistic and conceptual interpretations); however, I struggled to decide what to include from my significant amount of analysed data. Deciding which themes were prevalent and salient enough to present and discarding others which, although pertinent, didn't relate enough to the research question, sometimes felt like an act of violation both against deeply felt parental experiences, and the underpinning participatory philosophy of the study – 'killing my analytical darlings' was sometimes difficult.

#### **5.4.2 Implications for practice**

I remain mindful that the ideographical root of IPA is arguably not suited to making generalised 'top tips for practice'. However, it does provide and illuminate key points for consideration and reflection which have implications for professional practice, presented below.

##### **5.4.2.1 LAs and schools**

One of the justifications for my research was to examine whether the Children and Families Act (2014) and associated SEN CoP has delivered on its promises for greater transparency and information sharing with parents... has it embedded greater choice and greater control in educational decision making?

The findings of the present small scale study – in line with Ofsted's recent report which reflects on these reforms and their impact (Ofsted, 2022), and reports in the national media (Tickle, 2017) – suggest that while parents do feel some increased autonomy, they often feel unsupported and lacking guidance (concurring with Smith, 2020). For Sarah and Natalie, who had experienced both the statementing and EHCP processes, there was increased complexity with the latter, which they, and other parents, saw as a barrier to more marginalised groups.

Concurring with previous research, the key factors cited by parents when seeking appropriate secondary provision included, "safety, care, inclusivity, unconditional respect for individual worth and potential" (Bagley, et al., 2001, p. 305). There was a sense from some that this was most likely to be achieved via a specialist placement, but the majority felt that it could be possible in mainstream, if the

additional needs could be well supported and understood in an inclusive flexible environment. However, several participants experienced a sense of resistance from some of the mainstream schools they visited. Bagley et al. wrote in 2001 that, “the English education system is increasingly being driven in the direction of *privileging the academic*” (p. 305), it seems that this remains the case.

Mindful of the findings of the current study, I present, in brief, implications for LA and school practice (refer also to provocative propositions in section 4.4.2).

#### LA Implications:

- Counter negative discourse associated with 'warrior' parents. Instead provide a listening ear and open communication/support, as this is what parents indicated they needed. Ensure that meaningful, non-tokenistic, collaboration takes place.
- Ensure SEN caseworkers (i.e. EHCP coordinators) have the autonomy and time to communicate with and guide parents, and that they provide consistent support.
- Make statutory processes, SCPs, and school criteria, transparent. Keep parents informed. Cut professional jargon and “*fancy questions*” (Denise, p. 18) to increase accessibility for all.
- Work to create more schools, both specialist and mainstream, “*that will support academic achievement but also autistic needs*” (Rose, p. 21). Size, support, routines and good communication should be key considerations when establishing these provisions.
- Mainstream schools should be supported to become systemically inclusive. Opportunities for training and organisational change should be encouraged.
- Additional high needs funding should be available to schools to effectively support ASC/SEN and LAs should work with schools to ensure that SEN budgets are ringfenced.

#### School implications:

- Counter negative discourses associated with ‘pushy’ parents. Instead provide a listening ear and open communication/support, as this is what parents want. A single point of contact for parents would be useful, i.e. a parent liaison role.
- Early intervention and support for social and communications difficulties to buffer them turning into later SEMH difficulties.
- School ethos should flex for individual differences and see autism as *"just another way of being human"* (Natalie, p. 10).
- Provide well-resourced provision for ASC and SEN. Flexibility and nurture should be built into the system to account for individual difference.
- Universal approaches should be embedded and provide training for ALL staff in SEN and ASC (i.e. AET training).
- Specialist provisions should have high expectations (in accordance with SEN legislation) and should provide opportunities for both academic (and vocational) achievement.

#### 5.4.2.2 EP practice

Engaging with parent participants in this participatory and phenomenologically orientated research has enabled a more nuanced and holistic understanding of what they may be experiencing as they attempt to navigate the educational journey with a child with additional needs. I am better aware of the trauma and judgement they may be feeling and facing, and of how formal systems and processes, of which we EPs are a part, may be perceived and experienced by them as hostile or derisory. Sarah’s powerful comments, among others, relating to people who *“just listen”* and *“who are kind”* (p. 22), have reinforced my belief in the power of mindful attunement and connection to make people feel contained and meaningfully supported and their feelings and emotions acknowledged. In terms of my personal practice, working with parents during this AR project has further embedded my wish to always recognise the potential of the person sitting across the table from me, to assume professional humility in my interactions, and

to work collaboratively and reflexively, empowering and supporting those who feel marginalised and isolated. Below I present a brief summation of implications for my own and wider EP practice stemming from the research findings.

EP practice implications:

- Where possible EPs should challenge oppressive views, systems and 'fixed' ideas about autism and disability.
- At a LA level, EPs should make efforts to build a good working relationship with the SEN team and explore opportunities for joint working regarding statutory and SCPs. For example:
  - EPs could support their SEN colleagues in a supervisory capacity to help them navigate and manage the conflicting demands of their roles.
  - \*EPs could potentially mediate, via systems-based work, better working relationships between EHCP coordinators/case workers and parents, e.g. by illuminating the interacting factors faced by families, and by helping families to understand the constraints faced by LA systems – bringing everybody to a shared understanding and facilitating the collaborative planning of steps forward. (\*Ultimately, EPs could train SEN teams in systems-based understanding and approaches, and supervision could then be offered to support).
- Senior EPs should be involved in the Cycle 4 follow up workshop, and the drawing up and implementation of any resulting frameworks for practice – perhaps being the link professional between micro-, meso- and exosystems.
- EPs should work with schools to make them aware of the interacting factors that may be affecting autistic children and their families (relating to both school settlement and SCPs).
- EPs should work between systems, e.g. school and family, to ensure that children with ASC, and their parents, are being flexibility and mindfully supported.
- EPs could support families during the SCP, i.e. by empowering families through strengths-based approaches or promoting resilience.



- EPs, working with an interactionist and systemic lens, could spend time with families exploring the stress associated with navigating statutory and SCPs, providing tools to help them counter it.
- Where possible, EPs should be involved in the Year Five annual review process to facilitate discussion around how individual needs could be best supported and what kind of provision should be put in place/made available.
- EPs should encourage SENCOs to identify 'marginalised' families who are likely to need greater support to navigate statutory and SCPs.
- EPs could engage with schools to understand some of the cultural, relational and environmental factors that can promote a sense of belonging for autistic children and their families.
- EPs could support organisational change work to encourage a more systemic approach to inclusion – potentially via tools like AI.
- EPs could support whole staff training around autism and inclusion. EP support could take the form of supervisory sessions with SENCOs and/or support staff.
- EPs could support schools to unpick needs beyond the label of autism.

#### **5.4.3 Next steps and future research**

Cycle 4 of this AR will be a follow up by a workshop of key LA professionals and those parents who wish to be involved – this workshop will finalise the AI process, ensuring that there is a commitment “to what will be” (Cooperrider & Whitney, 2005, p. 25). I intend to share my research with my LA, autism charities, and SENCO networks, and explore the potential to convert my thesis into a journal format for publishing. I will also explore the potential to publish frameworks of practice resulting from the study.

Mindful of the findings from all 3 cycles of the AR – the literature review, semi-structured interviews, and focus group – the bullet points below present and contextualise suggestions for future practice.

- No longitudinal studies exist that cover the primary to secondary SCP, transition, and outcomes of mainstream and specialist placements.

Addressing this gap could provide further useful information about the varying experiences of the SCP process, transition, and how satisfied families have been with different types of placement.

- The literature review revealed an underrepresentation of the voices of autistic CYP themselves in school choice research. One could argue that no research about CYP with autism is truly participatory if the CYP themselves are not involved, especially in the planning of action steps and ways forward.
- EHCP Coordinators/SEN Caseworkers were also underrepresented. Their involvement (and that of autistic CYP) would allow us to access different voices and different perspectives regarding SCP's (and how processes and practices could be improved).
- Given the success of the FG and its utility in enabling collaborative purposeful participatory engagement, FGs could be utilised in future AR to not only to formulate action steps (Cycle 3) but also to explore the 'situation at present' (i.e. Cycle 2).
- A deeper exploration of SCPs and wider educational journeys for children with autism and their families could be gained via an ecosystemic framework which considers interacting factors.
- The accessing of marginalised voices would greatly benefit future research – this could include, for example, parents with additional needs or mental ill health, refugee families with EAL etc. The experiences of parents who were not allocated their preferred provision could also be explored. The accessing of marginalised voices would have to be mindfully planned. For example, it may be necessary to liaise with a range of different gatekeepers (which could include SEN caseworkers and SEN/ASC support groups, EPs, and parent-to-parent support groups). Additional pre-data gathering sessions may also be beneficial to build rapport and relationships. Thought should be given to how to best access personal experience and meaning making, for example, picture prompts or visual storyboarding may be useful, or techniques such as Q-methodology (Stephenson, 1953), in which participants sort and rank statements or other stimuli presented on cards while 'thinking-out-loud' - allowing for data to be collected in a more 'side-by-side' and potentially less

intimidating/more inclusive way.

- It would be useful to investigate inclusive practice in secondary mainstream provisions, particularly in the wake of 'new' Multi Academy Trusts. Have market forces and an increased focus on 'academic' subjects impacted inclusion and/or mental health of CYP with SEN and/or autism?
- This study is among others where maternal experiences tend to be extrapolated to represent parental experience. To counter this gender bias future research should also try and access the voice of male parents/carers.
- To further explore discourses associated with battles and quests with regards to supporting children with ASC or a SEN, parental experiences could be considered via narrative research or Foucauldian Discourse Analysis (FDA).

## **5.5 Conclusions**

The phenomenological and AR nature of this study has contributed new knowledge via an in-depth phenomenological exploration of parental experience when choosing and securing secondary provision for their child on the autistic spectrum, the factors that influenced their decision making, and their thoughts on improvements to processes and practice. There has also been reflection on associated systemic and psychological processes and consideration of implications for professional practice and future research.

My hopes for the study are:

- That it will be a useful contribution to wider research in the field of autism and special needs, and will also be of benefit to LAs, schools, and the professional EP community.
- That professionals who engage with autistic children and their families remain mindful of the difficult journeys that many have faced, not only during the secondary SCP, but the wider educational journey – and of the difference that professional allies can make if they listen and are kind, committed and supportive.

- That professionals avoid the negative connotations of the ‘warrior’ label and recognise that this is not a mantle that parents want to assume, preferring purposeful collaboration instead.
- That marginalised voices are proactively identified and mindful support put in place to address systemic inequality in the SCP.

As shared in the introductory chapter this research coincides with the LA’s SEND Transformation Programme which aims over four years to support the creation of new school places and improve existing facilities for CYP with SEND in the county (in which the research is based). To achieve these goals the LA is developing processes to encourage more meaningful collaboration with families and individuals – this action research lends itself well to this, with the capacity to be further extended. My final hope therefore, is that it will be an agent for change, that LA professionals learn from the insights parents have shared and that a framework of practice is developed from Cycle 3’s provocative propositions – signalling the intent for meaningful collaboration going forwards.

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## Appendices

### Appendix 1: Overview of research papers included in the literature review, including CASP & MMAT appraisal

Study title Year Author(s) Journal	Research purpose/ aims	Context and participants	Design and methodology	Main findings (inc. example conclusions/recommendations)	Critical appraisal using the CASP and MMAT appraisal tools (with decision on quality of study)
Parental narratives around decision-making regarding secondary educational provision for children with an Education, Health and Care plan – Smith, L., 2020  Doctoral dissertation, University of East London	Study captured parental narratives around decision making regarding secondary educational provision (SEP) for their child with special educational needs.	One local authority in England.  4 parents of CYP with an EHCP who had recently experienced the process of choosing their preferred SEP.	Qualitative – data collected via narrative interviews (which utilised 4 phases) and analysed using narrative oriented inquiry (which ‘valued each parent’s narrative as a unique and subjective experience of SEP decision-making’)	Due to the constructivist nature of the research findings were not generalised but attributed to individuals, they included:  Mr & Mrs Jack – narratives around 1) the marketisation of education, 2) lack of support to find an appropriate place, 3) sense of ‘them and us’, a battle/ different contexts and positioning  Mr Lee – narratives around 1) communication issues within the system and perceptions of a lack of interest in their child, 2) responsibility, whose responsibility is it? 3) identity positioning, notions of having to be a pushy parent.  Mr and Mrs Bing - narratives around, 1) being listened to and heard (or not) 2) professionals and diagnoses, 3) parental inclusion and	<ul style="list-style-type: none"> <li>Research aims clear and methodology/research design appropriate for research question and focus</li> <li>Good reflexive accounts throughout; also acknowledged that despite measures to “out” the researcher’s presence, it should be acknowledged to influence the research</li> <li>Recruitment strategy was purposefully limited to only 2 clear selection criteria to allow broader range of potential parents, who could contribute information about the specific phenomena focused on in research, to engage and contribute = appropriate strategy</li> <li>Methods for data collection well justified and made explicit. Methods of data collection and analysis selected based on Narrative orientated positioning of the research</li> <li>Some demographic information but not detailed, i.e. 4 interviews conducted with 6 parents – 3 male and 3 female, all identified as English, were within the age range of 25-74 years, and held a range of qualifications</li> <li>Relationship between researcher and participants considered in detail, including</li> </ul>

			<p>relationships during process (positive and negative)</p> <p>Mr Blake - narratives around, 1) taking a business non emotional approach to decision-making process, 2) the role of emotions, 3) Mr Blake's continual struggle to balance his emotional and objective thoughts supported the narrative identity of dissonance associated with the choice process.</p> <p>Conclusions/recommendations - The changes brought in by the CoP were mostly welcomed by parent participants, but a range of concerns were expressed, including practical aspects of implementation. A key concern raised was the lack of guidance provided by the CoP on how to implement the directed changes and indeed this is likely to have contributed towards observed variations in professional practice. Recommendations re. future research includes focusing on parental involvement in the EHCP process to reveal further insights and seeking the views of EHCP coordinators to illuminate their perspectives of the process.</p>	<p>potential bias and influence and how they responded to events</p> <ul style="list-style-type: none"> <li>• Ethical issues: <ul style="list-style-type: none"> <li>○ Details about research/confidentiality/handling of data/ right to withdraw explained to participants (outlined briefly)</li> <li>○ All ethical approvals attached</li> <li>○ Data analysis rigorous and clearly presented</li> </ul> </li> <li>• Findings were clearly presented but due to narrative nature of studies these were not generalised into overall findings (but presumably were trustworthy and credible)</li> <li>• Findings discussed in relation to orig research aims and questions but poss a lack of discussion about evidence for and against researcher findings.</li> <li>• Limitations of study and implications for practice considered.</li> <li>• Research contributed an updated understanding of decision making regarding secondary educational provision (SEP) for children with SEN in the current post SEN Code/EHCP context</li> </ul> <p><b>Decision regarding quality of study following critical appraisal using the CASP framework - High</b></p>
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<p>Parents' perceptions and experiences of the decision making process when choosing secondary school placement for children with statements of special educational needs: an interpretative phenomenological analysis - Booth, 2017</p> <p>Doctoral dissertation, University of Nottingham</p>	<p>Study aimed to develop a deeper understanding of parents' experiences and perceptions of the decision making process when choosing secondary school for their child with a statement for SEN.</p>	<p>One local authority in England.</p> <p>Six semi-structured interviews with eight parents</p>	<p>Qualitative - Interpretative Phenomenological Analysis (IPA) as the methodological approach.</p>	<p>Master themes highlighted the influence of emotional reactions when being shown round by staff in prospective secondary schools and the inconsistency of communication with professionals experienced by different parents.</p> <p>Conclusions/recommendations - Implications were discussed for supporting parents in feeling that they are able to make more informed decisions and in achieving a more consistent approach across professionals to support a more positive experience for parents.</p>	<ul style="list-style-type: none"> <li>• Research aims clear and methodology/research design appropriate for research question and focus</li> <li>• Good reflexive accounts throughout; also acknowledged that despite measures to "out" the researcher's presence, it should be acknowledged to influence the research. This is an integral part of Interpretative Phenomenological Analysis (IPA) as the methodological approach.</li> <li>• Recruitment strategy had 5 selection criteria – perhaps too limiting/narrowing? Those considered vulnerable omitted from sample – limiting hard to reach voices? Sampling strategy was via EP attending 'change of phase review' meetings – sampling bias, as these may not happen with involvement of EP for all children?</li> <li>• Methods for data collection well justified and made explicit. Methods of data collection and analysis selected based on IPA approach.</li> <li>• Relationship between researcher and participants considered in detail, including potential bias and influence and how they responded to events</li> <li>• IPA - it does acknowledge that this is limited to a representation of the researcher's own subjective interpretation of the expressed perceptions of the parents interviewed and does not claim to present generalisable truths.</li> <li>• The study aimed for a homogeneous sample of participants through purposive sampling (Smith, Flowers and Larkin, 2009).</li> </ul>
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					<ul style="list-style-type: none"> <li>• Social economic status, additional learning needs of a parent and ethnicity are all factors which may impact on a parent's experience of the decision making process. However, these were not controlled for within the inclusion criteria and so could have influenced the homogeneity of the group.</li> <li>• No exploration of what appropriate secondary looked like. Was follow up Q's about what advice they would give to other parents but not a focus groups for the sharing of views and collaboration around possible suggestions for future practice.</li> <li>• Focus was primarily on decision making and not wider factors.</li> <li>• Half participating families had children with ASC but study was not focusing specifically on the particular challenges that children with ASC face with regards to secondary provision</li> <li>• Ethical issues: <ul style="list-style-type: none"> <li>○ Details about research/confidentiality/handling of data/ right to withdraw explained to participants (outlined briefly)</li> <li>○ All ethical approvals attached</li> </ul> </li> <li>• Data analysis rigorous and clearly presented</li> <li>• Findings were clearly presented and discussed in relation to orig research aims and questions but poss a lack of discussion about evidence for and against researcher findings.</li> </ul>
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					<ul style="list-style-type: none"> <li>• Limitations of study and implications for practice considered.</li> <li>• Research contributed an updated understanding of parents' experiences and perceptions of the decision making process post 'new' SEN CoP – addressed a gap</li> <li>• Findings were clearly presented but due to narrative nature of studies these were not generalised into overall findings (but presumably were trustworthy and credible)</li> </ul> <p><b>Decision regarding quality of study following critical appraisal using the CASP framework</b> - <b>High</b></p>
Choosing a secondary school for young people with autism: A multi-informant study Choosing a secondary school placement for students with an	The study aimed to determine the factors that immediately influence secondary-school choice for young people with autism.	One London local authority  Multiple informants: parents of children with autism (n=7) young people themselves prior to secondary	Semi-structured interviews  Thematic analysis	<p>Parents emphasised the anxiety and burden of the decision-making process. There was, however, substantial agreement among adult groups on the factors necessary for a successful secondary school placement: a nurturing, flexible and inclusive environment that emphasised both academic and life skills.</p> <p>Few adults, however, mentioned the importance of children's social relationships – a factor that featured</p>	<ul style="list-style-type: none"> <li>• Aims of study clearly presented but not research question</li> <li>• Research design was appropriate</li> <li>• Although main themes of relevant literature was discussed, they were not critically reviewed</li> <li>• Studies were compared to some extent, but not in great details, some reasoning for variation in results but not in depth analysis.</li> <li>• Recruitment strategy was appropriate but limited to one borough. No discussion of potential reasons for not being able to recruit head teachers as planned.</li> <li>• Data was collected in way the suited research and interview procedure/questions adapted for the different types of participant. An interpreter</li> </ul>

<p>autism spectrum condition: A multi-informant study - McNerney, C., Hill, V., Pellicano, E. , 2015</p> <p><i>International Journal of Inclusive Education</i>, 19(10), 1096-1116.</p>		<p>school entry (n=6) parent advisors (n=5) secondary-school professionals (n=5)</p> <p>No demographic information mentioned</p>		<p>prominently in the reports from young people.</p> <p>Conclusions/recommendations - These findings highlighted the different perceptions of those involved in making decisions about the educational placements of children with autism.</p>	<p>was provided for two Sylheti-speaking parents. Ethics procedure briefly outlined (1 sentence)</p> <ul style="list-style-type: none"> <li>• No detail about how the research was explained to participants</li> <li>• The study contained no critical examination of researcher role or reflection on potential bias and influence during interviews/analysis/selection of data. No reflexivity noted. No reflection on how researcher responded to events during study.</li> <li>• Overview of TA and fact that process was inductive, but no in depth overview of analytical procedure</li> <li>• In terms of data analysis: <ul style="list-style-type: none"> <li>○ 100% participants were from one London borough – geographical bias</li> <li>○ Parent participants (n=7) - 6 mothers (approx. 86%) and 1 father (approx. 14%) – recruitment criteria shared but not recruitment process</li> <li>○ Child participants (n=6) - 100% were boys (no girls), aged between 10years 11months to 11years 11months</li> <li>○ School staff participants - 1 male headteacher and 4 SENCOs (3 female – 75%) – randomly selected schools contacted</li> <li>○ LA staff (n=5) parents advisors – 100% female</li> <li>○ No information about whether all children had a diagnosis or an EHCP</li> </ul> </li> <li>• Themes and findings concisely and clearly presented but credibility of findings not discussed e.g. triangulation, respondent validation, more than one analyst)</li> </ul>
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					<ul style="list-style-type: none"> <li>• Findings did relate back to research aims and research did address a gap relating to securing secondary provision for children with autism</li> <li>• To provide a fuller picture they elicited the views and perspectives of not only parents but key professionals, including school staff and parents advisors employed by the local authority, about their experiences of supporting and working with parents and young people with autism.</li> <li>• Researchers did not consider the role of deeper social and ideological factors, e.g. race or ethnicity, language, socioeconomic status, in shaping the underlying preferences of informants, but noted that these factors will be important to attend to in future work.</li> <li>• Findings were discussed in relation to contribution the study makes to existing knowledge or understanding (e.g. in relation to current practice or policy, or relevant research-based literature).</li> <li>• They v briefly study noted potential limitations, e.g. focus on a limited number of individuals from one particular London local education authority, rendering it possible that the issues raised are idiosyncratic to this context.</li> <li>• V brief suggestion for future research focuses, i.e. whether this new legislative context improves the decision-making process for parents of autistic children and further to examine the factors underpinning a successful transition to secondary school using a longitudinal design.</li> </ul>
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					<b>Decision regarding quality of study following critical appraisal using the CASP framework - Medium</b>
<p>'Nowhere that fits': the dilemmas of school choice for parents of children with Statements of special educational needs (SEN) in England - Bajwa-Patel, Meanu Devecchi, Cristina, 2014</p> <p><i>Support for Learning, 29(2), 117-135.</i></p>	<p>This paper argues that, despite legislation that outlines a parents right to choose a school, for many parents whose children have a statement of SEN the choice of a school is often a dilemma as nowhere seems to fit.</p>	<p>One local authority in England</p> <p>65 families of children with SEN aged 4 – 13 years old (majority of children 12-13 years old)</p>	<p>380 postal surveys (17% response rate = 65 families) Survey adapted version of 'School choice survey' by Bagley and Woods (1998).</p> <p>N.B. The survey data being reported in the paper was part of a larger doctoral study.</p>	<p>Factors influencing decision were child's SEN and the specialist staff and facilities available. LA featured highly as a source of information. However, the role of the LA was not always positively viewed. Parent partnership was used by relatively few parents.</p> <p>Depending on type of SEN some parents felt that they did not have a choice. Some of those who felt that they did have a choice had to 'fight' for it.</p> <p>Conclusions/recommendations – there was some contradictory findings relating to the fact that parents felt they had little choice of school placement, but then expressing satisfaction with their child's educational provision. The dichotomy between special and mainstream schools was found to be false, with the quality of provision rather than type of school viewed by parents as the important factor. Suggestions are made with regard to the LA and</p>	<ul style="list-style-type: none"> <li>• Aims of paper related to an argument that 'nowhere fits' – potential confirmation bias from outset. No research question presented.</li> <li>• Survey design was appropriate and taken from previous doctoral research (which was mentioned but not referenced...why???) Survey was designed with reference to survey used in previous research by Bagley and Woods (1998)</li> <li>• Low response rate of 17% meant that only 65 out of a potential 380 were surveyed</li> <li>• No reference at all to methods/criteria of selecting participants, only that survey 'sent out via SEN team'</li> <li>• Absolutely no information at all about analytical procedure (although would be accessible via original, unnamed (!), doctoral study)</li> <li>• Data was presented qualitatively and graphically, results were to some extent generalisable which increased validity</li> <li>• In terms of data analysis: <ul style="list-style-type: none"> <li>○ All participants were from one geographical area in south-east of England – geographical bias</li> <li>○ Over half of respondents (51%) had children in special schools (compared to 34% in mainstream and 15% in SRB type provision) – sampling bias</li> <li>○ No information about whether all children had a statement of SEN</li> <li>○ Majority of sample were related to children 12-13years – age bias</li> </ul> </li> </ul>

				<p>schools ensuring they provide a comprehensive package of services to meet the needs of children.</p>	<ul style="list-style-type: none"> <li>○ 21 out of the 65 were communication and interaction needs i.e. ASD/Aspergers = approx. one third, has numbers of respondents in terms of identified need</li> <li>● Acknowledges bias in respondents – higher response rate expected from dissatisfied parents. ‘not easy to read parents’ views and feelings’ (pg132).</li> <li>● Relevant studies included but databases unknown, uk and wider studies from English speaking countries considered, but not non-English speaking</li> <li>● Although main themes of relevant literature was discussed, they were not critically reviewed</li> <li>● Studies were compared to some extent, but not in great details, some reasoning for variation in results but not in depth analysis.</li> <li>● No detail about how the research was explained to participants</li> <li>● The study contained no critical examination of researcher role or reflection on potential bias and influence during interviews/analysis/selection of data. No reflexivity noted. No reflection on how researcher responded to events during study.</li> <li>● Findings concisely and clearly presented but limited critical discussions, credibility of findings not discussed e.g. triangulation, respondent validation, more than one analyst)</li> <li>● Findings did relate back to research aims and research did address the dilemmas of school choice for parents of children with SEN</li> <li>● Researchers did consider the role of demographic factors, e.g. diagnosis, distance</li> </ul>
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					<p>to school, age and educational level of parents, .e.g. noted that 40% of respondents were graduates, which is not typical and leads to biases. Discussion of limitations of study was very brief.</p> <ul style="list-style-type: none"> <li>• No real consideration of deeper social and ideological factors, e.g. race or ethnicity, language, socioeconomic status, in shaping the underlying preferences of informants, but noted that these factors will be important to attend to in future work.</li> <li>• Findings were briefly discussed in relation to contribution the study makes to existing knowledge or understanding (e.g. in relation to current practice or policy, or relevant research-based literature).</li> <li>• No suggestions for future research focuses but some for educational practice, i.e. schools doing more to ensure they provide a more comprehensive package of services to meet the needs of children, such as SALT.</li> </ul> <p><b>Decision regarding quality of study following critical appraisal using the CASP framework - Medium</b></p>
Working together? Parent and local authority views on the process of obtaining appropriate educational	A study which aimed to explore the views of both parents and local authorities, focussing on how both parties	Across the UK  Parents of children with ASD with mean age of 8-9 years old.	Mixed approach:  1. 738 postal surveys consisting of closed items and 2 open questions	Despite majority of parents gaining the first choice placement for their child, they found the process of choosing and obtaining school placement bureaucratic, stressful and time consuming.	<ul style="list-style-type: none"> <li>• Aims of paper very clear from outset. No research question presented.</li> <li>• Although main themes of relevant literature was discussed, they were not critically reviewed</li> <li>• Studies were compared to some extent, but not in great detail, some reasoning for variation in results but not in depth analysis.</li> </ul>

<p>provision for children with autism spectrum disorders - Tissot, C., 2011</p> <p><i>Educational Research</i>, 5 3(1), 1-15.</p> <p>= this study was an update to 2006 study (considered below) which considered only parental experiences and perceptions</p>	<p>perceive and experience the process of determining educational provision for children with autism spectrum disorders (ASD) within an English context.</p>		<p>(used in previous 2006 study)</p> <p>2. The views of local authority personnel from five local authorities were gathered through the use of semi-structured interviews.</p> <p>Analysis - quantitative analysis of the closed response questionnaire items, and theme-based qualitative analysis of the open responses and interviews with local authority personnel.</p>	<p>Parents perceived alternative placement suggestions to be financially motivated rather than in the best interests of their child.</p> <p>Interviews with local authority personnel showed an awareness of these concerns and the complex considerations involved in determining what is best for an individual child.</p> <p>Conclusions/recommendations - study highlights the need for more effective communication between parents of children with ASDs and local authority personnel at all stages of the process</p> <p>4 themes:</p> <p>Early diagnosis obtaining provision working together finalising the placement.</p>	<ul style="list-style-type: none"> <li>• Research design and methodology appropriate and sample size for parent survey was relatively large (738 = 34.3% return rate) – national distribution via 2 national charities therefore avoiding geographical bias. Quantitative methods utilised to capture as any parent views as possible, but no in depth analysis of meaning making possible via this method.</li> <li>• 96% cyp had ASD diagnosis, 90% had statements</li> <li>• Views of LA officials gathered via small sample (n=5) of semi-structured interviews – from 5 different LA's (out of 10 contacted)</li> <li>• Aimed to gather views of LA officials to address a gap in the research</li> <li>• Recruitment strategy was suitable and enabled access to a large number of parent participant – no details given about sampling criteria. Recruitment also appropriate for LA interviews but again no detail given about sampling criteria. Very brief justification given as to why each data collection method as chosen.</li> <li>• No information at all about how the quantitative and qualitative data was analysed. Nothing shared relating to whether methods were modified during the study. Therefore not able to ascertain whether data analysis was sufficiently rigorous.</li> <li>• No mention of relationship between researcher/participants or any biases – lack of shared reflexivity.</li> <li>• Ethical permissions briefly touched upon, but no details about research/confidentiality/handling of data/ right</li> </ul>
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					<p>to withdraw and how it was explained to participants.</p> <ul style="list-style-type: none"> <li>• Data was clearly organised into themes and presented to support findings.</li> <li>• Findings did relate back to research aims.</li> <li>• No real consideration of demographic factors apart from type of school. No real consideration of deeper social and ideological factors, e.g. race or ethnicity, language, socioeconomic status, in shaping the underlying preferences of informants, but noted that these factors will be important to attend to in future work.</li> <li>• While the discussion did give a good overview of the research and difficulties faced by both parents and local authorities around inclusion and inclusive practice, it did not offer suggestions for improvement to practice or future research – instead raising 2 questions that need answering to improve ways of working together and henceforth outcomes, namely: <ol style="list-style-type: none"> <li>1. Is the current system transparent enough?</li> <li>2. Is it reasonable to ask parents to accept alternatives to what they see as the one provision that is right for their child?</li> </ol> </li> <li>• Research was valuable and addressed a significant gap in literature pertaining to parent choice for children on the autistic spectrum.</li> </ul> <p><b>Decision regarding quality of study following critical appraisal using the CASP framework</b>  - <b>Medium</b></p>
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<p>Where do Children with a Statement of Special Educational Needs Transfer to at Change of Phase from Primary to Secondary School and How do Parents Choose Which Provision is Most Suitable for their Child - Byrne, Andrew, 2010</p> <p>Doctoral dissertation, University of Birmingham</p>	<p>The study aimed to examine the decisions of parents' of children with SEN when choosing a secondary provision for their child and the factors that influence this. The purpose in selecting pupils with the same identified needs and educational histories is to attempt to explore other factors that might be playing an important, influencing role in the different outcomes: parents choosing</p>	<p>One local authority. system.</p> <p>All these pupils attended their local primary school in year 6 but then transferred to differing provision: mainstream high; resource provision within mainstream; or special school.</p> <p>5 case studies with parent participants:</p> <p>Case study 1 – Year 7, female, Pakistani,</p>	<p>Qualitative - multiple case study design</p> <p>Semi-structured interviews (following case study protocol) - underpinned by the theoretical framework arising from the review of literature and the theoretical interests of socio-cultural and activity theory</p> <p>The transcribed interviews were coded using what Miles and Huberman's (1994) 'start list' of codes, which in this case is derived from the theoretical</p>	<p>The study found that in the case of the two children who went to a mainstream school, parents had only visited one school, the school chosen, and they felt that neither the child's primary school nor other professionals had influenced them in making their choice. The parents of the two children who had transferred to a special school, had both visited two different special schools on the advice of the child's primary school; but neither felt that they were really free to make the choice that they wanted. The parents of the only child who transferred to a resourced provision, described the process of obtaining a place for him as a battle.</p> <p>Conclusions/recommendations - where the choice of provision at change of phase is undecided by the parents or where a special school placement is indicated, the Educational Psychologist should check with parents if they have considered and visited a mainstream school as well as a special school. It is also suggested that there may be an implication for SENCO's in primary schools around having a clear understanding of the rights of parents to choose a mainstream provision and understanding the complexity of</p>	<ul style="list-style-type: none"> <li>• Research aims clear and methodology/research design appropriate for research question and focus</li> <li>• Case study design = reflexive accounts throughout; also acknowledged that despite measures to "out" the researcher's presence, it should be acknowledged to influence the research.</li> <li>• Recruitment strategy was purposefully designed and followed.</li> <li>• 4 out of five studies (80%) were of Pakistani background – potential cultural bias</li> <li>• two cyp in mainstream, two in special school, 1 in SRB</li> <li>• Methods for data collection well justified and made explicit. Methods of data collection and analysis selected based on case study protocol and theoretical propositions derived from the research literature. In addition the research questions also aimed to gather data that related to socio-cultural and activity theory...however this may have narrowed the question range and narrowed the chance of a free flow of unprompted and undirected information, i.e. restrictions placed on questioning by multiple case design study parameters and CHAT descriptors and their seemed to be a lack of probing</li> <li>• Theoretical frameworks were well chosen to illuminate research aims but I'm unsure whether they brought the depth of findings that were intended.</li> <li>• Findings were clearly presented but felt limited given extensive consideration of methodology</li> </ul>
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	different types of provision.	<p><b>mainstream high school</b></p> <p>Case study 2 – Year 7, male, Pakistani, <b>mainstream high school</b></p> <p>Case study 3 – Year 7, female, Pakistani, <b>specialist provision for pupils with complex difficulties</b></p> <p>Case study 4 – Year 7, male, Pakistani, <b>specialist provision for pupils with complex difficulties</b></p>	<p>framework and from the theoretical interests of socio-cultural and activity theory reflected in the case study questions. The coded data was then entered onto a checklist matrix as described by Miles and Huberman (1994) – described as useful in multiple-case studies which require comparability of formatting and measurement.</p>	<p>need that a special school should be providing for.</p>	<p>and theoretical frameworks – process seemed to outweigh outcomes.</p> <ul style="list-style-type: none"> <li>Relationship between researcher and participants considered in detail, including potential bias and influence and how they responded to events</li> <li>Ethical issues: <ul style="list-style-type: none"> <li>Details about research/confidentiality/handling of data/right to withdraw explained to participants (outlined briefly)</li> <li>All ethical approvals attached</li> </ul> </li> <li>Data analysis rigorous and clearly presented</li> <li>Socio-cultural framework enabled a deeper consideration of social and ideological factors, e.g. race or ethnicity, language, socioeconomic status, in shaping the underlying preferences of informants, but noted that these factors will be important to attend to in future work.</li> <li>Findings were clearly presented but due to narrative nature of studies these were not generalised into overall findings (but presumably were trustworthy and credible)</li> <li>Findings discussed in relation to orig research aims and questions.</li> <li>The research was very detailed and reflexive, which led to an overall rating of high quality – and it did contribute an updated understanding of where the children transfer to. However, I did feel the golden thread between methodology, discussion and findings were at times difficult to follow and there was a relative lack of conclusions and new information</li> </ul>
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		Case study 4 – Year 7, male, White British, <b>resourced provision for pupils with autistic spectrum disorder in a mainstream high school</b>			<p>regarding how parents choose which provision is most suitable for their child with SEN.</p> <p><b>Decision regarding quality of study following critical appraisal using the CASP framework – High</b></p>
<p>Securing provision for children with autistic spectrum disorders: the views of parents - Tissot, C., 2006</p> <p><i>Perspectives in Education, 24(1), 73-86.</i></p>	<p>A questionnaire based study designed to seek the perspectives of parents about the process of securing appropriate educational provision for their child with autism spectrum disorder.</p>	<p>Across the UK</p> <p>Parents of children with ASD with mean age of 8-9 years old.</p>	<p>738 postal surveys consisting of closed items and two open questions (used later in 2011 study) – analysed quantitatively and qualitatively, i.e. quantitative analysis of the closed response questionnaire items, and theme-based qualitative analysis of the</p>	<p>Although a clear majority of families were happy with the end decision of placement, most families were significantly less happy with the process to determine that provision. Most families found this process difficult to navigate and frustrating. This caused a high level of stress for a significant proportion of families.</p> <p>4 themes:</p> <p>Obtaining educational provision Satisfaction with the process Relationship with the educational provider Effect on the family</p>	<ul style="list-style-type: none"> <li>• 96% cyp had ASD diagnosis, 90% had statements</li> <li>• Recruitment strategy was suitable and enabled access to a large number of parent participant – no details given about sampling criteria.</li> <li>• No information at all about how the data was analysed. Nothing shared relating to whether methods were modified during the study. Therefore not able to ascertain whether data analysis was sufficiently rigorous.</li> <li>• No mention of relationship between researcher/participants or any biases – lack of shared reflexivity.</li> <li>• Ethical permissions briefly touched upon, but no details about research/confidentiality/handling of data/ right to withdraw and how it was explained to participants.</li> <li>• Findings were well synthesised and clearly organised into themes, and presented with research aims in mind, providing insight into</li> </ul>

			open responses	<p>Conclusions – It was found that many factors impact the choices made to determine educational provision for an autistic child. Some of these are within the child and the beliefs that stakeholders share about the nature and causes of autism; others are more closely related to context and options available. Although there is agreement on the presentation of the Triad of Impairments, the variability and cause of each is not agreed. This can lead to potential disagreement in how to best meet the educational needs of child as a result of a difference of opinion.</p>	<p>the experience of parents with autistic children.</p> <ul style="list-style-type: none"> <li>• No real consideration of demographic factors apart from type of school. No consideration of deeper social and ideological factors, e.g. race or ethnicity, language, socioeconomic status, in shaping the underlying preferences of informants, but noted that these factors will be important to attend to in future work.</li> <li>• The conclusion gave a thorough overview of difficulties faced by parents around accessing appropriate school places and inclusion but it did not offer suggestions for improvement to practice or future research</li> <li>• Despite the weaknesses discussed this was a pioneer study and had value in addressing a significant gap in literature pertaining to parent choice for children on the autistic spectrum. Findings were clear and additionally shone a light onto local authority views/involvement.</li> </ul> <p><b>Decision regarding quality of study following critical appraisal using the CASP framework - Medium</b></p>
Implementation of School Choice Policy: Interpretation and Response by Parents	The paper was intended to provide empirically-based insights into the preferences	Three case study areas within the UK  All parents with children transferring from Primary	Data was drawn from the findings of a large scale study - The Parent and School Choice Interaction Survey	Concern amongst parents that a secondary school would be chosen which did not perpetuate what was perceived as the inadequate and often insensitive handling of their child's SEN by their primary school.	<ul style="list-style-type: none"> <li>• Aims of paper clear from outset. No research question presented.</li> <li>• Although main themes of relevant literature was discussed, they were not critically reviewed</li> <li>• Studies were compared to some extent, but not in great detail, some reasoning for variation in results but not in depth analysis.</li> </ul>

<p>of Students with Special Educational Needs - Bagley, Carl; Woods, Philip A.; Woods, Glenys, 2001</p> <p><i>British Educational Research Journal</i>, 27(3), 287-311.</p>	<p>, perceptions and responses of parents of children with SEN in terms of school choice.</p>	<p>to Secondary in three case study areas. Sample includes the sample from Bagley and Woods (1998)</p> <p>It drew on analyses of quantitative and qualitative data generated by a large-scale, more general research study on school choice, funded by the UK Economic and Social Research Council</p>	<p>(PASCI), a postal longitudinal investigation in three geographical study areas. The original survey focused on <u>all</u> parents, not just those of cyp with SEN.</p> <p>However this paper focused on the total of 240 parents drawn from the larger sample that identified their child as having SEN.</p> <p>Of these 26 parents were interviewed (nine of the children had a Statement of SEN).</p> <p>This paper reports findings from one area</p>	<p>Parents of children with SEN in two, out of three, case study areas rated convenience for travel in their top three influences on choice of school.</p> <p>Similar findings to earlier paper Bagley and Woods (1998), i.e.:</p> <p>Confusion between process of school choice for all parents compared to those with statements of SEN – tremendous confusion and uncertainty. Middle class more informed consumers All visited at least one provision. Majority spoke to friends with children with SEN.</p> <p>Factors which influenced decision – intrinsic- personal/social, i.e. SEN facilities, safety, security, care, inclusivity, unconditional respect for individual worth and potential, location – lack of funding for transport. Often NOT academic related. Most felt had a choice, only those who were restricted by finances for transport felt restricted.</p> <p>Conclusions/recommendations -</p>	<ul style="list-style-type: none"> <li>• Research design and methodology appropriate for generating both generalisable insights and exploring parental experience.</li> <li>• 3 contrasting case study areas were selected to counter geographical bias, i.e. a middle class in a town, working class in a high unemployment urban area (with an identifiable ethnic minority community), and a semi-rural area – the response rate (of families transferring to secondary schooling) was comparable in each area.</li> <li>• Recruitment strategy linked only to the fact that parents had stipulated that their child was special needs on survey, i.e. self-selecting parental replies, subjective rather than objective. No subsequent follow-up interviews were conducted. N.B. compared to overall survey sample, SEN was only 5.9-7.0% compared to national average of 20%</li> <li>• Recruitment strategy was suitable and enabled access to a large number of parent participant – no details given about sampling criteria.</li> <li>• No information at all about how the quantitative and qualitative data was analysed. Nothing shared relating to whether methods were modified during the study. Therefore not able to ascertain whether data analysis was sufficiently rigorous.</li> <li>• No mention of relationship between researcher/participants or any biases – lack of shared reflexivity.</li> <li>• No mention of ethics or ethical procedures.</li> <li>• Qualitative and quantitative data was clearly organised and presented.</li> <li>• Findings did relate back to research aims.</li> </ul>
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			<p>and draws on interviews with:</p> <p>12 senior managers</p> <p>3 SENCOs 1 SEN officer 9 parents (5 children with statements)</p>	<ul style="list-style-type: none"> <li>• Some brief consideration of demographic factors. No real consideration of deeper social and ideological factors, e.g. race or ethnicity, language, socioeconomic status. Even though minority population was surveyed.</li> <li>• While the discussion did give a good overview of the research, dominant discourses, tension between policy and practice and difficulties faced by parents, it did not offer suggestions for improvement to practice or future research.</li> <li>• Research contributed an updated understanding of school choice process and factors affecting school choice – interesting in that it highlighted that academic factors seemed less important to parents of cyp with SEN.</li> </ul> <p><b>Decision regarding quality of study following critical appraisal using the CASP framework - <b>Medium</b></b></p>
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## Appendix 2 – Examples of CASP and MMAT appraisal criteria

### CASP (2006)

Title: ..... Author(s) and date: ..... Study No: .....	Yes	No	Can't answer
<b>Critical Appraisal Skills Programme Qualitative Checklist.</b>			
1. Was there a clear statement of the aims of the research? What was the goal of the research? Why it was thought important?			
2. Is a qualitative methodology appropriate? If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants. Is qualitative research the right methodology for addressing the research goal?			
3. Was the research design appropriate to address the aims of the research? If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?			
4. Was the recruitment strategy appropriate to the aims of the research? If the researcher has explained how the participants were selected. If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study. If there are any discussions around recruitment (e.g. why some people chose not to take part).			
5. Was the data collected in a way that addressed the research issue? If the setting for data collection was justified. If the researcher has justified the methods chosen. If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? If the methods were modified during the study. If so, has the researcher explained how and why? If the form of data is clear (e.g. tape			

recordings, video material, notes etc). If the form of data is clear (e.g. tape recordings, video material, notes etc). if the researcher has discussed saturation of data.			
6. Has the relationship between researcher and participants been adequately considered? If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes in the research design.			
7. Have ethical issues been taken into consideration? If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study). If approval has been sought from the ethics committee.			
8. Was the data analysis sufficiently rigorous? If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process. If sufficient data are presented to support the findings. To what extent contradictory data are taken into account. Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.			
9. Is there a clear statement of findings? If the findings are explicit If there is adequate discussion of the evidence both for and against the researchers' arguments. If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst). If the findings are discussed in relation to the original research question.			
10. How valuable is the research? If the researcher discusses the contribution the study makes to existing knowledge or understanding			

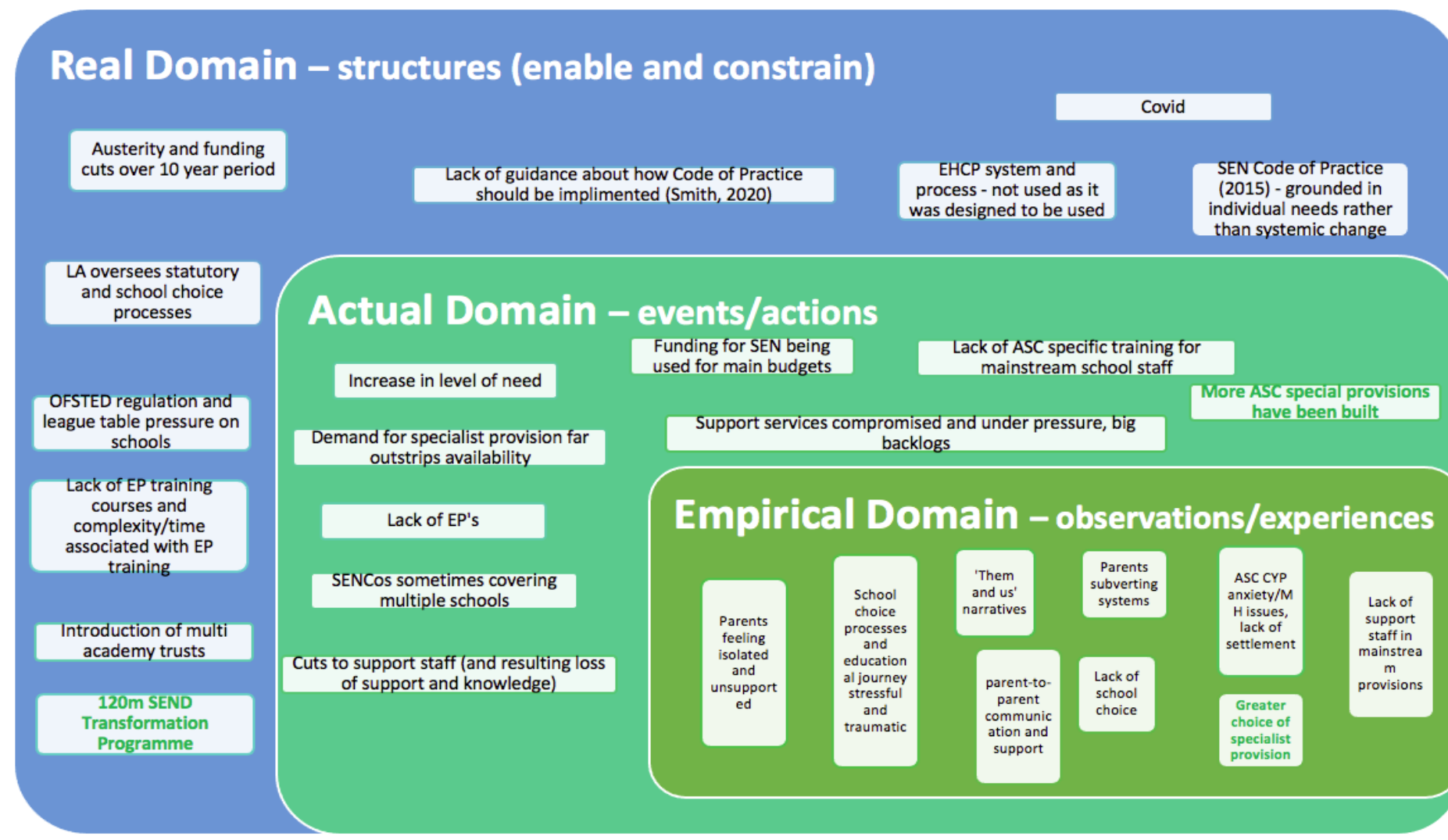
e.g. do they consider the findings in relation to current practice or policy or relevant research-based literature? If they identify new areas where research is necessary If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.			
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## MMAT (2018)

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	<i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5. Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				



**Appendix 3: Critical realist framework applied to current study (N.B. not comprehensive/complete, just an attempt to frame thinking)**



## Appendix 4: Interview schedule

### Opening statement

I would like to begin by thanking you again for taking part in this research. The aim of the research is to explore your experience of choosing secondary provision for your child 'X' and the factors that influenced your decision-making. It is hoped that the findings will help inform both school and local authority processes and practices and ultimately improve the support that they offer to parents of children with autism while they are going through the process.

I need to check that I have your permission to record this interview so that I can write it out afterwards. I would like to reassure you that the recording will then be deleted.

– ask for permission to write name on consent form,

No names will be used in the final research so it will not be possible for anyone apart from you and me to know that you have taken part.

If you wish to change your mind either now, during, or after the interview that is ok – just let me know.

If you decide after the interview that you do not want your information to be used in the report that is ok – just let me know.

I will also do a quick debrief after the interview in line with university policy...

### Interview Questions

1. *Opening questions about child and current secondary provision – keep this bit brief!!*
  - a. Could you first tell me a little bit about X?
  - b. Where does X currently attend?
  - c. Is X enjoying his/her time there?
2. *Questions relating to school choice and a child on the autistic spectrum*
  - a. How did X cope with previous schooling?
  - b. How has having a child with autism influenced your choice of secondary provision? In what ways?
3. *Questioning to develop an understanding of events and processes experienced and an initial exploration of factors influencing school choice*
  - a. Can you tell me about when you first started to think about choosing a secondary school for X?
  - b. When considering a secondary placement for X what factors influenced your decision-making?
4. *Process:*
  - a. Could you briefly outline the process you went through?
  - b. Could you sum up the process in 3 words? – then 'could you tell me a bit more about why you choose those words?'
5. *Personal qualities and relationships – looking at parents' personal qualities*
  - a. What kind of personal qualities and internal strengths do you feel you possess, that helped you during the process?

- b. What are the key relationships you have that have helped you during the process? How did they help?
- 6. *Reflective question exploring ways in which process and support could be improved (lead into FG...)*
  - a. What advice would you give to another parent who is going to be choosing a secondary provision for their autistic child?

#### *Closing of interview*

- Check if there is any other information participants feel is important for research to know.
- Check how participant feels following the interview.
- Thank participant for taking part and share debrief statement.
- Ask participant if they would like to be involved in focus group, explain its purpose and that it is voluntary and there is no pressure to be involved. If they would like to be involved provide them with an information sheet and consent form.
- Remind participants of what will happen to data and how it will be stored, used, and shared.

Throughout questioning, I may reflect on what participant has said and ask further questions to clarify things. Additionally prompts will be used to develop:

1. An understanding of emotions and thought processes, e.g.:
  - How did you feel after ... (e.g. you spoke to...?, you visited...?, the meeting?)
  - What did you think about ... (e.g. the school?, ... point of view?, that comment?)
  - What were you thinking when... (e.g. you met...? you saw...?)
2. Additional exploratory prompts may also be used, e.g.
  - Can you tell me more about that?
  - Is there anything else?

## Appendix 5 – Interview Consent Form



University of  
East London

### **Choosing and securing secondary provision for their child on the autistic spectrum – an action research project investigating parental motivations, experiences, and suggestions for improvement to practice**

By signing below, I give permission/agree that:

1. I have read the information letter relating to the above research study and understand what the research is about.
2. I have been given the opportunity to ask questions and know who to contact should I have any more questions.
3. I agree to take part in the interview.
4. I understand that my involvement in this study, and particular data from this research, will remain strictly confidential and that any files containing information about myself will be made anonymous. Only the researcher involved in the study will have access to identifying data.

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I hereby freely and fully consent to participate in the study. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

Please sign below to show your agreement with the above statements and to agree to take part in the research.

Name:

Date:

Signature:

.....

Researcher's Signature

Date:

## Appendix 6 - Debrief Sheet



University of  
East London

**Choosing and securing secondary provision for their child on the autistic spectrum – an action research project investigating parental motivations, experiences, and suggestions for improvement to practice**

### **What are we trying to learn in this research?**

We are trying to learn about the experience of choosing and securing secondary school provision for parents of children on the autistic spectrum.

### **Why is this important to researchers or the general public?**

Prior research relating specifically to school choice for children on the autistic spectrum is negligible. The current research hopes to redress this by illuminating the experiences of parents with children on the spectrum, as well as highlighting motivations and factors that influence choice-making.

It is hoped that the findings will help inform both school and local authority processes and practices and ultimately improve the support that they offer to parents of children with autism while they are going through the process.

### **What if I have questions later?**

If you have any questions about the research or ethical concerns at a later date the following information may be useful:

**Researcher:** Louise Somner

**Supervisor:** Helena Bunn ([H.Bunn@uel.ac.uk](mailto:H.Bunn@uel.ac.uk))

**Ethical concerns:** Chair of the School of Psychology Research Ethics Sub-committee: Dr. Ian Tucker, School of Psychology, University of East London, Water Lane, London E15 4LZ. [i.tucker@uel.ac.uk](mailto:i.tucker@uel.ac.uk))

### **What if I was emotionally affected by the research and feel like I need support?**

Should you, for whatever reason, become distressed after sharing your views and experiences, help can be sought either via your GP or via Wellbeing Norfolk (call 0300 123 1503), find further links and self-referral form at [www.wellbeinghands.co.uk](http://www.wellbeinghands.co.uk).

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

### **Confidentiality and Right to Withdraw**

- I as the researcher am interested in your experiences of choosing and securing secondary school provision for your autistic child.
- I as the researcher want to emphasise that this is not a test of your knowledge and there are no right or wrong answers. I am purely interested in your views.
- As the researcher, I am the only person who will have access to your audio recordings.
- All data collected will be confidential and anonymised.
- Transcriptions may be viewed by supervisor and anonymised extracts by examiners of the dissertation.
- Anonymised extracts may also possibly be used in future publications
- All information provided by you will be kept confidential and used for research purposes only (it will be retained for 5 years in the UEL Research Repository in line with university policy and then destroyed).
- The data will form the basis of my research project which will be submitted to the University of East London for assessment.
- You are free to withdraw from the research study at any time without explanation, disadvantage, or consequence. Separately, you may also request to withdraw your data even after you have participated data, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

## Appendix 7 – Participant Inclusion and exclusion criteria and rationale

INCLUSION CRITERIA	RATIONALE
Parents of a child with an independent clinical diagnosis of autism	Ensuring greater homogeneity for IPA analysis. Parents were selected as it was considered that they could provide the best insight into the school choice experience.
Parents of an autistic child with an education, health and care plan (EHCP)	Ensuring greater homogeneity for IPA analysis. Ensuring the process of school choice can be discussed in the context of the 2014 SEN Code of Practice, through which the statutory process of issuing an EHCP takes place.
The child attends secondary provision at the time of the interview	Ensuring greater homogeneity for IPA analysis. The child has had sufficient time in school for parents to have experienced the entirety of the school choice and transition process
The child attends either: <ul style="list-style-type: none"> <li>a. a mainstream secondary school;</li> <li>b. unit/base for children with ASC attached to a mainstream secondary school (known as Specialist Resource Bases – SRB);</li> <li>c. a special school for children with ASC.</li> </ul>	Ensuring a broad spread of educational provision, both mainstream and specialist are considered within the research.
The child will have been educated in a mainstream primary or SRB attached to a primary prior to transition to secondary provision.	Ensuring greater homogeneity for IPA analysis. Each child will have experienced a similar mainstream educational and support context.
The children of parent participants attend school within x (the same) local authority	Ensuring greater homogeneity for IPA analysis. This places the research within a geographic and administrative context.

EXCLUSION CRITERIA	RATIONALE
Parents of a child without an independent clinical diagnosis of autism	It would be more difficult for the researcher to ascertain whether autism is the primary need without a clinical diagnosis.
Parents of a child without an EHCP	Most specialist provisions require an EHCP for entry. An EHCP evidences that children have a level of need that is over and above that which can be provided through typical special needs support.
Parents of a child not attending a secondary provision at time of interview	Parents may not have yet gone through the entirety of the school choice and transition process, or could have gone through it too long ago to remember details.
Parents of a child who did not attend a mainstream primary provision	It is assumed that there would be greater homogeneity if children of parent participants had all experienced mainstream primary. Specialist schools often cater for both primary and secondary age ranges and therefore a typical



	school choice process and transition may not have been experienced.
Parents of children whose children are not within x local authority	The research would not be within the same geographic and administrative context.

## Appendix 8 – Participant information sheet



University of  
East London

### **Choosing and securing secondary provision for their child on the autistic spectrum – an action research project investigating parental motivations, experiences, and suggestions for improvement to practice**

Main Research Question: What are the lived experiences of parents when choosing and securing secondary provision for their child on the autistic spectrum?

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Dear name

Thank you very much for your interest in my research project.

My name is Louise Somner and I am a Trainee Educational Psychologist from the University of East London working at Norfolk County Council. As you have been informed I am carrying out research into parents' experiences of choosing and securing secondary school provision for their children on the autism spectrum. I believe that you have recently gone through this process yourself and I would very much appreciate your input.

#### **What will I be asked to do?**

I would be grateful if you would take part in an interview about your experiences, thoughts, and feelings while going through the process and the factors which may have influenced your decision-making. This interview can take place either at your home, school, or online, wherever you feel most comfortable.

The interview will be audio recorded so that it could be written up afterwards. Pseudonyms will be used in the written transcript and the recording will then be deleted. In the final report no original names would be used or any other information that could identify you; therefore no one reading it would know who is

being talked about or who has taken part. The interview should take approximately one hour.

All information provided by you will be kept confidential and used for research purposes and dissemination only (it will be retained for 5 years in the UEL Research Repository in line with university policy and then deleted; some parts of transcripts will be used for the dissemination of findings and publication).

You will have the right to withdraw from the study at any time before the point of analysis (*Date 2021/2022*).

*N.B. There will also be an option for you to be involved in a follow-up focus group to discuss ways in which practice can be improved, but this will be entirely voluntary and there is no obligation to be involved in it.*

### **What will the benefits of the study be?**

It is hoped that the findings will help inform both school and local authority processes and practices, and ultimately improve the support that they offer to parents of children with autism while they are going through the process.

### **What if I agree and then later change my mind?**

You are free to withdraw from the research study at any time without explanation, disadvantage, or consequence. Separately, you may also request to withdraw your data even after you have participated data, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

### **What if I need someone to interpret for me?**

If you would not feel confident or do not wish to be interviewed in English an interpreter can be provided. Please contact the researcher Louise Somner to arrange.

### **What should I do next if I want to take part?**

If you would like to take part, please contact me via the email address below. You will then be contacted to arrange an interview and for the researchers to answer any questions you may have. If you have any further questions or queries nearer to the interview time or after the interview please telephone me on XXX, or email me at .

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Helena Bunn. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: [H.Bunn@uel.ac.uk](mailto:H.Bunn@uel.ac.uk)

**or**

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Ian Tucker, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: [i.tucker@uel.ac.uk](mailto:i.tucker@uel.ac.uk))

Yours Sincerely

Louise Somner

Trainee Educational Psychologist

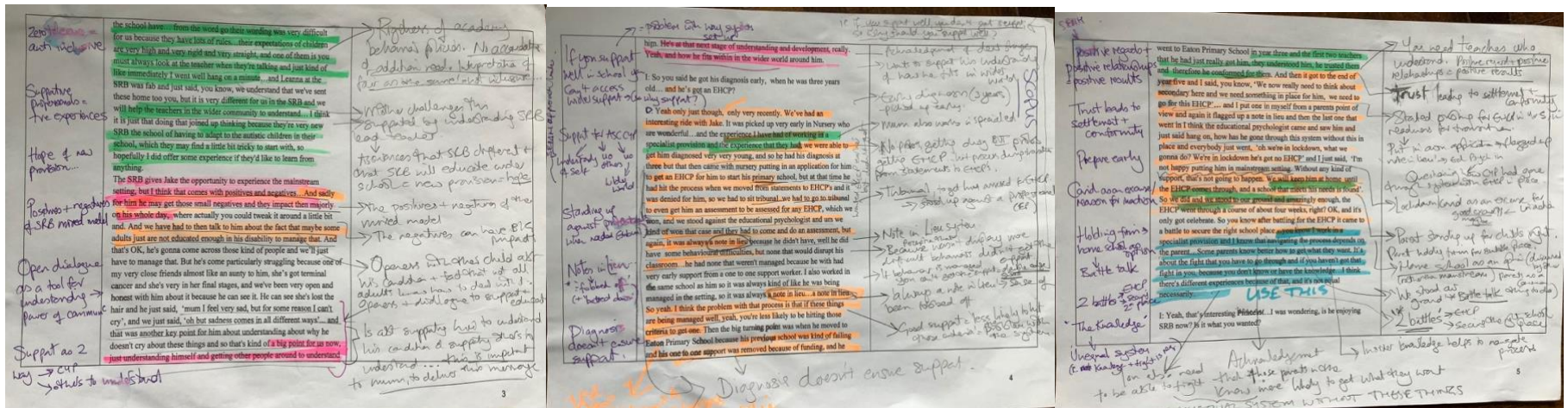
## **Appendix 9 - Phases of parent recruitment:**

1. Emails will be sent to SEN team/EP's telling them about research and asking them if they could be involved in the identification of participants and/or school SENCO gatekeepers. Follow-up emails and calls will be made.
2. Participants/SENCOs identified will be contacted by the identified SEN team/partnership member or EP's who have worked with them. This initial contact will investigate parental interest and provide reassurance. Those SENCOs/parents who are happy to be contacted will be sent an initial email with attached information letter by the researcher. Included in the information letter will be the contact details of the researcher, in order to ask further questions about the research/research process. Information letters will include information about follow-up focus group and the potential to be involved. The service of an interpreter will be provided to those participants who request it.
3. Interview times and locations (i.e. online, in school, or in parents' homes, or in a room in a local authority building) will be negotiated and set up with parents. A reminder will be sent out to participants 24-48 hours before the scheduled interview day.
4. On the day of the interview, before questioning begins, both written and verbal consent will be sought and participants will be informed about their right to withdraw from the study. After completion of the interview participants will be familiarised and provided with a debrief form. Participants will be told about the focus group and asked if they would like to be involved, if yes they will be provided with an information sheet and be asked to complete a consent form. Interpreters will be offered if required.
5. Parents will be notified by email of the time and location of the focus group. On the day of the focus group, both written and verbal consent will be sought and participants will be informed about their right to withdraw.

## Appendix 10a – Initial noting and identification of emergent themes

- Descriptive comments – plain text
- Linguistic comments – *italic*
i>
- Conceptual comments – underlined
- Reflexive comments – **dark orange text**

(N.B. It should be noted that notes for transcripts were done by hand, as in photographic examples below, the following section was transcribed for including into the appendices)



<p>zero tolerance = anti-inclusive</p> <p>support professionals = positive experiences</p> <p>Hope (associated with a new provision...)</p> <p>Positive and negatives of SRB model</p> <p>Small negatives have a large impact</p> <p>Open dialogue as a tool for understanding = The power of communication</p> <p>Understanding as 2 way - CYP and those who interact with him. Hints here of the social model.</p> <p>3 pronged approach to educating ASC child</p>	<p>the school have... from the word go their wording was very difficult for us because they have lots of rules...their expectations of children are very high and very rigid and very straight, and one of them is you must always look at the teacher when they're talking and just kind of like immediately I went well hang on a minute...and Rosemary at the SRB was fab and just said, you know, we understand that we've sent these [rules] home too you, but it is very different for us in the SRB and we will help the teachers in the wider community to understand... I think it is just that doing that joined up thinking because they're very new SRB the school of having to adapt to the autistic children in their school, which they may find a little bit tricky to start with, so hopefully I did offer some experience if they'd like to learn from anything.</p> <p>The SRB gives Jake the opportunity to experience the mainstream setting, but I think that comes with positives and negatives...And sadly for him he may get those small negatives and they impact then majorly on his whole day, where actually you could tweak it around a little bit and. And we have had to then talk to him about the fact that maybe some adults just are not educated enough in his disability to manage that. And that's OK, he's gonna come across those kind of people and we'll just have to manage that. But he's come particularly struggling because one of my very close friends almost like an aunty to him, she's got terminal cancer and she's very in her final stages, and we've been very open and honest with him about it because he can see it. He can see she's lost the hair and he just said, 'mum I feel very sad, but for some reason I can't cry', and we just said, 'oh but sadness comes in all different ways'... and that was another key point for him about understanding about why he doesn't cry about these things and so that's kind of a big point for us now, just understanding himself and getting other people around to understand</p>	<p>Rigidity of Academy behaviour policies. No accommodation of additional needs. <u>Interpretation of fair as 'the same' but not inclusive.</u></p> <p>Mother challenges rigidity. Supported by understanding SRB lead teacher.</p> <p><i>'Joined up thinking', implies a sense of an analytical planned approach to inclusion with everybody working together. There is acknowledgement that adjustment may be 'tricky', i.e. shift and change not always easy.</i></p> <p><i>Denise's comment of 'so hopefully I did offer some experience...suggests that she wanted the relationship with the SRB to be reciprocal. A 2 way street.</i></p> <p><u>A sense here of the negative impact of ignorance...the word 'tweak' is implying that small adjustments can make a big difference.</u> The fallout associated uninformed decisions which can have a major impact on Jake.</p> <p><i>'Those kind of people' – positioning...those who understand vs those who don't? <u>The uninformed and ignorant?</u></i></p> <p>There is a sense here that Denise values honesty and open dialogue with her son, and wider professionals, to support and educate.</p> <p>It's about supporting him to understand his condition and supporting others to understand. <u>This is important to Denise, it seems important to her to deliver this message, sense that it is something she wants to promote.</u></p> <p>Denise is educating Jake about his connections with himself (i.e. understanding of his condition), others (i.e. those kind of people) and the wider world (wants to support his understanding of how he fits with the wider world)</p>
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<p>Specialist knowledge &amp; parent-professional liaison as helping expedite processes – knowledge and cooperation</p> <p>Standing up against professionals – them and us, standing against power (the fight)</p> <p>System paradox - so why support?</p> <p>Notes in Lieu perceived as a way to delay process, sense of being fobbed off = frustration</p>	<p>him. He's at that next stage of understanding and development, really. Yeah, and how he fits within in the wider world around him.</p> <p>I: So you said he got his diagnosis early, when he was three years old... and he's got an EHCP?</p> <p>D: Yeah only just though, only very recently. We've had an interesting ride with Jake. It was picked up very early in Nursery who are wonderful...and the experience I have had of working in a specialist provision and the experience that they had, we were able to get him diagnosed very young, and so he had his diagnosis at three but that then came with nursery putting in an application for him to get an EHCP for him to start his primary school, but at that time he had hit the process when we moved from statements to EHCP's and it was denied for him, so we had to sit tribunal...we had to go to tribunal to even get him an assessment to be assessed for any EHCP, which we won, and we stood against the educational psychologist and um we kind of won that case and they had to come and do an assessment, but again, it was always a note in lieu because he didn't have, well he did have some behavioural difficulties, but none that would disrupt his classroom...he had none that weren't managed because he with had very early support from a one to one support worker. I also worked in the same school as him so it was always kind of like he was being managed in the setting, so it was always a note in lieu...a note in lieu. So yeah. I think the problem with that process is that if these things are being managed well, yeah, you're less likely to be hitting those criteria to get one. Then the big turning point was when he moved to XXX Primary School because his previous school was kind of failing and his one to one support was removed because of funding, and he</p>	<p>Acknowledgement of developmental stage</p> <p><i>'Interesting ride' – fairground analogy, up and downs, high and lows.</i></p> <p>No problems getting diagnosis - attributed to parents and professionals working together, of their joint experience in special needs bringing a positive outcome – <u>the power of 'the knowledge'?</u></p> <p>EHCP process throwing up barriers... attributed to transition from statements to EHCP's</p> <p>A diagnosis won't necessarily lead to an EHCP...</p> <p>Tribunal to get him 'even' (<u>tribunal at this point seems to be constructed as unnecessary?</u>)</p> <p><i>'Stood up against EP' – fight analogy, sense of standing up against power</i></p> <p>Note in Lieu system (need to find out more about this) = <u>sense of being fobbed off</u></p> <p>'Behaviours' lessened by effective support</p> <p>Paradox – If child is supported well/doesn't exhibit behavioural difficulties you don't support well you don't get support...<u>so why should you support well?</u> <u>Containment/making reasonable adjustments seen as a potential barrier to EHCP.</u></p> <p><i>Repetition of 'note in lieu' conveys sense of frustration</i></p> <p>If behaviour is managed you can't get support = <u>double edged sword = the EHCP system as discouraging of effective inclusion. Leaves the system open to manipulation?</u></p>
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<p>Positive regard plus positive relationships = positive result – SEMH discourse and narrative</p> <p>Trust = settlement and conformity</p> <p>Prepare early</p> <p><u>Covid</u> as an excuse recently in action</p> <p><u>Holding firm – homeschooling is an option – Battle talk</u></p> <p>Two battles – EHCP and securing a secondary place</p> <p>The knowledge – unequal system (i.e. knowledge and the fight is required)</p>	<p>went to XXX Primary School in year three and the first two teachers that he had just really got him, they understood him, he trusted them and therefore he conformed for them. And then it got to the end of year five and I said, you know, ‘We now really need to think about secondary here and we need something in place for him, we need to go for this EHCP’... and I put one in myself from a parents point of view and again it flagged up a note in lieu and then the last one that went in I think the educational psychologist came and saw him and just said hang on, how has he gone through this system without this in place and everybody just went, ‘oh we’re in lockdown, what we gonna do? We’re in lockdown he’s got no EHCP’ and I just said, ‘I’m not happy putting him in mainstream setting. Without any kind of support, that’s not going to happen. We will keep him at home until the EHCP comes through, and a school that meets his needs is found’. So we did and we stood to our ground and amazingly enough, the EHCP went through a course of about four weeks, right? OK, and it’s only got celebrate. So you know after battling for the EHCP it came to a battle to secure the right school place...you know I work in a specialist provision and I know that navigating the process depends on the parent...Some parents know better how to get what they want. It’s about the fight that you have to go through and if you haven’t got that fight in you, because you don’t know or have the knowledge...I think there’s different experiences because of that, and it’s not equal necessarily.</p> <p>I: Yeah, that’s interesting process....I was wondering, is he enjoying SRB now? Is it what you wanted?</p>	<p>You need teachers to understand. <u>Positive regard and positive relationships = positive results = SEMH narrative.</u></p> <p>Trust leading settlement and conformity (<i>I need to acknowledge my SEHM biases in this interpretation</i>)</p> <p>EP as someone who can challenge decisions and illuminate need...seeing the bigger picture.</p> <p><u>Lockdown/Covid</u> as an excuse for inaction-<u>good excuse maybe?</u></p> <p>Mainstream provision positioned as lacking adequate support for additional needs.</p> <p>Denise fighting again and standing up to the system, for her child...<u>the warrior parent</u></p> <p><u>Homeschooling</u> as an option (discussed by other parents as a common thing to do if don’t get place feel right) – rather than sending to mainstream</p> <p><i>“we stood our ground” = battle talk</i></p> <p><u>Two battles – the EHCP and securing the rightful place</u></p> <p>Insider knowledge helps to navigate the process. Navigation as parent dependent....parents positioned as needing to steer the process....suggests a need for proactivity. <i>‘Navigate’ analogy, i.e. need for planning a clear route through dangerous terrain.</i></p> <p>Acknowledgement that those parents in the know = more likely to get what they want and You also need to be able to fight = <u>unequal system without the knowledge and the fight</u></p>
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<p>Professional voices influencing thinking and decision making</p> <p>Mainstream not inclusive enough</p> <p>He sits in the middle - where to go?</p> <p>Heightened behaviours especially schools off putting/- worries about impact</p> <p>Right people plus right place = conformity (self-devised formula, from SEMH background?)</p>	<p>D: Yes, it is completely. We wasn't sure what we wanted, we knew very early on when he had his diagnosis, even as early as three, and kind of as he went in to see his last appointment with Doctor XXX that gave him his diagnosis. But he would at some point need something more than mainstream, however she made it really clear and we were really clear that he could easily go the other way with, you know if you've got severely autistic children that can't manage their behaviour...he would be that, he' kind of sits in the middle. He's got struggles, we know he's got struggles and he presents well and that masks some of his needs and so it was really difficult in choosing the right place for him because, well you didn't want him to go the other way, um, where he would then copy and practice and pick up on some of the other things, some of the other difficulties that children have for being autistic, so it was really important for me to get the right place... we didn't know what that place was, we thought maybe when The XXX school was built that that would be the right place for him... I did a visit for some research from my school to The XXX and I thought I don't know if this is the right place for him...</p> <p>I: So why was that? What were your thoughts about The XXX when you visited it?</p> <p>D: I mean The XXX was lovely and it was just, I talked to some of the staff there, and it was very apparent that some of the children do struggle with their behaviour there... they can be quite violent, they can be quite explosive, and they have a lot of, um, one to one sessions that are withdrawn from the classroom. And that was just something that we felt he didn't necessarily need, because if we get the right place and the right people, he likes to conform for people he likes to</p>	<p>Listening to a professional voice. Information given has influenced future decision making.</p> <p>Power dynamics and positioning, something to consider at all times as professionals</p> <p>'more than mainstream' sense that mainstream will not be inclusive enough from early on</p> <p><u>'go the other way' – over to the dark side? Sense of the fight being about stopping this from happening...stopping him from picking up behaviours that are 'too autistic', wanting him to fit into the wider world</u></p> <p>Because he sits in the middle didn't want behaviours to impact by am behaviours to be impacted by more severely autistic young people... He copies things and picks things up... Made getting the right place even more important</p> <p>This 'in the middle narrative' familiar. Need to not let this influence how I engage with rest of data</p> <p>In the middle – narrative used by lots of parents of ASC children I have talked to...neither here <u>or</u> there...leading to confusion – sense of the SRB as addressing this <u>'middleness' – a provision in the middle for ASC children in the middle?</u></p> <p>right place for him = individual perspective - different for each child or young person</p> <p>Thoughts that special school may be right but after visit was put off by behaviours that other young people displayed e.g. violent explosions - <u>didn't want this...too 'special'?</u></p>
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i) Emergent themes clustered to form superordinate themes:



ii) Formation of subordinate themes:



iii) Example of table of superordinate and subordinate themes and graphic representation of superordinate theme

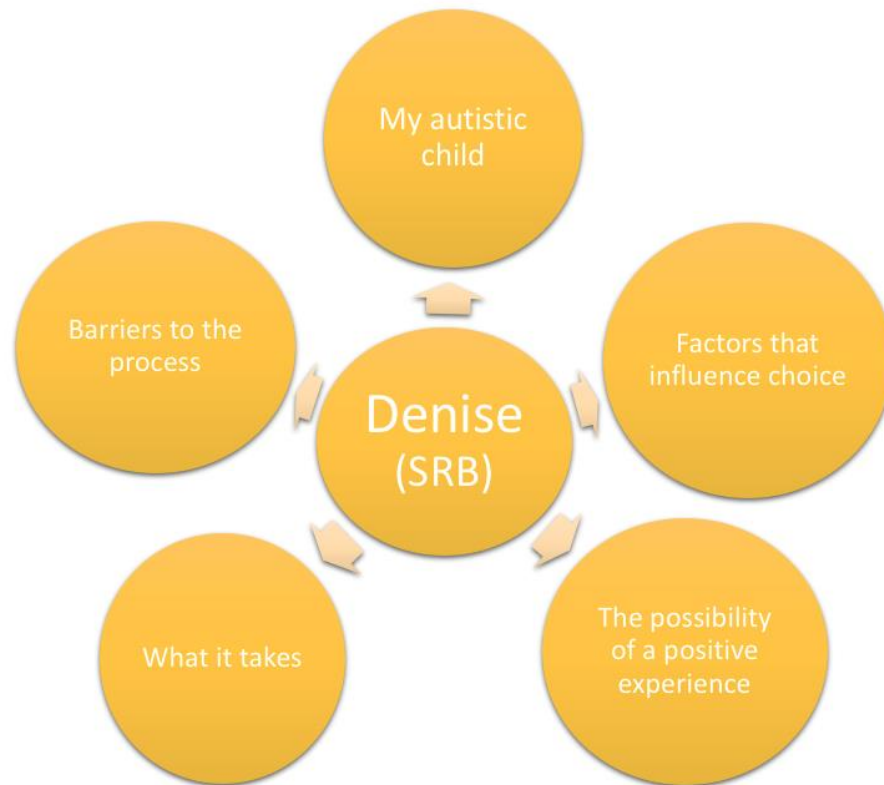
<b>Superordinate and subordinate themes</b>	<b>Exemplifying word/extracts</b>	<b>Page</b>
<b><i>My autistic child</i></b>  His needs  The power of clarity, a safe base, and belonging – helping him to understand himself	<i>he doesn't show his emotions around how he struggles, but when what we do see is that we'll find him becoming frustrated quite quickly. He often will self-harm, not in a very dangerous self-harm way, but very low level.</i>	2
	<i>Well there's a lot to do with his anxieties and yeah communication problems because maybe he misunderstands things. And, um, it's given him some quite negative barriers to overcome in terms of curricula, because he likes to follow his interests but anything out of his interests he's just not as interested in... therefore why would he want to learn about them</i>	13
	<i>That's where it all goes wrong, you know. And he masks and hide his very well and he could walk into a mainstream classroom and nobody would pick him out of the crowd ...but his difficulties are huge. He just hides them incredibly well.</i>	15
	<i>so that's kind of a big point for us now, just understanding himself and getting other people around to understand him. He's at that next stage of understanding and development, really. Yeah, and how he fits within in the wider world around him.</i>	3-4
	<i>the big turning point was when he moved to XXX Primary School because ... the first two teachers that he had just really got him, they understood him, he trusted them and therefore he conformed for them.</i>	4-5
	<i>she made it really special for him. He was the first one that ever went to the SRB so they got him to stand at the bottom of the stairs and be their model, and they took pictures of him, he was in the newspaper and it was just as fantastic. It was just made so special for him...</i>	10
	<i>...it is about making children feel safe and secure in learning</i>	13
	<i>The SRB have flexed and adapted for him, so that's something that he now feels very safe with, because its tailored for him it helps him understand who he is in the world, and it's a small space has got everything that he needs in it. He's safe in there. Therefore, he can then dip his toe into the classroom shall we say, and always have the reassurance that he's got a safe space, no matter what happens that space has been built purposely for him, it's really essentially important.</i>	16
<b><i>Barriers to the process</i></b>  The system is broken  'batted back'	<i>I think the problem with the process is that if things are being managed well in primary you're less likely to be hitting those criteria to get one [an EHCP]</i>	4
	<i>And actually I went to one school where the SENCO said, 'I'm gonna hold my hands up and tell you I can't meet its needs', and that was then it that was for me, I lost faith in the whole system...I was like if you are actually telling me you can't meet his needs, then there is absolutely no way I'm putting him into mainstream,</i>	21

	<p><i>and you know right now we're gonna hold off....He'll be home schooled until we find one that meets his needs.</i></p> <p><i>If I didn't have the knowledge of special needs and how things work it would have been dreadful, awful...I can say even now with my knowledge, we're going through the process now with Sid (younger brother) and it is 10 times harder now than it was with Jake because, because, I'm not really sure why....</i></p> <p><i>we named some places and it just kept being battered back... it was always, 'it's gonna go to panel at the end of this half term and we'll wait and see what's offered', but there wasn't any space available in any of them, so it was like, 'we're gonna put it to the next panel'... then 'there's no space, there's no space' – that was the one that we were really keen on, there was never any space.</i></p>	<p>16</p> <p>19</p>
<p><b>What it takes</b></p> <p>3 fights</p> <p>The knowledge (...and also...)</p> <p>If you don't have 'the fight' and 'the knowledge' you don't get</p>	<p><i>Battle &amp; battling</i></p> <p><i>I'm not happy putting him in mainstream setting. Without any kind of support, that's not going to happen. We will keep him at home until the EHCP comes through, and a school that meets his needs is found'. So we did and we stood to our ground and amazingly enough, the EHCP went through a course of about four weeks</i></p> <p><i>Some parents know better how to get what they want. It's about the fight that you have to go through and if you haven't got that fight in you, because you don't know or have the knowledge...I think there's different experiences because of that, and it's not equal necessarily.</i></p> <p><i>some have got the diagnostic fight, then you've potentially got the EHCP fight, and then you've got the fight to find the correct placement</i></p> <p><i>I realised that I had to be proactive. It was like yeah, flip it back. I realised it was down to me to be proactive, you can't just sit within the process, you have to keep pushing within it</i></p> <p><i>The parents who haven't got the skills, or confidence, or maybe they've got special needs themselves, you know they could also be on the spectrum or have learning disabilities, or have struggles with mental health...They watch their children struggle in mainstream secondary schools and their experience is just awful, and there's nobody fighting their corner for them, there's nobody saying, 'let me help you'. Where is the system of support for the parents who need support?</i></p>	<p>5 &amp; 16</p> <p>5</p> <p>5</p> <p>23</p> <p>20</p> <p>17</p>
<p><b>The possibility of a positive experience</b></p> <p>Power of communication</p> <p>Power of positive relationships and supportive professionals</p>	<p><i>Because if you can't have that communication, the barriers can't then get knocked down</i></p> <p><i>That communication is pivotal, it's absolutely key. Their main problem is with communication, so there needs to be that communication on their behalf.</i></p> <p><i>Well the issue we had as they kept changing the EHCP coordinator...but actually in the end she [the coordinator] was great, she said I'm gonna stick with you through your story and I'll make sure that we're really honest with you about panel meetings and about what happens in them.</i></p> <p><i>Actually from my point of view, with the end point in mind, seeing him now and how he is thriving, then 'absolutely amazing'. Yeah, if you manage to get the place you wanted, and it has worked out</i></p>	<p>12</p> <p>12</p> <p>20-21</p> <p>23-24</p>



	<i>for your child, cause that's who all the fighting has always been about, then the relief is huge, and it is amazing. You see the outcomes that they do with him and you couldn't ask for a more wonderful place and, you know, my husband actually said he feels that those staff there are exactly their as with the effort that I put into where I work... I see them putting the same effort in with him that I do where I work, they care like I do</i>	
<b>Factors that influence choice</b>	<i>he kind of sits in the middle. He's got struggles, we know he's got struggles and he presents well and that masks some of his needs and so it was really difficult in choosing the right place for him because, well you didn't want him to go the other way, um, where he would then copy and practice and pick up on some of the other things, some of the other difficulties that children have for being autistic, so it was really important for me to get the right place...</i>	6
'The best of both worlds'	<i>what people have to kind of understand is that even though he is autistic and he had difficulties, he still needs to be challenged in that way. And the same with the children that I teach at school... we have to push the barriers, we have challenge, we have to do this in order for them to ever overcome...it is about making children feel safe and secure in learning but it's also about putting that little bit more effort in making sure that those kind of things happen</i>	13
Yes to inclusion, no to zero tolerance	<i>I thought The Arc might be step too far, whereas at the SRB he could sit in the middle and have the best of both worlds</i>	7
Worries about impact of fully specialist setting	<i>But the policies the school have... from the word go their wording was very difficult for us because they have lots of rules...their expectations of children are very high and very rigid and very straight, and one of them is you must always look at the teacher when they're talking and just kind of like immediately I went well hang on a minute... I think it is just that doing that joined up thinking because they're very new SRB the school of having to adapt to the autistic children in their school, which they may find a little bit tricky to start with, so hopefully I did offer some experience if they'd like to learn from anything.</i>	3
Lessons taken from my job role	<i>Because of previous difficulties we knew that he was not gonna manage a huge environment, so the kind of big factor was where can he go that's got a small environment with the right people who are gonna support him and understand him. That was kind of key for me.</i>	18
Transport	<i>safe space to go to, where there was a person that could reassure him or give him structure</i>	15
	<i>I said to the school that you need to be really open and honest with me, we need to work together and be as consistent as we can with him, otherwise we're gonna get have a big problem. I have to make really difficult conversations to parents in the setting that I work, I build the relationships with them and then we can talk about things really openly, and I think that is what I then expect from other people.</i>	12
	<i>It was just the fact that they couldn't, or wouldn't, put on a taxi for him that stopped it all in its tracks, and it was just that was just really sad for us. So transport is a thing too, that's a factor I guess. But actually we feel he could have made it in XXX as a mainstream, with the support from the SRB, but they couldn't kind of facilitate the transport.</i>	19

iv. Graphic representation of Denise's superordinate themes

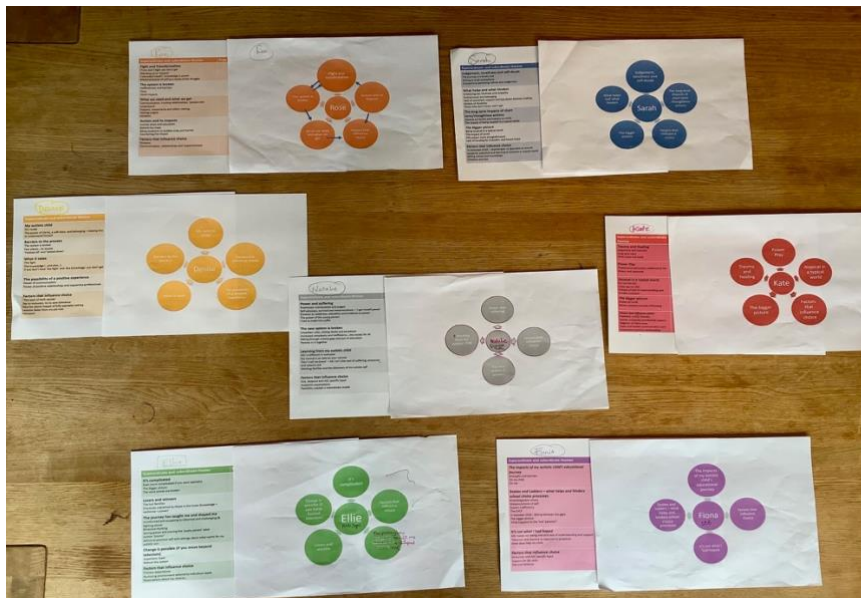




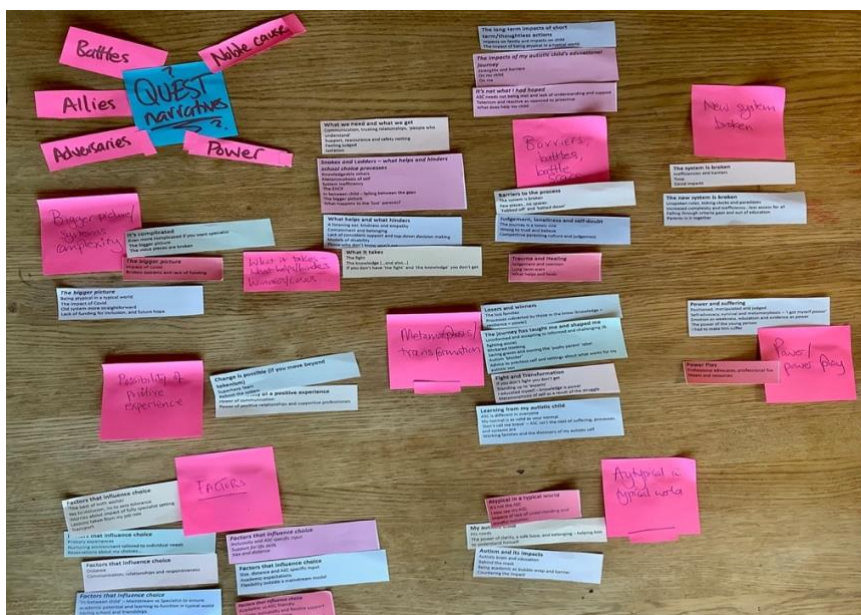
## Appendix 10c – Analysis example – Identifying patterns across cases

The final cross-case analysis is shown in tabulated form in **section 4.3.2 of findings chapter**. The images below show the initial stages of finding connections and patterns between participants' superordinate and subordinate themes, while remaining mindful of individual idiosyncrasies. The process involved grouping and regrouping until final cross-case patterns (master themes) were decided upon.

- i) Superordinate (and subordinate) themes and associated thematic diagrams laid out for initial comparative analysis.



- i) Example of initial grouping (there were more) of participants superordinate themes into patterns across cases. Each colour text corresponds to an interview participant.



## Appendix 11 – Overview of structure and stages of focus group

### FOCUS GROUP – 03/12/21 10:30 (Approx 90 mins)

Timing	Element	Content
5 mins	<b>Welcome &amp; Introductions</b>	<p>a. Welcome, b. consent check (check all happy for me to put digital sig on consent form) and anonymity reassurance, c. Introduction of self and invite P's to introduce themselves (can use pseudonyms if prefer), d. explain that we are very time-limited so workshop will have to be fairly fast-paced, and check 90 mins ok for all... explain that a paper and pen will ideally be required</p> <p>b. Remind P's of main two research questions:</p> <ol style="list-style-type: none"> <li>What are the lived- experiences of parents when choosing and securing secondary provision for their child on the autistic spectrum</li> <li>What are the factors that influence your choice of educational provision</li> </ol> <p>c. <i>Focus Group main question – How can practices and support be enhanced and adapted to improve the experience of the secondary school choice process for both parents and young people on the autistic spectrum?</i></p> <p><b>Provocative propositions/suggestions for improvement to practice developed as a result of focus group will be presented at a workshop of key local authority special educational need (SEN) partners</b> and possibilities/action steps discussed - Key professionals involved making decisions with regards to the school choice process, e.g. the Head of High Needs SEN and Disability and the Principal Educational Psychologist. Also...Professionals who liaise directly with families during the school choice process, e.g. EHCP coordinators, Special Educational Needs Coordinators (SENCOs), and educational psychologists...<u>and hopefully representation from this group</u></p>
5 mins	<b>Ground rules</b>	<p>Before we begin I need to quickly talk you through ground rules so that we all feel safe and willing to participate:</p> <ul style="list-style-type: none"> <li>• Participation in the focus group is voluntary. It's all right to abstain from discussing specific topics if you are not comfortable.</li> <li>• All responses are valid – there are no right or wrong answers.</li> <li>• Please respect the opinions of others even if you don't agree.</li> <li>• Try to stay on topic; we may need to interrupt so that we can cover all the material.</li> <li>• Speak as openly as you feel comfortable.</li> </ul> <p>Avoid revealing very detailed information about you</p>

		<p>personally or others (including professionals you have worked with). If possible please do not mention professionals by name (professional title should be used instead, or a pseudonym if you prefer).</p> <ul style="list-style-type: none"> <li>• Help protect others' privacy by not discussing details outside the group.</li> </ul> <p>Any that need to be added?</p>
15 mins	<b>Feeding back main findings from the cross-case analysis</b>	<ol style="list-style-type: none"> <li>Share the fact that it soon became clear that the secondary choice process isn't just one process but a culmination of a few processes, i.e. the diagnostic process, the EHCP process, and the school choice process</li> <li>Feedback main findings</li> <li>Anything to add? Any thoughts or comments?</li> <li>Introduce the fact that in the focus group we will be focusing on themes related to school choice processes.</li> <li>Work with participants to come up with areas within which h to consider and develop provocative propositions, e.g. <ol style="list-style-type: none"> <li>Support/guidance</li> <li>Information sharing/clarity of information</li> <li>Untokenistic collaboration</li> <li>Help for marginalised families</li> </ol> </li> </ol> <p>We will be taking these 4 areas into a process known as Appreciative Inquiry</p>
5 mins	<b>Explain the philosophical basis and purpose of using AI</b>	<ol style="list-style-type: none"> <li>Overview of AI - Appreciative Inquiry was developed as an organisational change tool. It doesn't say that there are no problems (we know there are!) but it DOES give you the opportunity to think around and discover solutions in a new and different way. In the very limited time, we have for the focus group I was mindful that too much emphasis on what's not working could take up all of our time and prevent action planning and positive and possible next steps. So we going to instead use</li> <li><b>Share graphic and take them through stages:</b> <ol style="list-style-type: none"> <li>Define - Explain that the interviews and identification of 3 key areas <u>defined</u> what we are going to be looking at.</li> <li>Discover – In AI, a constructivist perspective, we will think around what has worked well in our 4 areas, and what the exceptions are to negative experiences</li> <li>Dream – Blue sky thinking and Provocative Propositions</li> <li>Design – First steps</li> <li>Destiny – the workshop with key members of SEN/EPSS teams inc where framework developed as a result of</li> </ol> </li> </ol>
10 mins	<b>Discovery Phase</b>	<ol style="list-style-type: none"> <li>In the Discovery phase, we will think around what has worked well in our 4 areas- <b>show on visualiser</b> &amp; ask</li> </ol>

		<p>them to write them down -, and what the exceptions are too negative experiences. Questions:</p> <ol style="list-style-type: none"> <li>I'd like you to have a 30-sec pause to think about which of the 4 you feel is the most important to address, and why (although we will consider them all)</li> <li>Thinking about that area, think about what has worked, and what was valuable/effective about it.</li> <li>What made it possible?</li> <li>How did it feel for you?</li> <li><b>Repeat for all areas....</b></li> </ol>
25 mins	<b>Dream Phase</b>	<ol style="list-style-type: none"> <li>This phase involves thinking about IDEAL SCENARIOS...with what works in mind we will imagine what the ideal would be in terms of the 4 areas. For each we will develop a statement (known as a provocative proposition)...positively describing our ideal situation as if they are already happening, e.g. <u>'Information about the entry criteria for different educational provisions is easily accessible'</u>, <u>'EP's will be involved in EHCP reviews leading up to transition to guide with regards to appropriate provision'</u>, <u>'Families have access to a consistent and available point of professional contact during the school choice process'</u>....i.e. it involves asking the question 'what would X (e.g. communication/information sharing) look like if it worked well?</li> <li>Open discussion - Facilitate an open discussion about 'ideals' first</li> <li>Provocative propositions – ask participants to scribe some ideas down (ideally for each area but just whatever they can do) – feedback (LS to scribe on visualiser)</li> </ol>
20 mins (optional)	<b>Design – possible and positive action planning</b>	<ol style="list-style-type: none"> <li>This is a co-constructed 'designing' of possible and positive first steps forward...</li> <li>Choose one of generated PP's for each area and on visualiser, ask participants to imagine they had travelled forward in time one of two years, things are working better, what do you think has made the provocative proposition possible? Ask them to think about this for a chosen 1 of their PPs...</li> <li>Ask for feedback and a possible first step towards making it happen</li> </ol>
5 mins	<b>Ending the session</b>	<ul style="list-style-type: none"> <li>End the discussion by summarising the main points. If there is time, invite participants to reflect on the main ideas, and ask if they have any additional thoughts to share.</li> <li>Thank the group for participating; remind them to know how the discussion results will be used.</li> </ul>

During the focus group summarise contributions, develop/clarify ideas and suggestions, and balance participation. Possible probes will include:

- Can you say more about...
- Can you give an example?
- XXX says X. Does anyone have further thoughts on this?
- Does anyone else have some thoughts on that?
- Who else has something to say?
- I would like to hear more from...
- These are important and interesting points. However, we need to bring the discussion back to our main focus on...
- Do you agree with this? (Or, How do you feel about that?)
- Are there other recommendations that you have, or suggestions you would like to make?

## APPENDIX 12 – Focus Group Information Sheet



University of  
East London

### **Choosing and securing secondary provision for their child on the autistic spectrum – an action research project investigating parental motivations, experiences, and suggestions for improvement to practice**

Main Research Question: What are the lived experiences of parents when choosing and securing secondary provision for their child on the autistic spectrum?

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#### **What is the purpose of the focus group?**

The main purpose of focus group research is to share experiences and enable a dynamic and positive exchange of ideas.

Most importantly the focus group will be your opportunity to have your say about the school choice process and how it could be improved. Research has shown the transformational value of focus groups in terms of improving services and processes (e.g. Cunningham-Burley, Kerr & Pavis, 1999; Johnson, 1996; Kitzinger, 1994).

It is hoped that the outcomes of both the main body of research and the focus group will help educate and inform decision-makers and shape future practices, levels of information, and support.

*N.B. Before the focus group findings of individual interviews will be fed back to participants.*

#### **What happens during the focus group and how will I be involved?**

The focus group will be made up of up to 8 participants and will be held either virtually or face-to-face (TBC, depending on circumstance).

The researcher will act as facilitator and will try to make you feel as comfortable and relaxed as possible.

After introductions, experiences can be shared by those who wish to share them (this will be completely voluntary), then strengths and areas of possible



improvement to the existing school choice process will be discussed as a group (via a collaborative strength-based approach known as Appreciative Inquiry).

Below is an outline of the role of the facilitator and the ground rules of the focus group for your information.

The researcher will:

- Guide the process
- Ask clarifying questions
- Summarise what has been said and check understanding
- Re-direct focus if it strays too far off-topic
- Re-phrase questions when necessary
- Introduce topics and questions
- Steer group and manage interactions

Ground rules, so that we all feel safe and willing to participate:

- Participation in the focus group is voluntary. It's all right to abstain from discussing specific topics if you are not comfortable.
- All responses are valid – there are no right or wrong answers.
- Please respect the opinions of others even if you don't agree.
- Try to stay on topic; I may need to interrupt so that we can cover all the material.
- Speak as openly as you feel comfortable.
- Avoid revealing very detailed information about you personally or others (including professionals you have worked with). If possible please do not mention professionals by name (professional title should be used instead or a pseudonym if you prefer).
- Help protect others' privacy by not discussing details outside the group.

### **What will happen after the focus group?**

The results of this focus group will be shared with the local authority.

It is hoped that the findings will help inform both school and local authority processes and practices, and ultimately improve the support that they offer to parents of children with autism while they are going through the process.

### **What if I have questions later?**

If you have any questions about the research/focus group or ethical concerns at a later date the following information may be useful:

**Researcher:** Louise Somner

**Supervisor:** Helena Bunn ([H.Bunn@uel.ac.uk](mailto:H.Bunn@uel.ac.uk))

**Ethical concerns:** Chair of the School of Psychology Research Ethics Subcommittee: Dr. Ian Tucker, School of Psychology, University of East London, Water Lane, London E15 4LZ. (i.tucker@uel.ac.uk)

### **What if I was emotionally affected by the research and feel like I need support?**

Should you, for whatever reason, become distressed after sharing your views and experiences, help can be sought either via your GP or via Wellbeing Norfolk (call 0300 123 1503), find further links and self-referral form at [www.wellbeinghands.co.uk](http://www.wellbeinghands.co.uk). Support can also be found via The Samaritans, call 116 123 or email [jo@samaritans.org](mailto:jo@samaritans.org). Additionally, ASD Helping hands can offer support and counselling if required (call 01362 or email [asdhelpinghands@gmail.com](mailto:asdhelpinghands@gmail.com))

### **Confidentiality and Right to Withdraw**

- I as the researcher am interested in your experiences of choosing and securing secondary school provision for your autistic child.
- I as the researcher want to emphasise that this is not a test of your knowledge and there are no right or wrong answers. I am purely interested in your views.
- As the researcher I am the only person who will have access to your audio.
- All data collected will be confidential and anonymised.
- Transcriptions may be viewed by the supervisor and anonymised extracts by examiners of the dissertation.
- All information provided by you will be kept confidential and used for research purposes only (it will be retained for 5 years in the UEL Research Repository in line with university policy and then destroyed).
- Anonymised extracts may also possibly be used in future publications.
- The data will form the basis of my research project which will be submitted to the University of East London for assessment.
- You are free to withdraw from the research study at any time without explanation, disadvantage, or consequence. Separately, you may also request to withdraw your data even after you have participated data, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).



## Appendix 13 – Ethical approval letter

### School of Psychology Research Ethics Committee

### NOTICE OF ETHICS REVIEW DECISION

### For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**REVIEWER:** Lucia Berdondini

**SUPERVISOR:** Helena Bunn

**STUDENT:** Louise Somner

**Course:** Prof Doc Child Edu Psych

**Title of proposed study:** Choosing and securing secondary provision for their child on the autistic spectrum – an action research project investigating parental motivations, experiences and suggestions for improvement to practice

#### DECISION OPTIONS:

1. **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.
2. **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 not required but the student must confirm with their supervisor that all minor amendments have been made before 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.
3. **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.

#### DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

*(Please indicate the decision according to one of the 3 options above)*

APPROVED

**Minor amendments required** *(for 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:

*(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

**ASSESSMENT OF RISK TO RESEACHER** *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

**YES** / NO

**Please request resubmission with an adequate risk assessment**

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐

HIGH

**Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.**

☐

MEDIUM (Please approve but with appropriate recommendations)

☒

LOW

**Reviewer comments in relation to researcher risk (if any).**

**Reviewer** (*Typed name to act as signature*): Lucia Berdondini

**Date:** 08/03/2021

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee*

**RESEARCHER PLEASE NOTE:**

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, 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 a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

## Appendix 14 – Parent participants bullet point pen portraits and superordinate themes

### Denise

- Denise had a gentle humour and presented as warm, friendly and articulate.
- Her son, 'Jake', is at a recently opened Specialist Resource Base.
- Denise works at a special school for children with social-emotional problems and this has, to some extent, informed her thinking about how her son should be effectively supported.
- Denise also has an older son.
- She has had a positive experience with the newly established SRB, however, she acknowledges the school choice journey as stressful.
- She identified barriers related to inefficiencies in the system and a lack of specialist places.
- She shared views regarding the need for regular communication and clarity of processes.
- She felt she was helped during the SCP and wider educational journey by productive relationships with knowledgeable others and by her ability to be proactive and push for what she wanted, "... you can't just sit within the process, you have to keep pushing within it" (p 19)



*Denise's superordinate themes*

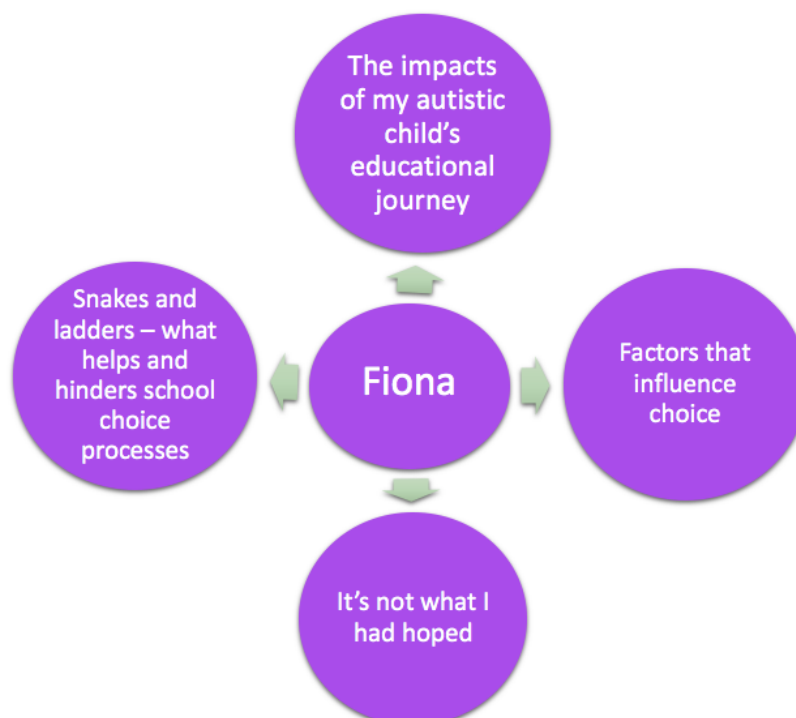
## Ellie

- Ellie came across as friendly, warm, and very well-informed.
- Her son, 'Archie', attends a very popular special school for children with autism (a free school opened in the last few years).
- Ellie works at a charity supporting families of children with special needs.
- Ellie also has a younger son without special needs.
- She has generally had a positive experience with the specialist placement.
- She reflected that she wanted her son to be at a mainstream primary to interact with 'every kind of child'. However, she now wonders whether it was the right choice, or did 'more damage than good'.
- She identified barriers related to inefficiencies in the system and the lack of specialist places.
- She, like other participants, feels that having a child with additional needs and engaging in a 'battle' to ensure he is supported in education have shaped and changed her.
- She is aware of the bigger picture regarding LA constraints and funding issues and shared opinions regarding how this impacts support and inclusive practice.
- She shared examples of parents, including herself, subverting systems.
- She acknowledged inequalities in the system, with some parents knowing better how to navigate processes and having the confidence, knowledge, and competence to fight – while others fell to the wayside.
- She positions parents as isolated and alone in their struggles, learning how to fight and seeking advice and reassurance from parent support groups and charities.



## Fiona

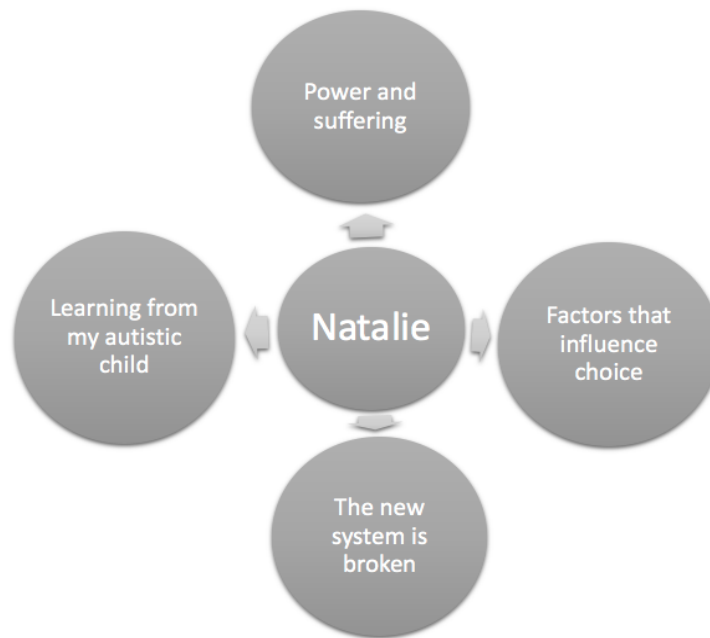
- Fiona presented as a warm, open, and considered thinker. She is well informed and able to see all sides to an argument.
- Fiona works as a teaching assistant in a mainstream primary school.
- Fiona also has an older son without special needs.
- Her son, 'George' attends an established SRB in a large city high school. Fiona's experience of the SRB has not been what she had hoped. Support has been perceived as reactive (linked to a serious incident and mental health struggles of her child) rather than proactive.
- She acknowledges how much having a child with additional needs has transformed her, as she has had to overcome her fears and stand up to those in professional positions.
- The impacts of processes associated with secondary school choice on both her and her son are reflected upon.
- She notes how many families find themselves falling between the gaps in special school provision, often seeking each other for advice and reassurance.
- She positions parents as isolated and alone in their struggles, learning how to fight and seeking each other for advice and reassurance.



*Fiona's superordinate themes*

## Natalie

- Natalie came across as friendly, driven and a little battle weary.
- Her son, 'Peter', attends an independent special school for children with autism.
- Natalie is a full-time mum - educating, supporting, and caring for her three sons with additional needs. Our focus was on her middle son Peter.
- Natalie also has a diagnosis of ASD (which she sought a few years ago).
- She feels that systems and processes need to adapt to a wider range of 'normal'. She, like other parents, feels that it is systems and processes, not the condition of autism itself, which cause suffering and trauma to individuals and families.
- She feels that the EHCP process is much more complex than the old statementing system (which she went through with her oldest child), leading to greater barriers for many parents and less agency and voice.
- She acknowledges how previous hardships and experiences have shaped and changed her. Positioning these, ironically, as 'lucky' in terms of giving her the strength and resilience to have kept on going in difficult and adversarial situations.
- The significant (negative) impacts of processes associated with the wider educational journey and SCPs are reflected on.
- She notes how those families with less power find themselves falling between the gaps in special school provision. Power and power differentials are a theme that is returned to throughout her meaning-making.
- She positions parents as isolated and alone in their struggles, learning how to fight and seeking each other for advice and reassurance.

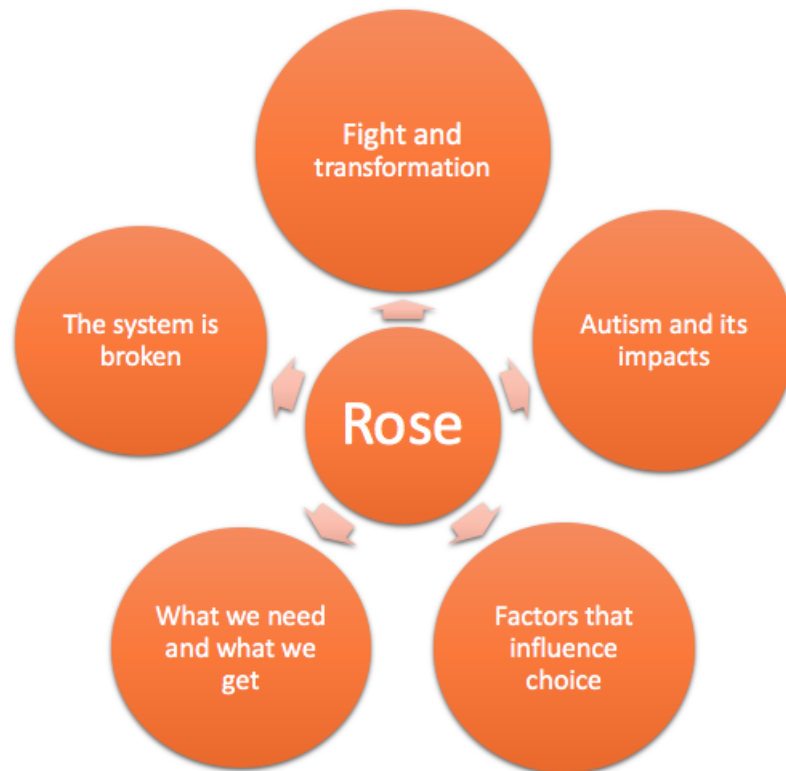


*Natalie's superordinate themes*

## Rose

- Rose was friendly, positive and articulate.
- Her son, 'Sam', attends a small secondary school.
- Sam is academically able, and although specialist schools were considered, Rose was keen for Sam to go to mainstream if it was 'a good fit'. Rose felt that special schools perhaps didn't provide the academic input that both she and Sam wanted.
- Rose works in a special school as a teaching assistant.
- Rose and her family moved into the county a few years ago from the Midlands. Sam had had EP involvement from his previous county and was on the neurodevelopmental pathway but had to begin the process again after moving to current county.
- After difficulties in a previous primary setting (where Sam "really struggled" and found things "really hard"), the move to a small nurturing rural school improved settlement and lessened Sam's anxieties. Rose had some anxiety about Sam's move to a larger secondary setting. However, she is generally pleased with how he has been supported, describing him as 'loving it' and 'blossoming'.





*Rose's superordinate themes*

## Sarah

- Sarah was approachable and articulate with a considered and quiet demeanor. She became emotional when talking about a professional who was kind and supportive – the wider impact of the journey with her autistic child was obvious.
- Her son, 'Ted', attends a mainstream secondary school.
- Sarah works for the LA in an advisory capacity.
- Sarah has felt very alone and unsupported during the educational and school choice journey.
- Watching her child struggle to adapt to a 'typical' world and the judgement she has faced from other parents has had an obvious and profound effect on her.
- She shared the difficulties parents face when they have an 'in-between' child, who is academically able enough to attend mainstream but has profound struggles when attempting to function in a 'typical' world.
- She is aware on a personal and professional level of the bigger picture regarding LA constraints and funding issues, which she feels impact on affective inclusion in mainstream. However, she also

acknowledges recent positive steps forward in terms of the increasing availability of specialist provision.

- She feels that the old statementing system was more efficient and easier to navigate than the EHCP system.



*Sarah's superordinate themes*

## Kate

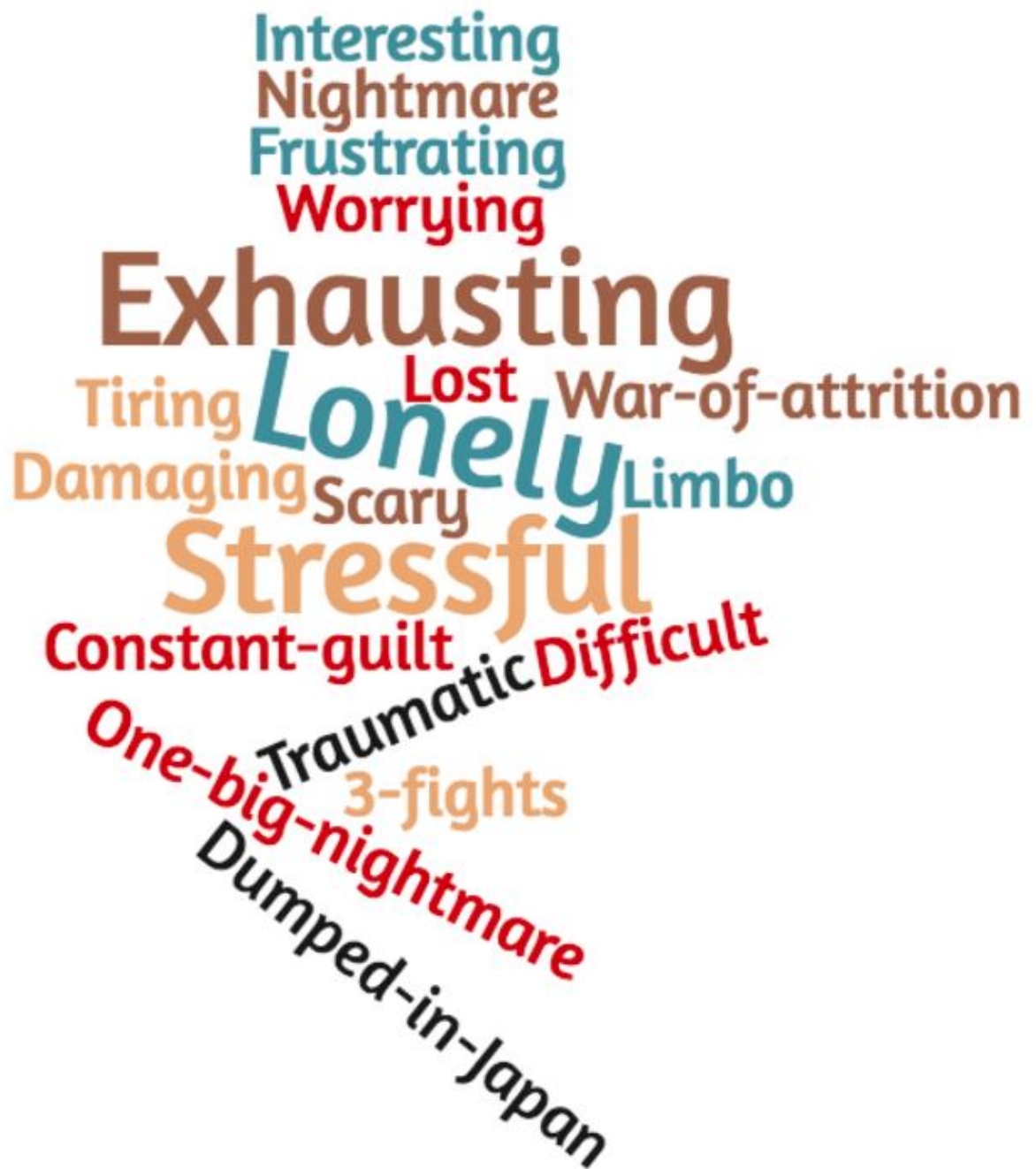
- Kate presented as bubbly, confident, determined, and articulate.
- Her son, 'Felix', attends a mainstream secondary school.
- Kate works in the LA in an advisory role.
- Kate also has an older daughter and is married to a supportive husband who has recognised, through having an autistic child (who experiences the world in a similar way to himself), that he too may be on the spectrum.
- Kate referred to Felix throughout the interview either as 'Felix' or 'they'. The use of the pronoun 'they' may indicate that Felix is non-binary.
- Kate frequently said, 'Felix would say...'. Attempting to accurately and honestly portray their story and experiences was important to her.
- She, Felix, and her family have had a very difficult and traumatic experience of the educational journey, particularly at primary school. Much of her narrative related to the trauma they had faced, and how it continues to affect them.

- Kate feels that Felix's inclusive mainstream secondary setting has helped to address and 'heal' this trauma.
- Power and power-play factored, both explicitly and implicitly, in much of Kate's narrative.
- Kate strongly feels that it is not autism in and of itself that leads to anxiety and trauma, but a lack of supportive and understanding systems which fail to make adaptations for an atypical brain.



*Kate's superordinate themes*

Appendix 15a – Words parents used to describe school choice process and educational journey with their child



Appendix 15b – Words parents used to describe personal qualities needed during the school choice process and educational journey

