

**“It is the responsibility of adults to find ways of understanding young people’s views, rather than children and young people trying to make themselves heard.” (Rome et al., 2015, p. 293)**

**An exploration of the experiences of children and young people considered to have additional educational needs, in taking part in decision making processes in an English educational context.**

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**Declaration**

This thesis is being submitted for the award of Doctorate in Applied Educational Psychology. I declare that it is my own work and does not include material that is the work of others without acknowledgement, that I have consulted all materials cited, and I have not submitted this assignment for any other academic award.

## Overarching Abstract

This thesis explores the experiences of children and young people (CYP) with additional educational needs (AEN) of taking part in decision-making processes (DMP) within the context of the English education system. It contains four chapters: a systematic literature review, a critical consideration of research methodology and ethics, an empirical research project and a reflexive chapter, which considers the personal and professional implications of the thesis.

**Chapter 1:** The systematic literature review explores the experiences of CYP with AEN in participating in decision making processes in light of the legislation changes brought into place in 2014, which underpin CYP's right to be active participants in such processes. Thematic synthesis was used to analyse six papers, following a detailed process of searching and selecting. Key Themes were identified as: How CYP are viewed by adults around them; The decision-making process; CYP's views; and Relationships and Context. A theoretical framework was developed which explored how these themes relate to one another. The review highlights the importance of how both participation and CYP are conceptualised by adults around them within the context of DMP and how this influences the DMP and the CYP's agency within that process. This is further shaped and underpinned by the relationships around the CYP and how these support their participation in the DMP and by the CYP's own views and experiences.

**Chapter 2:** Chapter 2 provides a critical consideration of research methodology in relation to my empirical research project on the experiences of girls with Autism Spectrum Disorder (ASD) in taking part in decision making processes (DMP). In this chapter I layout my own epistemological stance, I relate the findings from my SLR to my methodological approach and explore the practical and ethical complexities which underpin the approach to and design of my study.

**Chapter 3:** *'It's my health care plan I should know what's going on.'* The purpose of this empirical report is to develop an understanding of the lived experiences of girls with ASD in contributing to their educational provision as part of the planning process for their Education Health and Care Plans (EHCPs) and Annual Reviews (ARs). The project was undertaken in the North East of England and adopted a qualitative approach. Semi-structured interviews were carried out to explore the experience of autistic girls of being part of EHCP and AR processes. The interviews were analysed

using Interpretative Phenomenological Analysis (IPA). The participants' experiences are discussed in the light of the wider literature and the implications this has for future practice. Through developing an understanding of the girls' experiences, I hope that this will inform practice for professionals in supporting girls with autism in being part of DMP and developing guidelines which enhance the quality of the EHCP plans to reflect young people's thoughts and wishes.

**Chapter 4:** This chapter provides a reflective and reflexive account of the research process and outcomes and what this means for me as a trainee practitioner and researcher. I consider the implications for future practice both personally and more generally and how these may come about.



## Acknowledgements

I think this short poem beautifully and accurately captures my journey to becoming an EP:

***“My candle burns at both ends; it will not last the night; but ah, my foes, and oh, my friends - it gives a lovely light!”***

By Edna St Vincent Millay

Thank you, Hugh, for believing in me and ‘encouraging’ me to go for it. Thank you for listening to my rants, proof reading, cups of tea, all the lifts to university and for picking up the slack when I wasn’t around. I really couldn’t have done it without you. I love you.

Lily, Jude, and Hebe: just having you three around always makes everything better. I am sorry I have been less present than I would have liked to be over the last three years. Thank you all for just being you.

My sister, Pippa, died just before I got on the DAppEd Psych. This course has been really tough at times. I have kept going thinking of her and holding on to the fact that life is full of tough moments and remembering these moments are often rich and affirming and we always come out the other side, somehow, somewhere. Thanks Pippa.

Dr Wilma Barrow, my supervisor: thank you. I have learnt so much from our conversations and your support has been invaluable.

To my fellow Year 3s: You have really been an inspiration and I am grateful to have been on this journey with such an amazing bunch of people. Thank you.

Finally, to the Secret Hug Club: So much laughter, so many tears, so many hours spent together. You two have been the best company. Thank you.

## Contents

### ***Chapter 1: An exploration of the experiences of children and young people with additional educational needs of being involved in decision-making processes which affect their lives in an English educational context. .... 9***

Abstract .....	9
1.1 Introduction.....	10
1.2 Method .....	13
1.3 Findings.....	24
1.4 Discussion .....	29
1.5 Conclusion and implications for practice and research .....	35

### ***Chapter 2: A critical consideration of research methodology in relation to my empirical project..... 37***

2.1 Introduction.....	37
2.2 Literature review and implications for research.....	37
2.3 Research design and my epistemological position .....	38
2.4 Research Methodology and ethical considerations.....	44
2.5 Moving forward.....	47

### ***Chapter 3: The experience of girls with autism of being part of Education Health and Care Plan and Annual Review decision-making processes; “It's my health care plan I should know what's going on.” ..... 48***

3.1 Introduction.....	49
3.2 Methodology.....	53
3.3 Findings.....	57
3.4 Discussion .....	67
3.5 Conclusion and implications for research and practice .....	71

### ***Chapter 4: A reflective Synthesis of professional and academic learning, as a result of the research process. .... 74***

4.1 Introduction.....	74
4.2 Personal Reflexivity.....	74

4.3 Epistemological and methodological reflexivity .....	75
4.4 Implications .....	78
<b>References .....</b>	<b>81</b>
<b>5.0 Appendices .....</b>	<b>87</b>
5.1 Appendix A: Scoping search records .....	87
5.2 Appendix B: Protocol.....	102
5.3 Appendix C: Screening of final 19 papers .....	107
5.4 Appendix D: Developing a rationale for not using a quality assessment tool.	118
5.5 Appendix E: Thematic Synthesis stage 1 .....	120
5.6 Appendix F: Phase 2 Coding across the studies.....	125
5.7 Appendix G: Code table with quotes .....	127
5.8 Appendix H: Stage 3 generating analytical themes.....	139
5.9 Appendix I: Semi-structured interview questions informed by IPA.....	140
5.10 Appendix J: Participant and parent/carers information sheets.....	148
5.11 Appendix K: Consent forms.....	153
5.12 Appendix L: Interview Questions and Information Sheet about EHCP process for participants.....	155
5.13 Appendix M: Examples of IPA Process .....	159
5.14 Appendix N: Participant friendly summary of research project.....	168

## List of Figures

Figure 1: Hart's Ladder of Participation (Hart, 2008) .....	12
Figure 2: The PRISMA framework.....	16
Figure 3: Key themes emerging from a review of CYP with AEN and their participation in decision-making processes .....	24
Figure 4: Understanding Children's Ability To Participate: An Ecological Model (Gal, 2017). .....	30
<i>Figure 5: Conceptualising Article 12 of the UNCRC (Lundy,2007)</i> .....	41
Figure 6: Assisting Children to an (in) formed view (Lundy& McEvoy, 2012).....	54
Figure 7:The recruitment process.....	55
<i>Figure 8: Super-ordinate and sub- themes emerging from IPA</i> .....	58

## List of Tables

Table:1 PICO Table.....	14
Table 2: Literature Search Terms .....	15
Table 3: Descriptive summaries of included studies .....	19
Table 4: Contribution of studies to each theme .....	23
Table 5: An ecological systems understanding of review findings .....	31
Table 6: Key elements of participation adapted from Lundy (2007) .....	46
<i>Table 7: Participants' demographic characteristics</i> .....	57
<i>Table 8: The five stages of IPA</i> .....	57

# **Chapter 1: An exploration of the experiences of children and young people with additional educational needs of being involved in decision-making processes which affect their lives in an English educational context. <sup>1</sup>**

## **Abstract**

**Aims:** This review aims to explore the experiences of children and young people (CYP) with additional educational needs (AEN) of being involved in decision-making processes (DMP) which affect their lives in an English context.

**Rationale:** English legislation and Special Educational Needs and Disability (SEND) guidance reforms took place in 2014 which placed CYP with AEN central to such DMP. This is a notable change to policy and process and this review focuses on subsequent experiences of CYP.

**Method:** Current literature was systematically searched and searches were refined, until six papers were selected to be included in the analysis. A thematic synthesis approach was applied to support the generation of new ideas pertaining to my specific question (Thomas & Harden, 2008).

**Findings:** Findings suggest that how CYP with AEN are conceptualised links closely to their participation in DMP and is influenced by four key factors; the context of DMP; how the CYP are viewed by adults around them as part of DMP; CYP's relationships with adults around them and CYP's lived experiences and their expressions of these.

**Limitations:** Thematic synthesis is an emerging framework and analysis and interpretation of included studies and their findings is subjective. Further interpretations may have added depth and meaning.

**Conclusions:** Research which explores CYP's lived experiences since legislation and guidance changes, remains limited. Findings suggest that DMP in which CYP with AEN take part in England are varied and context driven and underpinned by adult understanding of CYP needs, positive and open relationships which support active participation and where DMP are valued within the culture of the environment where they take place.

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<sup>1</sup> 'I have prepared this for submission to 'Education and Child Psychology.'

**Keywords:** Children and young people, decision-making processes, SEN, educational needs, England.

## **1.1 Introduction**

This systematic literature review (SLR) explores the experiences of children and young people (CYP) with additional educational needs (AEN) in England. CYP's rights to express their views and contribute to decisions about issues that concern them are laid out in Article 12 of the United Nations Convention on the Rights of the Child (UNCRC)(UN General Assembly, 1989). These rights are central to English legislation, policy, and guidance. The Children and Families Act (CFA) 2014 and SEN Code of Practice (COP) (2015) position parents/carers and CYP centrally in DMP which affect them. This is a notable change to Special Educational Needs (SEN) policy and process and this SLR focuses on the experiences of CYP in the years since reforms about CYP's rights in relation to DMP came into effect.

### **1.1.1 Key Terms**

A definition of key terms being used in this SLR:

#### **Special Educational Need (SEN)**

An SEN is defined by the COP as:

*"... a learning difficulty or disability which calls for special educational provision to be made."* (Department for Education, 2015, p. 15).

#### **Additional Educational Need (AEN)**

An additional educational need (AEN) can be defined as any sort of need a learner may be experiencing and is not necessarily a SEN. It can be any need that impacts on learning and can be permanent, changing or temporary (Soan, 2013).

Scoping searches for this review highlighted an overall lack of research in this area since legislative reforms took place. A number of papers focused on CYP with autism and on CYP with additional needs that could not be clearly defined by a diagnostic label. The use of the term AEN allowed for inclusion of papers about CYP in DMP with needs which are not always recognised by labels associated with SEN which are commonly used in an English educational context. This also allowed for inclusion of papers additional to those which focused on solely autistic CYP.

## **Participation**

Article 12 of the UNCRC states that children have the right to be heard on matters affecting them, which is a participation right, and that these views should be given due weight (Pare, 2015). This assumes CYP to be individuals in their own right with views, feelings and needs worthy of consideration (Gal & Duramy, 2015). There is a distinction between individual and group participation (Mager & Nowak, 2012) and the approaches which support this (Sinclair, 2004). In this SLR I refer to ‘participation’ in the context of CYP taking part in DMP about their individual learning contexts.

### **1.1.2 Context and rationale for this literature review**

The findings of a recent report, on how the CFA 2014 has impacted on CYP’s participation in DMP concerning SEN provision in English Local Authorities (LAs), reflect differences across LAs in working with CYP as part of statutory assessment (SA) (Riddell, Gillooly, Harris, & Davidge, 2019). Key issues highlighted include:

- CYP’s rights inconsistently ingrained in routine practice;
- LAs operating under fiscal constraints impacting on workloads, time, and resources available to systematically involve CYP in DMP;
- increased capacity needed by LAs to improve practice in working with CYP to support them in sharing their thoughts and being part of DMP;
- mismatch between actual participation and that required by statute; and
- ongoing tensions in determining weight given to the views of CYP compared to parents/carers and professionals.

A lack of research into how CYP with SEN can shape and challenge adult dominated discourses and DMP has been identified (Bradbury-Jones, Isham, & Taylor, 2018). In the context of children’s rights in education, in research carried out prior to reforms, CYP identified involvement in decision-making as the most important issue to them (Lundy, 2007).

Research suggests active participation in DMP benefits CYP in several ways, including development of meta-learning skills, increased self-knowledge and feelings of greater responsibility for progress and change (Goodall, 2019; Harris & Davidge, 2019; Lundy, 2018), increased motivation and agency and understanding of democratic processes (Gal & Duramy, 2015). Exclusion from such processes

potentially impacts negatively on CYP in present and future situations (Rose & Shevlin, 2004) and is effectively denying CYP their rights.

There are a wide-range of frameworks which support thinking and exploration of the conceptualisation of CYP participation and which are underpinned by psychological theory (Gal, 2017; Hart, 2008; Shier, 2001). Hart's metaphor of the ladder of participation (figure 1) illustrates varying levels of CYP participation (Hart, 2008) and highlights the often adult-led nature CYP involvement. Hart (2008) emphasises that his ladder was not intended to be used as an evaluation tool. Hart offers the ladder as a starting point to consider participation and to provide a schema to support a critical perspective to the conceptualisation of CYP participation and it is with this intention that it is used within this study.

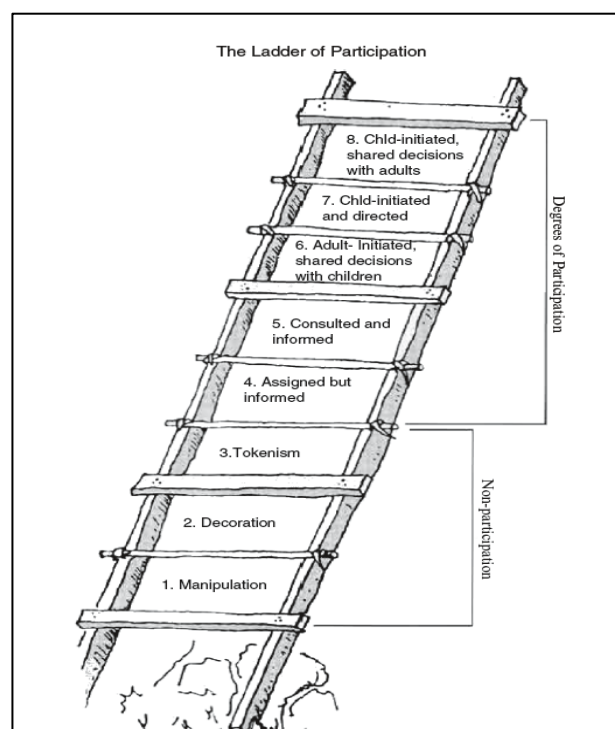


Figure 1: Hart's Ladder of Participation (Hart, 2008)

The ladder highlights that participation can be tokenistic (McKay, 2014), however tokenism can be viewed as a starting point that can begin with listening to CYP's views (Lundy, 2018).

### 1.1.3 Existing reviews of CYP and participation in DMP

Initial scoping searches found the following SLRs focusing on CYP participation in different contexts, the key findings are outlined below:



- The complexities and contradictions in participatory research with vulnerable children and young people: A qualitative systematic review (Bradbury-Jones et al., 2018);
- Effects of student participation in decision-making at school. A systematic review and synthesis of empirical research (Mager & Nowak, 2012); and
- Participation in decision-making processes in an early childhood setting (Correia, Camilo, Aguiar, & Amaro, 2019).

None focus specifically on SEN DMP in an English context, post CFA 2014 and COP 2015 changes.

#### **1.1.4 Rationale and Literature Review Question**

This SLR aims to fill a gap in the current literature and will focus on what participation in DMP looks like for CYP in an English context since the CFA 2014 and COP 2015. This paper will take a broad focus to provide a systematic review of qualitative studies about CYP with AEN's participation in DMP. I am interested in the lived experiences of CYP involved in DMP since 2014 and qualitative studies allow for exploration at greater depth as to how a phenomenon occurs. I will explore the following question:

What are the experiences of CYP with AEN in England of being involved in DMP which affect their lives in an educational context?

#### **1.2 Method**

This review is conducted from a social constructionist perspective. Social constructionism views individuals' understanding the world as a result of their individual experiences of it and how they make sense of them within their social, historical, and linguistic contexts (Burr, 2015). Questioning realities through this lens provides space to consider the contexts in which they exist and the systems which shape such contexts (Bronfenbrenner, 2006). However, it also means accepting that there are multi-voiced versions of any given phenomenon, which are constructed through social interactions within our contexts (Gergen, 2009).

Bronfenbrenner reflected with criticality on his bioecological model of human development as it developed over time (Tudge et al., 2016). Within this study Bronfenbrenner's later iteration of his model (2006) is used to conceptualise CYP participation. This model focuses on the proximal processes between people and

their environments which occur over time and in doing so provides a bio-psycho-social and systemic approach to understanding contexts in which CYP participation takes place. Such an approach moves away from a medical model of disability which may focus on a within-person construction of SEN/AEN and participation and emphasises person-context interrelatedness and the different systems and processes which are active (Tudge et al., 2016) within DMP.

### 1.2.1 Literature Search Strategy

Scoping searches (*See Appendix A*) revealed a prevalence of qualitative and mixed-method studies which describe and explore CYP and participation in DMP, therefore this SLR will focus on such studies to explore the review question. This will allow for a clear picture of what CYP with AEN's experiences of DMP in a current English context. A research protocol (*See Appendix B*) was developed to guide the research process.

A Population, phenomena of Interest and Contexts (PICO) table was used (Joanna Briggs Institute, 2014) in order to develop my search strategy, outline my inclusion criteria and to avoid exclusion of potentially relevant papers through being too specific (*See Table 1*).

PICO Table	
Review Question	<b>What are the experiences of CYP with AEN in England of being involved in DMP which affect their lives in an educational context?</b>
Population	CYP in the England of compulsory school age (5-18) who have an AEN
Phenomena of Interest	CYP who have participated in DMP about educational issues which affect them DMP
Context	English post CFA (2014) and SEN COP (2015) reforms Any context in which CYP might be involved in DMP with professionals about their education The context of children's right to participate in DMP about matters which directly affected their lives

*Table:1 PICO Table*

Terms for CYP, participation, decision-making and AEN were combined systematically to search for papers (See Table 2).

Terms related to CYP	Terms related to participation	Terms related to decision-making	Terms related to legislation and guidance	Terms related to AEN
<b>Young people</b>	Participation	Decision-making	United nations conventions on the rights of the child UNCRC	Special educational needs SEN SEND
<b>Children</b>	Voice	Education and Health Care Plan EHCP	Children's rights	Disability
<b>Pupil*</b>	Engagement	Transition	SEND code of practice	Inclusion
<b>Student*</b>	Involvement	Co-production Co production		Inclusive Practice
<b>Adolescent*</b>	Autonomy			Additional Educational Needs AEN Additional Needs
<b>Youth*</b>	Self-determination			
<b>Young people</b>	Efficacy			
	Self-efficacy			
	Co-production			
	Decision-making			

Note: Asterisks acts as a wildcard symbol which broadens a search by finding words which start with the same letters.

Table 2: Literature Search Terms

### 1.2.2 Identification of Papers

The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) framework was adopted to support a systematic and rigorous process of identifying empirical studies (Moher, Liberati, Tetzlaff, & Altman, 2009). Figure 2. outlines the stages of the search process.

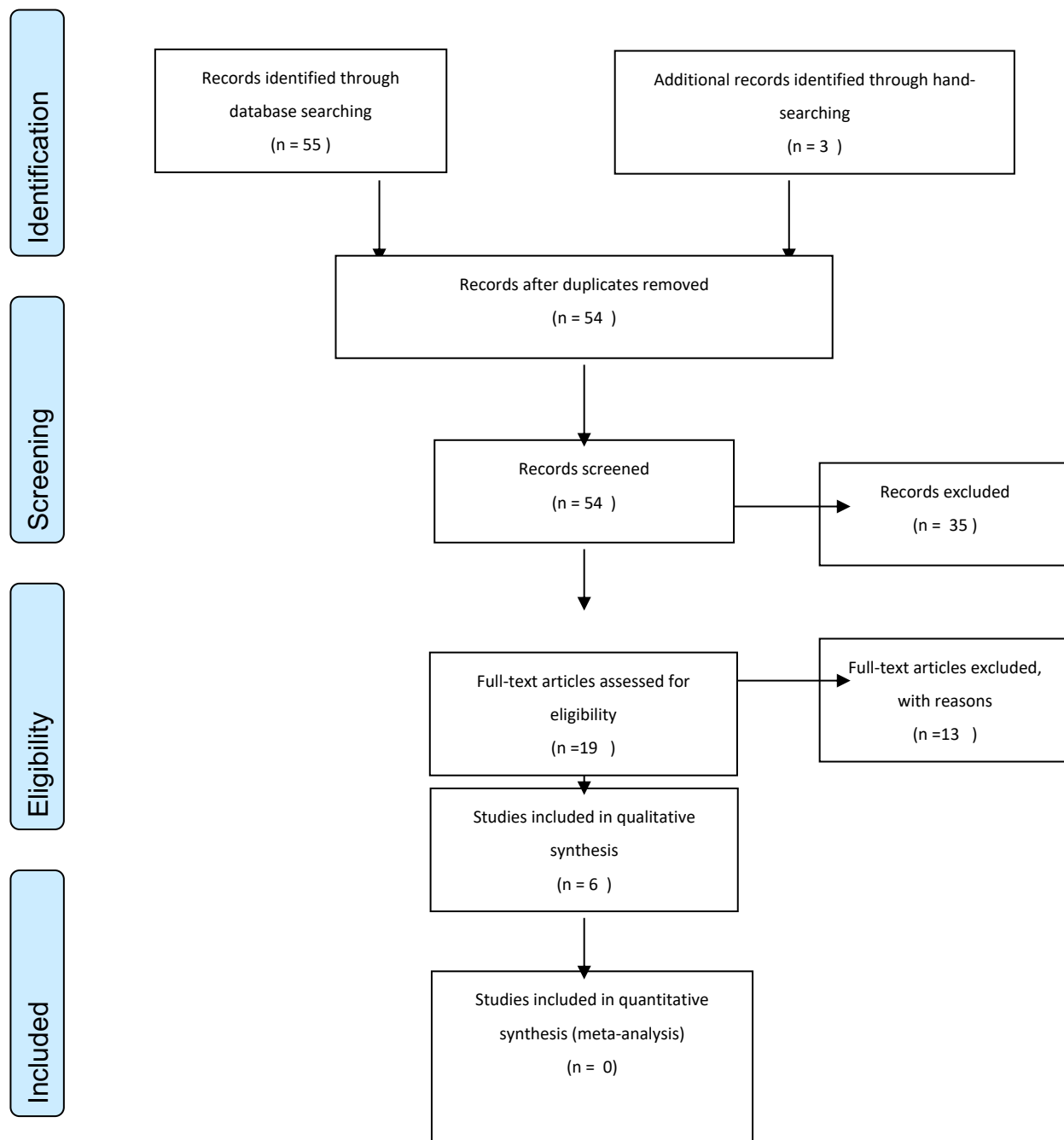


Figure 2: The PRISMA framework

Four databases (Eric, Ebsco, Psych Info and Scopus) were systematically searched from 3<sup>rd</sup> October to 12<sup>th</sup> December 2019. Hand searches of relevant journals, references and citations were also carried out.

The initial search yielded 54 studies of which 35 were excluded after screening. The remaining 19 (See *Appendix C*) were read in full and analysed using pre-defined inclusion criteria:

1. The study focused on CYP of compulsory school age (5-18) identified as having AEN.
2. Research was conducted in England
3. Studies focused on CYP involved in DMP in an educational context
4. Studies were published in a peer-reviewed journal
5. Qualitative and mixed method studies were included
6. Studies reported primary data
7. Studies were published between 2015- 12<sup>th</sup> December 2019.

13 studies were excluded leaving 6 papers to be included in the review.

### **1.2.3 Quality Assessment**

An assessment of quality was not carried out on the included studies for several reasons (See *Appendix D*):

- From a social constructionist epistemological position quality can be viewed as a constructed concept rather than fixed. Therefore, not assessing the quality of each study from a subjective position allows for consideration of the constructs and rationale of the researchers' chosen approaches. I accept there are several valid approaches to research and object to the notion of an objective criteria based on a fixed construct of perceived quality.
- Assessing the quality of the research may potentially exclude the experiences of young people which may provide rich and valuable insight.
- Including studies from a range of approaches can potentially achieve a higher level of abstraction (Britten et al., 2002).
- There is a lack of research in this area and therefore I want to consider all available research rather than reducing this on the basis of an externally imposed measure of quality.
- The synthesis of findings from the papers in this review intends to offer a novel, contextually based interpretation rather than fixed truth.

- Papers will be included on the basis that they are valid for my review (Aguinaldo, 2004).

Table 3: Descriptive summaries of included studies

Primary data within each study consisted of participant voice (Allan & Duckworth, 2018; Fayette & Bond, 2018a; Gaona, Palikara, & Castro, 2019; Rome, Hardy, Richardson, & Shenton, 2015), researcher voice (Gaona, Castro, & Palikara, 2019) and a mixed approach including both (Zilli, Parsons, & Kovshoff, 2019).

Article details	Research Focus	Sample (Who and how many?)	Setting	Study Method/ Design	Decision-making Process	How are CYP involved?	Findings
Allan, David Duckworth, Vicky (2018) <b>Voices of disaffection: Disengaged and disruptive youths or agents of change and self-empowerment?</b> <i>British Journal of Special Education</i> 45 (1), 43-60.	Bourdieu's concept of capital is used to explore 14-16 yr. old girls' perspectives undertaking a vocational course as a strategy for re-engagement	Ten 14-16 Yr. old girls Girls who were seen as disaffected and accessing a vocational learning programme	Vocational learning programmes in NE England	Semi-structured interviews Thematic analysis using an Interpretivist paradigm (Radnor 2002)	The CYP involved can choose a setting to attend and they can decide whether to engage in the learning there or not	The views of the CYP are sought in order to understand their experiences and how this relates to their autonomy	The participants sought to be heard in school but were not heard or what they had to say wasn't valued in school context. They feel valued and empowered in their vocational environment. Curriculum should be wide ranging to engage and include all. The participants reclaimed their agency through their own agency.
Fayette, Rainart Bond, Caroline (2018) <b>A Qualitative Study of Specialist Schools' Processes of Eliciting the Views of Young People with Autism Spectrum Disorders in Planning Their Transition to Adulthood</b> <i>British Journal of Special Education</i> 45 (1) 5-25.	This research explores CYP with ASD participation in transition process and planning for adulthood. 1. How do special schools elicit the views of young people with ASD in preparation for transition to adulthood? 2. To what extent are these processes perceived to be effective?	Nine teachers were interviewed and a transition meeting was observed in one school to explore these processes. Two parents of one YP going through transition were also interviewed.	Two specialist schools in the north-west of England	Multiple case study design (Yin 2013) Purposive sampling (Palys 2008) Audio-recorded semi-structured interviews. Thematic analysis, following the methods outlined by Braun and Clarke (2006)	The process of eliciting student's views as part of the decision-making process from the perspective of professionals working with YP with ASD wanting to ensure they are part of DMP to prepare them for transitions towards adulthood and how to do this effectively.	The CYP are part of a three phase person centred process Phase 1: Staff get to know the pupils Phase 2: Support pupils to make informed choices Phase 3: Elicit pupils' views	Effective processes of eliciting and including the views of young people with ASD require a person-centred ethos, and a commitment from all staff to elicit the pupils' views and develop processes that enable pupils to make informed decisions throughout their time in school. The findings also provided support for the use of communication tool. While the pupils' views are given 'due weight' throughout the decision-making process, it is only one of many factors that are considered in making the final decisions on what their transition to adulthood will entail. Final decisions still tend to be made by schools and LA due to limited resources
Gaona, Carolina Castro, Susana Palikara, Olympia (2019) <b>The views and aspirations of young people with autism spectrum disorders and their provision</b>	1. What were the methods used to capture the views of young people on their EHC plans? 2. What are the functioning dimensions identified as the views, wishes, and aspirations	Twelve CYP with diagnosis of ASD age 16-19 transitioning to post-16 settings	Secondary schools and FE providers in Greater London	Purposive sampling A systematic content analysis approach was used, first inductively, and then deductively using the International	CYP expressing views and future aspirations as part of the EHCP process	CYP gave their views in section A of the plan and this is mapped against the rest of the plan and analysed to see if their views are	At time of transition CYP in study wish for higher levels of autonomy in self-care, domestic life and mobility that would enhance participation in home, school and community life. Discrepancies in organisation and content of EHCPs across different Local Authorities (LAs). More specific guidance

in the new <b>Education Health and Care plans in England <i>Disability and Rehabilitation</i> 41 (6) 1-12</b>	of young people with ASD? 3. Does the provision as described in EHC plans match the aspirations of young people with ASD?			Classification of Functionality, Disability and Health: Children and Youth Version (ICF-CY) framework and codes to analyse the content of 12 EHC plans.		taken into account in provision mapping	and PCP approaches needed. Universal language needed. More consistency in matching CYP views with provision.
Gaona, Carolina Palikara, Olympia Castro, Susana (2019) <b>'I'm Ready for a New Chapter': The Voices of Young People with Autism Spectrum Disorder in Transition to Post-16 Education and Employment <i>British Educational Research Journal</i> 45 (2) 340-355.</b>	To explore the views of CYP with ASD in their transition to post-16 education and employment through semi-structured interviews, following an inductive thematic analysis. The focus is on understanding the meaning of the lived experiences of transitioning to post-16 education for individuals with ASD, in light of the changes introduced by the new SEND legislation in England.	Twelve CYP with diagnosis of ASD Age 16-19	Four secondary schools and one further education provider in Greater London	Semi structured interviews x 12. Thematic analysis.	Decisions about transitioning from school to post-16 education and how this links to important aspects of life such as independence, friendships, free time	CYP were asked about their experiences over transition period, including their feelings, experiences of decision-making processes etc. using visual formats such as talking mats to express views and opinions.	Themes of independence, ambivalence of feelings about change and the future, friendship and free time, family and school support and bullying constitute key descriptors of their experience and could help steer the conversation of transition. The findings of this study provide further evidence of the use of visual stimuli as communication support.
Rome, Aidan Hardy, Jessica Richardson, Jamie Shenton, Felicity (2015) <b>Exploring Transitions with Disabled Young People: Our Experiences, Our Rights and Our Views <i>Child Care in Practice</i> 21 (3) 287- 294.</b>	A paper written by CYP exploring transitions and CYP as decision makers	50 CYP age 12-19	CYP's human rights project based in NE England for CYP with disabilities.	Participatory research through 'Agenda Days' using interactive methods to explore issues raised by CYP. Facilitators write a report at end of day to sum up issues and share.	CYP as researches finding out about what peers with AEN thought about transitions and being part of DMP in this context	CYP conducted their own research as to what they would like to happen in transitions and how they would like to be involved in DMP and why	CYP said being informed, having a say in decisions affecting their lives, being listened to, being given time to get used to new situations and need for continuity were important themes which emerged. CYP felt it was the responsibility of adults to find ways of understanding CYP's views rather than CYP trying to make themselves heard.



<p>Zilli, Chantelle Parsons, Sarah Kovshoff, Hanna (2019)</p> <p><b>Keys to engagement: A case study exploring the participation of autistic pupils in educational decision-making at school</b></p> <p><i>British Journal of Educational Psychology.</i></p>	<p>To provide a detailed exploratory analysis of practices that enable autistic pupils to participate in educational decision-making, and to generate new knowledge about pupil participation in a school context.</p> <ol style="list-style-type: none"> <li>1. What school practices enable autistic pupils to participate in decision-making about their school experiences?</li> <li>2. How are the views of autistic pupils used to inform decisions about their school experiences?</li> <li>3. When do autistic pupils feel their voices have been heard</li> </ol>	<p>Four male pupils aged 11–15, with autism spectrum diagnoses, and eleven staff members</p>	<p>Specialist independent school for CYP with ASD, South of England</p>	<p>Observations were made of pupils in lessons, and pupils completed a 'photovoice' activity focusing on where they felt 'most listened to' in the school. Staff members participated in semi-structured interviews.</p> <p>Framework for Participation (Black-Hawkins, 2010) as an analytical frame.</p>	<p>How autistic pupils take part in day-to-day decisions in schools, such as what work to do or with whom they collaborate in the classroom.</p>	<p>Observations were made of pupils in lessons, and pupils completed a 'photovoice' activity focusing on where they felt 'most listened to' in the school.</p>	<p>A range of practices supported pupils' participation in everyday decision-making, underpinned by a respectful and positive culture led by the senior management team. The focus was on what learners can do and how they make decisions to facilitate achievement. Pupils and staff developed mutually respectful relationships, within which boundaries were negotiated and compromises offered. Flexibility through decision-making was provided within the timetabling and content of the curriculum. Pupils' special interests and expertise were valued as 'keys' to supporting their engagement.</p>
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#### 1.2.4 Data Synthesis and Extraction

The six final review papers are summarised in Table 3. A thematic synthesis approach (Thomas & Harden, 2008) was adopted involving three distinct stages:

- Stage 1: Coding of text in each study line by line
- Stage 2: Development of descriptive themes within and between each study
- Stage 3: Generation of analytical themes going beyond the primary studies to generate new interpretive constructs.

This method aims to preserve a transparent link between the primary studies and conclusions of the review and allows for generation of new ideas pertaining to my specific question as none of the included studies explicitly answer this.

##### Stage 1: Initial Coding

The six studies were entered into NVivo, (specialist software for use with qualitative data analysis). Initial coding of each study's findings was carried out line by line and free codes were generated inductively to try and capture the meaning of each sentence. I revisited each study several times leading to the creation of sub-codes as concepts which were translated from one study to another. This process was repeated until no new codes were generated. A total of 27 codes were created (See *Appendix E*).

##### Stage 2: The development of descriptive themes

Codes were grouped according to differences and similarities between them until a clear visual representation of key themes was formed (See *Appendix F*). Several codes were combined and the relationships between codes was further explored, which generated themes, and allowed for an overview of the contribution of each study towards themes (See *Table 4*). Revisiting the review question and exploring the emerging themes visually (See *Appendix F*) allowed for conceptualisation of the relationship between themes to capture the meaning of the initial codes and to move towards Stage 3.

##### Stage 3: Generating Analytical Themes

Under the overarching theme of 'Participation in DMP' four main analytical themes were constructed and several sub-themes within these. The review question was

Main Themes and Sub-themes	Allan, David Duckworth, Vicky (2018) Voices of disaffection: Disengaged and disruptive youths or agents of change and self-empowerment?	Fayette, Rainart Bond, Caroline (2018) A Qualitative Study of Specialist Schools' Processes of Eliciting the Views of Young People with Autism	Gaona, Carolina Castro, Susana Palikara, Olympia (2019) The views and aspirations of young people with autism spectrum disorders and their provision in the new Education Health and Care plans in England	Gaona, Carolina Palikara, Olympia Castro, Susana (2019) 'I'm Ready for a New Chapter': The Voices of Young People with Autism Spectrum Disorder in Transition to Post-16 Education and Employment	Rome, Aidan Hardy, Jessica Richardson, Jamie Shenton, Felicity (2015) Exploring Transitions with Disabled Young People: Our Experiences, Our Rights and Our Views	Zilli, Chantelle Parsons, Sarah Kovshoff, Hanna (2019) Keys to engagement: A case study exploring the participation of autistic pupils in educational decision-making at school	Number of studies contributing to theme
	1	2	3	4	5	6	
<b>The Decision-making Process</b>							
The Purpose of the decision	√	√	√	√	√	√	6
The process of the DMP	√	√	√	√	√	√	6
The outcome of the DMP	√	√	√		√	√	5
<b>The Context</b>							
Context of the immediate environment	√	√	√	√	√	√	6
Context of the wider environment	√	√	√	√	√	√	6
<b>Relationships</b>							
How CYP are viewed by adults	√	√	√	√	√	√	6
How adults are viewed by CYP	√	√		√	√		4
What supports/underpins these relationships	√	√		√	√	√	5
<b>CYP's Views</b>							
Audience/Being Listened to/ Heard	√	√	√	√	√	√	6
Views being acted upon	√	√	√		√		4
Contributions by each study	10	10	8	8	10	8	

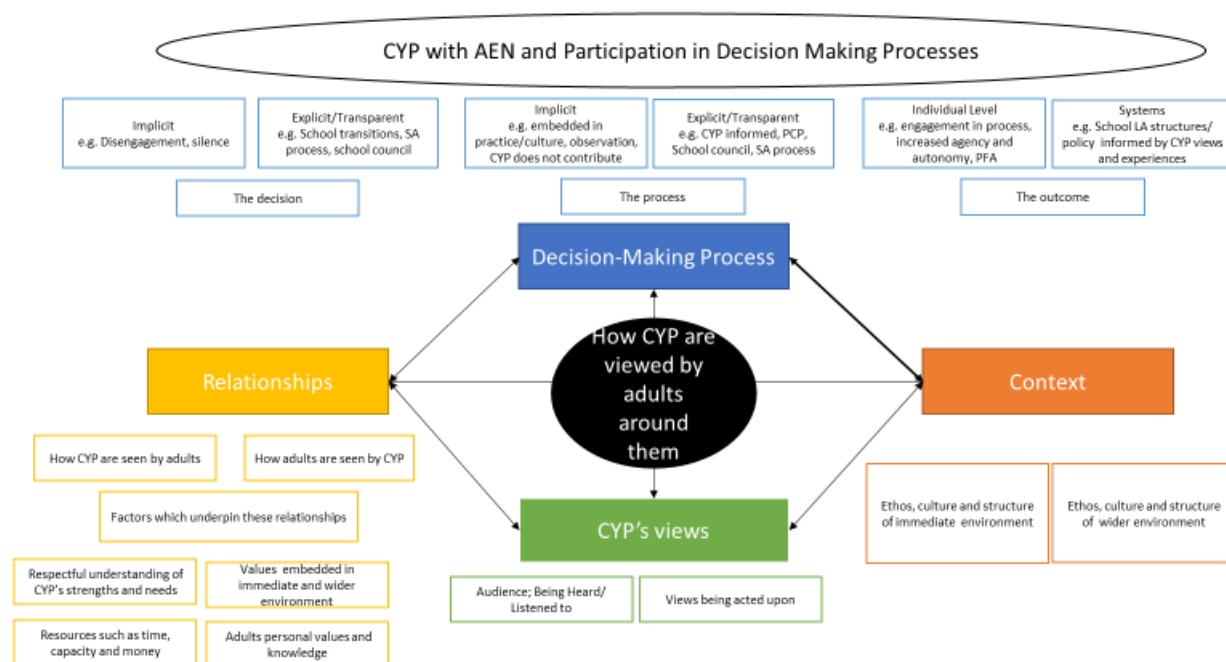
Table 4: Contribution of studies to each theme

revisited using the descriptive themes constructed through inductive analysis of the study findings.

Key factors underpinning DMP and CYP's participation in them appeared common in all 6 studies. Through exploration more analytical subthemes began to emerge and the relationship between these was mapped to address the review question. *Figure 3* presents four key themes and sub-themes and their relationships to one and other. A detailed description of the findings from the synthesis is provided in the following section.

### 1.3 Findings

This section describes the analytical themes and their relationships to one another, generated through thematic synthesis to understand the experiences of CYP with AEN of participating in DMP in an English educational context. Six qualitative studies were analysed (See *table 3*) which explored CYP's views (Allan & Duckworth, 2018; Gaona, Castro, et al., 2019; Gaona, Palikara, et al., 2019; Rome et al., 2015) or views of adults working with them (Fayette & Bond, 2018a) or both (Zilli et al., 2019) and their experiences of DMP within their contexts.



*Figure 3: Key themes emerging from a review of CYP with AEN and their participation in decision-making processes*

#### 1.3.1 Main themes

Under the overarching heading of 'CYP with AEN and participation in DMP' four universal and interrelated themes were identified; DMP, CYP's views, Context (in

which DMP occurred) and Relationships. These four main themes relate to a fifth central theme; how CYP are viewed by adults around them. A total of 22 sub-themes was identified (See figure 3). I will report the main themes below and explore them critically in the discussion section.

### **1.3.2 Main theme 1: How CYP are viewed by adults around them**

All papers consider the relationship between CYP and adults. Findings suggest that CYP can engage in implicit and explicit DMP in contexts where adults understand CYP's needs and make environmental adjustments. This is supported by adults building relationships with CYP and occurs when CYP are viewed as agentic.

Adults facilitate, develop and structure DMP at an exosystemic level and largely shape the proximal contexts where DMP take place. DMP in which CYP participate are underpinned by the relationships they have with adults. This central theme is interrelated to the four main themes and explored critically in relation to them.

### **1.3.3 Main theme 2: The DMP**

This theme focuses on the decision being made, the process involved, whether this is implicit or explicit to CYP, and the outcome of the DMP.

#### **The Decision**

Decisions described in the studies range from everyday decisions about participation in a learning context (Allan & Duckworth, 2018; Fayette & Bond, 2018a; Zilli et al., 2019) through to transitions between educational settings (Allan & Duckworth, 2018; Gaona, Palikara, et al., 2019; Rome et al., 2015) to contributing to formal processes like SAs where CYP's views are meant to inform DMP (Fayette & Bond, 2018a; Gaona, Castro, et al., 2019; Rome et al., 2015). Decisions were either explicit in their nature, where adults working with CYP were transparent about DMP, or they were implicit and often embedded in the everyday cultural context of the DMP, such as pupil-led lessons (Zilli et al., 2019).

Only one decision described was CYP-led (Rome et al., 2015); across the five other studies opportunity for decision-making was initiated by adults. CYP talked explicitly about decisions and felt their active role was important: "*Young people wanted to have a say in decisions affecting their lives and be listened to*" (Rome et al., 2015, p. 291). CYP were supported in developing agency through involvement in a range of decisions as illustrated in the sub-theme below.

## **The Process**

The process describes what happened for a decision to be made and varied depending on context. Aspects of the process which were important to CYP were being informed about the decision (Rome et al., 2015), and flexibility and choice (Zilli et al., 2019) in the DMP. Across all papers, being active in DMP required adult understanding of CYP's individual needs to inform how they might actively support their participation.

One study raised the importance of reflecting on the consistency of participation facilitation in statutory DMP (Gaona, Castro, et al., 2019). Such reflections indicate the concept of participation can be context dependent and varies between contexts.

## **The Outcome**

The outcome is the result of the DMP at an individual or wider systems level. Outcomes included improved attendance (Allan & Duckworth, 2018; Zilli et al., 2019), better engagement with learning, active participation in DMP in preparation for adulthood (Fayette & Bond, 2018a) and, at a systems level, shaping LA policy, structure and DMP (Rome et al., 2015).

### **1.3.4 Main theme 3: CYP Views**

#### **Audience, being heard and listened to**

The studies suggested CYP represented themselves in a variety of ways to their audiences, through their behaviour, vocally or with the support of facilitating adults and communication tools as part of the DMP and could be seen to give "... *valuable insights into what staff did that helped them to feel heard.*" (Zilli et al., 2019, p. 16)

Rome (2015) considered people with power to make change needed to be listening and open to acting on CYP's views: "*Attending the event were the Commissioning Manager from the local authority...and all of the key stakeholders in the services that young people will transfer into...*" (Rome et al., 2015, p. 292)

This was not the case across all the studies and researchers acknowledged the danger of tokenistic practices despite legislative requirements:

*"Broad statements such as 'he was present at the annual review meeting' appear to portray the young person's involvement in decision-making, as intended by the SEND Code of Practice; however, these portrayals do not provide enough evidence*

*of being the participatory, person-centred approaches to SEND advocated by the Children and Families Act 2014.” (Gaona, Castro, et al., 2019, p. 8)*

### **CYP’s Views being acted upon**

How CYP’s views were acted upon linked to how their views were represented and interpreted by adults. This ranged from not being listened to, being marginalised and silenced (Allan & Duckworth, 2018), not being represented (Gaona, Castro, et al., 2019), to being heard (Rome et al., 2015) and facilitated in participating in a person-centred way (Fayette & Bond, 2018a).

Misinterpretation of voice was considered to potentially disempower and disengage CYP in DMP (Allan & Duckworth, 2018). Two papers highlighted ways of avoiding misrepresentation by developing shared objectives with CYP (Allan & Duckworth, 2018) or revisiting CYP’s views to check for consistency (Fayette & Bond, 2018a). In one study CYP created a DVD to share with wider audiences within a LA and raised awareness of their views (Rome et al., 2015) which potentially negated the risk of misrepresentation.

### **1.3.5 Main theme 4: Relationships**

Key relationships were considered important in all aspects of DMP and were underpinned by a range of complex factors. Systems active within the wider environment influenced CYP and adult relationships in DMP: *“Teachers’ beliefs and practices can influence their perceptions of students’ abilities, resulting in a typologising of students, such as focusing on whether they can illustrate the recognised capital or not.”* (Allan & Duckworth, 2018, p. 54)

CYP were aware of adult perceptions and their sense of autonomy was affected by this positively, when they felt respected and valued by teachers (Allan & Duckworth, 2018) or parents (Gaona, Palikara, et al., 2019), and negatively when they felt potentially undermined when their views conflicted with adults’ (Fayette & Bond, 2018a).

Many studies reported that it took an attuned and timely approach to support relationship-building (Allan & Duckworth, 2018; Fayette & Bond, 2018a; Rome et al., 2015; Zilli et al., 2019) and to understand CYP’s needs and support them effectively in DMP (Fayette & Bond, 2018a; Zilli et al., 2019). Professionals reported that CYP’s views change over time and that it was important to recognise and act upon this (Fayette & Bond, 2018a).

Studies reflected on potential power imbalances between CYP and adults in DMP and suggested approaches, such as co-production, to address this (Gaona, Palikara, et al., 2019). Power imbalances were influenced by the systems within which DMP took place. Some systems were considered by researchers to view children as agentic and facilitated CYP-led research (Rome et al., 2015), while other systems, such as mainstream secondary school, potentially silenced and excluded children who were unable to operate successfully within them (Allan & Duckworth, 2018). Adults working with CYP often made decisions about what they perceived as best for the CYP (Fayette & Bond, 2018a; Gaona, Palikara, et al., 2019; Zilli et al., 2019) suggesting a power differential between adults and CYP can influence DMP.

### **1.3.6 Main theme 5: Context**

DMP were influenced by contextual factors including the CYP's own experiences, the relationships within the CYP's immediate and wider environment and the interrelated systems and structures at regional and national level. CYP, through participation in DMP, have direct and indirect influence on surrounding systems over time (Gal, 2017).

The contexts of the studies varied and the ethos of the immediate environment of the DMP was considered to affect CYP's feelings about, and engagement in, DMP (Allan & Duckworth, 2018; Fayette & Bond, 2018a; Gaona, Castro, et al., 2019). When CYP felt comfortable in their environment they engaged in DMP, even when the DMP concerned leaving that environment (Gaona, Palikara, et al., 2019; Zilli et al., 2019). This suggests the importance of DMP taking place within a safe space where CYP can participate.

Some CYP's negative experiences of mainstream education contrasted with more positive experiences within alternative provision. In such contexts some CYP were perceived as "... *empowered in their peer groups, and perhaps in their community, there is still a gulf between community and school status,*" (Allan & Duckworth, 2018, p. 56). This illustrates how wider political, economic, and educational systems can influence provision within the local community and CYP's experiences of it.

Through participation in DMP processes some CYP shared their socio-cultural values and lived experiences at local government level to help shape future policy as a result of SEND reforms (Rome et al., 2015, p. 293). In some contexts, DMP were clearly informed by national legislation and guidance, which advocates an approach



informed by the CYP's views and needs (Fayette & Bond, 2018a; Gaona, Castro, et al., 2019). Environmental factors such as funding (Fayette & Bond, 2018a), curriculum constraints (Zilli et al., 2019) and understanding and implementation of legislation and time (Gaona, Castro, et al., 2019) effected DMP. The contexts of DMP were constrained by policy and legislation and budget set at a national level.

## **1.4 Discussion**

This review aimed to identify what participation in DMP looks like for CYP with AEN in an English context since legislative reforms about CYP's rights in relation to DMPs came into effect in 2014. Research which explores CYP's lived experiences, as opposed to perceptions of these experiences by adults involved, since legislation and guidance changes, remains limited. Overall only 6 studies which met the inclusion criteria were identified. It is noted that four out of six papers specifically focused on participants with autism, perhaps highlighting an increase in focus on research on this particular area of SEN in relation to DMP.

The review highlights the importance of how both participation and CYP are conceptualised by adults around them within the context of DMP and how this influences the DMP and the CYP's agency within that process. This is further shaped and underpinned by the relationships around the CYP which support their participation in the DMP and the CYP's own views and experiences. How CYP with AEN are conceptualised links closely to their participation in DMP and is influenced by four key factors (*see figure 3*):

- The context of DMP
- How the CYP are viewed by adults around them as part of DMP
- CYP's relationships with adults around them
- CYP's lived experiences and their expressions of these

### **1.4.1 The context of DMP**

CYP's participation in DMP which affect their lives relates to factors beyond their context and control such as personal characteristics (Fayette & Bond, 2018a; Zilli et al., 2019), parental views (Gaona, Castro, et al., 2019; Gaona, Palikara, et al., 2019), other relevant adults views (Allan & Duckworth, 2018; Zilli et al., 2019) and the structures of systems at organisational, local and national level (Gaona, Castro, et al., 2019; Zilli et al., 2019). An ecological systems perspective (*see figure 4*) explores

the interrelated system around a child through concepts of process, person, context and time (Bronfenbrenner, 2006).

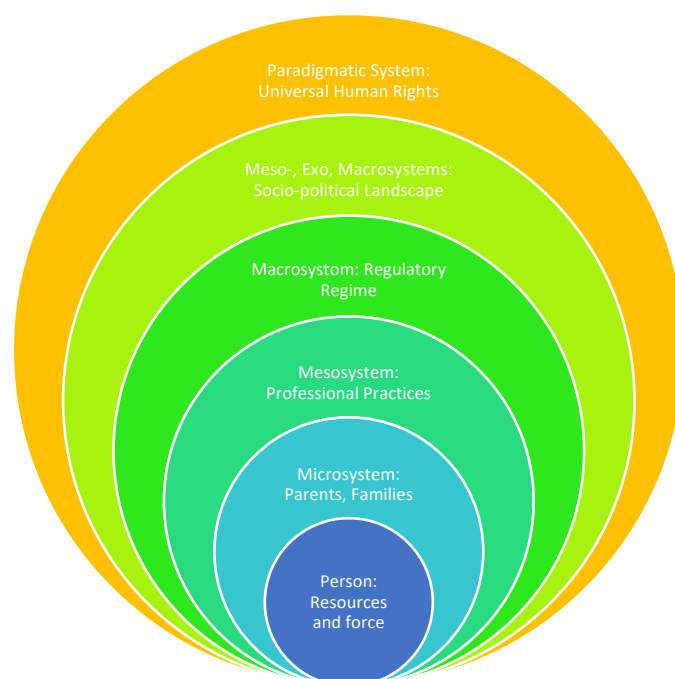


Figure 4: Understanding Children's Ability To Participate: An Ecological Model (Gal, 2017).

Gal's (2017) adaptation of this (see *figure 4*) provides a helpful framework for understanding the review findings and how they influence/are influenced by context and by CYP in the DMP as illustrated in the *table 5* below.

Environmental Context	Meaning	Findings from review about what influences DMP
<b>Person</b>	-the characteristics and resources available to the CYP and of the CYP	<ul style="list-style-type: none"> <li>Agency and capital of CYP (Allan &amp; Duckworth, 2018; Rome et al., 2015; Zilli et al., 2019)</li> <li>CYP's understanding of themselves (Allan &amp; Duckworth, 2018; Fayette &amp; Bond, 2018a; Gaona, Palikara, et al., 2019; Rome et al., 2015)</li> <li>CYP's communication of thoughts and feelings as part of DMP (Allan &amp; Duckworth, 2018; Gaona, Palikara, et al., 2019; Rome et al., 2015)</li> </ul>
<b>Microsystem</b>	- family characteristics, dynamics and interactions with CYP	<ul style="list-style-type: none"> <li>How family views CYP (Allan &amp; Duckworth, 2018; Gaona, Palikara, et al., 2019)</li> <li>Working with family and family's views of what is best for CYP (Gaona, Castro, et al., 2019; Gaona, Palikara, et al., 2019)</li> </ul>
<b>Mesosystem</b>	-environments external to the family that CYP has direct contact with	<ul style="list-style-type: none"> <li>Adults working with CYP who understood their AEN (Allan &amp; Duckworth, 2018; Fayette &amp;</li> </ul>

		Bond, 2018a; Gaona, Castro, et al., 2019; Gaona, Palikara, et al., 2019; Zilli et al., 2019) <ul style="list-style-type: none"> <li>• How adults view CYP (Allan &amp; Duckworth, 2018; Fayette &amp; Bond, 2018a; Gaona, Castro, et al., 2019; Gaona, Palikara, et al., 2019; Rome et al., 2015; Zilli et al., 2019)</li> </ul>
<b>Exosystem</b>	- Areas which the CYP has no direct contact but which significantly influence the CYP's development	<ul style="list-style-type: none"> <li>• Policy and processes such as EHCP assessments (Gaona, Castro, et al., 2019; Rome et al., 2015)</li> <li>• Funding and resources available for CYP and DMP (Fayette &amp; Bond, 2018a; Rome et al., 2015)</li> <li>• Transitions between settings (Allan &amp; Duckworth, 2018; Fayette &amp; Bond, 2018a; Rome et al., 2015)</li> <li>• Opportunity to work at an exosystem level influencing policy and practice (Rome et al., 2015)</li> </ul>
<b>Macrosystem</b>	-larger social, political and legal forces affecting CYP and their families	<ul style="list-style-type: none"> <li>• The influence of legislation and guidance such as CFA (2014), UNCRC and COP (2015) (Allan &amp; Duckworth, 2018; Fayette &amp; Bond, 2018a; Gaona, Castro, et al., 2019; Rome et al., 2015)</li> </ul>

*Table 5: An ecological systems understanding of review findings*

The socio-political landscape surrounding CYP and DMP is multi-layered and effects all systems around a CYP; including the influence of political ideologies on the DMP, how CYP sit within these ideologies and how this influences the professionals who work with CYP and the contexts the CYP are situated in (Gal, 2017). Political ideologies shape how CYP are seen by adults in terms of their value to society and those deemed to have less to offer can be less valued within their context or systems (Bradbury-Jones et al., 2018; Hartas, 2011; McKay, 2014). This wider societal context can impact on how CYP in DMP are viewed; for example disaffection can be seen as intrinsically related to exclusion from education, training and employment and, ultimately, to reduced civic participation (Hartas, 2011), such as in DMP which affect their lives.

Formal processes of DMP such as SA, perhaps serve to construct a conceptualisation of CYP and participation stemming from political ideology where CYP are seen as supported and active in sharing their views. On the basis of this review, this often contradicts the reality of CYP's lived experiences. It is important to note that in some instances CYP participation in DMP is simultaneously restrained by rigid process structures (McKay, 2014) and external factors such as time and

resources available (Riddell et al., 2019) impacting on the extent to which they are able to participate.

All DMP sit within a cultural and historical context which shapes understanding of what these processes mean to those involved; this includes CYP (Thomson, 2011). Consideration by adults of the contextual influences which are active in DMP and CYP's understanding of these may support a DMP which is meaningful for all involved.

#### **1.4.2 How the CYP are viewed by adults around them as part of DMP**

CYP's level of participation appeared to relate to how participation is conceptualised by those involved in DMP. Adults who work with CYP with AEN in DMP arguably understand participation based on the systems which are active around them (Gal, 2017) and their experience of these systems. Participation is often conceptualised as an explicit action rather than embedded in the ethos of the context in which it takes place. Findings reflect how participation differed between contexts and did not always comply with legislation and policy guidance.

It is important to remember it is the right of a CYP to be involved in DMP and not a gift to be given by adults working with them (Lundy, 2007). The UNCRC has been adopted in a number of countries and has supported a re-conceptualisation of the relationship between CYP and adults in which CYP are viewed as agentic and actively engaging with the social, political and economic worlds around them (James, 2007). This disrupts preconceptions about the dependence of CYP on adults for guidance and protection and the power balance between the two groups (Bradbury-Jones et al., 2018). Review findings illustrate that CYP with AEN are agentic as decision-makers in their lives and the world around them when adults recognise their agency.

CYP with AEN often rely on the advocacy of others to participate in DMP. This problematises the idea of CYP as active participants in their own right (McKay, 2014). Adults working with CYP as part of DMP possess epistemic agency (Sewell, 2016) in their privileged knowledge of systems which support understanding and structure of DMP. Adults, therefore, are responsible when CYP are epistemically excluded (Sewell, 2016). Thus it is important that CYP are seen as active partners in the DMP and have the information needed to participate fully (Thomson, 2011). Hearing children respectfully involves affording them credibility as "knowers" (Murriss,

2013, p. 257), and supports their agency to make thoughtful decisions about practices of which they are a part.

Embedding meaningful participation of CYP with AEN in policy and organisational culture potentially changes how CYP and adults view each other. This review's findings suggest when CYP were active in explicit DMP they had been embedded in the ethos of the DMP contexts. CYP are supported in the DMP process by adults who understand their individual needs and who listen, notice and facilitate all forms of communication, support CYP in being informed about the DMP, avoid misrepresentation and who are reflexive in their practice (Bradbury-Jones et al., 2018; Thomson, 2011).

#### **1.4.3 CYP's relationships with adults around them**

Relationships which support effective participation within this review are built on trust and respect and occur when CYP are supported and encouraged to participate and given clear and transparent information about the process (Bradbury-Jones et al., 2018; Gal, 2017). The relationships CYP have with others in DMP are often influenced by parental views (Harris & Davidge, 2019) and contextual factors such as curricula or behaviour policies (Bradbury-Jones et al., 2018). These factors can potentially marginalise CYP in DMP. Professionals' perceptions of CYP with AEN and their motivation and skill at working with them appear to be key factors in supporting CYP with AEN participation DMP (Gal, 2017; Hartas, 2011).

#### **1.4.4 CYP's lived experiences and their expressions of these**

This review's findings show CYP's participation in DMP is shaped by their experiences within immediate and wider systems around them. CYP understand participation in the context of the socio-political structure within which they are situated. Their perceptions and those of the adults around them and their context varies over time (Gal, 2017). CYP who choose not to participate in DMP are often perceived as disaffected, or pathologised rather than being seen as influenced by systemic factors which effect their participation (Bradbury-Jones et al., 2018; Hartas, 2011). Findings suggest that when there is a contextual shift in the way CYP are perceived by others this affects the CYP's lived experience and their own self-perception.

This suggests that by viewing CYP as expert in their own lives and respecting their views, adults working with CYP in DMP can avoid abuse of power.

Different perspectives bring different meanings to the DMP context. Making meaning from CYP's views in DMP can be problematic. Adult interpretation is not value free and in ascribing meaning to a CYP's view further meaning is added (Thomson, 2011) highlighting the tension between acting to empower and to control (Fielding, 2004). Adults working with CYP have a legal responsibility to listen and an ethical responsibility to recognise the impact of the imposition of their own assumptions as frameworks by which to understand others (Levinas, 1981).

In contexts where participation is conceptualised as a process which is not solely reliant on verbal expression through language (Allan & Duckworth, 2018; Fayette & Bond, 2018a; Rome et al., 2015; Zilli et al., 2019) then AEN need not be perceived as a barrier for CYP participation in DMP. CYP with AEN can make-meaning through DMP and communicate this to others with varying degrees of participation, adult support, and representation. Review findings suggest participation is often linked closely with agency and that non-participation and silence can also be ways of participating and sharing views and voice (Allan & Duckworth, 2018; Bradbury-Jones et al., 2018; Thomson, 2011).

In contexts where CYP were listened to respectfully as part of DMP they were perceived as experts in their own lives. The importance of this perspective is summed up by Rome et al. (2015):

*"... disabled children and young people have a valuable, insightful and important contribution to make. It also demonstrates that it is the responsibility of adults to find ways of understanding young people's views, rather than children and young people trying to make themselves heard."* (p.293)

Adults working with CYP with AEN as part of DMP need to consider approaches which support critical and reflexive practice (Billington, 2006) in order to acknowledge how individual CYP are perceived within their context and the range of complex factors (See figure 3), as suggested by the review findings, which underpin this.

#### **1.4.5 Limitations of the current review (Strengths and limitations of the included studies and the review process)**

The thematic synthesis framework guided this review. This is an emerging framework and analysis, and interpretation of included studies and their findings is subjective.

This SLR was carried out by one researcher and further interpretations may have added depth and meaning. However, findings are not presented as truth, but as an interpretation. Therefore the crucial issue is transparency to ensure readers can see how this interpretation was reached (Arruda, 2003). A small number of studies met the inclusion criteria for the review, highlighting the lack of research exploring CYP with AEN in DMP in an English context.

## **1.5 Conclusion and implications for practice and research**

### **1.5.1 Implications for future practice**

Review findings suggest that professionals need to consider how CYP with AEN are conceptualised within the systems in which DMP take place and how this relates to the conceptualisation of participation in light of COP (2015) and CFA (2014) reforms. The use of frameworks (Gal, 2017; Lundy, 2007) to guide DMP and explicit training about participation may support professionals working with CYP with AEN in guiding their practice and CYP through such processes.

Adults working with CYP need space and time to reflect on practice and values. This supports a criticality both of the context and the DMP in which CYP are expected to participate (Billington, 2006; Lundy, 2007). It is also important to consider the discourses which influence those involved in DMP. This includes reflexivity in ascribing meaning to CYP's views, and views of others involved in the DMP and working towards a shared agreement of what has been said and what this means going forward (Thomson, 2011).

### **1.5.2 Implications for research**

Policy and legislation in England position CYP centrally within DMP. Their experiences are key to understanding how professionals can better support meaningful participation within DMP through developing an understanding of effective practice and barriers to participation. Much existing research focuses on adults' experiences of DMP rather than those of CYP with AEN.

### **1.5.3 Conclusions**

This review aimed to explore CYP with AEN's experiences of being part of DMP in an English context, following legislative and policy reforms which place their views and participation centrally. Research which explores CYP's lived experiences, as

opposed to perceptions of these experiences by adult's involved, following changes in legislation and policy, remains limited. Findings suggest that DMP involving CYP with AEN in England are varied, and context driven. They are underpinned by adult understanding of CYP needs, positive and open relationships which support active participation. They are underpinned further where DMP are valued within the culture of the environment in which they take place. DMP and CYP with AEN may be better supported in the future by adults who approach such processes with criticality and reflexivity.



## **Chapter 2: A critical consideration of research methodology in relation to my empirical project**

### **2.1 Introduction**

Chapter 2 provides a critical consideration of research methodology in relation to my study of the experiences of girls with Autism Spectrum Disorder (ASD) in taking part in decision making processes (DMP) in relation to educational planning. Chapter 3 will provide a detailed warrant and rationale for my research topic and will set out my precise methods; this will not be included here. In this chapter I will lay out my own epistemological stance. I will relate the findings from my systematic literature review (SLR) in Chapter 1, to my methodological approach. I will then explore the practical and ethical complexities which underpin the approach to and design of my study.

#### **2.1.1 Terminology**

There is a diversity of preference around the terminology used to refer to people with autism. Research carried out in the UK autism community showed consensus on the terms 'autism', 'on the autism spectrum' and 'autism spectrum disorder' (Kenny et al., 2016). Kenny et al (2015) suggest professionals prefer to use 'person first' language, however many people with autism felt that their autism was an intrinsic part of their identity and preferred terminology such as 'autistic person' which reflects this. There is no universally accepted way of describing autism and this will be reflected in my varied use of terminology (Cascio, Weiss, & Racine, 2020).

### **2.2 Literature review and implications for research**

#### **2.2.1 Findings from my SLR**

Findings suggest a lack of research in an English context concerning the participation of children and young people (CYP) with additional educational needs (AEN) in DMP in education, and most existing research focuses on adult perspectives. English legislation positions the views of CYP with AEN as integral to DMP in education; thus, their experiences of such processes are vital to informing practice which supports CYP to actively participate in DMP affecting their lives. It is important to explore what effective support for CYP engaging in DMP looks like and the barriers to this. This may inform professionals as they implement change and support CYP to be agentic in their lives.

The findings of my literature review suggest that how DMP, and CYP with AEN, are perceived by adults around them influences their participation in such processes. CYP can actively participate and have influence in DMP where they and their needs are understood in ways which support active involvement. This involves valuing CYP as autonomous agents and giving their views due consideration in DMP. My research is underpinned by assumptions which consider CYP as expert in their own lives and aims to privilege their own accounts of their experiences and to value their participation in sharing these experiences.

### **2.2.2 Researching with autistic CYP**

CYP with disabilities highlight that they are often excluded from participation due to the adult perception that it is too hard to make necessary adjustments which support their participation in DMP (VIPER, 2013) or research. It is the role of the researcher/practitioner to develop and adapt appropriate methods to support all CYP to engage in such opportunities (Bradbury-Jones et al., 2018; Fayette & Bond, 2018b).

Within the wider literature about researching the experiences of CYP it is noted those with disabilities are less commonly involved in research and there is a need for inclusive, adaptable research design and methods which support participation (Bailey, Boddy, Briscoe, & Morris, 2015). This requires consideration of autism-associated barriers to research participation, such as communication and interaction difficulties (Fayette & Bond, 2018b); including idiosyncratic use of language, difficulties engaging in reciprocal conversations, heightened feelings of anxiety, finding it hard to recognise and express emotions (Preece & Jordan, 2010), inflexible thinking and difficulty processing abstract concepts and disliking change (Beresford, Tozer, Rabiee, & Sloper, 2004). The voice of autistic girls is further underrepresented in the research body about autistic CYP's experience (Gould, 2017; Tomlinson, Bond, & Hebron, 2019). This may be because females with autism are often underdiagnosed compared to males due to differences in presentation and a diagnostic gender bias (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015; Loomes, Hull, & Mandy, 2017) in the literature.

## **2.3 Research design and my epistemological position**

### **2.3.1 Epistemology and research design**

In order to evaluate the contribution of this study to the knowledge-base, it is important to have a clear understanding of the epistemological basis of the study's research methods (Willig, 2013). I have adopted a qualitative approach which reflects a social constructionist epistemological position as the basis of my research design which aims to gain a better understanding of the experiences of girls with ASD in DMP. This will emphasise identifying meaning, perspectives and understanding (Goodall, 2019; MacLeod, 2019; Willig, 2013) from the participants' unique lived experiences. In an attempt to ensure transparency (Arruda, 2003) in the research, I aim to explicitly address how I conceptualise CYP, my role as interviewer and the process through which I create meaning from interview data (Wescott & Littleton, 2005). This will be explored further below. This section will consider my position as a researcher and how this might impact upon the research process and participants.

I am writing and researching from a paradigm where CYP are considered agentic and where their unique views and experiences are valued in contributing to and extending knowledge bases of a wide variety of phenomena (Bradbury-Jones et al., 2018; Christensen & Prout, 2005; James, 2007; Kellett, 2010; Lundy & McEvoy, 2012). This approach seeks to avoid epistemic injustice (Murrells, 2013) and supports CYP's right to express their views and for these views to be considered by adults with critical reflection (Bae, 2009; Siraj-Blatchford & Siraj-Blatchford, 1997). This will involve consideration of my role as researcher and how my own views and bias may affect my research (Murrells, 2013). It is also important to consider that agency can be seen as, at least partly, determined by factors such as social circumstances and cultural context (Hammersley, 2017) which may limit the extent to which it may be exercised by CYP.

### **2.3.2 Quality and validity**

It is important to consider the validity of this research and the extent to which it describes and explores the phenomena it sets out to and whether it tells the reader anything important, interesting or useful about the phenomena (Kacprzak, 2017). The research process can be viewed as both rigid and fluid in nature (Arruda, 2003) and fixed notions of validity and quality do not align with this.

I adopted Interpretative Phenomenological Analysis (IPA) (J. Smith, P. Flowers, & M. Larkin, 2009) as a research approach to gain insight into participants' experiences evidenced by the representation of these in an interpretive narrative form which

attempts to provide a structured form of meaning (Danaher & Briod, 2005). The fluid nature of a qualitative approach provides space to address validity issues through discourse with participants involving exploration and challenge. Further validity stems from the real-life setting of the research and reflexivity (Willig, 2013) of the researcher. Several frequently cited frameworks offer approaches to assessing the quality of qualitative research (Elliott, Fischer, & Rennie, 1999; Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2017; Yardley, 2000) which often propose a systematic presentation of analysis which is reflexive and grounded in data and a transparent awareness of the theoretical and contextual space of the research and the implications of this (Smith et al., 2009; Willig, 2013).

Transparency throughout the research process provides a basis for the reader to conceptualise validity through their own interpretation, without the need for a formal framework which can be seen as a fixed construct (Arruda, 2003). This also reflects the notion that there is no fixed point which can be triangulated to enhance understanding in research. Different voices contributing to the research reflect differing positions and there is no assumption that some are 'truth' and others are not. (Greene & Hogan, 2005). Through accessible research records which create a coherent and rigorous chain of evidence (*See appendices L-M*) (Smith et al., 2009; Yin, 2014) I will support transparency and reflect upon issues of validity and quality without prescribing to a fixed notion of perceived quality.

### **2.3.3 Children's rights-based approach**

My approach was informed by Lundy and McEvoy's (2012) approach to children's rights, in relation to the UNCRC, as specified below, in which:

*"Children are given information (Articles 13, 17 of UNCRC) and adult guidance (Article 5 of UNCRC) while their views are in formation, in order to be assisted in determining and expressing what will then be both a formed and informed view (Article 12 of UNCRC)."*(p. 140)

I aimed to support CYP to be informed participants with space and agency to consider, develop and express their own views as part of this research project. I also started from the position that CYP are experts in their own lives (Dockett & Perry, 2007). Lundy's (2007) model, which conceptualises article 12 of the UNCHR, underpinned my approach to support meaningful participation for CYP in this research context (*see figure 5*).

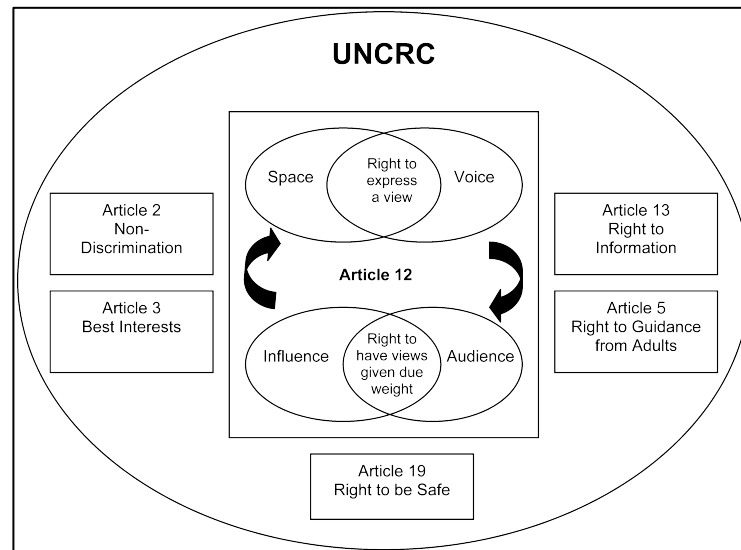


Figure 5: Conceptualising Article 12 of the UNCRC (Lundy, 2007)

I viewed CYP's experience of being part of DMP as their right enshrined in CFA 2014 and the UNCRC. Research suggests CYP support the rights agenda (Riddell et al., 2019) and consider autonomy in DMP which affect their lives as important to them (Lundy, 2007; Rome et al., 2015; VIPER, 2013). I recognised that conceptualisation of participation is complex and goes beyond the children's rights agenda. In this research I took the view that CYP's right to participate is a given and not something to be or debated in the context of its merits or disadvantages.

#### 2.3.4 Methodological approaches to support research with autistic people

Research over the last decade has explored different methodological approaches to overcome barriers and support autistic CYP's participation in research and contribute their experiences to the growing knowledge base. Such methods include an individualised approach and consideration of how to support participants in giving (or not giving) informed consent, thinking carefully about use of language and question structure to support participant understanding and engagement and creative and flexible methods to support participants to share their views, including the use of technology (Harrington, Foster, Rodger, & Ashburner, 2014; Scott-Barrett, Cebula, & Florian, 2019). Due consideration of power dynamics, the nature of the research relationship and how the research is disseminated are also important (Fayette & Bond, 2018b; Scott-Barrett et al., 2019). In designing this research, I have considered this literature and used it to inform decisions I reach about the research process.

People with SEND, specifically those with ASD, including girls, are not an homogenous group (Tomlinson et al., 2019). Research methodology must reflect this and focus on individuals as unique beings, avoid making assumptions about ASD (Harrington et al., 2014; Scott-Barrett et al., 2019) and demonstrate understanding of what ASD means to different people in different contexts.

In considering how data is gathered and analysed, in the context of researching the experiences of girls with ASD, IPA was chosen as an appropriate method (MacLeod, 2019). IPA focuses on the importance of individual experience and acknowledges that individuals place meaning on all they experience and this warrants exploration in its own terms (Smith et al., 2009), especially in the context of under researched areas. Lack of research about autistic CYP's experiences, especially that of girls, highlights a lack of knowledge base to support understanding of how girls with ASD experience different aspects of their lives and what this means.

Use of IPA acknowledges the limitations of attempting to understand the inner-world of another and recognises that participants' accounts offer a valid interpretation of a phenomenon which is contextualised further and interpreted through the researcher's analysis (Smith et al., 2009). This double hermeneutic acknowledges the differences between the researcher's and participant's experiences of the world (MacLeod, 2019) allowing for the development of new knowledge which considers this relationship in order to further understanding.

The transient nature of 'voice' is important in the context of research interviews, as views shared by a participant in one instance may change and be influenced by context (Thomson, 2011). Consideration of social context supports meaning-making from participants' views (Willig, 2013). Further understanding is supported by reflexivity about the extent to which language may construct, rather than describe an experience. A social constructionist lens supports the view that the description of an experience is a version of that experience which is constructed at a given moment in time (Wescott & Littleton, 2005; Willig, 2013). This research regards CYP's views as a snap-shot of their views at a given moment in time and not as a finite truth and will sit within the sequential context of their interview to support understanding of context and validity of meaning (Silverman, 2019).

IPA supports creative methods and flexibility in generating research data (Smith et al., 2009) which sits comfortably alongside suggestions for methods for conducting

research with autistic CYP from the literature in this area. IPA offers a holistic analysis method which values individual experience. IPA acknowledges that externally-imposed ideas, such as sharing information with participants to support their understanding of the research topic, may offer support in making sense of the experience (MacLeod, 2019).

Without research approaches which support autistic people to share their experiences, there is a danger that the autism knowledge-base will be informed by non-autistic people and imposed upon those with ASD (Milton, 2012). In the existing knowledge base about autistic CYP, much of the literature focuses on male presentation of ASD, leading to a potentially male biased knowledge-base. This highlights the importance of developing approaches to research which facilitate the participation of autistic females. Accessible versions of my research will be made available to participants (and their families) as I view them as autistic stakeholders (MacLeod, 2019) and hope that by sharing this I will show my appreciation for their participation and reflect that the research could not have taken place without their contribution.

### **2.3.5 Adapting to research during a pandemic**

Nationally imposed social restrictions due to COVID-19 during 2021 prevented face to face interviewing. This presented an opportunity to explore virtual ways of conducting research and adapting them to meet the needs of potential participants. The use of online video-calling platforms in research is a relatively new and growing phenomenon (Adams-Hutcheson & Longhurst, 2017; Sipes, Roberts, & Mullan, 2019; Webber, 2020).

Research conducted virtually reduces the relational and sensory aspects which may be experienced during face to face interviewing (Adams-Hutcheson & Longhurst, 2017). It could be argued, that in the context of conducting research with autistic CYP this may be an advantage as the challenge of some social experiences (Preece & Jordan, 2010) as well as heightened sensitivity to the sensory environment (Sproston, Sedgewick, & Crane, 2017) may be mitigated to some extent in a virtual context. Recent research however has suggested that autistic adults experienced sensory sensitivities, heightened cognitive load and anxiety when using video-calling platforms (Zolyomi et al., 2019). It is therefore important to consider a flexible approach which supports individual participants' choice to participate in a way in

which they are comfortable and effectively supported (Hill, 2006). The impact of digital interferences, such as poor internet connection (Adams-Hutcheson & Longhurst, 2017) can impact on research and should also be carefully planned for.

## **2.4 Research Methodology and ethical considerations**

It can be argued that the relationship between ethics and quality in practitioner research is intrinsic and fundamental (Groundwater-Smith & Mockler, 2007). Ethical approval was obtained from Newcastle University Faculty of Humanities and Social Sciences Research Ethics Committee and I adhered to BPS (BPS, 2018) ethical code. Ethics can be seen as an on-going process in which ethical dilemmas are considered and negotiated (Cutcliffe & Ramcharan, 2002). My methodological and ethical approach is further informed by Lundy's rights-based model of participation (See *Figure 1*), literature on children's participation within research and on research with autistic individuals (as outlined in this Chapter). This section aims to focus on ethical considerations beyond procedural requirements.

I considered procedural ethics as embedded in my decision-making throughout the research process (Guillemin & Gillam, 2004) and as informing ethical processes within this research. Procedural ethics, such as obtaining consent from parents and participants, are supported by ethical process which consider issues of consent with criticality. Such considerations include looking beyond formal consent for further signs of consent, such as perceived level of participant engagement, in case the participant has consented due to acquiescence (Preece & Jordan, 2010). Ongoing establishment of informed consent (Cutcliffe & Ramcharan, 2002) supported opportunities for participants to give or withdraw their verbal and written consent (Cascio et al., 2020) throughout the research up to the point of data analysis.

Transparency about my role and research intentions provided clarity about the nature of the participant/researcher relationship and a clear start and end to the research relationship (Cutcliffe & Ramcharan, 2002) supported by a visual timeline. Such transparency potentially mitigates risk of power imbalance through 'faking-friendship' (Duncombe & Jessop, 2002) for the sake of research. The ongoing process of researcher-reflexivity about researcher- participant relationships strengthens awareness of how power imbalance may influence the research process with CYP although this is not always possible to detect (Murriss, 2013). Checking in with participants about how they think and feel about the research process supported



reflexivity, as did reflection on practice throughout the research process (Fayette & Bond, 2018b).

Constraints of time and movement meant I was unable to apply a methodology which actively involved CYP beyond providing data (albeit with active involvement as to how they would like to do this), therefore my methodology cannot be considered participatory (Bishop, 2014). I sought to apply some of the principles of participatory research in that I employed a creative and flexible approach to facilitating the meaningful contribution (Bailey et al., 2015) of autistic girls to this research. I explicitly sought the views of autistic girls to acknowledge and address the privilege afforded to adult views about autistic girls in research (Bradbury-Jones et al., 2018; Fayette & Bond, 2018b).

My approach considered the need to provide participants with a safe and inclusive *space* to express views, appropriate information, guidance and means to express their *voice*, an *audience* who listened to their views responsibly and a commitment that their views were taken seriously and acted upon (*influence*) (Lundy, 2007). *Table 6* provides examples of how these were reflected in decisions taken in planning and implementing this research.

<b>Key Element of participatory Approach</b>	<b>Meaning</b>	<b>How this will be addressed in the current study</b>	<b>What this will look like in the current study</b>
<b>Space</b>	Children must be given a space to express a view	Participants identified a space where they would like to work.	Participants offered choice of being interviewed either at home or school
<b>Voice</b>	Children must be facilitated to express their views	Information in a format tailored to the individual participant's communication needs and a variety of resources to support expression was available to participants should they have chosen to use them.	Potential participants were supported to give informed consent through a medium of their choice. Participant's preferred method of communication was taken into consideration and acted upon. They were supported in sharing their views as 'informed' participants. Resources available to support this included; Social stories, comic strip conversations and video recordings to prepare participants for the interview; Talking Mats, pens and paper, Lego, Play Doh, computer technology, email, online chat function, self-recording and written responses to support expression of views during the interview.
<b>Audience</b>	The view must be listened to	Transparent approach to all aspects of young person's participation.	Participants were viewed as agentic and expert in their own lives. IPA was used to gain some understanding of participants' lived experiences. Findings were disseminated to participants in an accessible format such as providing a version for CYP and families which summarised the research using accessible language.
<b>Influence</b>	The view must be acted on, as appropriate.	Participant views were reflected authentically, supported by participant choice in setting and methods and inform my research. I was clear that I expressed their views through my interpretation and will use them to help inform future practice, at the very least within my work.	I was transparent with participants about my role and the potential influence of the research. Research disseminated as appropriate.

*Table 6: Key elements of participation adapted from Lundy (2007)*

Literature about research with autistic people suggests that addressing potential power imbalances is key to ethical practice (Cascio et al., 2020). My use of semi-structured interviews informed by IPA positions the participant as agentic and expert in their own experience (Bradbury-Jones et al., 2018; Milton, 2012) and intentionally seeks to empower the participant.

Open communication with participants fostered trust and respect and provided them with information which supported their practical understanding of the research and what it meant to take part (Lundy, 2007). This was further supported by my interest in participants' thoughts and experiences. Such an approach was supported through providing (*See Appendices J and L*)

- a video recording in which I explained the research process and what it involved for the participants;
- time and space to address questions and concerns;
- an accessible participant information sheet;
- the option of an initial video platform meeting with me, in which the participants chose to have the camera on or off and use the chat option; and
- time and space to make an informed decision about whether or not they wish to take part (Goodall, 2018).

This approach took into consideration the social and communication needs often associated with people with autism, provided a coherent link between my role as researcher and the research process and allowed for participants to choose how to interact, receive information, address questions and supported understanding (Scott-Barrett et al., 2019). In recognising individual participant's needs, for example, processing speeds and styles and preferred tools to facilitate dialogue, I recognised and respected individual diversity and actively supported participation. A transparent approach mitigated potential risk of deception and ensured participants had the opportunity to have all their questions answered and any further information they needed in advance of data collection so they were informed (Lundy, 2007).

## **2.5 Moving forward**

The nature of obtaining, representing and interpreting CYP's views in research is laden with ethical dilemmas. Through acknowledgement of the methodological considerations in this research I hope to support ethical, reflexive, and critical professional practice. This can be supported further by asking a series of questions when working with CYP as part of the research process:

*"How do we speak of children?  
How do we speak with children?  
How do we write of children?  
How do we listen to children?  
How do we listen to ourselves (when working with children)?"*  
(Billington, 2014, p. 113)

### **Chapter 3: The experience of girls with autism of being part of Education Health and Care Plan and Annual Review decision-making processes; “It's my health care plan I should know what's going on.”<sup>2</sup>**

#### **Abstract**

**Aims:** The aim of this research was to explore the experiences of girls with autism spectrum disorder (ASD), of being involved in their Education Health and Care Plan (EHCP) or Annual Review (AR).

**Rationale:** Autistic girls’ active participation in EHCP/AR processes is underpinned by international and English legislation and guidance. Recent literature suggests a need for high quality research to better understand the school experiences of girls with autism to support them in an educational context. Few studies include girls’ perspectives. Their lived experiences are key to understanding how to better support the active involvement of autistic girls in decision-making processes (DMP).

**Method:** A qualitative methodology guided by Interpretative Phenomenological Analysis (IPA) was adopted. Two participants took part in semi-structured interviews. Data was analysed using IPA.

**Findings:** Findings from IPA highlight how participants’ experiences of EHCP/AR processes are bound in the context of where they took place and how they had shared their views in the past; this in turn shapes their identity as learners. Neither participant had a clear knowledge of the EHCP/AR process as neither had been explicitly involved. The theme of language linked to the EHCP/AR processes as meaning was derived from the girls’ lived experiences. Much of the language linked to these processes held little meaning for the girls.

**Limitations:** Restrictions due to coronavirus impacted on recruitment and method of data collection. Participant responses were brief and perhaps impacted by the interview context and social and communication difficulties associated with autism.

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<sup>2</sup> ‘I have prepared this for submission to ‘The European Journal of Special Needs Education.’

**Conclusions:** Participants' experience appeared to be context-bound. Neither participant felt informed of the EHCP/AR process or supported to be actively involved. Without effective support, participants remained on the periphery of these processes. This reflects the power dynamics which are active within such processes and serves as a reminder that it is professionals' responsibility by law to support CYPs' active involvement in DMP

**Keywords:** autism, ASD, decision-making process, children's rights, participation, education health and care plan, annual review.

### **3.1 Introduction**

This chapter reports on empirical research which aimed to explore the lived experiences of girls with Autistic Spectrum Disorder (ASD) participating in educational planning through the Education Health and Care Plan (EHCP) and Annual Review (AR) processes. Recent literature suggests a need for high quality research to better understand the school experiences of girls with autism to support them in an educational context (Fayette & Bond, 2018b; Gaona, Castro, et al., 2019; Hebron & Bond, 2019; Tomlinson et al., 2019). Few studies include girls' perspectives (Cook, Ogden, & Winstone, 2018; Goodall & MacKenzie, 2019; Sproston et al., 2017; Tomlinson et al., 2019; Tomlinson, Bond, & Hebron, 2021): their lived experiences are key to understanding how to better support the active involvement of autistic girls in decision-making processes (DMP).

Autistic girls' active participation in EHCP/AR processes is underpinned by international and English legislation and guidance. The participation of children and young people (CYP) is also central in statute and guidance which inform EHCP/AR processes. In one study exploring autistic CYP's views there are discrepancies in autistic CYP's views and how they are reflected in EHCPs which merits further research (Gaona, Castro, et al., 2019) and this small scale exploratory study intends to respond to this.

#### **3.1.1 Terminology**

##### **ASD**

ASD is classified as a complex neurodevelopmental condition characterised by the presence of difficulties in social interaction and communication, and restrictive, repetitive and stereotyped patterns of behaviour, which cause clinically significant

impairments in different areas of functioning (APA, 2013). Diagnosis is often complex due to the heterogeneous nature of ASD and there is a wide spectrum of symptoms and characteristics common to those with autism which can also occur in people with other conditions (Hayes, Ford, Rafeeqe, & Russell, 2018). People with ASD present variable levels of performance and patterns of behaviour (de Schipper et al., 2015; Hayes et al., 2018).

The lack of universal agreement on describing autism (Cascio et al., 2020) is reflected in the terminology used to describe autistic individuals in this research and reflects findings from research within the UK autism community indicating preferences towards the terms 'autism', 'on the autistic spectrum' and 'autism spectrum disorder' (Kenny et al., 2016).

### **EHCP and ARs**

An EHCP is a document describing the needs of CYP with special educational needs and disabilities (SEND) and the provision needed to meet them within the English education system. The EHCP aims to focus on the individual's aspirations and support required to achieve them in educational, health and social care terms. EHCPs are underpinned by multiagency collaboration supporting development of an understanding of how to meet a CYP's needs and an expectation of joint-decision making about provision through participatory and person-centred approaches (Department for Education & Department for Health, 2015). EHCPs are subject to an Annual Review (AR) during which adjustments are required to be made according to need and underpinned by participatory and person-centred approach.

### **3.1.2 Background literature:**

#### **CYP's right to contribute to DMP in English SEND legislation and policy**

The rights of all CYP to express their views and contribute to decisions about issues concerning them are presented in Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) (UN General Assembly, 1989) which informs current key English legislation, policy and SEND guidance. The Children and Families Act (CFA) 2014 and SEN Code of practice 0-25 years (COP) (2015) centrally position parents/carers and CYP in DMP which affect them. Under current legislation CYP may request an EHCP assessment and must be kept involved in and informed of the process through

- consultation on proposed content and draft copy of the EHCP;
- being able to request specific provision; and
- inclusion of their views, interests and aspirations (Harris & Davidge, 2019).

The CFA 2014 stipulates that children's views are integral in DMP which affect their lives and they are entitled to the opportunity and appropriate support to express their views alongside assurance these will be listened to and acted upon (Harris & Davidge, 2019).

It is five years since these reforms came into effect and this research intends to explore the perceptions of girls with ASD, regarding how their rights are upheld in the context of EHCP/AR planning.

Recent research exploring how the CFA 2014 has impacted on CYP with SEN's participation in EHCP DMP in England highlights inconsistencies in interpretation and application of legislation across contexts. While reform supported some increased participation of CYP in EHCP DMP, barriers still remained, and it was unclear to what extent CYP's views were acted on (Riddell et al., 2019; Sales & Vincent, 2018).

### **Girls with ASD and DMP**

Recent research on autistic CYP's views and provision in EHCPs reflects Riddell et al's (2019) findings. The research suggests there are discrepancies at local, regional, and national level in equality and consistency of how CYP's views are represented and elicited in EHCP planning processes. It suggests a lack of evidence of person-centered approaches (advocated by the CFA 2014) being used in the EHCP processes (Gaona, Castro, et al., 2019). There is a lack of research about educational experiences conducted from the perspectives of CYP with ASD and even less research exists about the educational experiences of girls with ASD (Fayette & Bond, 2018b; Goodall, 2019). Such perspectives are key in order to inform policy and practice for supporting their participation in DMP (Cook et al., 2018; Goodall & MacKenzie, 2019; Moyse & Porter, 2015; Sproston et al., 2017; Tomlinson et al., 2019, 2021).

There is growing awareness in the literature that autistic girls can present differently to boys (Cridland, Jones, Caputi, & Magee, 2014; Lai et al., 2015). In particular, research suggests they are better at masking difficulties and appearing to cope within a school setting which can impact on their social emotional and mental health. Within

the autism literature there is recognition that less is known about the specific experiences of girls (Cook et al., 2018; Cridland et al., 2014; Tomlinson et al., 2019). This may be attributed to the under-recognition of ASD in girls (Loomes et al., 2017; Mandy & Lai, 2017) compared to males due to differences in presentation and a diagnostic gender bias (Lai et al., 2015; Loomes et al., 2017), misdiagnosis with conditions such as anxiety and depression and later diagnosis compared to males (Begeer et al., 2013). Furthermore, research is often conducted on the basis of the perspectives of autistic boys (Dean, Harwood, & Kasari, 2017), professionals working with autistic CYP or parents of autistic CYP (Goodall & MacKenzie, 2019; Sproston et al., 2017). The male to female ratio meeting the criteria for ASD diagnosis is estimated to be around 3:1 (Loomes et al., 2017) and thus deserves appropriate representation within the literature.

Findings from a related literature review indicate that the way CYP and DMP are perceived by adults around them relates to CYP's participation in DMP. When CYP's individual needs are understood and supported by a relational and dialogic approach in DMP (Fielding, 2004) this arguably recognises their right to active participation in their own lives. People with ASD are often excluded from DMP, consultation and research (Ellis, 2017; Pellicano, Dinsmore, & Charman, 2014). In England recognition of children's rights and legislation and guidance places an obligation on professionals to use inclusive methods to support all participants to share their views regardless of ability (Fayette & Bond, 2018b).

### **3.1.3 Aims of this study**

This research explored the experiences of girls with ASD of being part of the DMP as part of their EHCP/AR. Although I hope findings will support the development of inclusive practice in supporting girls with ASD to be active agents in their own lives in an educational context, this research design cannot be considered transformative (McNamee & Hosking, 2012). The study sought to address the following research question:

How do autistic girls experience being part of DMP which affect their lives in the context of the EHCP/AR processes?



## **3.2 Methodology**

### **3.2.1 Methodological Approach**

I adopted a qualitative approach reflecting a social constructionist epistemological position and explored meaning, perspectives and understanding from the perspective of participants' unique lived experiences (Goodall, 2019; MacLeod, 2019; Smith et al., 2009; Willig, 2013). This was supported by a creative and flexible methodological approach which considered and adapted to participants' individual needs.

### **3.2.2 Research design**

I conducted semi-structured interviews shaped and informed by Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) (See Appendix I). A range of descriptive, narrative, evaluative and contrasting questions were developed, based on the guidance of Smith et al. (2009). The semi-structured interviews were further shaped and informed by the use of methodological approaches to support autistic CYP's participation (Harrington et al., 2014; Scott-Barrett et al., 2019). I intended to reduce the potential power imbalance between myself and the CYP taking part by positioning participants as experts in their own experiences (MacLeod, 2019). I aimed to use methods that supported the acquisition of 'authentic' knowledge about children's subjective realities (Grover, 2004) at a given moment and allow participants to share their experiences through inclusive and accessible means in a space (Lundy & McEvoy, 2012) which they will have identified as feeling comfortable. Methods were accessible to the individual, attempting to support them in forming and sharing informed and considered views (See *figure 6*).

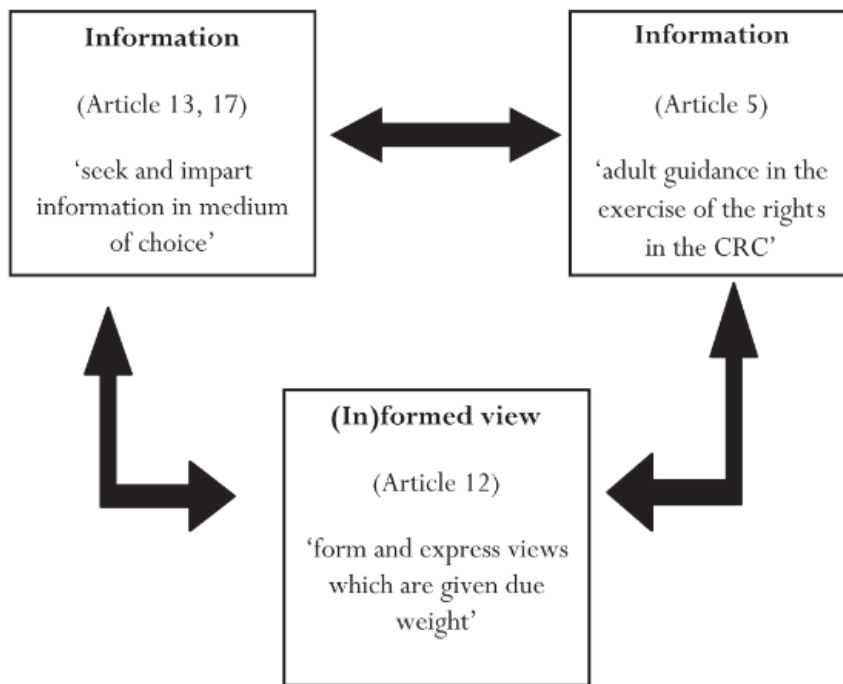


Figure 6: Assisting Children to an (in) formed view (Lundy& McEvoy, 2012)

### 3.2.3 Participants

Participants were recruited through purposive sampling. A sample size of at least two allowed for a potentially homogenous sample to support a detailed exploration of participants' insights about the research topic (Smith, Flowers, & Larkin, 2009). The exceptional pandemic circumstances, in which recruitment took place, impacted on potential participants and their families in a number of ways. Participant wellbeing was prioritised over a larger sample size. This meant that some potential participants were not included in the study as it was felt that the possible added pressure of taking part may impact negatively on their wellbeing.

An extensive recruitment process was followed (*see figure 7*). Potential participants were identified as girls who:

- (a) hold an EHCP which indicates a diagnosis of ASD
- (b) the young person is between 11 and 16 years of age
- (c) the young person has been through the EHCP/AR process within the last 12 months.

Information sheets were provided for CYP in written and video format to take into consideration differences in preferred communication methods (*See Appendix J*). Parental and participant consent was sought (*See Appendix K*). Participants were

provided with interview questions and information to support their understanding of EHCP/AR processes prior to the interview (*See Appendix L*). Participants chose how they would prefer to share their views. Recruitment and research was carried out in 2020 during the Covid-19 pandemic. Two CYP in North East England met the criteria and consented to participate in the research in keeping with a small sample size suggested by IPA methodology (Smith & Shinebourne, 2012).

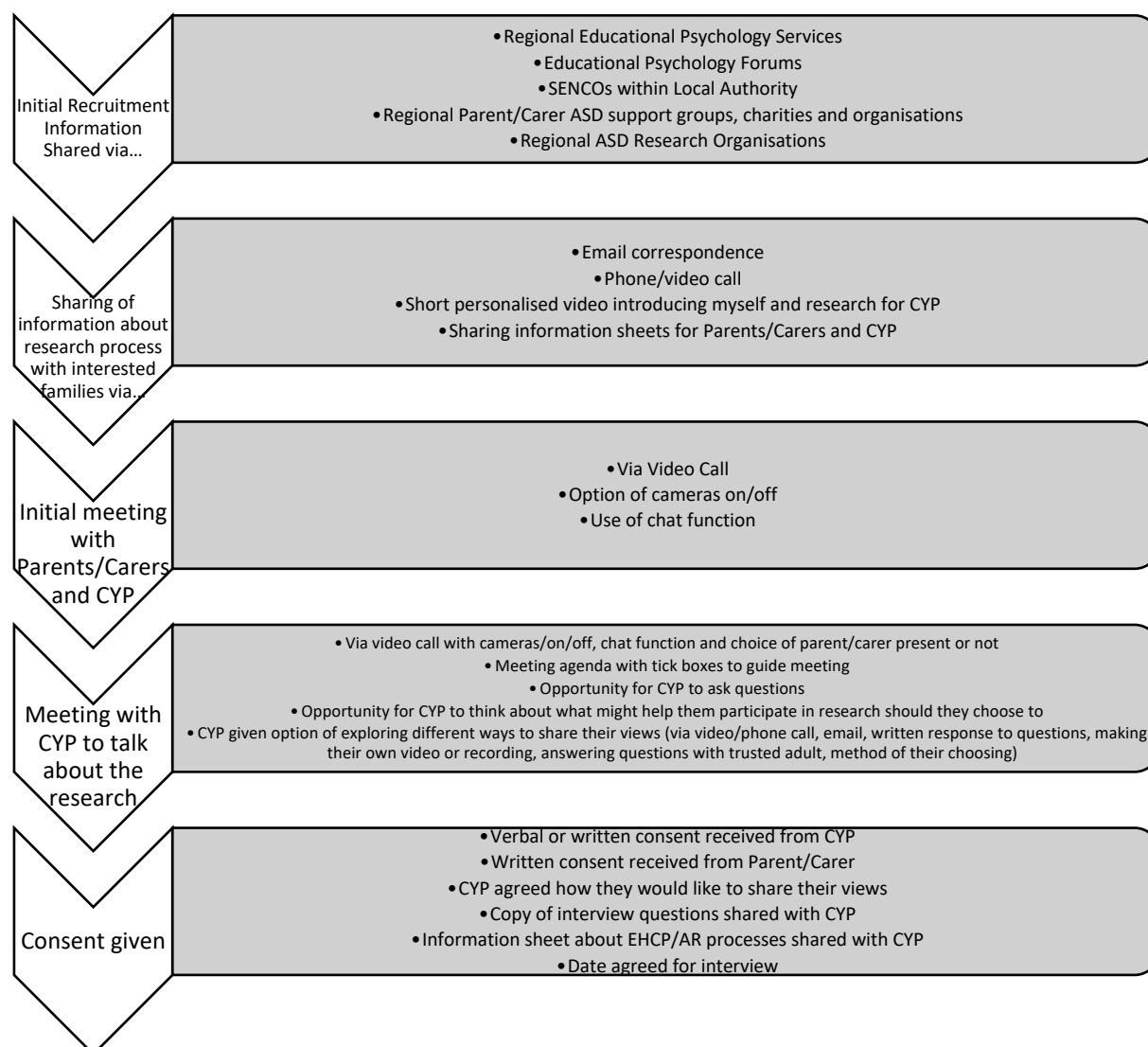


Figure 7: The recruitment process

### 3.2.4 Ethics

Ethical approval was obtained from Newcastle University Faculty of Humanities and Social Sciences Research Ethics Committee. My approach adhered to BPS (BPS, 2018) and HCPC (HCPC, 2016) ethical codes. This aimed to protect participants from harm and to maintain their dignity and psychological well-being at all times. I remained ethically attuned throughout the research process (Willig, 2013) by

attending to how the interview affected the participant, using relational approaches such as reflective listening (Pietkiewicz & Smith, 2014), and through revisiting consent and sign-posting participants to support if needed. Debrief information after the data collection was available to participants to address any questions, reflect on their experience and provide a formal ending to their participation in the research. A participant- accessible version of my study has been shared with participants at their request (*See Appendix N*). All data was stored confidentially and securely and destroyed after the research was completed.

### **3.2.5 Data Generation**

I conducted semi-structured interviews. Interview questions were informed and developed through careful consideration and application of IPA methodology (Smith et al., 2009)(*see appendix I*). Interviews were recorded via a secure video conferencing platform. Recordings were anonymised, transcribed, and stored securely. I developed participatory tools to support participants in expressing their experiences drawing on recommendations from prior research on supporting the participation of autistic CYP in expressing their views (Beresford et al., 2004; Fayette & Bond, 2018b; Goodall, 2019; Goodall & MacKenzie, 2019; Grover, 2004; Harrington et al., 2014; Scott-Barrett et al., 2019). Tools were tailored to meet the needs of individual participants and took into consideration their preferred methods of communication. They included:

- a visual representation and accessible fact sheet about the EHCP/ AR process;
- access to the interview questions prior to the interview in video and paper format;
- access to creative materials such as Lego, pens and paper if participants chose to draw or write in order to develop and share their responses; and
- the option to write or make their own recording in response to the interview questions should they choose not to meet directly.

Time was taken to familiarise participants with the interview process and the tools available to them.

Participant	Age	Year group	School Setting
Louise*	11	7	Mainstream Secondary School A
Kim*	12	8	Attended Mainstream Secondary School B and transferred to Specialist Setting in autumn term of Year 8

\*Pseudonyms

Table 7: Participants' demographic characteristics

### 3.2.6 Data Analysis

Interviews were recorded and transcribed verbatim. IPA (MacLeod, 2019) guided my inductive approach to analysis exploring the experiences of autistic girls' participation in EHCP /AR process through their accounts of their experiences (See *Appendix M*). The analysis was conducted in five stages (Smith et al., 2009; Willig, 2013):

1	Each text was read several times and notes taken to reflect initial thoughts and observations in response to the text.
2	Conceptual emergent themes were identified which characterised each section of the text
3	Emergent themes were then explored through their relationship to one and other and tentatively organised into super-ordinate and sub-themes and labelled to capture their essence. These themes were cross referenced with the original text throughout the process to ensure they made sense in relation to the original data.
4	A summary table for each of the super-ordinate and sub- themes was then produced with quotes to illustrate each theme for each transcript, followed by a visual representation of each theme (See appendix M)
5	Finally, the super-ordinate and sub-themes were integrated across transcripts in order to identify shared themes that reflect the experiences of the participants as a whole. Emerging super-ordinate themes were checked against the transcripts to make sure they were grounded in the data. The super-ordinate themes were recorded in a table alongside the sub-themes, identifying which participant invoked them and where they did this in the text.

Table 8: The five stages of IPA

Analysis findings are presented in the next section. They focus on higher-order themes which emerged and aim to give an account of the participants' experiences of EHCP/AR processes which have emerged from IPA and engagement with participant's accounts of their experiences.

### 3.3 Findings

This section presents five super-ordinate themes which emerged from IPA (See figure 2) related to the participants' experiences of the EHCP/AR processes. Three super-ordinate themes relate to the exploration of the participants' experiences of being part of EHCP/AR processes; Context, Identity and Sharing Views. These were underpinned by the fourth and fifth super-ordinate themes of EHCP/AR Process and Language and Meaning. The theme of Language and Meaning intersected with the themes of Context, Identity and Sharing Views. This section presents an account of

the interview data, using super-ordinate and subthemes, reflecting an interpretive understanding of the participant's experiences.

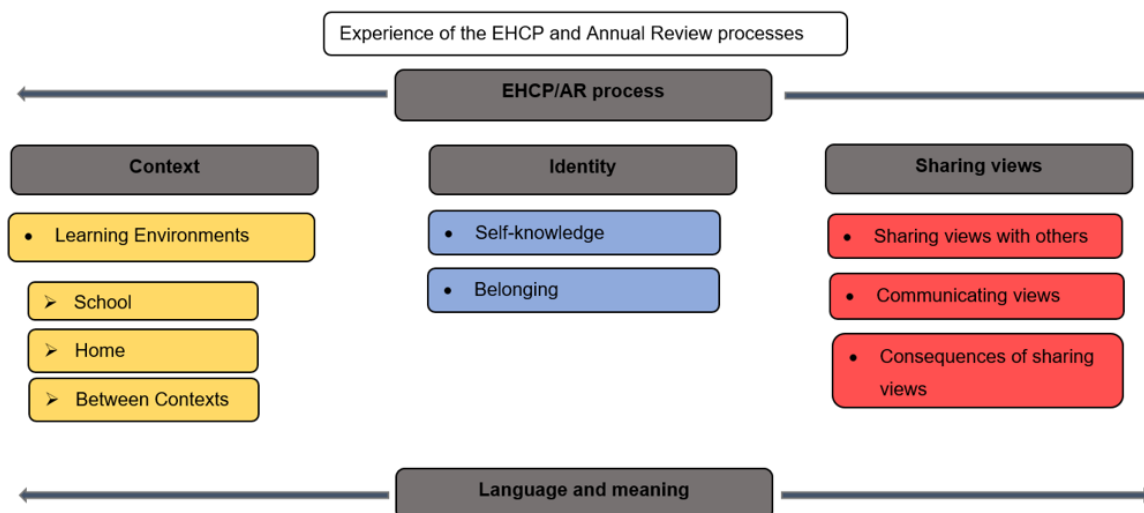


Figure 8: Super-ordinate and sub- themes emerging from IPA

Each participant has a diagnosis of ASD recognised in an EHCP. ARs have taken place for each participant in the last year and neither participant was explicitly aware of taking part.

### 3.3.1 Theme 1: Context

Participants' experiences of EHCP/AR processes linked to the context of their learning experiences.

#### **Learning Environments**

Louise was positive about her current school context (a specialist provision for autistic CYP). She found it "...Pretty fun...mainly. I get to do whatever I want to with some restrictions," adding "It rarely ever gets boring." Louise spoke with confidence and positivity, identifying restrictions but not framing them negatively and highlighting her engagement with school.

Kim attended a mainstream secondary school and reflected on her experience of accessing learning:

*"Err [pause] well...When I'm at school and...well the work's easier for me when I get help..."*

Kim spoke of getting "help" but did not articulate this further. She talked about her experience of home learning:

*“...I’m doing online work at the minute and everything is going ok...it’s fine.”*

Kim was comfortable learning at home and had a positive identity of herself as a learner reflected in her confident tone. Kim’s use of language and identity as a learner was self-assured. In contrast she seemed to struggle to articulate her thoughts when talking about topics she felt unsure about.

Kim shifted between two different learning worlds due to coronavirus related school closures and often found it hard to talk about her school experience in the home context where she was being interviewed:

*“[long pause] hmm...well I’m not going to school at the minute so it’s a bit hard to answer.”*

As a Year 7 student her experience of secondary school was disrupted and not established.

Like Kim, Louise’s narrative was shaped by her experience of education, in this case in both mainstream and specialist provision. These learning worlds seemed connected by the participants’ experiences within them and the home context from which they spoke with me. Shifting between different contexts and relating them to the present is not always easy or possible when some experiences, such as attending school, seemed to feel abstract and distant given that the interview took place during a period of lockdown.

### **3.3.2 Theme 2: Identity as a learner**

#### ***Self-knowledge***

How the participants viewed themselves as learners emerged through talk about their experiences. Kim identified as *“not struggling with anything at the minute.”* Kim explicitly talked about the present suggesting her past learning experience was linked to struggle. Her use of *“not struggling”* is revealing, as she related how she was doing to the concept of ‘struggle’ as opposed to using more self-affirming language such as “I am doing well.” Kim’s tone in this context was clear and confident conveying a positive self-identity as a home learner compared to past experiences.

Louise expressed uncertainty about how her EHCP related to her autism:

*Z: You’re not sure about it? Do you know at all why you’ve got one?*

*L: Errrrrr...yeah. Because I’m autistic. I think that’s the basic reason isn’t it?*

Louise knew her autism related to her EHCP though this knowledge was not explicit to her and so she was unable to articulate this. Learner-identity was further associated with negative past experiences of exclusion:

*“Yeah I’m still trying to like forget about it, ‘cos there’s still some like faded memories of it so...”*

For Louise, self-knowledge, and insight about how she feels as a learner in the present, appeared to be affected by past experience. Louise wanted to forget about what happened suggesting the memory of the experience remained troubling in the present.

### ***Belonging***

Louise felt a strong sense of belonging in her new school:

*“Well... the teachers do listen to me, and, like, now if I need a bit of space they allow me to have that and just, like, leave the classroom. And they leave by my own now and they check up on me like every 15 or 20 minutes.”*

Louise’s sense of belonging related to feeling heard and valued by adults and having space and autonomy to make decisions about managing her own behaviour. By checking in on Louise the staff showed she was valued, and they cared. Louise articulated her positive experience of feeling understood and respected in school enthusiastically and clearly.

Kim found it harder to articulate her feelings about school:

*Z: I wonder if you could tell me a little bit about what school is like for you...*

*K: It's okay.*

*Z: It's okay ?*

*K: Yeah*

Kim’s answers to questions about school were short, closed, and neutral. It felt as though she was reluctant to expand perhaps due to her home learning context being removed from the context of school. Kim’s short answers suggested it was difficult to think about school and perhaps she did not have the language to expand further when it felt distant.

Louise’s sense of belonging in school seemed to relate to how she positioned herself in comparison to the other students:



*Z: Is there anything about school that you're not so keen on?*

*L: The student.*

*Z: The students?*

*Z: So, with... some of the other...some of the other young people that go there?*

*L: Practically all of them are older than me.*

*Z: They're all older than you? And you're the youngest one there?*

*L: No I'm not the youngest...I'm like second youngest.*

*Z: Second youngest Okay, and everyone else is older than you?*

*L: Yeah.*

Louise showed insight into the school context and her place within this and expressed her uncertainty as to whether she belonged with the other students or not due to her age. Her sense of belonging in school is reflected in her knowledge of it. Louise related her prior experiences of belonging, to her own behaviour and the consequences of it:

*"I was getting excluded, for like... good reasons...but then that transferred into year eight for bad reasons, like wearing a hoodie."*

Louise showed insight into her own behaviour and related this to her school experience, which was one of repeated exclusions, suggesting she was not inclusively supported in that context.

The participants' sense of belonging was linked to how they viewed themselves in their learning contexts and the experiences which have shaped this. Within the participants' narratives their SEN and related EHCP/AR processes are rarely touched on suggesting these do not align with their self-identities and sense of belonging.

### **3.3.3 Theme 3: Sharing Views**

The participants spoke about their experiences of sharing views. These fell into three sub-themes:

#### ***With other people***

Louise talked about her experiences of sharing her views about school with others:

*Z: ...Do you ever share your thoughts and feelings about school?*

*L: Occasionally.*

*Z: Occasionally... who do you share them with?*

*L: Teachers... or parents. Mainly parents.*

Louise's use of the word 'occasionally' suggested sharing her views about school was not something that happened often and when it did it was with trusted adults. Later she explained "*I never told school about it,*" in relation to her thoughts and feelings about her school experience. This implies Louise was not given the opportunity to share her views in school or did not feel there was an adult in a school context who she could talk to, or perhaps who would listen.

When I explored contexts for sharing views with Kim, she indicated this was not an experience she was familiar with.

### ***Ways of sharing views***

Louise touched on different ways in which she was able to share her views:

*"That was sort of like a thing like for when we were walking back home. After the exclusion part."*

She talked with her father about her school experience as part of the daily shared routine of walking home from school together. Louise identified two ways she felt comfortable expressing herself:

*"I mainly like to talk about it. It's very occasionally when I write about it."*

She also expressed ideas about things she would like to change in society which she considered compiling in a document. Louise showed insight into her preferred methods of communication and articulately reflected on what had felt comfortable when sharing viewings in the past and indicated she had views she would like to share.

### ***Consequences of sharing views***

Louise's experience of the consequences of sharing her views ranged from being heard and listened to by adults, to not being believed. Louise acknowledged in the specialist provision she attended "*the teachers do listen to me,*" and she felt heard. Louise's most recent experiences of sharing her views contrasted with past experiences. In her previous secondary school, Louise felt things "*changed for the worst,*" as a result of sharing her views. She emphasised this further, reiterating what happened:

*"It changed for the worse, honestly."*

Louise's use of the word 'honestly' emphasised her perception of the truth and suggests her narrative of experience has not always been believed in the past. Louise talked about this experience further:

*"... getting excluded for a hoodie and then the teachers lying about what happened. To the point where I had to explain the actual story, because it was that lied about it was actually like unbelievable."*

Louise talked about how her perception of events did not align with teacher's perceptions. The use of the word 'unbelievable' suggests it was difficult for her to accept or align her version of events with that of school staff. She was however, able to share her views with trusted adults who valued her perspective:

*"Well I told it to, like, Dad and Mam and they were, like, this sounds a bit fake doesn't it? So they asked me for the truth about it, which was completely different."*

Louise's lived experience was important to her and represented her personal truth of what happened. It was important for Louise to be listened to by her parents and for her perspective to be acknowledged and valued. This highlights the way in which differing perspectives of a situation offer different versions of the truth and do not always align. When 'truths' differ some perspectives may be perceived as less valued or as 'untrue'. Such perspectives can only be explored if individuals are supported to share them and listened to.

### **3.34 Theme 4: EHCP/AR Processes**

The theme of EHCP/AR process intersected with the participants' contexts, their identities as learners and experiences of sharing views. The theme of EHCO/AR processes was also connected closely to the theme of Language and Meaning. Neither participant's experience reflected a secure knowledge *of* or active involvement *in* the EHCP/AR process.

Participants' experiences of EHCP/AR process varied from knowing nothing about the process to knowing something. Their responses reflected a sense of uncertainty about what they did know, neither spoke of what they knew with confidence. Louise was familiar with the phrases EHCP and AR:

*Z: ...What do you know about the education, health and care plan, the EHCP or annual reviews?*

*L: Literally nothing.*

*Z: Absolutely nothing?*

*L: Practically nothing, yeah.*

Louise responded to the question with clarity, her response suggests she did know something but perhaps lacked confidence in her knowledge to articulate this. She expanded further:

*"I've heard the words before. I know, like the basics of it. All I know, it's like a plan of how people can help me."*

She identified the function of an EHCP but did not know anything about the content or EHCP/AR process. Kim had heard of an EHCP but was not able to identify its meaning:

*"Err. I've heard of an [hesitant] er...E...H...C...P..."*

Kim's hesitant response suggested the language was vaguely familiar but held no meaning. During the interview I explained the EHCP/AR process to ascertain Kim's understanding of this:

*Z:...Does that make sense?*

*K: Yeah*

*Z: Yeah? it's Okay if it doesn't make sense, because it's a bit...*

*K: It does*

Kim affirmed and rearticulated her understanding of the process with confidence indicating this was a process she was able to understand if given the opportunity.

Louise identified a past experience where she worked with an adult and took part in an assessment:

*"Um, when I was like, having, like, sort of tests, umm, to see if I was autistic or not. Like with XXX from XXX Organisation. That's sort of like...that's sort of what I remember."*

Her recollection of what happened was unclear as was her understanding of the purpose of the process. Her identity was not linked to these experiences and she was unable to fully contextualise them or talk in detail:

*L: I don't know, no, since I was diagnosed, I believe.*

*Z: Okay*

*L: I don't know how long ago that was.*

*L: I believe it was mom or dad, I don't know the reasoning*

*Z: okay.*

*L: I believe it was probably because of school.*

Her use of language such as 'I don't know' and 'I believe' was tentative and positioned her in a liminal space between knowing about the EHCP/AR process and not knowing. Towards the end of the interview Louise seemed more comfortable in expressing her views and reflected on her knowledge of the EHCP/AR process:

*"It's my healthcare plan... I don't know what's going."*

Louise expressed a desire for ownership of knowledge about a document which was personal to her and her statement suggested a realisation that she has been powerless in a process in which her voice should have been central.

The participants explored the EHCP/AR process in the context of the past, present and looking to the future. The EHCP/AR process was clearly not part of either participant's narrative about their learning experience:

*Z:...Is there, somebody at school or at home, who talks to you about your EHCP or ever mentions it?*

*L: No, no.*

*Z: Can you remember ever talking about these questions or having a look at them with anyone?*

*K: No.*

*Z: No, so they don't seem very familiar at all? [Pause]*

*K: No*

*Z:... and it's not something you remember going through at all?*

*K:: No.*

Louise was repeatedly unable to remember involvement in the process:

*"I don't remember being asked in year 7."*

*"No, I can't remember."*

*"I had one [annual review] last Summer but I don't remember it."*

This suggested a sense of uncertainty as to whether she was included in EHCP/AR processes and implied that if she was, she was not aware.

Both participants were unfamiliar with being involved in EHCP/AR processes such as sharing their views with an adult in school or being part of planning meetings. Initially, when asked, Louise was unsure about being part of future EHCP/AR processes responding “*Sort of... yeah*”. Louise’s uncertain response may relate to prior negative experiences of sharing views with adults in school. As the interview ended Louise was more certain she should be included:

*“...it's my health care plan I should know what's going on.”*

The word ‘should’ was powerful and I interpreted this as a reflection of her growing understanding of her right to be part of the EHCP/AR process and her desire for ownership of it.

Overall, the participants seemed stuck in a space in between knowing and not knowing; both were familiar with aspects of the language associated with the EHCP/AR process and were able to touch upon their function. Neither, however, reported being explicitly included in these processes and therefore appear to lack the knowledge derived from active inclusion in the experience.

### **3.3.5 Theme 5: Language and Meaning**

The theme of language and meaning underpinned the four main themes and was connected to the participants’ experiences of EHCP/AR processes. Much of the language about EHCP/ARs was context driven and linked to process. The two participants were not explicitly included in such processes and were therefore limited in their knowledge and understanding of them as this comes through participation. Examples of this were interwoven through each theme and are set out explicitly in this brief section.

Both Louise and Kim are familiar with terms such as EHCP:

*K:... Er..I've heard about but but I don't think I...know...like.... about it.*

*Z: Hmm....So you don't know a lot about it?*

*K:: No, so I've heard the word but I don't know what it means.*

*Z: I wonder where you've heard the word, apart from me, talking about it, have you heard it at... home or at school.*

*K:: Err, my mam said it once but...I don't know what it means.*

*Z: Ok. So you've heard those words, you've heard those words before, but you're not sure what they mean.*

*K: Yeah [quietly]*

*L: "I've heard the words before. I know, like the basics of it. All I know, it's like a plan of how people can help me."*

Kim and Louise lacked the contextual understanding of the EHCP/AR process which did not appear to be linked explicitly to their school experiences or their self-identify- this arguably positions them as outsiders to the process. Their limited experience of the EHCP/AR process meant their knowledge of its meaning was limited in the context of learning, their identity as learners and their understanding of the processes.

### **3.4 Discussion**

#### **Summary of findings**

This study explored the experiences of two autistic girls of DMP as part of the EHCP/AR. The themes emerging from IPA highlight their experiences of EHCP/AR as context-bound and related to how the participants had shared their views in the past. This in turn seems to shape their identity as learners. Neither participant had a clear knowledge of the EHCP/AR process as neither could recall being explicitly involved. The theme of language linked to the EHCP/AR processes as meaning was derived from the girls' lived experiences. Much of the language linked to this held little meaning for the girls as they had not been actively or explicitly involved. The following discussion considers some issues arising from these findings and their implications.

#### **Context**

The participants' experiences of EHCP/AR processes appear to be shaped by the learning contexts in which DMP took place and the wider socio-political structures surrounding these contexts (Gal, 2017). Contextual culture influences how CYP are viewed by the professionals working within them (Allan & Duckworth, 2018; McKay, 2014; Prout & James, 2015) and the participants' experiences provide insight into how adults construct them (Fielding, 2004). Such contexts and constructs are constantly shifting (Gal, 2017). This is reflected in Kim's positive experience of home-learning and Louise's experience of exclusion and changing settings. Their

experiences included feeling secure within the setting and being excluded from it. The contexts in which the participants' EHCP/ARs sit are shaped by, and shape policy, both at national and local government, school, and individual level (Allan & Duckworth, 2018; Gal, 2017) and the complexity of these contexts and their interrelated nature impacts on the individual's experience of DMP.

### **Context and Identity**

The participants' experiences helped shape their identity as learners. Feeling heard potentially supported Louise's motivation, self-esteem and autonomy (Allan & Duckworth, 2018) as well as her development of self-management skills that will support her in being part of a neoliberal notion of a democratic society (Mager & Nowak, 2012; Sugarman, 2015) where self-knowledge is valued. Louise's behaviour in disengaging from mainstream school could be seen as agentic (Allan & Duckworth, 2018) as she exercised her right to disengage; highlighting that agency can be expressed and conceptualised in many ways and for many reasons (Hammersley, 2017). Louise's experience reflects how lack of adult understanding of the needs of autistic CYP, as perceived by autistic CYP, can impact negatively on well-being and self-esteem (Milton & Sims, 2016) and have long-term implications for adult mental-health and sense of belonging (Baldwin & Costley, 2016). Within DMP it is important for adults to recognise that CYP views are often not expressed explicitly.

### **Participation and context**

Conceptualising the participants experiences of being part of EHCP/AR DMP processes can be supported by using Hart's metaphorical ladder of participation (2008). Using such a conceptualisation would place Louise and Kim on the non-participation rungs of the ladder. This schema provides a starting point for the critical consideration of the complex nature of participation and its relation to context.

The participants' experiences reflect sociocultural factors which influence participation in school contexts (Hartas, 2011). Their experiences reflect how adults hold power through their privileged knowledge of EHCP/AR processes and their influence in decisions about how CYP are involved. This highlights a power imbalance where CYP's rights are denied through lack of support (Lundy, 2007) to participate in DMP, making them reliant on adult advocacy (McKay, 2014). Professional practice is influenced by socio-political context (Gal, 2017) and it is



important that professionals are able to reflect on how political ideologies affect their practice to ensure it is not detrimental to the rights of CYP they work with.

Evidence suggests adolescent autistic girls are well supported by learning environments with an inclusive ethos and where staff have an understanding of the needs of girls with autism at a general and individual level (Hebron & Bond, 2019). They are supported further by positive relationships with staff who are invested in supporting their autonomy (Gaona, Castro, et al., 2019; Sproston et al., 2017; Tomlinson et al., 2021). Making such factors explicit to girls with ASD might support their participation in DMP and their understanding of their identity as learners.

### **Participation and Identity**

Louise and Kim could not contextualise the EHCP/AR process in order to make sense of it as this was outside their experience and not linked to their identity. Their 'non-participation' (Hart, 2008) and lack of knowledge of the DMP highlights this. Evidence suggests that supporting the girls' ability to develop an understanding of their autism and how this relates to their EHCP as part of DMP can, potentially support development of increased self-awareness, reduce anxiety in a school context and support mental health (Milton & Sims, 2016; Tomlinson et al., 2021). This highlights the importance of supporting girls with ASD appropriately through developing understanding about their identities as learners to support meaningful participation in EHCP/AR processes.

### **Not being heard or included**

Louise's experience of sharing her views in a mainstream setting was linked to incidents which led to her exclusion where things changed for the worse when she shared her views. Communication and interaction difficulties are a common feature of ASD. Evidence suggests girls are often better at 'masking' such difficulties and staff may underestimate how difficulties associated with ASD impact on their school experience (Gould, 2017). Difficulties often go unnoticed which can impact on the support girls are offered to express their views (Eaton, 2019). Louise wished for her views to be considered respectfully by school staff and felt denied this opportunity which may reflect how she was viewed within the school context (Gal, 2017). Louise's behaviour in her mainstream setting appears to have been problematized denying her opportunity to share her perspective, perhaps due to tensions in her relationship with school staff (McKay, 2014) and the credibility they assign to her

views (Murriss, 2013). Louise's experience may reflect a lack of understanding of her needs and contrasts with her experience of being listened to and respected in her new setting.

### **Understanding the experiences of learners with autism**

Socio-political factors such as lack of SEN funding and staffing capacity (Gal, 2017; Harris & Davidge, 2019) impact on professional practice, available provision and CYP's experiences. CYP with ASD often struggle with aspects of communication and interaction, and benefit from individualized strategies to support them; this can be time consuming and costly. Research suggests it can be easier for professionals to defer to parent/carer views (Gaona, Castro, et al., 2019; Gaona, Palikara, et al., 2019) and make assumptions about an individual's capacity rather than referring to the Mental Capacity Act (2005) (Harris & Davidge, 2019). It is the responsibility of professionals, by law, to support CYP deemed competent to participate in DMP as part of EHCP/AR process. Not supporting them to do so can be considered an exercise of power. The participants' experiences highlight the exclusion of autistic CYP from DMP through adults speaking about and for them. In this study the findings suggest the participants may have not been provided with the conditions to contribute to DMP which affect their lives. Despite a policy discourse which suggests CYP are enabled to take part in DMP, the experiences of these girls suggests otherwise. These young women's views about their personal experiences should at least inform their EHCP.

Kim and Louise's responses reflected a lack of familiarity with the language associated with AHCP/AR and highlights a possible lack of opportunity to develop their understanding of the EHCP/AR process and what this means for them as individuals. This is particularly important for CYP with communication difficulties. Adults working with CYP as part of DMP hold privileged knowledge of the EHCP/AR process and it is their responsibility to share this with CYP to avoid epistemological oppression (Sewell, 2016).

The participants' experiences reflect findings from other research suggesting not enough has been done to include CYP with AEN in EHCP/AR and DMP processes in an educational context (Riddell et al., 2019) and that their ability to participate in DMP which affect their lives, is linked to factors beyond their given contexts (Gal, 2017). This firmly places the responsibility of supporting girls with ASD, like Louise and Kim,

to participate meaningfully in DMP, with professionals who work with them and highlights the need for a relational understanding and implementation of children's rights beyond the opportunity to express voice (Thomson, 2011).

## **Limitations**

Due to sampling from a very specific sub-group of the population and complications arising from coronavirus, participant recruitment was challenging. Participant wellbeing was prioritised as part of this process and difficult ethical judgments were made as to whether it was in potential participants best interests to take part in the study. Some participants were excluded from taking part as it was felt that the experience of participation might impact negatively on their wellbeing. The participants who took part in this study were both academically able autistic girls. However, despite careful preparation and use of support materials responses were often brief. The interview medium of video platform may have added to communication and interaction difficulties and limited the use of resources to support development of the interview discussion through non-verbal means.

The lack of research about autistic girls' perspectives of EHCP/AR DMP meant this research was an important starting point. IPA helped guide the analysis of the data and interpretation is subjective. Circumstances imposed by coronavirus may have limited my knowledge of the participants' contexts and thus influenced my understanding and interpretation of their experiences.

## **3.5 Conclusion and implications for research and practice**

### **3.5.1 Implications**

The participants' experiences suggested they were excluded from EHCP/AR processes. This implies the need for professionals, such as teachers, SENCOs and Educational Psychologists (EPs), working with all CYP with AEN, including autistic girls, to actively include CYP in EHCP/AR DMP as underpinned by current legislation and guidance. Girls' with ASD have a right to take part in DMP which affect their lives. This could be supported through reflexive professional practice facilitated by supervision or training. This could involve consideration of the impact of context, socio-political ideology (Gal, 2017; McKay, 2014; Thomson, 2011) and how this relates to the way CYP are conceptualised (Billington, 2014).

There is a growing range of research which supports understanding of CYP's participation in DMP which affect their lives (Gal, 2017; Lundy, 2007; Riddell et al., 2019). A developing body of literature is available exploring ways in which professionals can support CYP with ASD in being part of DMP (Cascio et al., 2020; Fayette & Bond, 2018a; Harrington et al., 2014; Zilli et al., 2019). There are also signs of a growing research interest specifically in girls with ASD (Goodall & MacKenzie, 2019; Sproston et al., 2017; Tomlinson et al., 2021). The literature highlights there is more to be done to develop an understanding of what autism means for girls and how they can be supported in an educational context (Tomlinson et al., 2021).

EPs could potentially play an important role in facilitating discussion to support the development of DMP which support active participation of girls with ASD and all CYP regardless of their AEN through training at a systems level as well as through individual casework.

EPs bring a psychological perspective and understanding, underpinned by psychological theory, to the concept of DMPs, which can be applied to help practitioners reflect upon systems and practices involved in DMPs. A framework such as Bronfenbrenner's ecological systems framework (2006) supports EPs and those they work with to understand the complex systems at play within DMP and in navigating them in order to support CYP participation.

EPs' skills can also be used in the application of processes and tools informed by psychological theory. Examples of this include EP use of consultation as a framework for supporting participation or EP's understanding of how to support autistic CYP to communicate their views through a range of approaches and tools. This demonstrates the potential for EPs to play a positive role in developing DMPs in which CYP are supported to play an active role should they chose to. Working in such a way highlights how EPs can support systemic changes which promote participation within schools and other organisations involved in making decisions about CYP with SEN.

As an EP and a researcher I will reflect on these experiences with criticality to inform and develop practice which supports active involvement in DMP for autistic girls.

### 3.5.2 Conclusion

This research aimed to explore the experiences of girls with autism being part of the EHCP/AR processes and active in DMP which affect their lives in an educational context. The study found that participants' experience appeared to be shaped by immediate and wider contexts. Neither participant felt informed of the EHCP/AR process or supported to be actively involved. Without effective support, participants remained on the periphery of these processes, lacking the tools or agency to take part. This may reflect the power dynamics within such processes and serves as a reminder that it is professionals' responsibility by law to support CYPs' active involvement in DMP.

There is limited research about the learning experiences of autistic girls. It is important not to view autistic CYP as a homogeneous group and it is key that adults working with autistic girls understand how autism may affect girls differently from boys and recognise what autism may mean for the individual they are working with. CYP are actively supported to be part of DMP processes through a relational approach where they are trusted, respected and their views are valued and acted upon. The experiences of the participants in this study highlight how culture and context can impact on CYP's participation in DMP to the point of exclusion and further marginalisation. As Louise says: *"It's my health care plan I should know what's going on."*

## **Chapter 4: A reflective Synthesis of professional and academic learning, as a result of the research process.**

### **4.1 Introduction**

In this chapter I reflect on my experience as a Trainee Educational Psychologist (TEP) and researcher throughout this research process to make sense of what the research process means for me on a personal and professional level and the implications it has for wider professional practice and research. I consider how meaning has been constructed throughout the research process, how this relates to my methodological approach and findings, and what implications this may have at an individual and wider professional level.

My values and practice are inter-related and are often hard to distinguish. My developing and changing understanding of theoretical and applied psychology shape, and are shaped by, my practice and are underpinned by my personal and epistemological values. Social constructionism supports a view that individuals understand the world as a result of their individual experiences of it and how they make sense of them within their historical, cultural and linguistic contexts (Burr, 2015). This epistemological stance rejects the notion of an objective reality. It supports my awareness of socio-cultural and political influences within my work contexts and accepts that several equally valid versions of any given situation exist which are context driven. It is important to recognise that some versions may hold more weight than others depending on context.

### **4.2 Personal Reflexivity**

Personal critical reflexivity has supported an exploration of how my value and belief system relates to my epistemological stance and how this has shaped my research approach. It also provides space to consider how assumptions I have made about the world and knowledge relate to and influence my research (Willig, 2013).

Throughout the research process I have kept a Research Journal where I reflected on how my personal values and beliefs have shaped my choice of research topic, approach to research and findings. These notes supported reflexivity and consideration of the implications of this research on a personal, professional, and wider level (*See appendix M p.167*).

My TEP experience and the value I place on human rights shaped my interest in CYP's rights, and their involvement in DMP which affect their lives. This is particularly

relevant to the area of EHCP/SA processes as this constitutes a high percentage of my workload. My practice and research experience has illustrated that CYP are not always involved in or central to DMP which affect their lives. Casework as a TEP involving working with CYP has illustrated many challenges that CYP with AEN face. As researchers, there is a clear need to explore CYP with AEN's experiences in order to support change in the sphere of professional practice (Bailey et al., 2015). This demonstrates how my values and experiences are intrinsic to my research.

A further intention of my research has been to explore the extent to which CYP's rights, in relation to DMP affecting their lives, have been brought to the forefront since guidance and legislative reforms. I have reflected on assumptions I made as a result of exploring recent research findings which suggested that a culture of CYP engagement in SEN processes and joint-decision making was developing (Harris & Davidge, 2019). This was not the lived experience for the participants in this research. To understand what this meant in relation to my research question, I had to separate my personal values and beliefs from the data, in order to remove researcher bias. In doing this I also had to acknowledge that this wasn't wholly possible, although reflexivity acknowledged the limits to the analysis and meaning-making process (Willig, 2013).

The research process has highlighted the complexities of representing and interpreting CYP's views and how this is laden with ethical dilemmas. I have held central to the research process that it is a CYP's right to share their views if they wish (or not). I have deconstructed concepts of 'voice' and agency in order to inform my research and work with ethicality (Fielding, 2004). In acknowledging this through my research, and because of my research, I aim to practice in ways which open up space for relational practice as an EP. Such practice supports young people in be able to share their thoughts and feelings. Research findings highlight the importance of how CYP are conceptualised within their contexts and the need for professional and personal reflexivity in considering the type of questions we need to ask when supporting CYP's participation.

#### **4.3 Epistemological and methodological reflexivity**

In this section I explore the relationship between my epistemological and methodological approach and different aspects of the research process.

One key feature of a social constructionist approach is the acknowledgement that knowledge is shaped by the historical, cultural and linguistic context in which it is situated (Willig, 2013). The use of IPA and acknowledgment of context through reflexivity has supported development of understanding of participants' experiences. A limitation of this is that there are several versions of the experiences the participants describe which may give rise to different understandings and no universal truth (Burr, 2015). Constructing research questions concerned with participants' specific experiences and applying a method which supported a systematic and reflexive approach, has supported a structured and critically reflective research process. Grappling with epistemological issues has supported reflexivity in acknowledging the limits of the research and of claims about knowledge (Willig, 2013).

I view Children's Rights as given, without critically questioning the impact of children realising these rights. This is not due to a lack of criticality; it is because they are enshrined in law. As I began the research, I realised I had assumed participants would have been afforded these rights in terms of being active, to some extent, in DMP. My researcher-role has involved searching for meaning and making sense of associations between my participants and their experiences and what these revealed to my inquiry (Tanggaard, 2013). In this research it was the participants' lack of experience of the phenomena in question that has shaped my findings and reflects the complex and context driven nature of their experiences, much like the research experience itself.

Assumptions that participants will have been supported in actualising their rights, may have limited the scope of the research because my interview questions were formed around exploring this topic. There is potential for epistemic violence when assumptions are made about the way that potentially 'othered' people, such as girls with ASD or CYP with AEN are conceptualized by others (Held, 2020) and reflexivity as a researcher-practitioner potentially avoids this. Through personal criticality and reflexivity (Bae, 2009) about the research process and careful consideration of how my own views and bias may impact I have sought to avoid epistemic injustice (Murriss, 2013).



## **Reflections on qualitative research, my chosen methodology**

The qualitative research process was not linear or straightforward. I had to be creative and adaptable due to the coronavirus pandemic, difficulty recruiting participants, potentially thin data and having to make difficult decisions about data use.

It is impossible to unpick how the participants' experiences shaped my interpretations and IPA acknowledges this in its reflexive approach (Smith & Shinebourne, 2012; Willig, 2013). The interview and analysis process were emotive, complex, and often challenging. These elements often made meaning-making from the data complex. However this process allowed for a sensitive handling of the data in the respectful and transparent way participant voice is analysed and presented to the reader (Smith & Shinebourne, 2012). It was challenging to distinguish between the participants' experiences and my interpretations of them; reflexivity and constant re-referring to my notes and interpretation from different stages of analysis was crucial in making sense of this.

Difficult choices had to be made about data use. This highlighted that researcher judgements may result in the omission of concepts which are embedded in the lived experiences of the participants (Held, 2020). This dilemma can be described as a double hermeneutic, and highlights the complexities of interpreting the interpretation of the lived experiences of others (Smith & Shinebourne, 2012). No judgements are context free and one way I tried to avoid epistemic violence was by acknowledging the importance of context. I have done this in relation to lived experience and writing from a children's rights perspective, where it is the adult responsibility to uphold children's rights and support CYP to participate in DMP which affect their lives.

I have acknowledged the influence of context in my research. I view my understanding of research methods, process and my interpretations of data as context-bound. My findings are an interpretation of a unique perspective of an experience at a given moment in time. I did not set out to do more than develop an understanding, through analysis, of others' lived experiences. It is, perhaps, what meaning these interpretations take on for myself and others which is important.

## **Participants**

Participant recruitment was challenging. A number of factors contributed to this, such as impact of coronavirus and participant's communication and interaction difficulties. I tried to maximise participant recruitment and had to make ethical decisions about potential participants.

Some potential participants felt anxious about the idea of talking to me or had complex personal situations at the time of recruitment, e.g. one potential participant was experiencing an episode of psychosis. I had to ensure an understanding that there was no obligation to take part and to prioritise participant health. Email communication with potential participants and their parents allowed for follow-up of initial interest in taking part. A clear cut-off point had to be determined to avoid them feeling pressured into being part of the research. I was clear that there was no obligation to take part and I would not contact them again unless I heard from them first.

I have had to contend with a lack of data. Several factors may have impacted on this. The lack of opportunity to work face to face with participants and develop a rapport to support view sharing. I feel at times the use of video created another barrier to communication (Adams-Hutcheson & Longhurst, 2017). Participants found it difficult to talk for long and in detail, perhaps due to individual communication and interaction difficulties associated with ASD and compounded by the medium of video. Participants' lack of experience of the phenomena under investigation further limited the extent to which they could talk in interviews, impacting on the volume and depth of data. This highlights how language constructs the participants' reality. This provided insight into how the participants talked about their experience rather than the experience itself (Willig, 2013). This may be further linked to my assumption that the participants would have explicitly experienced EHCP/SA DMP and had prior experience of sharing their views about education. In this instance lack of data can be seen as a powerful finding in that it highlights what is lacking (Jacklin, Robinson, & Torrance, 2006).

## **4.4 Implications**

### **Personal**

Findings from my research have highlighted how CYP's rights, which are enshrined in law, can be systematically denied. The contexts in which this occurs are complex.

By developing my personal understanding of such contexts through this research and continuing to uphold and value human rights I hope to support others in doing so too.

### **As a researcher**

Exploring CYP with AEN's experiences of DMP is central to understanding their lived experience, to inform ethical and effective practice in upholding their rights to be active in DMP (should they choose to be). This is not, however, enough. This research has highlighted the importance of capturing the experiences and process involving those who 'other' potentially marginalised people (Held, 2020) such as CYP with AEN. Developing an understanding of why this occurs serves to reduce marginalisation, oppression, and othering, hopefully in order to affect contextual/environmental change.

As a TEP researcher I have developed my skills of observing, describing, listening, reading, and writing through constant reflexivity in my research journal, formal supervision and regular discussion with colleagues. Reflexivity has been integral to the research process and has helped me to feel comfortable with my own interpretations and improvisations of methodologies such as IPA (Ingold & Hallam, 2007). IPA has guided my approach and understanding of my data though it has not defined or limited the process. The framework has supported me to move forward creatively in the research process and develop an understanding of my data to address my research question. Frameworks will not define future research or practice for me. Frameworks will, rather, provide structure and a starting point for work which is often complex and challenging. In future research, co-construction of research questions and methods with participants would potentially avoid making assumptions about their experience and support their participation (Kellest, 2005).

### **As a TEP**

Relational practice underpins my approach to TEP practice. This is underpinned by an ethical approach (BPS, 2018) and involves spending time with those I work with to establish trust and shared objectives. The need for creativity and flexibility when working with CYP with autism has been emphasised by this research experience. This is something I will carry with me and develop within the limits of my practice with CYP.

The research process has shown how CYP's views can be important in developing practice which supports their engagement such, as making sure they have an understanding of DMP and making such processes explicit. This can be done through co-constructing and agreeing on ways of working with CYP and checking with them to reflect on my understanding of their views to support ethical and accurate representation of their wishes.

### **Wider Implications**

If professionals working with CYP act to empower and not control (Fielding, 2004) this potentially supports ethical practice and meaningful participation for CYP in DMP. This research experience has highlighted the need for systemic change in how adults working with children conceptualise them and understand and uphold their right to be part of DMP. As a qualified EP I hope to affect such change through working with professionals within the systems I practice in. This can potentially be done through training to support understanding of CYP's rights to be active in DMP and develop understanding of supporting CYP, whatever their needs, to contribute their views. I hope to do this through continued reflexive practice in which CYP and their families remain central.

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## 5.0 Appendices

### 5.1 Appendix A: Scoping search records

Scoping Search findings (highlighted yellow text might be included in final paper, pink are discounted, blue are maybe, green are reviews)

Title	Author	Journal	Year	Research	Theory	Review	Quant	Qual	School/Education	Other Setting	Keywords Comments Research or theory? If theory exclude Quant or qual New data? Aims and questions? Analysis on their data?
Children's right to participate in early childhood education settings: A systematic review	Correia, Nadine Camilo, Claudia Aguiar, Cecilia Amaro, Fausto	Children and Youth Services Review	2019								Right to participate Participation Early childhood education Peer-reviewed Children
The Rights of Children and Young People under Special Educational Needs Legislation in England: An Inclusive Agenda?	Harris, Neville; Davidge, Gail	International Journal of Inclusive <b>Education</b>	2019								Foreign Countries; <b>Student</b> Rights; Special Needs <b>Students</b> ; Disabilities; Educational Legislation; Stakeholders; Attitudes; <b>Participation</b> ; Compliance (Legal); Participative <b>Decision-making</b> ; Civil Rights; United Kingdom (England)  Rights; children and young people; special needs; autonomy
'I'm ready for a new chapter': The voices of young people with autism spectrum disorder in transition to post-16 education and employment	Carolina Gaona Olympia Palikara Susana Castro	British Educational Research Journal	2019								young people; autism spectrum disorder; post-16; voice

Participation and Rights of Children with Specific Needs of Educational Support in Castilla y León (Spain): Bridging the Gap between Policies and Practices	Casado-Muñoz, Raquel; Lezcano-Barbero, Fernando; Baños-García, M. Esther	International Journal of Inclusive Education	2019								Student Participation; Student Rights; Special Education; Student Needs; Foreign Countries; Inclusion; Disabilities; Children; Childrens Rights; International Law; Treaties; United Nations Convention on the Rights of the Child; Spain
Autonomy, Rights and Children with Special Educational Needs: The Distinctiveness of Wales	Ware, Jean	International Journal of Inclusive Education	2019								Foreign Countries; Student Rights; Special Needs Students; Personal Autonomy; Student Participation; Severe Intellectual Disability; Disabilities; Welsh; Educational Policy; Language Usage; Multiple Disabilities; Inclusion; Access to Education; Equal Education; United Kingdom (Wales)
The biggest extension of rights in Europe? Needs, rights and children with additional support needs in Scotland	Riddell, Sheila Carmichael, Duncan	International Journal of Inclusive Education	2019								Rights; children; additional support needs; autonomy; Scotland
Voices of disaffection: disengaged and disruptive youths or agents of change and self-empowerment?	Allan, David Duckworth, Vicky	British Journal of Special Education	2018								Bourdieu, student voice, disaffection, alternative learning environments, empowerment  voice is presented as a powerful mechanism for challenging the existing inequities of compulsory schooling in England  14-16 girls who are disaffected voicing their own views about education
Participation of youth in decision-	Mijntje D.C. ten Brummelaar Annemiek T.	Child and Family Social Work	2018								children's participation, children's rights, residential care, young people

making procedures during residential care: A narrative review	Harder Margrite E. Kalverboer Wendy J. Post Erik J. Knorth										
A qualitative study of specialist schools' processes of eliciting the views of young people with autism spectrum disorders in planning their transition to adulthood	Rainart Fayette & Caroline Bond	British Journal of Special Education	2018								autism, ASD, transition to adulthood, person-centred, pupil voice
A systematic literature review of qualitative research methods for eliciting the views of young people with ASD about their educational experiences	Rainart Fayette & Caroline Bond	European Journal of Special Educational Needs	2018								Voice of the child; participation; autism spectrum disorder; aSd; research methods  P353 good search terms, might be helpful for own search
Learning from children's voice in schools: Experiences from Ireland	Catherine FordeEmail authorDeirdre HorganShirley MartinAisling Parkes	Journal of Educational Change	2018								Children's participation Children's rights Education policy Relationships Student voice  Doesn't focus on cyp with AEN
Student voice in secondary schools: the possibility for deeper change	Mitra, Dana	Journal of Educational Administration	2018								Students, Secondary education, School change, School reform, Leadership, Organizational change  USA based
Facilitating the involvement of young people with ASD in organising their examination	Tyrrell, Beverley Woods, Kevin	Support for Learning	2018								autism, access arrangements, child, participation, views  Pupils were active in DMP about access arrangements nut only 3 in a case study

access arrangements											
Learning from Children's Voice in Schools: Experiences from Ireland	Forde, Catherine; Horgan, Deirdre; Martin, Shirley.	<b>Journal of Educational Change</b>	2018								Foreign Countries; Student Participation; Student Empowerment; School Policy; Children; Adolescents; Principals; Childrens Rights; Treaties; International Law; Parents; Teacher Attitudes; Student Attitudes; Parent Attitudes; Elementary School Teachers; Secondary School Teachers; Student School Relationship; United Nations Convention on the Rights of the Child; Ireland  Ireland not ENGLISH
Capturing the voices of children in the Education Health and Care plans: are we there yet?	Palikara, Olympia Castro, Susana Gaona, Carolina Eirinaki, Vasiliki	Frontiers in Education	2018								
A children's space? Participation in multi-agency early intervention	Lucas, S.	Child and Family Social Work	2017								child welfare, childhood, children's participation, communication and child social work, empirical research, assessment  Underpinned by different legislation to education based participation, focus on CAF
Children's participation in LAC reviews: A study in one English local authority	Pert, Hayley Diaz, Clive Thomas, Nigel	Child and Family Social Work	2017								advocacy for children, child care policy and practice, children's participation, independent reviewing officers, looked-after children  Underpinned by different legislation to education based participation, focus on CAF

A qualitative analysis of implementing shared decision-making in Child and Adolescent Mental Health Services in the United Kingdom: Stages and facilitators	Abrines-Jaume, N. Midgley, N. Hopkins, K. Hoffman, J. Martin, K. Law, D. Wolpert, M.	Clinical Child Psychology and Psychiatry	2016							Shared decision-making, child mental health, Child and Adolescent Mental Health Services, plan-do-study-act, implementation  Focuses on a specific method to facilitate participation in a CAMHS context
Student voice and the community forum: Finding ways of 'being heard' at an alternative school for disenfranchised young people	Baroutsis, Aspa Mills, Martin McGregor, Glenda Riele, Kitty Hayes, Debra	British Educational Research Journal	2016							Set in Oz
How Can We Improve through Pupil Participation? An Infants School Experience	Ceballos López, Noelia Susinos Rada, Teresa Saiz Linares, Ángela	Journal of Research in Special Educational Needs	2016							Student voice, infant school, mediated consultation strategies.  Set in Spain
The Pupils Voice in Different Educational Settings	Herz, Birgit Haertel, Nora	Journal of Research in Special Educational Needs	2016							SEBD pupils voice well-being at school  Set in Germany
Creating Spaces for Children's Agency: "I Wonder..." Formulations in Teacher-Child Interactions	Houen, Sandy; Danby, Susan; Farrell, Ann	International Journal of Early Childhood	2016							Teacher <b>Student</b> Relationship; Preschool <b>Children</b> ; Preschool Teachers; Classroom Communication; Educational Quality; Early Childhood <b>Education</b> ; Discourse Analysis; Video Technology; <b>Decision-making</b> ; Personal Autonomy; <b>Student Participation</b>
The revised send code of practice 0-25: Effective	Kennedy, Emma-Kate	Support for Learning	2015							SEND Code of Practice 0–25 children's participation in decision-making social emotional and mental health needs

practice in engaging children and young people in decision-making about interventions for social, emotional and mental health needs									Primary school based and possibly too soon after reforms  Worth a look?  ATTWOOD, L. (2013) The real implications of 'benevolent' SEN reform. Support for Learning, 28, 181–187.  WEBSTER, R. (2014) 2014 Code of Practice: How research evidence on the role and impact of teaching assistants can inform professional practice. Educational Psychology in Practice, 30, 3, 232–237.
The Danger of Subverting Students' Views in Schools	Messiou, Kyriaki Hope, Max A.	International Journal of Inclusive Education	2015						students' voices; inclusive education; subversion; teacher development; schools  Not focused specifically on CYP with AEN but including them
Freedom to Grow: Children's Perspectives of Student Voice	Quinn, Sarah Owen, Susanne	Childhood Education	2014						In Oz
Ready, Steady, Action: What Enables Young People to Perceive Themselves as Active Agents in Their Lives?	Sharp, Russell	Educational Psychology in Practice	2014						agency, relationships, empowerment, resilience, young people  Not really linked to legislation reforms
Young People's Voices: Disciplining Young People's Participation in Decision-Making in	McKay, Jane	Journal of Education Policy	2014						young people's voice, participation, advocacy, Foucault, governmentality



Special Educational Needs										I really want to include this but on the cusp of reforms
Introducing Forum Theatre to Elicit and Advocate Children's Views	Hammond, Nick	Educational Psychology in Practice	2013							Forum Theatre; creativity; voice; emancipation; liberation; social justice; empowerment; Boal
Creating Spaces to Belong: Listening to the Voice of Girls with Behavioural, Emotional and Social Difficulties through Digital Visual and Narrative Methods	Nind, Melanie Boorman, Georgie Clarke, Gill	International Journal of Inclusive Education	2012							participation – decision-making – qualitative methods – measurement development
Pupil Participation in Scottish Schools: How Far Have We Come?	Aston, H. J. Lambert, N.	Educational Psychology in Practice	2010							consultation, decision-making, learning participation
How EPs Record the Voice of the Child	Harding, Emma; Atkinson, Cathy	<b>Educational Psychology</b> in Practice	2009							Technical Writing; Student Attitudes; Educational Psychology; Psychologists; Focus Groups; Interviews; Content Analysis; Special Needs Students; Data Collection; Foreign Countries; Pupil Personnel Services; Educational Policy; Legislation; Writing Skills; Elementary Secondary Education; United Kingdom
Pupils as partners in education decision-making: responding to the legislation in England and Ireland	Shevlin, M. Rose, R.	European Journal of Special Needs Education	2008							
Evaluating children's Participation in SEN procedures:	Norwich, B. Kelly, N.	Educational Psychology in Practice	2006							

Lessons for educational psychologists											
"Voice" Is Not Enough: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child	Laura, Lundy	<b>British Educational Research Journal</b>									<b>Childrens Rights;</b> Foreign Countries; <b>Student</b> Attitudes; Models; Compliance (Legal); Educational Policy; Interviews; Focus Groups; Decision-making; <b>Student Participation;</b> International Cooperation; International Organizations; United Kingdom (Northern Ireland)

## Focused reading from scoping search

Title	Author	Journal	Year	Research	Theory	Review	Quant	Qual	School/Education	Other Setting	Keywords Comments Research or theory? If theory exclude Quant or qual New data? Aims and questions? Analysis on their data?
Children's right to participate in early childhood education settings: A systematic review	Correia, Nadine Camilo, Claudia Aguiar, Cecilia Amaro, Fausto	Children and Youth Services Review	2019								<p>Right to participate Participation Early childhood education Peer-reviewed Children</p> <p>Acknowledges reviews exist about International Lit on CYP's rights to participate and methods for listening to and consulting with young children and in various health contexts, one Australian specific. This review focuses on early years.</p> <p><b>Useful intro and structure and ref. to GAL 2017</b></p>
References	<p>Council of Europe (2017). Young people's access to rights. Recommendation CM/Rec (2016)7 and explanatory memorandum. Retrieved from <a href="https://rm.coe.int/1680702b6e">https://rm.coe.int/1680702b6e</a>.</p> <p>Gal, T. (2017). An ecological model of child and youth participation. Children and Youth Services Review, 79,57–64. <a href="https://doi.org/10.1016/j.childyouth.2017.05.029">https://doi.org/10.1016/j.childyouth.2017.05.029</a>.</p>										
Referenced by	Cited by 1 other Russian paper										

Title	Author	Journal	Year	Research	Theory	Review	Quant	Qual	School/Education	Other Setting	Keywords Comments Research or theory? If theory exclude Quant or qual New data? Aims and questions? Analysis on their data?
The Rights of Children and Young People under Special Educational Needs Legislation in England: An Inclusive Agenda?	Harris, Neville; Davidge, Gail	International Journal of Inclusive <b>Education</b>	2019								<p>Foreign Countries; <b>Student</b> Rights; Special Needs <b>Students</b>; Disabilities; Educational Legislation; Stakeholders; Attitudes; <b>Participation</b>; Compliance (Legal); Participative <b>Decision-making</b>; Civil Rights; United Kingdom (England)</p> <p>Rights; children and young people; special needs; autonomy</p> <p>Really useful for ENGLISH context and history of legislation leading up to the present time</p> <p>Also great for placing voice and participation rights within English school context</p> <p>Covers: Law and legislation that support participation Professional and parent POV Progress made Factors impacting on P and ways forward</p>
References	Riddell, S., and D. Carmichael. 2019. "The Biggest Extension of Rights in Europe? Needs, Rights and Children with Additional Support Needs in Scotland." International Journal of Inclusive Education. doi:10.1080/13603116.2019.1580925.										

	<p>Palikara, O., S. Castro, C. Gaona, and V. Eirinaki. 2018. "Capturing the Voices of Children in the Education, Health and Care Plans: Are We There Yet?" <i>Frontiers in Education</i>. doi:10.3389/ feduc.2018.00024.</p> <p>Davidge, G., and N. Harris. 2018. Working Paper 4: English Local Authority Survey Results. Edinburgh: CREID. SENChildren_WP_4.pdf.</p> <p>Harris, N. 2018. Working Paper 2: Legislative and Policy Developments in Special Educational Needs in England and Additional Support Needs in Scotland: Advancing Children and Young People's Rights. Edinburgh: CREID, University of Edinburgh. <a href="http://www.docs.hss.ed.ac.English/education/creid/Projects/39_ii_ESRC_SENChildren_WP_2.pdf">http://www.docs.hss.ed.ac.English/education/creid/Projects/39_ii_ESRC_SENChildren_WP_2.pdf</a>. <b>May be relevant for LA research later in the year</b></p> <p>ENGLISH criticised by UN about children's right to be heard (para 55): UNCRC (UN Committee on the Rights of the Child). 2016. Concluding Observations on the Fifth Periodic Report of the United Kingdom of Great Britain and Northern Ireland. CRC/C/CBR/CO/ 5. Geneva: Centre for Human Rights.</p>
Referenced by	0

Title	Author	Journal	Year	Research	Theory	Review	Quant	Qual	School/Education	Other Setting	Keywords Comments Research or theory? If theory exclude Quant or qual New data? Aims and questions? Analysis on their data?
'I'm ready for a new chapter': The voices of young people with autism spectrum disorder in transition to post-16 education and employment	Carolina Gaona Olympia Palikara Susana Castro	British Educational Research Journal	2019								young people; autism spectrum disorder; post-16; voice  Focus on CYP's experiences
References	Fayette, R. & Bond, C. (2018a) A systematic literature review of qualitative research methods for eliciting the views of young people with ASD about their educational experiences, European Journal of Special Needs Education, 33(3), 349–365.										
Referenced by	Cited by 0										

Title	Author	Journal	Year	Research	Theory	Review	Quant	Qual	School/Education	Other Setting	Keywords Comments Research or theory? If theory exclude Quant or qual New data? Aims and questions? Analysis on their data?
Voices of disaffection: disengaged and disruptive youths or agents of change and self-empowerment?	Allan, David Duckworth, Vicky	British Journal of Special Education	2018								<p>Bourdieu, student voice, disaffection, alternative learning environments, empowerment</p> <p>voice is presented as a powerful mechanism for challenging the existing inequities of compulsory schooling in England</p> <p>14-16 girls who are disaffected voicing their own views about education</p> <p>Explores the idea that only students with social and linguistic capital are afforded a voice in mainstream schools.</p>
References	<p>Baroutsis, A., Mills, M., McGregor, G., te Riele, K. &amp; Hayes, D. (2016) 'Student voice and the community forum: finding ways of "being heard" at an alternative school for disenfranchised young people', British Educational Research Journal, 42 (3), 438–453.</p> <p>Cremin, H., Mason, M. &amp; Busher, B. (2011) 'Problematising pupil voice using visual methods: findings from a study of engaged and disaffected pupils in an urban secondary school', British Educational Research Journal, 37 (4), 585–603.</p> <p>DfE (Department for Education) (2014) Listening to and Involving Children and Young People. DfE-00011–2014. London: DfE.</p> <p>Pennacchia, J., Thomson, P., Mills, M. &amp; McGregor, G. (2016) 'Alternative programmes, alternative schools and social justice', Critical Studies in Education, 57 (1), 1–5.</p>										

Referenced by	



Title	Author	Journal	Year	Research	Theory	Review	Quant	Qual	School/Education	Other Setting	Keywords Comments Research or theory? If theory exclude Quant or qual New data? Aims and questions? Analysis on their data?
The revised send code of practice 0-25: Effective practice in engaging children and young people in decision-making about interventions for social, emotional and mental health needs	Kennedy, Emma-Kate	Support for Learning	2015								SEND Code of Practice 0–25 children's participation in decision-making social emotional and mental health needs
References											
Referenced by	Cited by										

## **5.2 Appendix B: Protocol**

**What does the participation of children and young people (CYP) considered to have additional educational needs (AEN) in DMP which affect their lives, look like in a ENGLISH context?**

### **Background and summary of literature**

The rights of CYP to express their views and contribute to decisions about issues that concern them are laid out in Article 12 of the United Nations Convention on the Rights of the Child (UNCRC)(UN General Assembly, 1989). These rights are also central to current key legislation, policy and guidance in the ENGLISH. The Children and Families Act (CFA) 2014 and SEN Code of practice 0-25 years (COP) (2015) place parents/carers and children and young people (CYP) centrally in DMP which affect them. The CFA also introduces integrated Education, Health and Care Plans (EHCPs) to replace Statements of SEN. Other notable changes reflected in the CFA and COP include the age range extending from 0-25, the term 'behaviour' being replaced with the category of SEMH and the implications of this and the requirement for all local authorities (LAs) to publish a Local Offer. However, the main change this SLR will focus on is the bringing of CYP's rights to the forefront though developing a culture of CYP engagement in SEN processes and joint-decision-making.

At the time of writing it is 5 years since these reforms, which highlight CYP's rights in relation to DMP, came into effect. This SLR intends to explore how the introduction of CFA 2014 and the new COP (2015) have affected how CYP with any additional educational needs (AEN) participate in DMP.

### **Potential issues with CYP with AEN being involved in DMP**

A recent report, based on survey results completed by 37% of LAs in England, focused on exploring how the CFA 2014 has impacted on CYP's participation in decision-making processes concerning SEN and provision. Results reflected CYP and parent held very different views from LA. The results present a mixed picture, reflecting due to variations in LA approaches. Key issues highlighted include:

- CYPs rights are not ingrained consistently in routine practice
- Constraints under which LAs are currently operating and increasing work load impact on time and resources available to systematically involve CYP in DMP

- Training, support and more capacity for LAs to improve practice in working with CYP to support them in sharing their thoughts and being part of DMP
- “Sub-optimal” levels of CYP’s participation in EHCP assessments, it is a statutory requirement for LAs to consult with CYP as part of the EHCP process
- Tensions around where the CYP’s view sits amongst the views of parents, carers and other professionals (Riddell et al., 2019).

Harris and Davidge (2018) also noted, that when comparing their findings to the results of a similar survey conducted by the Department for Education with Parent Carer Forums there was a disparity between LAs perceptions of participation and parent and carers’ experiences. The Parent Carer Forum survey suggested that CYP’s participation and involvement, particularly in the EHCP process was incredibly low.

In the context of children’s’ rights, CYP identified a lack of say in decisions made about them as the single most important issue to them (Lundy, 2007). Research suggests the process of participation and being involved in DMP benefits CYP in a number of ways, including increased motivation and agency, development of meta learning skills, increased self-knowledge and a feeling of greater responsibility for progress and change (Harding & Atkinson, 2009; Hobbs, Todd, & Taylor, 2000). Exclusion from such processes has the potential to impact negatively on CYP in their present and future situations (Rose & Shevlin, 2004). Through participation, which is grounded in ethical practice and adheres to legislation CYP may develop insight and exercise agency in their own lives.

The ladder of participation illustrates a perspective on the degrees to which CYP are enabled and supported in participation (Hart, 2008). This is a useful tool to consider how CYP can participate in the decision-making process and highlights the adult-led nature of decision-making processes in which CYP with AEN are often involved. There is a danger of participation being tokenistic (McKay, 2014), however it can be argued that tokenism can be viewed as a starting point and one that can begin with, at the very least, listening to CYP’s views (Lundy, 2018).

### **Existing reviews CYP and participation in decision-making processes**

An initial scoping search of literature has found a number of SLRs which focus on CYP participation in different contexts and from different perspectives;

- Research and the context of CYP Participation (Bradbury-Jones et al., 2018; Fayette & Bond, 2018b)
- The effect of participation in decision-making processes on CYP (Mager & Nowak, 2012)
- Participation in decision-making processes in an early childhood setting (Correia et al., 2019)

None of the SLRs focus specifically on the ENGLISH context, post CFA 2014 and COP 2015 changes.

### **This current study's rationale and lit review question**

This SLR aims to fill a gap in the current literature and will focus on what participation in decision-making processes looks like for CYP in a ENGLISH context since the CFA 2014 and COP 2015. This paper will take a broad focus in order to provide a systematic review of qualitative studies which focus on the participation of CYP considered to have AEN, in decision-making processes to explore the following questions:

- What does participation look like for CYP with AEN? (How does it occur? What happens? Who facilitates?)
- In what contexts does participation in decision-making processes for CYP with AEN occur?
- What is the effect of participation? How is this known?

### **Methods**

I have adopted a social constructionist epistemology. Social constructionism views individuals understanding the world as a result of their individual experiences of it and how they make sense of them (Burr, 2015). This epistemological stance allows the researcher to be aware of socio-cultural and political influences within their work contexts and moves away from within-child deficit models of psychology. By questioning realities through a social constructionist lens there is the opportunity to support social progress and individual development by making outcomes explicit to ethical systems and political/social contexts in which they sit (Kelly, 2016). However, it also means accepting that there are several equally valid versions of any given situation and rejects the notion of an objective reality.

Scoping searches revealed a prevalence of qualitative and mixed-method studies which describe and explore CYP and participation in the decision-making process,

therefore this SLR will focus on such studies in order to explore the contexts in which participation has taken place and the reported experiences of those involved. This will allow for a clear picture of what participation in decision-making experiences looks like for CYP with AEN in a current ENGLISH context.

## Literature Search Strategy

In order to develop a search strategy I have used a PICO table: Population, phenomena of Interest and Context (Joanna Briggs Institute, 2014) in order to broadly plan my inclusion criteria so as to avoid the exclusion of potentially relevant papers through being too specific (Boland, Cherry, & Dickson, 2017).

PICOSS Table	
Review Question	<b>What does the participation of CYP with AEN in DMP which affect their lives, look like in the ENGLISH?</b>
Population	Children and young people in the ENGLISH of compulsory school age (5-16) Might narrow this to compulsory secondary school age (11-16) who have an additional educational need
Intervention	CYP have participated in DMP about decisions which affect them to any extent
Comparator	The participation processes compared to each other
Outcomes	Any type of outcome, such as ideas, practices, strategies, or benefits of participation;
Study Design	Any type of empirical research, involving quantitative, or mixed methods.
Setting	ENGLISH, any context in which CYP might be involved in a decision-making process with other professionals including studies focusing on school, social care and youth justice contexts about children's right to participate in DMP about matters which directly affected their lives.

## Identification of Papers

Three databases (Eric Ebsco, Psych Info and Scopus) will be systematically searched from 3<sup>rd</sup> October 2019 to \_\_\_\_\_ to gather relevant studies. Terms for CYP, participation, decision-making and AEN will be combined systematically to search for papers (See Table 2).

Terms related to CYP	Terms related to participation	Terms related to decision-making	Terms related to legislation and guidance	Terms related to AEN	Possibly add in terms related to context
Young people	Participation	Decision-making	United nations conventions on the rights of the child	Special educational needs	
Children	Voice	EHCP	Children's rights	Disability	

<b>Pupils</b>	Engagement	Transition	Law Legislation	Inclusion
<b>Students</b>	Involvement		Code of practice	Inclusive Practice
<b>Adolescents</b>	Autonomy			Additional Educational Needs

### 5.3 Appendix C: Screening of final 19 papers

PICOSS Table				
Review Question		<b>What does the participation of CYP with AEN in DMP which affect their lives, look like in an ENGLISH context?</b>		
Population		Children and young people in the ENGLISH of compulsory school age (5-16) Might narrow this to compulsory secondary school age (11-16) who have an additional educational need		
Intervention		CYP have participated in DMP about decisions which affect them to any extent		
Comparator		The participation processes compared to each other		
Outcomes		Any type of outcome, such as ideas, practices, strategies, or benefits of participation;		
Study Design		Any type of empirical research, involving quantitative, or mixed methods.		
Setting		ENGLISH, any context in which CYP might be involved in a decision-making process with other professionals including studies focusing on school, social care and youth justice contexts about children's right to participate in DMP about matters which directly affected their lives.		
Inclusion Criteria	1	Children and young people in the ENGLISH of compulsory school age (5-16) Might narrow this to compulsory secondary school age (11-16) who have an additional educational need	Exclusion criteria	<ul style="list-style-type: none"> <li>• Pre-2014</li> <li>• Outside of ENGLISH or England</li> <li>• Children under 5 or over people over 18</li> <li>• Quantative studies</li> <li>• Non-empirical papers</li> <li>• Wales, Scotland, Ireland</li> </ul>
	2	England		
	3	Any context in which CYP might be involved in a decision-making process with professionals including studies focusing on school, social care and youth justice contexts		
	4	Since 2014- present day		
	5	Peer reviewed		
	6	Qualitative and mixed method		

In an educational context, what does the participation of CYP with AEN in DMP which affect their lives, look like in the ENGLISH?

What is the decision-making process?

How are they involved?

Age of CYP?

Written from what perspective?

Green = Definitely take forward

Yellow= Maybe

Database	Paper	Author	Year	Journal	Research Q Decision- making process	Setting Context	Sample Age AEN	Terms used	Data collection and analysis method	Theoretical Framework	Findings	Include or exclude
E	School Belonging: Listening to the Voices of Secondary School Students Who Have Undergone Managed Moves	Craggs, Holly Kelly, Catherine	2018	School Psychology International	exploring implementation of SDM in Child and Adolescent Mental Health Services (CAMHS)context	CAMHS clinician perspective	6-18	Shared decision- making Plan-do-study- act logs	23 professionals completed 307 logs, which were transcribed and analysed using Framework Analysis in Atlas	Framework Analysis (Ritchie & Lewis, 2003). approach to qualitative data analysis developed for applied policy research.	Implementation of SDM in CAMHS requires key positive clinician behaviours, including preparedness to put in effort, trust in young people, and use of the approach flexibly.	Ex. V. clinical and no cyp views
E P	A Qualitative Study of Specialist Schools' Processes of Eliciting the	Fayette, Rainart Bond, Caroline	2018	British Journal of Special Education	This research explores CYP with ASD participation in transition process and planning for adulthood.	two specialist schools in the north- west of England	9 teachers were interviewed and a transition meeting was observed in one school to explore these processes	autism, ASD, transition to adulthood, person- centred, pupil voice	Multiple case study design. Audio- recorded semi- structured interviews. Thematic analysis,	Hart's ladder of participation	Effective processes of eliciting and including the views of young people with ASD require a person-centred	Y



	Views of Young People with Autism Spectrum Disorders in Planning Their Transition to Adulthood				1. How do special schools elicit the views of young people with ASD in preparation for transition to adulthood? 2. To what extent are these processes perceived to be effective?				following the methods outlined by Braun and Clarke (2006)		ethos, and a commitment from all staff to elicit the pupils' views and develop processes that enable pupils to make informed decisions throughout their time in school. The findings also provided support for the use of communication tool. while the pupils' views are given 'due weight' throughout the decision-making process, it is only one of many factors that are considered in making the final decisions on what their transition to adulthood will entail.	
E S	'I'm Ready for a New Chapter': The Voices of Young People with Autism Spectrum Disorder in	Gaona, Carolina Palikara, Olympia Castro, Susana	2019	British Educational Research Journal	This study aimed to explore the views of young people with ASD in their transition to post-16 education and employment through semi-structured	four secondary schools and one further education provider in Greater London	young people; autism spectrum disorder; post-16; voice	YP with diagnosis of ASD Age 16-19	Semi structured interviews x 12. Thematic analysis.		themes of independence, ambivalence of feelings about change and the future, friendship and free time, family and school support and	Include potentially. One participant was 19

	Transition to Post-16 Education and Employment				interviews, following an inductive thematic analysis. The focus is on understanding the meaning of the lived experiences of transitioning to post-16 education for individuals with ASD, in light of the changes introduced by the new SEND legislation in England.						bullying constitute key descriptors of their experience and could help steer the conversation of transition. The findings of this study provide further evidence of the use of visual stimuli as communication support. Further research needed in relation to young people's voice, particularly concerning methodological and practical implications of eliciting the views of young people with ASD	
E	The Rights of Children and Young People under Special Educational Needs Legislation in England: An Inclusive Agenda?	Harris, Neville Davidge, Gail	2019	International Journal of Inclusive Education	The rights of children and young people under special educational needs legislation in England: an inclusive agenda?	Professional and parents	21 professionals and parents from range of contexts		Semi-structured interviews  No explicit analysis method	we discuss the picture that has emerged from interviews and assess the potential implications for CYP's agency, autonomy and rights.	N=Not seen much evidence that within the system navigation has been eased for parents in the way that was intended, nor that the participation of children and young people	Maybe? Useful for background but not explicitly enough about CYP's experience

											has been greatly enhanced. Agency of children and even young people remains in general rooted in the involvement of their parents/carers.	
E	Choosing a Secondary School for Young People on the Autism Spectrum: A Multi-Informant Study	McNerney, Catherine Hill, Vivian Pellicano, Elizabeth	2015	International Journal of Inclusive Education	Determining the factors that immediately influence secondary school choice for cyp with autism.	London LA range of Y6 pupils with autism transitioning to Y7	7 parents, 6 CYP with asd, 5 parent advisors, 5 secondary school professionals	Autism education school parents decision-making SEN	Semi structured interviews Thematic analysis Braun and Clark		Different perspectives from different people. Not enough focus on taking into account CYP's views	Exclude...focus on parents and other adults, no discussion of methods of eliciting CYP' s views
E	Hearing the Voice of Children and Young People with a Learning Disability during the Educational Health Care Plan (EHCP)	Pearlman, Sara Michaels, Dina	2019	Support for Learning	Exploring how to elicit the views of CYP with intellectual and communication difficulties	Special school for CYP (age 7-14)	22 CYP Parents School staff SALT		Questionnaire and structured interview. Triangulation ANOVA		CYP could respond to a range of questions to share their views with relevant support and tools. This didn't tap in to CYP's views about EHCP an general education. Eliciting information is not the same as eliciting views and opinions.	Maybe...explores being part of the decision-making process by providing information for EHCP but limitation is that it doesn' t share views or opinions.

E	Pupil Participation and Playground Design: Listening and Responding to Children's Views	Pearson, Rebecca Howe, Julia	2017	Educational Psychology in Practice								Exclude CYP sample and aen not mentioned
E	Exploring Transitions with Disabled Young People: Our Experiences, Our Rights and Our Views	Rome, Aidan Hardy, Jessica Richardson, Jamie Shenton, Felicity	2015	Child Care in Practice	A paper written by CYP exploring transitions and CYP as decision makers	CYP's human rights project based in NE England	CYP with AEN age 12-20		Agenda days using interactive methods to explore issues raised by CYP. Facilitators write a report at end of day to sum up issues and share	Transformative Activist	Being informed, having a say in decisions affecting their lives, being listened to, being given time to get used to new situations, need for continuity. Responsibility of adults to find ways of understanding YP's views rather than YP trying to make themselves heard.	Maybe however not necessarily rigorous enough, but generated by CYP specifically about decision-making...
E	Engaging with Young Children's Voices: Implications for Practitioners' Pedagogical Practice	Shaw, Patricia A.	2019	Education 3-13	Explores EYS practitioners perspectives or policy and government drive towards formalising EY education in england and explores how engagement with children's voices might inform	Reception classroom in infant school	Professionals working in this context		Semi-structured interviews Thematic coding	Constructivist Interpretivist Bricolage (pragmatic, strategic and self-reflexive)	Practitioners show resistance in responding to voices of young children and are influenced by internal and external pressures in their decision-making	Exclude Looking at how cyp's voice might inform pedagogical practice. Not explicitly about children's decisions about their own lives

					future pedagogical practice							
S	A qualitative analysis of implementing shared decision-making in Child and Adolescent Mental Health Services in the United Kingdom: Stages and facilitators	Abrines-Jaume, N. Midgley, N. Hopkins, K. Hoffman, J. Martin, K. Law, D. Wolpert, M.	2016	Clinical Child Psychology and Psychiatry	To explore SDM (shared decision-making) in CAMHS and id clinician determined facilitators to SDM	4 ENGLISH CAMHS settings	23 CAMHS professionals completed 307 logs	SDM, child mental health, CAMHS, plan do study act, implementation	Use of log books which reflected on SDM completed by professional, then Framework analysis in Atlas		Relationships important, tool can be clunky, practitioner's needs to be willing to put in effort to use SDM tool. Clinician needs to use tool flexibly	Exclude More about clinicians needs than CYP
S	Generating authentic understandings of participation: Working with young people.	Charles, A	2017	Intersections (Hungary)	In this article, what young people said when they were asked to explain what participation meant to them is presented and explored. - What is participation? - Who is involved in your participation? - Where does your participation occur? - How does your participation occur? - What effects flow from	Local secondary school and local youth justice and resettlement and aftercare services	young people aged between 11-18 years an	Young people's participation; Children's rights; Decision-making; United Nations Convention on the Rights of the Child	a qualitative enquiry process, and one which sought to understand young people's views, opinions and lived experiences of participation	Transformative? Constructionist? Not explicit	young people consider adultinspired understandings of participation to be deficient. The key reasons for this conclusion are that: Adult-devised understandings were, in the view of young people, made by adults And for adults, not young people. In order for young people's participation to	Yes... maybe... print an dread

					your participation? Considers the nature and meaning of participation from CYP perspective						be meaningfully appreciated and comprehended by adults, new understandings of this topical concept are required and this article forms a solid foundation for future examination of this reality.	
S P	The Revised SEND Code of Practice 0-25: Effective practice in engaging children and young people in decision-making about interventions for social, emotional and mental health needs.	Kennedy, E. K.	2015	Support for Learning	Developing children's involvement in DMP through LM working with CYP with SEMH needs using PCP to create plans	Primary school	Not explicit which is problematic...no ages or number mentioned.	SEND COP, children participation in decision-making, semh needs	Case study Semi structured interviews	Solution focused practice, goal scaling	Suggests that goal scaling provided LM with a practical tool to better include C in decision-making processes about provision and its impact	Maybe... still a feeling of adults 'doing' inclusion to children as oppose to children being active
S	Nurturing the virtuous circle: Looked After Children's participation in reviews, a cyclical and	Roesch-Marsh, A., Gillies, A., & Green, D	2017	Child and Family Social Work								Exclude Scottish context

	relational process.											
S	Strengths and limitations of the Education, Health and Care plan process from a range of professional and family perspectives	Sales, N., & Vincent, K.	2018	British Journal of Special Education	The extent to which SEND COP reforms have successfully addressed some of the problems in statementing process	two Las in East Midlands	Parents, CYP and professional in	EHCP SEND COP Statement	Interviews, questionnaires, focus groups	Thematic analysis Braun and Clarke	New EHCP achieves greater parental involvement and more PCP. However inconsistency in interpreting and applying legislation in practice...	Maybe... But not focused just on cyp and decision-making processes
P	Voices of disaffection: Disengaged and disruptive youths or agents of change and self-empowerment?	Allan, D., & Duckworth, V	2018	British Journal of Special Education	Bourdieu's concept of capital is used to explore 14-16 yr. old girls perspectives undertaking a vocational course as a strategy for re-engagement	Girls who were seen as disaffected and accessing a vocational learning programme from a variety of schools in NE England	14-16 Yr. old girls n-10 'disaffected'	Bourdieu, student voice, disaffection, alternative learning environment, empowerment	Semi structured interviews Thematic analysis Interpretivist paradigm (Radnor 2002)	Bourdieu's concept of capital to examine the exposition of social processes, and to illustrate the potential for voice to be a mechanism for promoting capital and for tackling inequality, disaffection and marginalisation. We thus draw on concepts of capital and field as sensitising tools to explore student voice	The girls sought to be heard in school but were not heard or what they had to say wasn't valued in school context. They are valued and empowered in their vocational environment. Curriculum should be wide ranging to engage and include all...	Include
P	Hearing children's voices? Including children's	Macdonald, Gillian S.	2017	Child Abuse & Neglect								Exclude No link to CFA or educational contexts

	perspectives on their experiences of domestic violence in welfare reports prepared for the English courts in private family law proceedings											
P	Children and parent participation in child protection conferences: A study in one English local authority	Muench, Kerry Diaz, Clive Wright, Rebecca	2017	Child Care in Practice								Exclude No link to CFA or educational context
P	The new Special Educational Needs (SEN) legislation in England and implications for services for children and young people with social, emotional and behavioural difficulties	Norwich, Brahm Eaton, Andrew	2015	Emotional & Behavioural Difficulties	REFER TO THIS IN INTRODUCTION as this addresses the potential of reforms and also explains key points of CFA							Exclude



Hand	Autonomy, Rights and Children with Special Needs: A New Paradigm?	Riddell, Sheila Gillooly, Amanda Harris, Neville Davidge, Gail	2019	Not peer reviewed....								
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**Think about....**

**Perspectives...adults or CYP's of decision-making, co-construction**

**Perhaps needs to focus on CYP's experience as this is about them...**

**Look at included papers and maybes and ask more questions to help decide...**

**Specific focus on DMP**

**Also see what else Brahm Norwich has written since**

#### **5.4 Appendix D: Developing a rationale for not using a quality assessment tool**

- An assessment of quality was not carried out the included studies for a number of key reasons:
- Qualitative research can be seen as interpretivist (Walsh & Downe, 2006), which means from an epistemological point of view knowledge can be seen as a social construct (Crotty, 1998). From the same position quality assessment can be seen as constructed. Therefore not assessing the quality of each study from a subjective position allows for consideration of the researchers' chosen approaches and how these were, in themselves constructed, and why. I accept that there are several equally valid approaches to research and object the notion of an objective criteria based on a fixed construct of perceived quality. This contrasts with a positivist stance which would support an objective 'truth', and supports the notion that one version of events is not authoritative over any other (Walsh & Downe, 2006).
- This leads me to consider what constitutes quality, perhaps when exploring the experiences of CYP in decision-making processes quality can be about rigour and transparency and also about how these experiences are represented authentically and closely to the lived experiences.
- I hope to be able to explore the experiences of CYP in each study in order to potentially generalise these to a broader context. Assessing the quality of the research may potentially exclude the experiences of young people which may provide rich and valuable insight. Including studies that don't follow the academic norm for the area of research is in itself rigorous (Walsh & Downe, 2006).
- When selecting studies it has been important to consider who is speaking. In a cultural and historical context this can make a difference as to whether they are taken seriously and heard (Fielding, 2004). In the context of CFA and SEN COP reforms which are meant to uphold CYP's rights and support a person centred approach I feel it is important to consider all voices from research, including research conducted by young people. This is all the more important since their voice reflects the effects of policies and reforms which are in place to support them. This supports an idea of democracy which values CYP holistically and their voice is heard and taken seriously (Cockburn, 2007).

- Including studies from a range of approaches can potentially achieve a higher level of abstraction(Britten et al., 2002). There is a lack of research in this area since the reforms of the CFA(2014) and SEND COP (2015) and excluding research on the basis of a framework for perceived quality might leave too few studies to review.

## 5.5 Appendix E: Thematic Synthesis stage 1

An example of initial codes generated using Nvivo

# Coding Summary By Code

SLR

27/02/2020 11:18

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials
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## Node

Nodes\\Context

PDF

Files\\Exploring Transitions with Disabled Young People Our experiences Our Rights and Our Views

No 0.0122 1

1 ZW

Finally, young people talked about their feelings of isolation and mixed emotions, highlighting the need for continued support during transition periods which causes much anxiety and uncertainty:

When you move on you have to make big decisions about your future and that can be scary.

You can miss some of your friends, like when I moved into life skills and some of my friends went to college.

Having to move from one school to another, or on to college makes you feel nervous and sad as well as excited.

Nodes\\Context\\Decision-making through actions and behaviour

PDF

Files\\Allan\_et\_al-2018-British\_Journal\_of\_Special\_Education (3)

No 0.0210 9

1 ZW

Emily rejected the cultural capital of the school and her former actions contrast with her behaviour in the provider, such as her willingness to re-read her work (a task that her former teachers claim she avoided).

2 ZW

As such, she uses these actions to self-empower to gain recognition for her previously unacknowledged linguistic capital.  
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3 ZW

The pressure to accept the existing capital of the school often resulted in further marginalisation, but this was challenged through agentic disengagement.

Hyacinth's frustration through being silenced led to her refusal to conform:

27/02/2020 11:18

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials
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5 ZW

As such, the girls identify and address their needs, with the subsequent impact of this becoming evident in their further commitment to the provider:

Fiona: 'My behaviour has improved loads and my attendance is better. I never used to go to school... I'd bunk [truant]. I'm in

6 ZW

Thus, the girls disengage from school to reclaim agency and express a voice in the provider, whereupon they shape the curriculum:

'We said we wanted to work with clients and do some of the more advanced stuff and they said, "OK, let's give it a go". If that was school they'd say, "Well, we have to follow the guidelines ... you're not allowed to do that ... you can't just do what you

7 ZW

Their resistance to succumb to the dominant capital has resulted in a defence against the establishment and engagement in counter scholarly activities that value unacknowledged capital (Humphrey et al., 2004).

8 ZW

The girls took ownership of their narratives and their disengagement from school represents a reclamation of agency.

9 ZW

As a retaliatory mechanism, the girls disengage to self-empower

## Files\\Fayette\_et\_al-2018-British\_Journal\_of\_Special\_Education (2)

No 0.0162 4

1 ZW

2 ZW

The participants explained that giving students daily opportunities to choose not only reinforces their belief that students are 'free to go and make choices' (Mr Clark, SSS), but also helps 'to ensure that they understand choice-making procedures' (Mrs Smith, BSS), and hence prepares them for transition:

'when you're younger you start with the really early choice of what you want to eat or drink. As you get older, those choices change to what you

14 British Journal of Special Education ~ Volume 45 ~ Number 1 ~ 2018 ©2018 NASEN

3 ZW

Participants from both schools also identified students' behavioural patterns as means of communication, and hence used behavioural observations as another means of eliciting their views.

'picking up on students' behaviours, especially students with ASD. They will demonstrate through behaviour if they're not happy with a situation or if... they feel that they've made the wrong choice'

(Mrs Smith, BSS)

4 ZW

Even though pupils are invited to attend these reviews to present their views, some choose not to do so. In such cases, their teachers would represent their views based on what they wrote in their pupil voice booklets.

## Files\\Zilli\_et\_al-2019-British\_Journal\_of\_Educational\_Psychology (1)

No 0.0071 3

1 ZW

Taking breaks was a helpful strategy that enabled pupils to stay in the classroom. All pupils particularly valued this strategy and made decisions to use it in different ways:

Reports\\Coding Summary By Code Report

Page 2 of 39

27/02/2020 11:18

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials
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2 ZW

One caveat with this practice was that some pupils may have been uncomfortable with having too much choice: ... it kind of scared him for a little while but actually we sat down, did a brainstorm, each individual student decided what to make at the end of that term and Jack created the most amazing three-dimensional piece of sculptural work using random bits and pieces (Staff 5).

This highlights that contributing to decision-making is a skill that needs to be learned rather than assumed, with additional

3 ZW

Pupils described many changes to their school experiences after having had a discussion with senior management and that visits were not always about 'sorting issues' but also an opportunity to talk

## Nodes\\Context\\Environment

### PDF

## Files\\Allan\_et\_al-2018-British\_Journal\_of\_Special\_Education (3)

No 0.0193 10

1 ZW

The data show that all the girls sought to be heard in school but struggled with the way they were treated:

2 ZW

Ironically, however, she exercises far less agency in the provider environment

3 ZW

Emily conceptualises learning as an opportunity for personal development but links education with school and negative connotations. This process of metacognition leads to greater self-awareness

4 ZW

The girls suggest that school was a domain of disempowerment and their perceptions of the structural practices of the alternative environment highlight this further.

5 ZW

Fiona's experience of disempowerment in school contrasts with her time at the provider.

6 ZW

She argues that its informal approach enables her to feel comfortable enough to be critical, whilst also building a rapport with staff

7 ZW

Consequently, many structural constraints – such as behaviour management – were accepted without question, even when they mirrored the practices of school

8 ZW

However, agency and self-empowerment are evident in the narratives as the girls have utilised the provider environment as a critical space to reflect and to develop autonomy:

'I've learnt a lot since I've been here. I've been able to step back and think about what I wanna do when I leave. You don't get that in school. I think there's too much pressure on what we have to do, what exams we have to take'.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials
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9 ZW

school is often experienced as a site of intergenerational marginalisation (Duckworth, 2013) and social exclusion, and a domain for teacher- and peer-labelling.

10 ZW

they are empowered in their peer groups, and perhaps in their community, there is still a gulf between community and school status

## Initial 27 codes generated by stage 1 of analysis

Code	Description
Context	Environment- direct and wider, the decision-making process,
Decision-making through actions and behaviour	
Environment	
Environmental structures	
Ethos	
Identity	
Feelings about decision making	
Participation	How does it occur? What happens? Who is involved? Barriers and supports? Effects? Evaluation

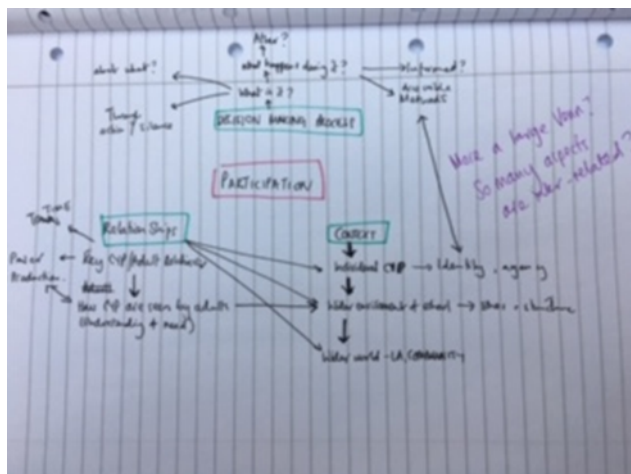
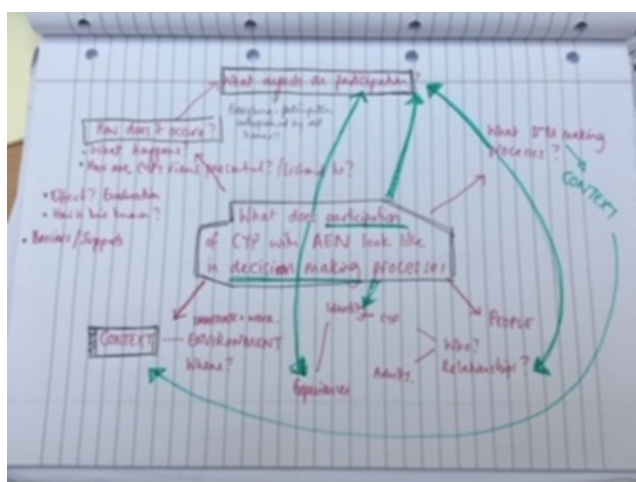
Being active having agency	
Accessibility	
Ways of supporting young people to be active	
Being informed	
effects of decision-making	
Reflection and evaluation	
Wanting to be heard	
Being heard at a systems level	
Being listened to	
How views are represented	
Listening	
Sharing experiences	
Past experiences	
People	Who is involved, what are their relationships, what underpins their relationships
Relationships	
coproduction	
How CYP are seen by adults	
Power	
Understanding of AEN	
Time	



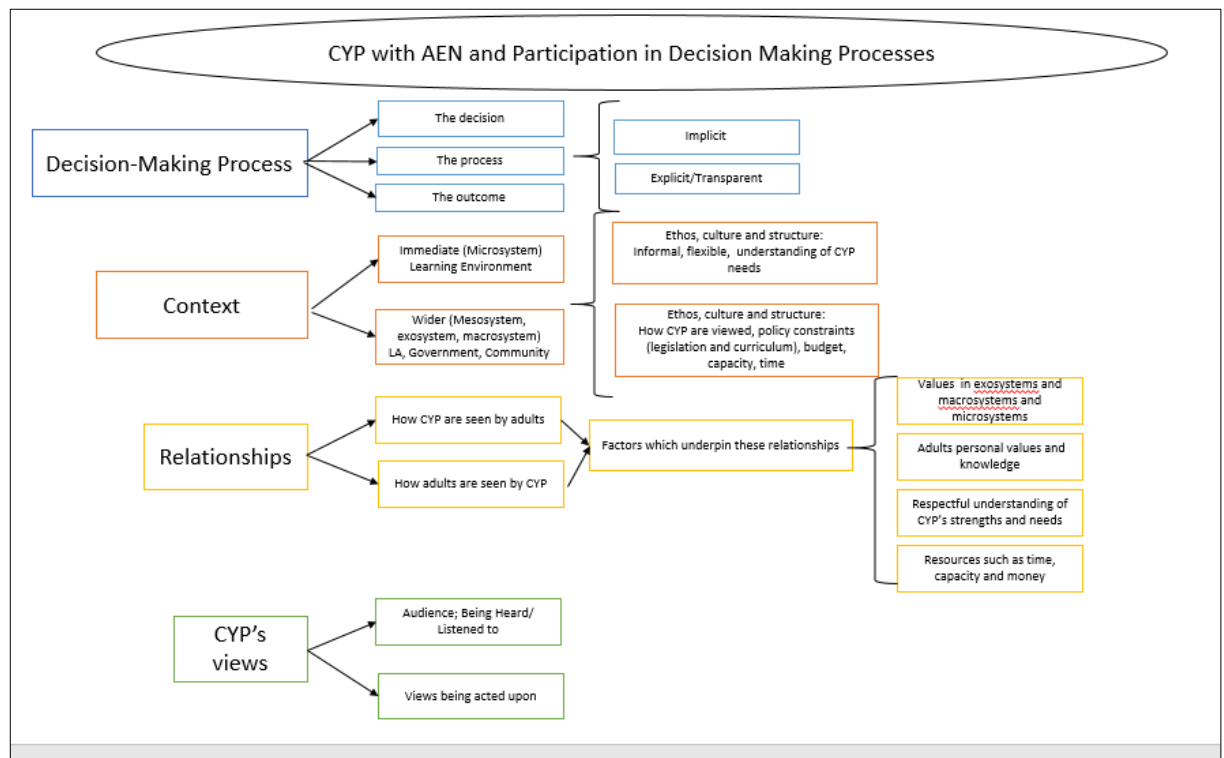
## 5.6 Appendix F: Phase 2 Coding across the studies

## Stage 2: The development of descriptive themes

I then looked for differences and similarities between the codes and started to group them into a visual representation to explore their relationships. This was a fluid and on-going process (*see below*). At this point I moved away from the Nvivo coding tables and started to develop my own table of codes to support the process of synthesis. I constructed a table of all the codes with quotes from each study represented alongside each code (See appendix G).



At this stage this resulted in 3 over-arching descriptive themes and several sub-themes within these. I then revisited the codes again and a fourth over-arching theme emerged. As the themes emerged and became clear I developed a visually representative tree structure (*See below*).



## 5.7 Appendix G: Code table with quotes

An example of the coding process during thematic synthesis.

	Allan, David Duckworth, Vicky (2018) Voices of disaffection: Disengaged and disruptive youths or agents of change and self-empowerment?	Fayette, Rainart Bond, Caroline (2018) A Qualitative Study of Specialist Schools' Processes of Eliciting the Views of Young People with Autism	Gaona, Carolina Castro, Susana Palikara, Olympia (2019) The views and aspirations of young people with autism spectrum disorders and their provision in the new Education Health and Care plans in England	Gaona, Carolina Palikara, Olympia Castro, Susana (2019) 'I'm Ready for a New Chapter': The Voices of Young People with Autism Spectrum Disorder in Transition to Post-16 Education and Employment	Rome, Aidan Hardy, Jessica Richardson, Jamie Shenton, Felicity (2015) Exploring Transitions with Disabled Young People: Our Experiences, Our Rights and Our Views	Zilli, Chantelle Parsons, Sarah Kovshoff, Hanna (2019) Keys to engagement: A case study exploring the participation of autistic pupils in educational decision- making at school
	1	2	3	4	5	6
Decision-making Process						
<p><b>The decision-</b> what is it about?</p> <p>What is its purpose?</p> <p>No. papers this theme is present in:6</p> <p>Not always explicitly</p>	<p>Emily rejected the cultural capital of the school and her former actions contrast with her behaviour in the provider, such as her willingness to re-read her work (a task that her former teachers claim she avoided).</p> <p>As such, she uses these actions to self-empower to gain recognition for her previously unacknowledged linguistic capital.</p> <p>The pressure to accept the existing capital of the school often resulted in further marginalisation, but this was challenged through agentic disengagement.</p> <p>Hyacinth's frustration through being silenced led to her refusal to conform</p>	<p>The participants explained that giving students daily opportunities to choose not only reinforces their belief that students are 'free to go and make choices' (Mr Clark, SSS), but also helps 'to ensure that they understand choice-making procedures' (Mrs Smith, BSS), and hence prepares them for transition: 'when you're younger you start with the really early choice of what you want to eat or drink. As you get older, those choices change to what you want to do... Whether or not you want to go out to the community or stay inside'</p> <p>These choices ranged from daily choices that impact only on them,</p>	<p>series of codes emerged relating to young people's independence and autonomy, and were linked predominantly to those belonging to the chapters of mobility (d4), self-care (d5), and domestic life (d6). The emergence of these codes stresses the significance of independence for participants and their families at a time of transition</p>	<p>participants reported feeling excited, expressing wishes to become more independent and acknowledging that these changes are intimately related to growing up.</p> <p>The above-mentioned participant hinted at a wish to live independently, which was later confirmed in the course of the interview. He was the only one who explicitly considered living outside the family home as an independence goal for his future.</p> <p>The study revealed that enrolling in post-secondary education and training, and becoming increasingly more independent,</p>	<p>Finally, young people talked about their feelings of isolation and mixed emotions, highlighting the need for continued support during transition periods which causes much anxiety and uncertainty: When you move on you have to make big decisions about your future and that can be scary. You can miss some of your friends, like when I moved into life skills and some of my friends went to college. Having to move from one school to another, or on to college makes you feel nervous and sad as well as excited.</p> <p>young people wanted to have a say in decisions affecting their lives and be listened to:</p>	<p>For two pupils, it was important to be able to direct the lesson in some way, whether this was through choosing resources or independently executing tasks. Noah spoke positively about his music lesson where he had the freedom to make choices</p> <p>Practices that drew on pupil interests ranged from entirely pupil-led lessons and projects to specific tasks within the lessons, which required negotiation</p> <p>Practical examples included pupils contributing to and, in some cases, leading decisions about projects in lessons and the types of clubs organized by the school.</p>

	<p>As a retaliatory mechanism, the girls disengage to self-empower</p>	<p>such as choosing foods or reward activities, to decisions that impact not only themselves but the whole school.</p> <p>For instance, BSS's recruitment policy states that applicants for teaching posts must be interviewed by a group of students whose opinions will be considered prior to any new appointments.</p> <p>The second phase involves providing the pupils with three types of support to make informed choices regarding the different aspects of adulthood.</p>		<p>constitute key transition goals and aspirations for young people with ASD at the end of their compulsory education journey</p> <p>All participants reported continuing education and training following the end of secondary school; however, the aspects of their future that most concerned them were related to everyday life activities and participation</p> <p>For more than half of participants, being independent translated into being able to move around outside the house on their own, as well as using public transport without assistance or supervision</p> <p>decision-making process was also linked to independence</p> <p>Regarding making big life decisions, all participants reported parents as key stakeholders and that school staff were great contributors to help them in the process.</p>	<p>When it's a "move-up" time you should have more review meetings and you should be able to talk about what you want to do and the help you will need. They should listen to us more about that.</p> <p>young people wanted to have a say in decisions affecting their lives and be listened to: When it's a "move-up" time you should have more review meetings and you should be able to talk about what you want to do and the help you will need. They should listen to us more about that.</p>	<p>The importance of extra-curricular activities to pupils, such as the student council and language club, also highlighted the value placed on access to and appreciation of other forms of learning</p> <p>Decisions about which extra-curricular activities pupils attended were made between staff and pupils. Sometimes, new clubs were created because of pupil interests; in David's case, the language club was created by the Spanish teacher because she noticed that David had an 'intense interest' in languages which was not catered for in the current timetable</p> <p>The school council was identified as an important forum for pupil participation. Decisions about who joined the student council were made through a democratic process involving the whole school.</p>
<p>Decision-making processes range from everyday decisions about participation in a learning context (1,2,6), making transitions from one educational setting to another (1,4,5) and contributing to formal processes such as EHCP where CYP's views are meant to inform decision-making processes which affect them (2,3,5).</p> <p>The primary purpose of these decision-making processes is to support the CYP to access and engage in learning and prepare for their future, for example:</p> <ol style="list-style-type: none"> <li>1. "As such, she uses these actions to self-empower to gain recognition for her previously unacknowledged linguistic capital." The girls made decisions through their choices to disengage and through their disengagement they were self-empowered. They gained agency as a result of their decision and what happened subsequently.</li> <li>2. "The participants explained that giving students daily opportunities to choose not only reinforces their belief that students are 'free to go and make choices' (Mr Clark, SSS), but also helps 'to ensure that they understand choice-making procedures' (Mrs Smith, BSS), and hence prepares them for transition:</li> </ol>						

- 'when you're younger you start with the really early choice of what you want to eat or drink. As you get older, those choices change to what you want to do... Whether or not you want to go out to the community or stay inside". CYP are used to making decisions in the context of their daily lives in school and this is extended in a structured and supported way in order for them to prepare for adulthood.
3. As part of 'Section A' 'the views, interests and aspirations of the child and their parents, or of the young person' of EHCP plans CYP share their views and aspirations for the future. These views should inform decision-making processes about provision.
  4. CYP were involved in decision-making processes within their educational setting as part of the process of PFA as they prepared for life after leaving school:  
"All participants reported continuing education and training following the end of secondary school; however, the aspects of their future that most concerned them were related to everyday life activities and participation."
  5. CYP felt it was important that they were actively part of DM processes about transitions:  
"young people wanted to have a say in decisions affecting their lives and be listened to:  
When it's a "move-up" time you should have more review meetings and you should be able to talk about what you want to do and the help you will need. They should listen to us more about that."
  6. Being part of DM processes was integral in supporting CYP to engage in learning in a school environment. This ranged from everyday decision-making within the classroom to wider decisions which affected the whole school:  
"The school council was identified as an important forum for pupil participation. Decisions about who joined the student council were made through a democratic process involving the whole school."

An end result of taking part in decision-making processes could be seen as PFA as though being active in DM processes CYP are empowered and gain agency as well as linguistic capital.

<p><b>The Process- What happens during it?</b> Is it informed? Are accessible methods used? How is it supported? Personal and Practical</p> <p>No. papers this theme is present in: 6</p>	<p>Thus, the girls disengage from school to reclaim agency and express a voice in the provider, whereupon they shape the curriculum: 'We said we wanted to work with clients and do some of the more advanced stuff and they said, "OK, let's give it a go". If that was school they'd say, "Well, we have to follow the guidelines ... you're not allowed to do that ... you can't just do what you want". But it's our education'. (Fiona)</p> <p>The girls took ownership of their narratives and their disengagement from school represents a reclamation of agency.</p>	<p>Participants from both schools also identified students' behavioural patterns as means of communication, and hence used behavioural observations as another means of eliciting their views. 'picking up on students' behaviours, especially students with ASD. They will demonstrate through behaviour if they're not happy with a situation or if... they feel that they've made the wrong choice' (Mrs Smith, BSS)</p> <p>Even though pupils are invited to attend these reviews to present their views, some choose not to do so. In such cases, their teachers would represent their views based on what they wrote in their pupil voice booklets.</p>	<p>Concerning the methods used to elicit these views, three plans mentioned the development of a slide presentation by the young people in which they introduced themselves and expressed their views;</p> <p>six plans included rather broad statements to refer to the contribution of the young people in their EHC process, i.e. 'he was present at the annual review meeting and communicated his aspirations' with no further indication of the processes underpinning these contributions.</p> <p>The findings of the study highlight variability in the ways the views of young people are elicited and portrayed in</p>	<p>a mixture of feelings that underpinned the experience of change</p> <p>participants reported feeling excited, expressing wishes to become more independent and acknowledging that these changes are intimately related to growing up.</p> <p>their excitement was also accompanied by uncertainty and sadness. They recognised that moving to new settings translated into leaving behind beloved places and people who had seen them grow up, to make room for new learning experiences and challenges.</p>	<p>Firstly, young people highlighted the importance of being given adequate information about what is happening and why</p> <p>Members of the research group were involved in recording and editing the DVD and then in promoting it at a multiagency event.</p> <p>The culmination of all of the work that has been carried out was the young people's involvement in planning and running the event in May 2014.</p> <p>The young people decided they wanted this to have a positive can "do" message, and have worked to this remit.</p>	<p>Taking breaks was a helpful strategy that enabled pupils to stay in the classroom. All pupils particularly valued this strategy and made decisions to use it in different ways:</p> <p>The importance of breaks, and the opportunity to choose when and where to take breaks, was illustrated by photographs of each of these locations, which represented places around the school where pupils felt 'most listened to'</p> <p>One caveat with this practice was that some pupils may have been uncomfortable with having too much choice: ... it kind of scared him for a little while but actually we sat down,</p>
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	<p>Thus, the girls reclaim identities that are not stigmatised by their inability to acquire the dominant capital; rather, they are celebrated for using linguistic capital, and telling their stories situates their 'voice' in the public domain.</p>	<p>Both schools' processes for eliciting the views of young people with ASD about their transition to adulthood are long and involve three phases, which are underpinned by their ethos</p> <p>effective processes of eliciting and including the views of young people with ASD require a person-centred ethos, and a commitment from all staff to elicit the pupils' views and develop processes that enable pupils to make informed decisions throughout their time in school.</p> <p>Even though pupils are invited to attend these reviews to present their views, some choose not to do so. In such cases, their teachers would represent their views based on what they wrote in their pupil voice booklets.</p> <p>All pupils with ASD were therefore given multiple opportunities to visit different post-16 educational provisions, as well as relevant work experiences, to enable them to evaluate their possible choices better.</p> <p>The findings also provided support for the use of communication tools such as Talking Mats, symbols, PECS, switches and/or</p>	<p>their EHC plans.</p>	<p>participants felt nervous or unsure about moving on to the next stage, revealing concerns about what they would be doing the following year</p> <p>one participant recognised that he would have liked further involvement in his work experience application and stressed feeling left out of his own application process. I'm not sure on the process because the teachers do all the applications and things, and it's quite secretive [...] I don't really like secrecy though, I would have liked more transparency. (YP 14, 16 years old)</p>	<p>Young people have been sampling and choosing new sensory support equipment.</p> <p>It has been recognised that the best people to choose new equipment will be those that are going to be using it, and they have helped to test out various pieces of equipment and then helped to identify the best ones so that resources are not wasted on equipment that is not useful to young people.</p> <p>The group had decided that a DVD which showed several young people describing their own personal stories would have both a more powerful impact than a report and also the potential to reach a wider audience</p> <p>young people highlighted the importance of being given adequate information about what is happening and why. They also suggested that they should have opportunities to spend time in potential new settings before making post-school decisions: When it comes to moving on into another service for your health stuff you just get told and then it happens. When you do visits you should get to do a "typical day" so you</p>	<p>did a brainstorm, each individual student decided what to make at the end of that term and Jack created the most amazing three-dimensional piece of sculptural work using random bits and pieces (Staff 5).</p> <p>This highlights that contributing to decision-making is a skill that needs to be learned rather than assumed, with additional guidance provided where needed.</p> <p>All four pupils took photographs of members of the senior leadership team, and for three pupils, David, Noah, and Jack, this represented one place where they felt most listened to within the school.</p> <p>These practices supported decisions that facilitated pupil access and achievement, especially in relation to focusing on the strengths and interests of the pupils and using these as 'keys to engagement'</p> <p>However, it was evident that pupils valued the flexibility to choose how and when they learned, and that they enjoyed the range of activities</p> <p>Allowing breaks/ timeouts in and out of the classroom for all pupils</p>
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		<p>behavioural observations to elicit and record the views of pupils with ASD.</p> <p>All students were given multiple opportunities to visit and experience a variety of employment and further education settings, such as colleges or community learning centres, where they could continue their education either by beginning an apprenticeship or attaining various qualifications from entry level to those that are necessary to progress to higher (university-level) education.</p> <p>SSS staff reported that every year, they invite former pupils with ASD who transitioned to college or employment to meet current transition-aged students.</p> <p>Staff believed that providing this alongside work experience enables students to build concrete references of what life after school would be like, and supports informed choices.</p> <p>'Sometimes, a child may say "I want to do gardening", but he has no idea what that entails. So letting them try things ... help them decide what they want to do.'</p> <p>(Ms Stevens, SSS)</p> <p>'We do a fantastic work experience programme</p>			<p>really get an idea of what you will be doing, not just a look around and see where things are.</p> <p>The third theme related to the pace of transitions, with participants saying they need more time to get used to new people and places and need some continuity with workers who know them well and respect their opinions: If you get used to one worker and then get another that can be bad because you feel like you're starting again.</p> <p>Finally, young people talked about their feelings of isolation and mixed emotions, highlighting the need for continued support during transition periods which causes much anxiety and uncertainty: When you move on you have to make big decisions about your future and that can be scary.</p> <p>You can miss some of your friends, like when I moved into life skills and some of my friends went to college.</p> <p>Having to move from one school to another, or on to college makes you feel nervous and sad as well as excited.</p>	<p>Timetabling and extra-curricular activities</p> <p>School council</p> <p>The observations of pupils in lessons suggested that breaks were taken flexibly and were pupil-led, rather than only through a timeout system where pupils physically left the classroom. In two separate observations of John, he stated: 'I can't think, I'm asleep'. Staff responded by offering a compromise that acknowledged the needs of pupils, such as asking if they would like to take a short break before trying to commence work.</p> <p>Staff also argued that sometimes compromising physical presence in the classroom in favour of doing work was necessary to meet the needs of pupils.</p> <p>There were also examples of situations where staff tapped into pupil interests to enable pupils to reach the goal of a lesson.</p> <p>The school council was identified as an important forum for pupil participation. Decisions about who joined the student council were made through a democratic</p>
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		<p>here which ... allows the students to understand what they can do' (Mrs Green, BSS)</p> <p>The staff from both schools reported that they do not have official means of evaluating their processes of eliciting the views of pupils or how these views are represented in the final transition plan.</p> <p>the school aims to place the views of the pupils at the centre of the planning process</p> <p>Mrs Smith commented that their new process is based on their belief that students know what they want and that most of them have the ability to make their own decisions. She also stated that this change in belief and process was explained to parents: 'The transition plan is all about the pupils' voice .. . We have to explain that to parents that it's not what they want ... it's the young person's choice'</p> <p>they were able to elicit the views of their pupils, regardless of their communication needs</p> <p>Pupils' views are then then recorded in 'pupil voice booklets' which are provided by the local authority and are presented in person-centred annual reviews</p>				<p>process involving the whole school.</p>
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		<p>at which the pupils' previous targets are reviewed and their transition to adulthood is discussed with their parents, school staff, local authority representatives and other relevant professionals.</p> <p>The findings also provided support for the use of communication tools such as Talking Mats, symbols, PECS, switches and/or behavioural observations to elicit and record the views of pupils with ASD.</p> <p>SSS staff reported that every year, they invite former pupils with ASD who transitioned to college or employment to meet current transition-aged students.</p> <p>These processes are underpinned by the staff's understanding that pupils with ASD experience varying degrees of difficulties with communication, changing routines, conceptualising abstract concepts and planning for the future – all of which affect their conceptualisation of transition to adulthood and, in turn, their ability to make informed decisions.</p>				
1.The girls demonstrated their agency by disengaging with school:						

"The girls took ownership of their narratives and their disengagement from school represents a reclamation of agency." They were then able to have the opportunity to engage in learning in an alternative learning provision. In this provision CYP were part of decision-making process in which their views and experiences were valued and listened to: "Thus, the girls reclaim identities that are not stigmatised by their inability to acquire the dominant capital; rather, they are celebrated for using linguistic capital, and telling their stories situates their 'voice' in the public domain."

Overall the DM processes are underpinned by legislation such as CFA and SEND COP which advocate PCP and CYP being active in DM processes. The processes which support DM within the studies describe practices such as:

1. Eliciting views through verbal and other forms of communication: "behavioural patterns as means of communication." (2) Thinking carefully about the methods of eliciting these views: "The findings also provided support for the use of communication tools such as Talking Mats, symbols, PECS, switches and/or behavioural observations to elicit and record the views of pupils with ASD." (2)  
"The school council was identified as an important forum for pupil participation. Decisions about who joined the student council were made through a democratic process involving the whole school." (6)  
It was important for CYP to be well informed, "young people highlighted the importance of being given adequate information about what is happening and why." Supporting CYP to understand the DM processes they are part of and thus have agency. "I don't really like secrecy though, I would have liked more transparency." (4)
2. Eliciting views formally, as part of wider processes such as choosing school resources, EHCP planning or preparing for transition to different settings and eliciting views as part of everyday practice to support CYP's social and emotional development;  
"The findings of the study highlight variability in the ways the views of young people are elicited and portrayed in their EHC plans." (3)  
"It was evident that pupils valued the flexibility to choose how and when they learned, and that they enjoyed the range of activities." (6)  
"Thus, the girls disengage from school to reclaim agency and express a voice in the provider, whereupon they shape the curriculum:  
'We said we wanted to work with clients and do some of the more advanced stuff and they said, "OK, let's give it a go". If that was school they'd say, "Well, we have to follow the guidelines ... you're not allowed to do that ... you can't just do what you want". But it's our education'. (Fiona)" (1)  
"Young people have been sampling and choosing new sensory support equipment. It has been recognised that the best people to choose new equipment will be those that are going to be using it, and they have helped to test out various pieces of equipment and then helped to identify the best ones so that resources are not wasted on equipment that is not useful to young people." (5)

<p><b>What happens afterwards?</b></p> <p><b>No. papers this theme is present in: 5</b></p>	<p>As such, the girls identify and address their needs, with the subsequent impact of this becoming evident in their further commitment to the provider: Fiona: 'My behaviour has improved loads and my attendance is better. I never used to go to school... I'd bunk [truant]. I'm in here every day'.</p> <p>Their resistance to succumb to the dominant capital has resulted in a defence against the establishment and engagement in</p>	<p>Although both schools had a strong commitment to pupil voice, there were some limitations to pupil participation within their processes</p> <p>Participants from both schools stressed the importance of providing concrete references for abstract concepts, as they were aware of the difficulties faced by pupils with ASD in conceptualising the future</p> <p>There was a collective agreement among all of the participants that the students' best interests</p>	<p>raises the question of the effectiveness of the implementation of the principle of participation of the young person in decision-making and their involvement in the development of their EHC plan.</p> <p>Broad statements such as 'he was present at the annual review meeting' appear to portray the young person's involvement in decision-making, as intended by the SEND Code of Practice; however, these portrayals do not provide enough evidence of being the participatory,</p>		<p>The culmination of all of the work that has been carried out was the young people's involvement in planning and running the event in May 2014.</p> <p>A number of young people from the eXtreme Group have been involved in designing new services as a result of the new Special Educational Needs and Disabilities reforms.</p> <p>The outcomes from the research have helped to transform the Transitions services. A Transitions Support Worker, whose key role is to support</p>	<p>Pupils described many changes to their school experiences after having had a discussion with senior management and that visits were not always about 'sorting issues' but also an opportunity to talk</p> <p>Three pupils also described a positive change in emotional state after taking a break (timeout) from the lesson</p> <p>As these pupils were previously excluded or at risk of exclusion from educational settings and were now attending school full-time, our findings suggest that</p>
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	<p>counterscholarly activities that value unacknowledged capital (Humphrey et al., 2004).</p> <p>Emily has learned to re-channel her emotions to circumnavigate her frustrations.</p> <p>Emily also appears to re-configure her learner status by reconceptualising learning and education: 'At school ... I know it's our education and all that, but you just learn about different subjects. It doesn't really mean anything. But here ... this is good ... this is what I need to learn to get a job'.</p> <p>Thus, the girls reclaim identities that are not stigmatised by their inability to acquire the dominant capital; rather, they are celebrated for using linguistic capital, and telling their stories situates their 'voice' in the public domain.</p> <p>For many students, having a voice can increase self-esteem and motivation, and this can discourage disaffection. Voice can also lead to greater metacognition and autonomy as students reflect on their own contribution to their situation (Allan, 2015)</p> <p>Arguably, the establishment of</p>	<p>should be placed at the centre of their transition planning processes</p> <p>Staff at SSS reported that they tend to discuss questions such as 'what did you like about the college?' which pupils then record in their personal diaries.</p> <p>Pupils who attend BSS, on the other hand, write a list of at least five things that they want in further education settings, based on what they like about their current school, such as 'seeing my friends ... being able to play music, play sports' (Mrs Green, BSS) which is used to evaluate each further education setting that they visited.</p> <p>The participants stated that communication is still modified even when pupils are able to communicate verbally. As one participant put it: 'You don't generally copy what they say. You give them a few options and discuss with them; draw things out, like why do they want to do that?'</p> <p>The views of pupils who communicate non-verbally are elicited through the use of Talking Mats (Cameron &amp; Murphy, 2002), symbols, Picture Exchange Communication System (PECS; Bondy &amp; Frost,</p>	<p>person-centred approaches to SEND advocated by the Children and Families Act 2014.</p> <p>Concerning the match between views and aspirations of young people with ASD and the provision developed for them, findings suggest that there is a relative match between the content of section A and sections F, G and H.</p>		<p>young people into adult services, has been appointed as a direct result of young people's feedback.</p>	<p>there was real value in taking such a flexible approach for the inclusion and engagement of these pupils.</p> <p>Although it may be difficult to determine whether shared ownership was the catalyst for the positive outcome identified by staff in this example or the resultant compromise, these findings suggest that engaging pupils as partners in decision-making may be an effective approach to managing difficult situations in the classroom.</p>
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	<p>opportunities for voice is a mechanism for encouraging learner autonomy, rather than functioning as mere tokenism. However, generating a voice that validly represents students' concerns can be problematic, particularly if a contractual relationship has not been established between the young person and the system.</p> <p>However, agency and self-empowerment are evident in the narratives as the girls have utilised the provider environment as a critical space to reflect and to develop autonomy: 'I've learnt a lot since I've been here. I've been able to step back and think about what I wanna do when I leave. You don't get that in school. I think there's too much pressure on what we have to do, what exams we have to take'.</p> <p>In the training provider, voice is acknowledged and the students are officially re-empowered as their status is validated with professional adult recognition</p>	<p>1994) and/or switches. The choice of method, and its efficacy, depends upon the staff's knowledge of ASD and individual students. 'We know that students with ASD struggling to communicate benefit from using different aids like symbols, PECS, Talking Mats or switches that's why we use them ... [the tools] work because we know which pupil prefers which tool.'</p> <p>The observed transition review at SSS followed the format of a person-centred review, and Ian's views were recorded in a pupil voice booklet, which Ian used as a prompt when Mrs Jones asked him to write down his thoughts on the white board in front of the other attendees.</p> <p>Support is also provided for pupils to evaluate possible choices, particularly with regard to deciding between further education settings, usually after each visit.</p> <p>The participants explained that giving students daily opportunities to choose not only reinforces their belief that students are 'free to go and make choices' (Mr Clark, SSS), but also helps 'to ensure that they understand choice-making procedures' (Mrs</p>				
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		<p>Smith, BSS), and hence prepares them for transition</p> <p>they all perceived their processes to be effective in eliciting the views of all pupils with ASD, regardless of communication levels</p> <p>They also reported that anecdotal reports from parents and students indicate their overall satisfaction with their process.</p> <p>the extent to which their views are incorporated in the transition meetings and plans varied</p>				
<p>Individual level:</p> <p>The outcomes of the study reflect what happens when students develop agency through being active in DM processes:</p> <p>“As such, the girls identify and address their needs, with the subsequent impact of this becoming evident in their further commitment to the provider: Fiona: ‘My behaviour has improved loads and my attendance is better. I never used to go to school.. . I’d bunk [truant]. I’m in here every day’.” (1)</p> <p>“The participants explained that giving students daily opportunities to choose not only reinforces their belief that students are ‘free to go and make choices’ (Mr Clark, SSS), but also helps ‘to ensure that they understand choice-making procedures’ (Mrs Smith, BSS), and hence prepares them for transition.” (2)</p> <p>“As these pupils were previously excluded or at risk of exclusion from educational settings and were now attending school full-time, our findings suggest that there was real value in taking such a flexible approach for the inclusion and engagement of these pupils.” (6)</p> <p>Important to reflect on the process: “raises the question of the effectiveness of the implementation of the principle of participation of the young person in decision-making and their involvement in the development of their EHC plan.” (3)</p> <p>“Broad statements such as ‘he was present at the annual review meeting’ appear to portray the young person’s involvement in decision-making, as intended by the SEND Code of Practice; however, these portrayals do not provide enough evidence of being the participatory, person-centred approaches to SEND advocated by the Children and Families Act 2014.” (3)</p> <p>Wider impact:</p> <p>At a LA policy level: “A number of young people from the eXtreme Group have been involved in designing new services as a result of the new Special Educational Needs and Disabilities reforms.” (5)</p>						

"The outcomes from the research have helped to transform the Transitions services. A Transitions Support Worker, whose key role is to support young people into adult services, has been appointed as a direct result of young people's feedback." (5)

At a school policy level:

"Although it may be difficult to determine whether shared ownership was the catalyst for the positive outcome identified by staff in this example or the resultant compromise, these findings suggest that engaging pupils as partners in decision-making may be an effective approach to managing difficult situations in the classroom." (6)

#### Translation of concepts between studies and descriptive themes

What is the D?

The process

How the process is supported

Outcomes range from at an individual level to informing wider systems and processes.

Important as part of PFA and reflective practice underpinned by legislation

#### Generating analytical themes

DM as a process which needs to be considered contextually:

DM

Context- wider and immediate...influences within context

Linguistic capital- Process is shaped by legislation and also influenced by how CYP are seen in the setting (context and relationships)

What happened as a result of DM process.... What is hoped for? What happens?

Agency

Self-efficacy

Lack of reported data as to outcomes

Explain how I got from phase 2 to here. Papers described processes, these ranged from individual such as participation in a lesson, refusing to engage to more formal and structured DMP such as EHCP or informing LA policy. What the process looked like, how CYP were supported as part of this related to/ was influenced by the context, both immediate and wider, and the relationships between adults and CYP within this context. The influence of context and relationships also varied...variation does not seem due to actual DMP but more how DMP is conceptualised. This is suggested by a lack of detail about outcomes as a result of CYP being part of DM. **Participants and authors of study don't see participation in DM as a process but as an event...**which leads me to think that there is little reflection on... Also some papers there is a lack of theoretical transparency or warrant. Does this relate epistemological context and the extent to which meaning can be developed without this...lack of grounding? Or does meaning come from process...e.g Participatory research and its transformative nature

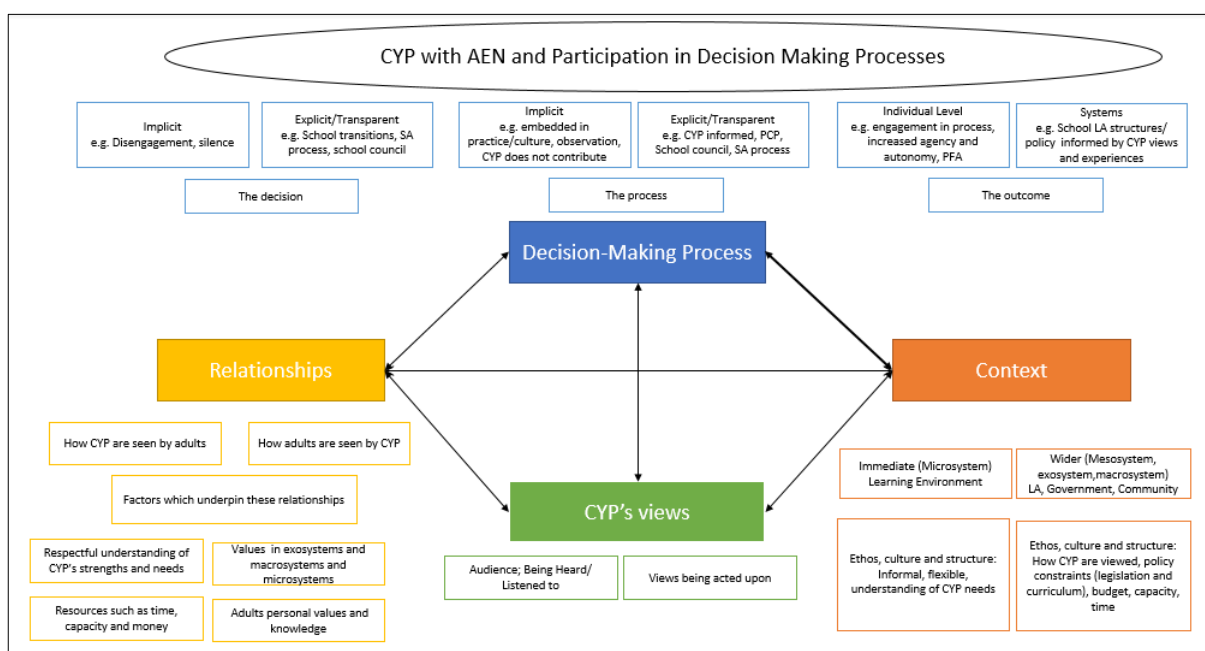
**How we conceptualise DM...and what this conceptualisation is influenced by?**

**Not the actual process but how we see the process**

**Are DMP implicit or explicit? This links to conceptualisation and what underpins this...context and things within this such as ethos and relationships**

## 5.8 Appendix H: Stage 3 generating analytical themes

Several codes were combined and as I did this I began to explore the relationships between codes which generated themes. It helped to revisit my question and explore the emerging themes visually in relation to my review question. This helped me to conceptualise the relationship between themes as I explored stage 3 of the thematic synthesis process and began developing analytical themes. The end result was a visual representations of 4 main themes and several sub themes which explored the DMP for CYP with AEN in the 6 review papers (see below).



## 5.9 Appendix I: Semi-structured interview questions informed by IPA

### Developing interview questions using IPA

Legislation and guidance	Children and Families Act 2014	SEN Code of Practice 2015	UN Convention on the Rights of the Child (CRC)
	<p><i>General principles</i> Local authorities (LAs) must have regard to (s.19):</p> <ul style="list-style-type: none"> <li>• children and young people's (CYP's) views, wishes and feelings,</li> <li>• the importance of CYP participating as fully as possible in decisions,</li> <li>• the importance of CYP being provided with necessary information and support to do so, and</li> <li>• the need to support them, to facilitate CYPs' development and help optimisation of their educational and other outcomes.</li> </ul> <p><i>Assessment</i> Young people (and children's parents):</p> <ul style="list-style-type: none"> <li>• may request an education, health and care assessment;</li> <li>• must be informed of the decision to assess/not assess and the reasons;</li> <li>• must be consulted when LA determines if assessment is necessary and have their views taken into account;</li> <li>• must be consulted within assessment process and have their views, wishes and feelings taken into account (children also have these rights);</li> <li>• have a right to receive any necessary information, advice and support; and</li> <li>• must be informed of the LA's decision on whether to make an EHCP. (s.36 and the 2014 Regs)</li> </ul> <p><i>EHCPs and personal budgets</i> Young people (and children's parents) have right to receive draft EHCP, consulted over its content, and informed of right to make representations and request the naming of a school/other institution in the plan. CYPs' 'views, interests and aspirations' must be included in the plan. Also a right to be consulted over the cessation of an EHCP. If an EHCP, CYPs' parents have right to a personal budget on request. Direct payment possible (ss 38 and 49 and the 2014 Regs).</p>	<p><b>Section A: The views, interests and aspirations of the child and his or her parents or the young person.</b></p> <p><b>(A) The views, interests and aspirations of the child and their parents, or of the young person</b></p> <ul style="list-style-type: none"> <li>• <b>Details about the child or young person's aspirations and goals for the future (but not details of outcomes to be achieved – see section above on outcomes for guidance). When agreeing the aspirations, consideration should be given to the child or young person's aspirations for paid employment, independent living and community participation</b></li> <li>• <b>Details about play, health, schooling, independence, friendships, further education and future plans including employment (where practical)</b></li> <li>• <b>A summary of how to communicate with the child or young person and engage them in decision-making.</b></li> <li>• <b>The child or young person's history</b></li> <li>• <b>If written in the first person, the plan should make clear whether the child or young person is being quoted directly, or if the view</b></li> </ul> <p><b>1.1-1.10 (Legislational context and decision making)</b></p> <p>The SEN Code amplifies the obligations on local authorities and schools to ensure children and</p>	<p>4.2. The expressed policy intention underpinning the framework of rights for children and young people set out in legislation in England and Scotland, and reflected in the codes on SEN in England and ASN in Scotland (and also Wales<sup>158</sup>), is in part to ensure consistency with the key principles in Art.12 of the UN CRC.<sup>159</sup></p> <p>Article 12 provides:</p> <p>1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.</p> <p>2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.</p> <p>In its periodic report to the Committee on the Rights of the Child in 2014 the UK confirmed that it 'fully endorses and</p>



		<p>young people's involvement in the range of decisions about their SEN and special educational provision. The SEND Regulations 2014 have established various procedural rights for parents and young people through obligations imposed on local authorities. (Special Educational Needs and Disability (SEND) Regulations 2014 (SI 2014/1530)</p> <p>They also include an obligation to consult with the child over an EHC assessment and to take into account their views, wishes and feelings. The regulations also state that the local authority must give consideration to the need for information, advice and support to be provided to a young person to enable them to participate effectively in an EHC needs assessment.</p> <p><b>Section 9</b></p> <p><b>Principles underpinning co-ordinated assessment and planning Relevant legislation: Section 19 of the Children and Families Act 2014 and Regulations 7 and 9 of the SEND Regulations 2014</b></p> <p><b>Involving children, young people and parents in decision-making 9.21-26, 9.49-50,9.61-62</b></p> <p>EHC plans should be used to actively monitor children and young people's progress towards their outcomes and longer term aspirations. They must be reviewed by the local authority as a minimum every 12 months. Reviews must focus on the child or young person's progress towards achieving the outcomes specified in the EHC plan. The review must also consider whether these outcomes and supporting targets remain appropriate.</p> <p>9.168 Reviews must be undertaken in partnership with the child and their parent or the young person, and must</p>	<p>promotes the principle that children and young people should have opportunities to express their opinion in matters that affect their lives'.</p> <p>160</p> <p>One of the other key points covered by the General Comment on Article 12 is the importance of providing feedback to children; this means that they should be told the outcome of the relevant decision making process and informed how their views were considered.</p> <p>Also see article 7 and 24...these do not stand alone but are part of a broader context</p> <p>(Harris, 2018)</p>
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		<p>take account of their views, wishes and feelings, including their right to request a Personal Budget.</p> <p><b>SEND COP AR</b></p> <p><b>Reviewing an EHC plan Relevant legislation:</b></p> <p><b>Section 44 of the Children and Families Act 2014 and Regulations 2, 18, 19, 20, and 21 of the SEND Regulations 2014</b></p>	
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<p>What does EHCP process look like in section A?</p> <p>An example from one LA</p>	<p>The SEN Case Worker (EHCP Coordinator) must ensure that the information in this section fully incorporates the views of the child or young person themselves and parents or carers.</p> <p>The SEN Case Worker (EHCP Coordinator) must specify which views being represented are those of the child or young person themselves and which are the views of the parents or carers.</p> <p><b>My Profile</b></p> <p>A child or young person could contribute information towards 'My Profile' within this section in a variety of formats, separately from the Introductory Meeting, if they choose to. An advocate may be helpful in this process.</p> <p>A person centred approach is essential to gathering the information required.</p> <p>The child/young person or his/her parents or carers can provide a photograph to be used within this section. If a photograph is not provided then remove this box.</p> <p>Details about play, health, schooling, independence, friendships, further education and future plans, including employment (where practical) should all be included in My Profile.</p> <p>'What's important to me now....' should include a summary of how to communicate with the child or young person and engage them in decision making.</p> <p><b>My Background</b></p> <p>'My Story' should include:</p> <ul style="list-style-type: none"> <li>•significant events in the child or young person's history, including dates</li> <li>•any diagnoses</li> <li>•learning history</li> <li>•after school clubs or community activities</li> </ul> <p>'My Family's Story' should include:</p> <ul style="list-style-type: none"> <li>•any specific health/medical/ social/economic needs of other family members that impact on the child or young person</li> <li>•who is important to the child or young person, including wider family members and/or significant others</li> <li>•relevant community issues / involvement</li> <li>•relevant housing issues</li> </ul>
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	<p>My current support should include, for example:</p> <ul style="list-style-type: none"> <li>•what has been accessed in the past, currently or due to take place in the future</li> <li>•current involvement and additional resources of services from education, health, social care and voluntary organisations / charitable trusts</li> <li>•current support networks accessed through the local offer</li> <li>•current additional and/or specialist support within an educational setting</li> <li>•current additional specialist services within social care, including individual budgets</li> <li>•current access to health provision, including continuing care arrangements</li> </ul>
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Questions informed by Smith et al. (2009):
Some kinds of questions for in-depth interviews
Descriptive- Please could you tell me....
Narrative- Can you tell me about how....
Structural- So what are all the stages involved in the process....
Contrast- What are the main differences between...and ...
Evaluative- How do you feel when....
Circular-What do think x knows about your.....
Comparative-How do you think your life would be if you....
Prompts- Can you tell me a bit more about that?
Probes- What do you mean by ....
<p>My thoughts: Use of descriptive and narrative questions, which are open in order to support development of thoughts and ideas.</p> <p>Use more closed questions as prompts in order to provides structure, if needed, for participants to develop their responses.</p> <p>Use IPA to inform questions, at the same time minimise language use for clarity and understanding due to participants social and communication difficulties.</p>

IPA and questions for semi-structured interview	Questions to ask participants <i>Types of questions informed by IPA guidance (Smith et al. 2009) and shown in italics.</i>	How to support this
<p>Re-dressing power balance by credibility checking with participants (MacLeod)- supports meaningful dialogue</p> <p>Seeking autistic view points</p> <p>IPA- be led by participant</p> <p>Open-ended and non-directive questions.</p> <p>Focused or specific questions should allow the participant to elaborate</p> <p>Participants can also produce accounts of their experience through different means, audio, writing, video, drawing (Willig)</p> <p>Open ended questions which can be: Descriptive, Structural, contrast, evaluative (Willig)</p> <p>CYP with ASD find answering open-ended questions challenging. Could be a pitfall of IPA. (Harrington et al.)</p> <p>However by establishing rapport and maintaining it, being flexible in supporting communication, being mindful of power balance and open and transparent this may help mitigate (Scott-Barret)</p>	<p>Clarify my research and my role</p> <p>Ask for verbal or written consent</p> <p>Remind participants it is ok to stop at any time</p> <p>Show participants voice recorder</p>	<p>Time line of research interview for participant to tick off</p> <p>Stop and break cards</p> <p>Refreshments available</p> <p>Opportunity to practice using Stop cards.</p>
	<p>Ice breakers- to find out about the participants and for them to find out about me if they would like to</p> <p><i>Supporting building rapport</i></p>	<p>All about me...questions game</p> <p>Drawing 'Me' map</p> <p>Talking Maps</p>
	<p>What is school like for you? <i>Descriptive</i></p> <p>Use of reflective listening to support participants in expanding what they might want to say</p>	<p>Talking mats, organise aspects of school into good, ok, not so good</p>
	<p>Can you tell me what you know about EHCPs or ARs?</p> <p><i>Narrative</i></p> <p>Prompts:</p> <p>What is an EHCP/AR? <i>Direct closed question to support understanding in case of social and communication difficulties</i></p>	<p>Information sheet and social story about AR and EHCPs (This will have been made available to participants before the interview)</p>
	<p>Tell me about your EHCP AR <i>Narrative</i></p> <p><i>Prompts:</i></p> <p>Why do you have one?</p> <p>How long have you had it?</p> <p>Is there someone at school or at home who talks to you about this? <i>Narrative</i></p> <p>Can you remember when you last talked about it? Who was involved? <i>Narrative</i></p> <p>What was it like? <i>Descriptive</i></p> <p>Does it make a difference? <i>Descriptive</i></p>	<p>Remind participants it's ok not to know</p> <p>Prompt cards with questions on which participants can pick</p> <ul style="list-style-type: none"> <li>- Not sure</li> </ul> <p>Pens, paper, Play D'oh and Lego available</p>
	<p>Recap...summarise and check in with participant</p>	<p>Opportunity for a break</p>

	<p>Let's have a look at section A of EHCP/AR (or equivalent for that child)</p> <p>Please could you tell me if you/what you remember about looking at these questions? <i>Descriptive</i></p> <p>Prompts:</p> <p>Can you tell me about what happened? <i>Descriptive</i></p> <p>Where did it happen?</p> <p>Who was there?</p> <p>How did you feel? <i>Evaluative</i></p>	<p>Blank section A or equivalent</p> <p>Copy of young persons section A or AR as appropriate</p> <p>As above</p>
	<p>After you completed this section can you tell me about anything else that happened? <i>Narrative</i></p> <p>Prompt:</p> <p>Can you tell me about any meetings you attended at school?</p> <p><i>Narrative</i></p> <p>Did you find out what happened with what you said? <i>Narrative</i></p> <p>Have you seen your annual review or EHCP? <i>Narrative</i></p> <p>Do you think what you said made a difference? In what way?</p> <p><i>Probe</i></p>	
	<p>What are your thoughts about the AR/EHCP process?</p> <p><i>Descriptive/ narrative</i></p> <p>Prompts:</p> <p>In what way do your views make a difference?</p> <p>In what way do you feel involved in the process?</p> <p>In what way do you think adults listen to your views?</p> <p>Do you notice if they are reflected in what happens at school?</p> <p>What helps you express yourself?</p> <p>How would you like it to be? <i>Narrative</i></p> <p>What would you like to happen in the future? <i>Contrast/ narrative</i></p> <p>What would it be like in an ideal world? <i>Contrast/narrative</i></p>	<p>Prompt cards: Good, bad, ok, not sure,</p> <p>Prompt cards: School staff, parents, friends, me, not sure, other</p>
	<p>Is there something else you'd like to say?</p>	

Part	Questions	Comments and types of question according to IPA guidance (Smith et al. 2009) in <i>italics</i> ).
1	My name is Zoe I will remind you of what we are doing today You can stop at any time Have you got any questions? Do you want to start the interview?	Establish rapport Make sure participants know what to expect and consent.
2	What is school like for you?  What do you like? What do you dislike?	<i>Descriptive</i>  <i>Prompts, comparative</i>
3	What do you know about Education Health and care Plans (EHCPs) or Annual Reviews (ARs)?	<i>Descriptive/narrative</i>
4	Tell me about your EHCP /AR  Helping questions:  Why do you have one? How long have you had it? Is there someone at school or at home who talks to you about this? Can you remember when you last talked about it? Who was involved? What was it like? Does it make a difference?	<i>Descriptive/narrative</i>  Prompts and probes which are <i>descriptive, narrative, structural and evaluative</i>
5	Let's have a look at section A of EHCP/AR (or equivalent for that child). This is where you talk about your views.  Helping questions:  Can you remember looking at these questions? Can you tell me about what happened? Where did it happen? Who was there? How did you feel?	I will show you a copy of the questions in this section.  <i>Descriptive, narrative, structural, evaluative</i>
6.	After you completed this section did anything else happen?  Helping questions:  Did you attend a meeting at school?	<i>Descriptive</i>  <i>Prompts, descriptive, narrative, evaluative</i>

	<p>Did you find out what happened with what you said?</p> <p>Have you seen your annual review or EHCP?</p> <p>Do you think what you said made a difference? In what way?</p>	
7.	<p>What are your thoughts about the AR/EHCP process?</p> <p>Helping questions:</p> <p>Do your views make a difference?</p> <p>Do you feel involved in the process?</p> <p>Do you think adults listen to your views?</p> <p>Are they reflected in what happens at school?</p> <p>What helps you express yourself?</p> <p>How would you like it to be?</p> <p>What would make it better?</p> <p>What would you like to happen in the future?</p> <p>What would it be like in an ideal world?</p>	<p><i>Narrative</i></p> <p><i>Prompts, descriptive, narrative, evaluative, comparative</i></p>
8.	<p>Is there something else you would like to say?</p>	
End	End of interview	

## 5.10 Appendix J: Participant and parent/carer information sheets



### Young person's Information Sheet to support meeting with the researcher

#### (Information to be read with the parent/carers and participant)

My name is Zoe and I am a Trainee Educational Psychologist who works in different schools in Newcastle. I work with lots of different children and my job is to find out what school is like for them and how to support them so they feel happy, safe and are able to learn.

As part of my training I am doing a research project. I would like to find out more about what school is like for girls with autism. I would like to know what about what it is like for you in school. I am really interested to find out more about what it was like for you when you were part of the Education Health and Care Plan (EHCP) process. Don't worry if you're not sure what that is. We can talk about it.

I hope that by listening to girls' experiences in school we can learn how to make things better for them, especially when it comes to being part of EHCP processes.

I have arranged to speak with you today to talk about what it would be like to take part in my research.

Today I will answer any questions and share some information with you. You can tick these off if you like.

☐

**What is an EHCP or Annual Review?**

I will give you an information sheet about this and we can talk about it

☐

**What question will you ask me?**

I will give you the questions to look at.

I will ask you the same questions if we do an interview

☐

**Where will the interview be?**

You can choose a place you feel safe and comfortable

☐

**When will it be?**

We can arrange that and I will let you know

☐

**How long will the interview last?**

This is up to you. We can stop at any time.



☐ **Who will be there?**

It will just be me, Zoe. Would you like anyone else there with you?

☐ I will show you all the prompts I have and my voice recorder / video platform.  
We can look at them now.

☐ **Why are you recording the interview?**

So I can remember what you say. I will keep the recording safe and delete when I have finished my project.

☐ **Do I have to talk?**

No, you can draw or write. I have lots of different ways you can share your experience. You don't have to share at all.

I am going to leave this information with you to think about. You can fill in the section below when you feel ready.

**Do you think you would like to take part in my research project?**

☐ Yes

☐ Not sure

☐ No

If you decide to take part you can change your mind at any time up to when I start to write up my project.

If you would like to take part are there any things you would like me to do that would help you?

Things like having a drink and snack, using a computer, putting the questions on a power point, we can talk about this and make sure you are happy.

Things that would help me if I take part in the research project:

Questions I have for Zoe:

**Information Sheet for Parents and Carers**  
**This is available in video format on request**

Dear Parent/Carer,

**Who am I?**

My name is Zoe Whitby and I am a Trainee Educational Psychologist, from Newcastle University who works in the Newcastle Educational Psychology Service as part of my training.

**What am I researching?**

I am doing some research and want to look at the experience of girls with a diagnosis of ASD of contributing their views as part of the Education Health and Care Plan (EHCP) planning and Annual Review (AR) process.

Through developing an understanding of the girls' experiences I hope that this will inform practice for professionals in supporting girls with ASD in being part of decision making processes and developing guidelines which enhance the quality of the EHCP plans to reflect young people's thoughts and wishes. This study has been approved by the Newcastle University Research Ethics Committee.

**Why is my child being invited to take part?**

I am inviting your child to take part in this research as she has been identified by the Special Educational needs and Disability (SEND) Team as meeting the participant criteria for taking part. The criteria for taking part is:

- (a) the young person has an officially recognised diagnosis of ASD;
- (b) the young person holds an EHCP;
- (c) the EHCP indicates the young person has a diagnosis of ASD;
- (d) the young person is between 11 and 16 years of age.
- (e) the young person has been through the EHCP/AR process within the last academic year at the time of recruitment.

**Do I have to take part?**

Participation in the research is entirely voluntary. If you decide you would like your child to take part you can change your mind up to the point where I begin to analyse the interviews.

Please read the information about the research, I have included a version for you to share with your child should you wish. Please contact me if you would like this in video format.

**What will taking part in the research involve?**

The research will involve an interview with your child in which I will ask her to share her experiences of being part of the EHCP or Annual Review process. I will ask her what this process means to her, what happened when she was part of it and how she would like it to be done in the future. I will provide information about these processes before the interview to support her understanding of the EHCP/Annual review process. Due to current restrictions as a result of Covid-19 the interviews will take place via video platform. If the restrictions are lifted then the interview can take place in space of your child's choosing, at home or at school.

So I don't miss any of what the young people say I will use a voice recorder or record the video interview so I can listen back and type everything they said. This interview data will be stored on a computer and password protected, and it will be deleted after it has been analysed.

No one will know who said what and no names will be given to anyone. The only people who will see this will be those who need to because of my research. You or your child can withdraw from the research at any time up to the point where I begin analyse the interviews.

Confidentiality and anonymity cannot be guaranteed when safeguarding issues arise as part of the research and I will follow local authority and university safeguarding procedures.

The research process will involve the following stages:

1. I will meet with you and your child, face to face or via video platform, depending on Covid-19 restrictions, to explain my research and answer any questions. I will bring with me, or provide in advance, all the things I will use during the interview so she has a chance to see them. This will include:
  - A copy of the interview questions
  - The different resources that will be available to your child during the interview to support her in sharing her experience such as pens, paper, Lego, visual symbols, Play'D'oh.
  - The voice recorder I will be using if applicable.
2. I will arrange to meet with your child at an arranged time and space to carry out the interview which will last no longer than an hour.
3. I will provide de-briefing information about what will happen to the interview information and how to contact me, I will also provide the opportunity for a final meeting if this would be helpful.

### **Are there any advantages or disadvantages to taking part?**

Taking part in this research will provide an opportunity for your child to think about the EHCP/AR process and share their thoughts and feelings about this. Should your child appear upset at any point I will cease the interview and make sure that an adult who can provide appropriate support is immediately aware.

There will be no explicit individual benefit to your child taking part in the research but I hope that your child's participation will help inform practice for professionals in supporting girls with ASD in being part of decision making processes and in developing guidelines which enhance the quality of the EHCP plans to reflect young people's thoughts and wishes.

## Who can I contact about this project?

### Researcher contact details

Please contact me if you have any questions at my email address:

[z.b.whitby2@newcastle.ac.uk](mailto:z.b.whitby2@newcastle.ac.uk)

You can also contact my supervisor, Wilma Barrow, should you have any further questions or complaints:

[w.barrow@newcastle.ac.uk](mailto:w.barrow@newcastle.ac.uk)

School of Education,  
Communication and Language Sciences,  
Newcastle University,  
King George VI Building,  
Queen Victoria Road, Newcastle, NE1 7RU

## Can I find out more about what will happen to my child's data?

Newcastle University will act as the data controller for this study. You can find out more about how Newcastle University uses your information at:

<http://www.ncl.ac.uk/data.protection> and/or by contacting Newcastle University's Data Protection Officer (Maureen Wilkinson, [rec-man@ncl.ac.uk](mailto:rec-man@ncl.ac.uk)).

If you wish to raise a complaint on how your personal data has been handled, you can contact the Data Protection Officer [rec-man@ncl.ac.uk](mailto:rec-man@ncl.ac.uk) who will investigate the matter. If you are not satisfied with the response or believe your personal data has been processed in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO) <https://ico.org.uk/make-a-complaint/>

## Do I need to do anything?

If you **do not** wish for your child to take part you do not need to do anything and I will not contact you again.

If you are happy for your child to be involved **please fill in the separate consent form provided, tick the boxes provided to give your consent and return via the envelope enclosed or scan to my email address (provided above) by the end of this week.** I will then contact you to answer any questions you may have and arrange a time to meet you.

Thank you.

Zoe Whitby  
Trainee Educational Psychologist

## 5.11 Appendix K: Consent forms

### Participant Consent Form

The participant can fill out this form themselves or give their verbal consent to the researcher.

My name is Zoe. I am a Trainee Educational Psychologist who works with lots of different children but today I'm just going to talk to you. I want to know school is like for you.

**I have explained the research to you and provided you with information about it. I have given you the chance to ask questions and you can continue to ask questions at any time.**

Please tick the box if you understand ☐

**It will just you and me having a talk and I won't write your name on anything so no one will find out what you have said unless we need to tell them something you tell me to make sure you are safe.**

Please tick the box if you understand ☐

**We can stop talking about things whenever you want to, or you can say you don't want to answer anything I ask you or show me the 'Stop' card.**

Please tick the box if you understand ☐

**Because I want to remember all the important things you say, I will be recording our conversation on a voice recorder or video platform. Once I have listened to it and written it down it will be deleted.**

Please tick the box if you understand ☐

**Are you happy to take part?**

Please tick the box to give your consent ☐

You can sign below to give your written consent if you want to.

Participant's name.....

Participant's signature..... Date.....

Or

Verbal consent given, please tick box ☐

Researcher Signature.....Date.....

Written/Verbal (delete as appropriate) consent

Thank you. Zoe Whitby

**Consent Form for parents/carers**

*The experiences of girls diagnosed with Autistic Spectrum Disorder (ASD), in one Local Authority (LA), of contributing their views as part of the Education Health and Care Plan (EHCP) planning and Annual Review (AR) process.*

If you are happy for your daughter to be involved in the above research project **please fill in this consent form, tick the boxes provided to give your consent and return via the envelope enclosed or scan to my email address (below) by the end of this week.** I will then contact you to answer any questions you may have and arrange a time to meet you.

If you have any further questions please contact me at [z.b.whitby2@newcastle.ac.uk](mailto:z.b.whitby2@newcastle.ac.uk) or my supervisor; [w.barrow@newcastle.ac.uk](mailto:w.barrow@newcastle.ac.uk)  
School of Education, Communication and Language Sciences,  
Newcastle University,  
King George VI Building,  
Queen Victoria Road, Newcastle, NE1 7RU

**If you consent for your child to take part in the research project above, please tick the boxes and sign below.**

1. I have read the information provided and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my child's participation is voluntary and that I am free to withdraw at any time up until the research analysis process has begun without giving any reason (reference to rights can be made, if relevant). ☐
3. (If appropriate) I understand that the information collected about my child may be used to support other research in the future and may be shared anonymously in the form of a research paper with other researchers. ☐
4. I understand that my child's interview will be recorded using a voice recorder or secure video conferencing platform . This interview data will be stored on a computer and password protected, and it will be deleted after it has been analysed. ☐
5. I agree for my child to take part in the above study. ☐

Child's name.....

Parent/carer signature..... Date.....

Print name.....

Researcher Signature.....Date.....

## 5.12 Appendix L: Interview Questions and Information Sheet about EHCP process for participants



### Interview Questions

**There are no right or wrong answers**

**If you don't want to answer a question just write "Pass" or "I'm not sure."**

Part	Questions	
1	What is school like for you?	
	What do you like?	
	What do you dislike?	
2	What do you know about Education Health and care Plans (EHCPs) or Annual Reviews (ARs)?	
3	Tell me about your EHCP /AR	
	Why do you have one?	
	How long have you had it?	
	Is there someone at school or at home who talks to you about this? Can you tell me a bit about what that's like?	
	Can you remember when you last talked about it?	
	Who was involved? What was it like when you talked about it?	
	Do you think having an EHCP makes a difference to you at school? Can you tell me a bit about how it makes a difference	

4.	Let's have a look at section A of EHCP/AR (or equivalent for that child). This is where you talk about your views.	
<b>These are the questions young people are sometimes asked as part of the Annual Review or EHCP Process (You don't need to answer them, this is just an example)</b>		
	What do you enjoy about learning and could anything help you enjoy this more?	
	What do you enjoy doing at home? (Include any social activities you take part in)	
	Do you have any health issues that affect your life?	
	Would you describe yourself as a happy person? Is there anything that could make you feel happier?	
	What do you hope to do in the future?	
	Can you remember looking at these questions? Can you tell me about what happened?	
	Where did it happen? Who was there?	
	If you remember can you tell me a bit about how you felt at the time?	
5	After you completed this section can you remember if anything else happen?	
	Did you attend a meeting at school?	



	<p>Did you find out what happened with what you said?</p> <p>Have you seen your annual review or EHCP?</p> <p>Do you think what you said made a difference? In what way?</p>	
6	<p>What are your thoughts about the AR/EHCP process?</p> <p>These questions might help you to answer:</p> <p>Do you feel your views make a difference?</p> <p>Do you feel involved in the process?</p> <p>Do you think adults listen to your views?</p> <p>Are they reflected in what happens at school?</p> <p>What helps you express yourself?</p> <p>How would you like it to be when you share your views?</p> <p>What would make it better?</p> <p>What would you like to happen in the future?</p>	
8.	<p>Is there something else you would like to say?</p>	

## **What is an Education and Health Care Plan?**

An Education Health and Care Plan is often called an EHCP.

It is a document that has information about a young person and what they need to help them learn and develop.

In the EHCP:

- The young person shares their likes, thoughts and feelings about school and their hopes for the future.
- Adults who know the young person, like parents and teachers, share information about the young person and what it is like for them in school.
- Other adults who might work with the young person to help them, like Speech and Language Therapists or Educational Psychologists, sometimes share information about what they think will help the young person in school.

All these thoughts are put together in a plan called an EHCP.

The EHCP helps adults working with the young person to help them learn and develop.

The EHCP is reviewed once a year in an Annual Review.

## **What is an Annual Review?**

In the Annual Review these things might happen:

- The young person shares their likes, thoughts and feelings about school and their hopes for the future with a member of staff in school
- Adults who know the young person, like parents and teachers, share information about the young person and what it is like for them in school.
- Other adults who might work with the young person to help them, like Speech and Language Therapists or Educational Psychologists, sometimes share information about what they think will help the young person in school.

All these thoughts are put together to help update the EHCP.

The updated EHCP helps adults working with the young person to help them learn and develop.

The EHCP is reviewed once a year in an Annual Review.

### 5.13 Appendix M: Examples of IPA Process

- 
- |   |                                                                                                                        |
|---|------------------------------------------------------------------------------------------------------------------------|
| 1 | Each text was read several times and notes taken to reflect initial thoughts and observations in response to the text. |
|---|------------------------------------------------------------------------------------------------------------------------|
- 
- |   |                                                                                         |
|---|-----------------------------------------------------------------------------------------|
| 2 | Conceptual emergent themes were identified which characterised each section of the text |
|---|-----------------------------------------------------------------------------------------|
- 
- |   |                                                                                                                                                                                                                                                                                                                                 |
|---|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 3 | Emergent themes were then explored through their relationship to one and other and tentatively organised into super-ordinate and sub-themes and labelled to capture their essence. These themes were cross referenced with the original text throughout the process to ensure they made sense in relation to the original data. |
|---|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
- 
- |   |                                                                                                                                                                                              |
|---|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 4 | A summary table for each of the super-ordinate and sub- themes was then produced with quotes to illustrate each theme for each transcript, followed by a visual representation of each theme |
|---|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
- 
- |   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
|---|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 5 | Finally the super-ordinate and sub-themes themes were integrated across transcripts in order to identify shared themes that reflect the experiences of the participants as a whole. Emerging super-ordinate themes were checked against the transcripts to make sure they were grounded in the data. The super-ordinate themes were recorded in a table alongside the sub-themes, identifying which participant invoked them and where they did this in the text. |
|---|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
-

Stage 1: Each text was read several times and notes taken to reflect initial thoughts and observations in response to the text.

Emerging themes	Line	Transcript	Exploratory Comments
Does not explore feelings of uncertainty through language	35	K: Yeah.	
	36	Z: Okay, and I wonder if you could tell me a little bit about what	
	37	you like about school... So either school during lockdown or	
	38	when you actually get to go to school, what are the things that	
	39	you like?	
	40	K: Um...[long pause] I'm not sure really.	
	41	Z: You're not sure? It's a bit hard to think about isn't it,	
	42	especially when you're at home at the moment.	
	43	K: Yeah	
	44	Z: Are there any people that you like at school?	
	45	K: Like...like friends or anything?	
	46	Z: Yeah. Have you got some nice friends at school?	Tone same throughout
	47	K: Yeah.	
	48	Z: Yeah? [Long pause] And I wonder what the teachers are	
	49	like?	
	50	K: yeah... they're nice.	
	51	Z: They're nice?[Pause] Is there anything that you're not so	Time to consider when unsure
	52	keen on at school, can you tell me about anything you don't	Uncertainty- why?
	53	like so much?	Tricky to answer general questions for K?
	54	K: [Long pause] hmm... well I'm not going to school at the	
	55	minute so it's a bit hard to answer.	Checks in again when not sure
	56	Z: It's a bit funny to think about it isn't it? Because it's not like	Does not expand
	57	normal school at the moment ,yeah ,I get that, OK. <u>So</u> I'm	
	58	going to ask you a question now a little bit about what you	These relationships with key peers and staff
	59	know about Education Health and Care Plans, an EHCP or an	at school are something not talked about in
	60	annual review, okay? And I'm just going to share a screen with	detail. Acknowledged but not explored.
	61	you that shows you a little bit of information and I'll read	<u>Perhaps difficult to do this out of context?</u>
Uncertainty- Confusion between home and school contexts. Not knowing.	62	through it for you, so you don't need to read it, if you don't want	
	63	to OK? But I'm just going to go through it with you, if that's all	Does not expand when space left
	64	right?	Short clear non-descriptive language
ambivalent/neutral language	65	K: Yeah	
Seeks affirmation from adult	66	Z: Well, great... If I can find it, and here we go. Okay...	<u>Shifting between different contexts and learning worlds</u>
	67	It might take ...here we go... so hopefully... Can you see this?	<u>Physicality of space and memory?</u>
	68	K: yeah	Difficult to think about school context when not attending <u>school?</u> Offers an honest explanation

## 161

[illegible]

VOCABULARY

LANGUAGE

Thema	Line	Quelle
Personal emotional language?	154	2. wonder if you could tell me a little bit about what without in blue for you.
	155	3. wonder if you could tell me a little bit about what without in blue for you.
	156	4. It's like a...
	157	5. It's like a...
	158	6. It's like a...
	159	7. It's like a...

Comments

headache

Thema	Line	Quelle
Next language	115	2. wonder where you've heard the word, apart from me, talking about it. I think you heard it at...
	116	3. I think you heard it at...
	117	4. I think you heard it at...
	118	5. I think you heard it at...
	119	6. I think you heard it at...

Comments

tell answers, reorganized in future context  
familiar language yet has no meaning

PROCES

Thema	Line	Quelle
Personal emotional experience of process Power	147	2. So Questions like what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning
	148	3. So Questions like what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning
	149	4. So Questions like what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning
	150	5. So Questions like what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning
	151	6. So Questions like what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning
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	158	13. So Questions like what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning
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	160	15. So Questions like what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning
	161	16. So Questions like what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning and what do you enjoy about learning

Comments

Not part of process to not familiar with language  
but familiar with language or comparison with  
language is not part of the process (blacks  
homeworks)  
Power process language

Thema	Line	Quelle
Personal uncertainty next part of process	167	K. Hiromi... I don't think I had any meetings...
	168	K. No?
	169	K. No...

Comments

Not a process line identifies with

Thema	Line	Quelle
Language process experience	170	2. And, have you ever seen a copy of your education health care plan or your annual... annual review is in
	171	3. And, have you ever seen a copy of your education health care plan or your annual... annual review is in
	172	4. And, have you ever seen a copy of your education health care plan or your annual... annual review is in
	173	5. And, have you ever seen a copy of your education health care plan or your annual... annual review is in
	174	6. And, have you ever seen a copy of your education health care plan or your annual... annual review is in
	175	7. And, have you ever seen a copy of your education health care plan or your annual... annual review is in
	176	8. And, have you ever seen a copy of your education health care plan or your annual... annual review is in

Comments

Stage 3: Emergent themes were then explored through their relationship to one and other and tentatively organised into super-ordinate and sub-themes and labelled to capture their essence. These themes were cross referenced with the original text throughout the process to ensure they made sense in relation to the original data.

## CONTEXT = LEARNING

### Context = Experience?

## Home v Sch.

Theme	Line	Quote	Comments
Home	29	2. Yeah? So, what's it like when schools OK for home?	
Learning	30	2. Yeah? So, what's it like when schools OK for home?	
Context	31	3. Um... often I'm doing extra work at the minute	
	32	and everything's going like... it's fine... I'm not struggling with anything at the minute.	
	33		

Theme	Line	Quote	Comments
Context and language	51	2. They're new [Pause] Is there anything that you're not so keen on at school, can you tell me about anything you don't like so much?	Shifting between different contexts and learning words
	52	3. Um... well, I'm not going to school at the minute so it's a bit hard to answer.	Physicality of space and memory
	53		
	54	3. [Long pause] Yeah... well I'm not going to school at the minute so it's a bit hard to answer.	
	55		

Theme	Line	Quote	Comments
Context identity	200	2. Okay, and it's a bit difficult to remember when you're not been at school, when before Christmas anyway isn't it?	Experience bound in context and time, abstract when removed from it
	201	[Chuckle]	
	202	3. [Shouts and smiles]	
	204	2. It's a while ago.	

Theme	Line	Quote	Comments
Language	191	2. Oh... [Pause] And is there anything else, and any changes that are made at school that make school a bit easier for you or not really?	Language bound in how we perceive the world as we are communicative
and explicit v implicit experience	192	3. Yeah... not really.	
	194	3. Yeah... not really.	

Theme	Line	Quote	Comments
Language and experience/context	182	2. Yeah... about school work that you do, or about just making school, like the classroom environment, a bit easier for you can you think of any differences that they make for you or any changes that they make?	Moving between two worlds of learning and how we communicate
	183	3. Um... well, when I'm at school and... well the works easier for me when I get help [long pause]	
	184	2. So when the work is a bit tricky? You can get a bit of help with it sometimes?	
	185	3. Yeah.	
	186	2. Yeah? Oh...	
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## VOCABULARY

### LEARNING

Theme	Line	Quote	Comments
Home	29	2. Yeah? So, what's it like when schools OK for home?	
Learning	30	2. Yeah? So, what's it like when schools OK for home?	
Context	31	3. Um... often I'm doing extra work at the minute	
	32	and everything's going like... it's fine... I'm not struggling with anything at the minute.	
	33		

Theme	Line	Quote	Comments
Context and language	51	2. They're new [Pause] Is there anything that you're not so keen on at school, can you tell me about anything you don't like so much?	Shifting between different contexts and learning words
	52	3. Um... well, I'm not going to school at the minute so it's a bit hard to answer.	Physicality of space and memory
	53		
	54	3. [Long pause] Yeah... well I'm not going to school at the minute so it's a bit hard to answer.	
	55		

Theme	Line	Quote	Comments
Context identity	200	2. Okay, and it's a bit difficult to remember when you're not been at school, when before Christmas anyway isn't it?	Experience bound in context and time, abstract when removed from it
	201	[Chuckle]	
	202	3. [Shouts and smiles]	
	204	2. It's a while ago.	

Theme	Line	Quote	Comments
Language	191	2. Oh... [Pause] And is there anything else, and any changes that are made at school that make school a bit easier for you or not really?	Language bound in how we perceive the world as we are communicative
and explicit v implicit experience	192	3. Yeah... not really.	
	194	3. Yeah... not really.	

Theme	Line	Quote	Comments
Context and language	51	2. They're new [Pause] Is there anything that you're not so keen on at school, can you tell me about anything you don't like so much?	Shifting between different contexts and learning words
	52	3. Um... well, I'm not going to school at the minute so it's a bit hard to answer.	Physicality of space and memory
	53		
	54	3. [Long pause] Yeah... well I'm not going to school at the minute so it's a bit hard to answer.	
	55		

Theme	Line	Quote	Comments
Context identity	200	2. Okay, and it's a bit difficult to remember when you're not been at school, when before Christmas anyway isn't it?	Experience bound in context and time, abstract when removed from it
	201	[Chuckle]	
	202	3. [Shouts and smiles]	
	204	2. It's a while ago.	

## NOT KNOWING = RECOGNITION

## RECOGNITION

Theme	Line	Quote	Comments
Home	29	2. Yeah? So, what's it like when schools OK for home?	
Learning	30	2. Yeah? So, what's it like when schools OK for home?	
Context	31	3. Um... often I'm doing extra work at the minute	
	32	and everything's going like... it's fine... I'm not struggling with anything at the minute.	
	33		

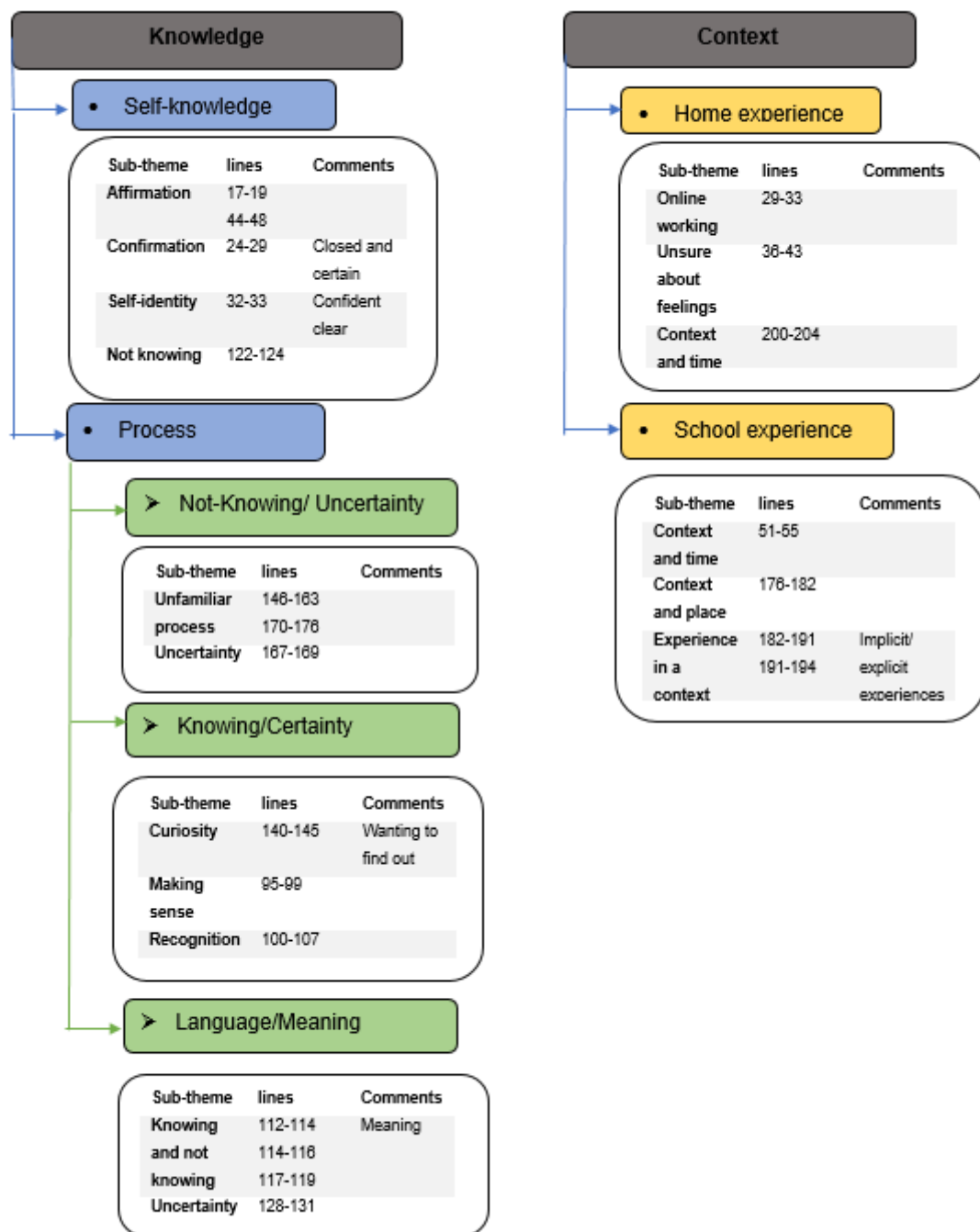
Theme	Line	Quote	Comments
Context and language	51	2. They're new [Pause] Is there anything that you're not so keen on at school, can you tell me about anything you don't like so much?	Shifting between different contexts and learning words
	52	3. Um... well, I'm not going to school at the minute so it's a bit hard to answer.	Physicality of space and memory
	53		
	54	3. [Long pause] Yeah... well I'm not going to school at the minute so it's a bit hard to answer.	
	55		

Theme	Line	Quote	Comments
Context identity	200	2. Okay, and it's a bit difficult to remember when you're not been at school, when before Christmas anyway isn't it?	Experience bound in context and time, abstract when removed from it
	201	[Chuckle]	
	202	3. [Shouts and smiles]	
	204	2. It's a while ago.	

Theme	Line	Quote	Comments
Language	191	2. Oh... [Pause] And is there anything else, and any changes that are made at school that make school a bit easier for you or not really?	Language bound in how we perceive the world as we are communicative
and explicit v implicit experience	192	3. Yeah... not really.	
	194	3. Yeah... not really.	

Theme
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## Emergent Themes transcript 1





Stage 4: A summary table for each of the super-ordinate and sub- themes was then produced with quotes to illustrate each theme for each transcript, followed by a visual representation of each theme

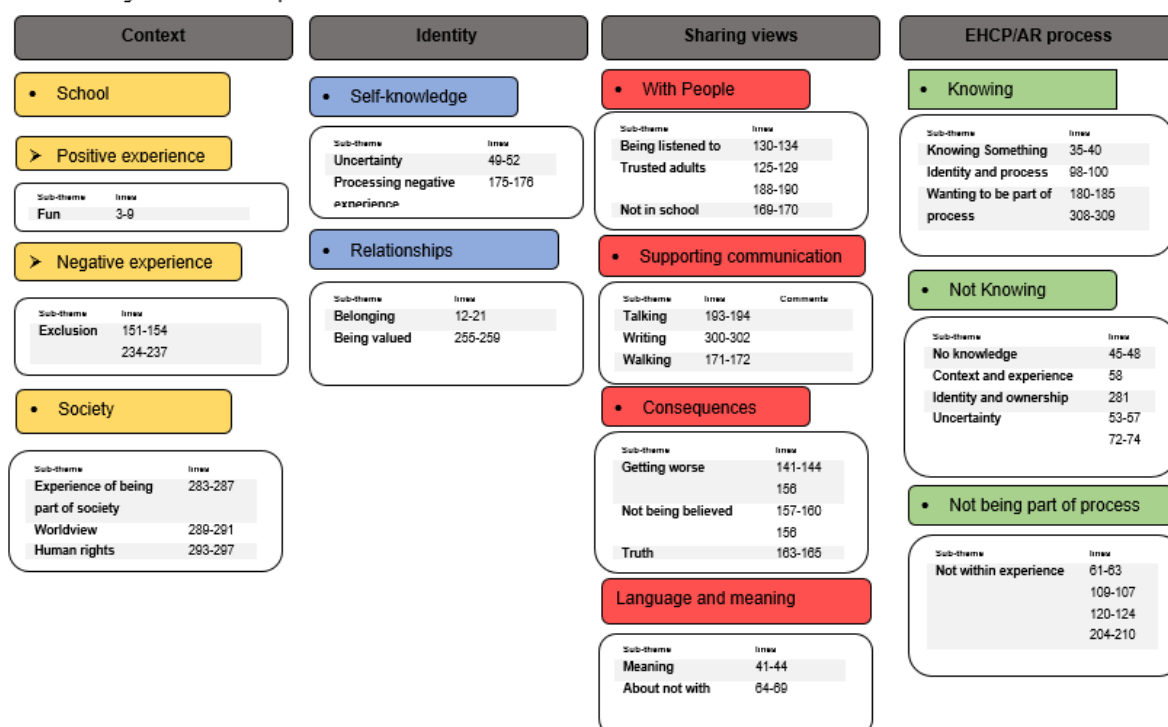
Theme	Line	Quote	Comments
Knowing and not knowing-honesty	28 29	L: Yeah...but that's only in secondary area I don't know how many there is in Primary.	

Theme	Line	Quote	Comments
Knowing something	25 36 37 38 39 40	Z: OK, the next question I'm going to ask is, what do you know about the education, health and care plan, the EHCP or annual reviews? L: Literally nothing. Z: Absolutely nothing? L: Practically nothing, yeah.	

Theme	Line	Quote	Comments
Knowing something language		Z: Do you know anything at all? Have you heard the words before? People talk about the word... L: I've heard the words before. I know, like the basics of it. All I know, it's like a plan of how people can help me.	

Theme	Line	Quote	Comments
Not knowing	45 46 47 48	Z: Okay, so that is the basics of it. So it's a plan of how people can help you. Ok, great. Can you tell me a little bit about your EHCP? L: I have no idea about it.	

Emergent themes transcript 2





Stage 5: Finally the super-ordinate and sub-themes themes were integrated across transcripts in order to identify shared themes that reflect the experiences of the participants as a whole. Emerging super-ordinate themes were checked against the transcripts to make sure they were grounded in the data. The super-ordinate themes were recorded in a table alongside the sub-themes, identifying which participant invoked them and where they did this in the text.

EXPERIENCE...

MEANING

KNOWLEDGE / KNOWING...

NOT KNOWING / UNCERTAINTY...

LANGUAGE

UNDERSTANDING OF PROCESS

EXPERIENCE

AWARENESS OF PROCESS...

CONTEXT...

SELF + EXP.

Context (Home v Sch.)

Protester

Knowing

Not Knowing

Lang.

KIM'S EXPERIENCE... EHCP / AR DMP

MEANING FOR KIM IS BOUND IN:

(SELF + ENVIRONMENT)

UNDERSTANDING / KNOWING w/ certainty...

SELF-KNOWLEDGE or IDENTITY...

LANGUAGE KNOWLEDGE

~~THE~~ PROCESS KNOWLEDGE...

CONTEXT...

↑

THESE MAKE THE EXPERIENCE.

KIM makes meaning from this...

THE EXPERIENCE

SELF-KNOWLEDGE IDENTITY

LANGUAGE + KNOWLEDGE

KNOWLEDGE OF PROCESSES

CONTEXT.

THESE SHAPE MAKE THE MEANING OF EXPERIENCE

THE EXPERIENCE MAKES THE MEANING

EXPERIENCES

OF learning...

School

Home

DH. priv.

L +

L -

Interactions

This supports identifying sharing...

EHCP / AR

LANGUAGE

Narrative

Understanding

Inclusion

Identity as a person

as a learner

Sharing views?

EXCLUSION

- From School

- From Home...

LEG IN HER

BIN-GEL

MEANING

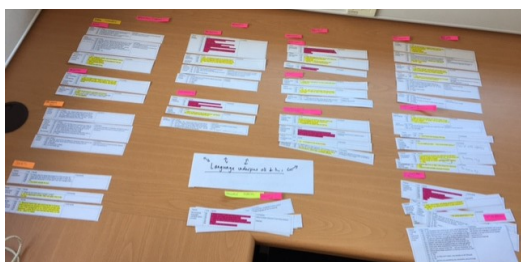
LANGUAGE

EXPERIENCE / UNDERSTANDING

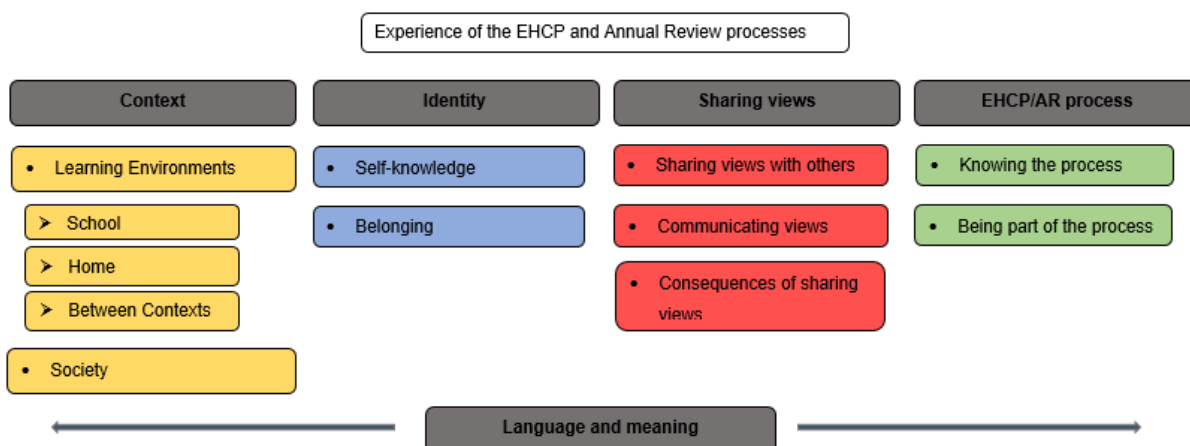
Knowing the literal meaning of something is different from experiencing it + developing understanding.

This shows how common these have emerged across the two transcripts from quite different narratives of similar experiences. I have been finding it hard to place 'language' within any particular theme and from close examination and playing with the themes I think that language is interconnected to them all. Language is context driven, it derives from experience and its meaning is interrelated with these things. The girls have commented throughout that they know words and not their meaning or are uncertain or unsure- this is because the meaning of such words would come from their lived experiences- experiences they have not been part of. Their lack of knowledge or confidence with such language represents how it is not part of their world or experience. They have a shared experience of being on the edge or outside of processes which are about them. Their lack of narrative or difficulty in speaking about processes is due to this. What became clear from Louise was that she very much wanted to be part of the process and identified it as being about her and entwined with her identity.

Merging the themes:



Themes		
A. Context		
Sub-themes	Lines	Notes
<ul style="list-style-type: none"> <li><b>School</b></li> </ul>		
L: Err... pretty fun... mainly. I get to do whatever I want to with some restrictions. Z: ...with some restrictions. So it's pretty fun? Can you tell me what's fun about it. L: Well, practically anything. Z: Oh wow. L: It rarely ever gets boring. Z: It rarely ever gets boring?	3-10	Engaging and positive experience
Z: Yeah... About... about school work that you do, or about just making school, like the classroom environment, a bit easier for you can you think of any differences that they make for you or any changes that they make? K: Err [pause] well... When I'm at school and... well the works easier for me when I get help [long pause]	180-185	Experience of being helped
L: Yeah, by two hours in I get taken out of school already. P: So Louise's experience of school, especially the secondary school, hasn't been, it hasn't been... L: the best [giggles]	236-239	Negative experience of previous school- exclusion
<ul style="list-style-type: none"> <li><b>Home Learning</b></li> </ul>		
K: Um... often I'm doing online work at the minute and everything's going okay like... it's fine... I'm not struggling with anything at the minute.	31-33	When Kim says most is when she is confident and assured. She related to the home environment and has the language to talk about herself as a learner within it.
<ul style="list-style-type: none"> <li><b>Between Contexts</b></li> </ul>		
Z: Okay, and I wonder if you could tell me a little bit about what you like about school... So either school during lockdown or when you actually get to go to school, what are the things that you like? K: Um... [long pause] I'm not sure really.	36-40	Language perhaps connected to context- shifting between two contexts



## **5.14 Appendix N: Participant friendly summary of research project**

### **The experience of girls with autism of being part of EHCP and Annual Review decision-making processes; “It's my health care plan I should know what's going on.”**

This is a summary of my research project to share with young people and families who took part.

#### **What did I do?**

I am training to be an Educational Psychologist (EP). An EP's job involves working with children to understand how they learn best.

As part of my training to be an EP I did a research project.

I wanted to find out more about what school is like for girls with autism. I was really interested to find out more about what it was like for girls with autism being part of the Education Health and Care Plan (EHCP) and Annual Review (AR) planning.

#### **Why did I do it?**

I think that adults working with young people can learn a lot from young people's experiences. I hope that by listening to girls' experiences in school I can learn how to support them better, especially when it comes to being part of EHCP and AR planning.

In my job as an EP I hope I will be able to support adults working with young people to help young people be part of EHCP and AR planning. This will potentially help young people share their thoughts and ideas about how they would like to be supported in their learning.

#### **What happened?**

Two girls with Autism and EHCP plans agreed to help me with my research. They both lived in North East England. In research it is important that people taking part can't be recognised in real life, so I gave the girls false names. Kim was in Year 7 and Louise was in Year 8.

Kim and Louise each took part in an interview with me. I asked them questions about what school was like for them and about their experiences of being part of EHCP and AR planning. I recorded the interviews and wrote them out. I then spent a lot of time looking very closely at the interviews to try and understand Kim and Louise's experiences.

## What did you find out?

From looking closely at what Kim and Louise said I found out that there were five things which seemed really important when it came to being part of EHCP and AR planning:

1. Where learning happened	2. Identity	3. Sharing View	4. EHCP/AR Processes	5. Words and Meaning
Kim and Louise's learning took place at school and at home.  What these settings were like made a difference to how their experiences.  Some of their experiences were positive and some were negative.	How Kim and Louise saw themselves as learners linked to how they felt about being in school and their experiences of school.  It was important that young people felt valued and listened to.	Kim and Louise had positive and negative experiences of sharing their views with adults inside and outside of school.  Sometimes they felt adults listened to them and other times they felt unheard.	Louise and Kim's experience suggested that they had not been included in EHCP/AR processes at school.  They did not know very much about EHCPs and ARs as this was outside of their experience	Louise and Kim did not remember being part of EHCP/AR processes.  We learn words and what they mean from our experiences. Words to do with the EHCP/AR processes had little meaning for Louise and Kim because they had no memory of being part of these processes.

## So what?

Louise and Kim's experiences show that there are things adults working with girls with autism could do differently. These could be:

- Doing training to better understand what autism is like for girls and different ways of supporting them in school
- Thinking about how adults think about children. It is important to remember children have rights to share their views and be part of decision-making about their lives.
- Doing more research with young people to find about their experiences so we can learn from them and make learning better for them.

## What does this mean overall?

Kim and Louise's experiences of school showed that they were not actively part of EHCP/AR planning. This mean that they did not know very much about EHCPs and ARs.

It is young people's right to be part of these processes. It is important that adults working with young people like Louise and Kim help them to share their thoughts and ideas about their learning. Adults can do this by helping young people to understand what EHCPs and ARs are and by supporting them to share their ideas in a way they are comfortable with.

Children and young people's views about their education are really important and they should be able to share them. Louise sums this up:

*"It's my health care plan I should know what's going on."*