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UNIVERSITY OF SOUTHAMPTON

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

School of Psychology

**The participation of autistic pupils in decision-making about their school
experiences: A case study of one school**

by

Chantelle Zilli

Thesis for the degree of Doctorate in Educational Psychology

June 2018

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

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THE PARTICIPATION OF AUTISTIC PUPILS IN DECISION-MAKING ABOUT THEIR SCHOOL EXPERIENCES: A CASE STUDY OF ONE SCHOOL

Chantelle Zilli

Research has highlighted the importance of increasing the participation of autistic pupils in decision-making about their school experiences. This is a timely and relevant topic to explore due to national policy changes that prioritise the full participation of children with Special Educational Needs and Disabilities (SEND) in decisions that affect their lives. Reviews in the literature examined how published research defined participation and studied how pupils with SEND participated in their local community. However, these reviews did not consider decision-making or specifically focus on the experiences of autistic individuals. A systematic review was conducted to address this gap in the literature. Findings highlighted a focus on formal processes such as meetings for transition planning and individual education plans, rather than day-to-day decisions at school, with the majority of studies using quantitative research methods.

A case study of one school was conducted to provide rich, detailed context-dependent knowledge of school-related decision-making that is lacking in the literature. Sixteen participants took part in the research: four autistic pupils, two carers and ten members of staff. Data collected were photographs pupils took of places where they felt listened to, lesson observations and semi-structured interviews with pupils, carers and staff. The Black-Hawkins (2010, 2014) and Florian et. al (2016) Framework for Participation provided the lens with which data was analysed. The results captured four dominant themes in the data: access to the school and the classroom, access to the curriculum, a focus on what learners can do, rather than what they cannot, and relationships of mutual recognition and acceptance between pupils and staff.

Findings highlighted that the culture of the school appeared to create opportunities for pupils to decide when and how they learn, manifested both in the flexibility of school systems and in the interactions between staff and pupils. A partnership approach to decision-making was a particular feature of interactions, involving negotiation and reciprocal feedback between staff and pupils. However, for some pupils having to take decisions created anxiety, which suggests that decision-making is a skill that may need to be learnt and supported. Carer perspectives did not feature prominently in the findings, which may indicate that day-to-day school practices are less visible to carers.

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Academic Thesis: Declaration Of Authorship

I, CHANTELLE ZILLI declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

The participation of autistic pupils in decision-making about the school experiences: A case study of one school

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signed:

Date: 03.09.18

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Definitions and Abbreviations

| | |
|--------|--|
| ADHD | Attention Deficit Hyperactivity Disorder |
| ADOS | Autism Diagnostic Observation Schedule |
| ASD | Autism Spectrum Disorder |
| ASSIA | Applied Social Sciences Index and Abstracts |
| CEBM | Centre for Evidence-Based Management |
| CINAHL | Cumulative Index of Nursing and Allied Health Literature |
| CoP | Code of Practice |
| DSM | Diagnostic and Statistical Manual |
| DT | Design and Technology |
| EBP | Evidence-Based Practice |
| EHCP | Education, Health and Care Plan |
| EP | Educational Psychologist, Educational Psychology |
| ERIC | Education Resources Information Centre |
| GCSE | General Certificate of Secondary Education |
| HT | Head Teacher |
| IBSS | International Bibliography of the Social Sciences |
| ICT | Information and Communications Technology |
| ID | Intellectual Disability |
| IEP | Individual Education Plan |
| IT | Information Technology |
| LA | Local Authority |
| OECD | Economic Co-operation and Development |
| PSHE | Personal, Social and Health Education |
| RCT | Randomised Control Trials |
| SC | Structured choice |
| SEMH | Social, Emotional and Mental Health |
| SEN | Special Educational Needs |
| SENCo | Special Educational Needs Co-ordinator |

Chapter 1

| | |
|------------|--|
| SEND | Special Educational Needs and Disabilities |
| SLT | Senior Leadership Team |
| USB | Universal Serial Bus |

Chapter 1 Exploring how autistic pupils participate in decision-making in an educational context

1.1 Introduction

1.1.1 Basis for the review

Ensuring that children feel listened to and are enabled to fully participate in the decisions that affect them is a prominent theme in research, policy and educational practice. This is reflected in, for example, a renewed emphasis on pupil participation in the Special Educational Needs and Disabilities (SEND) Code of Practice (2014) and recent publications on strategies for seeking the views of young people, particularly those with special educational needs (e.g. Begon, 2017; Fox, 2016; Hodgetts & Park, 2017; White & Rae, 2016). Participation in decision-making is especially important for young people with SEND because they are often given fewer opportunities to share their views than typically developing peers despite important decisions regularly being made by adults about their care (Cefai & Cooper, 2010; Franklin & Sloper, 2006, 2009). Moreover, research shows that when pupil views are sought, they offer valuable insights into their experiences which often differ from the perspectives of adults (Frederickson, Dunsmuir, Lang, & Monsen, 2004; Pollock & Stewart, 1998).

Exclusion from decision-making, such as opportunities to choose when and how one learns, may particularly affect autistic pupils.¹ This may be due to difficulties with social communication and social interaction and/or co-occurring learning difficulties, which can present real challenges to eliciting the views of children and young people on

¹ The term 'autistic pupils' or 'pupils on the autism spectrum' will be used throughout this document in line with the preferences of the autistic community and literature arguing that identity-first language may help to reduce the stigma linked to disabilities (Gernsbacher, 2017; Kenny et al., 2015)

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the autism spectrum (Brewster & Coleyshaw, 2011; Fayette & Bond, 2017). Researchers suggest, for example, that some autistic pupils find it difficult to co-operate with others, express their ideas and respond to open-ended questions about the future – all potential barriers to using traditional interview methods (Macintosh & Dissanayake, 2006; Preece & Jordan, 2010). Perceived difficulties may also affect practitioner expectations around the ‘types’ of pupils who are unable to participate in decision-making, thereby further limiting their access to contexts where decisions are made (Lewis, 2009).

This issue presents a pertinent need for research on the conditions in which autistic pupils participate in decision-making. Although studies are beginning to identify creative methods for gathering the views of autistic pupils and eliciting ‘voice’, this is often limited to the purposes of research (e.g. Fayette & Bond, 2017). As such, published guidance on school-based practices to enhance participation in decision-making is lacking, particularly in the form of a systematic review, which through the synthesis of vast amount of research, is increasingly being regarded as a helpful tool for practitioner psychologists (Boyle, Connolly, & Mackay, 2016). Currently, there is only one systematic review conducted by Mager and Nowak (2012) on decision-making at school and this is related to the participation of typically developing pupils in a specific decision-making process: school councils. Other reviews, have examined ‘participation’ as a construct (Imms et al., 2016) and participation outcomes for children with disabilities (Adair, Ullenhag, Keen, Granlund, & Imms, 2015). These reviews, however, focused on actively participating in any life situation rather than decision-making. Conducting a review that specifically focuses on autistic pupils *and* their participation in decision-making in an educational context therefore addresses a significant gap in the literature. Given that terms for ‘participation’ are often used interchangeably in research such as ‘engagement’, ‘consultation’ and ‘involvement’ (Imms et al., 2016), this review is also unique in its analysis of literature using a conceptual framework for participation.

1.1.2 Legislation and change

All professionals working within the field of education have a legal obligation to ensure that children and young people are supported to take part in decision-making that affects their lives. The revised Special Educational Needs Disabilities (SEND) Code of Practice (2015) states that the first principle underpinning its legislation is:

Local Authorities (LA) in carrying out their function under the Act in relation to disabled children and young people and those with Special Educational Needs (SEN) **must** have regard to:

- a) the views, wishes and feelings of the child or young person
- b) the importance of the child or young person participating as fully as possible in decisions and being provided with the information and support necessary to participate in these decisions

(p. 19, Department for Education and Department of Health, 2015).

These principles do not solely apply to professionals working within the LA, including social workers or educational psychologist, and to early years' settings, schools and colleges. Although these principles are not new – The United Convention on Rights of the Child (1989) and the previous version of the CoP in 2004 both emphasised the importance of seriously considering a child or young person's perspective – the revised CoP (2014) places children and their families at the centre of decision-making within SEN processes (Tutt & Williams, 2015). This shift came about through consultation with young people with SEND who felt that they needed to be more involved in discussions about their support or provision and choices for the future (DfE, 2014). It is therefore paramount that those working in education understand not only *when*, but especially *how* to facilitate the participation of children and young people in decision-making processes within their professional practice.

1.1.3 The Framework for Participation

The Framework for Participation is a theoretical framework designed to aid the analysis of practices relating to pupil participation in schools (Black-Hawkins, 2010, 2014; Florian, Black-Hawkins, & Rouse, 2016). Contained in the Framework are sections exploring four aspects of participation: *access, collaboration, achievement and diversity*, each with a list of *who, what* and *why* questions for examining the contextual factors that enable or hinder participation. Whilst the Framework is designed to explore participation within all aspects of school life, the Framework is used in this review to specifically consider participation in decision-making.

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The construct of 'participation' is conceptualised by Florian et al., (2016) in seven principles, which underpin the sections of the Framework:

Participation...

1. Impacts upon all members of a school and all aspects of school life
2. Is a never-ending process, closely connected to barriers to participation
3. Is concerned with responses to diversity
4. Is distanced conceptually from notions of 'special educational needs'
5. Requires learning to be active and collaborative for all
6. Necessitates the active right of members to 'join in'; and
7. Is based on relationships of mutual recognition and acceptance

(Taken from Black-Hawkins, 2010 p. 28)

The central argument within the Framework is that when these principles are enacted in a school, through policies, practices and day-to-day interactions, pupils are more likely to have opportunities to be included and achieve. These ideas were influenced by case studies exploring the complex relationship between inclusion and achievement in different schools (Corbett, 1999; Florian et al., 2016). One of the key findings was the role of school culture and organisation in promoting or limiting inclusion and achievement. This led Black-Hawkins (2010) to highlight the importance of steering away from a narrow view of inclusion, which is related to numbers of children on the SEN register within a school, towards a broader view which emphasises the importance of complex contextual factors within a school.

There are different approaches to understanding pupil participation in schools; however, the Framework for Participation (Florian et al., 2016) is the most well suited for the current review. Firstly, it was specifically developed with both the researcher and practitioner in mind, contrasting other models of participation which target a general audience. Shier's (2001) *Pathways to Participation*, for example is promoted as an evaluation tool that could be used with any adult working with children, such as teachers, with the aim of enhancing children's participation. However, the Framework for Participation offers something different: a tool which could be used to support a rigorous research process through the use of questions for systematic reflection about school practices, and the provision of data that could be collected from schools and the literature. See Appendix

G for examples of data provided by Florian et, al. (2016). Using the Framework for Participation to guide the selection and analysis of articles was therefore helpful because it enabled the researcher to understand a body of research within a theoretical framework relevant to the study of school-based practices.

1.1.4 Current review

The objective of this review is to identify the current research on the participation of autistic pupils in school-related decision-making using the Framework for Participation as a guide; the most recent version is presented in Florian et al., (2016). The Framework provides a basis for practitioners and researchers to reflect on *who*, *what* and *why* of participation with a focus on four areas: Access, Collaboration, Achievement and Diversity. To provide a focus to the review, the researcher selected the *who*, *what* and *why* questions and adapted them to examine decision-making processes in educational contexts, forming three research questions to be explored:

1. *Who* does and does not participate in decision-making? And who decides?
2. *What* are the practices that promote participation in decision-making? What are the practices that reinforce barriers to participation in decision-making?
3. *Why* do these practices that promote participation in decision-making take place? Why do these practices that reinforce barriers to participation in decision-making take place?

By using these questions to examine the current state of research, it is hoped that new insights will be provided into the characteristics of pupil participation in decision-making within the autism community and how this process may be enhanced. This review will also address the gap in the literature by focussing on all forms of decision-making (as opposed to specific areas such as school councils) and including only research with autistic children and young people.

1.2 Methods

1.2.1 Definitions

When considering literature with autistic pupils, the researcher understood *Autism Spectrum Disorder (ASD)* to be 'persistent deficits in social communication and social interaction together with restricted repetitive patterns of behaviour, interests, or activities', as described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013 p.299). The term *Participation* is defined using the principles of the Framework for Participation (Florian et al., 2016) which draws upon the following definition:

Participation in education involves going beyond access. It implies learning alongside others and collaborating with them in shared lessons. It involves active engagement with what is learnt and taught, and having a say in how education is experienced. But participation also involves being recognised for oneself and being accepted for oneself. I participate with you, when you recognise me as a person like yourself, and accept me for who I am.

(Booth, 2002, pg. 2)

The researcher defined *decision-making* as one or more individuals making choices that affect his/her/their lives. In the context of this review, these choices must relate to the individual's experiences within an educational setting. This includes: i) individual decision-making where matters affect pupils as individuals such as selecting a classroom activity, school placement or adjusting a care plan ii) collective decision-making where decisions affect pupils as a group iii) formal processes such as Education and Health Care Plan reviews and ii) informal processes such as interactions between a pupil and a teacher in the classroom.

1.2.2 Search terms

A list of search terms for 'participation' was compiled using key words from the principles of the Framework for Participation (Florian et al., 2016). Search terms for other key words such as 'autism', were generated by looking at terms used in articles and

previous systematic reviews. All search terms were initially piloted in a scoping search of the literature within two databases: PsycINFO and Scopus. This enabled the author to identify the size and relevance of the literature generated from the search terms.

Following the pilot, two search terms were added based on key words in relevant papers: 'adult' and 'university' were included after reading articles on decisions surrounding the transition to adulthood and higher education (e.g. Bell, Devecchi, Mc Guckin, & Shevlin, 2017). The final list of search terms is in Table 1.

Table 1

Search Terms

| Participation | Pupil | Autism | Decision | School |
|---------------|--------------|----------|------------|------------|
| Participation | Pupil | Autism | Decision | School |
| Collaboration | Student | Autistic | Choice | Nursery |
| Join | Child | ASD | Preference | College |
| Access | Youth | ASC | | Classroom |
| Engage | Young person | Asperger | | Education |
| Together | Adolescent | | | Academy |
| Acceptance | Teenager | | | University |
| Recognition | Adult | | | |
| Inclusion | | | | |
| Achieve | | | | |
| Contribute | | | | |
| Alongside | | | | |
| Having a say | | | | |
| Involve | | | | |

The following key word combinations were used in the final search: (particip* OR collabor* OR join* OR access* OR engag* OR together OR accept* OR recogni* OR inclus* OR achiev* OR contribut* OR alongside OR "having a say" OR involv*) AND (pupil* OR student* OR child* OR youth OR "young pe*" OR adolescen* OR teen* OR adult*) AND (autis* OR ASD OR ASC OR asperger*) AND (decis* OR decid* OR choice* OR

Chapter 1

preference*) AND (school* OR nurser* OR college* OR class* OR educat* OR academ* OR universit*). Truncating words with a * enabled all derivatives of that word to be included in the search; for example, engag* would generate: engagement, engaging, engaged.

1.2.3 Inclusion and exclusion criteria

Pre-defined inclusion and exclusion criteria were set prior to completing the search. This ensured that the articles identified only related to autistic pupils, participation in school-related *decision-making* (not in leisure activities or general school experiences) and that the study took place in an educational context. The inclusion and exclusion criteria were trialled in a scoping search of the literature in two databases: PsycInfo and Scopus. Articles that were unpublished theses, book chapters, conference proceedings or written in other languages were excluded from the search. Following the trial, two amendments to the criteria were made which maximised the number of relevant papers that could be included in a wider search. Firstly, the author eliminated a requirement for articles to clearly describe the diagnosis of autism, for example, by providing details of an Autism Diagnostic Observation Schedule (ADOS) as the majority of articles did not provide background details for the diagnosis. Secondly, the criteria for participants were broadened to include autistic pupils with comorbid difficulties, which was felt to be less restrictive given the high numbers of autistic pupils identified with comorbid diagnoses of anxiety disorder and attention deficit hyperactivity disorder (ADHD). The final inclusion and exclusion criteria are shown in Table 2.

Table 2

Inclusion and exclusion criteria for the search

| Include | Exclude |
|---|---|
| Pupils must be between 0 and 25 years old, in line with the age group to which the Special Educational Needs and Disabilities (SEND) Code of Practice applies | Pupils within the general population or participants with special educational needs that are not described as having a diagnosis of ASD |
| Autistic pupils and pupils with comorbidities such as ASD and an anxiety disorder | Research carried out in any environment outside school such as a medical clinic, the child's home or local community |

| | |
|--|--|
| Data must have been collected in an educational context such as a nursery, school or college as decision-making processes within these contexts are of specific interest | Research where the focus is on the participation of <i>parents/carers/siblings/peers</i> of autistic pupils in decision-making |
| Participation must relate to decision-making processes that occur in educational contexts, for example, choice of classroom activities, school placement, curriculum subject or support plan | Research on the experiences of autistic pupils in education, where there is no focus on decision-making |
| Literature reviews and articles published as full texts in peer reviewed journals | Participants above the age of 25 years old |
| Written in English | Material in books, Doctoral and Master's level theses or dissertations |
| | Opinion pieces or commentaries |
| | Articles published pre 1989 |

Articles were restricted to those published after 1989 due to the volume of papers generated in the search. 1989 was a suitable cut-off point as article 12 in the United Nations Convention on the Rights of the Child in 1989 is often referred to in the literature as the beginning of a movement which emphasised the importance of listening to the views of children and young people (Lundy, 2007). It was therefore anticipated that fewer articles of relevance would be published before this date.

1.2.4 Data sources

Using the search terms in Table 1, a search of the literature was undertaken in fourteen electronic databases between October and December 2017: PSYCInfo, PSYCArticles, Medline, PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Web of Science, Scopus, Teacher reference centre, Applied Social Sciences Index and Abstracts (ASSIA), International Bibliography of the Social Sciences (IBSS), Psychology and Behavioural Sciences Collection, Social Care Online, Australian Education Index and Education Resources Information Centre (ERIC). A range of databases were chosen within the spheres of education, psychology, social sciences, medicine, health and social care as decision-making within schools could include involvement with multi-disciplinary professionals. Journals relevant to Educational Psychology (EP) practice and/or Autism were also searched electronically or by hand:

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Educational Psychology in Practice, Educational and Child Psychology, Psychology in the Schools, Good Autism Practice, International Journal of Inclusive Education and Focus on Autism and other Developmental Disabilities.

Searches were restricted to titles, abstracts and key words in each database. All papers retrieved were then collated in software called Covidence—a screening and data extraction tool for aiding the production of systematic reviews (Innovation VH, 2018). Duplicates of articles were automatically removed by Covidence leaving approximately two thousand articles to be screened using the inclusion and exclusion criteria in Table 2. The screening process occurred in two stages: 1) title and abstract and 2) full text review. Each stage of the search is outlined in the PRISMA diagram shown in Figure 1.

1.2.5 Quality assessment

Articles were quality assessed using two checklists from the Critical Appraisal Skills Programme (CASP, 2013). The checklist for qualitative research contains 10 questions which focus on three broad issues: Are the results of the review valid? What are the results? Will the results help locally? For articles using quantitative data, the researcher adapted the CASP case-control checklist so that it could apply to any research design, shown in Appendix A. For mixed-methods research, the adapted checklist in Appendix B was used with the addition of two questions specific to qualitative research: the consideration of ethical issues and the rigorous analysis of qualitative data. For the purposes of comparing study quality, every question allocated a 'yes' response was awarded a mark of '1' and those with a 'no' response a mark of 0; a similar approach has been taken in previous research using the CASP checklists (e.g. Wedlock & Turner, 2015).

Other checklists such as Downs and Black (1998) and those from the Centre for Evidence-Based Management (CEBM) were deemed less appropriate to assess research in this review for various reasons. Firstly, the Down's and Black (1998) checklist focuses on medical interventions, and many of the articles retrieved here are not interventions but rather studies using a case study or cross-sectional research design. The author also considered the CEBM checklists but unlike the CASP, they do not provide detailed explanations of every question which helpfully guides the author's assessment of research quality. This is important because some of the questions in the CEBM checklists have

vague descriptions which are open to interpretation; for example, question seven in the CEBM checklist for survey data refers to a 'satisfactory' response rate without defining a 'satisfactory' threshold.

1.2.6 Data extraction

A data extraction form shown in Appendix C was used to identify the following information in each study: 1) article features such as publication year, author and country of origin, 2) participant demographics such as age, gender and diagnosis, 3) study location such as the classroom or playground, 4) type of data collected for example, survey, interview or observational data, 5) decision-making process such as transition planning meeting and 6) findings relating to the three questions of the Framework for Participation (Who, What and Why) (Florian et al., 2016).

1.3 Results

1.3.1 Overview of studies

Figure 1 displays each stage of the review and the number of articles retrieved from the database search. A total of seventeen full text articles were extracted for data and analysed using the Critical Appraisal Skills Programme (CASP) checklists for quality assessment. All articles were published between 2001 and 2017 in peer-reviewed journals; Fourteen were conducted in the USA, one in Australia (Hatfield, Ciccarelli, Falkmer, & Falkmer, 2017), one in the Republic of Ireland (Bell et al., 2017) and one in the UK (Horton, 2015). Twelve of the studies were quantitative; eight of these employed a single-case design, one a longitudinal and three studies a cross-sectional design. Four studies were qualitative and one study employed a mixed-methods design. Table 3 provides a descriptive summary of each study.

Most studies focussed on evaluating the impact of choice-based interventions or on features of post-secondary transition. Eight studies evaluated the impact of choice on pupil behaviour and engagement using case studies of autistic pupils (Barry & Burlew, 2004; Ledford, Lane, Shepley, & Kroll, 2016; Mechling, Gast, & Cronin, 2016; Newman, Needelman, Reinecke, & Robek, 2002; Peterson, Caniglia, & Royster, 2001; Rispoli et al.,

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2013; Smeltzer, Graff, Ahearn, & Libby, 2009) with only one study recruiting a larger sample of pupils (N = 26) (Lough et al., 2012). The remaining four quantitative studies focussed on transition planning for post-secondary education, three of these utilised a national data set of transition-aged youth with disabilities in the U.S.A. which included autistic pupils (Griffin, Taylor, Urbano, & Hodapp, 2014; Shogren & Plotner, 2012; Wei, Wagner, Hudson, Yu, & Javitz, 2016). The four qualitative studies in the review analysed: pupil experiences before and after secondary transition (Bell et al., 2017), pupil experiences of an annual review meeting (Horton, 2015), the use of a self-determination framework in the school curriculum (Held, Thoma, & Thomas, 2004) and the experiences of pupils who use augmentative and assistive communication (Woodfield & Ashby, 2016).

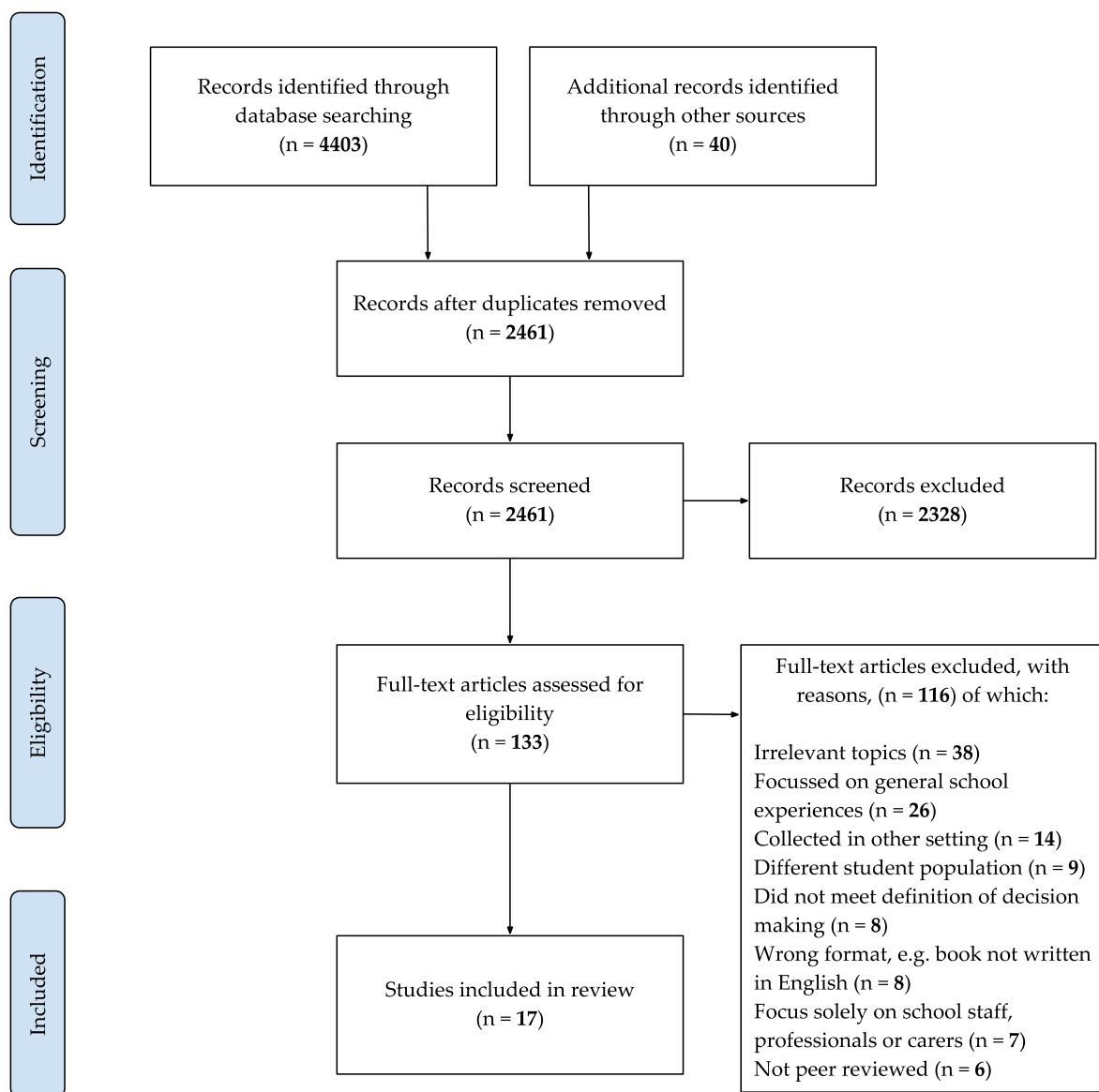


Figure 1. PRISMA flow chart to illustrate the stages of the systematic search

1.3.2 Quality appraisal

The quality of studies varied considerably. Table 3 shows a summary of each study with a description of sample, key findings and the overall rating of quality assigned using the CASP checklists. Appendix D shows a full list of the rating given for each item on the CASP per study. The lowest scoring articles were Horton (2015) and Peterson et al., (2001) which scored 2 and 3 out of 10; the highest scoring article was Wei et al., (2016) which scored 11 out of 11. Of the twelve quantitative studies, only five conducted statistical analyses on their data (Griffin et al., 2014; Lough et al., 2012; Rispoli et al., 2013; Shogren & Plotner, 2012; Wei et al., 2016) with only one study accounting for confounding variables (Wei et al., 2016). None of the four qualitative studies conducted sufficiently rigorous data analysis or provided a clear statement of findings, making it difficult to independently interpret the results. Woodfield and Ashby (2016) for example, did not describe the type of analysis conducted on the data despite providing sufficient quotes to support and illustrate their findings.

Table 3

Summary of studies included in the review

| Study and country | Aim | Sample | Decision-making process | Method and findings | Quality rating |
|-------------------------------|--|---|---|---|----------------|
| Rispoli et al., (2013) USA | To compare the impact of two choice-based interventions on challenging behaviour | N=4 3 with autism, 1 with Asperger's Age 5 to 11 years, 3 male and 1 female | <i>Across-activity:</i> Choosing one of two activities <i>Within-activity:</i> Choosing which materials, location to do activity | ABAB alternating treatment design. (A= no-choice baseline, B = choice conditions). Challenging behaviour observed by researcher during sessions and measured using rate per minute of target behaviours. Challenging behaviour lower in choice conditions for all participants with large effects (Tau-U 0.93 within-activity and 0.94 across-activity, with 90% CI between 0.7 and 1). | 9/11 |
| Lough et al., (2012) USA | To examine the effects of choice on the quality and duration of a colouring activity | N=26 22 male, 4 female Age 8 to 15 years Diagnosed with autism (no reference to source) | Choosing one of three pictures to colour vs. picture allocated | Compared no-choice and choice condition. <i>Duration:</i> time on task. <i>Quality of drawing:</i> number of colours used and amount the page was coloured. Significantly more colours used and time colouring during choice vs no-choice condition with small effect sizes (percent coloured, $d = 0.06$, markers used, $d = 0.20$, time coloured, $d = 0.30$) | 9/11 |
| Aguilar et al., (2016) USA | Test the use of an assessment to identify preference for a specific language | N=1. Male, age 6 diagnosed with autism (no reference to source). Scored in severe range on Autism Rating Scale. | Choosing language of instruction | 30 exposure trials and 10 choice sessions where participant indicated preference by selecting one of three switch presses with vocal recordings: 'work in English', 'work in Spanish' and no recording. 87.9% of choices were Spanish and 7.1% for English but no statistical analysis. | 6/11 |

| Study and country | Aim | Sample | Decision-making process | Method and findings | Quality rating |
|-----------------------------|--|--|--|--|----------------|
| Mechling et al., (2016) USA | Explore the impact of high-preference stimuli paired with choice on duration of task performance | N=2 Male, age 13 and 14 years diagnosed with autism by psychologist | Choosing rewards | ABAB alternating treatment design (A = no choice, given tangible preferred item, B = choice of preferred items on screen prior to task completion). Participants received preferred item once tasks were in the "finished box". Both pupils completed tasks in less time in choice condition but no statistical analysis. | 7/11 |
| Newman et al., (2002) USA | Test whether choice increases speed of skill acquisition | N=3 Male, age 7, 11 and 12 years diagnosed with autism (no reference to source) | Choosing order of activity and reward | Two conditions: teacher vs. student selection of rewards and program order. Skills taught by the experimenter: shape, object and colour identification. Skill mastery: 90% accuracy on three consecutive sessions. No difference in performance across conditions. No statistical analysis. | 5/11 |
| Peterson et al., (2001) USA | Reporting effects of an intervention to reduce challenging behaviour | N=1 Male, age 10 years diagnosed with autism (no reference to source) | Choosing between teacher's plan and pupil's plan | <i>Pupil plan</i> : working alone and receiving a break with teacher attention. <i>Teacher plan</i> : working with teacher assistance. During choice condition, there was a decrease in 'inappropriate behaviour' by the last three sessions but no observational data or statistical analysis. | 3/11 |
| Smeltzer et al., (2009) USA | Examine effect of choice on task duration, on-task behaviour and challenging behaviour | N=3 Male, age 6 diagnosed with autism (data from 2 other participants were excluded as they were from a different population) | Choosing order of tasks. Choosing between teacher selecting task order, or the pupil selecting the order | Alternating treatment design: choice of task order, no-choice, choice of pupil or teacher selection, no choice. <i>On-task behaviour</i> : orienting head towards task, ' <i>problem</i> ' behaviour: rate of target behaviour per minute. In experimenter selected conditions, there was higher task duration and rate of problem behaviour and lower on-task behaviour. No statistical analysis. | 6/11 |

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| Study and Aim country | Sample | Decision-making process | Method and findings | Quality rating | |
|----------------------------|---|---|--------------------------------------|--|------|
| Barry & Burlew (2004) USA | Test the use of social stories to teach choice-making skills and play skills | N= 2 1 male (age 7), 1 female (age 8) with autism (no reference to source) | Choosing activities during free play | ABCD multiple-baseline design (A = baseline choice-making in nursery, B = social story about choosing play materials and observations, C = social story about playing with peers and observations, D= social stories available with teacher help removed). All data collected by teacher and teaching assistant. <i>Choice-making</i> : level of prompting the pupil needed to make a choice, measured on a Likert scale. In phase B, both required less intrusive prompts to make a choice but no statistical analysis. | 6/11 |
| Ledford et al., (2016) USA | Exploring the effects of three interventions on task engagement, number of social interactions, proximal play and physical activity | N=2 Male, age 4 years diagnosed with autism (no reference to source) | Choice of toys in outdoor play | <i>Low-effort intervention</i> : access to five random materials in common area of playground. <i>Structured-choice (SC) intervention</i> : offered choice between two different materials every 2-3 minutes. <i>Enhanced intervention</i> : structured choice of activities plus prompts for physical activity every 2 minutes. Interventions implemented by class teacher, observational data collected by researchers using 10s time-sampling. Percentage of time spent: on task, in a social interaction and engaging in proximal play was highest in SC conditions for both pupils. No difference in condition for physical activity. No statistical analysis. | 6/11 |

| Study and country | Aim | Sample | Decision-making process | Method and findings | Quality rating |
|-----------------------------------|--|--|-----------------------------|---|----------------|
| Shogren & Plotner (2012) USA | To compare the characteristics of transition planning for students with Intellectual Disability (ID), autism or other disabilities | <i>Parent interview</i> N=730 ID, N=830 autism, N=6,080 other disabilities <i>School survey</i> N=420 ID, N=420 autism, N=3,150 other disabilities Parents and school professionals of youth receiving special education services, no reference to source of diagnosis NLTS2 data set | Post 16 transition planning | Utilised the data set of the National Longitudinal Transition Study-2 (NLTS2) on secondary and postsecondary transition experiences of pupils receiving special education in the USA between the years 2000 and 2010. Calculated mean ratings and/or percentage of pupils per participant group for data related to transition services and support. Compared to students with ID and other disabilities, students with autism were significantly more likely to have an advocate present at their transition meeting; less likely to be 'active' participants; less likely to have met with teachers to set post-graduation goals (significance levels $p < 0.01$), based on reports from their teachers and parents. | 9/11 |
| Hatfield et al., (2017) Australia | Explore factors related to transition planning processes | N=162 83 parents, 53 school professionals, 26 young people with autism without intellectual disabilities, (no reference to source), years 9 to 12, 73% male | Post 16 transition planning | Online questionnaire asking about demographics, current and ideal transition planning, barriers and enablers to transition planning. Kruskal-Wallis test to examine significant differences in group responses with $p < 0.05$. Qualitative data analysed using constant comparative method. Young person reported to be part of transition planning team but parents often coordinated the meetings, helpful factors to the process: individualised to meet needs, strengths-based, flexible options, having a structure with clear goals. | 11/13 |

| Study and country | Aim | Sample | Decision-making process | Method and findings | Quality rating |
|-------------------------------|---|--|-----------------------------|--|----------------|
| Griffin et al., (2014) USA | Identify factors related to pupil involvement in transition planning | Utilised NLTS2 data set. N=320 270 male, 50 female youth with autism receiving special education services and on role in transition planning age 14 -16 years (no reference to source of diagnosis) | Post 16 transition planning | <i>Outcome variable:</i> teacher rated level of student involvement in transition planning on a Likert scale from 1 to 4 (1 = did not attend, 4 = took a leadership role. <i>Predictor variables:</i> demographics, parental involvement, educational experiences and student characteristics. Regression analyses highlighted four significant predictors of pupil attendance at the meeting: discussion of post-school plans at home, lower parental involvement at school, higher expressive communication skills, more time spent in mainstream settings, $p <0.001$. | 10/11 |
| Wei et al., (2016) USA | Assess the relationship between transition planning, goal setting and college enrolment | Utilised NLTS2 data set. N=920 Wave 1, 660 Wave 2 Youth with autism receiving special education services; 85.4% youth were male, age 14 – 16 (no reference to source of diagnosis) | Post 16 transition planning | <i>Outcome variable:</i> enrolment in community college or a 2 or 4-year college or university. Pupils who participated in transition planning had significantly higher odds of college enrolment than pupils who did not participate, $p < 0.05$; this was after controlling for covariates such as gender, age, race, disability severity, family income, mother's education level, school achievement and parental expectation of attending college. | 11/11 |
| Held et al., (2004) USA | Evaluating the impact of curriculum on transition for one pupil | N=1 Male with autism (no reference to source), likely 18 – 21 years based on program enrolled (age not specified) | Post 16 transition planning | Observations, pupil and teacher interview and document analysis (but no examples of this data). The author states that the pupil was helped to express his views in the transition meeting by recording his voice in a PowerPoint and practising his responses before the meeting. | 3/10 |

| Study and Aim | Sample | Decision-making process | Method and findings | Quality rating | |
|---|--|---|--|---|------|
| country | | | | | |
| Woodfield & Ashby, (2016) USA | Identify practices that support the inclusion and participation of 3 autistic pupils | N=3 2 male, 1 female age 16 to 18 diagnosed with autism (no reference to source). Communicate via typing. | Day to day decisions in school e.g. taking breaks, timetable changes | Six classroom observations per pupil and 60 – 90 minute semi-structured interviews with students, parents and school staff. Themes: strategic access methods, building relationships, materials management, scheduling, prioritising communication, home/school communication. | 5/10 |
| Bell et al., (2017) Republic of Ireland | Explore pre-post transition experiences with a focus on i) resources and support and ii) issues and barriers | N=6 Male, age 17-19 diagnosed with autism (no reference to source) | Post 16 transition planning. Types of choices: <ul style="list-style-type: none">- Choosing college- Choosing career- Choosing to disclose disability | Semi-structured interviews pre-and post-transition analysed using 'lean coding'. Key points in author's discussion of themes at <i>pre-transition</i> : pupils appreciated guidance to make career choices and frequent access to this over many years, choice of college influenced by facilities and relationships. Possible issues: no formal process of transition planning for post-secondary work and education within school, some career personnel lacked ASD specific knowledge, stress from leaving supportive relationships. <i>Post-transition</i> : deciding whether to disclose ASD label and access support, managing academic demands. | 7/10 |
| Horton, (2015) UK | Explore ways to enhance pupil participation in annual review meetings | N=3 CYP, N=68 school staff 3 male, 1 female with a diagnosis of autism or Asperger's (no reference to source), years 9 to 13 in two secondary schools. Staff from 11 schools; diverse roles. | Year 9 annual review meeting | Four student interviews using open ended questions and visual aids, analysed using thematic analysis (no reporting). Staff surveys with proportion of responses on an item used to highlight themes in the data. 53/66 staff reported that it was important for pupils to attend their annual review. Authors suggest the following barriers to participation: pupil's social communication skills, understanding of the purpose of the meeting, anxiety and low self-esteem. | 2/10 |

1.3.3 Sample characteristics

Studies included pupils aged 4 to 19 years old, with the sample size ranging from 1 to 6 pupils in the qualitative studies or those with a single-case design (Aguilar, White, Fragale, & Chan, 2016; Barry & Burlew, 2004; Bell et al., 2017; Held et al., 2004; Ledford et al., 2016; Mechling et al., 2016; Newman et al., 2002; Peterson et al., 2001; Rispoli et al., 2013; Smeltzer et al., 2009; Woodfield & Ashby, 2016). Studies which utilised data from the National Longitudinal Transition Study 2 (NLTS-2) in the USA (Wagner, Newman, Cameto, Garza, & Levine, 2005) contained samples with more than 300 participants (Griffin et al., 2014; Shogren & Plotner, 2012; Wei et al., 2016).

It is difficult to determine whether the heterogeneity of the autistic population was represented in the studies because there was very little background detail provided on participants. Most of the case studies referred to participants 'with autism' or 'diagnosed with autism' without information on ethnicity, attainment, language skills or the diagnostic process; the only exception is Mechling et al., (2016) who describes where and when the diagnosis was given for each pupil as well as their verbal skills and performance on psychometric assessments. The larger studies using the NLTS2 data set also provided more detail on demographics; for example, Wei et al., (2016) stated that participants in the study were enrolled for special educational services in 'the autism category' and that national public health surveys indicated that 95% of pupils in this category meet the DSM-IV-based criteria for autism.

1.3.4 Decision-making

There were various forms of decision-making examined across the different articles. Nine studies focussed on pupils making choices between activities, language instruction, the order of tasks, how tasks are completed, plans for the day, lesson duration, and the reward given; seven studies focussed on the process of transition planning (six for post-secondary education and one for a year 9 annual review). However, in many of the studies, decision-making was orchestrated by the researcher in an experiment that took place in a quiet room within the school; the results of these studies may therefore lack ecological validity as the choices were not offered by a familiar adult or within the context

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in which pupils would typically make these choices (e.g. during a lesson). Exceptions to this are three studies (Barry & Burlew, 2004; Ledford et al., 2016; Peterson et al., 2001) where a choice-making intervention was implemented by the pupils' teacher within their regular classroom or school playground. Among the studies on transition, the decision-making process examined was participation in a transition planning meeting (Griffin et al., 2014; Shogren & Plotner, 2012; Wei et al., 2016) or annual review meeting (Horton, 2015) with two studies focussing on the wider transition process (Bell et al., 2017; Hatfield et al., 2017). All seventeen articles are discussed in the following sections, with each section corresponding to a question in the Framework for Participation (Florian et al., 2016).

1.3.5 **Question one: Who does and does not participate in decision-making? And who decides?**

The first question in the Framework for Participation (Black-Hawkins, 2014) is '*who does and does not participate? And who decides?*'. In the context of decision-making, this means considering which pupils make choices about their education and are involved in processes where decisions are made, contrasting the profile of pupils who are excluded from decision-making.

The most robust finding comes from research on transition planning. A study by Shogren and Plotner (2012) found that autistic pupils were significantly less likely to 1) attend their transition meeting and 2) be characterised as 'active' participants than pupils with Intellectual Disabilities (ID) or other disabilities, as reported by their teachers in a survey. However, the authors did not provide a definition of 'active participation' to enable readers to understand how autistic pupils participated differently during the transition meeting compared to other pupils. Another finding was that autistic pupils were significantly less likely to have met with teachers to set post-graduation goals than pupils with ID or other disabilities, according to their parents (30.4% of parents of autistic pupils said yes, compared to 50.4% of parents of pupils with ID and 57.8% of parents of pupils with other disabilities). These results appear credible because of the large sample of pupils in the study: 430 with autism, 420 with ID and 3150 with other disabilities, who were recruited from a range of geographic locations and educational settings in the U.S.A. including public and private institutions and mainstream and special schools, thereby

minimising selection bias. Research findings reported by Wei et al. (2016) using the same national data set are consistent with the above findings; they identified that only four in ten youth with autism participated in transition planning.

In terms of pupil characteristics, two studies suggested that autistic pupils began transition planning for post-secondary education in Year 10 (Hatfield et al., 2017) or on average at the age of 14.4 years (Shogren & Plotner, 2012). Griffin (2014) also found that higher expressive language skills and percentage of time spent in mainstream significantly predicted the attendance of autistic pupils at their transition meeting. However, it is worth noting that the majority of these studies were conducted in the U.S.A with no equivalent study on the UK population of autistic pupils.

The profile of pupils who participated in decision-making outside of transition planning is less clear. Most of the research on choice-making interventions is limited to case studies of autistic pupils and was conducted with pupils of varying ages with a range of cognitive skills. However, one common thread is that many studies (e.g. Peterson et al., 2001; Rispoli et al., 2013; Smeltzer et al., 2009) were conducted with pupils who are described as displaying behaviours which school staff found difficult to manage in a classroom environment. In these cases, the researchers aimed to use choice-based activities to either reduce challenging behaviour or increase task engagement. As many of these choice-based activities were offered to pupils by the researcher in an artificial situation, it is difficult to determine whether the pupils typically made these choices within their classroom environment. Another challenge is that many of the authors did not describe their recruitment strategy, which could have provided details on the motive for using a choice-based intervention with a particular pupil.

1.3.6 Question two: What are the practices that promote participation in decision-making? What are the practices that reinforce barriers to participation in decision-making?

In the context of decision-making, these questions invite the examination of environmental factors which enable or inhibit autistic pupils to be a part of making choices and decisions about their education. Some examples of practices given by Florian et al., (2016), include day to day social interactions within the school, policy documents,

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school culture and classroom activities. The practices identified within the review varied across studies, according to the perspectives of those involved and the type of decisions made.

1.3.6.1 Quantitative studies

Of the seventeen studies reviewed, only two quantitative studies specifically aimed to identify practices that promoted the participation of autistic pupils in decision-making. A study by Barry and Burlew (2004) suggested that the use of Social Stories in pre-school classrooms helped autistic pupils to independently choose activities during free play. The intervention was implemented by the classroom teacher who created the Social Stories using photographs of the activities available in the play centre; the researchers found that the two autistic pupils who took part in the study displayed a higher rate of independent choice-making following the intervention. However, due to the small sample size, no statistical analyses were conducted on the data. This means that it is difficult to identify whether the findings are due to the intervention or other confounding factors.

A more reliable finding was reported by Griffin et al. (2014) who used regression analyses on survey data to identify factors predictive of pupil attendance and participation in transition planning meetings. The authors found three factors that significantly predicted active participation: pupils having greater self-advocacy skills, more frequent discussions between pupils and carers about plans for post-secondary education, and lower parental involvement at school. Only two of these factors would be considered a 'practice' under the Framework of Participation: pupil-parent discussions about transition and lower parental involvement, the latter of which was measured using parental ratings of the frequency of their attendance at meetings and school events. Indeed, all of the factors were measured using self-rating scales completed by staff or parents; for example, teachers rated pupil self-advocacy on a 4-point scale according to how well pupils ask for what they need -- surprisingly this did not capture the perspectives of autistic pupils on their own skills, which may have been different to the perceptions of staff.

1.3.6.2 Qualitative studies

Factors that promote the participation of autistic pupils in decision-making may also be gleaned from analysing the qualitative studies (Hatfield et al., 2017; Held et al., 2004; Horton, 2015; Woodfield & Ashby, 2016). The majority of these studies specifically focused on formal decision-making: transition planning, Individual Education Plan meetings and annual reviews with only one study by Woodfield & Ashby, (2016) referencing day-to-day decisions in the classroom.

Hatfield et al., (2017) conducted a qualitative analysis of survey responses from autistic pupils, their parents and school professionals to examine factors related to a successful post-secondary transition. Although the questions did not focus on pupil participation in planning meetings, the themes identified practices that may facilitate young people to make decisions in the transition process. The authors reported, for example, that young people wanted the focus of transition to be about their strengths, which helped them to tell teachers what they liked and were good at; wanted a clear understanding of the planning process, and the option to change their minds about decisions made, if needed. Hatfield et al., (2017) also identified a theme called 'adolescent motivation, anxiety and insight' which provided examples of factors that might reinforce barriers to participation. The authors referred to comments from parents and professionals who reported that pupils showed high anxiety during transition and a lack of understanding of why planning was important, reducing pupil motivation to take part in the planning process. However, as the qualitative research was conducted within a mixed-methods study, where authors also reported on quantitative data, there was insufficient detail on the procedures for qualitative data analysis and use of quotes to support findings.

Two other qualitative studies conducted by Held et al., (2004) and Horton, (2015) also provided some insight into the participation of autistic pupils in decision-making but had the lowest ratings of methodological quality in the review. In Horton (2015), pupils suggested the following changes to Year 9 annual reviews: allowing students to stay for the whole meeting, slowing the meeting pace, going through the agenda beforehand, being asked if they understood everything, focussing more on pupils and less on parents—however, as these were retrospective comments, it is unclear if and how these

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practices might have better facilitated their involvement in the meeting. Held et al., (2004) provides reflections on a teacher's experience of supporting transition planning for one pupil. Practices which appeared to enhance the pupil's participation in Individual Education Plan (IEP) meetings were: supporting the pupil to use information and communications technology (ICT) to record his ideas, opportunities for the pupil to practise responses to questions before the meeting and staff teaching pupils how to use PowerPoint to structure their own IEP meeting. In both studies, however, there is very little data to support the authors' conclusions, making it difficult for others to independently interpret the findings. This is particularly the case in Held et al., (2004), which describes the research findings without any reference to the data that were collected or the use of quotes to support arguments.

One qualitative study by Woodfield & Ashby, (2016) was unique in that it gave insights into informal decisions made within the classroom, in the context of exploring practices related to inclusion rather than decision-making. There was data, for example, suggesting that staff adopted an individualised approach to learning, which took account of pupil requests to take breaks during activities in the lesson. A strength of the study was the use of detailed quotes and observations to support findings, using multiple participant perspectives including those of autistic pupils. However, identifying examples of decision-making within the study was made difficult by the fact that much of the data related to general participation, for example, pupils answering questions in the classroom rather than specifically to decision-making. Moreover, as the authors in Woodfield and Ashby, (2016) had not defined key terms such as 'inclusion' and 'participation' it was unclear whether decision-making was considered part of these constructs. Without these definitions it is difficult to know whether the findings that promote inclusion can also be considered to promote decision-making, as operational definitions influence the lens in which data is collected and analysed.

1.3.6.3 Studies on choice-based interventions

Seven of the studies reviewed found that using choice-based interventions, such as offering pupils the choice of which activity they wanted to do, increased task engagement, skill acquisition and pro-social behaviour (Ledford et al., 2016; Lough et al., 2012; Mechling et al., 2016; Newman et al., 2002; Peterson et al., 2001; Rispoli et al., 2013;

Smeltzer et al., 2009). None of these studies focused on participation in decision-making as an outcome; for example, they could have measured differences in the number of choices made pre-post intervention or gathered pupil views on their choices. Another case study used micro switches to assess the preferred language instruction of a non-verbal pupil with autism who was regularly exposed to two languages (Aguilar et al., 2016). From the data, the authors argued that pupils with severe language delay could indicate clear preferences and therefore practitioners should be identifying ways to assess their preferences at school so that lessons could be adequately tailored. An implication of this finding could be that regularly offering pupils opportunities to make authentic choices is one practice that acts as a step to enhancing pupil participation in decision-making.

1.3.7 Question three: Why do these practices that promote participation in decision-making take place? Why do these practices that reinforce barriers to participation in decision-making take place?

In the Framework for Participation (Florian et al., 2016), the *why* questions explore the reasons underpinning the *who* and *what*, with an explicit focus on the values and beliefs that shape the practices identified. This section arguably involves a greater degree of interpretation than the previous two as none of the research reviewed specifically addressed this topic as a research question or discussed the author, participant or policy values underpinning the findings. The author has therefore focussed on articles that identified practices promoting participation and screened: a) the introduction sections to identify the goal of the research and b) the discussion sections to extract information referring to possible causes or mechanisms for the results.

Five studies identified practices that promoted the participation of autistic pupils in decision-making, each of which will be discussed in turn. Barry and Burlew, (2004) used social stories to develop the choice-making skills of pre-school children with autism. The authors stated that the purpose of this intervention was to “enable children to participate successfully in the free-play time in their ESE classroom” (p. 46). More specifically, the goal was to increase pupils’ ability to independently choose an activity and go to the chosen play centre with minimal adult prompting. However, there was no reference to or rationale for why it would be important to develop this skill for autistic pupils or increase pupil participation in free-play. In Griffin et al., (2014), the authors identified three factors

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predictive of pupil participation in transition planning: higher pupil self-advocacy skills, discussions at home about post-school options and lower parental involvement at school. The authors proposed that pupils with higher self-advocacy skills were more likely to participate in transition planning because parents and staff perceived these pupils as more competent than those with lower self-advocacy skills. This perception of competence was proposed to lead to more opportunities for these pupils to participate, though no evidence was provided to support this purported mechanism. It is unclear what values and beliefs underpinned parental choices to discuss post-school options with their children or become involved in schooling and how this may differ from the values of parents who made different choices.

In three qualitative studies (Hatfield et al., 2017; Held et al., 2004; Horton, 2015) it was difficult to identify the values and beliefs underpinning practices because many of the authors' assertions were not sufficiently supported by data from participants. In the absence of data, there is no insight into the values and beliefs of the practitioners or parents who implemented the practices identified. There was some discussion of possible mechanisms for the findings in Hatfield et al., (2017)—namely that the focus on a strengths based approach may have underpinned by beliefs relating to the importance of individual identity rather than normative development. Hatfield et al., (2017) also discussed reasons for using different approaches to transition planning by drawing on literature in the field. Firstly, they suggested that a focus on individual strengths and interests in the transition planning meeting can lower anxiety for autistic pupils, capture their individual identity and allow their voices to be heard. They also referred to research suggesting that a structured plan can help parents and pupils to have a clear understanding of the process and that this increases the chance of pupil employment. Whether these are the actual reasons practitioners implement these practices is unclear.

1.4 Discussion

1.4.1 Summary of studies reviewed

This review aimed to identify the current research on the participation of autistic pupils in school-related decision-making using questions in the Framework for

Participation (Florian et al., 2016) to interrogate the literature. Seventeen studies were included in the review, each rated for methodological quality using the Critical Appraisal Skills Programme (CASP, 2013). The studies varied in quality with those conducting research with large-scale survey data generally rated higher than those using single-case design or qualitative data. A key finding was the prevalence of studies focusing on formal decision-making processes such as meetings to review Individual Education Plans and prepare for the transition to post-secondary education, rather than informal decisions in the classroom. In the context of transition planning, there was also evidence that autistic pupils were less likely to participate in their own transition planning meeting than pupils with intellectual disabilities or other disabilities. This further highlights the need to understand the practices that enable autistic pupils to participate in school-related decision-making.

Comparing data across studies was made difficult by different and/or lack of operational definitions of terms. Interpreting why practices promoted participation in decision-making was therefore left to the judgement of the reader; for example, 'active participation' was not defined in (Griffin et al., 2014), so it was unclear which aspects of the participation of autistic pupils in the meeting were promoted by post-school discussions at home. Other facilitative practices were identified in this review including the use of Social Stories and ICT, but each practice was only supported by one study and there was very little discussion of the beliefs and values underpinning their implementation, which may have provided insights into their effectiveness. Half of the research included in the review examined the use of choice-based interventions with autistic pupils, but their purpose was not to identify which practices facilitated pupils to make more choices, but rather assessing whether providing choices effectively reduced behaviours perceived as challenging, or in a few cases increased engagement and skill development (e.g. Ledford, Lane, Shepley, & Kroll, 2016).

1.4.2 Pupil perspectives

Only four of the seventeen studies sought the views of autistic pupils, which implies that there is still insufficient research on autistic perspectives to inform the current evidence-base on their participation in school-related decision-making. This arguably validates concerns expressed in the literature around the lack of involvement of the

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autistic community in research and the use of narratives that do not consider the subjective experiences of participants (Milton & Bracher, 2013; Milton, Mills, & Pellicano, 2014). Valuing autistic views in the research process is argued to be particularly important for shifting a narrative that focuses on deficit rather than strengths and acknowledging the diverse experiences of those on the autism spectrum (Milton & Bracher, 2013). In the context of this review, a deficit view is perhaps most evident within the literature on choice-based interventions, where the focus is on behaviours that are viewed by others to be problematic.

The lack of autistic perspectives on choice and decision-making at school does not appear, however, to be replicated in other areas of education research. There are, for example, many studies that aimed to understand the experiences of autistic pupils in primary, secondary and post-secondary education settings (Hill, 2014; Humphrey & Lewis, 2008; Loyd, 2015; Shepherd, 2015). A systematic review of qualitative methods used in research with autistic pupils also suggests that increasingly varied methods are being used by researchers to elicit the perspectives of autistic pupils such as drawing, photo-elicitation and walking tours (Fayette & Bond, 2017). It may be that the current literature on school-related decision-making is largely informed by quantitative research which uses methods of data collection that, by nature, do not aim to elicit subjective experiences. Though in some cases, studies that used variables such as self-rating scales which captured the perspectives of participants in numerical form, could have included the views of autistic pupils in addition to carers and school staff (e.g. Griffin, Taylor, Urbano, & Hodapp, 2014). An alternative explanation is that the literature identified in this systematic search was limited by a mismatch between the terms operationalised in the current review and how those same terms are used in the research. For example, the literature on 'choice' was focussed on behaviour management interventions for specific pupils rather than choice in the context of promoting pupil participation in decision-making. Using terms such as 'voice' may have generated articles that fit more with the purposes of the review, despite not being a term used within the principles of the Framework for Participation (Florian et al., 2016).

Nevertheless, the findings highlight that the perspectives of autistic pupils are underrepresented in the sample of studies included in this review. This finding suggests

that future research should focus on eliciting the views of autistic pupils in relation to their participation in decision-making; sections of the Framework could be extended to incorporate a focus on pupil perspectives in order to do this.

1.4.3 The 'Why' section of the Framework

There are few articles in the review which discuss practitioners' rationale for implementing practices, which suggests that this is not considered a part of the research process. However, Florian et al. (2016) argue that examining why a practice takes place is the most important element within the Framework, because the beliefs and values of practitioners are closely tied to the culture of the school, thereby influencing the practices that are designed, implemented and prioritised. An emphasis on practitioner rationale in research calls into question what should be considered Evidence-Based Practice (EBP). The American Psychological Association defines EBP as 'the integration of the best available research with clinical expertise in the context of patient characteristics, culture and preferences' (p. 280 American Psychological Association, 2006). Research evidence in EBP is often linked to methodologies considered to be the most robust, such as Randomised Control Trials (RCTs) which produces rules for the purposes of generalisation to other contexts—though the application of these rules in educational settings is highly contested (Mark Fox, 2011; Kennedy & Monsen, 2016; Simons, Kushner, Jones, & James, 2003).

The implication of focusing on values and beliefs is that findings in research, cannot be considered independently of the views of users responsible for its implementation—in this paradigm, research evidence would not be seen as solely the 'rule' or 'practice', but also the values and beliefs that shape its implementation. There is support for this view of research evidence within educational psychology research. For example, Fox, (2011) argues that the effectiveness of an intervention is closely linked to explanations of why it is beneficial for a particular child and that this insight is not provided in research that focuses solely on generalising rule-based knowledge. Some theoretical models, such as Argyris' (1999) theory of single and double loop learning, also argue that practitioner beliefs are an underlying variable that directs a course of action, and through the action, a successful outcome—if so, applying research evidence to school practice, independent of

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an understanding of staff beliefs may be likely to fail in a setting where the beliefs are different (Kennedy & Monsen, 2016).

As very few studies in the review mentioned practitioner beliefs, there is work needed to encourage researchers to question the rationale of practitioners, as part of exploring the practices that promote the participation of autistic pupils in school-related decision-making. If examining practitioner beliefs is to be a core part of the research process, this should also be reflected in the checklists used to analyse the quality of data generated in research. The Critical Appraisal Skills Programme (CASP, 2013), for example, does not include an explicit section on reflexivity, nor for the researcher or practitioner, though these have been found in other checklists (Tong, Sainsbury, & Craig, 2007). Future research could also use the Framework for Participation (Florian et al., 2016) to exclusively examine the values and beliefs underpinning different school-related practices with autistic pupils. This may provide insights into what influences one school to choose one practice over another as well as identify the research methods that would be most helpful for eliciting the beliefs and values of participants. Asking the 'right' questions may be particularly important within this element of the Framework because values are often hidden and may be more difficult to identify (Black-Hawkins, 2010).

1.4.4 Strengths and Limitations of the review

A strength of the review is the wide range of databases searched within the fields of education, psychology and medicine, including journals specific to educational psychology practice. Findings also address a significant gap in the literature, as there is currently no systematic review on the participation of autistic pupils in school-related decision-making. The review is also informed by a theoretical base through the use of The Framework for Participation (Florian et al., 2016) to guide the selection and analysis of articles. The search terms for 'participation' for example, are those within the principles of The Framework, rather than selected haphazardly from different terms in the literature. Though this comes with a caveat that relevant articles may be missed due to the exclusion of search terms not included in the Framework. There are other limitations that come with setting specific pre-defined inclusion and exclusion criteria. For example, there were studies that focused on school-related decision-making which narrowly missed the inclusion criteria because the research was conducted in the pupil's home, rather than in

an educational setting (e.g. Hagner, Kurtz, May, & Cloutier, 2014). Future reviews in this area could expand search terms to include home contexts, which would incorporate autistic pupils who are home educated or those with extended school non-attendance. Searching grey literature might also identify interesting findings in this area, particularly as an increasing amount of research is now being shared via social media (Tutelman et al., 2018).

1.4.5 Summary

Despite the limitations of the research examined in this review, there are key findings that are relevant to school practice. The lack of attendance and active participation of autistic pupils in their own transition meetings highlights that they may be vulnerable to exclusion from decision-making (Shrogen et. al, 2016; Wei et.al, 2016). Although the research specifically focussed on transitions rather than a broad range of decisions, the finding that autistic pupils participated significantly less than peers with other disabilities, begs the question of the nature and extent of their involvement in school-related decisions more generally. Professionals working in schools should therefore monitor when autistic pupils do or do not attend formal meetings about school-related decisions and when they do attend, the extent to which they participate.

Based on the research in this review, there are different practices schools could adopt to promote participation within the context of a meeting as well as informally in the classroom. The use of ICT provided the opportunity for one autistic pupil to effectively communicate his views in an Individual Education Plan meeting, which could be applied to other contexts. Opportunities to record ideas on a computer in the pupil's preferred format and practise responses to questions ahead of the meeting was identified by researchers as particularly helpful (Held et al., 2004). In the context of transition planning, strategies that might be helpful are: a) focussing on strengths in the meeting b) providing a clear understanding of the process and why it is important for pupils to take part c) frequent discussions between parents and pupils about transition planning and the different options available d) staff giving pupils the opportunity to change their mind if needed and e) promoting expressive language skills if this is an area of difficulty. Strategies a, b, and d are particularly important because they were identified by the pupils themselves as practices they wanted during transition planning (Hatfield 2017). For

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informal decisions in the classroom, school practices predominantly focussed on supporting pupils to state their preferences and make choices independently. The evidence presented in Barry and Burlew (2004) highlights that the use of Social Stories in a nursery classroom helped autistic pupils to independently choose activities during free play. This practice could easily be transferred to a school context given that the strategy was implemented by the classroom teacher rather than the researcher. Findings from seven case studies of autistic pupils showed that providing a choice of which activity to do, materials to use, or order of the activity to complete increased on-task behaviour in the classroom (Ledford et al., 2016; Lough et al., 2012; Mechling et al., 2016; Newman et al., 2002; Peterson et al., 2001; Rispoli et al., 2013; Smeltzer et al., 2009). Schools should therefore give autistic pupils regular opportunities to make simple decisions about how they learn, as this practice is likely to increase their engagement in the classroom.

Chapter 2 The participation of autistic pupils in decision-making about their school experiences: A case study of one school

2.1 Introduction

2.1.1 Context

There is increasing interest in finding ways to ensure that autistic pupils participate in the decisions that affect their lives. Research has devoted much attention to identifying creative methods for eliciting the views of autistic pupils and the factors associated with their participation in decision-making contexts (Bell et al., 2017; Fayette & Bond, 2017; Griffin et al., 2014; Hatfield et al., 2017; Pellicano, Hill, & Croydon, 2014; Shogren & Plotner, 2012; Wei et al., 2016). However, much of this understanding is dominated by large-scale, quantitative research focusing on formal decision-making processes such as school transition meetings. We therefore know very little about the participation of autistic pupils in informal decision-making, such as day-to-day decisions in the classroom. A lack of qualitative research also means that the current evidence base provides information on broad trends in decision-making, but very little detailed, contextual knowledge on the practices that take place in school or the perspectives of those who participate. It is important to provide these insights so that: a) practitioners gain knowledge from a real-world context to inform their practice and b) the evidence base for pupil participation is informed by the views of pupils on the autism spectrum, which is often considered to be underrepresented in the literature (Fayette & Bond, 2017; Flyvbjerg, 2006; Hill, 2014). The current work aims to address this gap in the research through a case study of one school, which intensively examines decision-making in context, from the perspectives of autistic pupils, their carers and the school staff who support them.

2.1.2 Autism Spectrum Disorder (ASD)

The term autism, or Autism Spectrum Disorder (ASD), is typically defined by researchers and clinicians according to the fifth edition of The Diagnostic and Statistical Manual of Mental Disorders: DSM-5, which states that ASD is characterised by persistent impairments in social communication and interaction, along with repetitive patterns of behaviour, activities and interests (American Psychiatric Association, 2013). Under the DSM-5 classification, all individuals are diagnosed under a single category of Autism Spectrum Disorder, following the removal of Asperger's Syndrome as a subgroup, which previously distinguished individuals with average or high cognitive and language skills (Wing, Gould, & Gillberg, 2011). In the current study, all participants were diagnosed pre-2013, before the publication of the DSM-5 classification. The causes of ASD are shown to be of a biological nature, but there is still much debate about the specific mechanisms involved, with research suggesting genetic components and differences in neurodevelopment (Ecker, Bookheimer, & Murphy, 2015; Hicks, Ignacio, Gentile, & Middleton, 2016; Iacoboni & Dapretto, 2006).

Children and young people on the autism spectrum represent a large proportion of pupils who require additional support from schools and other services. The Department for Education (2017) states that 2.8% of the pupil population (242,185 pupils) have a statement or Education, Health and Care Plan (EHCP), with 26.9% of these pupils identified as having a primary need of autism—the most common area of need for pupils with an EHCP in the January 2017 school census (Department for Education, 2017). Moreover, UK prevalence rates estimates 1.1% of the adult population are on the autism spectrum, however a recent study in Northern Ireland has reported this figure to be on the increase, with prevalence as high as 2.5% in 2017 among children aged 4 – 15 years old (Information and Analysis Directorate, 2017; The NHS Information Centre Community and Mental Health Team, 2012). The prevalence rate is a concern because research shows that outcomes for children and young people on the autism spectrum are often poor, with mental health and school exclusion identified as some of the priority areas for intervention (Brede, Remington, Kenny, Warren, & Pellicano, 2017; Crane, Adams, Harper, Welch, & Pellicano, 2018). Supporting autistic pupils in education settings is therefore a topical issue; certainly within Educational Psychology practice, there is

increasing interest in identifying effective interventions, reflected in a recent special issue in the Division of Child and Educational Psychology on Autism in Educational Contexts (Boyle, Dunsmuir, Greig, Mackay, & Stringer, 2017).

2.1.3 Importance of pupil participation

To effectively support autistic pupils, school practices need to be influenced by the views and wishes of the child or young person. This is not only an argument advocated by research on the benefits of pupil participation for pupils, families and practitioners, but by legislation mandating the participation of children and young people in decision-making (Hill, 2014; Mager & Nowak, 2012; Noyes, 2005; Pedder & McIntyre, 2006). The Special Educational Needs and Disabilities (SEND) Code of Practice (2015) states that organisations such as schools and local authorities must ensure that pupils with SEND and their families participate in the decisions that affect them, and are given the tools to participate as fully as possible, and the onus is on practitioners to identify means in which to enable participation, particularly when there are barriers to doing so (Department for Education & Department of Health, 2015). In an educational context, this might involve autistic pupils expressing views on what work they do in the classroom or the design of an intervention put in place to support them; in some cases, with the aid of an advocate or adult they know well.

It is important to state that arguments for the importance of pupil participation are not new; the moral and political justifications are well documented, with references to a range of legislative acts including the United Nations Convention on the Rights of the Child (1989) and The Children Act (1975,1989) (Fielding, 2004; Kaba, 2001; Kirby & Bryson, 2007; Noyes, 2005). However, the SEND Code of Practice (DfE/DoH, 2015) brought the agenda of pupil participation back to the forefront of current UK practice. This is shown in recent publications discussing the ways in which Educational Psychologists (EPs) listen to children (Begon, 2017) and the value of using psychological frameworks to reflect on pupil participation within EP practice (Mark Fox, 2016; Hawkins & Soni, 2018; Vingerhoets & Wagner, 2016). Research in this area is therefore both relevant and timely to the profession of educational psychology as well as to teachers and other practitioners looking to understand how pupil participation might be implemented in practice.

2.1.4 Participation as a construct

'Participation' as a term is poorly operationalised and often used interchangeably in the literature with other related terms such as 'consultation', 'involvement', 'voice' and 'engagement'. Imms et al. (2016) conducted a systematic review of definitions for participation used in the literature and identified 38 measures of participation across the 25 studies included in the review, with the majority not providing operational definitions. Moreover, 11 of the studies used 'engagement' and 'participation' interchangeably. Although the reviewers conducted searches in a range of databases in the fields of education, psychology and medicine, the authors specifically focussed on intervention research with quantitative data, which therefore provides few insights into how participation is used and understood within qualitative research, and by design excluded studies which did not measure the outcome of an intervention. Within clinical research, articles often use a broad definition of participation from the World Health Organisation: 'involvement in a life situation' (Adair et al., 2015; Willis et al., 2017; World Health Organization, 2007 p. 16). Conversely, education research appears to use definitions related to a school context, and the research question(s) studied. Mager and Nowak (2012), for example, defined participation as 'student involvement in collective-decision-making processes at the school or class level' (p. 40), therefore using 'participation' as a synonym for 'decision-making'. Together these studies highlight that 'participation' may be defined differently in different fields of research and according to the purposes of the research questions examined.

2.1.5 Research on pupil participation

Research on the participation of pupils with SEND in decision-making either focuses on pupils with disabilities, encompassing a wide range of needs (Cavet & Sloper, 2004; Franklin & Sloper, 2006, 2009), or pupils in specific groups, such as those with social, emotional, and mental health needs (Kennedy, 2015). Pupils on the autism spectrum also warrant particular attention as they may be especially vulnerable to exclusion from

decision-making. Researchers highlight that autistic pupils are less likely to participate in decision-making than pupils with other additional needs (Griffin et al., 2014; Shogren & Plotner, 2012; Wei et al., 2016). Whilst this finding relates specifically to attending and actively participating in transition planning, the findings suggest that vigilance is required to ensure that autistic pupils are also not excluded from other types of decisions.

The research on the participation of autistic pupils in decision-making appears to be largely dominated by large-scale survey data and/or focus solely on formal processes such as transition planning or annual reviews (Bell et al., 2017; Franklin & Sloper, 2006, 2009; Griffin et al., 2014; Hatfield et al., 2017; Horton, 2015; Shogren & Plotner, 2012; Wei et al., 2016). These studies provide helpful insights into the numbers and characteristics of autistic pupils who participate in these processes and the factors enabling or inhibiting their participation. However, as the studies focus on formal decision-making, there is limited understanding of whether and 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. Moreover, due to the lack of qualitative research, there is little detailed, contextualised knowledge of the contexts of their participation, or the perspectives of those who participate, representing an important gap in the research. There is, however, related qualitative literature on interventions to aid making choices in the classroom, in the context of qualitative case studies of autistic pupils (Barry & Burlew, 2004; Mechling et al., 2016; Newman et al., 2002; Peterson et al., 2001). Nonetheless, much of this research appears to be underpinned by values different from the current study—a desire to reduce challenging behaviour rather than a desire to enable autistic pupils to participate in decision-making, so that they are rightly included within the matters that affect their education. This means that the outcomes of these studies often relate to measurements of disruptive behaviour or skill development rather than participation outcomes.

Research by Franklin and Sloper (2006, 2009) also influenced the focus of the current study. Although their research related to pupils with disabilities in general, and not specifically autism, the areas of future work identified by authors directly informed one of the study's research questions. The authors examined the participation of disabled pupils in reviews of plans to monitor their care and other decision-making processes within 71 social services departments in the UK, primarily through survey data. At the end of the

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study, Franklin and Sloper (2009) identified some helpful trends but called for 'a closer examination of informal approaches to participation, which may be more appropriate for some disabled children' and 'research on what might be changing for disabled children as a result of participation activity'(p.13). This raised questions into how the views of autistic pupils are used to inform decision-making in schools.

The current study therefore addresses three gaps in the literature. Firstly, a wider range of decision-making processes are examined, including informal day-to-day decisions in school. Secondly, the outcome of participation for pupils is explored by examining how their views inform decisions about their school experiences. Thirdly, a case study approach provides the qualitative level of detail that is missing from the current literature.

2.1.6 A case study

Case study methodology is not a new approach to examining school practice; it has been used by researchers extensively to examine pupil participation and related concepts such as inclusion and citizenship education (Black-Hawkins & Florian, 2012; Wilson, 2009). However, it has not been specifically applied to the participation of autistic pupils in decision-making at school. One of the benefits of using case study methodology is that it is well suited to the aim of providing an in-depth analysis of pupil participation in one school context. As stated by Thomas (2016), case studies are not used for the purposes of generalisation but for providing rich, detailed knowledge of one phenomenon in a real world context. An important part of this approach is polyhedronation—the use of multiple methods of data collection, from multiple perspectives, to examine in depth the complexity of the case to be studied (Thomas, 2016). In doing so, case studies provide readers with multi-layered context-dependent knowledge, from which they can gain analytical insights (Flyvbjerg, 2006). Arguably this type of knowledge is beneficial to education practitioners who work in messy, complex school environments where generalised rules from positivist research may be difficult to apply in context (Kasari & Smith, 2013).

2.1.7 Research aims and questions

Using the case study design categorisations described in Thomas (2016), the research aims of the current study were both exploratory and instrumental:

- (i) Exploratory: to provide a detailed, exploratory analysis of practices that enable autistic pupils to participate in decisions about their education;
- (ii) Instrumental: to generate new knowledge about pupil participation that will lead to greater awareness amongst education practitioners, changes to school practice and improved outcomes for autistic pupils.

The research questions therefore reflect these aims:

- (1) What school practices enable autistic pupils to participate in decision-making about their school experiences?
- (2) How are the views of autistic pupils used to inform decisions about their school experiences?
- (3) When do autistic pupils feel their voices have been heard?

These questions were based on gaps in the literature as well as a desire to value the perspectives of autistic pupils so that their views directly contribute to practice in this area.

2.2 Methods

2.2.1 Epistemology and design

The research was based on a critical realist epistemology, which states that 'reality' is socially constructed but can also be known (Ritchie & Lewis, 2014). Unlike positivism, this means that comments from participants in an interview or observation are still seen as providing valuable insights into the reality they experience, despite comments themselves being subject to interpretation (Easton, 2010). A critical realist position also influenced the choice of research methods, for example triangulating data to illuminate the phenomenon studied. This is an approach which would not be adopted in a constructionist paradigm, where the focus is on the role of discourse in shaping meaning (Easton, 2010). Arguments put forward in the discussion of findings therefore reflect the

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most likely realities that exist within the school, justified through the analysis of a range of data, from multiple perspectives.

A qualitative case study design was selected for the research. The 'case' is at the level of the school as an organisation and not at the level of the autistic pupils who took part in the study. This means that the pupils are compared and analysed in relation to the wider case of the school. Following the guidance in Thomas (2016) the parameters of the case study are described in Appendix E.

2.2.2 Analytical frame

According to Thomas (2016), every case study should have an analytical frame within which to interpret the data. In the current study, participation is understood within the Framework for Participation which is designed to be used by practitioners and researchers to reflect on the school practices that facilitate participation in school life (Black-Hawkins, 2010, 2014; Florian et al., 2016). The sections of the framework relate to four aspects of participation: *access, collaboration, achievement and diversity*. This is also captured by the definition of participation used by the authors:

Participation in education involves going beyond access. It implies learning alongside others and collaborating with them in shared lessons. It involves active engagement with what is learnt and taught, and having a say in how education is experienced. But participation also involves being recognised for oneself and being accepted for oneself. I participate with you, when you recognise me as a person like yourself, and accept me for who I am.

(Booth, 2002, p. 2, cited in Black-Hawkins, 2010)

As the framework was developed iteratively through case study research in schools and is underpinned by principles which fit with the purpose of the research, it was deemed the most appropriate tool with which to frame the current case study. Other frameworks used in Educational Psychology such as Hart's (1992) ladder of participation were less appropriate as they were not developed with the researcher in mind and therefore lacked the level of detail provided by the Framework for Participation, which also describes procedures for data collection and analysis as well as more detailed aspects of

participation in practice. The four sections of the Framework are described in detail in Florian et al. (2016 p. 61-69).

2.2.3 The case school

The case school provides specialist provision for pupils with a range of needs including social, emotional and mental health (SEMH) difficulties and learning difficulties. It is located in the south of England across three school sites and has approximately fifty pupils on roll. The school caters for children of both primary and secondary school age, whose needs have not been met in a mainstream setting or pupil referral unit. Fifty percent of the school population have diagnoses of autism, making the school an appropriate setting for the current study. Class sizes are small, with approximately 2 to 5 pupils per class depending on the curriculum subject and group dynamics. There is a high staff to pupil ratio in every class. Staff have different roles in the school such as senior leadership, pastoral support, subject teachers, tutors and occupational therapy assistants. The role of tutors is similar to a teaching assistant in mainstream schools, where they support specific groups of children in different lessons throughout the school day.

The school is part of a local initiative to improve provision for autistic pupils through research and the sharing of good practice. The school joined this initiative because they have a large proportion of autistic pupils, many with additional needs including SEMH difficulties that were not met in mainstream education settings. It was therefore viewed as a school population suitable for the purposes of the research since autistic pupils and pupils with SEMH are particularly vulnerable to marginalisation from decision-making processes (Brewster & Coleyshaw, 2011; Kennedy, 2015). However, the author acknowledges that locating the study in a specialist education setting means that the population may not be representative of autistic pupils in other education settings.

2.2.4 Sample of participants

Four autistic pupils formed the focal point of data collection at the school; Table 4 shows their demographic information. All pupils had a diagnosis of autism or Asperger's syndrome, given by the Child and Adolescent Mental Health Service before the

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introduction of the DSM-5 in 2013 and could all communicate using speech. The pupils were all White British and/or European with multiple additional needs, including attention deficit hyperactivity disorder (ADHD), attachment difficulties, Tourette's syndrome, anxiety and one or more were looked after by the local authority. The pupils were all working towards completing their General Certificates of Secondary Education (GCSEs), one pupil at foundation level.

Table 4
Pupil demographics

| | Gender | Age | Joined | EHCP | Diagnosis |
|-------|--------|-----|--------|------|-----------|
| Noah | M | 14 | 2014 | Yes | Asperger |
| Jack | M | 13 | 2015 | Yes | Asperger |
| John | M | 11 | 2015 | Yes | Autism |
| David | M | 15 | 2015 | Yes | Autism |

In total, 18 participants from the school took part in the study: 4 autistic pupils, 2 carers and 11 staff members. The aim was to create four participant triads: pupil, carer and staff perspectives for each pupil. Data from a range of adults around a pupil can help enrich their unique perspectives, through a comparison of views on the same issue (McLaughlin & Rafferty, 2014). The carers of each pupil were invited to take part; however, only the carers of 2 pupils consented to participate. Alternative options for data collection were offered to carers such as telephone interviews or home visits, but the carers declined to participate due to work commitments. Members of staff who knew the pupils well and worked with them in different capacities were also recruited; this resulted in 3-4 staff perspectives per pupil. In some instances, the same member of staff provided data on 2 or 3 pupils. Table 5 shows an overview of participant numbers, the roles of the staff who took part and the type of data collected.

2.2.5 Recruitment and procedure

The researcher identified the case school through academic staff at the University of Southampton. This enabled the identification of a school with a pupil population that would meet the aims of the research. At the point of recruiting the school, the Head Teacher was contacted and all procedures regarding consent, data collection and

debriefing were explained. This provided an early opportunity to discuss logistics and any queries about the project, after which point written consent was given for the school to take part, using the forms in Appendix O and P.

Table 5

Summary of data collected from participants

| Pupil | Photos | Observations | Interviews | |
|-------|--|--------------------------------|------------|--|
| | | | Carer | Staff |
| Noah | One to one room, Juniors' room, Maths room, Meeting room, Senior management office, Music room, Pokemon, Friend, Tutor | Science, Maths, Outdoor Ed. | Yes | Pastoral support, one to one/PSHE, SENCo |
| Jack | Asst Head, Asst Head's office, Tutor, Office, Meeting room (site 1), Meeting room (site 2), HT | English, Enrichment, Food Tech | No | Asst Head, art teacher, SENCo |
| John | Toys, Food made, Food tech teacher, IT teacher, Asst Head, Pupil with stick, Art teacher | PSHE, Maths, Food Tech, DT | No | Pastoral support, OT assistant, key stage 2 teacher, tutor |
| David | SENCo, Spanish teacher, Tutor, HT, One to one, Outdoor area, Art teacher, Food tech teacher, IT teacher, Asst Head, Spanish room | Maths, Music, Spanish | Yes | Spanish teacher, pastoral support, tutor |

Autistic pupils at the school were recruited through the senior leadership team via opportunity sampling, where participants are selected based on convenience. This was necessary due to the small size of the school and the variability of pupil timetables. With pupils receiving a range of one-to-one provision throughout the week, it was important that pupils were available on the days on which the researcher collected data. All carers and pupils were initially approached to take part by the Head Teacher or Deputy Heads of the school. This gave them an opportunity to ask any questions about the project with a familiar adult before considering participation. Once carers and pupils showed interest in the study, the staff sent carers an information sheet outlining all procedures with consent forms, shown in Appendix Q and R. Following written consent from carers, the researcher

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then approached pupils to talk about the purpose of the research with assent forms and a child-friendly summary of the stages of the project, shown in Appendix S, Appendix T Appendix U. School staff were recruited through multiple methods including snowball sampling, where a staff member or pupil put the researcher in contact with another potential participant. In other instances, the researcher approached staff members who would aid understanding of a lesson observation or a pupil's participation in a specific process, for example, their role in the student council.

2.2.6 Data collection

All data were collected at the school site between September 2017 and January 2018. Three sources of data were used to achieve polyhedrenation within the case study: field notes from lesson observations and informal discussions with staff; photographs taken by the pupils of chosen locations, people or objects within the school; and verbal data from semi-structured interviews with participants. See Table 5 for an overview of the number and type of observations and photos taken during the project. Pseudonyms are used throughout this document and features in photographs which might identify the school or participants were removed to maintain the confidentiality of participants or other members of the school.

Observations. Pupils were observed in three different lessons spanning different dates and times to capture a range of experiences. The observer-as-participant approach was chosen, where the researcher made notes during the observations whilst interacting with pupils and staff at various points (Marinsson, 1998). During the observation, the researcher made notes about the context such as the number of pupils and staff, lesson topic, atmosphere and room layout following guidance in Robson and McCartan (2016). Attention was then paid to any examples of decision-making in the classroom, as defined by the researcher, noting down the words used by pupils and staff as much as possible. A printed copy of the Framework for Participation was also taken to observations to guide the identification of important elements. At the end of the week, field notes were typed on the computer for later data analysis. An excerpt of an observation is shown in Figure 2.

All pupils were observed in at least two lessons before carrying out the pupil activity. The purpose of this was to increase familiarity between the pupil and the

researcher prior to conducting photo-elicitation. Choice of observations were influenced by participants. During the initial meeting with pupils, the researcher asked them to select one lesson in which they wanted to be observed. This was often their favourite subject, providing a topic the researcher could engage them in to build rapport. Subsequent observations were then based on a range of factors: lessons available to see on the day of data collection, pupil preferences and staff recommendations.

Food Tech, lessons 1 and 2

Three pupils in the classroom and two adults. The regular food tech teacher wasn't there. Began with tutor time – options for pupils to share concerns at the start of the lesson.

The teacher then gave feedback on the test they did in a previous lesson. Teacher said to Jack 'Jack you got 8/9 on the test. She (the teacher) was really impressed with the level of detail in your book and the language you are using – if you carry on like this, you'll be working at Year 11 standard. The only question you got wrong was the one on crossbuns'

Teacher then said:

'Right I've got a question for you...'

T: These sheets, do you think that they help?

Other pupil: yes because they help you remember things

T: Right I've got an idea... would you like a key word book to help you with your GCSE? It will have a list of words from the lesson that we've used and you can google search the definitions and write them in

Jack: are you asking us if we want extra homework?

T: no I'm asking you if you want a key word book to help you achieve a higher level in your GCSE?

Noah: yeah why not

T: Great I'll set them up today so you can use them for next week

Figure 2. Excerpt of field notes from an observation

Photo-elicitation. Each pupil took photographs of things in the school which represented them feeling listened to; some examples were given to pupils as a guide, such as a room, person or school subject. The activity took place in three stages: a meeting with the pupils to plan which photographs they wished to take in the school, a lesson in which to take the photographs, and an audio-recorded discussion of their photographs where they explained their choices. Having three stages was important for ensuring that pupils had ample opportunity to think about the photographs that were significant to them. An overview of this process is given in Appendix N. At the stage of gaining assent to take part in the study and at the start of the pupil activity, a child-friendly summary of the

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activity was given to the pupil (shown in Appendix T). One pupil required the presence of a staff member throughout each stage due to outbursts of anger that could be difficult to manage. Visual methods were chosen for a number of reasons including a desire to move towards participatory methods of data collection where data is generated by participants rather than researchers and studies suggesting that visuals can be helpful for reducing inhibition and evoking more detailed responses than traditional interview methods (Fayette & Bond, 2017; Hill, 2014; Prosser & Loxley, 2008). Asking pupils to generate photographs for the purposes of research is a method that has already been used with the autistic population, for example, to understand their lived experiences of school and college (Sheperd, 2015; Hill, 2014; Beresford 2004). Several benefits to using this approach were noted in the research. Discussing photographs rather than asking pupils direct questions helped to minimise face-to-face interactions which could be a source of social anxiety for autistic pupils. Moreover, the photographs were taken and edited by the pupils themselves which meant that they were familiar with the materials to be discussed ahead of meeting the researcher and had concrete reference points when answering questions. The latter is important given research suggesting that autistic pupils find it difficult to answer abstract questions and therefore may not feel comfortable with traditional interview methods (Beresford 2004).

Semi-structured interviews. Interviews with staff and carers took place in a location in the school that was familiar to participants. The researcher explained the purpose of the study at the start of the interview and reminded them of their right to withdraw at any time. Each interview lasted approximately 20 – 30 minutes. A guide for the conversation was created with the flexibility to discuss in more detail any areas of interest, as shown in Appendices L and M. Interviews were audio-recorded and any reflections on the interview were written as a memo to aid data collection or analysis. At times, the interviews were interrupted due to assistance needed in other areas of the school; in these cases, the recording was paused and continued on their return. Appendix H shows an extract of a transcript with staff 3.

2.2.7 Ethics

This research received approval from the University of Southampton School of Psychology Ethics Committee and Research Governance in June 2017 (ref: 26537). All

carers gave their written consent for pupils to participate in the study; pupils gave their assent. Staff and carers who took part, gave their written consent to be interviewed and have these audio-recorded. Written consent was also given by staff to have their photographs taken during the project, using the forms in Appendix X and Y. It was stressed in all consent and assent forms that anonymity would be maintained with pseudonyms used in any written materials for the project, which was reiterated verbally. At the start of both the interview and pupil discussion of photographs, participants were reminded that the recording would be stored securely on a password-protected USB stick. At the end of the interview, participants were given a debrief sheet with details of how their data would be used and who they could contact for more information about the project, shown in Appendices Z, AA and BB.

Given the use of a case study design, the researcher was acutely aware that collecting data for lengthy periods in one school could have various effects on participants. Asking staff to organise appropriate times and locations for interviews, for example, places additional pressure on resources, and therefore a flexible approach to data collection was taken. This involved moving between different school sites when needed, adjusting times of interviews on the day and completing written work when there were gaps in the schedule. As data collection for each pupil occurred over several sessions in school, it was also important that details around consent, anonymity and withdrawal were reiterated at various points in the project, such as after the first lesson observation and the start of the pupil activity. Upon finishing data collection for a participant, the researcher explained to pupils and staff that they would see the researcher around the school speaking with other participants, and at the end of the project would receive feedback on the findings. Explaining what would happen next was viewed as particularly important for pupils who may have become attached to the researcher given the amount of time spent in school; this was an ethical issue identified in other projects conducted by Educational Psychologists in schools (Fox & Randell, 2002).

2.2.8 Data analysis

Interview transcripts, field notes and photographs were analysed deductively using Framework Analysis, which is a method of systematically analysing qualitative data using a set of a priori codes, derived from theoretical concepts in the literature, research

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questions and/or topics in the data set (Ritchie & Lewis, 2014; Ritchie & Spencer, 1994).

One of the benefits of Framework Analysis is that it provides a helpful structure for classifying large amounts of data and enabling comparisons of frequency and patterns of themes across a data set (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The stages of Framework Analysis in Ritchie and Lewis (2014) and Gale et al., (2013) influenced the researcher's approach to analysis but were adapted for the purposes of the current study. In order to allow for inductive codes in the data, the researcher created 'other' categories for data that did not fit within the deductive codes. A combination of inductive and deductive coding is often considered helpful for ensuring a balance between staying close to the subjective experiences of participants and identifying themes important to the research question (Fereday & Muir-Cochrane, 2006). The process of analysis taken by the researcher is outlined below and in Figure 3.

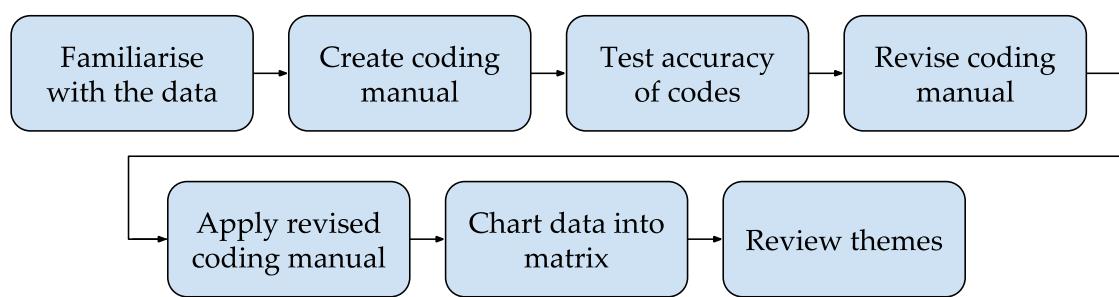


Figure 3. Stages of analysis undertaken by the researcher.

2.2.8.1 Stage 1: Familiarise with the data

Audio recordings were transcribed verbatim by the researcher to stay close to the data. Pupil, staff and carer transcripts related to each pupil were then re-read alongside the field notes and photographs, to facilitate the identification of connections between

Noah is very passionate about moving to the new school site full-time because he will be able to do the course he likes. Instead, Jack prefers the main school site because he gets to see other member of the school more regularly. This made me think of Principle 2 of the Framework for Participation, which states that some practices (in this case moving sites) can promote participation for some, whilst reinforcing barriers to participation for others.

Figure 4. A memo including reflections on two participant interview transcripts

different sources of data. Initial ideas about the data were recorded on memos to provide an audit trail and support analysis at later stages (see example in Figure 4).

2.2.8.2 Stage 2: Create coding manual

At this stage, operational terms were created for each section of the Framework for Participation (Black-Hawkins, 2016) as shown in Appendix F. Some terms were not adequately defined by the authors of the Framework, so were formulated based on examples of evidence they provide for each section of the Framework and data discussed in their case study research in schools (p. 183–188, Florian et.al 2016). Each of the four sections of the Framework: *access*, *collaboration*, *achievement* and *diversity* then formed four over-arching deductive codes, each of which including several sub-codes based on the questions in the Framework; Table 6 shows an example of codes for the theme of *access*. The second and third research questions (Q2. How are the views of autistic pupils used to inform decisions about their school experiences? Q3. When do autistic pupils feel heard?) were also used to create additional codes within the manual. ‘Other’ categories were included to allow for any data that could not be categorised using the manual.

Table 6

Deductive codes for the theme ‘Access’ used in the coding manual

| Abbreviated codes | Description |
|-------------------|--|
| ACC WHO | Who has access |
| ACC WHO DA | Who is denied access |
| ACC WHO D | Who decides |
| ACC WHO P | Who participates in decisions about access |
| ACC WHO EP | Who is excluded from participating in decisions about access |
| ACC WHO DP | Who decides who participates in decisions about access |
| ACC WHO O | Who other |
| ACC WHAT PRO | What practices promote access |
| ACC WHAT PRO D | What practices promote decision-making in relation to access |
| ACC WHAT BAR | What practices are barriers to access |
| ACC WHAT BAR D | What practices are barriers to decision-making about access |
| ACC WHAT O | What other |
| ACC WHY | Why are some pupils afforded greater access |
| ACC WHY DA | Why are some pupils denied access |
| ACC WHY PROM | Why is a practice promoted |
| ACC WHY BAR | Why do the barriers take place |
| ACC WHY O | Why other |

| | |
|--------------|---|
| ACC HOW C | Pupil views about access lead to some change for pupil, staff, practice |
| ACC HOW N | Pupil views about access sought but no change |
| ACC HOW O | How other |
| ACC WHEN PER | Location where pupils feel listened to |
| ACC WHEN PLA | Person with whom pupil feels listened to |
| ACC WHEN O | When other |

2.2.8.3 Stage 3: Test the accuracy of codes

The purpose of this stage was to test how accurately the codes categorised the data. Data for one triad of participants (a pupil, their carer and three associated teachers) were printed and coded by hand using the coding manual. A triad of data rather than a single transcript were used to ensure the researcher captured themes relevant to pupil, carer and staff perspectives. Segments of meaning were coded, ranging from a single line to a paragraph of text. Operational definitions in Appendix F and examples of evidence given from the authors of the Framework for Participation (Florian et al., 2016 p. 183–189) guided the identification of data that could be categorised in each section of the manual. The abbreviated codes were noted in the margins of the transcripts with comments on important themes and possible revisions to the manual.

2.2.8.4 Stage 4: Revise the coding manual

The manual was revised in order to reflect the content of data used in Stage 3. Guidance suggests that a manual is complete when all data relevant to the research question can be coded (Brooks, McCluskey, Turley, & King, 2015). New codes were created to accommodate important patterns in the data whilst some existing codes were collapsed. One of the biggest areas of revision related to where autistic pupils felt their voices were heard. As this was a research question rather than a discrete element of the Framework for Participation (Florian et al. 2016), the categories initially assigned described the types of photographs taken, for example ‘place’ or ‘person’ rather than the nuanced views presented by pupils, which then informed a list of inductive sub-codes shown in Appendix I.

2.2.8.5 **Stage 5: Apply revised coding manual**

After the revisions were made, the new version of the manual was applied to the entire data set using NVivo 11, a computer program that assists with managing large volumes of data (QSR International Pty Ltd, 2018). The annotation feature in NVivo was used to document reasons for placing sections of the data in particular categories to aid later stages of data analysis; see Appendix J for examples showing how this feature was used in NVivo.

2.2.8.6 **Stage 6: Chart data into a matrix**

After applying the coding manual to all of the data, a matrix was created in a spreadsheet, with a list of the participants and themes; data from every transcript, field note and photograph was then summarised for each theme. The purpose of this stage is to represent the core ideas of participants using their own words as much as possible, with references to illustrative examples of data. This is argued to be helpful for reducing the data in a way that facilitates identifying patterns; for example, empty cells in the matrix could reveal themes that are not dominant for particular participants (Gale et al., 2013).

2.2.8.7 **Stage 7: Review themes**

The researcher reviewed each theme in the matrix, aiming to make connections within and across participants and sources of data. Any interesting findings were noted; for example, themes that were dominant for particular pupils and deviant cases, themes most related to decision-making and those that were surprising, in terms of how they answered the research questions or contradicted the researcher's expectations. The researcher decided on themes to report in the findings, based on data that most related to decision-making and the research questions. For example, the theme of *COLLABORATION: Members of staff learning with others beyond the school* provided insights into the practices that promoted or inhibited collaboration between parents and staff but did not relate to decision-making with autistic pupils and therefore was not reported.

2.2.9 Reflexivity

To ensure that readers can independently interpret findings, it is important that researchers make clear their own backgrounds, principles and interests, which impact on their interpretation of data (Ritchie & Lewis, 2014; Thomas, 2016; Tong et al., 2007). In so doing, the researcher follows the recommendations of Thomas (2016) who argued that the position of the researcher needs to be stated using the first person, thereby reflecting the active role of the researcher in analysing the data.

I am a female student on the doctoral programme in Educational Psychology. At the time of data collection, I visited the case school two days per week whilst on placement in a different local authority for the remaining three days. Working in Educational Psychology, my views of pupil behaviour are highly influenced by frameworks that I use in my practice and have studied during my academic career. Positive psychology, for example, often directs my attention to looking for the situations in which an individual flourishes. This could therefore have impacted the extent to which I was sufficiently critical of practices that were ineffective during observations and data analysis. The Framework for Participation (Florian et al., 2016) was helpful for reminding me to search for barriers and deviant cases. My experience of working in schools may also have led me to dwell on particular aspects of the data over others; for example, highlighting data that provided insights into issues that I have seen schools grapple with in relation to supporting autistic pupils or evidence for practices which schools may be reluctant to implement. My agenda in carrying out this project is to provide information useful to schools and EPs in the local authority in which I work.

2.3 Results

There were thirteen themes in the data, each representing one sub-section from the Framework for Participation (Florian et al., 2016). The thirteen themes are listed in Appendix K. 'Joining the school and the classroom' was the only sub-section from the Framework that was not a theme in the data. This was unsurprising given that the current study did not focus on the procedures for admission into the school; all other themes related to practices that were either observed in school or discussed in interviews. There were some tensions regarding whether to report themes in relation to the Framework or a

specific decision-making process. Some examples of decision-making related to more than one theme from the Framework and therefore reporting examples would avoid repetition in the report. Moreover, some themes—whilst related to a section in the Framework—did not help to answer a research question, such as the theme of *collaboration: members of staff learning together* and therefore would not be relevant to the report. Focusing on specific examples could, however, devalue the broader social context in which decision-making takes place such as the role of relationships and school culture. Given that the Framework for Participation was used to deductively analyse the data as described in the methods section, reporting the findings in relation to the same Framework would help to create a coherent picture of how the data was interpreted. It was therefore decided to report themes in relation to the Framework.

Here the researcher focuses on three over-arching themes in the analysis: *ACCESS: staying in the school and the classroom, access to the curriculum; ACHIEVEMENT: focusing on what learners can do, rather than what they cannot; and DIVERSITY: the recognition and acceptance of pupils by staff*. These themes are highlighted for discussion as they were most related to pupil participation in decision-making and were dominant themes across different forms of data and multiple participant perspectives. Observations, interviews and photographs are referenced to illustrate themes. The number of quotes used within this section per participant is documented in Table 7 to provide information regarding the range of perspectives that were captured as well as how, and whose, voices are represented herein.

Table 7

Representation of direct quotes used in the report of the findings

| Participant | Number of quotes |
|-------------|------------------|
| Noah | 5 |
| Jack | 3 |
| John | 2 |
| David | 4 |
| Carer 1 | 1 |
| Carer 2 | 0 |
| Staff 1 | 4 |
| Staff 2 | 2 |

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| | |
|----------|---|
| Staff 3 | 4 |
| Staff 4 | 3 |
| Staff 5 | 3 |
| Staff 6 | 2 |
| Staff 7 | 2 |
| Staff 8 | 4 |
| Staff 9 | 3 |
| Staff 10 | 3 |

2.3.1 ACCESS: staying in the school and the classroom

Taking breaks during the lesson was viewed as a strategy that helped pupils to stay in the classroom. All pupils particularly valued the timeout system, where they could choose to leave the classroom for a break. Each pupil made use of this system in different ways; Noah often used the one-to-one room, David an outdoor area of the school, John the garden, and Jack the office of a Deputy Headteacher. The importance of timeouts was exemplified by photographs of each of these locations, which represented places around the school where pupils felt listened to (see Figure 5).

All of the pupils placed their photographs of timeout areas in 'the most listened to pile' during the pupil activity, suggesting a broad interpretation of 'listen' that went beyond the exchange of verbal information. Rather, it could be that pupils felt listened to when they had an outlet for managing their feelings or specific difficulties in the lesson; three of the pupils described a positive change in emotional state after taking a timeout from the lesson:

I relieve my stress in the form of rage. It don't really change me, just helps me calm down (John)

That's where I go for a timeout...it's nice out there... it just sorts out my mind a little bit so I can go back to the lesson with a better frame of mind (David)

It helps anyone who is having an issue so like if you're not in right frame of mind you can go in there, you can chill, you can throw stuff at stuff...and you can de-stress and I feel like that's important for all students to have (Noah)



Noah – one-to-one room



Jack – Deputy Headteacher office



John – garden (subject removed)



David – outdoor area

Figure 5. Photographs pupils took of places where they felt listened to; for each pupil one photograph was a location in the school where they take 'timeouts'. Subject was removed in the photograph taken by John to protect anonymity.

One pupil alluded to the idea that school culture made it easy for pupils to use timeouts when they needed to during lessons. Noah said:

Sometimes if I'm just like ahh I'm having a bad day, I'm just not gonna bother with this... I'm gonna go and chill and you can totally do that... everyone needs it, everyone likes it, everyone uses it

The use of "You can totally do that" in Noah's quote, suggests that staff members were accepting of pupils taking breaks in lessons. This was supported by the staff interviews, which described the benefits of the timeout system and how it was used:

They can utilise a timeout system where they get like ten minutes to walk around the grounds of the school, kind of clear their minds (Staff 10)

Before he would have a huge meltdown... huge, whereas now he can say actually I'm having time out... can I have timeout now and he'll take himself out and he'll come back in (Staff 6)

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For one pupil, the challenge with the timeout system was accessing the resources he liked to use if they were located at a different school site; when John was asked what he did to calm down on other sites, he said "I don't really know. I don't really know what I would do". John's comments suggest that moving across sites could be a barrier to some pupils accessing specific resources or rooms they prefer using during timeouts from lessons.

The observations of pupils in lessons suggested that breaks were also taken organically, rather than only through a timeout system where pupils physically left the classroom.

Observation 1

During the PowerPoint presentation, John started to spin his chair after completing three slides. Teacher said: "let's do one more slide and then we can have a spinning war" John said: "No let's have one now" and started spinning. Teacher responded by spinning his chair. He spun for one minute and then went back to work. (Lesson period 4)

Observation 2

Teacher: anything else you can think of that is a protein?

Noah: I can't think, I'm asleep

Teacher: well why don't I start the lesson for the other two and then when they've started I'll come back to you?

Noah: that would be great thank you (Lesson period 1)

In both observations 1 and 2, pupils stated their views with: "I can't think, I'm asleep" and John spinning his chair initially, later saying "no let's have one now". Staff responded to these initiatives by offering a compromise that acknowledged the needs of pupils. Due to events on the day, I could not gauge the motivations of teachers in these observations, however, comments from other staff suggested that flexibility was needed to allow pupils "to do what they need to do" in order to engage in the lesson.

Staff 5: how can I... yell at a student for wandering around a room when he's got an ADHD diagnosis? I mean really??!

Researcher: so how would you do it differently then? How would you handle that situation if he suddenly started wandering?

Staff 5: I would... I've got a student who does that now... and It's like, right ok... you know you really do need to be sitting down doing some work, don't you? I'm quite happy for you to walk around... but you do need to get this done by the end of the lesson...

so actually it's allowing them the ability to do what they need to do whilst also reining them in and reminding them that this is a classroom environment

The use of “reminding them that this is a classroom environment” highlights that while breaks were accepted by staff as necessary, it was expected that pupils would still do work in the lesson. A similar approach appeared to be taken by the teacher in Observation 2, who allowed Noah to rest for a period with the reminder that she would come back to him when the other pupils started work.

Staying in the classroom was more of a dominant theme for John than for the other pupils, as John took breaks more frequently in lessons and found some lessons difficult to attend. Staff working with John managed this through “trial and error” (Staff 8), “including him in the choices” (Staff 7), “working around his feelings” (Staff 6) and thinking about the context in which requests were made (Staff 8). To illustrate these concepts in practice, here is an observation of John transitioning from a food technology lesson to a design technology lesson.

Observation 3

After food tech, John ran out of the building. Two staff ran after him and shortly after, another staff member went outside to assist bringing him back in. When John came back inside he went into a cupboard, lay on the bottom shelf and closed the doors. Staff 8 said to me he tries to do this before every DT lesson because he doesn't like DT – I wondered whether climbing into a cupboard was a way for him to feel safe. I also wondered what it is about DT that he doesn't like. A teacher approached the cupboard to try to help Staff 8 – the teacher stood beside the door to the cupboard where John was hiding and asked curiously “Why are you in the cupboard? Why don't you want to go into DT?”. John didn't say anything. The teacher then said “do you remember that boy Tim, he used to go to the cupboard too when he was a bit worried and it calmed him” John didn't say anything. The teacher said to Staff 8 “sorry, I tried” and walked back to the pupil she was supporting. After the teacher left the cupboard, Staff 8 responded by asking John “do you want to play tennis for 5 minutes and then try to do some DT work? We're not going to the lesson today but we still need to do the work?” He got up and went outside to the tennis court.

John's 'views' about his DT lesson were all expressed non-verbally here by running outside and later hiding in the cupboard. In this case, offering a break in the form of playing tennis and then a compromise was an effective strategy for bringing John out of the cupboard. His tutor felt that this would help John to re-engage with the lesson:

If we can sort of like take him away from and try and do a bit of an activity and then if I act like I'm not even bothered about the lesson then he sorts of takes his mind off it and we do 5,

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10 minutes of play and then even if he doesn't want to do it in the class we can try it in a different environment...that normally helps him engage as well (Staff 8)

The use of “acting like I’m not even bothered” alluded to a sense that she helped John to feel calmer about going into lessons by reducing pressure. Staff also argued that sometimes compromising physical presence in the classroom in favour of doing work, was necessary to meet the needs of pupils. Another staff member who often worked with John on a one-to-one basis said: “we don’t... it’s not regimented... you know they don’t come in and they’re feeling really distraught we don’t say right that it’s, go into class go do your work... it’s... we work around the children and their feelings” (Staff 6). However, when staff responded to pupil views, they also considered the context in which requests for timeouts were made; “if it’s a lesson he can normally stay in you’re like let’s just try this... give it a minute or two and then if he really can’t engage he’ll ask for a timeout you go” (Staff 8).

“Compromise” was mentioned by all staff in relation to creating an environment that would invite pupils to stay in lessons and/or do the work, particularly in cases where pupil choices were unrealistic. In the extract below, the compromise was around John’s ideas for how to improve his lesson the next day. John’s teacher felt that giving him the opportunity to discuss changes to the lesson would improve his behaviour:

Staff 7: I would also include him in the choices so today John you’ve had a pretty shocking day so tomorrow how can we improve it? What do you think I can do to make your day better tomorrow? And I would say things like that

Researcher: do you feel he responded well to that and could offer some suggestions to you for things to do?

Staff 7: yeah they wouldn’t always be reasonable or rational to which I’d go actually that’s not gonna work but let’s say what if I did this, this and this, that’s a bit of a compromise... you’re getting a bit of time to do this and I’m getting... you’re doing the work that I want you to do and we’re like thumbs up and he’s like yeah why not. He’d agree to that and that would... I would find that would always work. It’s that compromise... that working together.

Many of the staff also talked about the importance of tapping into pupil interests. Staff referred to similar concepts to describe this such as finding “keys” (Staff 4) “hooks” (Staff 1) or “roots” (Staff 9) into what helps engage individual pupils. One teacher argued

that by finding these “keys” you encourage pupils to be invested in the school, which then reduces disruptive behaviour:

even the incident that we've got downstairs at the moment... if that child invests a little bit more, then they're less likely to disrupt because it matters to them you know so it's finding the... within each individual student you've got to find different keys into what they want to invest in there's an interest and... I think it's really important then cause... if they start to invest... whether it's Charlotte with her singing or whether it's Jack with the computers then they're more likely to invest in other things as well (Staff 4)

The pastoral support teacher gave an example where understanding pupils’ “hooks” could also help staff to encourage pupils to make choices in difficult situations, in this case encouraging Noah to return to a lesson:

Ten minutes ago Noah was up on the climbing wall, just sat there pretending to meditate... and the great thing I've got on him is... all the badges he's got cause he's very very proud of his badges, his achievements and his school council... well what's going on, just meditating... no you don't, you don't meditate on top of a wall it's quite simple you meditate downstairs so you're just doing it for a response, the response is if you continue to do this... do you think the students are going to want you to be in the student council? ... you're setting an example... and all of a sudden you see... you saw it in his face, he was like... yeah, yeah ok... (Staff 1)

2.3.2 ACCESS: access to the curriculum

This theme relates to practices that focus on timetabling and extra-curricular activities. Three of the pupils were affected by changes to their timetable or tutor group. Staff members arranged the timetables, though they were also subject to change dependent upon on the needs of pupils, and in some cases, pupil request. Participants suggested that changes to the timetable were often made when group dynamics were challenging:

He [Noah] still has problems and he clashes with people in his class but the type of school that it is... where they are able to... almost able to do... bespoke timetables they can move people around in the class and um so he does settle eventually with his peers (Carer 1)

Well I know that with him [David] being unhappy in the last tutor group he was in he obviously spoke to SLT [senior leadership team] and obviously they made the change for him to come to this tutor group cause obviously it was making him unhappy (Staff 10)

Their comments suggest that staff approached decisions about the timetable with flexibility and consideration of the views of pupils. However, one staff member noted that

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they also valued discussing different strategies with pupil to manage in class before deciding whether to make changes:

Staff 1: he [Noah] wants answers there and then... what are you gonna do about it... what about my class group

Researcher: how do you manage that

Staff 1: I think it's a little bit of negotiation with him... 'you need to be trying this Noah'... try and give him another chance to be able to cope with the class

Whilst Noah “wants answers there and then”, other autistic pupils may find it difficult to vocalise their views. The data suggest that staff need to carefully monitor those who might internalise difficulties associated with timetable or group changes:

He then doesn't have a timetable for that day... so he doesn't always know where he is supposed to be and who he is going to be with... and I think David never acts up... never expresses anger or anything but he just caves in... and I think maybe the stress of some of that has affected him... but because he's... generally speaking affected quietly...you know it maybe... maybe we're not hearing his voice as much as we should (Staff 9)

David requested changes to his timetable when he was unhappy (see quote from Staff 10, p. 68), which may be discrepant with this description of him. Alternatively, it may be that there are teachers and contexts where he feels more comfortable to share his views.

In terms of extra-curricular activities, all pupils talked about a club or role in the school which they enjoyed; for John it was the ICT club, for Noah the student council, for Jack the student council and ICT monitor and for David, the language club. The importance of these activities to pupils was demonstrated by the photographs they took, shown in Figure 6.



Jack – student council meeting room (site 2)

Noah – student council meeting room (site 1)



John – ICT club



David – language club

Figure 6. Photographs pupils took in relation to their extra-curricular activities.

Three of the pupils decided that their extra-curricular activity represented a place in the school where they felt *most* listened to; this was linked to interactions with staff and pupils attending the club or activity and the time they spent dedicated to it:

I've got the Spanish room which is where I like... I feel listened to... I spend a lot of time in there so yeah (David)

he's my ICT teacher, I'm going to his club today at ICT club, hopefully today (John)

the meeting room... uh people do tend to listen especially the fellow members of the council because they do... they all have their own opinions and I like to listen to them all and they listen back and it works really well (Noah)

Decisions about which extra-curricular activities pupils attend are 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, whilst for Noah, a Pokemon club was created on his request.

This um intense interest in languages has really been the last two years and I'm sad for David that actually the timetable... certainly last year didn't allow him to do very much which is why I put on two clubs a week for him to do extra (Staff 9)

He wants to run a Pokemon club after school um... so... obviously he will take the lead, that's his idea (Staff 3)

In deciding to set up an activity, staff were influenced by pupil interests, the current resources available and whether they believed it would benefit the pupils. One teacher also said that the school wanted to send pupils the message that "*they have got a voice and they are listened to*" by meeting their requests for activities:

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they've asked for more trips out to better engage their education... part of the school football team, they wanted to be taken seriously and play other schools so now that's happening, I think it just makes them feel calm... of course they are going to kick back at it... the type of students we have... but they're turning up every day our attendance is brilliant and they know they have got a voice and they are listened to (Staff 3)

Decisions about who joined the student council were made through a democratic process involving the whole school, “the students all have a vote, the staff have a vote and it came out that Noah was the one who got the most votes... um which he's extremely proud of” (Staff 1). However, staff commented that the process of democracy might not always be effective when votes are equalised and do not result in a candidate.

One of the practices that helped decision-making to take place within the student council were meetings which were consistently scheduled, and the expectation was that everyone attended. One teacher explained that in previous schools student councils were unsuccessful because meetings were not prioritised by staff:

I've been to different schools in a similar environment as this is where we started a student council and then because... not that staff didn't take it seriously but they didn't have the time to make sure that it was diarised so it wasn't on that important list so it just got forgotten about and lost so the children just thought oh well they don't care (Staff 3)

The importance of the student council was echoed through comments from both Noah and Jack; Noah described his role as “the most important role in the school” and that he was “very determined to make sure that the council of this school is very fruitful”, whilst Jack said: “it makes you feel important and you get your ideas listened to”.

2.3.3 ACHIEVEMENT: focusing on what learners can do, rather than what they cannot

Lessons were designed to focus on the strengths, interests and expertise of pupils in the classroom. For two of the 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, for example, where he had the freedom to make choices about what he did:

I've always really enjoyed the music room because you can just like... seeing as music is just a one-on-one lesson you can go in there... you can play whatever you want... you can look at whatever you want... within reason... and you can just enjoy yourself, you don't have to really worry about how I'm going to get like my As in Maths and English and everything

else... I can just go to the music room and enjoy myself and forget about a lot of things (Noah)

Noah's comments suggest that music lessons are a subject where the content was led by pupil interest, and that this reduced the pressure to achieve, when 'achievement' was framed in terms of academic attainment. A teacher echoed these views in an informal conversation with the researcher, as shown by this field note in Figure 7.

The teacher said that in music, pupils feel "safe and comfortable" in this space and able to express themselves that they are a completely different person.

The teacher also said that "it's about going with the pupil's interests" e.g. if a pupil likes Minecraft he will ask them to listen out for what music they can hear playing.

Figure 7. Excerpt from a field note on a conversation with a teacher

Both Noah and the teacher described positive emotions in relation to music lessons – the experience of "enjoying yourself" and feeling "safe and comfortable". Whilst the outcome of a pupil-led lesson has not been observed by the researcher in context, the positive effects of this were also been noted by other staff applying similar principles. Another teacher described, for example, using what she called "tutorial sheets" with each member of the class where pupils decided on art projects for the term:

They would then choose four targets they would like to achieve within the next term or... four things they want to do in art... they've always wanted to do... you know it might be building a snowman out of paper mache. That's fine write it down, cause actually what I'll do is... I'll take what you've written down and I will structure a project around that for you... so they will see that actually I am listening to them, they then engage in the subject... in the project because it's something that they've decided on (Staff 5)

From the teacher's perspective, the engagement of pupils in her classroom was due to the pupils deciding on what to do in the lesson, decisions which would likely reflect their own interests and skills. One caveat with this practice was that some pupils may have been uncomfortable with having too much choice. The teacher said that Jack found it difficult to choose a project at first:

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)

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Her comments highlighted that contributing to decision-making may be a skill that needs to be learned rather than assumed, with additional guidance provided where needed.

Another issue presented by the teacher was that this flexible way of teaching may not work in every subject: "I can't imagine it working in every subject... well what do you want to do? I want to read a comic, no really that's really not gonna work". The degree to which pupils chose the content of lessons may therefore vary from subject to subject. It might be that in core subjects, pupils made decisions within the confines of a task set by the curriculum. Another staff member said for example, that John particularly enjoyed Science lessons when there were experiments. She explained that:

he's like ah we get to go out... we did leaves and stuff and he got to go and collect a leaf so there's that bit of control... and then into the classroom and then put nail varnish on it and he got to do it with the sellotape so it's like him that's doing so it's like this is his lesson not someone doing it for him...he really likes it... so that's why food tech is up there as well like he's cooking cause like that's his lesson (Staff 8)

The idea of "*his lesson*" suggests that staff increased engagement through providing opportunities for self-directed tasks, which gave pupils an element of control. This echoed comments from Noah who talked about enjoying "*playing whatever you want*" in music lessons. Although John did not vocalise the importance of having "*his lesson*", he did take a photograph of some jelly that he made during a food tech lesson (Figure 8), which may indicate the importance of having the space to direct his own learning and that he felt proud to have a tangible example of his efforts.



Figure 8. Photograph John took of a dish of jelly that he made during a food tech lesson

In situations where pupil interests were in conflict with the goal of the lesson, staff reached a compromise. The Spanish teacher, for example, frequently discussed "negotiating a route" to the goal of the lesson, where the goal was fixed but the route was flexible:

I guess as with any student... they might take the easiest route, which isn't always going to get you the learning that you need...so I think it is important to give as much as you can while remembering what the goal is, this is where we've got to get to... and they might say no I don't want to do that and we'll say OK that's fine but we still need to get to there... and to negotiate a route to it (Staff 9)

In David's case, this "negotiation" often involved decisions about what tasks to do and how to do them. David was described by staff as having a "deep interest" in languages, which could often steer attention away from tasks in the lesson. One teacher managed this through the language clubs that she set up for David. She explained: "that's the deal I have with him... we've got to do the stuff that you need to do, but in the clubs...we can do things that you're interested in on that day". In English, one staff member said that David wanted to write with his right hand, which was not his dominant hand and so impacted on the legibility of his writing. Staff compromised by offering handwriting lessons with his right hand:

Yeah so in English um he basically...I think it was over his handwriting actually. What has been said is that David is actually left-handed but he tends to write a lot right-handed. I think for David it was like well no I can write with whatever hand I want to write. I think it was because it was picked up by the English teacher that his handwriting was a bit untidy so he was told to write with the hand that he normally writes in but now to support David with wanting to write with his right hand um I think they are gonna put him in like for some sessions" (Staff 10)

Practices that drew on pupil interests therefore ranged from entirely pupil-led lessons and projects to specific tasks within the lessons, some of which involved negotiation along the way. There were also more subtle examples of situations where staff tapped into pupil interests to enable pupils to reach the goal of a lesson. John's tutor described "playing on" John's interests to help him make the blackcurrant dish displayed in Figure 8 during a food tech lesson:

John actually hates fruit... but I managed to get him to use red and black currants or at first he would only use black currants but there weren't enough...red currants are the same as black currants.. they're just a different colour... there is no difference and like cause he likes to squeeze them and open them up we can do it they're the same.... He was like yeah they are and his favourite colour is red so I played on that quite as well, the red power rangers he likes that and Pokemon is red just like all the different little things that he likes, he was like oh yeah, oh ok yeah fine we'll do it (Staff 8)

2.3.4 DIVERSITY: Recognition and acceptance of pupils by staff

This theme relates to the practices that promote mutual relationships of acceptance and recognition among staff and pupils. All of the pupils identified members of staff who they felt listened to them at school. This was exemplified by photographs pupils took of different subject teachers, tutors and members of the senior leadership team. Pupils identified a range of practices which staff did that helped them to feel listened to such as “sorting issues” (Jack and Noah), “listening to me when I struggle” (David), receiving “a hundred percent of the attention” (Noah), “giving advice” (David) and being a “friend” (John). David took eleven photographs of staff, the most photographs out of all four pupils highlighting the importance of his relationships with staff.

Time staff spent with pupils influenced the quality of relationships for both David and Jack:

yeah well I definitely feel listened to by [teacher name]... I spend most of my time with her.. she's been there from the start as well for me... I guess there are some people I speak to more than others and that's just... I spend a lot of time with them so I have more of a stronger relationship with them (David)

I usually speak to [first name, senior leadership team] every day about something...at least once a week, quite often ...he usually speaks to me at all times unlike name [first name, senior leadership team], he's usually very busy and you don't get to speak to him very often (Jack)

For Noah, time spent with staff was considered a less important factor:

He hasn't been my tutor for too long, only for like a term and a half but I feel like we're kind of on the same level, he understands where I'm coming from... he knows what's happening and bless him... he's trying so hard to learn about Pokemon (Noah)

A teacher also discussed the importance of learning about pupil interests to build relationships; she spent time researching computers, which Jack was “obsessed with” to “get that banter going” with him in her lessons. Other staff also described making visits to the students’ care home, where they were able to see pupils in a different context and learn about their interests. One teacher described below the benefits of the care home visits:

You can see them, what they're like outside of school and then relate that back in... what hook can you get... what thing can you get from there... you see what they're interested

in... so then when you are in trouble in school, you've got a topic to talk to them about (Staff 1)

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. Jack explained that:

He [senior leadership team] will always listen to me if he's available and... he will always sort out the issues for me. He [senior leadership team] the same... um... I get to speak to him all the time, he will always sort out issues for me and try. (Jack)

There was a sense that one of the reasons for putting senior management in the 'most listened to' pile was to do with their status of power within the school. Jack said: "they can actually sort it out properly for me" which was echoed by Noah who said: "yes cause obviously it's the big boss people... they're the ones who make the final decisions". Pupils described many changes to their school experiences after having had a discussion with senior management but that visits weren't always about "sorting issues" but an opportunity to talk; Noah said: "sometimes I just like going up there to just have a talk because it's rather relaxing and enjoyable". This suggests that the positive quality of pupil relationships with staff could be seen within senior management as well as with other staff at the school. One staff member suggested that these relationships help pupils to speak to staff about decisions:

"and I think the relationship with him.. what works... and if he asks for time out he's like come on sally let's go we need to have a chat" (Staff 8)

Staff argued that it was also important for pupils to accept staff and see them as human beings in order to build positive relationships. Staff believed that spending time in different contexts helped to promote this acceptance, not just at home and school but also within different subject lessons:

When I get into their home they talk on their level... it's got nothing to do with me, I'm just there to look after them and we'll go to flip out, we'll go... you know do whatever they wanna do, play games and build a relationship and people actually see that I'm just a normal person, not just some teacher who walks around, I care for them you know. (Staff 2)

I think that that's quite important for them to see us not just as school teachers cause you get boxed sometimes and... somebody might look at somebody and go I don't like him... for instance a maths teacher (mumbles)... they'll go Maths teacher, horrible don't like him... do you actually know him? outside of the school he might be a lovely bloke... but because he teaches maths which isn't your favourite lesson you're instantly gonna go, oh I don't like him... I think it's important for them to see that we're human as well. (Staff 1)

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The comment below suggests that the practice of teachers spending time in different contexts was also viewed positively by pupils:

well when I used to do outdoor ed. as a subject he used to come and help out...um so I know him in other subjects as well... and now I know him in music which is nice (David)

Helping pupils to relate to staff perspectives may also be key to creating relationships of mutual acceptance. Staff frequently made reference to explaining the reasons behind their decisions, comments or choices to pupils so that they better understood the purpose of a course of action:

ok Jack let me explain to you why... cause he [senior leadership team] is doing this and the reason for that is... and maybe I'll ramble on a little bit about the subject but explain in more intricate detail than I normally would with a student (Staff 4)

we are trying to meet your needs but if we don't meet your needs these are the reasons why and these are the reasons why you're best off where you are and to his credit, he [Noah] does take that on board (Staff 1)

This may be a particularly helpful practice for some autistic pupils. Staff 4 reported that Jack is much calmer when he received detailed explanations about a decision, "if it's I can't deal with this now, I'll come back to this... go away a second Jack then that's when that frustration point would just keep... bubbling away and then it could become an issue". Comments from pupils suggested an awareness of staff perspectives, which could point to the effectiveness of this strategy. Jack said for example, "I wondered today if it would be possible for uh me to go over to [site name] but it's not possible because there are too many students there... but I believe everyone is coming over here later".

2.4 Discussion

The study aimed to identify the school-based practices that enabled autistic pupils to participate in decision-making about their school experiences; how their views were used by adults to inform decisions; and when autistic pupils felt their voices were heard. By conducting a case study to address these aims, this research provides detailed insights into how autistic pupils participated in decision-making at a specific school—a topic under-researched using qualitative methodology. The Framework for Participation (Florian et al., 2016) provided the lens through which the data were analysed. The findings highlighted that many of the school practices focussed on involving pupils in

decisions related to accessing the classroom and curriculum; for example, there was evidence that pupils decided when they took breaks in lessons, and aspects of lesson content. Pupils' participation in these decisions appeared to be facilitated by their interactions with staff as well as the systems within the school; for example, staff actively seeking pupil views on how to improve the lesson and the flexibility of the timetable to accommodate changes suggested by pupils. At the heart of these findings were the perspectives of pupils, who provided valuable insights into the contexts and staff behaviours that enabled them to feel that their voices were heard. These practices and perspectives connect to wider themes in the literature, which are important for contextualising the findings.

2.4.1 Wider context

There was evidence that the curriculum and the systems within the school were flexible, which appeared to create opportunities for pupils to make decisions about how and when they learn. Practical examples included pupils contributing to and in some cases leading decisions about projects in lessons and the types of clubs organised by the school. These practices are in line with recommendations from the Organisation for Economic Co-operation and Development (OECD, 2008), who argue that creating a flexible and diverse curriculum is vital to providing an equitable education system that is enticing for all learners, thereby increasing the likelihood of more pupils staying in school. The importance of extra-curricular activities to pupils, such as the student council and language club also highlighted the value of other forms of learning. The OECD states that 20% of learning occurs outside of the classroom and that adjusting classroom practice alone is not sufficient for improving the academic performance of pupils (OECD, 2008). Given the type of data collected in the current study, it is difficult to determine if the flexibility of the curriculum at the case school directly impacted on the academic attainment of the pupils. However, it was evident that pupils valued the flexibility to choose how and when they learn, and that they enjoyed the extra-curricular activities they participated in at the school. As these pupils were previously at risk of exclusion from educational settings and were now attending school full-time, the findings in this study could provide further support for OECD policy guidance indicating that promoting access

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to the school and the curriculum is important for meeting the needs and interests of a wider range of pupils.

While the pupils appreciated the opportunity to influence their schooling, staff suggested that making choices was unfamiliar territory for some pupils. A teacher's comment that one pupil "felt scared at first" about the prospect of deciding on the topic for the lesson, suggests that adults cannot assume that children and young people have the information and skills they need to make decisions. This argument is echoed in literature around decision-making with autistic pupils and pupils with disabilities (Fayette & Bond, 2017; Hatfield et al., 2017; Pellicano et al., 2014; Rix, Hall, Nind, Sheehy, & Wearmouth, 2009). For example, the autistic pupils in Hatfield's (2017) study identified that they were anxious about making decisions about their transition to post-secondary education and that they wanted clear information about the planning process. This suggests that adults should carefully consider what scaffolds need to be used to support autistic pupils to feel confident about making decisions about their education.

There was evidence that the decisions pupils made about their school experiences were part of the wider culture of the school rather than offered by staff as an intervention specific to pupils on the autism spectrum. For example, taking breaks when pupils chose to during lessons or the use of tutorial sheets to decide on a project were practices used by all pupils. This finding contrasts with the literature on choice-making interventions for autistic pupils which were designed as a behaviour management tool for specific learners (Newman et al., 2002; Rispoli et al., 2013; Smeltzer et al., 2009). The rhetoric around the use of choice-making interventions in some articles appeared to be focussed on control and discipline; for example, reducing 'problem behaviour' (Smeltzer et.al, 2009 p. 742) or 'challenging behaviour' (Smeltzer et. al, 2009 pg. 67), though it is difficult to tease apart whether this language reflects the beliefs of the authors or the staff who implemented the intervention. Nevertheless, this appeared to contrast with the beliefs of staff at the case-study school in the current study who discussed choice in relation to the engagement of all pupils and the valuing of pupil expertise and voice.

Features of staff interactions with pupils in this study resonated with a 'partnership approach' to decision-making advocated by May (2004), where staff and pupils share the power in making decisions through negotiation, joint goals and

reciprocal feedback. For example, one staff member asked a pupil what *she* could do differently to improve his day, which resulted in actions that reflected the ideas of both parties. Approaching the pupil in this way appeared to create an opportunity for him to contribute to decisions about changes to his lesson, which he might not have had otherwise. 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 children as partners in decision-making may be an effective approach to managing difficult situations in the classroom.

Pupils felt listened to by staff across the school, from tutors to members of the senior leadership team. This may have provided a relational context that facilitated the views of pupils to be heard, valued and acted upon. In the context of multi-professional partnerships, research suggests that the quality of relationships affects the extent to which individuals feel able to speak with each other and value views that are different to their own (Lasker, Weiss, & Miller, 2001). This is arguably reflected in the current study, where pupils and staff appeared to appreciate each other's perspectives on decisions made. One staff member also suggested that her relationship with a pupil, helped the pupil to approach her when he wanted to speak about any concerns. This is a finding that is in line with education research arguing that pupil-adult relationships are the primary vehicle for increasing children's participation in decision-making, as relationships are proposed to influence what pupils are able to say and which voices are heard (Mannion, 2007). If building relationships is important for facilitating participation in decision-making, staff should consider how to build positive relationships with autistic pupils at their school. Pupils in the present study gave valuable insights into what staff did that helped them to feel heard, for example, "sorting issues" and learning about their interests. Schools could therefore begin by asking pupils what they consider to be important in developing relationships with staff.

Relative to the young people and school staff, the voices of carers are underrepresented in the findings of the current study. Carers did provide valuable insights into the behaviour of their children at home and how the case school could work more collaboratively with carers, which will be acknowledged in other dissemination from this research to inform practice in this area. However, the carers did not provide

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data that addressed the research questions, which were focused on school-related decision-making. Carers mentioned formal processes where they participated in decision-making with their child at school, for example reviewing the Education and Health Care Plan but did not comment on how the pupils were supported within this process nor on day-to-day practices within school. It may be that many of the approaches schools use to enable autistic pupils to participate in decision-making are not visible to parents, and could be shared more explicitly. Alternatively, the interview guide may not have included questions that enabled carer perspectives to be captured in this area and if so, researchers will need to carefully consider how methods for eliciting the voices of parents and carers on this topic can be improved.

In summary, there were a range of practices that the case school implemented which promoted the participation of autistic pupils in decision-making. These practices include: relationship building; adults negotiating changes to lessons with pupils; a system whereby pupils choose when, where and with whom to take breaks during lesson; and pupil-led lessons and extra-curricular activities. It is important to note that the findings reported reflect the values of staff at the case school. In the interviews multiple staff referred to the importance of harnessing pupil interests in order to better engage them in education, with each staff member using similar terms to describe this, such as “hooks” or “keys” into pupil interests and motivations. These values were therefore shared among staff and underpinned practices such as pupil-led lessons. Research argues that practitioner values are a hidden factor influencing the effectiveness of a course of action, and that applying the same course of action in a context without these values may be ineffective (Kennedy & Monsen, 2016). When schools and educational psychologists consider the findings from this research, it is therefore important to reflect on the values of the staff who would implement the practices reported here and how a different set of beliefs might impact the effectiveness of these practices.

2.4.2 Implications for schools and Educational Psychologists (EPs)

Although this research used a case study approach, which means that practices may not be applicable to other schools with different systems and pupil populations, case studies are nonetheless often used as a method of teaching and learning within education settings (Flyvbjerg, 2006). In this case, the findings highlighted learning points which

could help practitioners to reflect on how to promote the participation of autistic pupils in decision-making within their local context:

1. *A culture that promotes flexibility in school systems may enable autistic pupils to make decisions about how and when they learn.* Practitioners should consider where the curriculum is more flexible, and where opportunities could be created for pupils to directly influence the activities they do in school. This is particularly important because pupils valued making decisions and/or influencing decisions about matters that were important to them. Where possible, these practices should be considered within a whole-school approach rather than as a targeted intervention.
2. *Decision making is a skill that may need to be learnt.* The findings suggested that some pupils may appear unsure or even worried when asked to make decisions. Therefore practitioners should be mindful of this when asking pupils to take part in decision-making and may need to provide pupils with additional information and guidance, both about some of the available choices and potential processes involved with and/or outcomes of these choices.
3. *A partnership approach to decision-making may be helpful for creating actions that are agreeable to both staff and pupils.* The findings provide several examples where staff at the case school approached students using strategies such as negotiation, which were reported to result in positive outcomes. Schools could learn from the examples and scripts used by staff at the case school and consider how these might be adapted in a different context. Staff should also consider how to develop relationships with pupils to make partnership working more effective. Pupils valued the relationships with staff at the case school and identified the actions of staff that were important. Practitioners should consider asking pupils at their school about what teachers can do to help them feel heard.
4. *Carers may not be aware of how their children participate in decision-making at the school.* Schools should consider how to make their day-to-day practices more explicit to parents and carers, and share more information on how their children participate in decision-making at the school.

Educational Psychologists work within systems that provide support to schools, through methods such as consultation, assessment and training (Ashton & Roberts, 2006).

The five principles above could therefore be considered by EPs when working with schools to promote the participation of autistic pupils in decision-making. EPs might also refer to these principles in relation to their own work with pupils, for example, when planning a multi-professional meeting in which pupils attend and contribute to decision-making. However, as the types of decisions reported in the current study were often day-to-day decisions in the classroom rather than decisions within a meeting, EPs will need to also consider research that provides insights into pupil participation in formal decision-making processes such as person-centred planning meetings (e.g. Hagner, Kurtz, May, & Cloutier, 2014).

2.4.3 Limitations and future research

When considering the findings and implications of the research, it is important to take account of the following limitations. Autistic pupils in the study had diverse needs, but may not have fully represented pupils on the autism spectrum; for example, those in minority ethnic groups or those who use augmentative and assistive communication methods. Another possible limitation is that for one of the pupils, a staff member was present for every session of the pupil activity which may have limited the photographs he took and what he felt able to say during the recorded discussion. However, this decision was taken because staff felt that he would feel more comfortable with the presence of an adult he knew well. The findings also lacked the views of carers, which meant that data were not triangulated with their views.

The research could also have taken a stronger participatory approach which has been argued to be beneficial because it promotes a research process that is conducted *with* rather than *on* participants, it ensures that the views and experiences of autistic individuals in the research are authentic, and promotes a vested interest in the findings among stakeholders (Milton & Bracher, 2013; Turtle, McElearney, & Scott, 2010). Some aspects of this study were driven by participants, for example, staff suggested to interview three members of staff in a range of roles rather than only the class tutor and pupils generated their own data by taking photographs. However, if this study were to be re-implemented, the researcher would seek the views of participants on other aspects of data collection and analysis; for example, on which methods would be most suitable and engaging for eliciting their 'voices' such as drawings, photographs or walking interviews

– methods which have been previously used to gain the perspectives of autistic pupils (Fayette & Bond, 2017; Shepherd, 2015). In future research, gathering the views of parents through a focus group may also help to a) improve the interview schedule for capturing their perspectives and b) generate research questions related to decision-making which would be interesting and relevant to stakeholders.

There were also disadvantages to using the Framework for Participation (Florian et. al, 2016) to guide data collection and analysis. Some sections of the Framework were more well defined than others, which presented difficulties when operationalising terms. For example, the authors described 'access' as a broad term that goes beyond physical access in schools, with no definition of other forms of access or the behaviours one would expect to observe if a pupil were accessing the school in a way that met the principles of the Framework. This meant that the operational definition for this term was deduced from the examples of evidence given for each section of the Framework by Florian et.al, (2016) and case studies that used the Framework (e.g. Black-Hawkins and Florian 2012), rather than an explicit definition from the Framework's authors. Using the Framework for Participation to deductively analyse the data also presented challenges when data did not fit within the Framework. For example, the diversity section of the Framework described the importance of pupils being accepted by staff regardless of gender, sex, disability and a range of other characteristics. However, there was data in the study that suggested it was also important for staff to be accepted by pupils, but no feature of the Framework accommodated this data—it was helpful to include 'other' categories in these cases. Based on the current study, the Framework could be improved by clearly operationalising all terms for researchers and broadening the section on diversity to include 'the acceptance of staff by pupils'. The latter fits with the principle of the Framework which emphasises the importance of the participation of all members of a school community, rather than specific groups.

Despite the above limitations, there were some advantages to using the Framework deductively. Given the amount of interviews and visual data collected, it was helpful to begin to organise the data with deductive themes which fit with the ethos of the study and the research questions. Moreover, using the Framework as a guide for data analysis allowed an examination of decision-making within pupils' broader participation

Chapter 2

in school life. Doing so highlighted facilitative aspects of the wider school environment such as school culture, which may have been missed with a narrow focus on specific examples of decision-making. The Framework was also designed with education researchers in mind and had been used previously in case study research in schools, therefore lending itself to the methodology of this study.

As this was a time-limited project, it was not possible to seek the perspectives of the participants on the themes in the data. However, an executive summary of findings will be produced for the pupils and staff who took part. After the participants have shared their thoughts and given feedback, a final summary will also be distributed to the whole school.

2.4.4 Conclusions

Case study methodology is a valuable research approach that generates context-dependent knowledge, which can be used as a source of learning for schools (Flyvbjerg, 2006). To date, this is the first case study of a school with the aim of understanding the practices that enable autistic pupils to participate in everyday and informal decision-making within school. The findings are rich and detailed, supported through the use of multiple methods of data collection and perspectives. Whilst specific to the systems and population of one school, the data are presented within the complex systems of schools, making the analytical insights highly accessible to practitioners. It is hoped that schools and educational psychologists will use the principles as a reflection tool for considering how they might promote the participation of autistic pupils in different educational contexts.

Appendices

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Appendix A CASP checklist for qualitative research

Critical Appraisal Skills Programme (CASP, 2014) checklist for qualitative research.

| Screening | YES | NO | Notes |
|---|-----|----|-------|
| 1. Was there a clear statement of the aims of the research? | | | |
| 2. Is a qualitative methodology appropriate? | | | |
| 3. Was the research design appropriate to address the aims of the research? | | | |
| 4. Was the recruitment strategy appropriate to the aims of the research? | | | |
| 5. Was the data collected in a way that addressed the research issue? | | | |
| 6. Has the relationship between researcher and participants been adequately considered? | | | |
| 7. Have ethical issues been taken into consideration? | | | |
| 8. Was the data analysis sufficiently rigorous? | | | |
| 9. Is there a clear statement of findings? | | | |
| 10. How valuable is the research? | | | |

Appendix B CASP checklist for quantitative research

Amended checklist for quantitative research, informed by items on the CASP (2014) case-control and cohort checklists.

| Screening | YES | NO | Notes |
|---|-----|----|-------|
| 1. Did the study address a clearly focussed issue? | | | |
| 2. Did the authors use an appropriate method to answer their research question? (from CASP case) | | | |
| 3. Was the sample recruited in an acceptable way? (made more generic to cover 'cohort' and 'cases') | | | |
| 4. Were the variables accurately measured to minimise bias? (merged Q3 and 4 from cohort and Q5 from case, made 'outcome' and 'exposure' generic) | | | |
| 5. What confounding factors have the authors accounted for? Have the authors taken account of the potential confounding factors in the design and/or in their analysis? | | | |
| 6. What are the results of this study? | | | |
| 7. How precise are the results? | | | |
| 8. Do you believe the results? | | | |
| 9. Can the results be applied to the local population? | | | |
| 10. Do the results fit with other available evidence? | | | |
| 11. Do the authors discuss the implications of this study for practice? (from CASP cohort) | | | |

Appendix C Data extraction form

Data extraction form used to identify relevant information from studies included in the review.

| | <i>Data to be extracted</i> | <i>Notes</i> | <i>Limitations</i> |
|-------------------------|---|--------------|--------------------|
| Identification features | Article number (to uniquely identify study) | | |
| | Article Title | | |
| | Author | | |
| | Year of publication | | |
| | Type of publication | | |
| | Country of origin | | |
| Study overview | Study objectives | | |
| | Design (RCT, case study?) | | |
| | Setting (school, college, nursery?) | | |
| Participants | Age | | |
| | Gender | | |
| | Autism description (EHCP? ADOS?) | | |
| | Sample size | | |
| | Multiple stakeholders? | | |
| Data | Decision-making process (school council, consultation?) | | |
| | Data collected (observational, interview, survey?) | | |
| | Outcome (themes identified? effect size?) | | |
| Participation Framework | 1. WHO does and does not participate in decision-making? Who decides? | | |
| | 2. WHAT are the practices that promote participation in decision-making? WHAT are the practices that reinforce barriers to participation in decision-making? | | |
| | 3. WHY do these practices that promote participation in decision-making take place? WHY do these practices that reinforce barriers to participation in decision-making take place? | | |

Appendix D Rating of studies using the CASP checklist

Table 8

Ratings given to qualitative studies using the Critical Appraisal Skills Programme (CASP) checklists

| Qualitative study | Clearly states aims | Appropriate qualitative method | Research design explained | Recruitment strategy explained | Data collection explained | Researcher-participant relationship considered | Ethical issues considered | Sufficiently rigorous data analysis | Clear statement of findings | Valuable research | Total rating out of 10 |
|---------------------------|---------------------|--------------------------------|---------------------------|--------------------------------|---------------------------|--|---------------------------|-------------------------------------|-----------------------------|-------------------|------------------------|
| (Bell et al., 2017) | Yes | Yes | Yes | Yes | Yes | Yes | No | No | No | Yes | 7 |
| (Woodfield & Ashby, 2016) | Yes | Yes | Yes | Yes | Yes | No | No | No | No | No | 5 |
| (Held et al., 2004) | No | Yes | Yes | Yes | No | No | No | No | No | No | 3 |
| (Horton, 2015) | Yes | Yes | No | No | No | No | No | No | No | No | 2 |

Appendix D

Table 9

Ratings given to mixed-methods studies using an amended version of the CASP checklist

| Mixed methods | Addressed clearly focussed issue | Appropriate research method | Recruitment strategy explained | Accurate measurement of variables | Confounding variables considered | Appropriate statistical analyses | Precise results e.g. confidence intervals | Credible results | Ethical issues discussed | Sufficiently rigorous analysis of qual data | Applicable to local population | Results fit with other evidence | Total rating out of 12 |
|-------------------------|----------------------------------|-----------------------------|--------------------------------|-----------------------------------|----------------------------------|----------------------------------|---|------------------|--------------------------|---|--------------------------------|---------------------------------|------------------------|
| (Hatfield et al., 2017) | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | No | Yes | Yes | 10 |

Table 10

Ratings given to quantitative studies using an amended version of the CASP checklist

| Quantitative study | Addressed clearly focussed issue | Appropriate research method | Recruitment strategy explained | Accurate measurement of variables | Confounding variables considered | Appropriate statistical analyses | Precise results e.g. confidence intervals | Credible results | Applicable to local population | Results fit with other evidence | Implications discussed | Total score out of 11 |
|----------------------------------|----------------------------------|-----------------------------|--------------------------------|-----------------------------------|----------------------------------|----------------------------------|---|------------------|--------------------------------|---------------------------------|------------------------|-----------------------|
| (Aguilar et al., 2016) | Yes | Yes | No | Yes | No | No | No | No | Yes | Yes | Yes | 6 |
| (Lough et al., 2012) | Yes | Yes | No | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | 9 |
| (Rispoli et al., 2013) | Yes | Yes | Yes | Yes | No | Yes | No | Yes | Yes | Yes | Yes | 9 |
| (Mechling, Gast, & Cronin, 2016) | Yes | Yes | Yes | Yes | No | No | No | No | Yes | Yes | Yes | 7 |
| (Newman et al., 2002) | Yes | Yes | Yes | No | No | No | No | No | Yes | Yes | No | 5 |

| Quantitative study | Addressed clearly focussed issue | Appropriate research method | Recruitment strategy explained | Accurate measurement of variables | Confounding variables considered | Appropriate statistical analyses | Precise results e.g. confidence intervals | Credible results | Applicable to local population | Results fit with other evidence | Implications for practice discussed | Total score out of 11 |
|---------------------------|----------------------------------|-----------------------------|--------------------------------|-----------------------------------|----------------------------------|----------------------------------|---|------------------|--------------------------------|---------------------------------|-------------------------------------|-----------------------|
| (Peterson et al., 2001) | No | Yes | No | No | No | No | No | No | Yes | Yes | No | 3 |
| (Smeltzer et al., 2009) | Yes | Yes | No | Yes | No | No | No | No | Yes | Yes | Yes | 6 |
| (Barry & Burlew, 2004) | Yes | Yes | No | Yes | No | No | No | No | Yes | Yes | Yes | 6 |
| (Ledford et al., 2016) | Yes | Yes | No | Yes | No | No | No | No | Yes | Yes | Yes | 6 |
| (Shogren & Plotner, 2012) | Yes | Yes | Yes | Yes | No | Yes | No | Yes | Yes | Yes | Yes | 9 |

Appendix E Case study design

Table 11

Case study design (adapted from Thomas 2016)

| | Design | Description | Application to project |
|---------|--------------|---|---|
| Subject | Outlier case | It reveals something interesting because it is different from the norm | The case school – it is interesting because the pupils with ASD at <i>this</i> school have needs that were not previously met in a mainstream setting or pupil referral unit, making them the most likely pupils to be marginalised from decision-making processes as identified in the literature. |
| Purpose | Exploratory | Find out more about the problem/topic and establish its 'shape' – what is happening, for whom and why? | Find out about the practices in school that enable autistic pupils to participate in decision-making about their school experiences. Facilitated by using the Framework for Participation. |
| | Instrumental | Inquiry serves a purpose – the aim is to better understand a phenomenon with a view to make things better | Provide new knowledge about pupil participation that will lead to greater awareness amongst education practitioners, changes in school practice and improved outcomes for pupils with ASD. |

| | | | |
|----------|----------------------------------|--|---|
| Approach | Drawing a picture (Illustrative) | Provide a rich, well-rounded picture of the phenomenon so that the reader can 'get inside' the issue/topic, enabling connections to be made | Provide a picture of pupil participation in <i>this</i> school context. The picture will be rich and well-rounded by analysing multiple sources of data from multiple stakeholder perspectives. |
| | Interpretative | The analysis that takes place is <i>interpretative</i> – reflecting on people's words and behaviour in order to make sense of the meaning behind them; it is an approach which demands immersion in the subject. | Immersion in school environment through multiple observations and interviews with range of stakeholders. Field notes kept over the course of data collection with research questions and analytical frame guiding reflections from each session. |
| Process | Single case | A single thing studied in depth through the collection of data that is <i>retrospective</i> (related to past phenomenon), <i>snapshot</i> (case looked at in one period of time) and/or <i>diachronic</i> (showing change over time) | In depth study of <i>one</i> school. Retrospective data collected through interviews; parents and staff reflect on pupil participation in school. Snapshot data collected through observations over 1 or 2 school terms; reflections on events as they occur. |

Appendix F Operational Definitions

Table 12

Operational terms of sections within the Framework for Participation

| Terms | Operational Definitions |
|---|--|
| Access | 'Being there' – both in terms of physical presence and the ability to understand and do activities. |
| <i>Joining the school and the classroom</i> | Practices that decide on which pupils are admitted to the school and accepted on roll. |
| <i>Staying in the school and the classroom</i> | Practices that promote pupil attendance at school, physical presence in the classroom and management of challenging behaviour. |
| <i>Access to spaces and places in the school and classroom</i> | Practices that promote pupils physically accessing different areas and resources within the school and create a welcoming school environment. |
| <i>Access to the curriculum</i> | Practices which enable pupils to understand and perform curricular and extra-curricular activities. |
| Collaboration | 'Learning and working together' – this includes 'making authentic choices about what they learn as well as how they work together to support each other's learning'. Practices which enable pupils to work with others in lessons and across the school to develop new skills, knowledge and experience. |
| <i>Students learning together in the school and in classrooms</i> | Practices which enable staff to work together across different roles and contexts, to develop new skills, knowledge and experience. |
| <i>Members of staff learning together in the school and in classrooms</i> | Practices which enable staff to work with parents, other schools and external agencies to develop new skills, knowledge and experience. |
| <i>Members of staff learning with others beyond the school</i> | |
| Achievement | Supporting everyone's learning – "this section is predicated on a view that everyone can learn and that many different forms of progress should be valued" (p. 392, Black-Hawkins, 2014) |
| <i>Regarding progress in learning as an everyday expectation</i> | Pupils and staff have high expectations of their own learning and data is used to monitor progress. |
| <i>Valuing and rewarding a range of achievements</i> | Progress in any area such as social skills, attendance, behaviour, participation in extra-curricular activities is |

| | |
|--|--|
| | celebrated as an achievement, not just academic attainment. |
| <i>Focusing on what learners can do rather than what they cannot</i> | Tasks in lessons are not beyond what a learner can do and reflect pupil expertise (e.g. interests and experience) so that the lesson is appropriate for all. |
| <i>Using formative assessment to support learning</i> | Data on pupil progress is used to inform changes to lesson content and delivery, in the short and medium term. |
| Diversity | |
| <i>Recognition and acceptance of students, by staff</i> | Relationships of mutual acceptance and recognition – “all members of the school have a right to be themselves whilst accepting the responsibility to value others” (p. 397, Black-Hawkins, 2014) |
| <i>Recognition and acceptance of staff, by staff</i> | Practices “acknowledge, appreciate and celebrate the diversity of students and those in which differences are overlooked, misunderstood or treated with intolerance” (e.g. gender, class, ethnicity, disability) (p. 187 Florian et al., 2016) |
| <i>Recognition and acceptance of students, by students</i> | Staff respect colleagues regardless of role, and support those who experience difficulties in the classroom, appreciating the diversity of staff (e.g. gender, class, ethnicity, disability). |
| | Students “acknowledge, appreciate and celebrate the diversity of students and those in which differences are overlooked, misunderstood or treated with intolerance”(e.g. gender, class, ethnicity, disability) (p. 187 Florian et al., 2016) |

Appendix G The Framework for Participation: examples of evidence

| Terms | Examples of evidence* |
|--|---|
| Access | |
| <i>Joining the school and the classroom</i> | Admissions policies both within school and the local authority, attitudes towards the admission of particular students, information on which students attend and why |
| <i>Staying in the school and the classroom</i> | Policies and practices concerning student attendance and exclusion e.g. internal, fixed-term and permanent exclusions, pupil's on roll but out of school |
| <i>Access to spaces and places in the school and classroom</i> | Policies concerning physical accessibility to areas of the school for staff, pupils, carers and visitors. Practices that create and maintain a welcoming and safe school e.g. anti-bullying, induction policies, rewards and sanctions. |
| <i>Access to the curriculum</i> | Practices around timetabling and access to the wider curriculum e.g. policies that affect which students do particular subjects, lunch-time and after school clubs, withdrawal from classes and access to school trips. |

*Examples of evidence were taken from pg. 182 -184 in

Appendix H Extract of a transcript for Staff 3

Throughout this transcript all names have been changed to ensure anonymity

R: so the first question really is just about your role in the school, could you tell me a bit about that?

Staff 3: I'm [deleted information about staff role that would identify him/her]

R: ok

S: so I'm [deleted information about staff role that would identify him/her]

R: so quite a varied role then

S: varied role and as part of that...um I help with the student council

R: yeah

S: so I will organise and run the elections at the start of the year

R: hmmn

Staff: um and then basically I hand over to the students because I like to empower them so I make sure that meetings take place and I help to diarise the meetings

R: hmmn

Staff: but my role really is as an observer that everything is put in place for them rather than actually run their meetings

R: could you give me an example of a typical meeting and what it would look like?

Staff: yeah ok so we have [pupil name] who is the chairman...I'll go for our first meeting actually.. he had a soft toy so what we did we promoted the rules of what it looks like to be a student council and be part of a meeting... so it's turn taking

R: hmmn

S: and promoting that sort of thing so [pupil name] would give the cuddly toy to anybody who wished to speak.. um he would gather the agenda beforehand um and it's actually run as any normal meeting would be run in any sort of...

/interrupted interview/ time: 02: 45

R: um you were saying about the council and that you've got the system in place with the cuddly toy.. how does that work? Do you find it effective as a strategy?

S: well I must admit I find that the meetings run themselves.. we've got a very good student council.. I think they all take it very seriously. One of our members who was Vice President decided actually it wasn't for him

R: ok

Appendix I Extracts of version 1 and 2 of the coding manual

Table 13

An extract of Version 1 of the coding manual for codes HOW and WHEN

| Abbreviated codes | Description |
|-------------------|---|
| ACC HOW Change | Pupil views about access lead to some change for pupil, staff, practice |
| ACC HOW N | Pupil views about access sought but no change |
| ACC HOW O | How other |
| ACC WHEN PER | Location where pupils felt listened to |
| ACC WHEN PLA | Person with whom pupil felt listened to |
| ACC WHEN O | When other |

Table 14

An extract of Version 2 of the coding manual, with changes to codes HOW and WHEN

| Abbreviated codes | Description |
|---------------------------------|--|
| ACC HOW Change | Pupil views lead to a change e.g. staff implement pupil request |
| ACC HOW No but explain | Staff do not implement pupil request but explain why |
| ACC HOW Unknown | Pupil views lead to no change, decision or explanation |
| ACC HOW O | How other |
| ACC WHEN Emotional State | Pupils describe an emotional state linked to feeling or not feeling listened to |
| ACC WHEN Context | Pupils describe contextual features e.g. number of people, atmosphere, receiving one-to-one attention |
| ACC WHEN Person characteristics | Pupils describe the characteristics of people with whom they feel or don't feel listened to e.g. age, appearance, status |
| ACC WHEN Have conversation | Pupils describe being able to have a conversation which is listened to |
| ACC WHEN Making changes | Pupils describe the importance of adults making changes after listening to pupil views |
| ACC WHEN Sorting issues | Pupils describe the importance of 'sorting issues' |
| ACC WHEN Pupil interests | Pupils describe the importance of their interests/achievements |
| ACC WHEN Other | |

Appendix J Extracts of NVivo annotations

When labelling each segment of data, the researcher labelled which code or sub-code the related to the data and wrote reflections on the reasons for assigning this category.

Created: 7 May 2018 By: CMB

Focus on what the learners can do - Here the teacher is drawing on the strengths and interests of the pupil rather than focusing on the aspects of arts he finds difficult.

started joining the lessons, I was still on

T: structured lessons... **all of the lessons I deliver are very very bespoke to the individual**

R: **ok**

T: lots of chatting with him initially, finding out what he was into

R: **hmmn**

T: he was quite a reluctant student

R: **ok**

T: thought he was awful at art

T: how can I...yell at a student for wandering around a room when he's got an ADHD diagnosis? I mean.. really?!

R: so how would you do differently then? How would you handle that situation if he suddenly started wandering

T: I would... I've got a student who does that now... and It's like, right ok.. you know you really do need to be sitting down doing some work, don't you? I'm quite happy for you to walk around... but you do need to get this done by the end of the lesson... so actually it's allowing them the ability to do what they need to do

R: **hmmn**

T: whilst also reining them in and reminding them that this is a classroom environment

I talk to them...

Created: 7 May 2018 By: CMB **.80% coverage**

Access - enables pupils to stay in lessons and complete work because they are getting those movement breaks. In my experience, when staff don't do this the situation can escalate and pupils end up with an internal exclusion....

R: **hmmn**

T: so actually

R: **hmmn**

Appendix K Themes

There were thirteen themes identified in the data. Each theme is listed below under the headings from the Framework for Participation (Florian et al., 2016).

ACCESS

- Staying in the school and the classroom
- Access to spaces and places in the school and the classroom
- Access to the curriculum

COLLABORATION

- Students learning together
- Members of staff learning together
- Members of staff learning from others beyond the school

ACHIEVEMENT

- Regarding progress in learning as an everyday expectation
- Valuing a range of achievements
- Focusing on what learners can do, rather than what they cannot
- Using formative assessment to support learning

DIVERSITY

- Recognition and acceptance of students by students
- Recognition and acceptance of staff by staff
- Recognition and acceptance of students by staff

Appendix L Carer Interview schedule

PARENT INTERVIEW SCHEDULE (Version 2; Date: 21.05.17)

Study title: The participation of autistic pupils in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli

ERGO Study ID number: 26537

Thank you for coming to talk to me today. We are here to talk about your child's experiences of participating in decisions at the school. I have nine questions that I would like to ask you but you don't have to answer every question if you don't want to. What we talk about will only be used for the project and there are no right or wrong answers - I would just like to hear about your views and experiences. I am going to record our discussion today because I need help to remember what we've talked about. At the end of our discussion, I will transfer the recording to a password protected memory stick and delete the recording from the device. Only those directly involved in the research will listen to the recording. Of course, you can take a break at any time during the interview or if you change your mind about participating, I can stop the recording, delete it and none of your information will be used in the project. After the project is finished, I will write a final report of the findings. As you know, I won't type your name or the school's name as all data is kept anonymous. This means that even if small quotes are used in the write-up, no-one will be able to tell who said it. My final write-up will be shared with people interested in the project and you will be able to see this report too.

Is there anything you would like to ask me? How are you feeling today/how has your day been/how did you get here today?

1. Could you tell me a bit about how X came to this school?
2. What has been their experience of the school so far?
 - What is going well/not so well?
3. During his/her time at the school, how has X shared his/her views about life at school?
4. Could you give me an example where you and your child participated in a decision about their school experiences?
 - Who was there? Where did it take place? How long? When?
 - What went well/not so well?
 - What was your child doing in the discussion/meeting? How did they participate?
 - What helped?
 - What decision was made?
 - Did you participate in these discussions? If so, what was your experience of being included?
5. How does this compare to his/her previous schools?
6. What helps your child to participate in these sort of discussions? What doesn't help?
7. How important do you think it is to involve children and young people in decision-making?
8. Can you suggest any improvements to pupil participation within the school?
9. Is there anything else you would like to tell me about how your child has participated in decisions in the school?

Appendix M Staff interview schedule

STAFF INTERVIEW SCHEDULE (Version 2; Date: 21.05.17)

Study title: The participation of autistic pupils in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli

ERGO Study ID number: 26537

Thank you for coming to talk to me today. We are here to talk about pupil participation at the school, focussing mainly on the participation experiences of a pupil you work closely with. I have eight questions that I would like to ask you but you don't have to answer every question if you don't want to. What we talk about will only be used for the project and there are no right or wrong answers - I would just like to hear about your views and experiences. I am going to record our discussion today because I need help to remember what we've talked about. At the end of our discussion, I will transfer the recording to a password protected memory stick and delete the recording from the device. Only those directly involved in the research will listen to the recording. Of course, you can take a break at any time during the interview or if you change your mind about participating, I can stop the recording, delete it and none of your information will be used in the project. After the project is finished, I will write a final report of the findings. As you know, I won't type your name or the school's name as all data is kept anonymous. This means that even if small quotes are used in the write-up, no-one will be able to tell who said it. My final write-up will be shared with people interested in the project and you will be able to see this report too.

Is there anything you would like to ask me? How are you feeling today/how has your day been/how did you get here today?

1. Could you tell me a bit about your role in the school?
2. How important do you think it is for pupils to participate in making decisions within school (for example, in class)?
3. What sorts of decisions are made with pupils?
4. Could you give me a recent example of when X pupil has collaborated with you to decide about something related to his/her experiences in school?
 - Who was there? Where did it take place? How long? When?
 - Who initiated the discussion?
 - What went well/not so well?
 - What did the pupil do in that discussion? How did they give their views?
 - What helped?
 - What changed as a result of participation? For the young person/parent/teacher
5. What do you think you would identify as particularly good practice in this regard? How has this differed in schools where you've practiced before?
6. Could you suggest any improvements to pupil participation within the school?
7. Do you think that the emphasis on pupil participation in the Code of Practice has changed what you do as a teacher/pastoral support worker/tutor in this area?
8. Is there anything else you would like to tell me about how children participate in decisions in the school?

Appendix N Pupil activity

PUPIL ACTIVITY METHOD PROTOCOL (Version 2; Date: 21.05.17)

Study title: The participation of autistic pupils in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli

ERGO Study ID number: 26537

As the researcher only has two days a week in which to conduct the research, it is estimated that each pupil activity will be conducted during three individual lessons over the course of two weeks. Each lesson lasts between 45-50 minutes, depending on the lesson. Each pupil will meet with the researcher individually, during three stages of data collection:

| | |
|------------------------------------|---|
| Setting the scene | Estimated to take up to 1 lesson Reminded of the purpose of the project and right to withdraw Opportunity to ask questions Given schedule for the week – allocated lesson slot for taking photos and date for photo-elicitation interview Talk through photo activity using researcher script Opportunity to jot down initial ideas for photos A member of staff is nearby should they have any questions |
| Taking photos | Children have up to 1 lesson in which to take photos Accompanied by the researcher and one member of staff around the school Photos taken with a digital camera that is <u>only</u> used for the project Pupils take approx. 15-20 photos each Researcher shows them Appendix A again to remind them of the aim of the activity The researcher will bring a diary to take notes on the order and nature of photos taken, for example, areas of the school where the pupil has spent more time taking photos and any reflections that the pupils share at this stage School staff who the pupils want to take photos of will be asked their verbal permission beforehand. After the session with the pupil finishes, the researcher will then give the adult a consent form to obtain written consent for including photos in thesis write up and any published materials. Pupils view photos on camera screen after each shot, with option to re-take any they are unhappy with At the end of the session, photos are transferred to a secure password protected USB and deleted from the internal camera storage |
| Photo-elicitation interview | 1 lesson in which to discuss the photos This session consists of two parts: general discussion and photo sorting task The researcher uses the scripts in Appendix B Discussion recorded on a dictaphone and transferred to a password protected USB for secure storage Pupils reminded that participation is voluntary and they have the right to withdraw at any time Researcher brings two printed copies of the photos – one is given to the pupil to keep at the end of the interview A member of staff is nearby should they have any questions |

Researcher script

Thank you for taking part in the project. I would like you to take photographs about feeling or not feeling listened to at your school. Your photos could be of **places** in the school where you feel or *don't* feel listened to. They could also be of **people** or **objects** in the school that represent you feeling or not feeling listened to.



- Remember, there are no right or wrong answers – these are all your own ideas!
- Your photos will help me to understand how pupils are listened to at your school. It will also help me to think about how we can make the school better.
- No-one is going to get upset with you if you say there is nowhere that you feel listened to. The school really wants to know how they can improve!
- Before we use the camera, we can talk about your ideas and write down the types of photos you want to take

Plan for taking photos

- We will walk around the school together when you take the photos
- One of your teachers will always be with us
- For your safety, do not walk and take photos at the same time
- If you are unsure about anything, you can ask me or your teacher questions at any time
- You have one lesson to take your photos
- If you want to take a photo of a person, you must ask them first if this is OK.
- You can take around 15-20 photos



- After you take your photos, I will move them to a password protected USB stick where they will be kept safe. I will then delete your photos from the camera.
- On another day, I would like to show you the printed copies of your photos and ask you questions about them. This will help me to learn more about why you took each photo. I will bring two printed copies of the photos – one for you to keep and one for the project.
- Remember you can stop taking part in the project at any time. You can do this by choosing not to take photos or telling a teacher.

Photo elicitation interview

1a. General discussion script

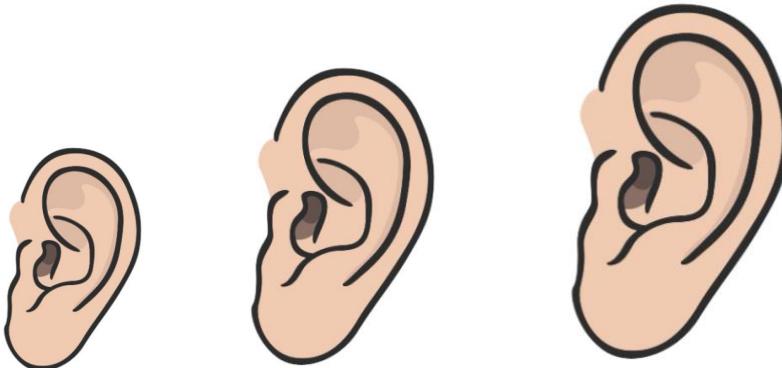
Today is really an opportunity for us to look at all the wonderful photos you took when we last met! I have two copies of each photo - one is for the project and one is for you to keep at the end. We have all of your photos here on the table for us to look at and what I want to understand is why you took them and why they are important to you. There are no right or wrong answers - it is about me listening to you and all of your ideas. We have one lesson to talk about your photos but you can talk as little or as much as you want and you can stop the conversation at any time.

As we talked about before, I am going to record what we say using this device (show the electronic device to the pupil) to help me remember what we have said. Only myself and other researchers involved in the project will listen to the recording. I will type up what we say about the photos but I won't type your name or the school's name as I'm not allowed to. This means that even if small quotes are used in the write-up, no-one will be able to tell who said it. When I have written down what we have said, I will delete the recording. Your photographs will only be used for the project. My final write-up will be shared with people interested in the project and you will be able to see this report too.

If you would like to take a break at any time, you can point to or lift this yellow card (researcher demonstrates this action) and I will stop the recording. If you have any questions or would like to stop the activity, you can speak to *NAME OF TEACHER* who will be next door.

1. Is there anything you'd like to ask me before we start or anything you are unsure about? / how has your day been so far? / How do you feel about looking at your photos?
2. Which photo would you like to talk about first?
3. Tell me more about this photo...
 - a. who/what/where/when?
4. That's interesting... why did you take a photo of...?
 - a. What does it mean to you/represent...?
 - b. What do you like/not like about that?
 - c. I remember when you took this photo you said... tell me more about that...
5. Why do you feel or not feel listened to/accepted/have a say etc. in this area of the school?
6. Is there anything that you would like to change about this...?
 - a. What might help you to feel more listened to ...?
7. What could we write down on the back of the photo to help me remember what we've said?
8. Do you have any questions for me?

1b. Photo sorting task script



*

Now I would like us to do a practical exercise with your photos. Look at all the photos and put them into three groups: under the big ear, I want you to put all of the photos that show you being most listened to, under the medium ear, where you are sometimes listened to and under the small ear, where you are not/least listened to. Some pupils have a lot of photos in one pile and only one or two in the other groups. Others have a few in each pile. These are all your own ideas so you can put the photos wherever you like – even halfway between two groups if you can't decide. Follow up questions depending on where pupils have placed their photos:

- Why did you put these photos in the 'listened to' pile?
- What helps you feel listened to here? (e.g. within the environment)
 - o Prompt – I am a student too. I feel listened to when my teachers ask me what I think about my lessons and make changes based on what I've said.
- Why did you put these in the 'not listened to' pile?
- Is there anything the school could do to make this better? What would help you to feel more listened to here?
- What words could we write next to the photo to help us remember what you've said? (write on post-it notes)

Take photo of the groupings and annotations

*Images of the ears are sourced from www.twinkl.co.uk in line with their copyright policy

Appendix O Information sheet for the Headteacher



INFORMATION SHEET FOR HEAD TEACHER (Version 2; Date: 21.05.17)

Study title: The participation of autistic pupils in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli

ERGO Study ID number: 26537

Dear

I am a student at the University of Southampton. I am studying a course called Educational Psychology, which will help me to support children to learn well and feel positive about school. As part of my course, I am doing a research project on the participation of children with autism in decision-making at school. This involves an in-depth analysis of pupil participation at one school. I hope the results of the project will help me to better understand good practice in this area.

Before you decide to take part, please read the information below. If you are happy for you and your child to take part, you will be asked to sign a consent form.

What is the project about?

I would like to understand what school practices (e.g. social interactions, school policies and teaching strategies) help autistic pupils to participate in decisions about their school experiences. To do this, I would like to observe at least six autistic pupils in a range of school contexts (e.g. subject lessons and education plan review meetings) and explore their experiences of participations through photographs they take of places they feel listened to at the school. I would also like to interview their parent/guardian and school staff to gain more information about each pupil's participation experiences at the school and their views of pupil participation more generally (e.g. examples of when the pupil shared their views about school life, what helped and suggestions for improvement).

Why has the school been asked to take part?

The pupils at this particular school fit the purpose of the research because they are those who are most likely to be marginalized from decision-making processes according to the research literature—autistic pupils and pupils who have had unsuccessful mainstream placements. The research is focussed on the participation experiences of children with autism in decision-making at school. I will therefore be specifically seeking consent from parents of at least six children with autism at the school, as stated on their Education Health Care Plan and/or Statement of Educational Needs and assent from the young person themselves. It will also be helpful to speak to the school staff that work closely with these pupils so that I have a range of views which gives me a more well-rounded picture of each pupil's participation experiences at school.

What will happen to participants if they take part?

The researcher will carry out observations of approximately six autistic pupils at the school in a range of decision-making contexts such as subject lessons and education plan reviews. These same pupils will also be asked to take photos of places in the school where they feel listened to and explain their choices to the researcher using their printed photos as prompts. The parents of the pupils and the staff that work closely with them will be asked to complete a semi-structured interview lasting approximately 30 minutes; the purpose of the interview is to seek their views on each pupil's participation experiences at the school. Both the parent/staff interviews and the discussion with the pupil will be recorded on an electronic device, later transcribed and analysed using thematic analysis. The photos and recordings will be stored on a secure, password protected memory stick. School documents such as the school's behaviour policy might also be included in the analysis but this is not the priority source of data.

Are there any benefits to taking part?

The information participants give could help us to improve our understanding of the practices that help autistic pupils to participate in decisions about their school experiences. The results could also improve the nature of pupil

participation at your school as well as benefit other schools who want to improve practice in this area.

What are the possible disadvantages?

I do not think there will be any risks or dangers from taking part in the project.

Will people find out about what they say during the interview?

Everything they say in the interview will be kept 'confidential'. This means that I will not tell anyone what a specific person has talked about. The recordings will be deleted from the electronic device after the interview; they will only be stored on a secure password encrypted memory stick. However, if they say something which makes me worry about a child's safety or the safety of others, I will have to share this information.

I will write a report about all of the information collected in the research. All of the responses they give will be kept 'anonymous' in line with data protection regulations. This means that names or any other information which might identify who they are will not be written in the report. I will not be able to access their personal information—this will be kept with the school.

What will happen to the results of the project?

Once I have collected and analysed the data, I will write a report about the findings which will form part of my doctoral thesis in Educational Psychology, as required by the University of Southampton. A summary of the findings will also be shared with the school and those who took part in the research.

Do I have to take part?

Your participation in the project is entirely voluntary; you do not have to consent to take part if you do not want to.

What if there is a problem or I change my mind?

If you are worried about the research, you can speak to the Head Teacher (MarkFry@newforestcare.co.uk) or the researcher (Chantelle Zilli C.Zilli@soton.ac.uk).

You can also stop the interview at any time. If you decide not to continue, the audio recording will be destroyed and none of the information will be used in the report.

What happens if something goes wrong?

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ.

Phone: +44 (0)23 8059 3856, email fshs-rso@soton.ac.uk

Appendix P Consent form for the Head teacher



HEAD TEACHER CONSENT FORM (Version: 2; Date: 21.05.17)

Study title: The participation of pupils with autism in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli
ERGO Study ID number: 26537

Please initial the box(es) if you agree with the statement(s):

I have read and understood the Information Sheet (Date: 21.05.17/Version 2) and have had the opportunity to ask questions about the study.

I agree to my school taking part in this research project.

I understand that the interview with school staff and parents and the pupil activity will be audio recorded.

I understand that the audio recordings and photos are securely stored and destroyed after twelve months unless further permission from participants is given.

I understand that the school's participation is entirely voluntary and that I may withdraw consent at any time without my legal rights being affected.

I understand that the data collected will be *anonymous* and that children's names and the school's name will not be written in any materials used in the research, including the write-up of the project

I understand that the data collected will be *confidential* and that no-one will know what a specific person has talked about unless there is a risk to themselves or others

Name of Head Teacher (print name).....

Signature

Date.....

Appendix Q Information sheet for carers



INFORMATION SHEET FOR PARENT/GUARDIAN (Version 2, Date: 21.05.17)

Study title: The participation of autistic pupils in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli

ERGO Study ID number: 26537

Dear

I am a student at the University of Southampton. I am studying a course called Educational Psychology, which will help me to support children to learn well and feel positive about school. As part of my course, I am doing a research project on the participation of children with autism in decision-making at school. This involves an in-depth analysis of pupil participation at one school. I hope the results of the project will help me to better understand good practice in this area.

Before you decide to take part, please read the information below. If you are happy for you and your child to take part, you will be asked to sign a consent form.

What is the project about?

I would like to understand what school practices (e.g. social interactions, school policies and teaching strategies) help autistic pupils to participate in decisions about their school experiences. To do this, I would like to observe six autistic pupils in a range of school contexts (e.g. subject lessons and education plan review meetings) and explore their experiences of participations through photographs they take of places they feel listened to at the school. I would also like to interview their parent/guardian and school staff to gain more information about each pupil's participation experiences at the school (e.g. examples of when the pupil shared their views, what helped and ideas for improvement).

Why have I been asked to take part?

The research is focussed on the participation experiences of children with autism in decision-making at school. I will therefore be specifically seeking consent from parents of autistic pupils at the school, as stated on their Education Health Care Plan and/or Statement of Educational Needs. The consent will be for the participation of both the parent and the young person in the research. It is helpful to have both parent and pupil views in the study as this gives a more well-rounded picture of the pupil's participation experiences.

What will happen to me if I take part?

You will be asked to complete a questionnaire about your child's behaviour over the last 3 months, for example, their attention and social interaction skills. This information will help the researcher to make adaptations to the pupil activity where appropriate. You will also complete a semi-structured interview with the researcher which will take place at an agreed time at the school. The questions will be about the participation experiences of your child at school. The Head Teacher will provide a quiet room where no one else can listen to what you are saying. It will take approximately 30 minutes to complete. During the interview, your responses will be recorded on an electronic device. After the interview, the recording will be moved to a 'secure' memory stick so that it can be stored safely. It is secure because the memory stick can only be opened with a password which prevents others from listening to what you have said. You do not have to answer every question if you do not want to and you can withdraw from the interview at any point if you change your mind.

What will happen to my child if they take part?

Your child will be observed in up to five decision-making contexts within the school, for example, subject lessons and review meetings for behaviour plans. During the observation, I will take notes on how the pupil participated, for example, whether and how they chose activities, worked with others and shared views about their preferences. To minimise any discomfort your child may feel about being observed, s/he will be introduced to the researcher during the consent process and be given advance notice of when the observation will take place. The researcher will also dress in casual clothes to every visit (e.g. jeans and t-shirt) and limit the amount of notes taken during the observation to only key information and abbreviations, which might help pupils to feel more comfortable about being observed. Spending time in the classroom over multiple observations will also help him/her to become more familiar with the researcher.

The researcher will also ask your child to take part in an activity that will take approximately two to three lessons to complete. During one lesson, your child will be asked to take photographs about feeling or not feeling listened to at school. Photos may be of, for example, places, people and objects in the school. If your child takes a photo of themselves or another person *and* this photo is used in the report, their faces will be blacked out so that no-one will be able to identify who they are (see example below). Any other information in the background that could also identify the pupil or the school will also be blacked out.



During the project, your child will be accompanied by the researcher and a member of school staff at all times. This means that when they walk around the school to take the photos, there will always be a familiar adult who they can talk to. They will be told in advance when the activity will take place. After the photos are taken, they will be transferred to a secure, password protected memory stick and deleted from the camera.

The researcher will print two copies of the photos—one for the project and one for your child to keep.

During another lesson, *your child will also be asked to meet with the researcher to look at each photo and explain why they took them*. This discussion will be recorded on an electronic device and transferred to a password protected memory stick after the discussion. The recording will then be deleted from the device. The discussion will take place in a location that is most familiar and comfortable for your child within the school. A member of staff will be present in case they have any questions or want to stop the activity.

Are there any benefits to taking part?

The information you and your child give could help us to improve our understanding of the practices that help autistic pupils to participate in decisions about their school experiences. The results could also improve the nature of pupil participation at your child's school as well as benefit other schools who want to improve practice in this area.

What are the possible disadvantages?

I do not think there will be any risks or dangers from taking part in the project.

Will people find out about what I say or my child says during the interview/pupil activity?

Everything you and your child says in the interview and pupil activity will be kept '*confidential*'. This means that I will not tell anyone what we have talked about. The recordings will be deleted from the electronic device after the interview/pupil activity; they will only be stored on a secure password encrypted memory stick. However, if you or your child says something which makes us worry about their safety or the safety of others, I have to share this information with the appropriate agency.

All the responses you and your child give will be kept 'anonymous' in line with data protection regulations. This means that your name, the name of your child, teachers and the school or any other information which might identify who you are *will not* be written in the report. Therefore, even if small quotes are used in the write-up no-one will be able to tell who said it. Any printed photos included in the report will also be kept anonymous by blacking out the faces of persons and any other identifying features. I will not be able to access yours or your child's personal information—the Head Teacher will keep all of your contact details. After the project has finished, the photos and recordings will be kept in a locked cabinet at the university and destroyed after twelve months unless further permission from you is given.

What will happen to the results of the project?

Once I have collected and analysed the data, I will write a report about the findings which will form part of my doctoral thesis in Educational Psychology, as required by the University of Southampton. The report may also be submitted to a journal or other forms of publication. A summary of the findings will also be shared with the school and those who took part in the research.

Do I have to take part?

You do not have to give permission for you or your child to take part if you do not want to. Your child does not have to do the pupil activity or complete these forms if s/he does not want to. You may also stop the interview at any time if you do not want to carry on.

What if there is a problem or I change my mind?

If you are worried about the research, you can speak to Mr----, the Head Teacher ([Email address](#)) or the researcher (Chantelle Zilli C.Zilli@soton.ac.uk).

If your child feels uncomfortable about being observed in school or taking part in the pupil activity, they can change their mind at any time. You can also stop the interview at any time. If you/they decide not to continue, the audio recording and photos will be destroyed and none of the information will be used in the report.

What happens if something goes wrong?

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email fshs-rso@soton.ac.uk

Appendix R Consent form for carers



PARENT/CARER CONSENT FORM (Version 2; Date: 21.05.17)

Study title: The participation of pupils with autism in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli
ERGO Study ID number: 26537
RGO reference number:

Please initial the box(es) if you agree with the statement(s):

I have read and understood the Information Sheet (Date: 21.05.17/Version 2) and have had the opportunity to ask questions about the study.

I agree to my child and I taking part in this research project and agree to our data being used for the purposes of this study.

I agree to being interviewed and have this audio recorded.

I agree to my child taking part in the pupil activity and have this audio recorded.

I agree to the photos and quotes from myself and/or my child being used in the write up of this study and am aware that they will be anonymised and identifiable information removed.

I understand that the audio recordings and photos are securely stored and destroyed after twelve months unless my further permission is given.

I understand that my participation and that of my child is entirely voluntary and that I may withdraw consent at any time without my legal rights being affected.

Name of your child (print name).....

Name of parent/guardian (print name).....

Parent/guardian signature

Date.....

Appendix S Information sheet for pupils



INFORMATION SHEET FOR PUPILS (Version 2; Date: 21.05.17)

Study title: The participation of autistic pupils in decision-making about their school experiences:
A case study of one school

Researcher name: Chantelle Zilli

ERGO Study ID number: 26537

Dear

I am a student at the University of Southampton.

I am writing to ask if you would help me with my project.



Before you decide to take part, please read the information below. If you are happy to take part, you will be asked to sign the slip at the end of the letter.

What is the project about?

I would like to learn about the experiences of children with autism at your school:

I would like to find out about the decisions they make at school

I would like to understand where and when they feel listened to

I would like to know what schools can do to help them feel listened to at school

Why have I been asked to take part?

It would be helpful to speak to you and other children with autism at your school.

I would also like to speak to your parents and one of your teachers. This will help me to get different ideas about your experiences of making decisions at school.

What will happen to me if I take part?

Visiting your lessons

I would like to come to around five of your lessons. This will help me to learn about the decisions and choices you make in class. By seeing you in class, I will also learn about how you work with others and join in with activities.

I will tell you the days I will be coming to the school. I will also tell you the lessons I would like to go to but if there are lessons you don't want me to see – you can say "no" and that is OK.

In the lesson, I will sit at the table with you and the other pupils in your class. I will write notes about what I see, for example, the type of activity you did.

If you meet with a teacher about your education plan at school, it would also be helpful to see this.

Activity

I would like you to take **photos** about feeling or *not* feeling listened to at school. There are no right or wrong answers as these are all your own ideas!



I will come to your school and bring a camera for you to use.

We will walk together around the school when you take the photos. One of your teachers will also be with us.

We will have **one lesson** to take the photos – you will know which lesson we will use to take the photos.

If you take a photo of a person, their faces will be blurred in the printed photos so that no-one will know who the person is.

At the end of the activity, I will move all your photos to a 'secure' memory stick. This means that the memory stick can only be opened with a password so that the photos are kept safe. I will then delete your photos from the camera.

Seeing your printed photos

During another lesson, we will meet to talk about your photos – you will know which lesson we will use to talk about the photos.

I will bring two copies of the photos – one for you to keep and one for the project

If there are any photos you don't want to go in the project book that is okay – you can say "no" and I won't put those photos in the book.

I will ask you questions about each of the photos. This will help me to learn more about why you took each photo. When we talk about them, I will record what we say using an electronic device. After I will move the recording to a 'secure' memory stick.

Are there any benefits to taking part?

The information you give will help me to understand how you take part in decisions at school and help other adults to understand your experiences.

Your ideas could help improve your experience at school and the experience of other pupils.

Are there any disadvantages to taking part?

I do not think there will be any risks or dangers from taking part in the project.

If you feel uncomfortable at any time you can stop taking part at any time. You can also speak to Mr (HT name) if you have any worries.

Will people find out about what I say?

Everything you tell me during the pupil activity will be 'confidential'. This means that we will not tell anyone what we talk about. But if you say something which makes me worry about your safety or the safety of others, I have to share this information.

For my project, I will type up what you say during the pupil activity. When I finish writing my project into a book, other people will be able to read what you say. But all of your answers will be 'anonymous'. This means that the project book won't have your name or school name as I'm not allowed to write that. Even if small quotes are used in the write-up no-one will be able to tell who said it. Two examples are:

The child likes sports. He said "*I love football because it's fun. I play everyday*" which tells me that it is an important part of his life.

He also likes food but does not enjoy eating vegetables that are green. He said "*I hate broccoli because it's green and smells bad*" and other children in the group shared his view.

Do I have to take part?

You do not have to do the project or complete these forms if you do not want to.

You can stop at any time if you do not want to carry on.

What if there is a problem or I change my mind?

If you have any worries or questions about the project, you can speak to Mr (HT name) at any time. You can also speak to Chantelle, the student researcher (Chantelle Zilli: C.Zilli@soton.ac.uk).

If you feel uncomfortable or change your mind, you can stop me coming to your lesson or taking photos with you at any time. I will bring a blue card that you can use to show me that you want to stop being a part of the project.

If you decide to stop, the recording of us talking will be destroyed and none of the information will be used in the project book.

What happens if something goes wrong?

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email fshs-rso@soton.ac.uk.

Appendix T Summary of the pupil activity



1. Visiting lessons

I won't see more than five lessons

I can see your favourite lesson

Tell me if there is a lesson you don't want me to go to

You can change your mind at any time

2. Photo project

Take photos of places where you feel or don't feel listened to at school

We look at your printed photos together

You tell me about each photo



2. Speaking to adults who know you well

I want to know what your teacher and parents think about your experience at school.

I will ask them questions like: What helps this pupil to feel listened to in class?

How important is it for him/her to be a part of making decisions?

Appendix U Assent form for Pupils

If you would like to help me, please tick to show you agree with the following statements:

I understand what the research project is about

I agree to being observed/seen in class by the researcher



I agree to taking part in the pupil activity and have this audio recorded

I understand that the pupil activity will be *confidential* and no-one will know what I've talked about unless there is a risk to myself or others

I understand that what I say might be used as small quotes

in the write-up and that this will be *anonymous* so nobody will be able to tell who said it

I know that I can ask any questions and who I can ask

I know that I can change my mind at any time and that it is okay to stop taking part

Please sign your name to show you are happy to take part in the research

Name: _____ Signature:

Appendix V Information sheet for staff

INFORMATION SHEET FOR SCHOOL STAFF (Version 2, Date: 21.05.17)

Study title: The participation of autistic pupils in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli

ERGO Study ID number: 26537

Dear

I am a student at the University of Southampton. I am studying a course called Educational Psychology, which will help me to support children to learn well and feel positive about school. As part of my course, I am doing a research project on the participation of children with autism in decision-making at school. This involves an in-depth analysis of pupil participation at one school. I hope the results of the project will help me to better understand good practice in this area.

Before you decide to take part, please read the information below. If you are happy to take part, you will be asked to sign a consent form.

What is the project about?

I would like to understand what school practices (e.g. social interactions, school policies and teaching strategies) help autistic pupils to participate in decisions about their school experiences. To do this, I would like to observe at least six autistic pupils in a range of school contexts (e.g. subject lessons and education plan review meetings) and explore their experiences of participations through photographs they take of places they feel listened to at the school. I would also like to interview their parent/guardian and school staff to gain more information about each pupil's participation experiences at the school and their views of pupil participation more generally (e.g. examples of when the pupil shared their views about school life, what helped and suggestions for improvement).

Why have I been asked to take part?

The research is focussed on the participation experiences of children with autism in decision-making at school. I will therefore be specifically seeking consent from school staff that work closely with autistic pupils at the school, as stated on their Education Health Care Plan and/or Statement of Educational Needs. It is helpful to have school staff as well as parent and pupil views as this gives a more well-rounded picture of each pupil's participation experiences at school.

What will happen to me if I take part?

Each pupil that takes part in the study will be observed in up to five decision-making contexts within the school, for example, subject lessons and review meetings for behaviour plans. This means that you will see me in some of the contexts where you work with the pupil and I may ask you questions about the activities I've seen during the observation and/or in the interview (e.g. whether you feel the pupil was engaged, participated, what helped the activity to work well/not so well).

You will also be asked to complete a semi-structured interview with the researcher which will take place at an agreed time at the school. The questions will be about the participation experiences of the pupil you work with as well as your views about pupil participation at the school. The Head Teacher will provide a quiet room where no one else can listen to what you are saying and it will take approximately 30 minutes to complete.

During the interview, your responses will be recorded on an electronic device. After the interview, the recording will be moved to a 'secure' memory stick so that it can be stored safely. It is secure because the memory stick can only be opened with a password which prevents others from listening to what you have said. You do not have to answer every question if you do not want to and you can withdraw from the interview at any point if you change your mind.

Are there any benefits to taking part?

The information you give could help us to improve our understanding of the practices that help autistic pupils to participate in decisions about their school experiences. The results could also improve the nature of pupil participation at your school as well as benefit other schools who want to improve practice in this area.

What are the possible disadvantages?

I do not think there will be any risks or dangers from taking part in the project.

Will people find out about what I say during the interview?

Everything you say in the interview will be kept 'confidential'. This means that I will not tell anyone what we have talked about. The recordings will be deleted from the electronic device after the interview; they will only be stored on a secure password encrypted memory stick. However, if you say something which makes me worry about a child's safety or the safety of others, I have to share this information with the appropriate agency. All the responses you give will be kept 'anonymous' in line with data protection regulations. This means that your name, the name of pupils, the school or any other information which might identify who you are will not be written in the report. Therefore, even if small quotes are used in the write-up no-one will be able to tell who said it. I will not be able to access your personal information—the Head Teacher will keep all of your contact details. After the project has finished, the recordings will be kept in a locked cabinet at the university and destroyed after twelve months unless further permission from you is given.

What will happen to the results of the project?

At the end of the project, I will write a report about the findings which will form part of my doctoral thesis in Educational Psychology, as required by the University of Southampton. The report may also be submitted to a journal or other forms of publication. A summary of the findings will also be shared with the school and those who took part in the research.

Do I have to take part?

Your participation in the project is entirely voluntary; you do not have to consent to take part if you do not want to.

What if there is a problem or I change my mind?

If you are worried about the research, you can speak to Mr-----, the Head Teacher ([Email address](#)) or the researcher (Chantelle Zilli C.Zilli@soton.ac.uk). You can also stop the interview at any time. If you decide not to continue, the audio recording will be destroyed and none of the information will be used in the report.

What happens if something goes wrong?

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email fshs-rso@soton.ac.uk

Appendix W Consent form for staff



SCHOOL STAFF CONSENT FORM (Version 2; Date: 21.05.17)

Study title: The participation of pupils with autism in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli
ERGO Study ID number: 26537

Please initial the box(es) if you agree with the statement(s):

I have read and understood the Information Sheet (Date: 21.05.17/Version 2) and have had the opportunity to ask questions about the study.

I agree to taking part in this research project and agree to my data being used for the purposes of this study.

I agree to being interviewed and have this audio recorded.

I agree to quotes from myself being used in the write up of this study and am aware that they will be anonymised and identifiable information removed.

I understand that the audio recordings of the interview are securely stored and destroyed after twelve months unless my further permission is given.

I understand that my participation is entirely voluntary and that I may withdraw consent at any time without my legal rights being affected.

Name of school staff (print name).....

Signature

Date.....

Appendix X Information sheet for staff photographs



PHOTOGRAPHS INFORMATION SHEET (Version 2; Date: 21.05.17)

Study title: The participation of autistic pupils in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli

ERGO Study ID number: 26537

Dear

I am a student at the University of Southampton. I am studying a course called Educational Psychology, which will help me to support children to learn well and feel positive about school. As part of my course, I am doing a research project on the participation of children with autism in decision-making at this school. This involves different forms of data collection, including asking autistic pupils to take photos of people, objects and places in the school which shows where they feel or don't feel listened to. I hope the results of the project will help me to better understand good practice in this area.

I am writing to you specifically because one of the autistic pupils you know at the school would like to take your photo for the project. I am therefore writing to ask for your written permission to be photographed and have the photo printed for use in the research.

What will happen to the photo?

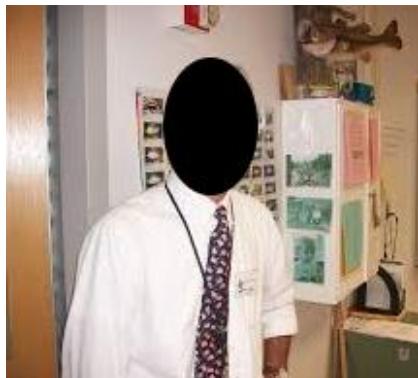
All photos the pupil takes, including your photo, will be printed and discussed with the researcher. This will involve a recorded discussion where the pupil explains why they took each photo.

After the photo is taken, it will be transferred from the camera to a 'secure' memory stick so that it can be stored safely for the duration of the project. It is secure because the memory stick can only be opened with a password which prevents others from seeing the photos. The photo will be deleted from the camera once it is on the memory stick.

After the project has finished, the photos will be kept in a locked cabinet at the university and destroyed after twelve months unless further permission from you is given.

This final report will be submitted as part of the DEdPsy professional qualification at Southampton University. The report may also be submitted to a journal or other forms of publication, which means that other adults can see the report. This is important to know because the final report may include this photograph but I will not write any names of the staff, pupils, parents or the school as all data will be kept anonymous so that no individual can be identified.

If the photo is printed for use in a journal publication, your face will be blacked out and any features that could identify the school (e.g. a display with the school's name) will also be blacked out. This means that no-one will be able to identify who you are from the photo. See example below:



Do I have to give my permission?

You do not have to give permission for your photograph to be taken if you do not want to.

What if there is a problem or I change my mind?

If you have any questions or want to know more about the project, you can speak to the student researcher, Chantelle Zilli: C.Zilli@soton.ac.uk. If you change your mind about the photo being used in the project, the researcher will destroy the photo and it will not be used in the report.

Appendix Y Consent form for photographs



PHOTOGRAPHS CONSENT FORM (Version 2; Date: 21.05.17)

Study title: The participation of pupils with autism in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli

ERGO Study ID number: 26537

RGO reference number:

Please initial the box(es) if you agree with the statement(s):

I have read and understood the Photograpbs Information Sheet (Date: 21.05.17, Version 2) and have had the opportunity to ask questions about the study.

I agree to my photograph being taken and used for the purposes of the research.

I understand that my name and the name of pupils, parents, staff and the school will not be written in any materials used in the research and that my face will be blacked out in the photo, so that no-one will be able to identify who I am.

I understand that the photo is securely stored and destroyed after twelve months unless further permission from me is given.

I understand that my participation is entirely voluntary and that I may withdraw consent at any time without my legal rights being affected.

Name (print name).....

Signature

Date.....

Appendix Z Staff and parent debrief sheet



Debriefing Statement (Version: 2, Date: 21.05.17)

Study title: The participation of pupils with autism in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli
ERGO Study ID number: 26537

A big thank you for taking part in this project!

The aim of this research is to understand how pupils with autism participate in making decision about their school experiences. The data from this study will help to develop our understanding of the practices (e.g. social interactions, school policies and teaching strategies) that help pupils with autism to better participate in decisions about their school life. The project could help to improve the nature of pupil participation at your school as well as benefit other schools who want to improve practice in this area.

The research will not use deception and results of this study will not include your name or the name of your child, school staff, the school or any other identifying characteristics. You may have a copy of this summary if you wish and you may also request a summary of the research findings once the project is completed.

Thank you again!

If you change your mind about participation or you have any further questions, please speak to Mr ----(HT) at the school or contact the student researcher, Chantelle Zilli: Chantelle.Zilli@soton.ac.uk

Signature _____ Date _____

From Chantelle

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email fshs-rso@soton.ac.uk

Appendix AA Pupil debrief script

Debrief script for researcher

The researcher will read the script below to explain to the children taking part in this study what a debriefing statement is. They will then read this to them and give them the document.

Child's debrief script:

Now we have finished talking about your photos, I wanted to say thank you for taking part in my research project. I have really enjoyed talking to you and finding out what you think about your experiences at school. I have something to give you, called a debrief statement. What this is, is a document that says what the research was about and who to contact if you have questions about the research after today or if you feel worried about anything we talked about.

If it is OK I would like to read this document to you and then you can keep it after. Your parent(s) also has one of these and their paper has contact details on so they can arrange for you to speak to someone if you do have questions.

Appendix BB Pupil debrief sheet



Debriefing Statement (Version: 2, Date: 21.05.17)

Study title: The participation of pupils with autism in decision-making about their school experiences: A case study of one school

Researcher name: Chantelle Zilli
ERGO Study ID number: 26537

A big thank you for taking part in this project!

- I came to your school so I could learn more about your experiences at school
- I enjoyed listening to all of your ideas!
- The photos you took and everything we talked about were very interesting – It will really help me to understand how you are being listened to at your school.
- Remember I won't write your name in the write-up because I'm not allowed to

Thank you again!

If you have any questions about the research, please speak to Mr ----(Head teacher).

Signature _____

Date

From Chantelle

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