

THE INCLUSION OF AUTISTIC CHILDREN IN THE CURRICULUM AND ASSESSMENT IN MAINSTREAM PRIMARY SCHOOLS

by

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Abstract

Growing numbers of children are being diagnosed with autism in the UK and, against a backdrop of increased legislative and administrative provisions for educational inclusion, more autistic children are being educated in mainstream primary school settings. However, while there is evidence of the continued exclusion of autistic children, their performance in school tests seems poor, and their longer-term outcomes impoverished. Meanwhile, debates continue about the nature of autism itself. My project, informed by the social model of disability, theories of language and interpretation, inclusion, difference and aspects of feminism, aims to uncover the reasons behind the difficulties autistic children are experiencing in schools, by considering if, and how they are accessing the curriculum and tests. Employing a predominantly interpretative paradigm and a case study design, and based in five mainstream primary schools in England, the views of school staff, autistic children and their parents, as well as a sample of autistic adults, are incorporated. My findings show that by setting aside the association of autism with impairments, listening to autistic children, engaging with them meaningfully and enabling their own learning styles and particular dispositions to be manifest, educational inclusion, and positive outcomes for all, are much more likely to occur. Consequently, in these findings, there are important understandings for guiding practical pedagogy to enable inclusion.

for my boy

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Table of Contents

| | Page |
|---|-------------|
| Introduction | 1 |
| Chapter 1: Literature Review | 6 |
| Chapter 2: Conceptual Framework | 51 |
| Chapter 3: Methodology | 84 |
| Chapter 4: Research Methods | 119 |
| Chapter 5: Findings (questionnaire data) | 143 |
| Chapter 6: Findings (observation and interview data) | 168 |
| Theme 1: Support for Children | 193 |
| Theme 2: School Curriculum | 211 |
| Theme 3: Educational Priorities | 227 |
| Theme 4: Assessment and Tests | 237 |
| Theme 5: Communication | 251 |
| Theme 6: Interests | 267 |
| Theme 7: Inclusion and Exclusion | 278 |
| Theme 8: Descriptions of Autism | 291 |
| Chapter 7: Summative Discussion and Conclusions | 305 |
| Appendices | ix |

List of Illustrations

| <u>Figures</u> | Page |
|---|-------------|
| Figure 1: Percentage of autistic children in state-funded primary, secondary and special schools in England, 2012 – 2014 | 16 |
| Figure 2: Pupils with SEN as a percentage of all pupils in England, 2012 – 2014 | 17 |
| Figure 3: Recruitment of Participants | 110 |
| Figure 4: Results of phone-calls to schools | 111 |
| Figure 5.1: Educational priorities of parents of children without SEND | 147 |
| Figure 5.2: Educational priorities of parents of children with SEND | 147 |
| Figure 6: Results (percentage) of parents’ structured question on school tests | 150 |
| Figure 7: Process of uploading and coding interview and observation data | 169 |
| Figure 8: Outlier 1 | 184 |
| Figure 9: Outlier 2 | 188 |
| Figure 10: Code mapping | 191 |
| Figure 11: Support for children | 207 |
| Figure 12: School Curriculum | 223 |
| Figure 13: Educational Priorities | 233 |
| Figure 14: Summary of impact of access to interests | 275 |
| Figure 15: An understanding of autism as the starting point to educational inclusion | 310 |
| | |
| <u>Plate</u> | |
| Plate 1: The living room of AA9 | 301 |

List of Tables

| <u>Tables</u> | Page |
|---|-------------|
| Table 1: Key word database search results | 14 |
| Table 2: Phonics results 2012 – 2014 | 20 |
| Table 3: Child and parent participants | 114 |
| Table 4: Summary of research instruments and dataset | 126 |
| Table 5: Methods of data collection for autistic children | 128 |
| Table 6: Summary of process of data collection | 129 |
| Table 7: School-based participants | 143 |
| Table 8: Results (RAW) of parents’ structured question on school tests | 149 |
| Table 9: Parents’ responses to open question about tests in school | 152 |
| Table 10: First cycle codes following final node management | 171 |
| Table 11: Reasons for providing support (school staff) | 193 |
| Table 12: Educational priorities: autistic adults and parents of autistic children | 228 |
| Table 13: Reasons why tests are difficult to access for autistic children | 239 |
| Table 14: Recommendations for adaptations/accommodations for tests | 244 |
| Table 15: Positive impact of accessing interests | 268 |
| Table 16: Reasons for spending time away from main cohort | 282 |
| Table 17.1: Autism is difficult to define | 291 |
| Table 17.2: Autistic children not as expected | 292 |
| Table 17.3: Autism is a spectrum condition | 292 |
| Table 17.4: Autism is a problematic condition | 293 |
| Table 17.5: Problems associated with autism | 294 |
| Table 17.6: Autistic people are different (strange) | 296 |
| Table 17.7: Autistic people are different (special) | 297 |
| Table 17.8: Perfectionism and attention to detail | 299 |
| Table 17.9: Autistic learning style | 299 |

Terms and Abbreviations

ASD: Autistic Spectrum Disorder

ASC: Autism Spectrum Conditions

Asperger's: a form of autism (see 'Terminology', p. 5)

LA: Local Authority

NC: National Curriculum

SA: School Action

SA+: School Action Plus

SATs: Standard Assessment Tests

SEN*: Special Educational Needs

SEND*: Special Educational Needs and Disabilities

Statement of SEN:** Statement of Special Educational Needs

EHCP:** Education, Health and Care Plan

*'SEND' replaced 'SEN' in 2014. Both acronyms are used in this thesis in accordance with the articles or reports referenced. In my discussion, I use the current term, SEND.

**EHCPs started replacing Statements of SEN in 2014.

List of Appendices

| | Page |
|---|-------------|
| 1. Appendices (1): Applications for ethical review A – C | ix |
| 2. Appendices (2): Representative sample* of research instruments: | xx |
| a. Recruitment letter (autistic adults) | |
| b. Semi-structured interview (class teacher) | |
| c. Participant information sheet (SENCOs) | |
| d. Child assent form | |
| e. Consent form (parents/carers) | |
| f. Focus group schedule (parents/carers) | |
| g. Letter to parents with no identified SEND | |
| 3. Appendices (3): List of references | xxx |

*Due to the high number of research instruments (29), and the fact that there were further subdivisions of these for individual participants and schools, it is not practical to include them all. However, I have included an example of each type of research instrument, as well as those highlighted in the main thesis: the latter incorporates examples of questionnaires.

INTRODUCTION

‘All that we lack at birth, all that we need when we come to man’s estate, is the gift of education.’ (Rousseau, 1762/1993, p. 6)

This quotation, which I included as part of my original, PhD research proposal written in 2012, serves as a reminder of my initial intentions when I decided to embark on a doctorate. While the completion of a thesis has felt at times like a Herculean – if not Sisyphean – task, the fundamental principle which has underpinned the entire endeavour has been that everyone can be enriched by education, and that this should be accessible on an equal basis to all children. Indeed, this tenet is enshrined in our international and national laws (Convention on the Rights of Persons with Disabilities [CRPD], 2006; Equality Act, 2010) and centres on the core notion of ‘inclusion’, a concept often cited, but highly contested, and subject to multiple interpretations (Norwich, 2008; Ravet, 2011). Meanwhile, as autism diagnoses are increasing (Baron-Cohen et al., 2009), so the numbers of autistic children in mainstream schools are growing too (Emam and Farrell, 2009).

However, the impact of these developments on inclusive practices is unclear. Indeed, if there remains a presumption of mainstream inclusion for all children (Children and Families Act, 2014), evidence of the exclusion of autistic children, in particular, suggests a disconnect between this ambition and reality. For example, Batten et al. (2006) found not only that exclusions of autistic children from school were increasing, but that growing numbers were out of school for more than a year (p. 37). Similarly, Humphrey (2008) maintains that autistic children are more than 20 times more likely to be excluded from school than children without SEN.

Meanwhile, discussions continue, unresolved, about the benefits of a modified curriculum, specialist pedagogies or alternative educational priorities for autistic children (Jordan, 2005; Jones et al., 2008). Indeed, while teachers experience strain as a result of the presence of autistic children in their class (Emam and Farrell, 2009), and the role of teaching assistants is unclear (Cremin, Thomas and Vincett, 2005), there is less focus on the impact of these debates and uncertainties on the children themselves. Further, data from the Department for Education (DfE) suggest autistic children perform poorly in school tests (DfE, 2013a), and that the longer-term outcomes of autistic people are impoverished too (Wittemeyer et al., 2011a). In addition, while some accounts focus on the apparently inherent difficulties associated with autism and inclusion (Wing, 2007), and others suggest that lack of teacher training is the source of difficulties (Barnard et al., 2002), much less attention concerns how autism is defined and conceptualised, and the relevance of this – if any – to educational practices for autistic children. Consequently, my aim at the start of my research project was to try to ascertain how autistic children are faring in mainstream primary schools, and whether problems arising at the earliest stages of their educational journey might provide insights into the broader issues described. I wanted to find out how they are ‘included’ in school, what their educational priorities might be, whether autistic children are accessing the curriculum and tests and if so, with what sort of support. In addition, I felt it would be important to explore how autism was conceptualised by school staff, for example, and to consider if any significance could be drawn from this in terms of the pedagogical approaches and general attitudes towards autistic children in schools. I hoped that by considering these issues, some insights might be provided into why the inclusion of autistic children in mainstream primary schools is apparently problematic, and to be able to offer suggestions on how this situation could be improved. Central to my goal, in a project predominantly informed by an interpretative paradigm, was a sense that only a multiplicity of

perspectives, derived from actual ‘cases’ where autistic children are placed – i.e. mainstream primary schools - could offer the nuanced information this issue demands. Therefore, a case study format, which permits ‘a rich picture’ and ‘analytical insights from it’ (Thomas, 2016, p. 23) provides the design my study required and the mixed methods it entailed. In addition, while I planned that school staff, autistic children and their parents would all be involved in my study, I also hoped that a sample of autistic adults who had attended primary school as children would provide additional insights, including on the issue of how autism is conceptualised.

As de Montaigne (1580/2003) wrote, ‘the most important difficulty’ in human learning is to consider ‘how to bring up children and how to educate them’ (p. 167). Indeed, through the labyrinthine processes of a PhD, with its different stages, hurdles and convolutions, it has felt ‘difficult’, but nonetheless ‘important’ to try to establish a better understanding of how autistic children might access education in mainstream settings, and embark on better paths for the future.

Structure and organisation of thesis

The thesis is arranged in seven chapters. In the first, the Literature Review, I describe my initial areas of reading and set out the different aspects of my review of the field of autism and associated literature relevant to my area of research. Chapter 2 concerns the theories and ideas which influenced my study, constituting a series of lenses through which the different parts of the research process might be perceived and analysed. They are the medical and social models of disability; language and communication; feminism; inclusion and difference. In Chapter 3, I set out the methodology of my project, exploring positivist and interpretivist frameworks and how these have relevance in the context of autism research, before explaining my own, predominantly interpretivist approach and overall project methodology. Following on from this,

I set out the aims and research questions of my project (p. 92), explaining in particular the issues relating to autistic children and adults who I planned to incorporate as participants in my study. In the same chapter, I describe my positionality (pp. 96 – 100), following which I explicate the research design of my project, which employs a case study format. I also summarise the ethical considerations which related to my project (more details of which, such as the applications for ethical review, are provided in Appendix A), followed by a description of my processes of sampling, selection and recruitment, as well as the results of these. In Chapter 4, I explicate my research methods, including my methods of data collection, the types of data I accumulated, the research instruments employed and a brief discussion of the ‘Hawthorne effect’ (Thomas, 2013a). In this same chapter, I describe and explain my methods of data analysis, which consisted predominantly of thematic analysis, but were also informed by discourse analysis, narrative analysis and secondary data analysis. I also expound the coding methods and tools which were used in my study.

My data were derived predominantly from questionnaires, semi-structured interviews and observations. Given the diverse nature of these data, I set out and analyse the findings from my questionnaire data only in Chapter 5, while the rest of the data are explored in Chapter 6. Both are occasionally informed by comments from my research diary. In Chapter 6, I also describe the methods of coding the data and the processes which led to the identification of eight interlinked themes, and include two instructive outlier examples which I consider merit attention as part of my analysis. The eight themes are then explored, using a format consisting of describing, substantiating and explaining my findings, followed by a summative discussion after each theme. In Chapter 7, the final chapter, I draw together the different strands of my study overall, highlighting key findings which I explore in greater depth, leading to some

conclusions. These incorporate indications about the broader applicability of my study and the significance of my research in the field of autism and education.

Autism Terminology

The use of language in relation to autism is a matter of some debate (Wittemeyer et al., 2013a). I have used the terminology – autistic spectrum disorder (ASD), autistic spectrum conditions (ASC) and Asperger Syndrome - in accordance with the articles and reports referenced. However, in my own discussion and analysis, and in keeping with the wishes of friends and associates who are autistic, as well as recent research (Kenny et al., 2015), I use ‘identity first’ language (i.e. autistic person), rather than ‘person first’ language (person with autism). For the same reasons, I do not use the term ‘disorder’, which derives from a medical and impairment model of autism. In addition, and notwithstanding a lack of consensus on this issue (Giles, 2013; Linton et al, 2013), I do not differentiate between ‘autism’ and ‘Asperger’s’, but have maintained the terminology used by participants where relevant.

CHAPTER 1: LITERATURE REVIEW

Introduction

To undertake a literature review in the field of autism is to enter an increasingly crowded arena, a point often emphasised via her Twitter account by Michelle Dawson, an autistic researcher affiliated with the Autism Clinic at the University of Montreal in Canada. Here she highlights the growing numbers of publications relating to autism as indicated by results from the search engine PubMed:

‘Autism research epidemic update: PubMed search for "autism" now returns more than 33,000 results, 11,238 (34%) of them since January 1, 2013.’ (Dawson, M. 2016, 12 March)

Dawson is not only underlining the increasing volume of research currently undertaken in the context of autism (Sweileh et al., 2016), but is making an ironic reference to concerns that, due to growing rates of diagnosis (Hertz-Picciotto and Delwiche, 2009), there might be an ‘autism epidemic’ (Gernsbacher, Dawson and Goldsmith, 2005; Gillberg et al., 2006). She is also perhaps hinting at the strong emphasis placed on autism etiology and epidemiology in autism research, a point which emerged from a report by Pellicano, Dinsmore and Charman (2013), where within the context of the UK, more than half of the autism research published and funded was found to be ‘devoted to understanding more about the underlying biology, brain and cognition of autistic people.’ (pp. 4 - 5). This compared starkly with areas such as complementary therapies and sensory-based treatments, for example, where in 2011, there were no publications at all within the search criteria (ibid., p. 27).

Therefore, what emerges from the outset of a review of autism literature is a sphere growing rapidly in size, but predominantly within certain, contested contexts. Initially, therefore, my

own, cautious incursions into the arena of autism literature were broadly in the areas of diagnosis of autism and the ensuing interventions, particularly within the UK. This initial reading was partly a result of the fact that as Pellicano, Dinsmore and Charman (2013) and Dawson (2016) imply, such texts are both plentiful and manifest. Subsequently, and in order to provide a contextual foundation stone for my review overall, this was followed by a consideration of the nature of autism itself, and how it is described and defined in different texts. This was followed by a more specific focus on educational issues, such as the educational provision, assessment and attainment of autistic children, a consideration of their educational priorities and outcomes, and pedagogical matters, such as teacher attitudes, questions relating to a modified curriculum, specialist pedagogies, teaching assistants and parents. In addition, I also consider the question of teacher training, and explore the legal rights to educational inclusion of autistic children and disabled children generally, and how these relate to their posited needs. Finally, I review texts concerning educational exclusion, before summarising the different parts of my literature review and explaining briefly how this impacted on the specific areas I decided to focus on in my own study, and how I might approach my research.

Diagnosis and interventions

In accounts concerning autism assessment and diagnosis (Rutter et al., 1999; Jones, 2002; le Couteur, 2003), autism is defined in quasi-medical terms as a ‘triad’ (Wing, 1980) of impairments, consisting of ‘severe impairments of social interaction, language abnormalities, and repetitive stereotyped behaviors’ (Wing and Gould, 1979, p.11), a definition which became incorporated into the main diagnostic handbook for clinicians, the Diagnostic and Statistical Manual of Mental Disorders, DSM-IV (1994). Even the updated version, the DSM-V (2013), where autism is classified under two broad categories of ‘persistent deficits in social communication and social interaction’ and ‘restricted, repetitive patterns of behavior, interests,

or activities' (Barrett, 2014), the core notion of the 'triad of impairments' is not fundamentally disrupted.

The response to these descriptions of autism is to attempt to remediate the deficits associated with the condition via interventions. Indeed, there is a plethora of treatments and therapies available: the UK charity Research Autism lists 1324 separate interventions under the title of 'Interventions, Treatments and Therapies'. These are designed to improve the functioning of the autistic individual and, especially within educational contexts, to promote corrective strategies to facilitate the child's learning and inclusion (Harrower and Dunlap, 2001; Crosland and Dunlap, 2012). Examples of specific techniques include the Treatment and Education of Autistic Children with Communication Handicaps (TEACCH) (Mesibov and Howley, 2003), Early Intensive Behavioural Intervention (EIBI) and other procedures addressing the issue of behaviour (Moyes, 2002; Remington et al., 2007; Fava et al., 2012), 'concept mapping' Roberts and Joiner (2007), therapeutic input (Drahotá et al., 2010), strategies to support communication and social interaction (McConnell, 2002) and peer-mediated interventions (Chan et al., 2009).

For Jones (2008) 'assessment should lead to intervention' (p. 86), and ought to follow swiftly from diagnosis (Jones et al., 2008). Consequently, within such a framework, assessment and intervention are seen as interconnected (Jones, 2002), and should be specific for each child (Guldborg, 2010). However, Jones (2002) and Parsons et al. (2011) question the evidence base for the effectiveness of interventions themselves, an issue also discussed in Kovshoff, Hastings and Remington (2011) in their follow-up to Remington et al. (2007), thus casting doubt on the 'early intervention' model (Jansson et al., 2016). Furthermore, in Armstrong, Galloway and Tomlinson (1993), a child's experiences and views of the assessment process are shown to have important implications for the results of that assessment. Indeed, according to Jordan (2005, p. 111), 'ASDs are transactional disorders', meaning that the individual responds to those around

him/her as well as the environment, and for Guldberg (2010), intervention must be seen as a two-way process, requiring others to adapt, as well as the child (p. 169). Moreover, the value-base and purpose of interventions is strongly critiqued in Milton (2014a), meaning the assessment, diagnosis, intervention model is thrown further into doubt. As a result, and in order to gain insights into the specific difficulties autistic children might be experiencing in school, it was necessary to delve further into the nature of autism itself, exploring beyond those descriptions offered and implied within the diagnosis and intervention model.

The nature of autism

As we have seen, individuals are typically diagnosed with autism by medical practitioners within health contexts, thus placing them in an impairment framework, in need of therapeutic interventions. Importantly, this negative conceptualisation of autism also triggers a drive to understand its underlying biology so that treatments and remedial inputs might be developed, and support provided (Mawhood, Howlin and Rutter, 2000; Howlin, Mawhood and Rutter, 2000; Hu-Lince et al., 2005). By extension, autism is considered within scientific spheres to have a genetic basis (Rutter et al., 1999), and there has been much research to attempt to identify those genetic components (Bourgeron, 2015) and a quest to define the elusive ‘autism phenotype’ (Lundström et al., 2015). Indeed, according to Sweileh et al. (2016), ‘molecular genetics of ASD is the primary hot topic’ (p. 1480) in the autism research field, and generates significant research funding (Pellicano, Dinsmore and Charman (2013).

However, the very nature of the declared autism deficiencies, and how they might provide a coherent description of and explanation for the condition itself, is the subject of much analysis and debate. This is particularly evident in the context of cognitive theories of autism, where posited impairments associated with autism are deemed to be 1) mind-blindness (the inability

to put oneself mentally in the position of another person [Baron-Cohen, Leslie and Frith, 1985]); 2) weak central coherence (a difficulty in understanding the general meaning of information rather than focusing on individual details [Briskman, Frith and Happé, 2001]) and 3) poor executive function (an inability to regulate and control cognitive processes [Happé et al., 2006; Rosenthal et al., 2013]). In such accounts, the extent to which these theories can explain the dysfunctions associated with autism are explored, as well as whether or not together, they can provide a unified description of the condition (Frith, 2006). This is also discussed in Rajendran and Mitchell (2007), who conclude that because the three main cognitive theories of autism have never been found to fully explain the condition, autism must therefore be a ‘multi-deficit’ disorder, a perspective they describe as ‘intrinsically alluring’ (p. 224).

While such descriptions provide an attempt to explain the perceived dysfunctions associated with autism, they also present efforts to account for the many exceptions as evidenced in those same studies. However, these exceptions are typically offered as yet further verification of disorder, rather than as an opportunity to question the whole basis on which this research is predicated. For example, in Shah and Frith (1982), the observed ‘islet of ability’ of some autistic children in terms of visio-spatial skills - which they state was ‘better than predicted’ - is described as being ‘related to cognitive deficit’ (p. 619). Similarly, Frith and Happé (1994), when trying to explain why autistic individuals ‘consistently pass false belief tasks’, suggest that this is evidence of an ‘additional cognitive abnormality’ (p. 115). In such accounts, rather than disrupting the conceptualisation of autism as a suite of cognitive impairments, anomalies in the data are interpreted as yet further evidence of dysfunction.

Furthermore, while signs of autistic ability, when detected, are framed negatively, similarities in findings between autistic and non-autistic individuals are presented as somewhat unexpected. For example, Rajendran and Mitchell (2007) pronounce as ‘surprising’ the fact that in some

aspects of their findings from experiments on ‘reading from eyes’, there was little difference between autistic and non-autistic individuals (p. 228). Likewise, they make the following comments about experiments to measure susceptibility in Ropar and Mitchell (1999, 2001):

‘Surprisingly, participants with autism were susceptible to the illusions to the same degree as participants without autism.’ (p. 239).

In addition, these disruptions to the impairment narrative which underscores genetic research and cognitive theories of autism also have implications about gender. In Brugha et al. (2007), for example, autism was found to be prevalent in approximately 1% of the population of England, but in 1.8% of men, and only 0.2% of women. Indeed, Baron-Cohen (2002a) posited the theory that autism is a manifestation of the ‘extreme male brain’, and several major studies have either very few or no female participants at all (e.g. Mawhood, Howlin and Rutter, 2000). It has therefore been argued that the focus on certain manifestations of the condition has resulted in the failure to describe how it might be exhibited in women (Gould and Ashton-Smith, 2011; Cheslack-Postava and Jordan-Young, 2012), and that either failing to diagnose or misdiagnosing women and girls can create numerous disadvantages for them in their education and working lives, for example (Lawson, 2014).

Consequently, the two dominant models of autism research – the quest to find a genetic source and analyses of cognitive impairments – fail to provide a coherent explanation for autism. Indeed, there is an increasing acknowledgement even within these fields that certain apparent deficits could in fact be framed as strengths (Happé, 1999; Baron-Cohen, 2002b) and that there is a need to abandon the concept of the triad of impairments and the quest for a single, genetic explanation for autism (Happé, Ronald and Plomin, 2006). Some have even argued that it is not

‘autism’ itself which is the source of any dysfunction, but associated difficulties, usually called ‘co-morbidities’ (Baird et al., 2006; Gillberg, 2015).

It is clear, therefore, that other descriptions of autism need to be considered and factored in to analyses of how to provide for better educational outcomes for autistic children in school. Molloy and Vasil (2002), for example, argue that Asperger Syndrome is a ‘socially constructed disorder’ (p. 659), ‘a convenient common category’ (p. 666) which simply enables practitioners to communicate easily with each other within the field of special education. Similarly, in a very small, but nevertheless fascinating, study Kim (2012), when considering how autism is conceptualised in Canada, Nicaragua and Korea, argues that the ‘multiple facets of autism reflect its different social implications intertwined with cultural expectations and assumptions within a given society’ (p. 543). In a larger study comparing the attitudes of UK-based Nigerians and English people towards a diagnosis of autism, Papadopoulos (2016) also found definitions and understandings of autism to be in part culturally-determined. Further, Ho (2004), in the context of learning disabilities, questions the value of the label itself, and suggests a focus instead on the ‘social, cultural, economic, and environmental conditions that may influence the child's learning’ (p. 90), a point also powerfully argued in Thomas (2012a). Indeed, Runswick-Cole, Mallett and Timimi (2016) even suggest that ‘moving away from diagnosing autism’ (p.10) would lead to better lives for those who are typically considered to be ‘autistic’.

Alongside these discussions, there has been an increased impetus to reassess the notion of autism as a collection of impairments. While for Graby (2012), for example, autism does not fit neatly into categories of either disability or impairment, Humphry (2014) argues that the impairment discourse alone can further reinforce lack of functionality on those upon whom it is imposed, suggesting that dysfunction is to an extent externally determined. These ideas have

been developed much further by autistic writers and scholars. Broderick and Ne'eman (2008), for example, posit that because the dominant models of autism fail to include the genuine insights only autistic individuals can provide, they are inherently misconceived. Further, Sinclair (1993) urged parents of autistic children in particular to desist from thinking of autism as a 'tragedy' visited upon them. Lawson (2008) presents a compelling case that autism is in fact a different form of ability - a 'diffability' - an alternative way of thinking and communicating, rather than a condition defined by impairments. Later, Lawson (2011) presented the theory of Single Attention and Associated Cognition in Autism (SAACA), arguing that autistic cognition simply operates differently from non-autistic intelligence and that current educational systems fail to accommodate this difference. For Milton (2014b), there is a 'qualitative difference' (p.1) to autistic sociality which has been both misunderstood and misrepresented as a flaw. In an important study, Dawson et al. (2007) were able to demonstrate how different assessment tools impact significantly on the results in relation to measurements of the cognitive abilities of autistic people, leading to the conclusion that their intelligence has been underestimated.

From this literature, an alternative conceptualisation of autism emerges: not one which is rooted in biological defects and cognitive deficiencies, but a disposition which is both potentially socially constructed and perhaps more appropriately described as a manifestation of human diversity, and therefore intrinsically valuable. It is also noteworthy that the original Wing and Gould (1979) study, which continues to have a strong influence on how autism is conceptualised even decades later, did not include any children in mainstream schools or resource provisions (Cigman, 2007), suggesting a significant limitation in sampling which is rarely taken into consideration. This area of reading, particularly texts derived from autistic

scholars, had a significant impact on the development of the theories underpinning my research and the creation of my research questions (p. 92).

Educational provision, attainment and assessment

My main source of information about the educational placements and attainment of autistic children, with a focus on the primary phase in particular, were the plentiful datasets provided by the Department for Education (DfE). This was a result of the fact that my initial database search had not yielded many results, as shown in Table 1.

Table 1: Key word database search results

| Key words (2002 – 2014) | British Education Index | Social Sciences Citation Index |
|---|--------------------------------|---------------------------------------|
| autism; primary school; education; inclusion | 3 | 1 |
| autism; mainstream; assessment | 1 | 1 |
| SATs*; autism | 0 | 0 |
| SATs; autistic children | 0 | 1 |
| SATs | 55 | 74 |
| *SATs = Standard Assessment Tests, taken at Key Stage 1 (Year 2) and Key Stage 2 (Year 6) in primary school | | |

As can be seen, while there appeared to be copious results pertaining to SATs generally, virtually none were found on these databases linking SATs, autism and assessment – or even inclusion – and mainstream primary schools.

Moreover, my literature review took place predominantly during 2013 and 2014, a period defined by both legal and policy change in the education sector in England (Children and Families Act 2014; DfE, 2014a). Consequently, trying to establish the core issues during a time

of flux was by no means straightforward, especially as the DfE alter both what information they collect from schools and how they select and present these data on a yearly basis (DfE 2015a). I therefore chose the years 2012 – 2014 in order to be able to make comparisons and establish any patterns across those years in relation to autistic children. This was also because the changes introduced in 2012 (DfE, 2012a), including the first publication of national data on Phonics, made comparisons using data prior to that date less valid. I analysed the DfE datasets from each of those years and extracted the relevant data in order to offer descriptive and derived statistics and explore any key themes or trends which might appear to be present.

Educational placements

According to my calculations using DfE data, autistic pupils formed 7.4%, 8.7% and 8.3% of all pupils with Special Educational Needs (SEN) in state-funded primary schools in England in 2012, 2013 and 2014 respectively (DfE 2012b; 2013a; 2014b). This compares with 8.6%, 9.8% and 10.7% for those same years in mainstream secondary schools and 20.4%, 21.5% and 22.6% in special schools (which include both the primary and secondary phases of education) (ibid. 2012b; 2013a; 2014b). Further data from the DfE (2012c; 2013b; 2014c) provide us with additional information about the educational placements of autistic children during those years, as shown in Figure 1.

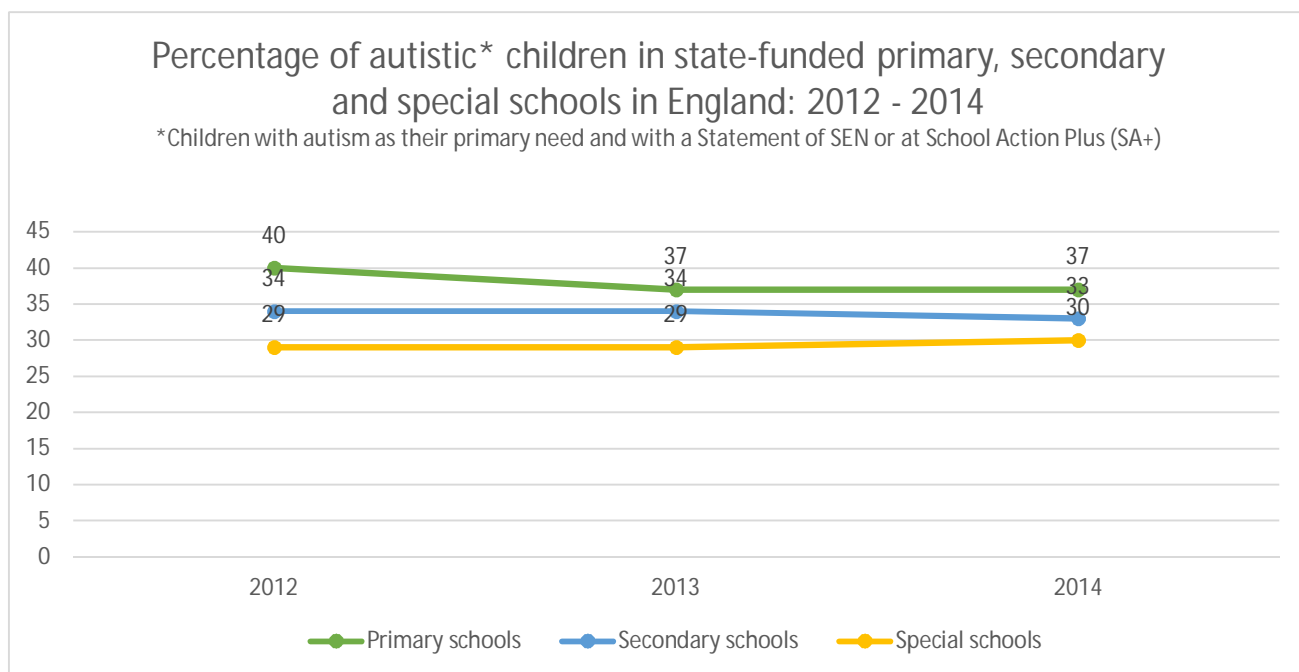


Figure 1: Percentage of autistic* children in state-funded schools in England, 2012- 2014
(DfE 2012c; 2013b; 2014c)

These figures suggest that approximately 30% of autistic children are educated in special schools, with the rest – the majority – placed in either mainstream primary or secondary schools. Further, by using data about total populations from the same DfE sources, I calculated that in 2012, 2013 and 2014, autistic pupils formed 0.58%, 0.67% and 0.64% respectively of the entire cohort of pupils in state-funded mainstream primary schools in England. In other words, according to these figures, autistic pupils formed between 1 in 156 and 1 in 172 of all pupils in those schools.

However, it soon became evident that these figures are partial at best, because the DfE only monitors autistic pupils (and other categories of disability) by ‘primary need’ and in accordance with whether they have a Statement of SEN or are supported by School Action Plus (SA+). Those autistic children who are on a lower level of support – School Action (SA) – or indeed have no formal additional support in place, are not specifically monitored in DfE data either in terms of their educational placements or their attainment. This is despite the fact that the

numbers of pupils who are supported through SA outnumber those with Statements of SEN or at SA+ combined. Again, by extracting the relevant data and making a few simple calculations, I was able to establish in this regard the proportions given in Figure 2.

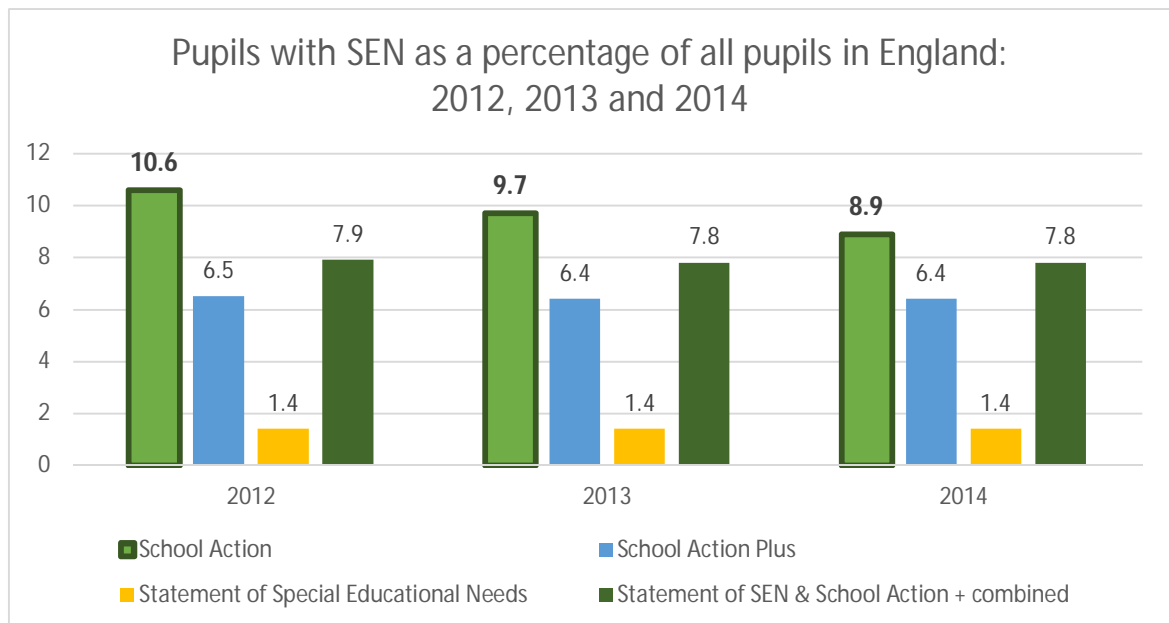


Figure 2: Pupils with SEN as a percentage of all pupils in England, 2012 – 2014 (DfE 2012b; 2013a; 2014b).

This means that there are potentially more autistic children in schools not being monitored within these data than those who are. Furthermore, given that the children on the highest levels of support only are being tracked through these data, this suggests that many more autistic children are present in mainstream settings than are indicated by these figures. Therefore, simply trying to ascertain the scale of the situation, based on how many autistic children there might be in mainstream schools, remained elusive on the basis of these data.

Furthermore, this situation is rendered even more complex by the fact that autism prevalence figures in the general population – which might provide a useful comparator in this case – are both varied and contested. While it is generally accepted that in recent years, there has been an increase in autism diagnoses (Baron-Cohen et al, 2009), what those actual rates are varies according to different studies. In Barnard et al. (2002, p. 5), for example, the figure of one child

in 86 having a diagnosis of autism is used, whereas Baird et al. (2006) found that autism prevalence was at a rate of 1% of the childhood population. This was reflected by the Office for National Statistics (2011), who assert a rate of 1.1% amongst children aged four to 16. In a relatively small study based in Cambridgeshire, Baron-Cohen et al. (2009) found a rate of 1.54% of children aged five – nine and for Kim et al. (2011), in a study in a South Korean community, the rate was 2.64% amongst children between the ages of seven and 12. Using the UK-wide Millennium Cohort Study, which included data from 18,522 families, Dillenburger et al. (2015) found that 3.5% of children are diagnosed with autism by the time they are 11 years of age (p. 331). Even though these figures are at times disputed on methodological grounds (e.g. Pantelis and Kennedy, 2016, who critique the Kim et al. [2011] study), more modest calculations still show a prevalence in excess of the figures represented in the DfE data (Mackay, Boyle and Connolly, forthcoming). What is evident therefore is that there is a lack of representation of autistic children in national education datasets, and that prevalence figures, while all in excess of those indicated by the DfE, are not especially helpful in this regard either.

Educational attainment

The picture which emerges from DfE data is one of poor achievement for autistic children in national assessment schemes. At the Early Years Foundation Stage, for example, which is usually assessed when children are aged five and in Reception class, the majority of autistic children (by primary need) are consistently shown to be in the lowest 20% of achievement (DfE, 2013b). At the end of Key Stage 1 (when the children are aged seven – eight), the results for 2012 also show that autistic children achieve significantly lower than the expected standard - Level 2 or above - than all children (including those with all levels of SEN) or even all SEN by primary need combined (DfE, 2013b) in Reading, Writing and Mathematics. Science is no longer monitored by the DfE at this stage and in 2013 and 2014, only the results for Reading

are available amongst the core subjects. Here too, only 40% and 42% respectively of autistic children are reaching the expected standard of Level 2, compared with 89% and 90% of all pupils (DfE 2014c; 2014d). At Key Stage 2, or Year 6, when the children are aged ten – 11, autistic children perform better in some areas than the category of all children with SEN by primary need combined, but there are still significant numbers of autistic children either not reaching the expected level or working below the level of the tests in the core subjects (DfE, 2012d; DfE, 2013c).

Furthermore, closer inspection of the data not only suggests that autistic children are failing to reach the ‘expected standard’ or make ‘expected progress’ in national assessment schemes, but that they might not even be participating in these tests at all. The data show that autistic children are also more likely to be disapplied from the tests themselves than either all children (including those with SEN) or the category of all children with SEN by primary need combined (DfE, 2013b; 2014c; 2014d). This is particularly evident in the results for Phonics, which was introduced in 2011/2012.

Table 2: Phonics results 2012 – 2014 (DfE 2012e; 2013d; 2014d)

| Phonics 2012 – 2014 (Year 1) | | | |
|--|---------------------------|-------------------------------|---------------------|
| | % Meeting standard | % Not meeting standard | % Disapplied |
| 2012 | | | |
| All children | 58 | 40 | 2 |
| All SEN PN* | 22 | 63 | 14 |
| ASD** | 24 | 45 | 30 |
| 2013 | | | |
| All children | 69 | 29 | 2 |
| All SEN PN* | 29 | 55 | 16 |
| ASD** | 28 | 39 | 33 |
| 2014 | | | |
| All children | 74 | 24 | 2 |
| All SEN PN* | 34 | 51 | 15 |
| ASD** | 32 | 37 | 30 |
| *All children with SEN by primary need and supported either by a Statement of SEN or at SA+. ** Children with autism as their primary need and supported either by a Statement of SEN or at SA+ | | | |

According to the figures in Table 2, the majority of autistic children are either not meeting the expected standard of Phonic decoding or they are simply disapplied from the tests themselves. However, and as we have already seen, ascertaining the significance of these figures is complex, not least because the total numbers of pupils in each category are substantially different and so comparisons of percentages must be approached with caution. Furthermore, while at least some autistic children appear to be excluded from these data, annual changes to how the progress of children with SEND is recorded by the DfE make genuine comparisons - and meaningful monitoring – difficult (DfE, 2015b). Indeed, Florian et al. (2004) describe the limitations of using national datasets to derive genuine insights into the attainment of children with SEN, while Smith (2008) similarly raises questions about whether ‘examination data be reliably expected to answer the demands we currently put on them’ (p. 25). Gorard (2001) also points

out the inadequacies of making comparisons across different years and syllabuses, for example, and Dockrell et al. (2012) question whether these data can provide sufficient ‘information to plan services and differentiate the curriculum’ (p. 173). Therefore, even though such data are considered to have their uses, such as an antecedent to primary data collection, for example (Gorard, 2002; Smith, 2008), the extent to which they can be relied upon to form a clear picture of the educational placements and attainment of autistic children in schools is debatable.

What seems evident, however, is that these data raise questions – at the very least – about the attainment and participation in tests of autistic children, and furthermore this, in turn, might have implications about their inclusion in mainstream settings. Dockrell, Peacey and Lunt (2002), for example, present concerns that children with SEN are being excluded from assessments and that schools struggle to be both effective in terms of ‘high attainments’ and ‘inclusive’ in the context of having high numbers of pupils with SEN (p. 36). Lloyd-Smith and Tarr (2000) also argue that since good performance in exams is seen to apply value to schools, ‘the key impediments to a school's success are seen as unsuccessful pupils and the disaffected’ (p. 58). Sinclair Taylor (2000) is also of the view that children are being excluded as a result of the introduction of league tables and the resulting pressure on schools to present a good picture of themselves academically (p. 31). Indeed, Lindsay (2007a) asserts that there is a negative correlation between inclusion and overall school attainment, to the extent that the schools with fewer children with SEN fare better overall (p. 15). However, this is countered in Dyson and Farrell (2007), who aver that statistics showing low attainment for schools with high levels of SEN, should be treated with caution, stating that they were unable to find ‘any convincing evidence that inclusion (...) has any meaningful negative impact on overall levels of attainment in schools’ (p. 124).

Assessment

It is noticeable that accounts concerning the assessment of pupils with SEND tend to be unquestioningly predicated on the notion that SEND equate to low ability. The DfE (2014f) for example, in a document setting out the changes to national assessment schemes in primary schools in England, appears to deal with Special Educational Needs and Disabilities (SEND) – the term used since 2014 - solely under the heading of ‘low attaining pupils’. Indeed, a further complexity is derived from the fact that ‘assessment’ in the context of the education of autistic children and the SEND arena in general is typically presented within a framework of ‘assessment’ and ‘identification’ of SEND. This is particularly evident in the Special Educational Needs (and Disabilities) Codes of Practice 2001 and 2014 (Department for Education and Skills [DfES] 2001; DfE, 2014a) where, in the more recent version, attainment in school (and other considerations) are subsumed into the broader imperative of identification of SEND. Similarly, in the latest Code of Practice, there is much less emphasis placed on access to the National Curriculum than in the 2001 version, even though now, teachers are urged to ‘use appropriate assessment to set targets which are deliberately ambitious’ (p. 94). Access to or participation in school examinations and tests are barely mentioned in either document, although the 2014 report does place a much stronger emphasis on qualifications, asserting that young people with SEND should be taking ‘nationally recognised’ and ‘substantial’ qualifications for apprenticeships and internships, for example (p. 131). These two documents provide an insight into a core issue within the context of SEND and scholastic attainment: the extent to which ‘assessment’ has a different meaning for children identified as having SEND than for those who do not. For the former, it concerns identification of ‘needs’ whereas for the latter, the emphasis is on attainment.

This issue is linked to another important question in the context of the assessment of children with SEND: whether or not standardised tests are appropriate for them. In a key report by Douglas et al. (2012), the complex matter of ‘inclusive assessment’ (amongst other issues) is addressed through a comparison of systems used in Australia, England, Finland, Scotland and the USA, leading to recommendations for Ireland. One of the conclusions is not only that assessment procedures ‘should be designed to include the diverse range of children and young people within the educational system’ (p. 4), but that ‘systems also need to be in place to record educational progress in (...) areas that may be of particular interest or concern to given stakeholders’ (p. 164). In other words, all children, regardless of their categorisation of SEND, should be included in local and national assessment schemes, and it might also be useful to assess and record additional information for some children too. Meanwhile, Wilkinson and Twist (2010), in one of the few accounts to tackle this issue specifically in the context of autism, assert that it is ‘not always clear where the line should be drawn between adapting assessments and providing alternative assessments for pupils with severe special needs’ (p. 10).

Both reports also tackle the issue of accommodations and adaptations to existing testing procedures so that children with SEND might access exams and assessments (now called ‘access arrangements’ in the UK [DfE 2014e]). According to Douglas et al. (2012), for children with SEND ‘assessments should be accessible (through suitable accommodation)’ (p. 4), but Wilkinson and Twist (2010) point out that there are no formal accommodations for summative assessments for autistic children, meaning that there ‘is an obvious need for clearer evidence-based guidance and increased teacher training to enable confident and consistent assessment accommodation judgements’ (p. 15). Nevertheless, and notwithstanding the limited attention paid to these issues in the UK, Jones et al. (2011), in the context of the inclusion of autistic children in mainstream schools, emphasise the importance of ‘equality of access’ (p. 26) for

tests and exams. Similarly, Wittemeyer et al. (2011b) consider that staff must be able to demonstrate ‘a good understanding of the framework for access arrangements for exams’ (p. 40) if autistic children are to be suitably included in school.

Florian et al. (2004), on the other hand, discuss whether accommodations for tests might in fact ‘invalidate’ the results of those tests and suggest that participation in national assessments could have a negative impact on pupils’ motivation and self-esteem (p. 119). Douglas et al. (2012) also found that amongst their sample of teachers in Ireland, the notion that it might be potentially stressful for children to participate in assessments was a reason for excluding them (p. 145). By contrast, Cox et al. (2006), in a study based in the USA - where the Individuals with Disabilities Education Act (IDEA) (1997) requires all students with disabilities to be included in state and local assessment and accountability systems (with appropriate accommodations, where necessary) – found not only that there was a correlation between accommodations for tests and the participation of students with disabilities in those tests, but that there was also a corresponding reduction in school exclusions. Similarly, Feldman, Kim and Elliott (2011) also consider that accommodations in tests for students with learning disabilities improve their test-related self-efficacy and motivation.

A further issue which underpins the subject of assessment and SEND is the identification of those children deemed to fall into this broad category. Croll (2002), for example, found that there is ‘a consistent tendency for the average level of attainment of pupils identified as having learning difficulties to rise as the levels of poverty in schools decrease and the levels of achievement rise’ (p. 52). In this study, children in the areas of least deprivation and described as having learning difficulties were considered to be a year behind their peers in reading age, whereas in schools in areas of greatest deprivation, children with learning difficulties were two to three years behind their peers (p. 50). This suggests that the identification of pupils with

SEND is at least in part socially determined, and that children identified as having SEND in one school, might not be in another.

This subjectivity which appears to be underpin identification of SEND was also found by Campbell (2015) to influence teacher assessments and result in ‘over and under-assessment of pupils according to their characteristics’ (p. 538). She reports that pupils with ‘any diagnosis of SEN are more likely to be judged as “below average” at maths compared to those without a diagnosis’ (p. 531), for example, and that this is due to ‘teacher-level bias’ (p. 518). Although methodologically complex, the article by Campbell (2015) raises further questions about the reliability of information which is publicly available about the performance in exams of pupils with SEND.

Educational priorities and outcomes

Questions about assessment are also linked to issues concerning what children with SEND should be learning in school, as well as short and longer-term outcomes. Both Douglas et al. (2012) and Wittemeyer et al. (2011a), for example, consider that assessment, in order to be meaningful, must also be linked to the question of outcomes. According to Douglas et al. (2012), there is too much emphasis on ‘inputs’ for children with SEN, and not enough on outcomes (p. 13), and Jones et al. (2008) underscore the importance of defining and planning good outcomes, particularly in relation to different types of academic provision. However, for Dockrell, Peacey and Lunt (2002), the ‘assessment of educational outcomes is fraught with technical problems’ (p. 41) and Parsons et al. (2011) found that there is a lack of coherence and consensus on which outcomes should be measured ‘when trying to determine the effectiveness of an intervention or educational provision more widely for those on the autism spectrum’ (p. 59).

Dockrell, Peacey and Lunt (2002) suggest that four possible measures that can be used to evaluate academic provision are those relating to 'academic, effective, social' and 'life-chance', and that gauges of outcomes might be 'educational attainment, measures of self-esteem, patterns of friendship or, infrequently, post-school outcomes of different provision' (p. 42). Douglas et al. (2012) found studies fell into four broad categories of attainment, attendance, happiness and independence-related outcomes (p. 2) and asserted that assessments should incorporate 'the broader aspects of the curriculum rather than those which are traditionally assessed through examinations and attainment tests' (p. 6). These should include, they argue, 'more specific outcomes such as resilience, self-esteem, well-being, relationship building, optimism, employment, independent living skills and successful transition after school' (ibid, p. 6).

Other accounts can be polarised between the need for academic achievement versus practical or social skill. Jones (2002) for example, considers that staff 'working with pupils with ASDs need to take a long-term perspective and work on skills needed in adult life during the school years' (p. 114) and Harvey (2011), when comparing the educational priorities of staff from mainstream schools, special schools and parents, found that 'academic learning was the least important outcome in the list for children with ASD and social skills was the most important' (p. 114). Dockrell et al. (2012) discovered that while parents' perspectives varied in terms of preferred outcomes, parents of autistic children were 'more likely to mention social outcomes, particularly friendships' (p. 150). Overall in this study of the needs of children with language impairments or autism, parents' main desired outcomes were found to fall into the categories of academic achievement, social development, social confidence, independence, 'being normal' and general happiness (ibid, p. 152). Parsons et al. (2011) argue that as well as academic attainment, 'other goals are equally important' for autistic children, including social

understanding, physical and emotional well-being and independence skills (p. 59). They also assert the following:

‘Many children on the autism spectrum can achieve a high level of academic success, but without the necessary skills and understandings in other areas of their life, may fail to benefit from these in terms of their future education, employment or living arrangements.’ (p. 59).

In these accounts, academic success is either considered to be as important as a number of other desired outcomes, or relatively unimportant. Moreover, the views expressed are predominantly from school staff or parents, rather than the children themselves. Teachers and parents, very broadly, reveal similarities in perspective, with outcomes relating to life skills, socialisation and independence being emphasised. However, when Wittemeyer et al. (2011a) interviewed autistic adults on this issue, ‘58% of respondents indicated that they had not achieved the qualifications they wanted at school’ (p. 38), hinting at a greater value placed on academic achievement than expressed by school staff and parents. Furthermore, the participation of autistic adults in the latter study led to the following assertion:

‘A striking outcome of this study was the expressed wish that ‘neurotypicals’ would stop imposing upon them their own views of ‘a good life.’” (p. 19).

In addition, most accounts provide a negative picture of the longer-term achievements and well-being of autistic children and adults. In the CRPD (2006), for example, it is asserted that ‘persons with disabilities are disproportionally affected by poverty and overrepresented among the poorest in the world’ (article 29), and Dockrell, Peacey and Lunt (2012) affirm that the ‘single most likely destination for many disabled people appears to be poverty’ (p. 46). The charity Ambitious About Autism (AAA) have highlighted that less than one in four autistic

young people continue their education beyond school and that young people with a statement of SEN at 16 are twice as likely to not be in education, employment or training as young people without SEN (AAA, 2012). For Wittemeyer et al. (2011a), school exclusion is a crucial factor in this area, asserting that ‘being permanently excluded from school is one of the main drivers of poor outcomes for any child’ (p. 48). From these texts therefore, a powerful chronicle emerges of poor life chances for autistic people. Even so, Stewart (2016) is of the view that because more women and girls are now being diagnosed with autism, there has been a shift in this narrative, given that some of these women at least, are in some senses ‘successful’, although it is not clear whether this is because of, or despite – or even simply coincidental to - being autistic.

Pedagogical issues

Teacher attitudes

The pedagogical issues raised by the existence of autistic children in schools tend to centre on the problems and difficulties this might bring. Aligned with this, and despite the fact that their impact on inclusive practices is debatable (Schuelka, 2016), there are a number of accounts reflecting ‘teacher attitudes’. In such reports, the high levels of stress experienced by teachers due to the presence of autistic children in their class are emphasised (Emam and Farrell, 2009; Syriopoulou-Delli et al., 2012). Glashan, Mackay and Grieve (2004) for example, asserted the following, based on a small-scale study:

‘All classroom teachers found that their experience of a child with autism was difficult and that they took at least a year to feel they were coping with the situation.’ (p. 57).

Teachers are ‘vulnerable to burnout due to the unique characteristics of these pupils’ (Emam and Farrell, 2009, p. 415), and find themselves unable to engage with or teach pupils who are

‘incapable of showing such emotions as excitement, enjoyment, pride or shame which are an integral part of academic activities’ (ibid, p. 413). For Lindsay (2007a), some teachers might have ‘positive attitudes in principle’ (p. 13), but these are tempered by practical considerations ‘with respect to meeting curricular demands’ (p. 13). Thus it is either the purported nature of autism itself which places a strain on teachers, and prevents the children from learning and progressing, or there is a sense that their presence is somehow discordant with core pedagogical processes. Indeed, (Humphrey and Symes, 2011) found that negative attitudes towards autistic children from teachers can also lead to social exclusion from their peers (p. 33), suggesting that teachers play a central role in facilitating - or not - the inclusion of autistic children.

Parents

A number of research and policy documents and legislation in the context of SEND reinforce the notion that parental expertise must be harnessed (Millar et al, 2002; Children and Families Act, 2014). Jones et al. (2008) recommend that ‘professionals’ need to develop ‘effective engagement’ with parents and carers (p. 7) and Guldberg (2010), considers that the lack of recognition of the value of parental input can be a barrier to inclusion.

However, it would appear that the tendency to problematise the presence of autistic children in mainstream schools has been equally extended to their parents in certain accounts. While some are deemed to have ‘unrealistic expectations’ (Glashan, Mackay and Grieve, p. 53), others are portrayed as controlling and manipulative. Cigman (2007) for example, refers to ‘parents who know how to play the system’ (p. xxiii), and asserts that policy-makers should not be swayed by those who are solely defending the interests of their own children. Meanwhile, if Batten et al. (2006) underline the high level of dissatisfaction amongst parents in terms of the support their autistic children are receiving, in Whitaker (2007) this is conveyed as a difficulty of

perception only (p. 174). For Parsons et al. (2011), parental involvement is important, but they need to be 'equipped with good psycho-educational information' for this to be considered valid (p. 59). The stigmatisation of parents appears to apply to mothers especially, who are placed under particular scrutiny, with their competencies overlooked (Ryan and Runswick-Cole, 2008; Lilley, 2013). Indeed, according to Slee and Allan (2001), parents are simply expected to legitimise the decisions of the associated professionals (p. 179), while Hodge and Runswick-Cole (2008), found that parents 'fear that if they question professionals or ask for additional information they will be categorised as difficult' (p. 641). According to them, parents feel 'disempowered' and 'devalued' (ibid., p. 639), as decisions about their children are made 'elsewhere' (ibid., p. 638). Further, this marginalisation of parental input even extends to research practices. In Syriopoulou-Delli et al. (2012) for example, teachers whose experience of autism was as a 'parent-relative' only, were not deemed to be 'significantly experienced' (p. 758). Meanwhile, Wittemeyer et al. (2011a) emphasise the need to create positive relationships between school staff and parents, citing the Lamb Enquiry (2009, p. 2), which called for 'a radical recasting' of this relationship, often typified by mistrust (p. 20).

Modified curriculum

Some accounts dwell on the issue of whether or not a modified - as opposed to 'universal' - curriculum is necessary in the context of the education of autistic children. According to Emam and Farrell (2009), for example, teachers feel 'completely trapped by the constraints of the national curriculum' (p. 414), while Whitaker (2007) asserts the following:

'Many of these children will require the explicit teaching of skills and understanding which are not part of the conventional academic curriculum.' (p. 170)

For Hesmondhalgh and Breakey (2001), lessons for autistic children ‘must take the pupil into areas s/he would be denied if it were left to the national curriculum’ (p. 142), which in itself cannot provide the ‘something more’ that such pupils require (p. 115). However, Douglas et al. (2012) avoided considering alternative curricula in their report precisely because of their association with ‘exclusion from a mainstream curriculum’ (p. 33). Further, Jordan (2005) asserts that the ‘child with an ASD, like any other child, is entitled to a broad and relevant (...) curriculum’ (p. 116), and Jones (2002) is of the view that the National Curriculum can in fact be adapted for autistic children (p. 80).

Specialist pedagogies

In connection with this, the question of specialist pedagogies is also raised. Whitaker (2007), for example, considers that for autistic children, ‘the means by which they learn and need to be taught may be significantly different from the majority of children’ (p. 170). Jones et al. (2008) also consider the impact of traditional teaching methods:

‘Most schools and colleges still use traditional teaching methods which rely on pupils being able to understand the language and social behaviour of teaching staff and other children.’ (p. 14).

The implication here is that ‘the language and social behaviour’ employed by school staff is not easily understood by autistic children, and thus their progress is hindered. Wing (2007), considers that all autistic children ‘need specialist techniques of teaching if they are to learn’ (p. 31), and uses this to argue for the placement of many autistic children in special schools, where she believes they would be in receipt of such expertise.

However, for Thomas and O’Hanlon (in Lewis and Norwich, 2005), the need for special pedagogies in the broader context of SEND is debatable, and they suggest that such approaches

might in fact contribute to further exclude children. Ravet (2011) also rejects the notion of ‘special pedagogies’ as they consolidate the notion that such children need ‘special’ teachers in ‘special’ contexts, thus enabling mainstream teachers ‘to absolve themselves from the responsibility of teaching them’ (p. 672). Meanwhile, Liasidou (2012) advocates ‘socially just pedagogies’ which ‘entail diversifying and changing the curriculum, teaching methods, structures, cultures and practices of current schooling, in order to meet learner diversity’ (p. 34). This is afforded through the concept of the ‘universal design for learning’ which, in an idealistic and arguably impractical description, includes all aspects of classroom design, teaching and participation (pp. 42 – 45). However, for Liasidou, it is this very diversity that suggests the need for specific teaching methods and programmes for autistic children, such as TEACCH and Applied Behaviour Analysis (ABA), which she describes as ‘very beneficial’ (p.45).

Further, Norwich and Lewis (2007), in a complex and theoretical article, consider how genuinely specialised teaching in the context of SEND actually is, and what the evidence base might be for specific pedagogies. They also set out the confusion which can arise between teaching methods and learning objectives:

‘In asking whether pupils with learning difficulties require distinct kinds of strategies, we were not asking whether these pupils need distinct curriculum *objectives*. We were asking whether they need distinct kinds of *teaching* to learn the same content as others without learning difficulties.’ (p. 128).

In this arena, they describe ‘the grey area where conventional school teaching interfaces with therapeutic interventions that are learning-based’ (p. 137), a dilemma also explored in Norwich (2008). In other words, specialist pedagogies may also inexorably lead to the setting of different

learning objectives, outside of the main curriculum, without the value of this being measured or questioned. Indeed, Wittemeyer et al. (2011a) found that studies on assessment and outcomes for autistic students focussed on ‘functional goals’ (p. 38), and ‘academic attainment did not feature’ (p. 37). In these ways, the arguments for both an adapted curriculum and specialist pedagogies in relation to the education of autistic children are revealed as complex and unresolved.

Teaching Assistants

The presence of Teaching Assistants (TAs), or Learning Support Assistants (LSAs) in the classroom is the source of much discussion and debate, according to a number of texts. Lindsay (2007a) for example, considers that there is a lack of evidence of what their impact might be on pupils’ progress and attainment. Similarly, Cremin, Thomas and Vincett (2005) cite studies which showed little by way of clear effects of TA support on pupil attainment. Meanwhile, Cigman (2007) considers the situation in starker terms, stating that ‘providing a one-to-one teaching assistant is usually of no help at all’ (p. 28) to autistic children.

Furthermore, Wittemeyer et al. (2011a) express concerns that, due to the perpetual presence of TAs, autistic children – and unlike other children - are not allowed to make mistakes because they are being constantly corrected (p. 48.). Millar et al. (2002), raise the issue of a TA being ‘velcroed’ to the child (p. 11) and Liasidou (2012) also discusses ‘the velcro model’ (p. 26). For her, ‘the constant presence and attention of a teaching aide’ means that ‘disabled students are isolated and socially marginalised from their peers’ (ibid, p. 26). Guldberg (2010) also noted more social interactions amongst children in small groups and ‘with lower adult involvement’ (p. 171), a point reinforced in Humphrey and Lewis (2008), where some autistic pupils felt that the presence of support staff served to underscore their differences from their peers, and

prevented them from integrating with the rest of the class. These issues were also emphasised in the newspaper article 'We end up hindering the pupils we're meant to help', where a teaching assistant asserted that 'too often, TAs can fall into the trap of becoming surrogate friends for vulnerable young people, who then become ostracised from their peers as a result' (The Secret Teacher, 2016). These problems, she asserts 'can go against the core principles of inclusive education and segregate those with SEND from other students' (ibid, 2016). What is evident, therefore, is that while teachers 'rely heavily' on TAs (Emam and Farrell 2009, p. 407), their role and effectiveness are unclear.

Teacher training

According to Batten et al. (2006), the overwhelming response to their survey from parents was that teacher training would make the biggest difference to their child's learning and experience in school (p. 14). Similarly, Barnard et al. (2002) recommended that the Teacher Training Agency 'should include modules in basic teacher training on how children with autism spectrum disorders learn' and that all schools 'should ensure that at least a proportion of their teaching staff have substantial training in autism' (p. 8). Without this, they warn, 'it will lead to integration without social inclusion or educational progress at best, and destructive behaviour and exclusion from school in the worst cases' (p. 8). Beaney (2006) recommends closer working between special and mainstream schools, and found that school leaders, in particular, endorsed the notion that the whole school staff should receive training in autism. This point is also reflected in Wittemeyer et al. (2011a), who explore the difficulties that can arise when teaching assistants and teachers might know more about autism than the Head teacher making the key decisions, for example (p. 48). However, Humphrey and Symes (2011), while advocating the importance of teacher training (p. 33), suggest that 'training may need to be differentiated for different school personnel' (p. 40).

Nash and Norwich (2010), set out to establish how much training is devoted to SEN on Post Graduate Certificate in Education (PGCE) courses in England. They found this ranged from one to 30 hours (with a mean of 12 hours) for primary school trainee teachers, and for secondary school trainee teachers, it was even less, ranging from two to 18 hours, with a mean of seven hours. Furthermore, they found that not all courses had specialist SEN staff, and subject tutors reported that ‘in most courses there was no clear means of formally linking SEN coverage in their specialism/curriculum module’ (p. 1476). In other words, trainee teachers might be ‘taught’ in some senses about SEN, but not about how this might impact on and influence their subject teaching. Even though the response rate to the Nash and Norwich (2010) survey was low – for example, only 38% of secondary programme directors responded and they excluded all courses which did not have an A or a B rating from Ofsted - this is an indication at least that teachers are receiving very little training in SEN, and in autism, even less. Ellis, Tod and Graham-Matheson (2012) also found that there was a strong view that initial teacher training did not adequately prepare teachers to teach pupils with a range of SEN, irrespective of how recently they had qualified.

Within the context of autism, the Department for Children, Schools and Families (DCSF), in response to the Disability Discrimination Act (2005), produced a suite of training materials for teachers aimed at helping them to understand and support autistic pupils in school (DCSF, 2009). Later, Wittemeyer et al. (2011b) developed a ‘Professional Competency Framework’ which provides a structured programme of information and training, enabling school staff to monitor the development of their understanding of autism and their aptitudes in working with autistic children. This was accompanied by the ‘National Autism Standards’ (Jones et al., 2011), which focussed more on schools and other educational settings (rather than staff), and aimed to establish a benchmark of high expectations for school leaders in this area. Both reports were

created via the Autism Education Trust (AET), and Cullen et al. (2013), in an evaluation of the AET training programmes using ‘theory of change’ as its mechanism, found that ‘the strongest evidence (relates) to the impact on staff confidence about their knowledge, understanding and skills’ (p. 96).

Nevertheless, Ambitious About Autism (AAA) (2013) found that 60% of teachers were of the view that they did not have enough training in autism (p. 2). In 2016, AAA joined forces with the National Autistic Society (NAS) to launch the ‘Every Teacher’ campaign, highlighting the fact that there is no compulsory autism training for teachers, and asserted that 44% of teachers ‘do not feel confident teaching autistic children’ and that ‘58% of children and young people on the autism spectrum said that the single thing that would make school better for them was if teachers understood autism’ (NAS, 2016). Nicky Morgan, then the Secretary of State for Education, subsequently announced that training in autism would be a compulsory part of initial teacher training (Espinoza, 2016), and commissioned a report to tackle this issue, amongst others (DfE, 2016). Although this report only refers to autism once throughout, it nevertheless represents a powerful endorsement of the importance of teacher training in the context of SEND, stating that this should be integrated across all aspects of the training, so that pupils with SEND can ‘access and progress within the curriculum’ (DfE, 2016, p. 17).

However, not all accounts endorse fully the concept of teacher training in SEND as constituting an important driver towards inclusion, particularly in its current form. For example, Allan (2008), fears that student teacher training might lay ‘the foundations for confusion, frustration, guilt and exhaustion by ensuring that student teachers feel they do not know enough to respond effectively to children’s needs’ (p. 19). Trainee teachers become inured to the sense that they are ‘incompetent’ in the face of ‘the full range of pathologies that will present themselves in the classrooms’ (ibid, p. 19). Further, they are caught within a ‘rigid system which works

against complex thinking’, pushing them towards ‘management of’, rather than ‘engagement with’ different pupils (ibid, p. 20). Moreover, because much of teacher training now takes place in schools rather than the university-based model, Campbell (2015) raises the following question:

‘If a trainee learns predominantly from the practices and norms in their placement school, with less time devoted to critical pedagogical theory, might this serve only to reinforce active stereotypes and expectations, with less scope for new ideas and the challenging of normative templates?’ (p. 540).

Thus, a tension emerges between the declared need for training, bolstered by professional expertise, and the concern that this framework might serve to further endorse ‘the marginality of the disabled child’ (Slee and Allan, 2001, p. 179).

Furthermore, the role and level of expertise of Special Educational Needs Co-ordinators (SENCOs) is rarely evaluated in these reports. Batten et al. (2006) for example, while recommending that SENCOs receive training in autism, do not appear to have the same expectations for their training and expertise that they do for other school staff. Similarly, Nash and Norwich (2010) give much prominence to the proficiencies of SENCOs throughout their report, but do not question how much training they might have actually had. Given that it has only been a requirement since 2008 for SENCOs to hold a teaching qualification (The Education [Special Educational Needs Co-ordinators] [England] Regulations 2008), and that from 2009 it became law that every new SENCO in a mainstream school to gain the Master’s-level National Award for SENCO within 3 years of taking up the post, (The Education [Special Educational Needs Co-ordinators] [England] [Amendment] Regulations 2009), this seems a surprising omission.

The rights of autistic children

By this stage of my review of the literature, I noticed several references to the ‘rights’ of autistic children to be included in mainstream settings, and considered it useful to clarify what they are and how they had arisen. After all, considerations about the educational placement, assessment and attainment of autistic children, particularly in the context of mainstream settings, must be underpinned by knowledge of their rights in this regard. The Salamanca Statement (UNESCO, 1994), for example, is an international accord which reinforced the notion of educational inclusion, and was agreed by signatories in order ‘to promote the approach of inclusive education, namely enabling schools to serve all children, particularly those with special educational needs’ (p. iii). This is backed up in legislation by the United Nations Convention on the Rights of the Child (UNCRC) (1989), which affirms the right to primary education, secondary and higher education too, which should be ‘accessible to all’ (article 28) and prepare a child ‘for responsible life in a free society’ (article 29) and ‘the fullest possible social integration’ (article 23). Consequently, the rights of disabled children to be educated and integrated into society are given the same weight as, for example, the right to life (article 6), the preservation of identity (article 8) and the protection from all forms of violence (article 19), thus establishing a powerful basis on which to support and advocate for disabled children. Importantly, the receipt of an education is not considered to be an end in itself, but seen as a conduit to societal integration.

Later, the CRPD (2006), asserts the requirement for an ‘inclusive education system at all levels’, and the right to the availability of education is extended further to ‘lifelong learning’ (article 24). Disabled children should be able to access education ‘on an equal basis’ along with other children in their communities, and this may only be realisable with the right ‘accommodation’, ‘support measures’, ‘augmentative and alternative modes, means and

formats of communication' (article 24). Such measures might be a necessary means to enable 'persons with disabilities to participate effectively in a free society' where the ultimate goal is 'full inclusion' (article 24). In addition, the CRPD (2006) promotes the concept of 'universal design', which is defined as follows:

'...the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.' (article 2)

Therefore, while advocating the importance of support measures and assistive inputs for disabled children, the ideal of a design which reduces this need to a minimum is established. It is the 'mainstream' environment itself which needs to adapt fundamentally in order to facilitate inclusion and, furthermore, reduce the need for this to even be a necessary and active process. In addition, the CRPD (2006) asserts the importance of 'mainstreaming disability issues' (preamble g) and states that disabled children have the right to be taught by well trained staff, including teachers with disabilities (article 24), as there must be 'respect for the right of children to preserve their identities' (article 3).

As far as national legislation is concerned, the development of this over recent decades is instructive. For example, the first Education Act in England was enacted in 1944 and although some children were deemed to be 'ineducable' (Runswick-Cole and Hodge, 2009), the education of disabled children has developed significantly since this time. The Warnock report (Department for Education and Science, 1978) broadly promoted the concept of the education of children with SEN (when the term was first used) in mainstream schools, and the Education Act (1981) provided that 'special educational provision' could now exist within an 'ordinary

school', as long as certain conditions, such as 'the efficient use of resources', were met (chapter 60, Preliminary 2).

Since then, further legislation such as the Education Reform Act (1988) and the Education Act (1996) continued to reinforce the importance of educational inclusion for pupils with SEN (Gillard, 2011). For example, Part IV of the Education Act (1996) confirmed the 'duty to educate children with SEN in mainstream schools' (chapter I, section 316) and also endorses the comprehensive application of the National Curriculum for all children (Part V), as well as the 'obligation to enter pupils for examinations' in those subjects (ibid, Part V, chapter. IV, section 402), with very rare exceptions. Subsequent Acts such as the Special Educational Needs and Disability Act (SENDA) (2001), which sets out the limited circumstances under which a place in a mainstream school might be refused, further entrenches those rights. The SENDA (2001) also tackles the matter of accessibility, with a view to 'increasing the extent to which disabled pupils can participate in schools' curriculums' (Part. 2, chapter 1, section 14). Later, the Equality Act (2010) asserts that a pupil must not be subject to exclusion, and affirms that qualification bodies must 'minimise the extent to which disabled persons are disadvantaged in attaining the qualification because of their disabilities' (Part 6, chapter 3, section 96). Therefore, while the right of disabled children to be placed in mainstream school environments is further embedded over time, this is accompanied by additional provisions such as inclusion in the curriculum, being entered for exams and broader issues of accessibility. In other words, inclusion is not simply about placement in a mainstream school.

Recently, the Children and Families Act (CFA) 2014 established that Statements of SEN were to be replaced by Education, Health and Care (EHC) plans (section 25). These may continue until the age of 25 (ibid, section 46), and their overall purpose is to provide support for all aspects of the child or young person's life, including, for example 'physical and mental health

and emotional well-being’, ‘social and economic well-being’ and ‘the contribution made by them to society’ (ibid, section 25). Thus, the education of children with SEND is seen in a broader context than that of the classroom and is ensconced as part of their wider needs and rights, echoing some aspects of both the UNCRC (1989) and the CRPD (2006).

Consequently, the various legal instruments and provisions show that over the last half century or so, the rights of disabled people have gradually increased to encompass all aspects of physical, emotional and social life. Mainstream education, which must include access to the curriculum and exams, for example, is considered to be a conduit to longer-term integration into society. Further, as we have seen, the international conventions, in particular, appear to denote a gradual shift away from the concept of ‘needs’ towards a sense that society, its systems and structures, must adapt in order to include a greater diversity of individuals. However, UK legislation, while embracing these tenets in certain regards, continues to represent the assessment of needs and diagnosis of a medical condition as necessary to obtain ‘rights’ in terms of educational support and placement, as is particularly evident in the CFA (2014). This is notwithstanding the fact that, the process of assessment, diagnosis and support can be seen as a driver of exclusion, rather than inclusion. Thomas (2012a) for example, argues the following:

‘The future contribution of inclusive education hinges on its ability to retreat from histories of identify-assess-diagnose-help and to examine the ways in which schools enable community and encourage students’ belief in themselves as members of such community.’ (p. 486).

Furthermore, despite the weighty legal provisions discussed, implementation and, ultimately, enforceability, are key. For example, a recent report by the United Nations Committee on the

Rights of Persons with Disabilities, which monitors the implementation of the CRPD (2006) by nation states, found that the UK was on ‘the threshold of grave or systematic violations of the rights of persons with disabilities’ (Committee on the Rights of Persons with Disabilities, 2016). Not only this, but the same report found that the Care Act 2014, a major piece of legislation introduced to provide support for disabled people, was similarly not compliant with the CRPD (2006) (Broach, S., 8 November 2016).

Needs versus Rights

The tension – and interdependence - between the ‘needs’ and ‘rights’ of disabled people that can be seen in legislation is also reflected in broader analyses (Ravet, 2011). While the needs-based standpoint rests broadly on a medical conceptualisation of disability, meaning that disabled children are viewed as impaired and thus in need of specialist support and pedagogies, for example (Jordan, 2005), this position is firmly refuted within the rights-based perspective (Molloy and Vasil, 2002). The ‘right’ of children in this context is to be taught in an inclusive environment (Batten et al., 2006; Woronko and Killoran, 2011) in which ‘unique differences’ are accommodated and integrated (Lewis and Norwich, 2005).

For Sinclair Taylor (2000), for example, educational developments have ‘shown little concern for children’s rights’ (p. 32) and the tenets of the UNCRC (1989) cannot be achieved within a system of ‘normal and non-normal schooling’ (p. 28). Indeed, according to Runswick-Cole and Hodge (2009), it is precisely the emphasis on needs, and its concomitant vocabulary of alienation, which is at the root of exclusionary practices. They argue for the replacement of the concept of ‘special educational needs’ with the notion of ‘rights’, asserting that in education ‘children and young people are disabled through the exclusionary practices of segregated schooling or by being labelled as having “special needs”.’ (ibid., p.199). Similarly, Terzi (2005)

rejects the ‘within-child model’ suggested by the very notion of special needs, and sets out the limitations inherent in the different classifications of SEN (p. 447).

Meanwhile, Ravet (2011), posits that the polarisation between ‘needs’ and ‘rights’ is unhelpful, and argues for an integrative position when considering the educational inclusion of autistic children. She considers that ‘labelling’ can be ‘exclusionary’ because it ‘emphasises difference which can lead to marginalisation’; but that it can also be ‘inclusionary as it makes it possible to identify and meet individual needs’ (p. 670). According to Ravet (2011), therefore, the concept of needs and rights do not necessarily conflict with each other, and might be usefully combined in an ‘integrative inclusionist position’ (p. 667), because the ‘two dominant perspectives can work together, rather than in opposition’ (p. 679).

Others have argued that the emphasis on children’s rights has had a paradoxically detrimental effect on their inclusion. Lindsay (2007a), for example, bemoans the ‘values-based not empirically based’ approach to educational inclusion (p. 18) and asserts that there is a lack of hard evidence that the emphasis on rights has led to good outcomes (Lindsay 2007b, p. 20). For Allan (2008), legislation in the context of inclusion and SEND has had a negative impact:

‘Well intentioned efforts to develop inclusive policy and legislation appear to always lead to the repetition of exclusion and add to the confusion, frustration, guilt and exhaustion experienced by teachers.’ (p. 25).

Liasidou (2012), while maintaining that ‘the traditional linkage of inclusion with special education should be jettisoned, while the linkage of inclusion with human rights should be urgently forged’ (p. 13), warns of the potential dangers of undermining the rights of some children by dint of asserting the rights of others (p. 17). For Rioux and Valentine (2006) the essential problem, which they discuss within an international and Canadian context, is the lack

of clarity and consensus on how disability is conceptualised, leading to a disconnect between the ambitions of legal provisions and the lived reality of disabled people:

‘For people with disabilities (...), there is a substantial (and widening) gap between the rhetoric of equality found in both international and domestic policy instruments and the actual policies and programs put in place to enable people to live, work, and play in our communities.’ (p. 56)

Therefore, despite decades of international and national legislation in relation to the educational inclusion of children with SEND, it is not clear how successful their implementation has been.

Exclusion

Notwithstanding these debates, it is also evident that pupils with SEND continue to be subject to a certain amount of educational exclusion. Dockrell, Peacey and Lunt (2002), for example, found that children who had Statements of SEN were far more likely to be permanently excluded than pupils without Statements (p. 32), a point echoed in Jones et al. (2008), who asserted that ‘pupils with Statements of SEN were over 3 times more likely to be permanently excluded from school than the rest of the school population’ (p. 92).

Furthermore, the situation appears to be even worse for autistic children (Batten et al., 2006; Humphrey, 2008). For example, in a survey of 500 families run by the charity Ambitious About Autism (AAA), 23% of parents reported that their autistic child had been formally excluded within the previous 12 months (AAA, 2013). In 2016, AAA launched their ‘When will ~~they~~ we learn?’ campaign (the excision is part of the title), and asserted, based on an analysis of DfE data, that autistic children are four times more likely to be permanently excluded from school than any other child (AAA, 2016). Indeed, these exclusions are not always legal, a point reinforced by the Office of the Children’s Commissioner in 2012:

‘These are situations when a school requires a young person to leave the premises but does not record it as a formal exclusion. This might be for a fixed, usually short, period of time, or in the worst cases indefinitely. It also refers to instances when a young person or their family is “persuaded” to move school, a move usually sold to the family and the child as an alternative to a permanent exclusion going on the child’s record.’ (p. 16).

These actions, they maintain, are in contradiction of Article 28 of the UNCRC (1989), and ‘informal’ or ‘unofficial’ exclusions are ‘illegal regardless of whether they are done with the agreement of parents or carers’ (p. 58). AAA, in a survey of over 700 families, also found that 45% of autistic children had been sent home illegally, or denied a full education (AAA, 2016). Furthermore, exclusion can operate in other ways, and incorporate, for example, being barred from participation in extra-curricular activities (Jones, 2002), from using certain equipment, going on school trips (AAA, 2016), or from being present in mainstream classes (Dockrell, Peacey and Lunt, 2002).

Another potentially damaging and exclusionary factor or, at the very least, an issue which could have a profoundly negative impact on the school experiences of an autistic child, is bullying. According to Batten et al. (2006), over 40% of autistic children have been bullied at school, which not only puts their emotional well-being at risk, but disrupts their education too:

‘Where children have been bullied, 62% of their parents say that the bullying led to them having to miss or change schools or to their child refusing to go to school at all.’
(Batten et al., 2006, p. 16)

Whitaker (2007) found a high level of concern amongst parents that their children were being bullied (p. 175) and for Humphrey and Lewis (2008), ‘social isolation, loneliness and bullying’ are ‘commonplace’ (p. 24) for autistic children. According to Humphrey and Symes (2011),

autistic children are up the three times more likely to be bullied than other children and ‘the social outcomes of pupils with ASDs in mainstream schools can be very negative’ (p. 42). Furthermore, the teacher plays a crucial role in facilitating the social approval of autistic children by peers because ‘the more negative relationship teachers had with such pupils, the less socially accepted they were by their peers’ (p. 33). Meanwhile, Hebron and Humphrey (2013) found that autistic children are more likely to be bullied than children without SEN or those who had other SEN.

However, while Dockrell, Peacey and Lunt (2002) suggest that more research is needed to find out whether pupils with SEN are in fact ‘more likely to bully’ (p. 34), for Norwich and Kelly (2004), the responsibility for this situation might rest with the process of mainstream inclusion itself. Furthermore, in some accounts, it is the very nature of autism which is deemed to provide the rationale for bullying. According to Humphrey and Symes (2011), for example, when teachers experience ‘challenging behaviour’ from autistic pupils, this leads to poor staff-pupil relationships and, in turn, peer rejection for those autistic children. Similarly, Batten et al. (2006) suggest that ‘difficulty with social relationships, ranging from being withdrawn, to appearing aloof and indifferent, to simply not fitting in’, seeming ‘insensitive to the feelings of others’ can all lead to bullying (p. 5). In an arguably unethical study by Dean, Fox Adams and Kasari (2013), a seven-year-old autistic girl was placed into social groups with non-autistic peers and shown to be gradually excluded and even ridiculed by them. This social rejection and bullying (although the latter term is not used in the article) is explained as a consequence of her autism, which is framed entirely negatively:

‘...because of rigidity, a tendency to fixate on details, repetitive behaviors, and difficulties with problem solving’ (Dean, Fox Adams and Kasari, 2013, p. 148).

For Dean, Fox Adams and Kasari (2013), 'in order to be accepted' the autistic pupil must be prepared to change and adapt because 'the student with ASD is held responsible for upholding the same cultural norms as typical populations' (p. 148). It would seem, therefore, that if autistic children are being bullied, it is because they are autistic.

In such accounts, autistic children are presented as disruptive, alien presences, unable to fit into an educational system that 'cannot be altered' to accommodate them (Glashan, Mackay and Grieve, 2004, p. 56). Indeed, Humphrey and Symes (2011) suggest that autistic children are particularly difficult to include in mainstream schools (p. 32), while Cigman (2007) criticises the 'radical inclusionists' (p. xix) and singles out autistic children as being especially unsuited to mainstream settings. Inclusion is posited as 'a problem', 'a technical matter', to be resolved via strategies and methods, rather than an issue to be thoughtfully explored in the context of values (Allan, 2008, pp. 18 – 19). Moreover, even though some reports underline the importance of adapting the school environment (Jordan, 2005), or providing therapeutic support (McCartney et al., 2010), they are still predicated on 'individual pathology perspectives' which focus on children's supposed deficits (Liasidou, 2012, p. 22).

In these ways, exclusion emerges as a potentially widespread phenomenon, multi-faceted in its manifestations and entrenched in a complex relationship with inclusion (Allan, 2010). Thomas (2012a), summarises well the possible harmful effects of various exclusionary practices:

'This is in the damage done to individuals' sense of worth and identity where they see themselves, through major differences between themselves and their peers, conspicuously excluded from the expectations, the activities, the resources, the worlds of those peers.' (p. 480).

Consequently, and notwithstanding the vast amount of legislation which endorses inclusive principles, debates continue about the suitability of mainstream placements for autistic children. Indeed, the very meaning of inclusion itself is in danger of denoting little more than being physically present within a mainstream school (Humphrey, 2008; Norwich, 2014), rather than overcoming barriers and creating equality of access (Rioux and Valentine, 2006).

Chapter summary

As I have described, my initial investigations into the field of autism and autism education started with texts which attempted to explain the underlying biology of autism and to link this with the apparent deficiencies associated with the condition. However, other accounts posited an alternative conceptualisation of autism, based on the notion of ‘difference’, rather than deficits. Moreover, while the rights of autistic children to be included in mainstream schools and broader society appear to be grounded in some powerful and longstanding legal provisions and policy documents, they seem to be subject to a great deal of exclusion, which is manifested in a number of different ways. Indeed, the presence of autistic children in mainstream schools is problematised and, by extension it would seem, so is the input and general mien of their parents. Furthermore, the difficulties associated with the education and general inclusion of autistic children are predicated on the very nature of autism itself, which is presented as a complicating and disruptive condition.

The autistic children themselves do not appear to be particularly thriving in mainstream schools, being at risk of bullying, and achieving poor levels of participation and attainment in tests. In addition, and notwithstanding the extensive emphasis placed on the assessment, diagnosis and (early) intervention model within professional circles, the journey of autistic children along their educational pathway appears uncertain and problematic. Considerable discussion

surrounds what their educational priorities and outcomes should be, and how these can be both measured and achieved, and whether they are better served by an assertion of their 'rights' rather than their 'needs'. Inclusion and exclusion therefore appear to be complex, interrelated phenomena.

Many texts focussed predominantly on the attitudes of teachers and other school staff and, while others incorporated the views of parents, it was not evident that their opinions figured in the setting of curricula and educational priorities for their children. Moreover, very few reports included the actual perspective of autistic children themselves, and those which did, rarely included children who might have limited spoken communication, raising questions about how representative they are.

There was very little analysis indeed of how the very uncertainty experienced by teachers about specialist pedagogies, as well as questions about adapted curricula and the deployment of teaching assistants, might impact on the children, both in terms of their learning and their general experience of time in school. In short, there seemed to be a lack of joined up thinking in which definitions of autism, support in school, inclusion and exclusion, educational priorities and attainment and longer terms outcomes were considered within a single account, incorporating the views and perspectives of school staff, parents, autistic adults and autistic children, thus presenting an obvious gap which I hoped my study, albeit in a small way, would address.

Moreover, while my review of the literature incorporated texts concerning the nature of autism, a range of issues pertaining to education and outcomes, as well as the needs and rights of children with SEND (and autistic children in particular), these were not the only materials which shaped my ideas as I proceeded towards the formulation of my research questions and

the design of my study. In the next chapter, I set out the ideas and theories which also influenced this project in its various stages.

CHAPTER 2: CONCEPTUAL FRAMEWORK

My research project did not operate under a single theoretical model; rather it was strongly influenced by a number of overlapping theories, ideas, debates and discourses. These discussions and philosophies shaped my study at every stage, but were the driving force behind the formulation of my research questions, and linked my review of the literature, where the focus was predominantly on autism, with broader issues, such as inclusion, as well as my methodology, findings and eventual conclusions. I have grouped these ideas and arguments into five categories: Medical and Social Models of Disability; Language and Communication; Feminism; Inclusion; Difference. In this chapter, I explore these ideas and indicate how they influenced my study overall.

Medical versus Social models of disability

The medical or individual (Hodge, 2014) model of disability is predicated on the notion that disability results from individual impairments or dysfunctions. According to Rioux and Valentine (2006), the medical model can itself be sub-divided into the ‘biomedical approach’ and the ‘functional approach’, although both are ‘based on individual pathology’ and lead to a drive to either eliminate or cure the disability, or ‘ameliorate the condition and provide comfort to the individual’ (p. 50). The virtue of this position might be to trigger the recognition for support and remediation (Bury, 2000), while for Baker (2006), this perception results in ‘the equation of disability with disadvantage’, which society seeks to mediate ‘through charitable services’ (p. 177). According to Hughes (2009), an adoption of the medical model might lead to the constitution of ‘biological citizens’ who form communities which ‘politicise, as well as medicalise their collective illness identity’ (Hughes, 2009, p. 679).

For those who subscribe to this conceptualisation, the emphasis is on the body and its biology (Hughes, 2009), where disability is potentially seen as a 'spoiled identity', an undesirable state to overcome, entirely located 'within the impaired individual' (Williams and Mavin, 2012, pp. 165 – 166). For its detractors, the medical model carries within it an 'inherent disablism', with 'normality' as 'the yardstick' against which disabled people are measured, meaning disability is considered to be 'outside the range of human experience' and consequently 'disabled people are not really human' (Hurst, 2000, p. 1084). According to McColl et al. (2006), the price of any support obtained via a medical conceptualisation of disability is 'the necessity of adopting the sick role and becoming a patient (...), rather than a citizen with full rights and participation' (p. 41). Furthermore, for Davis, Watson and Cunningham-Burley (2000), this standpoint has led to a medicalisation of childhood itself, meaning that 'children who do not achieve universal standardized developmental targets' are pathologised (p. 205). By extension, Terzi (2005) considers that the medical model as played out in educational environments results in 'perspectives emphasising individual limitations (which) end up overshadowing the role played by the design of schooling institutions in determining learning difficulties' (p. 446). Moreover, Ryan and Runswick-Cole (2008) found that this tendency to pathologise children can also be extended to their mothers, leading to a 'medical model of mothering' (p. 200), whereby problems are deemed to emanate from the very fact of having a disabled child, rather than the barriers they face.

The social model, on the other hand, suggests that disablement is derived not from the individual inherently, but from the limitations of societal structures and attitudes which impede the functionality of certain people. Here, disability is perceived as being 'on a continuum' (Pfeiffer, 2000, p. 1082), which potentially includes everyone, suggesting that the division between 'able' and 'disabled' is an artificial one. Furthermore, while certain conceptualisations

of the medical model might imply that disabled people are unavoidably limited and disenfranchised, within the social model they are perceived to be potentially liberated, empowered and politicised (Hughes, 2009). According to Jurkowski (2008), the social model of disability is innately enabling, allowing disabled people to 'challenge oppressive research methods and policies that do not include their perspectives and experiences' (p. 1). For Liasidou (2012), the very notion of inclusive education itself is founded on the social model, as it 'refers to the restructuring of social and, by implication, educational settings in order to meet the needs of all learners irrespective of their diverse biographical, developmental and learning trajectories' (p. 5).

However, the majority of accounts do not fit neatly into 'medical' and 'social' categories, and the issue as a whole is characterised by disputes and disagreements. Lindsay (2007b), for example, questions the value of the social model, since it provides that an individual is defined by external factors alone. Meanwhile, Rioux and Valentine (2006) identify four possible models overall, including an 'environmental approach', as 'increasingly, researchers find that the impact of disability is compounded by the failure of ordinary environments to accommodate people's differences' (p52). McColl et al. (2006), suggest the existence of five models: biomedical, philanthropic, sociological, economic and socio-political (p. 39), arguing that each has different implications for access to health services, income replacement and human rights, for example.

The divisions and overlaps within the medical and social model ideologies are particularly evident in a key policy document, the International Classification of Functioning, Disability and Health (ICF, also referred to as the ICIDH2), (World Health Organization, 2001), described as the 'gold standard' of medical and disability definition and classification (McColl et al., 2006, p. 27). Replacing the International Classification of Impairments, Disabilities and

Handicaps (ICIDH, 1980), it suggests that ‘environmental factors’ can impact upon a person’s ability to function well, and that society ‘may hinder an individual’s performance because either it creates barriers (e.g. inaccessible buildings) or it does not provide facilitators (e.g. unavailability of assistive devices)’ (ICIDH2 2001, p. 17). Here, ‘disability’ is defined as ‘a multidimensional phenomenon resulting from the interaction between people and their physical and social environment’ and it is ‘the interaction of the health characteristics and the contextual factors that produces disability.’ (ICIDH2 2001, p. 242). Thus, it is asserted in this document that ‘disability’ is a complex interaction between external factors and those located within the individual and that by extension, with the right support, disability can be reduced.

Perhaps unsurprisingly, this uneasy positioning between the medical and social models has led to a number of criticisms. Pfeiffer (2000) for example, totally rejected the ICIDH2 (2001), stating that it is still firmly ensconced in the medical model of disability and indeed associated with the mentality of eugenics. For Hurst (2000), the ‘whole ICIDH2 is very white and industrialised-country centred’ (p. 1086), and she notes the limited involvement of disabled people in its drafting. Bury (2000) on the other hand, who was one of the authors of the original ICIDH (1980), questions the necessity of the updated ICIDH2 (2001), virtually from the opposite perspective. He asks whether a revision was even needed, and suggests that the ‘social model’ has not ‘really engaged with the real issues facing the vast majority of disabled people’ (Bury, 2000, p. 1075).

Nevertheless, the notion of disability as deriving from interaction, rather than ‘within person’ fixed states, as partially espoused by the ICD1D2 (2001), is promoted by some commentators. According to Lindsay (2007b), for example, the social model itself ‘has been superseded’, as it ‘plays down or actively ignores both the within-child factors and the issue of interaction’ (p. 17). Shakespeare (2014) also considers that an ‘interactional approach’ can serve to highlight

the ways in which the circumstances of disabled people might be improved, and is of the view that it is unhelpful to place the social and medical models of disability in opposition to each other. For him, this perspective enables disability to be understood as ‘a complex and multi-factorial phenomenon’ (p. 84):

‘...disability is a complex interaction of biological, psychological, cultural and socio-political factors, which cannot be extricated except with precision.’ (Shakespeare, 2014, p. 26).

More specifically in the context of autism, a ‘transactional approach’ has been advocated by Guldberg (2010), based on the SCERTS model (Social Communication, Emotional Regulation, and Transactional Support, Prizant et al., 2003), which emphasises that ‘supports must be flexible and responsive to different social contexts and learning environments’ (Prizant et al., 2003, p. 306). This centres on the notion of ‘intersubjectivity’, whereby the ways in which people behave result from a complex interplay of ‘how people interpret the world and interact with each other’ (May, 1997, p. 14). However, autistic scholar Milton (2014b) queries whether ‘interactional expertise’ can ever be achieved by non-autistic researchers when working with autistic people, for example, even though, in his view, it should be ‘a basic standard for social scientific research’ (p. 3).

For some, the debate between medical and social models pivots on the question of impairment, which according to Slee and Allan (2001), is omitted within the social model of disability as it ‘represents a return to locating disability within the individual’ (p. 170). Allan (2010) later argues that the failure of the social model to acknowledge the reality of impairment has, in turn, caused commentators to reject the social model altogether, because this means a denial of the disabled body itself, a point also argued by Shakespeare (2014). For Williams and Mavin

(2012), 'impairment is a social as well as a subjective experience' (p. 170), a 'biological characteristic' which becomes a disability due to 'negative social responses to people with impairments as different from normative expectations.' (p. 167). Similarly, Devlin and Pothier (2006) argue the following:

'Whether the social construct incorporates just disability or disability with impairment, the point is that the problem is not the person with the disability. Rather, it is the pervasive impact of ableist assumptions, institutions, and structures that disadvantage persons with disabilities.' (p. 13).

In other words, the key issue is not whether impairments are incorporated as part of the social model paradigm, but rather the notions dictated by normative assumptions which hinder disabled people. For Devlin and Pothier (2006), disability is itself a social construct; it has 'no essential nature', but rather 'specific personal characteristics are understood as defects and, as a result, persons are *manufactured* as disabled' (p. 5).

Meanwhile Terzi (2005), advocates a middle ground, asserting that 'difficulties and disability' in education cannot simply be presented as 'socially constructed', as this viewpoint 'significantly overlooks the individual factors related to impairments' (p. 448). According to Terzi (2005), an impairment has to at least be acknowledged 'in order to avoid educational barriers' (p. 448), although she is clear that this is 'relational', as 'impairments become disabilities - that is, functional limitations - in certain educational arrangements but not in others' (p. 447). Moreover, Davis, Watson and Cunningham-Burley (2000), while criticising academic research which has been preoccupied with differentiating children on the basis of impairments, assert that the social model not only homogenises people, but 'does not incorporate an understanding that disabled children might be capable of affecting the structures

surrounding their lives' (p.206). Meanwhile, Gabel and Peters (2004) propose 'resistance theory' as a means to accommodate the medical and social models, arguing that each have elements of resistance within them, and that 'most of us resist our physical bodies in some way during our lifetime' (p. 597).

The ideas and debates about the medical and social models also run through research into autism which, as we have seen, sits uneasily within the context of disability. As discussed in the previous chapter, the majority of accounts present autism as a suite of deficiencies, where 'islets of ability' (Shah and Frith, 1982, p. 614) are perceived as little more than demonstrations of less severe dysfunction. According to Happé (1999), for example, autism is 'a devastating developmental disorder', and she considers that 'most autistic people also have general learning difficulties and low IQ' (p. 216). For Emam and Farrell (2009), difficulties for school staff are a result of 'ASD-related manifestations' (p. 407) while for others, the difficulties are shown to increase with age (Rosenthal et al, 2013). Significantly, early identification of these dysfunctions is deemed to be the basis on which to advocate for support, predicated predominantly on a medical conceptualisation of autism (Howlin, Mawhood and Rutter, 2000). In these ways, and in a manner evocative of the tension between 'needs' and 'rights' discussed in the previous chapter, access to support requires an allegiance with the medical definition of autism and an acceptance of its description as a condition characterised by deficits. This view appears to permeate educational practices: according to Molloy and Vasil (2002), for example, 'an acceptance of the medical model approach to disability is implicit in the field of special education' (p. 665). The consequence of this, they argue, is that if a child performs poorly in school, this is considered to be 'due to some problem with him or her and not as a result of educational practices' (ibid., p. 665).

In addition, medical descriptions of autism are also prevalent in the general media. Huws and Jones (2010) analysed representations of autism in British newspapers from 1999 – 2008, and found a predominance of discourses which ‘potentially dehumanise and marginalise autism and those individuals associated with this label or diagnosis’ (p. 101). Autism is presented as ‘an affliction’, of which certain people are ‘victims’ (p. 101), and rendered in a ‘homogenised way that failed to recognise human diversity’ (Huws and Jones, 2010, p. 102). Within this gloomy presentation, certain individuals are seen as overcoming these terrible odds, despite their condition, and so the ‘capacity of children diagnosed as having autism to achieve is therefore presented as being unexpected, yet inspirational’ (ibid. p. 102).

However, as discussed previously, alternative conceptualisations of autism might represent a shift within this debate. For example, Happé (1999) acknowledges the importance of conducting research into the strengths manifested by autistic people, while Baron-Cohen (2002b) suggests that society is inherently more accepting of certain characteristics than others, rejecting those more typically present in autistic people, meaning they are consequently considered to be disabled by dint of being autistic. Lawson (2011) goes further, asserting that ‘the autism spectrum should be considered not as a terrible tragedy that needs to be cured or redeemed, but as an important learning style’ (p. 23). Moreover, he argues that the ‘co-morbidities’ which are often identified and considered to be the source of the autistic dysfunction itself, are in some senses a matter of perception, to the extent that ‘co-occurring difficulties’ exist in the general population, ‘but this is often forgotten’ (Lawson, 2011, p. 31).

The debates between the medical and social models, combined with the different descriptions of autism set out here and in the previous chapter, had an important influence in my study overall, especially – as will be seen later in this thesis - in relation to the ways in which different participants conceived of autism.

Language and Communication

As outlined in the previous chapter, the association of autism with language dysfunction constitutes part of the diagnostic criteria for the condition and this notion is also embedded within professional and educational narratives about autism. In addition, research studies emphasise the link between language impairment and poor performance in school:

‘Regression models indicated that nonverbal and language abilities are important factors in predicting attainment on Key Stage 1 and 2 English and maths national curriculum tests. For Key Stage 2 tests, there was some indication that autism symptomatology predicted attainment.’ (Dockrell et al., 2012, p. 161)

The existence of language disorders for autistic people is also associated with impoverished longer-term outcomes (Howlin, Mawhood and Rutter, 2000), and so those who have limited verbal communication are considered to be especially impaired. However, Lawson (2008) critiques this view:

‘...language is considered the traditional normal currency of communication. Therefore, if you don't use language as your communication tool, you may be considered disabled, disordered or dysfunctional.’ (p. 74).

Consequently, the assumption is made that autistic people who ‘don’t talk’ must be ‘intellectually disabled’ (Lawson, 2008, p. 80). Moreover, this dysfunction is not deemed to centre solely on the failure to acquire a broad spoken lexis, for example, but on apparent narrative ambiguities (Norbury and Bishop, 2003), how ideas might be conveyed and what an individual chooses to relate (Loveland et al., 1990;). Dean, Fox Adams and Kasari (2013) noted that an autistic girl is rejected by her peers because of her ‘narrative delivery’, the ‘idiosyncratic/repetitive nature of her stories, and her persistence despite receiving peer

sanctioning' (pp. 151 - 152). Thus, language impairment in autistic people is considered to include both issues of linguistic development, the topics they choose to talk about, and how they communicate and engage in social situations. While some autistic people are deemed impaired because they are 'non-verbal', those who are 'verbal' might be similarly be viewed as dysfunctional due to apparently saying the wrong things, in the wrong way and at the wrong time.

Furthermore, while questions are raised about the linguistic competence of autistic people, the language which is used to describe them and other disabled individuals must itself be subject to scrutiny. For Grue (2015), the word 'disability' is 'polysemic', with 'multiple possible shades of meaning', although it is commonly – and pejoratively - used to refer to 'a lack or limitation in some capacity of the body, be it mental or physical' (p. 1). According to Pothier and Devlin (2006), the term 'disability' alone has negative connotations, since it indicates a lack of ability, while Lawson (2011) comments that 'being diagnosed with an autism spectrum *disorder* doesn't inspire confidence in either the individual themselves or others around them' (p. 17). For Slee and Allan (2001), the very language of special educational needs is 'based upon a medical model of pathological defectiveness' (p. 179), while for Terzi (2005), the notion of special needs rests on a 'within-child model' (p. 447), where the source of any educational difficulties is considered to be the child's impairments. Similarly, Runswick-Cole and Hodge (2009) argue that the term 'special educational needs' contributes to 'the loss of a child's identity behind the veil of a syndrome or condition' (p. 200) and so is part of 'exclusionary practices' (p. 199). Liasidou (2012) also considers that the language and discourses about inclusion can in fact perpetuate exclusion, while Humphry (2014) describes how 'deficit discourses' in educational environments can have 'debilitating effects' on the lives of those young people they are applied to, 'creating negative, damaging and often incontestable, singular

identities' (p. 486). In other words, special educational needs discourses themselves can become drivers of educational exclusion and long-term ostracism, an issue reflective of the Foucauldian view of how 'apparent humanitarianism of reason' might disguise 'techniques of oppression and marginalisation' (Downing, 2008, p. 20). Consequently, while autistic people might be considered impaired because of their lack of spoken language, or as a result of their communication and interaction style in social situations, they are potentially further marginalised and excluded by the ways in which they are described and spoken about by others. Indeed Klar-Wolfond (2008) calls for a completely different sort of language to be used when describing autism, one which emphasises the positive aspects of this disposition, as well as any support which might be needed.

In addition, philosophers of language and meaning urge us to consider these issues more deeply, and to reflect critically on the descriptions of certain categories of people as deviating from linguistic norms. According to Saussure, for example, language ('langue') is distinct from speech ('parole'), and sounds do not themselves have any kind of inherent meaning, but rather those ascribed by the speaker (Free, 1990). The relationship between the signifier (the sound, word or image) and the signified (the object or idea) is arbitrary, a convention which has been agreed upon within a certain context (Downing, 2008). Similarly, Byatt (2016) describes 'the shifts we have to make as readers and writers between thinking about words and things' and urges readers to take pleasure in this discrepancy. For Merleau-Ponty, on the other hand, speech is not some sort of (imperfect) representation of an object, a mere exchange of signs between speakers, but an embodiment itself, with its own presence and reality (Free, 1990). Derrida (1967) conceived of the notion of 'archi-écriture', an original form of language which precedes both speech and writing, rendering the distinction - and hierarchy - between them less evident.

At around the same time, in an essay about the interpretation of literary texts, Barthes (1968) wrote the following:

‘And so is revealed the whole being of writing: a text is made of multiple writings, which come from several cultures and which enter into a state of dialogue, parody and dispute with each other; but there is a place where this multiplicity is gathered together, and this place, is not the author, as we have said until now, but the reader...’ (Barthes, 1968, p. 66, translation by researcher).

In other words, there is no fixed meaning within a text, or a ‘correct’ interpretation of an author’s writing. According to these ideas, not only can disconnections occur between speaking and writing, thought, language and meaning, but we cannot assume that we all understand the communication of others in the same way. In the light of these philosophies, the accepted link between the intentions of the speaker, the objects or ideas identified through speech, and the understandings of the interlocutor, is fundamentally challenged. By extension, the declarations about meaning and non-meaning, definitions of sense and non-sense which might be ascribed to the language of autistic people by others must also be put in doubt. However, accounts of autism which focus on language and communication, show no such reservations or uncertainty:

‘Many questions remain to be answered about communication in autism. For example, how is odd intonation related to deficits in communication and social cognition? How do linguistic comprehension deficits relate to the various aspects of deviant language seen in the syndrome? What triggers the initial failure of social cognition and joint attention that seems to be associated with such pervasive communicative difficulties?’ (Tager-Flusberg, Rhea and Lord, 2005, p. 356).

There is no sense in this account that descriptions of ‘odd intonation’ or ‘deviant language’ might be subject to interpretation, that these are potentially arbitrary decisions made by one group of people about another. The focus here, as in so many studies, is not on how to understand autistic people, but how to explain their posited communication impairments, which are presented entirely unequivocally as alien and undesirable.

These issues become especially concerning when the language of disablement and special educational needs serves not only to exclude certain categories of individuals, as we have already seen, but potentially to disempower them too. According to Runswick-Cole and Hodge (2009), for example, ‘an overview of the development of the use of language in special education policy demonstrates the power of language over the lives of children’ (p. 198), while Liasidou (2012), citing Ball (2009, p. 5) argues how policy discourses make ‘particular sets of ideas obvious, common sense and ‘true’’ (p. 98). The meaning of ‘truth’ here is reminiscent of a Foucauldian perspective, where it constitutes ‘the invention of forms of knowledge and the conditions of their crystallisation into institutions of authority’ (Downing, 2008, p. 13). Therefore, these discourses ‘produce and sustain relations of power’ (Liasidou, 2012, p. 97) through the meanings they create, which in turn serve to exclude and disable others. According to Devlin and Pothier (2006), ‘language is deeply partial’ (p. 7), and issues of disability are ultimately ‘questions of power: of who and what gets valued, and who and what gets marginalized’ (p. 9). For Rioux and Valentine (2006), ‘the language around disability itself creates a circle of tension and confusion’ (p. 55) and so, according to Grue (2015), researchers must ‘keep looking for the ways in which disability – and disablement – is constructed, administrated, and policed through the socially and bureaucratically embedded use of language’ (p. 5).

Moreover, the certainty of the ‘deficit-oriented discourses’ (Liasidou, 2012, p. 99) can be contrasted with the scepticism and doubt which result from demonstrations of cogency from disabled people, particularly when expressed in an unanticipated fashion. Davis, Watson and Cunningham-Burley (2000), for example, found that staff in a special school either misinterpreted or ignored entirely attempts at communication from the children, which in turn impaired the efforts to communicate of those same children. This included an occasion when a member of staff had not believed a child who communicated that he had been to a football match, which subsequently turned out to be true (ibid, pp. 214 – 215). This disbelief on the part of school staff stemmed from the view that as a result of their impairments, the children were ‘not like us’ (ibid, p. 209). Wing (2007) asserts a number of times that the ‘understanding’ of autistic children is often lower than their speech suggests, stating similarly that some ‘may appear to have some pretend play’, but that this is in fact ‘an empty copy of other children’s play’ (p. 28). In the context of autism education, there is a generally held view that some children might have high level reading skills, but that their ‘comprehension’ is impaired (Jones et al., 2008; Dockrell et al., 2012). Consequently, these viewpoints suggest that autistic children might speak, read and play, but these actions are somehow devoid of meaning and are not necessarily indicative of understanding on their part.

Further, these issues arguably reach their zenith in debates about Facilitated Communication (FC). Originally devised to help people with cerebral palsy, FC involves support being provided by a ‘facilitator’ to a person who has limited or no speech, as well as motor control or planning difficulties, so that person can point to letters on a board or an electronic grid in order to spell out words. More recently, FC has been used to help autistic people to communicate, but has consistently failed tests of validity on the question of authorship when subjected to scientific, quantitative assessments (Schlosser et al., 2014). In these studies, the facilitator was shown to

be the ‘author’ of the words typed by the autistic person. For Erevelles (2002), however, the debates about FC ‘extend beyond questions of authorship and competency’, but describe ‘how and why particular kinds of knowledges are formed and act in relationship to particular institutions (e.g. law/education) and the roles prescribed to them (e.g. competence/incompetence)’ (p. 19). For Erevelles (2002), the discrediting of FC is based on ‘the humanist assumption that the subject is capable of fully representing himself/herself via the transparent medium of language’, rather than the poststructuralist view that language ‘is constituted via the play of multiple signifiers’ (p. 19). Furthermore, she argues, the techniques used to test the validity of FC require an assessment of ‘the “deviant” subject according to positivist rules and humanist rationality’ (ibid, p. 25):

‘Here, the presumed “author” (which in this case is the person with autism), has already been assigned to the space of Unreason (disability), and is now compelled to reclaim for himself/herself the role of rational subject by demonstrating his/her autonomy as the author.’ (Erevelles, 2002, p. 26)

Thus, according to Erevelles (2002), not only have autistic people been defined as disordered and in some senses irrational, but they are expected to prove their understanding through techniques which are predicated on notions of order and reason, and which (erroneously) presuppose that language is a transparent medium of thought. Therefore, while FC as an authentic means of communication is highly contested, including within the autistic community where it has been associated by some with abuse (Hearst, 2016), questions remain about how its validity has been assessed. For Klar-Wolfond (2008), a key issue within the broader autism context is the requirement to ‘base everything on our need for proof of either competence or incompetence’ (p. 115).

A further important example within the debate of validity when non-verbal forms of communication are used, is provided by the autistic activist Baggs (2006). Her video 'In My Language' which, at the time of writing, has reached 1.4 million views on YouTube, shows her humming, tapping, flicking and rocking, which she describes as 'my native language'. She 'translates' these physical responses by typing and using voice output software, which she employs apparently unaided. Baggs (2006) explains how the way she thinks and responds to her environment is 'so different from standard concepts or even visualization that some people do not consider it thought at all.' Similarly, she describes the contradiction between the fact that she is considered impaired because she struggles with the language of others, who are not correspondingly thought to lack ability even though they do not understand hers. However, - and perhaps somewhat consistently with the issues relating to belief and credibility previously described - Baggs has a number of detractors, some of whom describe her as a 'fraud' and in some senses faking her autism (Amanda Baggs Autism Controversy, 2009).

From these ideas and arguments, the conceptualisation of autism as typified by linguistic dysfunction emerges as complex and, in some arenas, contested. As will be seen in later chapters, these diverse views about language, communication and interpretation had important ramifications in my findings.

Feminism

There are some striking parallels between the difficulties experienced by autistic people, particularly in the context of exclusion and marginalisation as discussed in the previous chapter, and some feminist issues. According to Campbell and Wasco (2000), for example, there are in fact 'multiple feminisms', but they all have notions of 'marginalisation' at their core (p. 775). Similarly, Millman and Kanter (1987) examine how women can be excluded through societal

processes and discuss how ‘sociologists have focused upon the relationships between persons officially labelled deviant and the agents of social control’ (pp. 32 – 33). They also argue that in prevailing discourses, ‘the banal/mundane is overlooked’, with a focus instead on the genius artist, who is usually male (ibid., p. 33). Meanwhile, Ryan and Runswick-Cole aver that mothers of disabled children occupy a liminal space, marginalised by dint of their parenting role, where their actions are viewed with suspicion.

According to Parker (1999), and providing an important addition to discussions about language, meaning and power, some feminist researchers consider that this exclusion operates through language itself, as this is a medium through which ‘realities are constructed and continued’ (p. 17), with women often sitting ‘outside’ the dominant male language (p. 18). For Irigaray (1981), the governing discourse is deemed to be ‘phallogocentric’, defined by powerful narratives and authoritative, binary oppositions, in which the ‘the multiple nature of female desire and language’ are not permitted to flourish (p. 104). According to Cixous (1981) ideas about women are established through a series of linguistic oppositions:

‘Where is she?’

Activity/passivity,

Sun/Moon,

Culture/Nature,

Day/Night,

Father/Mother,

Head/heart,

Intelligible/sensitive,

Logos/Pathos' (Cixous, 1981, p. 90)

For Cixous (1981), thought has always operated through 'dual, *hierarchized* oppositions' (p. 91), including 'High/Low' (p. 90), within which women are always of the subordinate order. Earlier, in a ground-breaking historical, social and philosophical account of women's status in society, de Beauvoir describes how women are only defined in relation to men, and so always occupy the place of 'the Other':

'Woman determines and differentiates herself in relation to man, but man does not do this in relation to woman. She is the inessential as opposed to the essential. He is the subject, the Absolute, she is the Other.' (de Beauvoir, [1949], vol. 1, p. 16, translation by France, 2016)

Similarly, Kelly-Gadol (1987), considers that historically, in the same way as American black people, women have always been a socially oppressed group, defined by a sense of 'otherness' (p. 19). Within the context of disability, Devlin and Pothier (2006), critique the 'binaristic approach to disability' which, they argue, begets a process of 'othering' (p. 5). In addition, Hughes (2009) discusses the problem of 'othering', in which 'the normal' and 'the pathological' are separated (p. 686). Allan (2010) refers to 'a series of erasures and absences', 'the disappearance of the Other' (p. 603) from educational policies and practices, while autistic scholar Milton (2012) also describes the stigma of being 'othered', or 'defined as abnormal', which can mean that certain individuals are 'socially stigmatised, shunned and sanctioned' (p. 885). For Milton and Sims (2016), societal 'othering' can lead to autistic people experiencing 'problems with authority figures (expectations of obedience and conformity), stigma and bullying' (p. 526). This placement of autistic people into a separate category of 'others' – and notwithstanding the general perception of autism as a 'spectrum' condition - is followed in turn

by divisions within autism itself, with binary oppositions such as ‘high’ and ‘low functioning’, ‘verbal’ and ‘non-verbal’, ‘mildly’ and ‘severely’ autistic, terms deeply embedded within professional and research discourses. Furthermore, autistic people of exceptionally high ability – so-called ‘autistic savants’ – are perceived as ‘exotic others’, defined by the ‘medical freakery’ which typifies autism descriptions (Arnold, 2013).

Moi (1985) argues that Anglo-American feminism conceptualises the female self in an essentialist way, whereas French feminists do not, and so are better able to challenge the patriarchal orthodoxy from which these gender constructions emanate. This debate also has correspondences both in general disability and autism contexts. Hurst (2000), for example, considers that it has not been necessary to refer to a woman’s physical characteristics in order to assert her rights, stating that analyses of ‘the effects, pain and suffering of menstruation, the menarche, birth or sexuality on the individual woman’ are neither the means by which she might be classified as an individual, nor her role in society described (p. 1084). For disabled people on the other hand, Hurst (2000) contends that that it is still deemed necessary ‘to concentrate on the personal characteristics of the disabled individual’, which she considers is in itself is a form of disablism (p. 1084). Indeed, numerous autism studies focus on the physical characteristics of autistic people, in a quest to provide insights into possible causes for their putative dysfunctions. Aksu et al. (2013) for example, studied finger-length ratio, hair-whorl and hand dominance in a group of 37 autistic males and 121 ‘healthy’ males aged four – 18 years, reaching the following conclusion:

‘The autism group had more hair whorls than the control group and the hair whorls in the autistic individuals with left hand and left eye dominance were located further from the mid-sagittal line. We think that these novel findings might contribute to the determination of the phenotypic features specific to autism.’ (Aksu et al., 2013, p. 94).

Similarly, several studies have been conducted into the head circumference of autistic people, a review of which, conducted by Sacco, Gabriele and Persico (2013), concluded that ‘effect sizes and prevalence rates for macrocephaly and brain overgrowth in autism, confirm the variation of abnormal brain growth with age’, a finding they consider could be of ‘clinical use’ (p. 239).

These issues reveal the uneasy relationship between biology and autism, in which autistic traits are both medicalised and classed as undesirable, with autistic people shunted towards an alternative category of ‘abnormal’ or ‘other’. Moreover, just as feminist writers have argued that this ‘othering’ can lead to marginalisation, disempowerment and a lack of agency, I considered, as I planned my data collection in schools, to what extent this notion might be embedded within special educational practices and discourses about autism, and what the implications of this might be.

Inclusion

In the previous chapter, I set out the national and international legislative and procedural background to educational inclusion in the UK, and described how this has evolved over recent decades and the extent to which these provisions are predicated on concepts of both ‘needs’ and ‘rights’. In addition, I also reviewed some of the literature which indicates that notwithstanding these developments, autistic children are subject to high levels of exclusion, both from school settings and within them, during their school day. Furthermore, this disconnect between the ideals of the UN Conventions, for example, and the uncomfortable reality of poor attendance and performance in school tests and impoverished longer-term outcomes, suggests that the very meaning of ‘inclusion’ has itself become a fractured or potentially empty term.

For Jones et al. (2008), 'inclusion' must be compared with 'integration', with the latter meaning little more than placement within a mainstream school. Lindsay (2007a) explains further that while the concept of inclusion suggests that a setting must be adapted in order to meet the needs of certain pupils, integration implies that it is the child who must adapt. Even so, he argues, 'this distinction is not always clear in practice' (p. 3). Liasidou (2012) also discusses the difference between inclusion and integration, stating similarly that if the latter 'suggests simply relocating students into unchanged educational systems', the former 'suggests a radical re-organisation of schools in order to meet the diversity of learner needs' (p. 9). Indeed, a number of accounts emphasise the importance of adapting the environment for the inclusion of autistic children to be successful (Colley, 2007; Guldberg, 2010), arguing that these adjustments could potentially benefit all learners (Jones, 2002; Woronko and Killoran, 2011). Even so, the DCSF (2009), while stating that inclusion in mainstream education 'can be extremely beneficial for pupils on the autism spectrum' (p. 13), makes it clear that a school 'is not required to do anything under its scheme that is unreasonable or impracticable' (p. 24), implying a less than whole-hearted acceptance of these principles.

As well as adaptations to the environment, and in order to be more 'accommodating of children with significant difficulties', Norwich and Kelly (2004), consider that inclusion in mainstream schools may necessitate 'physical and curriculum adaptations', as well as 'social acceptance' (p. 62). For Jones et al. (2008), inclusion similarly means paying attention to the environment and teaching styles, but especially to relationships:

'Particular attention is given to the relationships the pupil is enabled to develop with other pupils (with and without autism), both within and outside the school, and the potential benefits to other pupils and staff.' (p. 20).

According to Jones et al. (2008), autistic children should not be excluded from extra-curricular events and likewise, Norwich and Lewis (2005) argue that as well as classroom teaching and the curriculum, inclusion must ‘go beyond general questions of the presence of children with special educational needs in (mainstream) schools’ and include ‘their social learning and participation’ (p. 2). Hesmondhalgh (2006) emphasises that mainstream teachers should ‘be listening rather than talking, be willing to facilitate their ideas, and aim for their dreams’ when educating autistic pupils (p. 113). There is, he emphasises ‘no model (...) no tick chart and no recordable evidence’ (p. 47) when it comes to the successful education of autistic pupils, because adaptations must be specific for individual children. Jordan (2005) meanwhile, takes the notion of ‘adaptations’ a step further: in making the case for ‘an inclusive curriculum’, she clarifies that this ‘is about its applicability to all from its inception and not about adaptations and extensions to make a non-inclusive curriculum more applicable to excluded groups’ (p. 117). In other words, curriculum planning must contain at the earliest stage the potential to include a diversity of learners, a concept evocative of the principles of the Universal Design for Learning advocated by Woronko and Killoran (2011), Liasidou (2012) and espoused by the CRPD (2006).

However, notwithstanding these suggestions and clarifications about how inclusion might operate, uncertainties remain about what inclusion actually means. Indeed, both Lindsay (2007a, p. 17) and Allan (2008, p. 48) ask the same question: ‘inclusion into what?’ For example, Jones (2002) and Jones et al. (2008) assert that ‘inclusion’ as a concept applies just as much to mainstream as special education settings, while Lindsay (2007a) hints at a similar position, suggesting that inclusion must not be conceived of as meaning only ‘full-time education in a mainstream class’ (p. 18). Indeed, Norwich and Kelly (2004), in a study which involved the participation of secondary school pupils with moderate learning difficulties,

concluded that ‘full-time mainstream class placement’ was contrary to the notion of ‘inclusive schooling’ (p. 62), as the pupils required time away from the main cohort, for example.

Meanwhile, Whitaker (2007) found high levels of satisfaction amongst parents of autistic children who attended special schools, and Hesmondhalgh and Breakey (2001) and Hesmondhalgh (2006) describe the benefits not only of a modified curriculum for autistic children of secondary-school age, but of a specifically designed resource base attached to a mainstream school. Further, Barnard et al. (2002), found that a third of schools had a negative attitude towards mainstream inclusion (p. 7), while in the foreword to Cigman (2007), Warnock criticises ‘the British Council for Disabled People (...) who regard inclusion in mainstream schools as something to which disabled children are entitled to as of right’, a rather concerning attitude given, as we have seen in the previous chapter, it is indeed their ‘right’. Further, Warnock identifies secondary schools as being particularly difficult for ‘a child with Asperger’s’, while Cigman, in the editorial foreword, uses highly emotive examples to argue against those she describes as ‘radical inclusionists’:

‘...the idea of including all children in the mainstream is hardly credible. What about the child who is brain-damaged and asleep most of the time? What about the 14 year-old in nappies, whose mental age is two? What about the child who is so autistic that she does nothing all day but rock?’ (Cigman, 2007, p. xxii).

For Cigman (2007), autistic children constitute ‘a group of children for whom the benefits of mainstream education are widely viewed with scepticism’ (p. xxiv). She considers, furthermore, that the bullying of autistic children is almost inevitable in mainstream schools, an argument she supports by describing the example of a boy who was slashed with an art knife. According to Cigman (2007), it is the within-child characteristics, the ‘social and communication

impairments', which are 'intrinsically more disabling in mainstream environments than physical impairments' (p. xxvii). In the same book Wing (2007) similarly criticises 'the theories of idealists who have no knowledge of or empathy for children with autism' (p. 28) by seeking to place them in a mainstream school, arguing that special school placements are more suitable for 'many, though not all' autistic children (p. 32).

According to Liasidou (2012) meanwhile, inclusion, in reality, is both conceived of and functions as little more than a sub-section of special education, 'within which several disguised forms of marginalization, discrimination and exclusion are operating' (p. 9). Furthermore, Liasidou (2012) considers not only that segregated remedial classes in mainstream schools - where the focus is on the child's deficits - are inherently exclusionary, but that resource units are equally problematic, as they are 'mini special schools' (p. 25):

'These units are starkly oriented to a segregating model, and seldom do they function as a transitional mode of education, aimed at facilitating the gradual inclusion of disabled children in mainstream classes.' (p. 25).

Indeed, Armstrong, Galloway and Tomlinson (1993) provide an interesting example of a child who, when placed in a unit for children with behavioural problems, assumed he must be 'bad', but when he was subsequently returned to the mainstream school, perceived this as an opportunity to be 'good'. Lloyd-Smith and Tarr (2000), referencing Sinclair-Taylor (1995), suggest that pupils' perceptions of the value of being placed in a resource base might be at variance with those of the school staff and associated professionals:

'...the pupils experienced the unit as excluding and marginalizing, not inclusive as professionals in the school and local authority believed it to be.' (Lloyd-Smith and Tarr, 2000, p. 61)

Furthermore, for Liasidou (2012), special schools do not provide the answer, as they are somewhat spuriously justified on the basis that they can better meet the needs of some children, thus 'leaving intact the normal operation of mainstream schooling' (p. 22).

Perhaps the uncertainty about the extent to which the concept of educational inclusion might apply to issues of placement explains in part the problematic nature of how it has come to be understood and described within mainstream contexts. According to Thomas (2012a), for example, inclusive education 'is still like an island, considered as a separate territory from mainstream education, with its own discourses, policies and practices' (p. 475). Similarly, for Liasidou (2012), inclusive education has been reduced to a 'special education artefact' (p. 21) where the focus 'is on the categorization of certain students as having special educational needs due to their low attainment, behaviour or disability' (p. 26). She considers that the 'traditional linkage of inclusion with special education should be jettisoned' (p. 13), and argues that the bracketing of inclusion within a special education framework enables schools to play the system whereby they 'discreetly marginalize and exclude certain students and prevent them from adding negative value to a school's performance indicators' (p. 20). Similarly, according to Slee and Allan (2001), too many of the methods, philosophies and approaches of special education have been used in the name of inclusion, a concept which can be misappropriated to reinforce 'unreconstructed notions of schooling and educational defectiveness' (p. 174). Instead, they argue, inclusive education should represent 'a fundamental paradigm shift' (p. 177), towards an understanding where inclusion is conceived of as a matter for all, not just for certain categories of children. Indeed, in a fascinating case study based in a school in Finland, Tarr, Tsokova and Takkunen (2012) found that terms such as 'inclusion' and 'special education' have very different meanings to how they are commonly used in the UK. Not only are all children deemed to be in receipt of 'special education' at some point or another during their schooling,

but the authors assert that the term ‘inclusion’ is not used by people, and ‘rarely appears in the lexicon of policy documents or published work’ (ibid, p. 694). This, they suggest, is because ‘inclusion’ is a given, rather than an ideal to be debated. From their study, which contained a consideration of the physical layout of the school and how teaching roles were assigned, the authors conclude that the school is an example of how to ‘reduce exclusion and isolation through skilful manipulation of the physical, institutional and communicative context’ from which, they state we (in the UK) ‘could draw some valuable lessons’ (ibid, p. 702).

Therefore, however educational inclusion might be defined and described within a UK context, it is clear that it remains a problematic and polarising notion, centred on the concept of ‘special educational needs’, and often revolving narrowly on questions of placement. Indeed, for Allan (2008), inclusion ‘appears to be in something of a sorry state, characterised by confusion, frustration, guilt and exhaustion’ (p. 3), with debates often run on ideological grounds, a point also made by Lindsay (2007a). For Slee and Allan (2001), ‘policy statements, legislation and special education texts are littered with conditional statements’ (p. 180) which reinforce the marginal status of the disabled child, in a society where certain people are constructed as ‘strangers’ (p. 178). As far as autistic children are concerned, and putatively as a result of their very nature, they are considered by some to be either more suitably placed in special school settings, or at best partially present only in mainstream schools. This is notwithstanding the plethora of accounts which advise how educational inclusion for autistic children might be achieved. Consequently, in my study, which centred on five mainstream primary schools in England, I endeavoured to understand how and to what extent the autistic children were ‘included’ in the curriculum and tests, as well as more broadly within those schools.

Difference

Wittemeyer et al. (2011b), in the Professional Competency Framework which was produced on behalf of the Autism Education Trust, and notwithstanding some references to ‘difficulties’, were careful to describe autism in a manner which predominantly avoided allusions to impairment and dysfunction:

‘Autism is a term used to describe a neurological difference in brain development that has a marked effect on how a person develops.’ (p. 12)

The authors set out ‘four areas of difference’ for educators to consider as they develop their understanding of autism, including ‘differences in how information is processed’ and ‘differences in the way sensory information is processed’ (ibid, p. 12). This conceptualisation is embedded in a framework which would enable staff to understand better how to support autistic children and further their participation in school, suggesting that notions of ‘difference’ are closely linked to ideas about inclusion. Similarly, Lawson (2008) argues that the ‘ideal’ of inclusion could be ‘a reality for many during school years’, if ‘difference was fostered as part of being normal’ (p. 96). In 2011, Lawson posited that autism should be thought of ‘as a cognitive difference or style’ (p. 41), in which ‘monotropic’ thinking, where an individual might concentrate very intensely on a particular topic, should be compared with ‘polytropic’ thinking, where the focus can be on different subjects or items, or attention can be switched easily from one to another. Many autistic people, Lawson (2011) considers, are ‘monotropic’ thinkers, but this is poorly understood by educators, and often misconceived as an impairment or an unwillingness to co-operate. Baron-Cohen (2002a) also deliberates whether Asperger Syndrome ‘should necessarily be viewed as a disability or, from a difference perspective, as a difference’ (p. 181). Whilst he concludes that the term ‘disability’ should be applied to Asperger

Syndrome, he also suggests that certain skills, such as a 'precise eye for detail' can lead to 'success rather than failure' (p. 189) in the right context. For Slee and Allan (2001), the 'legitimacy of difference' must not be denied if educational inclusion is to succeed, while Devlin and Pothier (2006) argue that 'disability demands coming to terms with difference' (p.12):

'Substantive equality necessitates taking difference into account in order to both identify the systemic nature of inequality and pursue solutions tailored to the goals of full inclusion and participation.' (Devlin and Pothier, 2006, p. 12).

However, other writers have suggested that there is in fact a 'dilemma of difference' (Norwich, 2008). This centres on whether a recognition of 'differences' leads to greater acceptance, but less support, for example, or to stigma, which might trigger necessary assistance. 'Difference', Norwich (2008) argues, can have both negative and positive connotations:

'The negative perception is that 'difference' reflects lower status, less value, perpetuating inequalities and poor quality provision and unfair treatment. The positive perception is that 'difference' reflects the recognition of individuality and individual needs and interests. It is this tension between these conceptions of difference that leads us to confront dilemmas of difference.' (p. 56).

In the foreword, Norwich (2008) argues that this dilemma operates across three areas of schooling: identification (whether or not to identify students with SEN), the curriculum (how much of the common curriculum is relevant to children with SEN) and placement (whether or not learning can take place in 'ordinary schools and classes'). Aspects of this debate are also set out in a somewhat impractical and convoluted analysis of 'unique differences' and 'general differences' in Norwich and Lewis (2005), where common, individual and group needs are

identified, and the place of children with SEN within these categories is discussed. Terzi (2005), in an article which in part compares two key reports by Warnock (Department for Education and Science, 1978; Warnock, 2005), is of the view that the apparent retreat from a belief in the value of mainstream schooling potentially for all learners, represented in the more recent report, also centres on the 'dilemma of difference'. According to Terzi (2005), this impasse is summarised as follows:

'This consists in the seemingly unavoidable choice between, on the one hand, identifying children's differences in order to provide for them differentially, with the risk of labelling and dividing, and, on the other, accentuating the 'sameness' and offering common provision, with the risk of not making available what is relevant to, and needed by, individual children.' (p. 443)

For Ravet (2011), meanwhile, the notion of autism as a form of 'difference' might be a more positive way framing autism and 'distinguishing behaviours' (p. 672). However, in her view, this also creates a potential difficulty of 'norm referencing', which not only raises the question of 'different to what?', but she considers might not be 'so obviously appropriate in cases where autism is accompanied by severe and complex difficulties with communication, socialisation and flexibility of thought, comorbid conditions and/or physical and mental health problems' (Ravet, 2011, p. 672). Humphrey (2008) also found mixed views from the participating pupils in terms of how much they wanted to blend in with the general cohort or the extent to which they might be proud of their differences. Interestingly, Norwich (2008) ends with a call to consult with children themselves, and he quotes one of his participants, a disabled teenager, who says that sometimes he wants to be treated the same as everyone else, sometimes differently, but that he likes to be asked (p. 217).

Consequently, while for some commentators, ‘difference’ has a positive value, which enables both the strengths and support needs of certain children to be recognised and addressed, for others, it is a concept which can be both constructive and negative, creating a ‘dilemma’ for educators. For others still, however, the very notion of difference is unhelpful, as it is ‘constructed through binaries, with one being the norm, and also superior’ (Williams and Mavin, 2012, p. 161):

‘One of the binary pair is recognized as the norm whose associated attributes and values establish social norms, to the negation and marginalization of those people (and their organizing requirements) considered ‘Other’.’ (p. 161).

For Williams and Mavin (2012) therefore, constructing an individual as ‘different’ is akin to ‘othering’, with the concomitant exclusionary attitudes and practices this brings. Similarly, Liasidou (2012) refers to the ‘individual deficit model of pathology and difference’ (p. 26), while for Allan (2008), standards for inclusion create ‘a problem and a spectacle of difference, to be managed and tolerated’ by trainee teachers in particular (p. 21). Within this conceptualisation, ‘difference’ is deemed to apply to some children only, those ‘upon whom inclusion is to be practised’ and are ‘marked out with special status’ (ibid, p. 40). This thinking is certainly borne out in a document by the DCSF (2009) which ostensibly sets out the ways in which the education of autistic children can be improved:

‘There are two main dimensions that lead to difference – intellect of the pupil and the severity of their autism.’ (DCSF 2009, p. 9).

There is little sense here that ‘difference’ is a positive concept. Indeed, according to Thomas (2012a), ‘inclusive educators must uncouple from the resolutely deficit-orientated history of exceptionality’ (p. 486), and he suggests that the ‘symbiotic relationship between measured

‘ability’ and alienation makes for the beginnings of a new psychology of difference’ (p. 481). Crucially, he argues, ‘the alienation and exclusion’ (p. 481) experienced by some students emerge from comparisons, and so assessments of learning disability are always relative. Indeed, Armstrong, Galloway and Tomlinson (1993) found that children often considered the assessment process itself to be some sort of punishment, and this would impact on how they ‘performed’ during that assessment. Moreover, associated professionals, conflicted by different loyalties - to their employer, the school, the child’s parents - ‘often felt constrained to define the problem in terms of difficulties the child presented to others’ (ibid, p. 128). This, they argue ‘raises important theoretical and professional issues about the relationship between professionalism and the construction and representation of childhood deviance’ (ibid, p. 130). Moreover, according to Slee and Allan (2001), ‘the discursive practices of special education proceed from essentialising views of normality and abnormality’ causing those ‘who are dispersed to the margins and beyond’ to be further excluded (p. 179).

For autistic scholar Lawson (2008), the whole question rests on the very concept of normality:

‘In developing a concept of normal based upon one particular set of norms, diversity and difference as part of everyday normal or typical life is being lost rather than cultivated.’ (p.26).

In other words, the issue is not so much about ‘difference’, how it might be defined, or whether or not it is a helpful concept, but our very definition of normality, which being particularly narrow, means that certain people inevitably fall outside of its limited parameters. Lawson (2008) is in no doubt of the destructiveness of this restrictive view of what constitutes ‘normal’:

‘...normal is not inclusive of difference and in its most rigid form perpetuates modes of behaviour that prevent the healthy development of positive self-esteem and ability in a varied and wide population of individuals.’ (Lawson, 2008, p.30)

According to Lawson (2008), therefore, it is this very narrow conceptualisation of normality that restricts, excludes, or potentially disables others. Indeed, in my study, the notion of ‘difference’, in relation to autism, emerged as complex and polysemic in its use.

Chapter summary

In the previous chapter, I set out the different areas of literature I had studied in relation to autism diagnosis and interventions, as well as those pertaining more specifically to the education of autistic children, such as teacher attitudes, educational assessment and attainment, as well as their broader rights, and how these might operate in relation to their posited needs. This reading not only helped to establish what the key areas might be in connection with my broad area of interest – the inclusion in the curriculum and assessment of autistic children in mainstream primary schools – but to identify possible gaps in the literature, including methodological approaches.

In this chapter, I have explored the ideas and theories which also impacted on my study and helped to shape the later stages of my project. For example, my analysis of the medical and social models of disability suggested not only that it was important to consider where the problems autistic children are experiencing in schools might be deemed to reside, but that how autism is conceptualised by participants is of relevance too. In addition, the issues pertaining to language and communication seemed highly pertinent to the ways in which autistic children might communicate and demonstrate their learning in schools, especially given the fact that autism is considered to be defined in part by speech and language disorders (Wing and Gould,

1979). Furthermore, and as I explain in the next chapter, these questions also carried methodological implications, given that I planned to include both autistic children and adults in my study, as well as a range of other participants.

Meanwhile, some ideas associated with feminism show a particular link between language and the problem of ‘othering’, but also, as will be discussed in the next chapter, offered insights into how to frame my own positionality as a researcher. Furthermore, diverse and, at times, fractured understandings about inclusion underscored the importance of considering not only how autistic children might be included in the curriculum and assessment in mainstream schools, but to try to establish how those decisions are arrived at in the context of educational priorities. Finally, the notion of ‘difference’, which is highly complex and dominates some aspects of the autism research field, and is generally considered to constitute a more tolerant and inclusive approach to autistic children and adults (Wittmeyer et al, 2011b), underscored the importance of exploring understandings and descriptions of autism as part of my study.

In the next chapter, I set out the methodology of my research project, starting with a brief discussion of interpretative and positivist frameworks and how these might operate in autism research. I then describe my own project methodology, including the aims of my study and my research questions (p. 92). I also explain the particular issues associated with including autistic adults and children in my project. The rest of the chapter is devoted to an explanation of my positionality (pp. 96 - 100), a description of my research design, and a summary of the core ethical considerations and my processes of sampling, selection and recruitment. My research methods are described and explained in Chapter 4.

CHAPTER 3: METHODOLOGY

Introduction

‘For as to what is said of the absolute existence of unthinking things without any relation to their being perceived, that is to me perfectly unintelligible. Their *esse* is *percipi*, nor is it possible they should have any existence out of the minds or thinking things which perceive them.’ (Berkeley, 1710 [Warnock, G., ed., 1981, p. 66]).

Berkeley, writing at the start of the 18th century, asserted that we can only know about material existence through our perception of it. Building on the theories of Locke (1689/2008), who argued we are all born with an empty mind – a ‘*tabula rasa*’ – meaning that knowledge is created entirely through ensuing experiences and sensory perceptions, Berkeley cautioned against assumptions by either ‘ancient or modern philosophers’ who all ‘proceed on the supposition that corporeal substance or Matter doth really exist’ (1710/1981, p. 89). Although part of a complex reasoning to prove the existence of god, he also forewarned of the suppositions of those involved ‘in the study of Nature’ (ibid, p. 89) who do not question the ‘reality’ of what they see and observe. In other words, material existence is not fundamentally knowable, only our perception of it.

Towards the end of the 19th century, and more specifically in the context of the social sciences, the French philosopher Comte presented an ontological shift away from what has been described as the subjective idealism of Berkeley’s philosophical stance and that of relativist thinkers who, in their most radical form, maintain that ‘there is no external reality independent of human consciousness’ (Robson, 2002, p. 22). Comte argued not only that the world is entirely accessible, but that intellectual understanding has progressed over time from the theological, to the metaphysical, ultimately resulting in the scientific, or ‘positive’ (Comte,

1853/2009), thus postulating an alternative epistemological procedure. He considered that our understanding of the world and the people within it can be drawn legitimately from empirical observations, which in turn permit the formulation of ‘laws governing the organization and movement of society’ (Turner, Beeghley and Powers, 2012, p.39).

Meanwhile, more contemporary philosophers such as Gadamer return to a critical stance on ‘scientific activity’, asserting that it seeks to ‘absorb hermeneutical reflection into itself and render it serviceable to science’ (Gadamer, 1976 [trans], cited by Holub, p.36). Gadamer dismisses the ‘domination of the scientific epistemological model’ (ibid., p. 38) which ‘seeks only to allow what cannot be doubted’ (ibid., p. 37). Instead, Gadamer (1960) considers that the knower necessarily has a stance and is always within a context, a ‘hermeneutic circle’, where meaning is only ever partially created and understood. Horizons of understanding might meet and overlap in order to produce knowledge, and while prejudice and bias can never be eliminated, these are in fact spurious goals (Gadamer, 1960). For Popper (1953), ‘conjectures and refutations’ are the essence of science, and every test of a theory must be an attempt to falsify it. Later, Bhaskar (1975) proposed ‘transcendental realism’, subsequently called ‘critical realism’, in which knowledge can be described as ‘transitive’ (our understanding of reality) or ‘intransitive’ (the world as it is). Therefore, social injustice, for example, must in some senses be held to be ‘real’ if it is to be tackled, and so critical realism potentially offers a compromise between interpretivist and positivist paradigms. For social scientists, complexities reside in the fact that the object of study is often the transitive domain i.e. what people think and believe, and so they require methods other than those embraced by natural scientists, especially if their research is to have ‘emancipatory potential’ (Robson, 2002, p. 41).

Importantly, interpretivism, unlike positivism, permits or even prescribes doubt, and suggests that while social reality can only be comprehended through the revelation of different

viewpoints and perspectives, this understanding is necessarily partial. Within this context, the endeavour is not to find causes, but is about 'shedding light on meaning' (Robson, 2011, p. 412). Thus if the goal of social science is to discover 'how we can come to know the social world and what properties it contains' (May, 1997, p. 7), to concentrate on subjectivity is to focus 'on the *meanings* that people give to their environment, not to the environment itself' (ibid., p. 13). Within such a framework, the emphasis is on people and 'what they think and how they form ideas about the world; how their worlds are constructed' (Thomas, 2013a, p. 108). Indeed, some argue that a multiple-perspective approach founded on the interpretation of people's experiences – phenomenology - could potentially provide 'the basis on which genuinely reliable knowledge could be constructed' (Eagleton, 1983, p. 56).

Furthermore, according to the feminist social scientist Smith (1987), 'the pursuit of objectivity makes it possible for people to be paid to pursue a knowledge to which they are otherwise indifferent' (p. 88), and so she considers that the only way of understanding 'a socially constructed world is knowing it from within. We can never stand outside it' (p. 92). Similarly, May (1997) explains how, according to some feminist researchers, the notion of a detached observer 'disguises the myriad of ways in which the researcher is affected by the context of the research or the people who are part of it' (p.20). Indeed, from a feminist perspective, the assumption that 'facts' can be collected on the social world merely serves to sustain the unequal power relationships that already exist in society (May, 1997). In addition, Campbell and Wasco (2000) consider not only that the 'emotionality' of science should be recognised (p. 786), but that for feminist postmodernists, science 'is the production of text, which is always located in a specific historical and cultural context, and always shaped by power' (Campbell and Wasco, 2000, p. 782). Therefore, while a scientific paradigm 'believes in the separateness of the researcher and researched' (Pring, 2000, p. 47), an 'interpretative and hermeneutic tradition'

(ibid, p. 55) provides that such boundaries are necessarily less distinct. Indeed, according to Flyvbjerg (2006), what can be described as ‘the phenomenology for human learning’ becomes ‘the most advanced form of understanding’ when researchers place themselves ‘within the context being studied’ (p. 236), as this is the only way to understand the viewpoint of others.

Therefore, if positivism suggests that ‘the things of the social world can be observed, measured and studied scientifically’ (Thomas, 2013a, p. 107), and facts are considered to exist in the population independently of how people interpret them (May, 1997), it could be argued that much research in the autism field is founded on this premise. Predicated on the medical model of disability which itself adheres to notions of dispassionate observations and scientifically provable facts, accounts discussed in the first chapter which demonstrate a preoccupation with the aetiology of autism appear to derive from a positivist paradigm. This is notwithstanding the fact that no ‘single explanation’ (Happé, Ronald and Plomin, 2006) for autism - and its posited incumbent impairments - has been found through these scientific studies. Furthermore, although - as discussed previously - there are increasing references in this category of autism literature to the ‘strengths’ which could be deemed to be associated with autism (e.g. Happé, 1999; Baron-Cohen, 2002b), the fundamental premise that autism is a ‘disorder’, for which an objective explanation - based on empirical research - must be found, has not been disrupted.

However, Grinker (2015) asserts that medicalised accounts of autism can in fact impede a broader understanding of autism. Milton (2014a) also criticises the concomitant emphasis placed on interventions generated by such a medical paradigm. Indeed, if phenomenology is ‘a science of human consciousness’ (Eagleton, 1983, p. 56) through which ‘researchers place themselves within the context being studied’ (Flyvbjerg, 2006, p. 236), a number of qualitative studies in the autism field derive from this construct. Humphrey and Lewis (2008) and MacLeod, Lewis and Robertson (2013) for example, present interpretative studies informed by

Interpretative Phenomenological Analysis (IPA), and are careful to draw tentative conclusions only from what is an avowedly 'subjective' procedure. IPA, which posits that experiences are of value in their own terms, also recognises our intersubjectivity, 'the shared, overlapping and relational nature of our engagement with the world' (Smith, Flowers and Larkin, 2009, p. 17) when dealing with social subjects. Furthermore, Humphrey and Lewis (2008) assert that their research serves 'to confront inequities that lead to social exclusion' (p. 26), and so could also be described as containing elements of a critical realist approach which 'criticizes the social practices that it studies' (Robson, 2002, p. 41).

If much research in the autism domain is dominated by medical accounts, founded on a positivistic paradigm, and in search of explanations for putative impairments, an interesting and arguably unique contribution to the field is provided by Dawson et al. (2007). They contest the conceptualisation of autism as characterised by dysfunctions, but from within a positivistic, medical framework. Presenting 'tests' and 'empirical observations' as desirable standards in a domain which has been apparently obfuscated by 'assumptions', they assert that typically, even when assessments of autistic people have shown evidence of cognitive strengths, these have been dismissed as 'low-level by-products of high-level deficits' because of the 'untested' suppositions on which they rest (Dawson et al., 2007, p. 657). Indeed, the authors present their own approach as more rigorous and objective than previous, supposedly scientific procedures. Based in the clinical context of the Hôpital Rivière-des-Prairies in Quebec, the authors set out to test empirically 'prevalent conceptions' (ibid., p. 657), such as that autistic people who have minimal verbal ability must be classified as 'low functioning'. Importantly, the authors do not carry out the cognitive assessments themselves, and there is no mention, nor consideration of the relevance of the fact that Dawson is herself autistic. Accordingly, while some have asserted that 'positivism is dead' (Byrne, 1998, cited by Robson, 2002, p.26) and that post-positivism -

which acknowledges, *inter alia*, the possible influence of the background of the researcher – has taken its place, the paper by Dawson et al. (2007) would suggest this is far from the case. Moreover, some of the ideas, methodologies and findings of this study were explored further in Soulières and Dawson (2011) and Barbeau et al. (2012), as well as in Mottron et al. (2007) and Nader et al. (2015).

Project Methodology

Overall, my project derives from an interpretivist paradigm and proceeds on the basis that the world is only partially knowable, via subjective explanations. Understanding is therefore derived from multiple and overlapping perspectives, and while accounts explored as part of my literature review tended to emphasise the opinions and experiences of class teachers – excluding autistic children and adults and, to a lesser extent, parents – I wished to broaden the range of viewpoints incorporated. Further, in my study, these diverse perspectives do not only result from individuals, but from different knowledges represented, for example, in legal instruments, national datasets and other forms of numerical data. In this, my project also borrows to a small extent from a more realist, positivist tradition (Gorard and Taylor, 2004), in which objective facts are considered to be existent, available and therefore useful (Turner, Beeghley and Powers, 2012). However, I rejected the experimental designs of studies aimed at finding the ‘causes’ of or, in some senses, the ‘cures’ for autism, because of the basic premises on which they rest. In particular, my study proceeded on the basis that the assumption that autism consists of various impairments should not be made.

From a phenomenological perspective, the researcher must try to place him/herself within the context of the people and phenomena being studied, even though, from a Husserlian point of view, it is nevertheless important to remain ‘conscious’ in order to ‘disengage from the activity

and attend to the taken-for-granted experience of it' (Turner, Beeghley and Powers, 2012, p. 13). Therefore, the majority of my research took place in schools, and my research methods were informed by a drive to try to understand the viewpoints of the different participants. Furthermore, within an interpretivist paradigm, language – the 'house of Being' (Heidegger, 1947) – is pre-eminent, and discourses vary across time and within different frameworks, while, from a Foucauldian perspective, discourses cannot be separated from questions of power (May, 1997; Allan, 2008). Consequently, the interplay of language as it is used both to describe autism and through interactions with autistic people is explored in my study. Further, given that my study was 'concerned with an individual's perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself' (Smith and Osborn, 2007, p. 53), my aim was not to provide causal links which, according to Gorard (2013), might only emerge from 'a standard RCT' or a 'natural experiment', and moreover, would always include 'an intervention' (p. 199).

Project Aims and Research Questions

At this stage of my study, I had established, via my literature review, the main issues pertaining to the inclusion of autistic children in mainstream primary schools: their rights, the difficulties they face, the support they receive and the problems of exclusion. Further complexities emerged in relation to teacher training, the curriculum and school tests. Underpinning these issues is the question of the very nature of autism itself and the lack of any consensus on its prevalence. It was also clear, moreover, that most studies based on a medical model proceed unquestioningly on an understanding that autism consists of a suite of deficits, and so effectively set out to prove the assumptions on which they rest. Meanwhile, qualitative studies typically failed to incorporate the views of all stakeholders, especially autistic adults and children.

Further analysis of medical and social models reveals additional complexities and dilemmas in relation to the education of autistic children, where embracing the former offers an apparent conduit to support, but the latter to understanding: neither is arguably sufficient to provide autistic children with what they need to thrive educationally and in the longer term. Some feminist theories afford instructive parallels on the problems of marginalisation and ‘othering’ faced by autistic people, with ‘difference’ emerging as a contested concept, potentially doing more harm than good. Similarly, the notion of inclusion itself is fraught with debates and dilemmas, and is subject to different interpretations, while philosophers of language and meaning cause use to question the association of autism with communication impairments.

Within this context, an interpretivist paradigm offers, not only a medium by which different perspectives can be collated, but an epistemological approach which enables assumptions to be challenged. Further, the secondary data which informed my study suggest that answers need to be sought in the very places where learning occurs, since datasets cannot provide us with the lived experience of autistic children. Therefore, I considered that the bulk of my research needed to take place in schools and should include a range of stakeholders: autistic children and adults, parents and school staff.

Consequently, my aim was to try to find out, by spending time in schools, whether these issues were being exemplified by those participants, as well as what the explanations and solutions might be. I also hoped that a sample of autistic adults who had attended mainstream primary schools as children would be able to offer important additional perspectives to my research questions:

1. Are autistic children accessing the full curriculum and tests in mainstream primary schools? If so, with what type of support?
2. What are the educational priorities for autistic children, and how are these set? What should they be?
3. How do the different adults who surround an autistic child and make key decisions about him/her – school staff and parents – conceptualise autism, and what significance (if any) can be drawn from this?
4. How can the experience, participation and outcomes of autistic children in mainstream primary schools be improved?

My overall approach was to have a multi-perspective study, incorporating the views of autistic children and adults, school staff and parents. Two of these categories of participants require particular discussion.

a) Autistic children

As has been seen in previous chapters, several legal provisions assert the right of disabled children to be educated in mainstream schools. However, they also have methodological implications for their participation in research studies. The UNCRC (1989), for example, states that a child has the right to express views ‘freely in all matters affecting the child’ (article 12), and that information may be imparted or expressed ‘regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child’s choice’ (article 13). Subsequently, the CRPD (2006) explicitly extended this right - which should be ‘on an equal basis with other children’ (article 7) - to disabled children too, stipulating that they should be ‘provided with disability and age-appropriate assistance to realize that right’ (article 7). Similarly, and within a national context, the Children and Families Act (CFA) (2014), asserts that ‘the wishes of (...) the young person’ (section 33) should be taken into account, and that

local authorities must have regard to ‘the importance of the child and his or her parent, or the young person, participating as fully as possible in decisions relating to the exercise of the function concerned’ (section 19). An example of the relevance of these legal provisions in a research context is offered in Pellicano et al. (2014), who sought to elicit the views of disabled children - more than half of whom were autistic - in 17 residential special schools in England. Devised within the framework of the UNCRC (1989), the report also references the CRPD (2006), the Equality Act (2010), the CFA (2014), as well as the non-statutory Code of Practice (DfE 2014a), using these provisions as a legal and moral rationale for their methodology.

Furthermore, the provision that a child’s views must be sought is indicative not only of the increasing rights of children, but of their changing status in society. Jenkins (1993) (cited in Lloyd Smith and Tarr, 2000, p. 63) for example, describes four historical stages of the position of children in society, in which they were initially deemed to be possessions, then subjects, and then participants, before ultimately becoming citizens. Christensen and James (2000) also argue that children have now been repositioned as subjects, rather than objects of research. These ideas are extended further into analyses of methods to facilitate the involvement in research of disabled children in Lewis and Lindsay (2000), Lewis (2004) and Lewis and Porter (2004), as well as in evolving participatory, collaborative and emancipatory models (Chappell, 2000; Humphrey and Lewis, 2008). Similarly, listening to the ‘voice’ of the child is recommended in Jones et al. (2008) and Norwich (2008).

However, Armstrong, Galloway and Tomlinson (1993) state that even though the UNCRC (1989) provides that children should be involved in their own assessments, this in fact rarely happens, and that a child’s lack of response, for example, is generally misinterpreted – to the detriment of the child – by those carrying out the assessment. Similarly, Allan (2008), argues that children are too rarely included in research which is about them, and that when they do

participate, they become ‘an exotic other, with their viewpoints placed alongside, or more often subjugated beneath, those of the professionals’ (p. 44). Indeed, in Humphrey and Lewis (2008), where the aim is to reveal the viewpoints of the pupils, the data are quantified and classified according to characteristics associated with Asperger Syndrome, such as ‘inflexible thinking’ and ‘being different/not normal’ (p.30). Thus, the pupils’ views are framed and filtered through a prescribed – and indeed medical – definition of autism, meaning it is not clear if we are *de facto* hearing the pupils’ ‘voices’.

What is evident, therefore, is that while there are legal, methodological and ethical imperatives to include children in research which is about them, the ways in which this might take place require some consideration. Lewis (2001), for example, describes some of the intricate methodological and ethical issues involved in interviewing children about inclusion, as well as in matters of spirituality (Lewis, 2009). Further, in 2010, Lewis describes the importance of allowing – and accounting for methodologically – ‘don’t knows’ and silence when interviewing children (Lewis, 2010). Pellicano et al. (2014), in a drive to include children and young people with limited communication skills in some cases, used a combination of ethnography and structured observations. Meanwhile Detheridge (2000), in a study involving children with severe learning difficulties, found that small scale interpretative approaches were more suitable than large scale quantitative approaches, and that ‘individual studies carried out in naturalistic settings’ (p. 114) worked best. My aim, therefore, was not only to try to facilitate the participation of autistic children in my study, but to try to ensure that my methodological approach enabled their contribution to be valued in the study overall.

b) Autistic adults

Huws et al. (2010) report that the ‘voice of the individual with autism is largely silenced’ in the press, with an absence of adult representation, meaning that ‘autism appears to be infantilised’

(p. 101). For Erevelles (2002), the notion that ‘persons identified as mentally disabled’ might somehow represent themselves brings about a crisis ‘according to positivist rules and humanist rationality’ (p. 25), leading to scepticism about the validity of their views. However, Nind (2008) considers that ‘people with learning/communication difficulties have something to say that is worth hearing and experiences that are worth understanding’ (p. 4), while Boxall and Ralph (2009) assert the importance of using visual methods in order to include people with Profound and Multiple Learning Difficulties (PMLD) in research. Wittemeyer et al. (2011a) emphasise the need to develop methodologies to help understand the views of autistic people with limited or no speech, a point also made by Jurkowski (2008) in the context of learning disabilities. Meanwhile, Silverman (2008), Pellicano et al. (2013) and Milton (2014b) call for greater efforts to involve autistic people in research about autism, and consider the methodological issues that such participation might require. For Milton (2014b), improvements in participatory methods are essential in the autism research field if it is to claim ‘ethical and epistemological integrity’ (p. 3).

These perspectives also have parallels with the concept of the ‘Ladder of Participation’ (Arnstein, 1969, cited by Milton, 2014c) which has been referenced as a measure of the involvement of autistic individuals in knowledge production, especially when that knowledge is about them. Here, the status of the ‘citizen’ is perceived as the most progressive position in society, with ‘citizen control’ located at the top of the ladder, and so is the most participative and desirable location for autistic adults (Dunn, 2014). Consequently, although the focus of my research is on mainstream primary schools and children of primary school age, I felt it was important to include adult autistic participants in order to gain their unique insights and perspectives on my research questions. For both the autistic adults and children, I needed to incorporate detailed ethical considerations in to my study and provide methods which were

flexible and adaptable to individual participants. This was in order to be able to approach some understanding ‘on a phenomenological level of lived experience’ (Milton, 2014b, p.6) the experiences of autistic people.

Positionality

According to Allan (2008), it is very important for researchers in educational inclusion to be explicit, not only about ontology and epistemology, but also about their own positions, especially as a researcher can never eradicate their own subjectivity. Furthermore Bourdieu (1993:11, cited by May, 1997), asserts that if a sociologist manages to produce any truth, it is precisely because he (Bourdieu refers to the male gender only) has an interest in doing so, and consequently the drive towards neutrality is ‘fatuous’ (p. 45). Therefore, the theoretical and methodological standpoints described earlier imply that I need to position myself within my own research project and try to account for the different influences and life experiences which might have impacted on my approach to this study. There are three aspects of my own personal and professional history which overlap with different components of this study:

1. Qualified teacher

I am a qualified teacher and worked for a number of years in mainstream secondary schools. This meant that during my data collection, I was able to understand the sorts of pressures teachers might feel in terms of their workload and as a result of the presence of a visitor in their classroom. In addition, and to some extent by contrast, I was fully aware of how parents can be perceived by school staff, having once – rather shamefully – shared this mentality myself: as complicating, disruptive presences who might challenge the knowledge and competence of the teacher expert. Further, I had been a foreign languages teacher and so I am relatively well attuned to nuances of speech and pronunciation. This was an advantage when spending time

with the autistic children, all of whom had some difficulty with speech, with some also negotiating different languages due to their family circumstances.

2. Previous employment with borough

At the time of starting my PhD, I had been working for six years as a specialist Inclusion Teacher for autistic children with, for four years, a particular role in the assessment and diagnosis of children with autism in the borough where my study was based. Although I was no longer in post by the time my data collection started, the fact of having recently been employed by the Local Authority (LA) facilitated considerably my access to the schools in the first instance, and appeared to put both school staff and parents at their ease, although for the latter group, there were occasional signs of suspicion that I was still somehow representative of officialdom.

As will be described, all mainstream primary schools in the LA were given an equal opportunity to participate in my study, and in the event, I had no prior knowledge of four of the five schools which volunteered, while I had reasonable knowledge of the fifth. I tried to remain open-minded about all of the schools, and to embed within my methods of data collection similar approaches and opportunities for all participants.

In addition, while the participating children and their parents were recruited via non-probability sampling (other than being associated with the schools in my study), it transpired that I already knew two of the children in my study from my time as an employee in the LA. I was able to report to the senior medical and SEND staff at the LA as part of my feedback, that spending time with the children, simply trying to get to know them and understand them in a non-clinic environment, was significantly more illuminating than formal assessment schemes which tend to be predicated on identifying diagnosable difficulties. Moreover, the parents' memory of the

assessment and diagnosis process, and the high importance placed on it at the time, appeared to have faded significantly during the relatively few intervening years. It served as a sobering reminder that those of us in professional roles should not exaggerate the impact we have on the lives of those we aim to support. In addition, from a research perspective, what might be considered important for participants at one time may easily change, and this contingency should be factored in to any research findings.

When I worked for the borough, I was part of a small team whose main role was to support children with SEND, and we all found that the children were often subject to some form of exclusion – usually educational – or another, a situation we found stressful and frustrating. It was not unusual for a team member, following a particularly difficult meeting with an education practitioner asserting they could not ‘meet the needs’ of a certain child, for example, to ‘let off steam’ to the rest of the team upon returning to the office. However, my own data collection took place under conditions of strict confidentiality, and so when I encountered situations in the schools which were difficult for some reason or another, I was not able to discuss them with anyone. Consequently, my research diary provided an important function in this regard. Moreover, I also knew from my own time as a teacher as well as the training programmes I ran as part of my most recent job, school staff do not ‘want’ to exclude children. Consequently, I felt it very important to remain as reflective as possible throughout the whole process, which was also facilitated by the act of writing my research diary.

3. Parent of autistic child

I am the parent of an autistic child, who at the time of writing, is 14 years of age. He went to a mainstream primary school initially, where we, his parents, encountered unending difficulties in trying to ensure he had the right support. We eventually gave up and placed him in a special school, which he currently attends.

Identifying the influence my experience as a parent of an autistic child on my research project is rather difficult and, to an extent, I am not convinced how instructive this would be. For example, if a researcher was conducting a study into the extent to which hair colour might influence where a teacher chooses to sit children in class, with the hypothesis that blonde-haired children tend to be placed at front, with those with brown hair at the back, would the hair colour of the researcher's children be considered relevant? Because even if the researcher's children had brown hair, and s/he considered that their class teacher always placed them at the back of the class as a result, does this *de facto* provide us with any meaningful information if – and this is crucial – the project itself is methodologically transparent and rigorous? Indeed, I presume that a high proportion of researchers in education have children who attend school, but do not consider it necessary to discuss their parenthood as part of their research.

Even so, in my own case, there is no doubt that the difficulties of educational inclusion my son experiences – which stand in stark contrast to my own, red-carpeted progression through education – impacted on my initial ideas about my research. Indeed, there were some situations, early in my data collection, which provoked memories of my son's time in primary school, and again, my research diary was essential in exploring these thoughts and trying to ensure that I remained reflective at all times. Furthermore, raising an autistic child provides me with particular insights that I might not have gained through my professional experience.

However, my sensitivity to injustice is a character trait rather than a stance conveniently adopted due to more recent life experiences. During my own time in primary school, because I generally found the work easy, I was often asked to help two other boys in my class, one of whom – I will call him Steve – clearly (I now realise, with hindsight) had some sort of a learning disability. At that time, my ambition in life was to be a teacher, and sometimes the class teacher would quip, as I was helping one of these boys, “Are you sure this isn't putting you off wanting

to be a teacher?” Steve then went to the same secondary school as me and we were in the same class in Year 7, where he was bullied rather terribly. I used to complain about this to the Head teacher, but sympathy and support were not forthcoming in any way. Years later, when I was home after my first year at university, I saw Steve who was by now in a wheelchair, having been pushed in front of a car by some boys. After a year during which I had had multiple intellectually, emotionally and socially enriching experiences in a cultivated city, Steve was being pushed around the shops in our humdrum northern town by his mum. This had a profound effect on me and became ‘a rooted sorrow’ (Shakespeare, *Macbeth*). It also gave me the first sense not only that an impairment or simply a difference of some sort becomes disabling when support is lacking, but that this can, in the worst circumstances, set an individual on a lifelong, downward spiral of increasing disablement. Furthermore, while I did become a teacher, I became rather bored by the job after a certain number of years, and yearned to earn a living through writing. Therefore, while the influence and impact of having an autistic son is rather self-evident in certain respects, it is more that parenthood has led to me finding a way to engage with issues of justice, disability and communication through writing, which I had not previously managed to do.

For the remainder of this chapter, I set out the research design of my study, followed by a synopsis of the key ethical considerations it entailed. I then describe my processes of sampling, selection and recruitment, followed by a summary of the chapter as a whole. The research methods I employed are described and explicated in Chapter 4.

Research Design

My research project broadly follows a case study design. While research design frames such as action research (often carried out by practitioners), ethnography (where the emphasis is on

participation, engagement and research in natural settings) or more participatory and emancipatory models informed the planning of my study, the in-depth, rich, descriptive components permitted by a case study format facilitated the detail my study required. Even though Gorard (2013) asserts that a case study ‘in isolation will never be the preferred design for any study that aims to be convincing or definitive’ (p. 18), I considered that a case study structure can ensure the necessary coherence in a project involving a number of participants in different locations, and permits a range of methods which were necessary in my project (Denscombe, 1998; Thomas, 2011). Moreover, as was seen in Johnston (1985), the very nature of a case study, which enables a recognition of individual diversity, is suited to research where alternative perspectives are considered. In addition, as Flyvbjerg (2006) argued, more understanding can be generated from close observation of single cases than statistics applied to large groups. Indeed, my own analysis of DfE statistics proved precisely this point. Furthermore, as Flyvbjerg (2006) and the feminist researchers discussed earlier also reasoned, case studies in themselves are not inherently more subjective than scientific studies, which are just as likely to reflect the bias of the researcher. Nevertheless, I was aware that the detail permitted by a case study design must be offset against the limited application of any findings beyond the specific case (Thomas, 2013a). Even multiple cases do not increase the possibilities of generalisation: Robson (2002) refers to the ‘very common misconception’ in multiple case study design that a ‘sample’ of cases would permit ‘generalization to some population’ (p.183). Furthermore, Gorard (2013) opines that once several cases are involved, the project is no longer a case study, but ‘it has usually become comparative, cross-sectional or something similar’ (p. 96).

In my own study, I employ the case study typology offered in Thomas (2011), where a distinction is drawn between the subject of the study (the case) and the object of the study (the

analytical frame through which the subject is explored). The cases are five mainstream primary schools (three primary schools, one junior school and one infant school) within a single LA in England where I consider the different perspectives, experiences and priorities of various stakeholders - staff, autistic children and their parents - on the same research questions, although there are necessarily certain variances for each category of participant. These schools – which are ‘local knowledge’ cases - provide the subject or lens through which the object of the study - its analytical frame - is illuminated and perhaps explained; that is, the inclusion, participation (or lack thereof) and outcomes of autistic children in relation to the curriculum and tests in schools.

According to Thomas (2011), once the subject and object of the study have been established, there are ‘numerous valid interpretations’ (p. 511) of the case study format. My approach is exploratory, illustrative and descriptive, rather than ‘theory-building’ for example (Thomas, 2011, pp. 518 - 519). The multiple cases of this design are investigated in parallel to each other and there are also some elements of comparison between them, although this proceeds predominantly from the different categories of participant (teachers, teaching assistants, children etc.). The overall design is flexible and iterative: one stage or phase influences or shapes the next. Furthermore, this design provides space for a range of methods which are necessary in order to support the engagement of different participants.

An important addition to the study is a group of autistic adults who attended mainstream primary schools in the UK when they were children. A further, non-autistic participant was the Community Paediatrician for the LA where the schools were based. She was able to provide insights into the methods of autism diagnosis and rates of prevalence in the borough.

My project is essentially idiographic rather than nomothetic in nature. This is notwithstanding the high value placed on randomized controlled trials (RCTs) in education research (Thomas, 2012b). Moreover, while the number of potential variables involved in my study are vast and impossible to measure, its focus is not an intervention of any sort which would render such an analysis useful. Further, given that the subject of my study is the perspectives of individuals, and the meanings they apply to situations and experiences, it is inductive, and not deductive in its approach. Indeed, these multiple perspectives – especially when allied with the secondary data (DfE datasets, legal instruments) discussed earlier – could be described as providing a form of triangulation. In addition, while my research is informed by the various theoretical constructs set out in the previous chapter, it is not driven by those theories (Pring, 2000; Gorard and Taylor, 2004; Thomas, 2011), because social life is ‘not amenable to understanding through the use of a single theoretical paradigm’ (May, 1997, p. 40). Therefore, rather than seeking to prove clear causal relationships, I aim for a detailed understanding of the situation for autistic children in schools and hope to derive insights into how different phenomena might interrelate, ultimately offering possible explanations. Therefore, my main purpose is to generate answers, or to contribute to understanding, rather than test hypotheses, and so this scheme will be predominantly generating of theory - albeit tentatively - in its approach.

Ethics

If it is maintained that the social sciences should not seek to ape the approach and methods of the natural sciences (May, 1997), there are parallels to this view in the arena of ethics too. Famous – and indeed, notorious – studies involving medical and psychological experiments (for example, Milgram, 1963) have influenced the development of strict codes of ethics in the field of medicine, covering issues such as consent, mental capacity, fairness and equity, and benefit and harm (British Medical Association, 2013). Similar codes have been developed in

the social sciences in the UK, principally the framework from the Economic and Social Research Council (ESRC, 2010; 2012) and, in the context of education, the guidelines from the British Research Association (BERA, 2011). In 2014, the incumbent shadow Secretary of State for Education, Tristram Hunt, even proposed a ‘teacher’s oath’, reminiscent of the Hippocratic Oath, taken by doctors (Heritage, 2014).

However, some argue that these provisions are simply the application of ‘bioethics’ written from a ‘bioscience perspective’ (Macfarlane, 2010) and so limit unduly what is necessarily a more fluid and context-dependent research sphere. Macfarlane (2010) suggests that ethical review procedures not only fail to capture ‘the uncertainty and unpredictable nature of the research process’, but that researchers may demonstrate little more than ‘sham compliance’ with these practices (p. 21). In their place, he proposes a set of ‘virtues’, a concept developed by Carpenter (2013), who considers that researchers should live in a principled and selfless manner, rather than conform to prescriptive codes, or follow set guidelines. Indeed, according to Pring (2000), virtues are simply ‘general dispositions to do the right thing at the right time’ (p. 151).

The authority of bioethics is evident in the scientifically conducted study by Dawson et al. (2007) where the priorities are ensuring lack of researcher influence, the acquisition of informed consent (to data collection and storage) and visibility of methods. The neuropsychologists who administered the cognitive assessments to the four groups of individuals who took part in the study - autistic children, autistic adults, non-autistic children and non-autistic adults – were unaware of the study and the hypotheses behind it. All participants were recruited and selected through apparently strict and transparent inclusion and exclusion criteria, and we are advised that the non-autistic adults received compensation for their involvement. These arrangements

(and the explanation of them) are seen as a necessary conduit to the ‘empirical scrutiny’ the researchers wish to achieve.

Meanwhile, in a study underpinned by more qualitative methods, the epistemological and ethical validity of the research by Humphrey and Lewis (2008) is also provided by the apparent unobtrusiveness of the researchers, albeit for different reasons. In their view, autistic teenagers are typically ‘a group whom research is more often than not conducted *on* than *with*...’ and so here, they should be ‘informed and knowledgeable participants’ whose contribution is unfettered. The pupils are provided with draft interview schedules in advance and pupil-friendly summaries at the end; they also supply commentaries which are subsequently incorporated into the final text. Consent was sought from the pupils themselves as well as the schools’ management teams and the pupils’ parents. Procedures around withdrawal and anonymity are described, and we are informed that the broader project is funded. The authors explain their awareness of the sensitivity of the issues being discussed and their consideration that the participants – by dint of being autistic – are a ‘vulnerable group’. Even so, the authors do not mention any follow-up procedures to some of the pupils’ disturbing accounts of bullying and even violence, issues which are covered in the BERA (2011) guidelines, for example.

The data collection for my own study could only start once the whole project had been submitted and agreed via the ethical review procedures of the University of Birmingham. My aim, in this multi-perspective study, was to have a range of participants: autistic children, their parents, a sample of parents of children with no diagnosed SEND, teaching assistants, SENCOs, curriculum managers and autistic adults. All of these participants, with the exception of the autistic adults (who I wished to recruit on a UK-wide basis), would be associated with a sample of mainstream primary schools in the LA where I had recently worked. My plan was to gauge the views and experiences of the various participants through a range of methods which will be

discussed in the next chapter. In addition, I wished to conduct an interview with the Community Paediatrician for the LA where my study was based, as she is responsible for co-ordinating the assessment and diagnosis of autism in the borough.

The different areas of ethical consideration in relation to my project are set out in Appendix A, the main application for ethical review which I submitted to the university. The principal areas covered were as follows:

1. Participants

Each group of participants required different ethical considerations, although there was an additional ethical imperative as far as the autistic children are concerned. Perceived as ‘vulnerable’ by dint of their youth and their disability (Macfarlane, 2010), an important ethical priority for my project would be to facilitate their inclusion nonetheless (Lewis and Porter, 2004). Similar issues also apply to the autistic adults, and for both groups, I wanted a flexible approach in a study ‘with’, rather than ‘on’ them (Nind, 2008). While my own project could neither be described as fully participatory nor emancipatory, it was certainly influenced by these models, and this was reflected in my research methods (Boxall and Ralph, 2009).

2. Recruitment

My project could not begin until I had obtained permission from the senior education managers of the borough where the schools were based. Once I obtained this, recruitment took place in several waves, which are explained in detail from p. 109 of this chapter. A major advantage was that I had worked in the LA until relatively recently, and so I already had an enhanced disclosure (DRB) check for the borough, thus facilitating my access to the schools.

3. Consent

It was anticipated that all of the adult participants would have the capacity to provide consent and, with the combination of an explanatory letter and an information sheet (see appendices submitted as part of ethical review application), as well as direct explanations from me if required, this consent would be fully informed. I also offered participants the opportunity to verify interview records or transcriptions (Humphrey and Lewis, 2008; Nind, 2011). As far as the autistic children were concerned, all of their parents or carers needed to provide written consent to their participation in the project as well as give permission for video footage to be taken. However, it was also possible for children to give their assent for both via an additional consent form (Appendix 15). The children were given the opportunity to review some of the video footage and to have deleted any sections they were not happy with. Time also needed be devoted to ascertaining how they communicate and whether alternative systems (Makaton, Proloquo2go, PECS) or formats (dairies, drawings) would be needed in order to facilitate their participation. The flexibility of methods provided by the case study format and the opportunity for in-depth investigation supports this approach.

4. Feedback

As part of my planning of the project from the point of view of ethics, I also wanted to ensure that all participants would have the opportunity to receive feedback on my findings if they so wished. For the LA (i.e. the senior managers and the Community Paediatrician), the school staff and the parents of the autistic children, I offered both a slide presentation and talk as well as a written summary. For the autistic adults, I proposed both a discussion and a written summary, and for the autistic children, a simplified, pictorially-based written summary (Robson, 2002; Hodge, 2014).

5. Withdrawal, confidentiality and anonymity

All participants were informed in writing and orally of their right to withdraw, and this was reiterated at different times during the process of data collection. All identifying features would be removed from my final data records and neither the borough, the schools, nor any of the participants would be identifiable. I would not share any comments made to me by adults or children unless they raised issues of safeguarding, child well-being or illegality.

6. Benefits of participation

For the school and related staff, this would consist predominantly of increased awareness and knowledge about autism and how to include autistic children in their schools, primarily via the feedback process, but also through informal discussion. Meanwhile, I hoped my study would provide the parents of the autistic children with an opportunity to speak openly about their concerns and aspirations for the children. For the autistic children and adults, my aim was that my project would give them the chance to express their views freely about what mattered to them educationally.

7. Risks

My main concern with the children was that I would constitute yet another person who passed transiently through their lives, which can so often be the case for disabled children (Nind, 2008). Therefore, I had to plan carefully in order to try to ensure both that they were not unsettled or stressed in any way by my presence, but at the same time, that they were not troubled by my permanent departure from the school either. As far as their parents were concerned, I needed to be careful that they were not upset in any way by my questions, given the highly emotive nature of the subject i.e. their own children. The main issue with the autistic adults was to try to ensure that my particular methods enabled them to communicate with confidence, and so, as with the children, I planned different possible methods of data collection for them.

More details on my application for ethical review are provided in Appendix A. Once I had met the children, I submitted an amendment (Appendix B) as I needed to conduct structured observations for two of the children who were very young and did not have an established means of communication. Before recruiting the autistic adults (which started after I had completed my data collection in the schools), I also submitted a further amendment (Appendix C), predominantly relating to methods of recruitment and participation.

Sampling, Selection and Recruitment

Having local, insider knowledge in the area where I was conducting my research was a considerable advantage at all stages of my study, but especially when recruiting participants. The sampling frame (Denscombe, 1998) was provided by the LA, and once my project was agreed by the Inclusion Manager for the borough, all mainstream primary schools were invited to participate, initially by email. There are 53 mainstream primary schools in the borough, including nine academies, one free school, three infant schools, three junior schools and four schools with an autism resource base. As my focus was typical school environments, those with a resource base for autistic children (or special schools), were not included, leaving a total of 49 schools at this point. In addition, I also secured the agreement to participate of the Community Paediatrician who is based in the same office complex as the Inclusion Manager.

Most of the recruitment of participants took place in six consecutive waves, which can be represented diagrammatically:

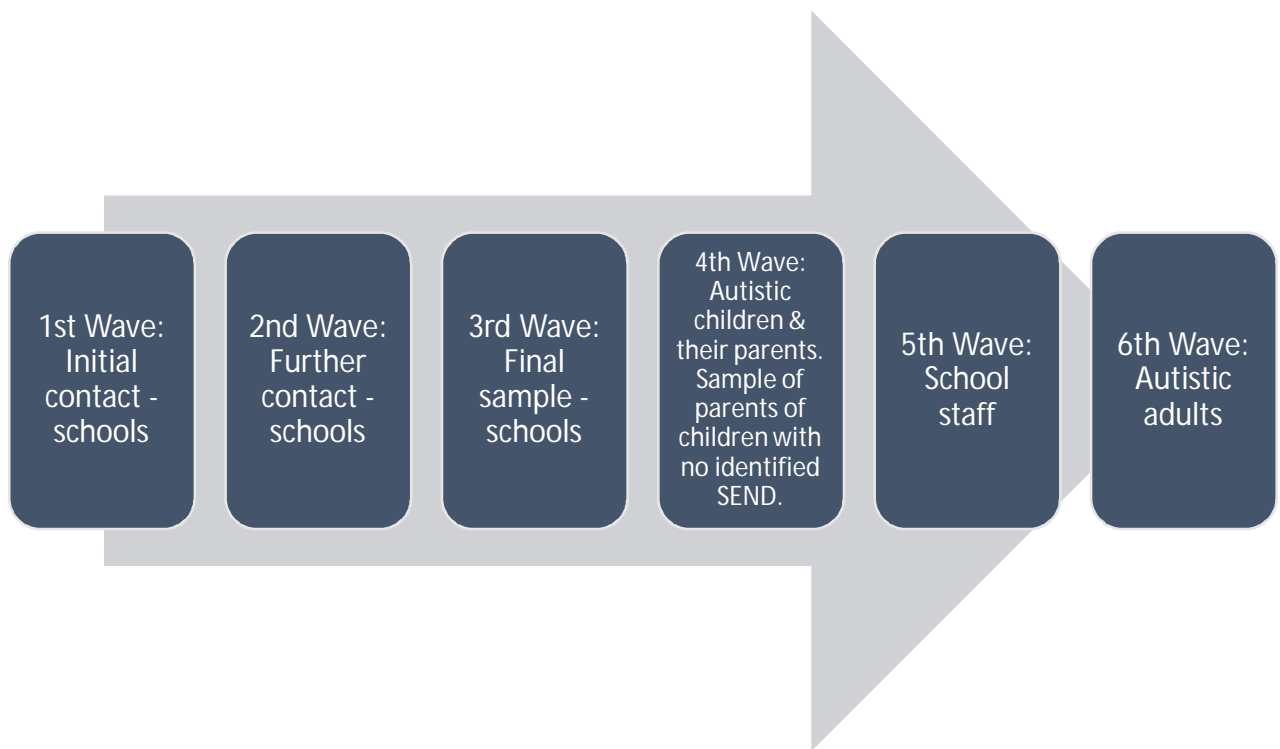


Figure 3: Recruitment of Participants

Recruitment: 1st Wave

Invitations were sent out by email initially and consisted of a brief explanation within the email itself as well as confirmation that I had permission to carry out this research from a senior manager in the borough. In addition, I attached a personalised, fuller letter of introduction and explanation, which also contained my contact details, and an Expression of Interest form. For the three schools which consisted of an infant and a junior school, I contacted the junior school only as these appeared to be the main part of the school from an administrative and managerial perspective. Consequently, I emailed 46 schools in total.

Recruitment: 2nd Wave

A week following my invitations to participate by email, I had not received a single response from any of the schools. Consequently, I tried to contact all of the schools once by telephone

and requested to speak to the school SENCO on each occasion. The phone calls took place over the course of four days, after which the situation was as shown in Figure 4.

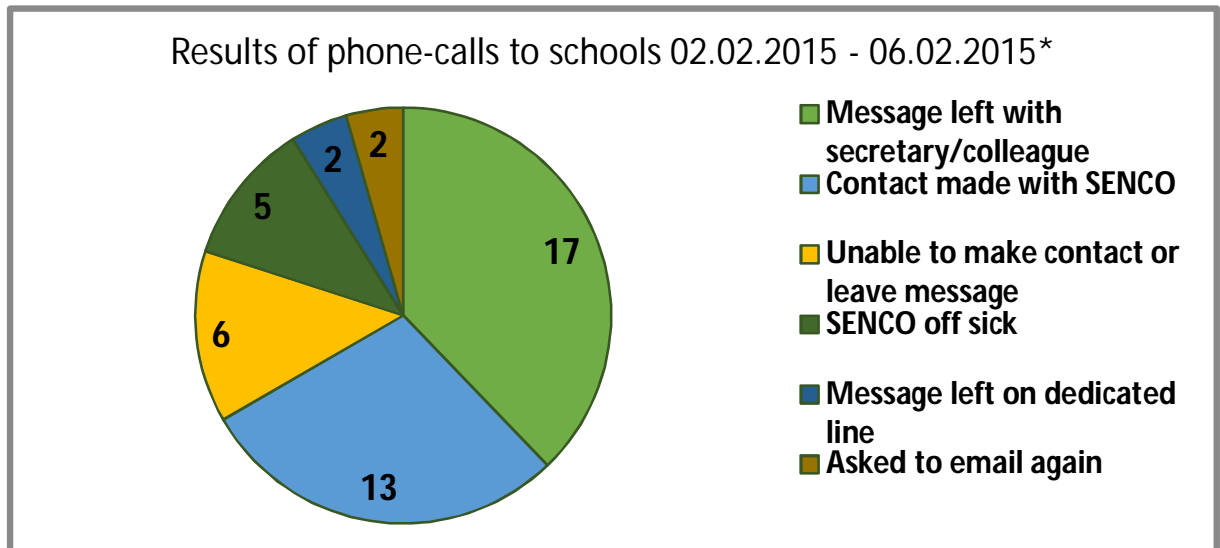


Figure 4: Results of phone-calls to schools

*One SENCO worked in two different schools, so the total is 45 out of 46 schools.

By this stage, I had only managed to discuss the possible participation in my research with 13 schools, less than a third of my original sample. The main difficulties are summarised in Figure 4. The fact that I either couldn't get through or got no further than the school secretary for nearly two thirds of the schools reduced considerably the sample I had started with.

Recruitment: 3rd Wave

At this stage, I was dealing with 39 schools, having excluded the six schools where I had been unable to get through or leave a message. For 26 of the 39 remaining schools, there was either no further response to my message or, having been asked to ring or email again, no more progress was made. From the 13 schools left, I had meetings in six schools (with SENCOs and Head teachers), from which five schools stated that they wished to take part in the project. They consisted of two community primary schools (one very large, the other relatively small), one state faith school, one infant and one junior school (the latter two are part of the same school,

although they operate relatively separately, with different SENCOs, for example, and so are treated as separate schools in this study). All five schools were in a densely populated, urban area.

The schools are labelled in the following way:

| | |
|----------------------|------------------|
| Infant School | School 1a |
| Junior School | School 1b |
| Small primary school | School 2 |
| Faith school | School 3 |
| Large primary school | School 4 |

Given that my sample was one of convenience rather than of purposive selection, I had potentially a less divergent sample than I had hoped for, as well as a recruitment bias which I had wished to avoid. While this has implications for the broader applicability of my findings, which will be discussed in the final chapter, I considered nevertheless that the sample was reasonably diverse despite this. Moreover, the main comparisons I sought to make were between categories of participant (teachers, teaching assistants, parents etc.), rather than between schools, and so there was still value in basing the study in these multiple cases.

Recruitment: 4th Wave

The next wave of recruitment was within the schools, and centred on the autistic children, their parents and sample of parents of children with no identified SEND. The lynchpin to this was the SENCO, who ostensibly provided me with the basic details (age, year group and gender) of all of the children in the school who had a diagnosis of autism, so that I could write to their parents. However, once I had started collecting data in the schools, I became aware of some

additional autistic children I had not known about initially. This was particularly the case in School 4, where the part-time SENCO was relatively new. There was another SENCO who was on extended leave, but her role was not covered by another member of staff. With nearly 70 children on her register of children with SEND, the SENCO in School 4 stated she did not know how many had a diagnosis of autism. In Schools 1b and 2, other autistic children were also either added after I had started my data collection or were mentioned as being unsuitable for one reason or another for my study. In this way, the school SENCOs were crucial in either enabling, or not enabling the participation of autistic children and their parents in my study, and constituted part of the series of gatekeepers I encountered at this stage of my study. Furthermore, and notwithstanding the theoretical and methodological arguments in favour of including the child's 'voice', the hurdles to recruitment that I encountered in my research are an indication of how truly complex this is, and how difficult it can be to achieve a 'representative' sample.

The recruitment of the parents themselves had to take into account the broad social and cultural mix of the borough, the need for interpreters in some cases, and the fact that some parents might feel disengaged or simply not have the time to take part. Following this phase of recruitment, my child and parent participants were as follows:

Table 3: Child and parent participants

| School | Age | Year group | Gender | Parent/Carer |
|--------|-----|------------|--------|---------------------------|
| 1a | 4 | Reception | M | 1 (F) |
| 1a | 5 | Year 1 | M | 1 (F) |
| 1b | 9 | Year 4 | M | 2 (<i>M</i> + <i>F</i>) |
| 2 | 4 | Reception | M | 1 (F) |
| 2 | 8 | Year 3 | M | 1 (F) |
| 3 | 8 | Year 3 | M | 1 (F) |
| 3 | 10 | Year 6 | M | 1 (F) + translator |
| 4 | 7 | Year 2 | F | 2 (<i>M</i> + <i>F</i>) |
| 4 | 7 | Year 3 | M | 2 (<i>M</i> + <i>F</i>) |
| 4 | 9 | Year 4 | M | 2 (<i>F</i> + <i>F</i>) |
| Total | | | 10 | (14) 10 |

Amongst the child participants, the only year group not represented was Year 5. Not all of the parents followed through with the focus group plans (or interviews, which were needed in some cases), resulting in ten parent (nine female and one male) participants in total.

In addition, for the purposes of comparing the educational priorities of the parents of autistic children with those of parents of children with no identified SEND, all of the parents in the same class as the autistic child/children who were part of my study were invited to complete a questionnaire. These questionnaires were completed anonymously.

Recruitment: 5th Wave

The penultimate wave of recruitment was of school staff. On the whole, this wave of recruitment was the most straight forward and was facilitated by the school SENCOs, who approached the school staff on my behalf. For nearly all of the schools, I was able to conduct an interview with both the class teacher and the teaching assistants who worked directly with the children in my cohort. However, I was aware of some purposive selection on the part of the SENCO in School 1b, who appeared to be selecting members of staff who he felt might have more knowledge about SEND. Furthermore, in four of the five schools, the SENCO was a senior member of staff and part of the senior management team: it was difficult to assess, therefore, how genuinely voluntary the participation of some of the teachers and teaching assistants was.

My school staff participants were as follows:

| | |
|--|--------------------------------|
| Teaching assistants | 15 |
| Class teachers | 12 |
| SENCOs | 5 |
| Curriculum managers/deputy Head teachers | 5 |
| Total | 36* (32 female, 4 male) |

*The SENCO and deputy Head teacher was the same person in one school. He completed two interviews in relation to each role.

Recruitment: 6th Wave

My final wave of recruitment – of autistic adults - took place after I had completed the data collection in schools, and was conducted on a UK-wide basis. The only criteria were that they had attended a mainstream primary school in the UK when younger and that they had a diagnosis of autism, either via a medical or associated practitioner or via self-diagnosis (although in the event, all had a formal diagnosis of autism or Asperger Syndrome). My recruitment strategy was as follows:

1. An autism rights group via a personal contact. Result: four participants (three female, one male).
2. An invitation via my Twitter account including a link to my university page (possible participants can enquire confidentially via ‘direct message’). Result: two participants, both female. An invitation via the ACER twitter account including a link to my university page and university email address. Result: one participant, male.
3. Message on the university intranet site – Canvas – on the ACER page. A member of staff from ACER also sent out a request to autistic participants involved in a project she was running. These messages resulted in three participants, all female.

This cohort, of eight female and two male participants, represented almost a reversal of my child participants in terms of gender, where there were nine boys and only one girl. Although detailed analysis of issues of gender in relation to autism was not within the scope of this study, the fact that higher numbers of female autistic adults participate in research projects has been highlighted in other studies (Kapp et al., 2013; Kenny et al., 2015). This is notwithstanding the fact that many more male children and adults are diagnosed with autism than female children and adults (Baron-Cohen et al., 2011). Consequently, the extent to which my sample of autistic

adults is representative or unbiased is not clear. However, as will be seen later in this thesis, given the diverse nature of autism itself, achieving a sample of this population which is somehow representative might not be a realistic goal in any event.

Chapter summary

In this chapter, I have set out how my project is informed by a predominantly interpretative paradigm, whereby as the researcher, I aimed to place myself within the context of the people and phenomena being studied. Those phenomena would consist of the attitudes, experiences and beliefs of my participants, who would provide multiple and overlapping perspectives on the inclusion of autistic children in mainstream primary schools, which I would explore across four core research questions. Indeed, my literature review, in particular, had suggested that the perspectives of different participants would be instructive – if not essential –, while the theoretical models discussed provided a series of lenses through which the responses of all participants might be considered. In this chapter, it has also been important to explore the key aspects of my own positionality, especially as I had been recently employed in the LA where my research took place. Moreover, and notwithstanding posited drawbacks of a research study employing a case study design (Gorard, 2013), this was entirely apt for my own project, permitting the in-depth enquiry needed, for example. In addition, I have described how the ethical issues associated with my proposed study are both complex and nuanced.

I have also explained - once ethical approval for my study was received and my data collection was underway – which sampling and recruitment methods I used, and how I aimed to give all schools an equal opportunity to take part in my study. When the schools were selected (in the event, through convenience sampling), I needed to recruit school staff and autistic children as

participants, and I have explained my processes and the results of these, as well as those for the sample of autistic adults whose perspectives I also considered necessary.

In the next chapter, I focus more specifically on the research methods I employed, the types of data I collected and the resultant dataset which I obtained. I explain how my data collection took place in a number of phases (summarised in Table 6, p.129), starting with permission from the LA and an interview with the Community Paediatrician, followed by, in chronological order, school staff, parents, autistic children and autistic adults. In this same chapter, I also elucidate my methods of data analysis.

CHAPTER 4: RESEARCH METHODS

In this chapter, I describe and explicate the methods I used both to collect and analyse data.

Methods of data collection

Introduction

Although my study involves multiple cases – i.e. schools – which serve as the subjects within the analytical frame (Thomas, 2011; 2016) of the inclusion of autistic children in mainstream primary schools, these cases were not being compared with each other. As will be seen, the comparisons which took place were predominantly between categories of participant: school staff, autistic children and adults, and parents. The process of the study was, therefore (in terms of Thomas's typology), a multiple study of parallel cases, each of which contained elements for comparison.

The case study format also permits a range of methods of data collection necessary for the diverse participants which, as set out in the previous chapter, is both a moral and an epistemological imperative, given that 'hitherto silenced or marginalised voices' (Slee and Allan, 2001, p. 176) must be heard if inclusion is to improve. Smith (1987), for example, refers to 'the ordinary problems respondents have of fitting their experience of the world to the questions in the interview schedule' (p. 93), and Begley (2000) describes the flexibility required in order to involve disabled children in research. Further, while my multi-perspective study enables an accumulation of information which could be described as a form of triangulation, this is further reinforced by different methods of data collection which centre on the core research questions: whether autistic children access the curriculum, with what sort of support, how their educational priorities are set and how autism is conceptualised in the first instance.

Types of data

So far in this thesis, I have broadly categorised studies in the autism field as either ‘quantitative’ or ‘qualitative’, with the former deriving, on a simplistic level, from a Positivist paradigm and the latter, an Interpretivist model. While much autism research does indeed fall broadly within these categories, it is nevertheless the case that it can be difficult, if not unhelpful, to assume that the difference between these procedures is clear or even desirable. According to Oakley (1998), for example, the purported division between quantitative and qualitative research methods simply reinforces ‘the socially constructed drama of gender’ (p. 725), while Flyvbjerg (2006) opines that this demarcation is a spurious one. Similarly, Gorard and Taylor (2004) assert that ‘the identification of *separate* qualitative and quantitative elements within a project can be one of the biggest obstacles to their proper integration’ (p. 4). Therefore, the issue is not whether data can be classified as quantitative (number-based) or qualitative (word-based), but to try to ensure that they are fruitfully integrated within a study incorporating mixed methods.

In addition, the high value placed on RCTs and experimental designs, for example (Thomas, 2012b), can be accompanied by ‘an illusory haven of “objectivity” in statistical analysis’ (Gorard and Taylor, 2004, p. 143) or other forms of numerical data which underpin quantitative methods. However, the quantitative data in my study were not, for example, to corroborate the findings from my qualitative data and to somehow increase the overall validity and generalisability of my findings, but to enable me to ‘gain a sense of the flavour of the data as a whole’ (Silverman, 2001, p. 35). Moreover, while these data, in combination with my word-based data, ‘do not aggregate toward a complete and rounded picture’ (Coffey and Atkinson, 1996, p. 14), they nevertheless produce ‘different aspects of the reality under investigation’ (Gorard and Taylor, 2004, p. 46). Indeed, these combined data serve to ‘reveal – or indeed

construct' the complexity of the data (Coffey and Atkinson, 1996, p. 14), rather than narrow down the ideas contained within them.

Research Instruments and Dataset

My research process overall was inductive and my approach flexible within an iterative design. While my research instruments enabled me to collect both quantitative and qualitative data, most fell into the latter category. In addition, I employed more than one research instrument for some of the participants, especially in the case of the children.

The quantitative data consist of simple categorical measurements across the research instruments (gender, age, child, adult etc.) and ordinal measures on questionnaires, or sections of them, as well as structured observations of two of the autistic children, where it has been useful to count the frequency of certain occurrences, such as instructions from the teaching assistant, or attempts from the child to desist from the activity, for example. My qualitative data are derived from semi-structured interviews, open questions on the questionnaires, unstructured observations, focus groups and my research diary. Some of the autistic adults opted to complete the interviews via email, but the process was still sufficiently flexible for these data to constitute part of my qualitative data. My research instruments, a sample of which are included in the Appendices, are as follows:

1. Questionnaires

There were four types of questionnaire. They permitted the collection of data from a range of participants in a relatively quick and easy manner, and by asking identical questions to the respondents in each category, enabled certain tentative comparisons to be drawn (Denscombe, 1998). All questionnaires were designed to be as time-efficient as possible, and to be clear and unambiguous visually and in terms of the layout and the formulation of the questions. They

included a combination of open-ended, closed and scaled questions, depending on the participant group:

- a) **SENCOs.** These were designed ostensibly to provide direct, objective and descriptive evidence on the autistic children in the school, and contained closed questions only. They also served as a basis for parts of the semi-structured interview which followed. All questions were worded positively and non-ranked, multiple answers were possible via multiple choice questions. One was completed for each autistic child in the school.
- b) **Class teachers.** These were very similar in format and design to those of the SENCOs and also aimed to provide direct, objective and descriptive evidence on the autistic children in the school, although the focus is more on the child in the classroom. One was completed for each autistic child in the class and, like the questionnaires for SENCOs, they enabled the collection of simple, numerical data.
- c) **Parents.** The parents of the autistic children in my cohort were issued with a questionnaire which was also sent to all of the parents in their child's class. This consisted of different question types, including a dichotomous, objective question, multiple choice or closed response options, a question inviting a scaled response and a blank response option with an open question. Apart from the first question, where parents were asked to identify whether or not their child had a SEND, the questions aimed to provide indirect, subjective evidence.
- d) **Autistic children.** Achieving a simple and accessible design for these questionnaires was a paramount consideration. Questions were short and consisted of trichotomous answers via a tick box. There were also some open questions with a blank response option. All questions were positively worded and aimed to provide indirect, subjective evidence.

2. Structured observations

Neither of the two youngest children in my cohort of autistic children - both of whom were aged four - had an established method of communication, and so it was not possible to conduct interviews with them, nor were they able to complete the questionnaire, even with help from a teaching assistant. Therefore, in addition to the unstructured observations, I employed an observation schedule, including event sampling on some occasions.

3. Semi-structured interviews

Data collection from the school staff, the Community Paediatrician, the autistic adults, most of the autistic children and some parents was via semi-structured interview and so this was the most predominant research instrument that I employed. Questions were both closed and open, and were structured to enable a gradual build-up of information during the interview and to reach a natural conclusion at the end (Thomas, 2013a), as well as to encourage each participant to speak relatively freely about the matters in hand. In order to provide comparisons between groups of participants, there were only small variations in the interview schedules for each category, which were themselves necessary in order to account for their different roles. Prompts and probes were used, but because of the need to respond flexibly to each of the participants, this was not systematic. Consequently, the interviews were more exploratory, rather than standardised (Oppenheim, 1992), providing the potential for more in-depth discussion and for nuances to be captured.

For the school staff and the Community Paediatrician, I wrote verbatim notes during the interview which I then copied up immediately. Interviews with parents and children were video recorded and then transcribed verbatim. Five of the ten autistic adults opted to complete the interview via email. For the remaining five, four elected to conduct the interview over the

phone, and one via skype text. I transcribed the interviews via my notes and sent them to the autistic adults for verification. For the participant who elected to conduct the interview via skype text, I copied the interview into a word document and sent it to her for approval. All of these interviews were conducted over two to three meetings.

4. Unstructured Observations

The observations were of the children only and most were unstructured. They were sampled in relation to educational activities in Reading, Phonics, Maths and Writing, as these are the same subjects measured through DfE data, as discussed in the literature review. The children were also video-recorded when they completed the questionnaires and during the process of providing consent in most cases. I aimed to be as open as possible and so, while I did not share immediately with staff the analysis of my observations, both school staff and children were shown sections of the video footage straight after it had been taken. The children also had the option of deleting any sections they were not happy with, and indeed this occurred on one occasion. Moreover, the children were also given the option of using the video recorder themselves and of interviewing me if they so wished, an activity they appeared to enjoy. When I transcribed the data, I also described the context and, where necessary, added further explanations by way of a 'running record' in order to provide further, related information.

5. Focus Groups/Group Interviews

My aim had been to run focus groups consisting of parents of autistic children and prepared questions aimed to gently sign-post the discussion to gain verbal data through their interactions, adopting what could be described as an 'essentialist' position, meaning that the emphasis was on participants' feelings, values and beliefs (Millward, 2012). I also hoped that the relative security provided by a group situation – the 'risky shift phenomenon' (Thomas, 2013a, p. 203) – would perhaps encourage parents to speak more freely than they would as individuals, with

my role being less interventionist than had been the case for the semi-structured interviews. I also anticipated that the group situation would provide the supportive environment that this group of participants required when tackling sensitive issues.

All of the parents of autistic children in the schools were invited to take part in the focus groups. However, in the event, very few responded, meaning that my sample was entirely one of convenience (although I would not have turned down any parents who wished to participate). This low response rate was in itself quite instructive: parents cited reasons of time, and not all had a positive relationship with their child's school. Furthermore, unlike the school staff, whose participation formed part of their working day, the same could not be said of the parents, who would need to take time out of either work or leisure/respite activities in order to join the focus group. Consequently, I was only able to run two very small group interviews, consisting of two parents and three parents each, while the other parent participants had a semi-structured interview, where I employed the same questions used to guide the focus groups in the interview. I video-recorded the focus groups and interviews and transcribed them afterwards.

6. Research Diary

By the end of my process of data collection my research diary was more than 55,000 words long. I completed it more or less on a daily basis and it fulfilled multiple functions. Initially, the diary simply enabled me to keep a factual record of the different stages of my data collection which might be useful for me to refer to at a later point. For example, the dates, times and content of phone conversations might be recorded here, or the outcomes of meetings at schools. However, my research diary also provided me with the means of recording important contextual information in relation to the interviews, for example, and to detail further thoughts and observations from my time in schools. Furthermore, my diary quickly acquired a reflective and even confessional role, where I explored my thoughts and responses, especially about situations

which had impacted on me emotionally. This was particularly necessary given the confidential nature of my data collection. It was also here that the analysis of my data began to evolve, as I noted down ideas that occurred to me along the way.

The research instruments I used, and the data they yielded, are summarised in Table 4.

Table 4: Summary of research instruments and dataset

| Participants | Research Instrument | Type of data | Quantity | Method of recording |
|------------------------------|---|----------------------------|--------------|--|
| Parents | Questionnaire | Quantitative + Qualitative | 63 | Self-completion |
| Parents of autistic children | Focus group prompt questions or semi-structured interview | Qualitative | 10 (parents) | Video + transcription |
| Autistic children | Questionnaire | Quantitative + Qualitative | 7 | Self-completion (with support) |
| Autistic Children | Structured observation | Quantitative + Qualitative | 2 | Video + transcription and event sampling |
| Autistic children | Unstructured observation | Qualitative | 7 | Video + transcription |
| Autistic children | Semi-structured interview | Qualitative | 8 | Video + transcription |
| Class teachers | Questionnaire | Quantitative | 14 | Self-completion |
| Class teachers | Semi-structured interview | Qualitative | 12 | Verbatim note-taking followed by immediate copying up. |
| SENCOs | Questionnaire | Quantitative | 16 | Self-completion |
| SENCOs | Semi-structured interview | Qualitative | 5 | Verbatim note-taking followed by immediate copying up. |

| Participants | Research Instrument | Type of data | Quantity | Method of recording |
|-------------------------|----------------------------|---------------------|-----------------|---|
| Teaching assistants | Semi-structured interview | Qualitative | 15 | Verbatim note-taking followed by immediate copying up. |
| Deputy head teachers | Semi-structured interview | Qualitative | 5 | Verbatim note-taking followed by immediate copying up. |
| Autistic adults | Semi-structured interview | Qualitative | 10 | Self-completion, or via note-taking + transcription, or Skype text. |
| Community paediatrician | Semi-structured interview | Qualitative | 1 | Verbatim note-taking followed by immediate copying up |

Table 5 provides additional detail on the data collection methods in relation to the autistic children, in order to highlight the necessity for mixed methods and a flexible approach in their case:

Table 5: Methods of data collection for autistic children

| | Year group | Age | School | Observations | Questionnaire | Interview | Other* |
|----------|-------------------|------------|---------------|---------------------|----------------------|------------------|---------------|
| Child 1 | Reception | 4 | 1a | | | | |
| Child 2 | Year 1 | 5 | 1a | | | | |
| Child 3 | Year 4 | 9 | 1b | | | | |
| Child 4 | Reception | 4 | 2 | | | | |
| Child 5 | Year 3 | 8 | 2 | | | | |
| Child 6 | Year 3 | 8 | 3 | | | | |
| Child 7 | Year 6 | 10 | 3 | | | | |
| Child 8 | Year 2 | 7 | 4 | | | | |
| Child 9 | Year 3 | 7 | 4 | | | | |
| Child 10 | Year 4 | 9 | 4 | | | | |

*Other. Child 2 elected to have a friend present during his interviews. Child 8 also conducted a short interview with me, which she video-recorded. During both interviews with Child 10, he opted to demonstrate part of what he wanted to convey visually, through actions and gestures. He also conducted a short interview with me, which he video-recorded.

My data collection took place between January and December 2015 and was arranged over five phases. Table six provides a summary and an overview of the entire process:

Table 6: Summary of process of data collection

| Phase 1 | | | | | |
|--|--|--|--|--|--|
| Ethical Review & permission from LA. Semi-structured interview: Community Paediatrician | | | | | |
| Phase 2: Schools | | | | | |
| Teaching assistants: semi-structured interview (n = 15) | Teachers: questionnaire and semi-structured interview (n = 12) | SENCOs: questionnaire and semi-structured interview (n = 5) | Deputy headteachers: semi-structured interview (n = 5) | | |
| Beginning of process of familiarisation with the autistic children | | | | | |
| Research diary | | | | | |
| Phase 3: Parents | | | | | |
| Parents of autistic children: 2 focus groups (n = 2 + 3) or Semi-structured interview (n = 5) Questionnaire (n = 9) (+ 4 parents of children with non-specified SEND) | | Sample of parents of children with no identified SEND: same questionnaire as for parents of autistic children (n = 50) | | | |
| Continued familiarisation with autistic children | | | | | |
| Research diary | | | | | |
| Phase 4: Autistic children | | | | | |
| Semi-structured interviews, observations, questionnaires (n = 10) | | | | | |
| Research dairy | | | | | |
| Phase 5: Autistic adults | | | | | |
| Semi-structured interview (n = 10) | | | | | |
| Research diary | | | | | |

Observer bias and ‘Hawthorne effect’

All of my visits to the schools were planned and agreed in advance with the school SENCO as I was, to a large extent, an ‘outsider’ in relation to them. This arrangement included the activities I carried out while I was there, where I was located, and the staff and children I engaged with. As part of this, the video-recorded observations of the children were agreed with school staff in advance and focussed on specific areas of the curriculum: Maths, Reading, Writing and Phonics. This was at my request and in keeping with the aims of my project. Therefore, in terms of the observations which are video-recorded, there is little possibility for observer bias on my part. Furthermore, as Table 6 above indicates, I spent a lot of time with the children before I started collecting any sort of data from them, and I did not have the sense that they were impacted by the camcorder when I started using it. However, the same could not be said of some of the school staff who, although I endeavoured to train the camera on the child only, needed considerable reassurance about the whole process. This in itself was a distraction, both for me and the child on some occasions, although I did not have the impression that this altered the core activity on any fundamental level. In addition, it was difficult for me to ascertain how much the school staff were impacted by my presence – the ‘Hawthorne effect’ – and whether or not certain activities and materials had been devised specifically because I was in the school and to give the impression of differentiation and autism-specific strategies, for example. Moreover, I was naturally ‘observing’ all of the time, and important contextual information was added as notes to either the transcriptions themselves or to my research diary. This included the various interruptions which inevitably took place in a busy school environment during both the interviews and the observations, especially as I was trying to avoid capturing other children on film.

In addition, although I aimed to be relatively neutral during the several interviews I conducted, I noticed, soon after those with school staff started, that they tended to focus on the difficulties they were experiencing in supporting autistic children, and that the interview overall could be dominated by a rather disconsolate and gloomy tone. I felt it important, from an ethical point of view, that interviews should end on a positive note, therefore I added the following question to all teacher and TA interviews:

‘What is the most positive aspect of having an autistic child in your class?’

While this had the desired effect, this is a factor in relation to my data about the positive conceptualisations of autism (as will be seen later, pp. 297 - 298), as some derive from the answers to this very question. However, I did not have the impression that school staff were somehow reluctant to speak positively about the autistic children, and that this information was somehow forced or reluctantly given. Indeed, most appeared to welcome the opportunity to address this very point.

All of these issues point to the high number of variables associated with my design, which are inevitable in a study involving human subjects placed predominantly in the ever-shifting environments of schools. While this impacts on the overall validity of my study as well as any claims about generalisability of findings, I aim to provide ‘a narrative’ rather than causal links (Becker [1998], cited in Thomas 2013a, p. 114). Moreover, as extracts from my research diary will reveal, and as Thomas (2013a) argued, it is impossible to pretend that I was ‘a dispassionate, objective observer’ during the research process, especially as ‘applied social research is complex – messy, even - often involving a knotty intertwining of ideas, facts and person’ (p. 272).

Methods of data analysis

At the start of my process of data analysis, all of my raw data constituted my dataset. In other words, at this stage I did not go through process of data reduction (Robson, 2011). The principle method of data analysis employed in this study is thematic or content analysis (Miles and Huberman, 1994; Strauss and Corbin, 1998; Braun and Clarke, 2006; Robson, 2002, 2011; Thomas, 2013a) via coding (Saldaña, 2016). However, just as I had needed different methods of data collection, other methods of data analysis, while not formally applied, also influenced the techniques used in my analysis (Coffey and Atkinson, 1996). Indeed, in keeping with the case study format, ‘analytical eclecticism is the key’ (Thomas, 2011, p. 512), and so discourse analysis, narrative analysis and secondary data analysis will also be discussed.

Discourse Analysis

Braun and Clarke (2006) argue that there can be overlaps between thematic analysis and discourse analysis, with the latter defined as the analysis of ‘talk and texts’ (Wetherell, Taylor and Yates, 2001) and the ‘study of language in use’ (Taylor, 2001, p. 5), particularly in social contexts. According to Thomas (2013a), the emphasis is on ‘the use of particular words, phrases, idioms, similes, kinds of rhetoric etc.’ (p. 242) and how notions are constructed through this use of words. Discourse analysis can also include conversation analysis, sociolinguistics, discursive psychology, critical discourse analysis and Foucauldian analysis (Wetherell, Taylor and Yates, 2001). According to Taylor (2001), language is ‘constitutive’, as it ‘creates what it refers to’ (p. 8). She also argues that it is through language that ‘certain things or people are either categorized together or separated out as different, and through language (...) value is attributed or denied’ (Taylor, 2001, p. 12). Similarly, for Parker (1999), ‘words and phrases do not come ready packaged with a specific delimited meaning’ (p. 2) and that while discourse

analysis will not tell us what is ‘correct’ or not, ‘it does alert us to the intimate connections between meaning, power and language’ (p. 6). Meanwhile Grue (2015), while discussing critical discourse analysis in relation to disability, also argues that ‘language (...) is power’ and posits that the role of the discourse analyst is ‘to ask what social, moral, and political arguments lie implicit in different discourses, and how they come into play’ (p. 4).

In addition, Parker (1999) emphasises the fact that ‘texts’ do not simply refer to written or spoken language and describes ‘a conception of textuality as a material force, with analysis of cities, organizations, gardens and sign language’ (p. 8), for example. Parker (1999) also considers how, according to feminist researchers, women have been located ‘outside’ of male language categories, meaning that their ‘voice’ has been lost or diminished (p. 18). Consequently, he suggests that while one of the disadvantages of discourse analysis is that it can be subject to charges of relativism and interview bias, thus diminishing its ‘ecological validity’, feminist perspectives have helped to shift attitudes in this area. Parker (1999) argues that from a feminist point of view, interview ‘bias’ is in fact seen as an important source of background knowledge and a valuable resource.

In my own study, all adult participants were asked to describe or define autism. In addition, participants made comments about the nature of autism at other times during interviews or informal discussions. While all of these conceptualisations of autism were considered as part of my content analysis, the inevitable focus on language, and the implications of this – especially within the theoretical framework of my study – were considered. For example, the juxtaposition of language ‘about’ autism and the actions of school staff were analysed, particularly in relation to notions of power and control. Furthermore, not all of my data came via speech or written text: the use of gesture was significant in some cases and one autistic boy chose to express himself via actions. An autistic adult provided me with a photograph by way

of an answer for part of her interview, suggesting that ‘voice’ needs to be considered in much broader terms than is typically the case. In other words, conventional discourses about autism might exclude the ‘voices’ of autistic people in both real and metaphorical terms. In addition, I considered that my own positionality as a former autism practitioner and teacher, as well as a parent of an autistic child, undoubtedly placed me in a situation of knowledge and understanding, rather than what is suggested by the pejoratively termed ‘interviewer bias’.

Narrative analysis

While the emphasis in discourse analysis is very broadly on language use and the implications of this for individuals and groups, the focus of narrative analysis tends to be on the story as whole (Matthews and Ross, 2010). Within these narratives, the researcher might be in search of epiphanies, plotlines or complications, for example (Czarniawska, 2004; Ward, 2012), or focus on the style and mode of narration (Wengraf, 2009). In this form of data analysis, the role of the interviewer or the audience is crucial and must be considered as part of the narrative, including, for example, the way in which the narrative is initiated and whether or not there are any interruptions (Matthews and Ross, 2010).

The semi-structured interviews which I employed for the majority of my participants did not permit an uninterrupted narrative from them. Moreover, although there was a degree of flexibility in the ways in which the interviews were conducted, the same groups of participants were asked the same questions, in accordance with the interview schedule. However, there were a few occasions of significant narrative or story-telling, where participants either digressed or, in the case of some of the autistic adults, used the fact that they were completing the interview by email to include longer narratives or stories. These are highlighted in my analysis as part of the broader thematic framework.

Secondary data analysis

The analysis of secondary datasets – namely, DfE examination data - formed an important, early stage analysis in my research project. According to Hakim (1982), secondary data analysis consists of the following:

‘...any further analysis of a survey or social dataset that presents interpretations, conclusions or knowledge additional to, or different from those presented in the first report or the enquiry as a whole and its main results’ (p. 12).

For Gorard (2001), incorporating secondary datasets as part of a mixed-methods research project run by a single researcher can work well when ‘allied to the flexibility of primary data techniques’ (p. 45). In Gorard (2002), he contends that contextual secondary data can be used ‘to argue that a problem exists to be solved by other techniques and to begin to describe the nature of the problem’ (pp. 234 – 235). Smith (2008) also considers that secondary data collection is ‘an unobtrusive research method’ with ‘the ethical benefit of not collecting additional data from individuals’ (p. 40), which permits subgroups to be analysed more robustly. Importantly, only when allied with primary data can its ‘strong links to equity and social justice’ (Smith, p. 49) be seen, because combined approaches alone can enable us to understand why those inequalities might exist. Furthermore, Smith (2008) argues that secondary data is essential for social scientists ‘to be able to describe the social world around them, posit theories and test them empirically’ (p. 26). She is of the view that official statistics are a valuable source of data for social scientists, and that it is foolhardy to leave them ‘for politicians, or even the media to do with what they please’ (Smith, 2008, p. 29).

Furthermore, it has also been argued that re-analysing secondary datasets is important because they may have been created in the first instance ‘to serve the information needs of policy-

makers in government' (Hakim, 1982, p. 22). Similarly, Smith (2008) asserts that 'official data in particular are not value neutral' (p. 22), and points out the irony of 'research into exclusion, which surveys only those pupils who are present in school' (p. 23). Indeed, according to Florian et al. (2004), there are significant numbers of children with SEN for whom 'the current SATs and GCSEs provide no meaningful data' (p. 119). Similarly, Gorard (2001), while noting the problem of 'missing comparators' and 'the use of bogus averages' (p. 77) in simple statistical analyses, emphasises the importance of treating secondary data figures 'with tentative scepticism' (p. 55), an approach he considers especially applicable to official examination statistics. In other words, it is precisely because official statistics might be unreliable that they should be explored, as the questions they raise and the inconsistencies they might present can be instructive.

My analysis of DfE examination datasets from 2012 – 2014 took place in 2014. It was beyond the scope of this project to consider the underlying data and the methodologies of its collection (Gorard, 2002), and comparisons between different sections of data, especially in relation to different years, were tentative at best, given the regular changes to syllabuses, methods of assessment and statistical representation (Gorard, 2001). However, the ways in which the DfE data are presented, the selection of statistics and what they appeared to indicate about how autistic children might be accessing the curriculum and tests in schools, as well as how their progress is monitored, played an important role in enabling me to frame the overall aims of my study. They also informed the research questions and methodology of my primary data collection, and subsequently provided a useful source of comparison with my findings based in schools. Therefore, having already been analysed in my literature review, these data are also referenced as part of my thematic analysis. More recent DfE data and reports will be considered briefly in the summative discussion of this thesis in Chapter 7.

Thematic Analysis

According to Thomas (2013a), the ‘constant comparative method’, which underpins thematic analyses of data, is the ‘basic analytic method of the interpretative researcher’ (p. 235). For Braun and Clarke (2006), thematic analysis ‘is a method for identifying, analysing and reporting patterns (themes) within data’ (p. 79), and should be considered ‘a foundational method for qualitative analysis’ (p. 78). This consists, on a very simple level, of going through the data a number of times, comparing different elements during this process, and eventually devising themes which summarise the data in a meaningful way. For Miles and Huberman (1994), the activity of data analysis can be described by three sub-processes: data reduction, data display and finally conclusion drawing and verification. Allied to thematic analysis is network analysis, construct mapping or ‘theme mapping’ (Thomas, 2013a), whereby the ways in which the different themes might interrelate are analysed.

Furthermore, and notwithstanding its association with qualitative research, thematic analysis does not derive from a uniquely phenomenological epistemology, as ‘theme discovery is practiced by avowed positivists and interpretivists alike’ (Ryan and Bernard, 2003, p. 86). In addition, thematic analysis is ‘not is ‘not necessarily wedded to a particular theoretical framework’ (Robson, 2011, p. 475), as it can be applied inductively from the data itself (in keeping with grounded theory approaches [Glaser and Strauss, 1967]), or pre-set themes will determine the entire analysis (Braun and Clarke, 2006; Robson, 2011; Thomas, 2013a). In short, it is a ‘method which is free of theory and epistemology’ (Braun and Clarke, 2006, p. 78).

Moreover, while an advantage of thematic analysis is that it permits different sections of data to be cross referenced and unified when relevant, this method also allows a balance to be struck between the concern that ‘anything goes’ in qualitative research and the need to provide an

analysis which is ‘theoretically and methodologically sound’ (Braun and Clarke, 2006, p. 78). Similarly, Richards (2005) considers that contentious issues about ‘coder reliability’ are not necessarily relevant, given that qualitative methods ‘are all about interpretation and individual agency’ (p. 98). Thematic analysis could therefore be viewed as a method which helps to counter the perception that findings from qualitative data are somehow less instructive than those based on quantitative data. Furthermore, Braun and Clarke (2006) also reject what they call a ‘naïve realist’ view of qualitative research, where the researcher simply ‘gives voice’ to their participants (p. 80): the process of thematic analysis is more dynamic and interpretative than this perspective suggests. In addition, while Ryan and Bernard (2003) warn of the dangers of analyses too strongly driven by theory, which might mean that they ‘only find what they are looking for’ (p. 94), they consider that if the researcher’s judgements are made explicit and clear, then validity can be ‘more, rather than less, likely’ (p. 103).

Coding

The different categories of data are initially drawn together through ‘codes’ (Strauss and Corbin, 1998; Braun and Clarke, 2006; Robson, 2011): these are fluid, ‘heuristic’ devices (Coffey and Atkinson, 1996; Saldaña, 2016) which permit the mechanics of the data analysis to take place. Coding can describe ‘a range of approaches that aid the organization, retrieval and interpretation of data’ (Coffey and Atkinson, 1996, p. 27), and not all analysts use the same term for ‘codes’. For Glaser and Strauss (1967) they are ‘categories’, Tesch (1990) refers to ‘segments’, while Strauss and Corbin (1990) employ the term ‘concepts’ (cited in Ryan and Bernard, 2003, p. 87). Thematic analysis consists of a number of stages or phases, within which coding, for Robson (2011) is effectively a form of constant comparison analysis, although Coffey and Atkinson (1996) consider that the coding is simply part of the process of analysis,

rather than the analysis itself. For Coffey and Atkinson (1996), codes are ‘tools to work with’, which can be ‘expanded, changed or scrapped altogether’ (p. 32).

According to Braun and Clarke (2006), there are six phases of data analysis which can be summarised as follows:

1. Familiarising yourself with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing the themes
5. Defining and naming themes
6. Producing the report.

For Strauss and Corbin (1998), there are three phases of analysis:

1. Open coding: separating the data into categories
2. Axial coding: linking the open codes together
3. Selective coding: identifying the central, core issues.

Meanwhile, Ryan and Bernard (2003) identify eight possible ‘observational’ and four ‘manipulative’ techniques and explain how themes can arise both from the data (an inductive approach), or from a researcher’s previous existing understanding of the phenomena under study (an a priori approach) (p. 88). In addition, they describe ‘etic’ and ‘emic’ themes, which refer to understandings held by outsiders rather than insiders (Ryan and Bernard, 2003, p. 104).

Richards (2005) describes three types of coding in qualitative research:

1. Descriptive: information is stored about the speaker in terms of gender, age etc. (and so in this, it is more like quantitative coding);

2. Topic: the allocation of topics to certain passages of text (involving little interpretation);
3. Analytical: the consideration of meaning in context, leading to the emergence of theory and theory affirmation.

For Richards (2005), coding is ‘a first step to opening up meaning’ (p. 94), and its purpose is to ‘ask questions about how the category relates to other ideas from the data, and construct theories about those relations’ (p. 87). Meanwhile, Saldaña (2016) considers that coding is ‘a cyclical act’ (p. 9), and describes six ‘first cycle’ coding methods, which themselves can be subdivided into 25 first cycle coding methods, one ‘first to second’ coding method, and finally six possible ‘second cycle’ coding methods.

For my own study, and given the mixed nature of my data, the model offered by Richards (2005) seemed the most suitable, although the allocation of topics, or codes, to different passages was more analytical than her framework suggests. However, I have also employed some of the models proposed by Saldaña (2016) in order to fine tune the process overall. My general position was essentialist to the extent that I wanted to ensure that unexpected themes were permitted to emerge inductively from the data (Ryan and Bernard, 2003; Robson, 2011). However, there were undoubtedly elements of a more constructionist approach, whereby meaning and experience are seen as ‘socially produced and reproduced’ (Braun and Clarke, 2006, p. 85). This is particularly evident in the comparisons I draw between different groups of participants within some of the themes, as well as the varying descriptions of autism offered by participants. Consequently, while the theoretical constructs described in Chapter 3 informed my data analysis (as they have all stages of this project), new theories, or reflections on existing theories were permitted to emerge during my analysis. Indeed, I consider that analysis was already taking place in some ways throughout the process of this study, including the choices I made during my literature review, the ideas which informed my study and the design of research

instruments, for example (Miles and Huberman, 1994). In addition, any significant contextual information, as well as illustrative comments from my research diary, are included as part of the analysis (Coffey and Atkinson, 1996) in order to try to achieve the transparency Ryan and Bernard (2003) recommend.

Analysis tools

Basit (2003) sets out the advantages and disadvantages of manual and electronic coding, one of the drawbacks of the latter being the temptation to quantify qualitative data. Similarly, Richards (2005) underscores the importance of having clear goals during the coding process and to identify the purposes of qualitative coding, warning also of the dangers of ‘over-coding’, as this can be, she suggests ‘a way of never finishing your project’ (p. 100). For these reasons, I used NVivo for my interview and observation data only, with the numerical, questionnaire data analysed separately and manually via simple, descriptive statistics. The data from the open questions on the questionnaires were organised into ‘temporary constructs’ (Thomas, 2013a) which informed the analysis of the interview and observation data. The latter data were uploaded onto NVivo in four consecutive waves and consisted of the transcripts of the semi-structured interviews and the video-recorded items from school staff (teaching assistants, teachers, SENCOs and deputy head-teachers), autistic children, autistic adults and parents. Extracts of data for each participant were assigned to different codes (or ‘nodes’) and nested sub-codes, with some extracts being assigned to more than one code or sub-code.

Given the high number of participants and the range of data collection instruments I employed, the data is analysed in the next two chapters:

1. Chapter 5: questionnaire data
2. Chapter 6: data from interviews and observations

In Chapter 5, I describe and analyse my findings from the questionnaire data from the parents, followed by those derived from the teachers, the SENCOs and finally the children. I also include a description of my methods of analysing each of the questionnaires, and set out the ways in which these data were employed in my study overall. The manner in which the different participants are identified is established in Table 7 on p. 143: this method of identification is used in the remainder of this thesis.

In order to provide additional contextual information, extracts from my research diary are occasionally included in the next chapter, as well as in chapter 6. The key elements of all data are considered together as part of the summative analysis in the final chapter (Chapter 7).

CHAPTER 5: FINDINGS OF QUESTIONNAIRE DATA

In this chapter, the findings from my questionnaire data are presented and analysed. These questionnaires were completed by two samples of parents, the teachers of the participating autistic children in my study, the school SENCOs and seven of the ten child autistic participants (three of the children did not have the speaking or writing skills to be able to access this method of data collection).

The different participants are identified in the following ways throughout the remainder of this thesis:

Table 7: School-based participants

| Schools (type) | Reference | SENCOs | Deputy head teachers | Teachers | Teaching Assistants | Autistic Children | Parents (of autistic children) |
|-------------------------|-----------|--------|----------------------|---------------|--------------------------|-------------------|--------------------------------|
| Infant | School 1a | S1 | | T1; T2 | TA1; TA2; TA3 | C1 (Reception) | P1 |
| | | | | | | C2 (Year 1) | P2 |
| Junior | School 1b | S2 | D1 | T3; T4 | TA4; TA5 | C3 (Year 4) | P3 |
| Small Community primary | School 2 | S3 | D2 | T5; T6; T7 | TA6; TA7; TA8; TA9; TA10 | C4 (Reception) | P4 |
| | | | | | | C5 (Year 3) | P5 |
| Primary (faith school) | School 3 | S4 | D3 | T8; T9 | TA11; TA12 | C6 (Year 3) | P6 |
| | | | | | | C7 (Year 6) | P7 |
| Large community primary | School 4 | S5 | D4; D5 | T10; T11; T12 | TA13; TA14; TA15 | C8 (Year 2) | P8 |
| | | | | | | C9 (Year 3) | P9 + P10 (co-parents) |
| | | | | | | C10 (Year 4) | |
| Total | 5 | 5 | 5 | 12 | 15 | 10 | 10 |

The Community Paediatrician is referenced as **CP**. The 10 autistic adults are referenced as **AA1; AA2; AA3; AA4; AA5; AA6; AA7; AA8; AA9** and **AA10**: these were assigned in no particular order. Due to the very small sample size, I did not feel it was valid to aggregate these participants in other ways, such as according to location (i.e. where they went to school) or gender.

| |
|--|
| <p>Parents' Questionnaire (quantitative and qualitative data)</p> |
|--|

Method of analysis: simple, descriptive statistics; category comparisons; temporary constructs

Questionnaires were issued to the parents of autistic children who were participating in the study. The same questionnaire was also issued to all of the parents of children in the same class as the participating autistic children.

Questionnaires issued:

| | |
|------------------------------|------------|
| School 1a | 60 |
| School 1b | 29 |
| School 2 | 58 |
| School 3 | 57 |
| School 4 | 88 |
| Total questionnaires issued: | 292 |

Questionnaires returned:

| | |
|----------------------------------|----|
| Parents of children with SEND* | 13 |
| Parents of children non-SEND** | 50 |
| Completed but most not usable*** | 2 |

Total questionnaires returned: **65 (22.2%)**

Total questionnaires analysed: **63**

*9 parents of autistic children (P1, P2, P3, P4, P5, P6, P8, P9 and P10); 4 non-specified special educational need or disability (SEND).

** Parents of children with no identified SEND (non-SEND)

***One of these was from P7, who told me during her interview (which was mediated via an interpreter), that she had not understood the questionnaire and so I was unable to rely on her answers.

For questionnaires which were part completed, I have included the completed parts in the analysis of the relevant sections. Therefore, the total numbers of replies are not the same for each question. These data have been aggregated into two broad groups: parents of children with no identified SEND (non-SEND) and parents of children with an identified SEND.

Question 1 (dichotomous):

My child has a special educational need: Yes/No

Yes = 13

No = 50

Question 2 (structured, rank order): educational priorities

- 1. What should your child get out of going to school? Please rank the following in order of importance (with 1 as your first choice, and 5 as your last choice):**

| | |
|------------------------------|--|
| Making friends | |
| Gaining independence | |
| Studying a range of subjects | |

| | |
|---------------------------------------|--|
| Improving knowledge and understanding | |
| Doing well in tests | |

For ease of reference in this analysis, the number categories have been assigned the following labels:

1 = most important

2 = quite important

3 = of average importance

4 = not very important

5 = least important

Parents of children with no identified SEND (non-SEND): n = 41

Parents of children with SEND (SEND): n = 11

Summary of results of the educational priorities of parents:

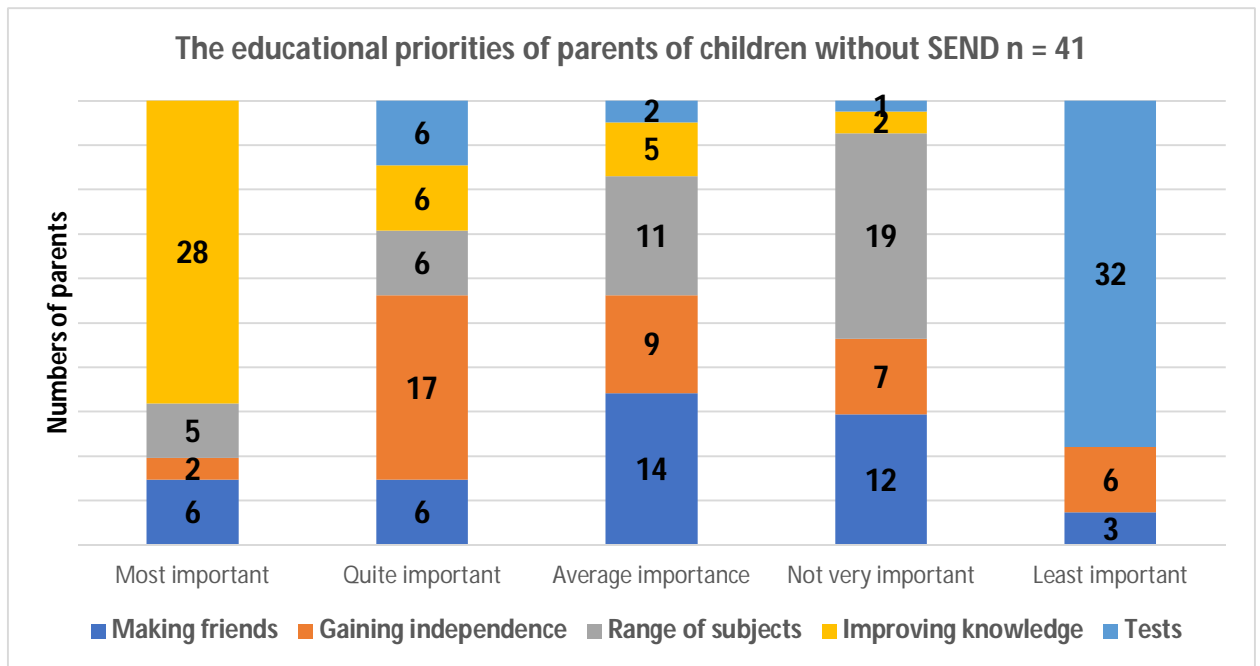


Figure 5.1: Educational priorities of parents of children without SEND

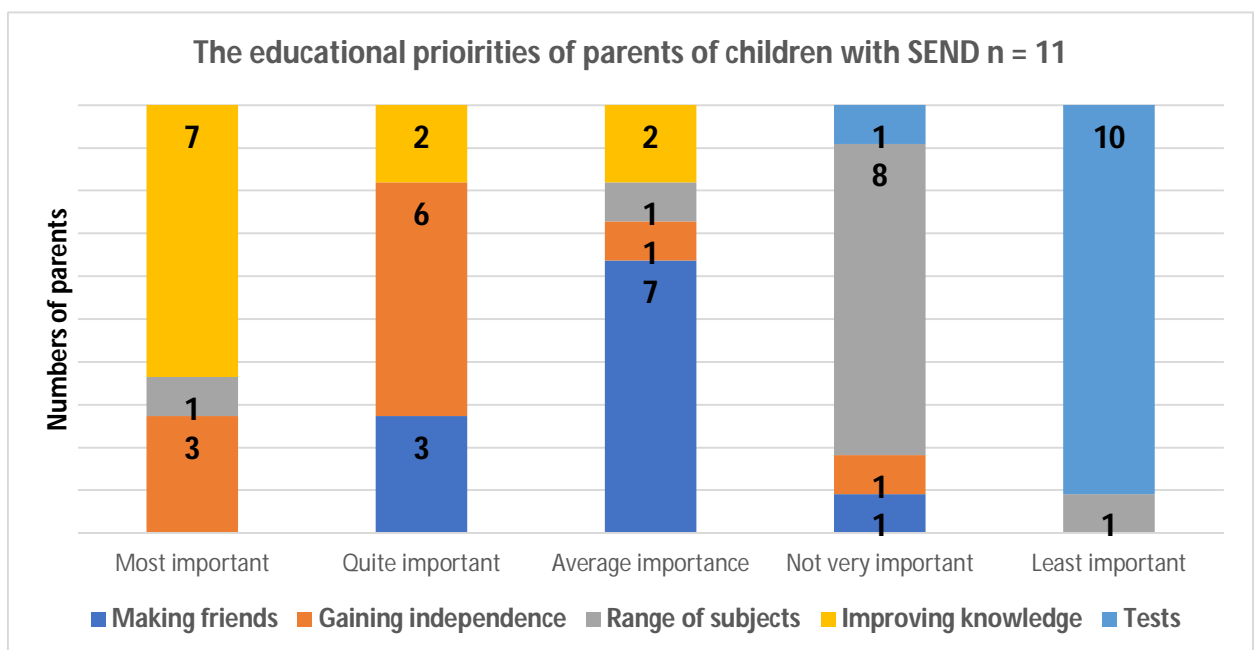


Figure 5.2: Educational priorities of parents of children with SEND

Analysis

Given the differences in numbers between the two groups of parents, comparisons between them are tentative at best. However, it is worth noting that the greatest areas of similarity between parents of a child with SEND and those who do not have a child with an identified SEND are in a) improving knowledge and understanding, which was felt to be the most important priority for both groups of parents and b) doing well in tests, which was considered to be the least important priority for both groups. There was more divergence in the other three categories: parents of children without SEND valued more studying a range of subjects than those of children with SEND; gaining independence was perhaps a slightly higher priority for parents of children with SEND than those of children without SEND; and making friends, while quite an important priority for parents of children with SEND, was the most important priority for some parents of children without SEND, while none of the parents of children with SEND ranked this as the most important priority.

Parents of autistic children who subsequently participated in a focus group or parental interview were able to expand on these points and related issues at that time.

Question 3 (structured, non-ranked, multiple option response)

What is your opinion of tests in schools? Please TICK any which apply:

| | |
|---|--|
| There are too many of them | |
| They are an important way of tracking my child's progress | |
| They don't test what really matters | |
| There should be more regular testing | |
| They get in the way of learning | |
| They are a good discipline for my child | |
| They are not relevant to my child | |

| | |
|--|--|
| My child finds them stressful | |
| My child seems quite relaxed about taking them | |

Table 8: Results (RAW) of parents' structured question on school tests

| What is your opinion of tests in schools? | Parents: children non- SEND (n = 46) | Parents: children with SEND (n = 12) |
|---|---|---|
| There are too many of them | 12 | 3 |
| They are an important way of tracking my child's progress | 26 | 9 |
| They don't test what really matters | 7 | 1 |
| There should be more regular testing | 7 | 2 |
| They get in the way of learning | 13 | 1 |
| They are a good discipline for my child | 21 | 2 |
| They are not relevant to my child | 3 | 3 |
| My child finds them stressful | 11 | 6 |
| My child seems quite relaxed about taking them | 22 | 2 |

Despite the small sample sizes in absolute terms and the difference in size between each group, it is useful to consider these results as a percentage.

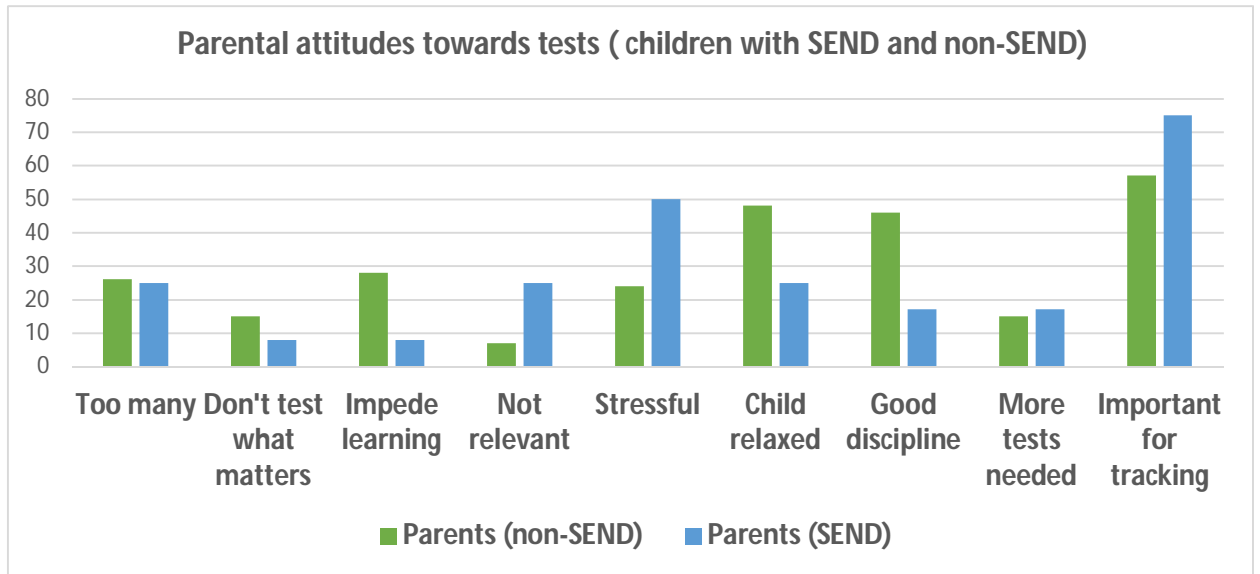


Figure 6: Results (percentage) of parents' structured question on school tests

Summary of attitudes and analysis:

Possible responses (which were mixed on the questionnaire) can be divided into positive and negative attitudes towards tests.

Positive:

- They are an important way of tracking my child's progress
- There should be more regular testing
- They are a good discipline for my child
- My child seems quite relaxed about taking them

Negative:

- There are too many of them
- They don't test what really matters
- They get in the way of learning

- They are not relevant to my child
- My child finds them stressful

Parents of children without SEND gave 122 responses in total (i.e. 122 ticks) = 2.65 per respondent. Of these, 76 were positive and 46 were negative i.e. approximately two thirds showed a positive attitude towards tests for their child. This is despite the availability of more negative than positive options. Parents of children with SEND gave 29 responses in total (29 ticks) = 2.4 per respondent. Of these, 15 were positive and 14 were negative i.e. approximately half showed a positive attitude towards tests for their child, while almost as many showed a negative attitude towards tests. Even though parents in both categories expressed the view that tests are an important way of tracking their child's progress, parents of children without SEND were more inclined to think that taking tests is a good discipline for their child, and that their child is also quite relaxed about taking them. Parents of children with SEND, on the other hand, were more inclined to consider that taking tests was stressful for their child, and that the tests might not be relevant to them. Both categories of parents showed a more positive attitude towards tests when being asked about their intrinsic value, rather than when asked to compare the importance of school tests in comparison to other educational priorities (as seen in Question 2).

Question 4 (open, unstructured)

Please write here any other comments you might have about testing in schools (box provided).

Total responses = 41

Non-SEND = 32

SEND = 9

The comments were grouped into temporary constructs and representative examples are shown in the table below:

Table 9: Parents’ responses to open question about tests in school

| Temporary constructs (Thomas, 2013a) | No. of comments SEND | No. of comments non-SEND | Typical examples of comments (reproduced as written) |
|---|----------------------|--------------------------|---|
| Testing is good/important | 2 | 10 | <i>“I think testing is important”</i> <i>“I feel tests are a good way of parents getting to know progress on a child’s development.”</i> |
| Testing is wrong/impedes learning/doesn’t show a child’s learning | 3 | 8 | <i>“Tests get in the way of more creative learning and disrupt children’s progress. Most are meaningless.”</i> <i>“My feeling about tests is that for my autistic son they will not always truly reflect his knowledge.”</i> |
| Testing is both good and bad, but might not be appropriate at primary school age. | 1 | 9 | <i>“Good to be tested I guess but does it <u>really</u> matter at 9 years old.”</i> <i>“I understand they do need to track children’s progress, but it is very defining for children to continually be levelled in such a linear way.”</i> |
| Child has positive attitude towards tests | 1 | 5 | <i>“My child is relaxed about them”</i> <i>“Some tests (Reading) he actually quite enjoys.”</i> |
| Child has negative attitude towards tests | 3 | 4 | <i>“My child really struggles and finds tests very stressful.”</i> <i>“children are very much aware they should try to achieve a certain level”</i> |
| Impact on parents | 0 | 6 | <i>“Testing should not...(be) a way of making parents and children feel inadequate from a young age.”</i> <i>“I like a test result so I can tell if my child is developing ok when compared to peers...”</i> |

| Temporary constructs (Thomas, 2013a) | No. of comments SEND | No. of comments non-SEND | Typical examples of comments (reproduced as written) |
|---|----------------------|--------------------------|---|
| Tests are not about the child, but about the school. | 1 | 5 | <i>“Testing in schools seems very political and more important for the school than for the child.”</i> |
| Teacher assessment is preferable. | 2 | 4 | <i>“Teacher assessment seems more accurate.”</i> |
| Adaptations/flexibility around tests would benefit my child | 5 | 0 | <i>“Children with SEN should approach testing in a different way.”</i> |
| The child shouldn’t be aware of being tested | 1 | 2 | <i>“Tests should only be carried out <u>without</u> the child’s knowledge, as a way of tracking or assisting the child’s learning.”</i> |

Analysis

The following points emerge in relation to Question 4:

- Only parents of children without a diagnosed SEND commented on the impact (both positive and negative) on them as parents.
- Only parents of children with SEND suggested that tests should be adapted so that more children can access them. This is noteworthy, because the fact that this might be desirable was hinted at in the letter to parents which accompanied the questionnaire (Appendix 23, p. xxix).
- Similarly, the non-SEND parents did not mention either autism or SEND in their written responses, even though the accompanying letter explained that this was a study in relation to the education of autistic children. The sole exception to this was a parent who left most of the questionnaire blank, but commented:

“Autustic childrens (sic) should be going to special care school not a public school.”

- These responses, along with those to Question 3, suggested that the issue of tests in primary schools can elicit strong views in parents, whether they are considered valuable or not.

The data from the whole questionnaire were used in the following ways:

1. To form a basis for some of the discussions with parents of autistic children in the interviews and focus groups;
2. To provide some of the initial codes when the interview and observation data were processed via NVivo;
3. To provide small points of comparison between parents of children with a SEND and those who do not have an identified SEND.

| |
|---|
| <p>Teachers' Questionnaire (quantitative data)</p> |
|---|

Method of analysis: simple, descriptive statistics

The teachers who had a participating autistic child in their class were asked to complete a questionnaire in relation to that child as well as any other autistic child who was in their class. All teachers of the participating autistic children took part, apart from the teacher of C2. Questionnaires were therefore completed for 9 of the participating children, and 4 additional autistic children who were not participants. C1 had two part-time teachers, who both completed a questionnaire, and so their results are presented separately.

Total number of questionnaires: 12 + 2 (14). (13 children)

Results

Question 1: How does the child access the typical curriculum?

| | |
|---|---|
| Fully, no differentiation | 3 |
| Fully, some differentiation | 3 |
| Fully, a lot of differentiation | 1 |
| Partially (all subjects) | 2 |
| Partially (not all subjects) | 1 |
| Very little, with a lot of differentiation | 2 |
| Not at all | 0 |

Question 2: How much time does the child spend in the classroom compared with the other children?

| | |
|------------------------|---|
| The same amount | 8 |
| Slightly less | 4 |
| About half | 0 |
| Very little | 0 |
| None | 0 |

Question 3: If the child spends time away from the classroom (or other places where the rest of the class is assembled e.g. for PE), what are the reasons? (Tick all that apply).

| | |
|---|------------------|
| Receiving input from specialist | 5 |
| Receiving specialist input from staff member | 2 |
| Working in small group on class targets | 3 |
| Working one-to-one on class targets | 3 |
| Working on alternative targets | 4 |
| Calming down | 2 |
| Other (please specify) | 1 (social group) |

Question 4: Which assessments does the child participate in? (Tick all that apply).

| | |
|---|----|
| All those taken by the rest of the class | 10 |
| Teacher assessments | 9 |
| End of Key Stage assessments | 6 |
| Specialist assessments | 2 |

Supplementary: Child C1 (2 teachers [T1 and T2], each covering 2.5 days per week)

Question 1. How does the child access the typical curriculum?

T1 Very little, with a lot of differentiation

T2 Very little, with a lot of differentiation

Question 2. How much time does the child spend in the classroom compared with the other children?

T1 The same amount

T2 About half

Question 3. If the child spends time away from the classroom (or other places where the rest of the class is assembled e.g. for PE), what are the reasons? (Tick all that apply).

T1 N/A

T2 Receiving input from specialist, receiving specialist input from staff member, working on alternative targets, loo visits, has lunch separately with a small group.

Question 4: Which assessments does the child participate in? (Tick all that apply).

T1 All those taken by rest of class

T2 Teacher assessments

Analysis

This small sample gives some useful indicators about the participation of autistic children in the school curriculum and tests in these schools. While there was a relatively even spread of responses to Question 1, indicating no set amount or method of curriculum access for the autistic children in this sample, all teachers considered that the autistic children spent either the same amount or slightly less than the same amount of time in the classroom than the other children in the class. The reasons for spending time away from the main cohort were varied, but most involved some form of specialist input or intervention. In other words, time away from the main cohort was considered to be for the benefit of the child. With regard to Question 4, which centres on assessments, these answers need to be considered with particular caution because of the fact that – in very general terms - teacher assessments are the norm in the earlier primary school years, with national tests becoming more predominant as the child progresses through the school. Even so, teachers assert that 11 of the 13 children in this group take part in the same assessments as the rest of the children in their class.

It is also useful to compare the answers of T1 and T2, who are referring to the same child (C1). The fact that they did not give the same answers in all cases could indicate differences in perception or perhaps a genuinely different approach to the same child.

The data from these questionnaires were used in the following ways:

1. To form a basis for the subsequent interview with the class teacher. It was also a useful ‘ice-breaker’ as some were nervous about the interview;
2. To provide me with very initial indicators about the participation and inclusion in the curriculum, classroom and tests of the autistic children in my cohort;
3. To provide possible comparisons between the perceptions of the teachers and the experiences of the children which I subsequently ascertained through the various research methods I used;
4. To inform the initial codes devised through NVivo.

| |
|--|
| SENCO Questionnaire (quantitative data) |
|--|

Method of analysis: simple, descriptive statistics

All five SENCOs who participated in my study were issued with a questionnaire for each of the autistic children in their school. They consisted of simple tick lists and were designed, as the teachers’ questionnaire had been, to be completed within a few minutes at most. These were done at an early stage of the data collection in the schools and the questions covered how much time the children spent in the classroom, the support the children received in school, as well as assessments and tests.

Sixteen questionnaires in total were completed. One child was omitted in School 2: the senior staff felt because of the very young age and complex diagnosis of this child, it would not be suitable to include him. Four children were omitted in School 4, including one of the participating children (C10). As already explained on p. 113, the SENCO (S5) was relatively new to this very large school and she admitted that she did not know who all of the autistic children were. The following extract from my research diary illustrates this point:

‘We had a bit of a chat and then we did the questionnaires. But S5 didn’t know the names or year groups of the children and so she had to keep checking on the computer. (...) We went through the questionnaires, but she was clearly making some of it up. I’d go far as to say that unless I can verify some of these things (e.g. via a class teacher), most of what she said needs to be discounted.’ (Research diary, 3.03.2015)

I have considered whether the questionnaires S5 completed could be a useful indicator of her perceptions or intentions in relation to the autistic children. However, the purpose of these questionnaires was to deliver primarily quantitative data. While, as we have already seen with the class teacher questionnaires, it is not clear that this is what they *de facto* deliver, it would serve little purpose to include here what was clearly guesswork on her part. Despite the fact that the meeting with S5 had been arranged specifically for the purpose of completing the questionnaires, a further extract from my research diary offers an explanation as to why it is perhaps understandable that she did not have this knowledge:

‘In her defence, she has only been in post since November 2014, and has 69 kids on her caseload. She said “I spend a lot of time here”, gesturing at the desk (...). She said she only has time to deal with problems as they arise i.e. she will deal with a particular child, and then move on to the next one that has come onto her radar.’ (Research diary, 3.03.2015)

Therefore, the five questionnaires from School 4 which were completed by S5 have not been included in the results below. (S5 later completed a semi-structured interview, and so her views and perspectives are included in the relevant sections later in this study).

Results (11 questionnaires)

Question 1: How much of the classroom timetable does the child take part in compared with the other children in the class?

| The same | Slightly less | About half | Very little | None |
|-----------------|----------------------|-------------------|--------------------|-------------|
| 4 | 5 | 2 | 0 | 0 |

Question 2: What type of additional support does the child receive in school? (Tick all that apply).

| None | Full time TA | Part time TA | External Specialist | Specialist technology | Other |
|-------------|---------------------|---------------------|----------------------------|------------------------------|--------------|
| 1 | 6 | 3 | 10 | 1 | PECS |

Question 3: Which assessments does the child participate in? (Tick all that apply).

| None | Teacher assessments | End of Key Stage assessments | Specialist assessments |
|-------------|----------------------------|-------------------------------------|-------------------------------|
| 0 | 10 | 7 | 5 |

Question 4: If the child takes part in some or all of the tests taken by the rest of the class, what type of support or adaptations does the child receive? (Tick all that apply).

| | |
|---|---|
| None | 5 |
| The same as at other times | 3 |
| Additional TA support | 3 |
| Specialist technology or use of a word processor | 0 |
| Sitting apart from cohort | 3 |
| A scribe | 1 |

| | |
|--|---|
| A reader | 4 |
| A prompter | 3 |
| A transcript (someone who rewrites for child due to poor handwriting) | 0 |
| Additional time | 4 |
| Early opening of papers | 0 |
| Other | 0 |

Analysis

The general perception from the SENCOs, like that of the class teachers, is that on the whole the autistic children spend the same amount of time or slightly less time in the class as the rest of the children in their cohort. Support is predominantly provided by a full-time or part-time TA, as well as via external specialists. Only one child is supported by any form of specialist technology (although not for tests), and the autistic children are stated to be participating in the usual classroom assessments, as well as specialist assessments. A range of support methods and accommodations are used for tests, but none uses specialist technology, a transcript or early opening of papers. Only one uses a scribe and none mentioned taking breaks (which was not listed here). Five of the autistic children in this sample receive no particular support during tests.

The uses of these data were as follows:

1. To provide an overview of participation and support for the autistic children in the school (although not for School 4);
2. To afford some insights into participation in tests and the support the children receive or do not receive;
3. To create some points of comparison between the perceptions of the SENCOs and the experiences of the autistic children;

4. To inform the initial codes at the early stages of NVivo coding work.

| |
|---|
| Children's Questionnaire (quantitative and qualitative data) |
|---|

Method of analysis: simple, descriptive statistics; initial constructs

Seven of the ten autistic children completed a questionnaire as part of a range of research methods employed to facilitate their participation. These children were C3, C5, C6, C7, C8, C9 and C10. C1, C2 and C4, aged four and five, were the youngest children in the cohort, and did not have the reading, writing nor - in the case of C1 and C4 – the speaking skills to be able to complete the questionnaire. The children who completed the questionnaire were supported by a TA, apart from C3, who was supported by me. This support was in the form of either prompting or, for the open questions, being a scribe if needed. The children appeared to find the first seven questions, where they only had to tick a box, particularly accessible and they completed these quite independently and cheerfully. In keeping with my methodological aim to highlight the views of the autistic children, and to not subjugate their input to those of the professionals (Allan, 2008), their responses are provided in full.

Question 1.

I enjoy school

Yes = 2

No = 1

Sometimes = 4

Question 2.

I enjoy working on my own

Yes = 1

No = 1

Sometimes = 5

Question 3.

I enjoy working in a small group

Yes = 4

No = 2

Sometimes = 1

Question 4.

I enjoy being with my class

Yes = 5

No = 2

Sometimes = 0

Question 5.

I like an adult to help me

Yes = 3

No = 1

Sometimes = 3

Question 6.

I like doing tests

Yes = 3

No = 3

Sometimes = 1

Question 7.

I think tests are important

Yes = 5

No = 2

Sometimes = 0

Question 8. (open question)

What do you want to do when you are grown up? (All answers given as written)

Work with computers (C3)

A chef (C4)

A school teacher because I can find out lots of things and use it to teach (C6)

Work first to fix things and then go in to football. Fix houses and cars and especially engines. (C7)

I'm not sure (C8)

Help my dad selling tomatoes and to help him play the guitar. I will also help my mummy taking photographs – she has lots of jobs. (C9)

To go to the martial arts tournament so I can have the prize money. I don't need a job because I want to train like fighting. I like to do a disguise. I will call myself the Red Tiger (C10)

Question 9. (open question)

What would make doing your school work easier for you?

By thinking with my brain (C3)

Writing on computer. Watching CBeebies. Working with my friends and TA10. Handwriting. (C4)

Not sure (C6)

Group, fun work and help by my assistant. If I get advise from my teacher and friends. (C7)

I'm not sure (C8)

When there was four very easy questions, actually 20, because I like 20, actually 55 and 3, so 58. (C9)

I don't know (C10)

Question 10. (open question)

What would make doing tests easier for you?

Prompted: On the computer. Get up and walk around. More pictures. (C4)

They are fine. (C6)

Fun test and an easy test. Looking forward to my (name of location) trip because I'm going for five days. (C7)

I'm not sure (C8)

Yes! I find them already quite easy for me (C9)

I don't know either. (C10)

Analysis

These simple questionnaires proved to be surprisingly instructive given the limited nature of the questions and the small sample size. The multiple-choice questions reveal a diversity of answers from the children in relation to their feelings about school, whether or not they like to work alone, have help etc. This very diversity is itself illuminating and contrasts with the various medical descriptions of autism discussed earlier in this thesis, in which autism is defined and classified according to specific and standardised traits and behaviours. These include limited social interests, for example, and yet some of the children in this cohort clearly appreciate the social aspects of learning. Moreover, five of the seven children asserted that tests are important, which could be deemed to contrast with the views of parents (both SEND and non-SEND), who considered that tests are not an important priority in school. Furthermore, I was careful to try to ensure that the children did not simply give the answers that they considered

either I or the TA present wanted to hear, as illustrated by the notes I made on the video transcription when C7 completed his questionnaire:

TA12: *What are you smiling about?*

C7: (pointing to question 1) *about this*

C7 smiles at first question on whether or not he enjoys school i.e. he doesn't want to write what he really thinks in front of us. TA12 and I encourage him to tick what he really thinks and say that no-one else is going to see it. He ticks 'sometimes'.' (Notes on video recording, 7.05.2015).

Some children – C3, C4, C7, C9 and C10 – used the open questions as an opportunity to talk about their interests. Two of the children – C3 and C8 – did not especially respond to the open questions, but followed the instruction I had given them to say if they weren't sure of an answer (C8) or if they were 'fed up' with the activity (C3) during the interview or questionnaire process. Moreover, C3 was the only child who was not supported by a TA at some point during my time with him and he was also the sole child who was not permitted to take time off lessons in order to engage with me. Consequently, it was more difficult to get to know him and he was evidently not especially happy about having to miss his free time. This was particularly as physical exercise - which he engaged in during break times - was an activity he valued highly, as will be seen later. Moreover, as will also be revealed later in this study, there were particular circumstances in which both C3 and C8 found it much easier to engage verbally, and these were very illuminating for the analysis overall.

The uses of these data were as follows:

1. To generate data from the children as part of the range of methods used in their case in order to maximise the opportunities for them to express their opinions and viewpoints;
2. To provide data which were factored into the initial codes.

Chapter summary

Overall, these data provided useful, early stage indications about the inclusion in the curriculum and tests of the children in the schools, as well as the educational priorities of the parents and the children. As far as the school staff were concerned, they also constituted a helpful ‘ice-breaker’ prior to their interviews, as the questionnaires were quick and easy to complete. In addition, these data were factored into the process of drawing up the codes as part of the analysis of the interview and observation data, which will be discussed in the next chapter. In this chapter (Chapter 6), the eight interlinked themes which emerged from my observation and interview data are set out, and I also draw on the findings from Chapter 5. In these ways, the analysis is an iterative process: one aspect of the data informs the next, gradually building towards an overall picture in relation to my research questions.

CHAPTER 6: FINDINGS OF INTERVIEW AND OBSERVATION DATA

Introduction

In this chapter, I present my findings and initial analysis based on my interview and observation data. I first explain the methods and processes of my coding and thematic analysis and then I describe and discuss the eight themes which emerged from these procedures. I also include two ‘outlier’ examples, which do not fit solely into one of the themes, but which nevertheless merit attention.

These qualitative data constitute the bulk of my data, and were uploaded onto NVivo and categorised using coding. This second wave of data analysis is necessarily more interpretative than the first, and consists of examples from interviews, structured and unstructured observations, and extracts from my research diary. I also reference and incorporate, where relevant, my findings from my questionnaire data, as well as the secondary datasets discussed in Chapter 1. These also help to establish the initial codes on NVivo. While some parts of the data are more fruitfully summarised in tables, I have aimed, on the whole, to let the data speak for themselves, rather than re-interpreting them. The analysis consists in drawing out themes from the data and establishing links, interconnections and contradictions between the various sources of data and the different groups of participants in relation to my research questions. The key elements of my findings and initial analyses are subsequently synthesised and explored further in Chapter 7.

Terminology

The process of ‘coding’ consists of assigning extracts of data to categories and sub-categories (and further sub-categories still). NVivo, a software package which enables this to be done electronically, uses the term ‘nodes’ to describe these categories. Therefore, the process of

‘coding’ consists of assigning the data to nodes, nested ‘child-nodes’ and ‘sub child-nodes’ in NVivo. These correspond exactly to the ‘codes’, ‘sub-codes’ and ‘sub sub-codes’ used in the subsequent analysis, which in turn, help to generate the ‘themes’ discussed in the rest of this chapter. Table 10 (pp. 171 – 180) sets out the results of the final exercise in node management: a ‘reference’ is a section of data; a ‘source’ an individual participant.

First Cycle Coding

My first cycle, exploratory coding methods were a combination of ‘holistic’ (‘grasping basic themes or issues in the data by absorbing them as a whole’), (Saldaña, 2016, p. 166), ‘structural’ (relating to a specific research question used in the interview), ‘descriptive’, ‘values coding’ and ‘themeing’ (ibid, p. 200). This process is also akin to what Richards (2005) describes as the first two phases of thematic analysis: ‘descriptive’ and ‘topic’. The interview and observation data were uploaded onto NVivo and coded in waves according to each participant group, in the following order (which in itself had no significance):

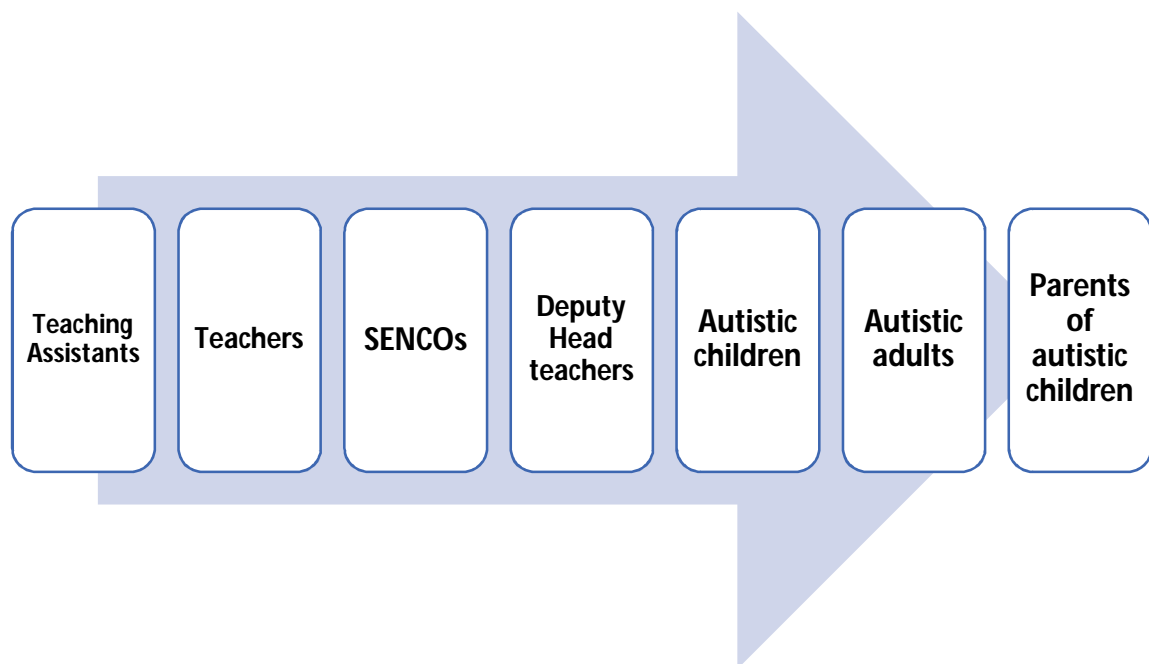


Figure 7: Process of uploading and coding interview and observation data

Sections or extracts of the interview and observation data were allocated iteratively to different nodes and nested child-nodes (and sub child-nodes) in NVivo. After each wave of participant data was added, I undertook a process of node management: nodes were added or conflated, titles and descriptions of nodes changed or the position of child-nodes was altered. In addition, I kept a record of the changes made after each wave of data allocation to different nodes. Nearly all parts of the raw data were assigned to different nodes and some extracts were assigned to more than one node (simultaneous coding). This process led to the drawing up of initial codes which are shown in Table 10: codes, nested sub-codes and further nested sub sub-codes are presented in alphabetical order and are aggregated according to the number of references and sources only. In this first cycle of coding, categories of participant and type of data are not distinguished.

Table 10

First Cycle Codes: Staff + children + parents + autistic adults (following final node management) (27.05.2016)

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|------------------|-------------------|----------------------|------------------------|-------------------|----------------------|---------------------|-------------------|----------------------|
| Ability | 9 | 10 | | | | | | |
| | | | Able - evident | 13 | 23 | | | |
| | | | Able – hidden | 11 | 18 | | | |
| | | | Autistic ability | 9 | 17 | | | |
| | | | Important to nurture | 1 | 1 | | | |
| | | | Low ability | 17 | 30 | | | |
| Age of child | 4 | 5 | | | | | | |
| Age at diagnosis | 13 | 14 | | | | | | |
| | | | Form of diagnosis | 13 | 24 | | | |
| | | | | | | Gender | 3 | 6 |
| Assessments | 6 | 8 | | | | | | |
| | | | Alternative assessment | 9 | 11 | | | |
| | | | New NC assessment | 9 | 17 | | | |
| | | | Teacher assessment | 20 | 30 | | | |
| | | | Tests | 14 | 35 | | | |
| | | | | | | Accommodations | 37 | 70 |
| | | | | | | Adaptations | 32 | 54 |
| | | | | | | Difficult to access | 41 | 83 |
| | | | | | | Disapplied | 14 | 15 |

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|--------|-------------------|----------------------|----------------------|-------------------|----------------------|------------------|-------------------|----------------------|
| | | | | | | Dislike | 4 | 10 |
| | | | | | | Easy to access | 24 | 42 |
| | | | | | | Humiliation | 5 | 8 |
| | | | | | | Important/useful | 14 | 25 |
| | | | | | | Language | 10 | 14 |
| | | | | | | Length | 4 | 5 |
| | | | | | | Not important | 3 | 8 |
| | | | | | | Stressful | 4 | 7 |
| Autism | 2 | 2 | Attention to detail | 4 | 5 | | | |
| | | | Behaviour | 13 | 21 | | | |
| | | | Can't define/label | 14 | 22 | | | |
| | | | Developmental | 7 | 8 | | | |
| | | | Different | 23 | 55 | | | |
| | | | Different - special | 12 | 19 | | | |
| | | | Different - strange | 12 | 21 | | | |
| | | | Distress | 14 | 30 | | | |
| | | | Dysfunctional | 1 | 2 | | | |
| | | | Empathy | 17 | 28 | | | |
| | | | Eye contact | 6 | 6 | | | |
| | | | Family member/friend | 4 | 9 | | | |
| | | | Inherited | 2 | 2 | | | |

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|----------|-------------------|----------------------|------------------------------------|-------------------|----------------------|----------------|-------------------|----------------------|
| | | | Learning style | 12 | 12 | | | |
| | | | Not how expected | 13 | 20 | | | |
| | | | Obsessive/set in ways | 29 | 44 | | | |
| | | | | | | Self-directed | 11 | 32 |
| | | | Perfectionism | 7 | 19 | | | |
| | | | Physical | 14 | 20 | | | |
| | | | Problems | 21 | 31 | | | |
| | | | Routine | 14 | 21 | | | |
| | | | Self-effacement | 4 | 11 | | | |
| | | | Sensory | 17 | 44 | | | |
| | | | | | | Noise | 20 | 63 |
| | | | | | | Zoning out | 18 | 42 |
| | | | Social communication - differences | 8 | 13 | | | |
| | | | Social interaction - problems | 32 | 55 | | | |
| | | | | | | Winning/losing | 2 | 6 |
| | | | Spectrum | 21 | 41 | | | |
| | | | Speech/communication problems | 15 | 22 | | | |
| | | | Understanding - problems | 13 | 21 | | | |
| Bullying | 10 | 28 | | | | | | |
| | | | Break times | 6 | 9 | | | |

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|------------------------|-------------------|----------------------|-----------------------------|-------------------|----------------------|--------------|-------------------|----------------------|
| Communication | 0 | 0 | | | | | | |
| | | | Difficulties | 3 | 12 | | | |
| | | | Disordered | 8 | 36 | | | |
| | | | Misunderstandings | 3 | 3 | | | |
| | | | Negative | 5 | 29 | | | |
| | | | Non-verbal | 2 | 26 | | | |
| | | | Positive | 8 | 30 | | | |
| Educational priorities | 10 | 20 | | | | | | |
| | | | Academic | 6 | 6 | | | |
| | | | Adapted curriculum | 5 | 15 | | | |
| | | | Independence | 6 | 8 | | | |
| | | | Social | 9 | 21 | | | |
| | | | Well-being | 10 | 18 | | | |
| Exclusion | 0 | 0 | | | | | | |
| | | | Experienced/felt | 6 | 8 | | | |
| | | | Extra-curricular | 5 | 6 | | | |
| | | | Inside classroom - separate | 9 | 23 | | | |
| | | | Outside classroom | 9 | 16 | | | |
| | | | Reasons | 20 | 30 | | | |
| | | | Reduced timetable | 9 | 13 | | | |
| | | | Small groups | 12 | 15 | | | |

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|------------------|-------------------|----------------------|-----------------------|-------------------|----------------------|--------------|-------------------|----------------------|
| | | | Societal | 6 | 8 | | | |
| Food | 2 | 10 | | | | | | |
| | | | Negative | 6 | 6 | | | |
| | | | Positive | 3 | 6 | | | |
| Future | 8 | 39 | | | | | | |
| Higher Education | 10 | 12 | | | | | | |
| Inclusion | 6 | 9 | | | | | | |
| | | | Criteria | 2 | 3 | | | |
| | | | Extra-curricular | 7 | 12 | | | |
| | | | Group work | 1 | 3 | | | |
| | | | How to facilitate | 21 | 31 | | | |
| | | | Impact on class | 9 | 13 | | | |
| | | | Important | 7 | 10 | | | |
| | | | Mainstream attendance | 10 | 10 | | | |
| | | | Societal | 2 | 2 | | | |
| | | | Whole class | 9 | 15 | | | |
| Infants/Juniors | 5 | 7 | | | | | | |
| | | | EYFS | 7 | 21 | | | |
| Interests | 15 | 49 | | | | | | |
| | | | Access to learning | 21 | 51 | | | |
| | | | Access to social | 9 | 17 | | | |

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|---------------------|-------------------|----------------------|------------------------|-------------------|----------------------|--------------|-------------------|----------------------|
| | | | Access to tests | 4 | 6 | | | |
| | | | Barrier to learning | 15 | 18 | | | |
| | | | Barrier to social | 4 | 4 | | | |
| | | | Change of subject | 3 | 14 | | | |
| | | | Computers | 12 | 36 | | | |
| | | | Expertise | 5 | 5 | | | |
| | | | Future plans | 4 | 8 | | | |
| | | | Greater independence | 5 | 13 | | | |
| | | | Improved communication | 7 | 24 | | | |
| | | | Source of comfort | 4 | 7 | | | |
| | | | Task refusal/rejection | 4 | 25 | | | |
| Levels | 13 | 23 | | | | | | |
| Mainstream/Special | 8 | 51 | | | | | | |
| Maths | 8 | 8 | | | | | | |
| | | | Dislike | 3 | 4 | | | |
| | | | Easy to access | 12 | 16 | | | |
| | | | Hard to access | 16 | 29 | | | |
| | | | Like | 8 | 23 | | | |
| | | | Tests | 9 | 10 | | | |
| Memory | 2 | 2 | | | | | | |
| National Curriculum | | | | | | | | |

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|--------------------------|-------------------|----------------------|-----------------------------------|-------------------|----------------------|--------------|-------------------|----------------------|
| | | | Doesn't meet needs/isn't accessed | 7 | 10 | | | |
| | | | Meets needs/is accessed | 4 | 6 | | | |
| | | | New NC | 3 | 7 | | | |
| | | | Old NC | 1 | 1 | | | |
| | | | Own/alternative curriculum | 15 | 25 | | | |
| P.E. | 15 | 19 | | | | | | |
| Parents | 12 | 19 | | | | | | |
| Phonics | 17 | 27 | | | | | | |
| Prof.Experience/training | 29 | 60 | | | | | | |
| Progress | 15 | 29 | | | | | | |
| Prompting | 5 | 5 | | | | | | |
| | | | High | 5 | 43 | | | |
| | | | Low/none | 4 | 35 | | | |
| Reading | | | | | | | | |
| | | | Difficult | 11 | 20 | | | |
| | | | Dislike | 3 | 4 | | | |
| | | | Easy | 5 | 7 | | | |
| | | | Important | 3 | 3 | | | |
| | | | Like | 14 | 29 | | | |
| | | | Literacy | 14 | 26 | | | |

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|---------------------|-------------------|----------------------|----------------------|-------------------|----------------------|--------------|-------------------|----------------------|
| | | | Negative experience | 3 | 3 | | | |
| | | | Sign of ability | 4 | 5 | | | |
| | | | Tests | 9 | 11 | | | |
| School/dislike | 10 | 26 | | | | | | |
| School/like | 13 | 35 | | | | | | |
| Secondary education | 18 | 62 | | | | | | |
| Social | | | | | | | | |
| | | | Barriers | 6 | 6 | | | |
| | | | Difficulties | 17 | 38 | | | |
| | | | Help in school | 3 | 3 | | | |
| | | | Like to be alone | 7 | 8 | | | |
| | | | Positive | 19 | 28 | | | |
| | | | Relationships | 26 | 54 | | | |
| | | | Younger children | 2 | 5 | | | |
| Support/experienced | 10 | 14 | | | | | | |
| | | | Negative | 12 | 67 | | | |
| | | | Positive | 13 | 23 | | | |
| Support/given | 12 | 21 | | | | | | |
| | | | Behaviour | 16 | 33 | | | |
| | | | Breaks & lunch-times | 7 | 8 | | | |
| | | | Communication | 2 | 3 | | | |

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|---------------------|-------------------|----------------------|--------------------|-------------------|----------------------|--------------|-------------------|----------------------|
| | | | Curriculum access | 23 | 38 | | | |
| | | | Emotional | 6 | 9 | | | |
| | | | Extra duties | 4 | 15 | | | |
| | | | Independence | 15 | 21 | | | |
| | | | Intervention | 7 | 8 | | | |
| | | | Keeping on task | 26 | 42 | | | |
| | | | Material/technical | 7 | 10 | | | |
| | | | Organisation | 9 | 14 | | | |
| | | | Physical | 4 | 5 | | | |
| | | | Positive | 7 | 8 | | | |
| | | | Safety | 3 | 5 | | | |
| | | | Socialisation | 7 | 10 | | | |
| | | | Specialist | 19 | 28 | | | |
| | | | Transitions | 4 | 4 | | | |
| | | | Understanding | 5 | 9 | | | |
| Support/effective | 14 | 24 | | | | | | |
| Support/ineffective | 7 | 65 | | | | | | |
| | | | Task repetition | 11 | 24 | | | |
| Work | 11 | 15 | | | | | | |
| Writing | 6 | 7 | | | | | | |
| | | | Difficult | 24 | 37 | | | |

| Code | Number of Sources | Number of References | Sub-code | Number of Sources | Number of References | Sub Sub-code | Number of Sources | Number of References |
|------|-------------------|----------------------|-------------------|-------------------|----------------------|------------------|-------------------|----------------------|
| | | | | | | Motor difficulty | 6 | 6 |
| | | | Dislike | 6 | 26 | | | |
| | | | Drawing | 4 | 10 | | | |
| | | | Easy | 3 | 4 | | | |
| | | | Like | 7 | 14 | | | |
| | | | Prefer computer | 7 | 13 | | | |
| | | | Sensory | 2 | 5 | | | |
| | | | Tests/assessments | 10 | 10 | | | |

Second Cycle Coding

The next stage of coding consisted of re-organising the codes so that the connections between them might start to emerge (Thomas, 2013a; Saldaña, 2016). For this, I employed ‘pattern coding’, which consists of grouping the first cycle codes into a smaller number of categories (Saldaña, 2016). In addition, I also incorporated elements of ‘axial coding’, which involves determining which codes are dominant and those less so, as well as seeking links between different codes and sub-codes across the categories already established (Strauss and Corbin, 1998; Saldaña, 2016).

However, before proceeding with the second cycle of coding, I needed to identify the extent to which the data might best be served by developing patterns (or axes) according to categories of participant (e.g. teachers, parents etc.) or according to the children themselves i.e. the perspectives of the relevant teachers, parents etc. in relation to each individual child. A third possibility – analysing data in accordance with year group or stage of education – was not viable due to the small sample size of children. During the process of initial coding - at which time, as I have already stated, some degree of analysis was necessarily already taking place - I did not develop a sense of potential themes and interconnections emerging from participants in relation to each autistic child. It was much more evident that the data revealed more when categories of participant were analysed together and in relation to each other. There were two key exceptions to this which I will set out here, as they are instructive as ‘outliers’ (Gorard, 2001; Thomas, 2011).

The codes and sub-codes referenced in relation to the two outlier examples and the remainder of this thesis are all drawn from those established in Table 10 (pp. 171 – 180).

Outlier example 1

Participants: School 1a; C1; TA2 (TA of C1); T1 (teacher of C1); S1 (SENCO of School 1a); P1 (Parent of C1)

Codes, sub-codes and sub sub-codes for which C1 is an axis:

Autism (obsessive/set in ways, self-directed); Communication (negative, non-verbal); Parents; Prompting (high); Support experienced (negative; unskilled; task repetition)

Context: S1 had been relatively dismissive of P1 during her interview, even though none of my questions to the SENCOs were about parents:

Interview question:

RW: In the questionnaire, you indicated what type of support the autistic children receive in school. What is the support they receive mainly for?

Reply (S1):

(...) His mum leaves him on the iPad all day. We've recently had a meeting with mum to get her to implement strategies at home. (S1, semi-structured interview).

C1's teachers were also prone to blame P1 for the difficulties he was experiencing in school. P1 on the other hand, was very positive about the school staff. Here she is explaining how well C1 is getting on at school:

Brilliant. The teachers are amazing, they're always keeping me up to date with everything daily. (P1, semi-structured interview)

Later in the interview, P1 was explaining how she felt autism could be described:

We were on holiday in Spain and there was a ball pool on the balcony. (C1) started taking all the blue balls out and we thought he was really smart. But when we tried to interfere with what he was doing, he went really mad. He did it the other day with some smarties – took all the blue ones out. (P1, semi-structured interview)

During one of my observations of C1, he showed a clear aversion to the colour blue when carrying out a matching activity under the instruction of TA2.

Notes from unstructured observation:

C1 starts putting the bears completely in the wrong place i.e. he is just doing his own thing with the bears. He holds on to blue bear. (...)

C1 complies with the green and red strip but is getting stuck on the blue and yellow one. He accidentally drops a blue bear and becomes preoccupied by it when he goes to retrieve it. (...)

C1 attends to the yellow and blue strip and places the four yellow bears, leaving 2 blue bears to be placed. He does one, the other is in his hand. When TA2 asks him to place the last blue bear, he says “No!” v clearly. C1 v reluctant to do it, smacks it onto its place on the card but doesn’t let go of the bear, cries out, flops to the floor. (...)

C1 whimpering sounding distressed. Flops to the floor and tries to crawl under table. TA2 pulls him back. Slapping table, squirming. C1 finishes the activity of sorts, but never actually places the blue bear, putting red ones down instead. (...) TA decides to finish the task even though he has not complied with either request in the end. C1 puts the two blue bears back in the tray first. (C1, unstructured observation).

During my interview with T1, one of C1's teachers, she asserted that he was very behind the other children in the class in every subject, with the exception of ICT.

The scenario of Outlier 1 can be represented diagrammatically:

School 1a

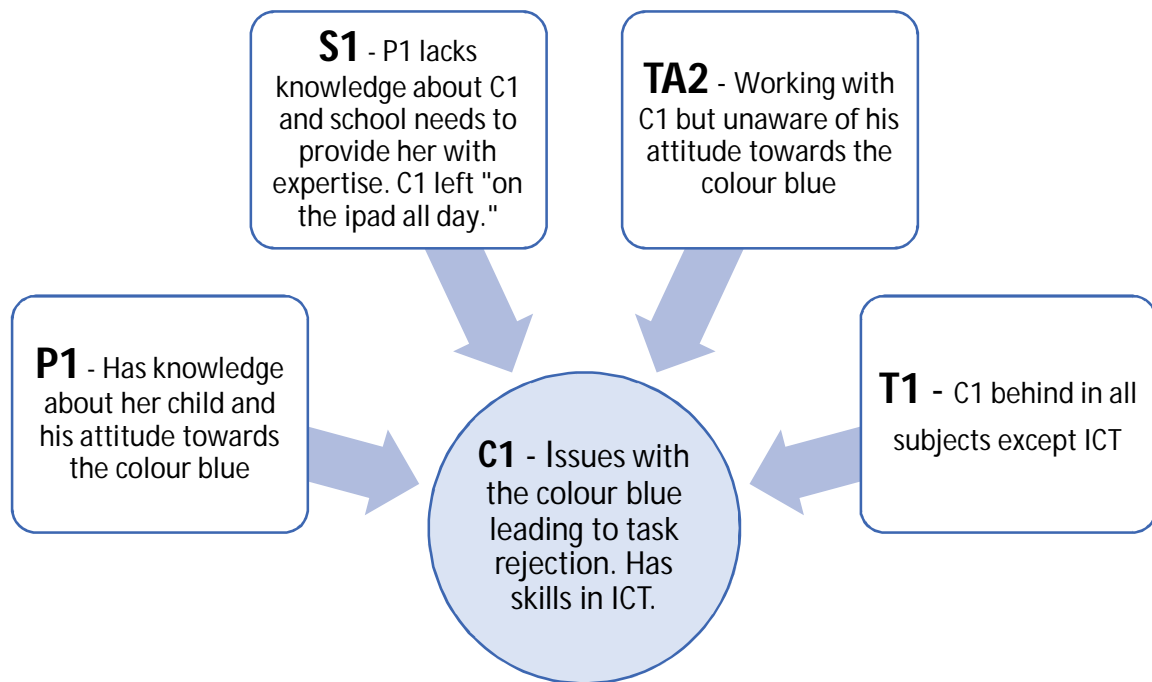


Figure 8: Outlier 1

This diagram shows that although the four adults are all connected to the child, the fact that knowledge is not being shared and expertise is deemed to rest with the school staff, rather than the parent, problems arise for the child in school. Moreover, the connection is not made between the fact that P1 lets her son play on the iPad (although, for what length of time, they simply cannot know) and his relatively strong skills in ICT.

Outlier example 2

School 1b; C3; P3 (mother of C3); T4 (teacher of C3); (AA1; AA3; AA4; AA6; AA7)

School 2; C4; C5; P4 (parent of C4); P5 (parent of C5); TA10 (TA of C5); (AA1; AA3; AA4; AA6; AA7)

Note: none of the autistic adults (AA1 – AA10) had any connection with any of the school staff, parents or children in this study.

Codes and sub-codes for which C3 and C5 are axes:

Autism (problems); Educational priorities (adapted curriculum); Exclusion (reasons); Interests; Maths (dislike, hard to access); Parents; P.E.

Context a): P3 was of the view that her son, C3, was generally getting on well at school, despite a few difficulties. The only subject she mentioned as being problematic was P.E. (which I did not ask about specifically):

C3 has a problem with losing. This happens in games in PE in school, at Cubs if they're playing games when he's 'out' – C3 just runs into the corner and starts crying. (P3, semi-structured interview)

T4 also considered that C3 found this aspect of P.E. difficult:

He finds PE difficult if he's not on a winning team. (T4, semi-structured interview)

However, C3 said that P.E. was one of his favourite subjects:

RW: What do you most like doing at school? What's your favourite thing to do at school?

C3: Err PE and ICT

(...)

RW: Do you want to tell me why you like PE?

C3: *I just literally like lots of exercise, playing like loads of games.*

Context b): Focus group discussion with P4 and P5 (parents of C4 and C5). P5 was expressing the view that it would be better if part of her son's curriculum was devoted to alternative targets and activities.

P5: *Yeah, so I'd rather he done more, as he goes through school that they focus more on things that he can do, rather than things that he...*

RW: *And again like I asked P4, you would be prepared for certain things to be dropped?*

P5: *Things to be dropped, yeah. PE to be dropped, things, you know*

RW: *Does he not like PE either? (i.e. like C4)*

P5: *He hates PE, he can't stand it (laughs)*

RW: *Why do you think that is then?*

P5: *I don't know, maybe it's a balance issues, maybe it's a...because (C5) likes throwing himself on the floor*

P4: *yeah, (C4) just won't get changed, he won't even put his PE clothes on (Focus group 2)*

I observed C4 to be an active child, who clearly enjoyed different physical activities in the playground. C5 was also described by school staff as being unable to take part in P.E. due to extreme sensitivity to noise. However, during one of his interviews, which was conducted by TA10, he asserted the following:

TA10: *What about lessons in school? What's your favourite lesson?*

C5: *Err...PE!*

TA10: (sounding surprised) *You like PE?*

C5: *Yeah*

TA10: *That's good – what do you like about PE?*

C5: *About putting music on*

TA10: *Ah you like the music. But do you now actually like the running around and doing stuff?*

C5: *I do like Running Club*

TA10: *Oh yeah, you've just gone to Running Club, haven't you. How was Running Club today?*

C5: *Good*

TA10: *Where did you run?*

C5: *Err...err...in (park location)*

TA10: *Oh, wow. And you're not tired or anything?*

C5: *Yes, I'm not. But I'm a little bit tired.*

TA10: *Well it's probably a good job we're having a bit of a sit down first, isn't it.*

C5: *Yeah*

TA10: *Yeah. So you think PE is your favourite lesson?*

C5: *Yes (C5, semi-structured interview)*

AA3, AA4 and AA7 made positive comments about P.E. or physical exercise at school. However, AA1 described the sensory issues she experienced as part of group games at school,

and the difficulties which arose from this, and AA6 recalled disliking Sports Day because of being stared at.

This scenario can be represented diagrammatically:

School 1b and School 2

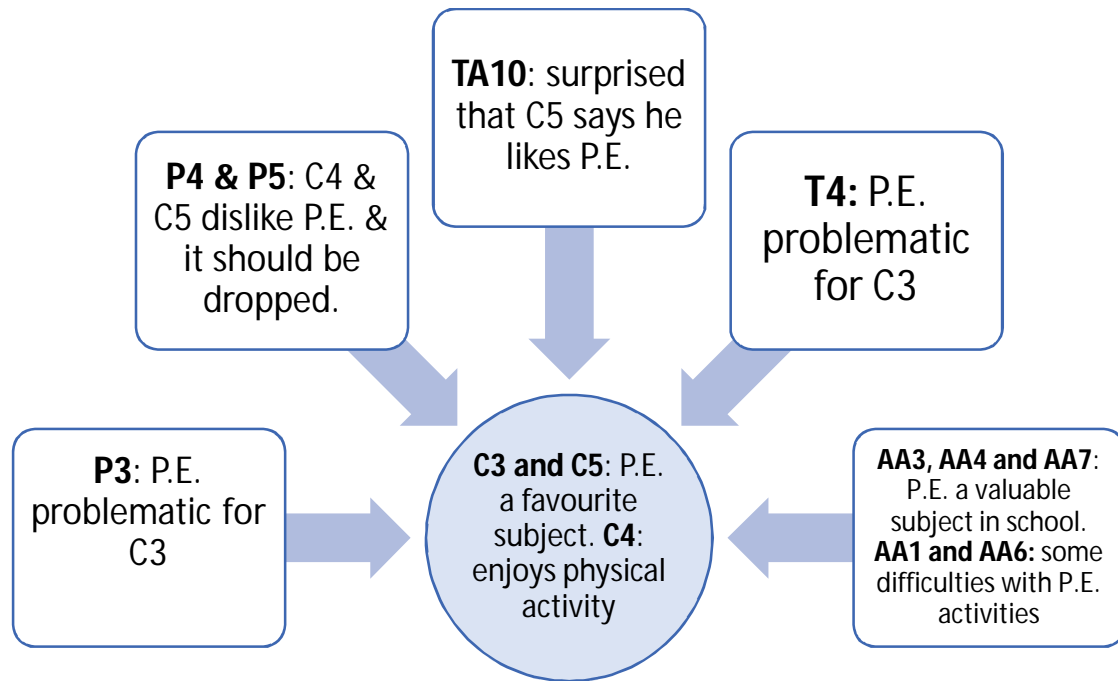


Figure 9: Outlier 2

This second outlier example is instructive because it suggests a possible divide between some of the autistic and the non-autistic participants, as well as differences of interpretation. For example, with the information that C3 provided, it might be the case that one of the reasons he becomes upset (if indeed he does become as upset as the adults suggest) when he loses at sport, is not so much that he is on the losing team, but because he is ‘out’, and can no longer engage in a physical activity he clearly values. Similarly, the reason why C4 refuses to get changed for P.E. might be a result of sensory or other issues, rather than an aversion to this part of the curriculum. Meanwhile, in the case of C5, it appears that he is making a very clear statement

about P.E. and his wish to participate, which he was not doing regularly during my time in the school (other than the lunch-time Running Club). In other words, there are indications here of significant discrepancies between the viewpoints of the autistic children and their parents and school staff, where the responses of the children to P.E. are being misinterpreted, leading to exclusion from a valued activity. In addition, and importantly for the purposes of this study overall, this discrepancy in perspectives is both rendered more visible and explicated by the input of the autistic adults.

The significance of both outlier examples lies in the revelation of divergences in viewpoints of certain participants in relation to individual children, and the consequences of these. However, as becomes evident in the second example in particular, analysing and comparing the perspectives of groups of participants, rather than in relation to each other as individuals, is ultimately much more instructive for my study. However, these outliers are nevertheless useful additions to the overall analysis, and a reminder that individual perspectives can have value within broader issues. Consequently, they are also referenced in relation to some of the themes discussed in the remainder of this chapter.

Themes

There were five elements of my study which contributed to the creation of eight themes described and analysed in the rest of this chapter:

1. Literature Review (pedagogical issues, school curriculum and tests, teaching assistants, needs versus rights, descriptions of autism);
2. Theoretical constructs (inclusion and exclusion, medical and social models of disability, difference, marginalisation, language and meaning);

3. My research aims and questions (if autistic children are accessing the curriculum and tests, with what sort of support, how autism is understood, how inclusion can be improved);
4. My findings from my questionnaire data (differences in educational priorities, questions about access to the curriculum and tests and classroom participation);
5. The interview and observation, which were organised through coding. During this lengthy process, I was making notes, changing the description and placement of nodes, and looking for links between them. Once this process was completed, the resultant codes were mapped in order to try to establish further patterns between them, as shown in Figure 10.

The mapping in Figure 10 shows that clusters are forming around the notions of ‘interests’ and ‘exclusion’ in particular. Other issues which are emerging as significant include school subjects, educational priorities, communication and interaction, support for children, inclusion and descriptions of autism. Further manual analysis of these concepts, combining the five components already described, led to the creation of the following, interlinked themes:

1. Support for Children
2. School Curriculum
3. Educational Priorities
4. Assessment and Tests
5. Communication
6. Interests
7. Inclusion and Exclusion
8. Descriptions of Autism

The rest of this chapter consists of descriptions and discussion of the eight themes identified.

Theme 1: Support for children

In this theme, I explore different aspects of the support provided for the autistic children in school: the reasons staff provided for that support, how it was experienced by the children, characteristics of effective and ineffective support, and how these are linked with prompting and task repetition. All codes referenced in this and the following themes are as set out in Table 10 (pp. 171 – 180), with the main connections between them represented in Figure 10 (p. 191).

i. Reasons for support (code: support given)

Using the number of sources (i.e. participants) as a measure, the rationale given by school staff for providing support for autistic children is presented in descending order in Table 11.

Table 11: Reasons for providing support (school staff)

| Sub-code | Number of sources (participants) | Teaching Assistant (TA) | Teacher (T) | SENCO (S) | Deputy Head (D) |
|-------------------|----------------------------------|---|-------------------------------|--------------------|-----------------|
| Number (n) | Total n = 37 | n = 15 | n = 12 | n = 5 | n = 5 |
| Keeping on task | 21 | TA1; TA2; TA3; TA4; TA5; TA7; TA9; TA10; TA11; TA13; TA14 | T4; T5; T6; T7; T11; T12; | S1; S4; S5 | |
| Curriculum Access | 19 | TA2; TA5; TA6; TA8; TA10; TA11; TA12; TA14; TA15 | T2; T3; T4; T8; T10; T11; T12 | S1; S2; S5 | |
| Specialist | 17 | TA5; TA8; TA9; TA11; TA13; TA15 | T1; T2; T4; T5; T9; T11 | S1; S2; S3; S4; S5 | |
| Behaviour | 16 | TA1; TA2; TA3; TA4; TA5; TA6; TA9; TA10; TA12; TA13; TA14; TA15 | T6; T11 | S2; S4 | |

| Sub-code | Number of sources (participants) | Teaching Assistant (TA) | Teacher (T) | SENCO (S) | Deputy Head (D) |
|---------------------------------|---|---------------------------------|---------------------|--------------------|------------------------|
| Independence | 12 | TA1; TA4; TA9; TA11; TA12; TA15 | T1; T6; T9 | S1; S3 | D4 |
| Material/technical | 9 | TA5; TA8; TA10; TA12 | T1; T2; T4; T9; T12 | | |
| Organisation | 8 | TA6; TA7; TA8; TA10; TA12 | T1; T2; T10 | | |
| Breaks & lunch-times | 7 | TA4; TA10 | | S1; S2; S3; S4; S5 | |
| Socialisation | 7 | TA1; TA4; TA6; TA7; TA10; TA13 | T12 | | |
| Intervention | 6 | TA1 | T2 | S3; S4 | D4; D5 |
| Emotional | 5 | TA4; TA6; TA8; TA11 | T2 | | |
| Physical | 4 | TA6; TA7; TA11 | T10 | | |
| Transitions | 4 | TA9; TA10 | | S2; S3 | |
| Understanding | 4 | TA6; TA12; TA14; TA15 | | | |
| Safety | 3 | TA1; TA10; TA11 | | | |

As Table 11 shows, school staff perceived that the main purpose of their support was to keep the children on task and to help them access the curriculum. Specialist support – either in the form of a visiting practitioner such as a Speech and Language Therapist (SLT), or via a staff member who had received training from such a specialist – was also considered to be an important justification for support, especially from the point of view of the SENCOs. This was sometimes stated to be provided in the form of material or technical support (e.g. visual

timetables), or via interventions, although it is noteworthy that the latter category did not feature strongly, given its prevalence in the literature about autism. Teaching assistants were particularly inclined to see their role as helping the child in relation to behavioural problems, and some considered that they also provided emotional support, or help with physical actions such as getting changed for P.E. and general self-organisation. Further, while independence is considered to be a fairly important justification for support, socialisation does not appear to be much of a priority for school staff, according to these data. The support provided by school staff is predicated predominantly on the notion of the needs, or lack of ability and functioning, of the children.

ii. Support experienced by the children and perceived by non-staff adults

The support provided as conceptualised by school staff can be compared with the support as it was experienced by the children, as well as how it was understood by parents and perceived by autistic adults. These viewpoints were derived from direct comments from participants in interviews, my own structured and unstructured observations, and extracts from my research diary. As far as the observations of the children were concerned, the positive or negative responses of the children were ascertained as follows:

- Signs of aversion to task may include e.g. chewing collar, destructive actions on items, throwing items, calling/shouting out.
- Examples of approval behaviours include smiling, affection to TA, care taken over activity, verbal approval.

In addition, these signs of approval and disapproval were combined with the specific remarks from the children, the knowledge of them I had derived during the familiarisation period,

information from their parents and school staff, as well as my own professional experience as a teacher and an autism trainer.

Some of the support was experienced by the autistic children in a positive way.

Code: Support Experienced (positive)

C1, C5, C7, C9 and C10 all stated or demonstrated that they valued the support provided by their teaching assistants.

Example:

C10 ends up chatting to the TA about other things (...). He has obviously raised some sort of a problem with her and this seems like a useful exchange i.e. he is using the hiatus to talk to her about something that is bothering him. Eventually TA15 says she will “speak to Miss X” (about the problem with lunch-times) and C10 gives her a big thumbs up i.e. he is happy with that. (Unstructured observation, C10).

P1 (parent of C1), P4, P5 (parent of C5), P6 and P7 (parent of C7) spoke positively about the support their children were receiving in school, showing some overlap between the views of the parents and their children in this context. (Note: the parents of C10 did not participate in the study).

Examples:

(TA11) is brilliant, I love her, and she’s very kind of dead pan, exactly what C6 needs, she’s very supportive, but very calm. (P6, semi-structured interview)

They’re just there for him and he enjoys it. (...) He likes her, he loves her, you can tell. (P1, semi-structured interview).

The positive views of the parents tended to focus on their children being understood by their teaching assistants, as well as there being a genuine emotional commitment and fondness for them. This perhaps contrasts with the more specific, practical views about support provided by school staff. However, the importance of emotional commitment was also echoed at times by the TAs themselves:

I've enjoyed seeing C5 blossom. I've known him since he was born. In nursery, C5 wouldn't speak. He responds to love, kindness and understanding. He says "I love you" to me. (TA9, semi-structured interview).

However, and notwithstanding the good intentions of school staff, the support experienced by the children, perceived by the parents and some of the autistic adults in my study was in some cases more often negative than positive.

Code: support experienced (negative)

Parents P2, P3, P5 and P6 expressed the view that their children either had insufficient support, or that they had had to fight for the support their children were currently receiving. P5 and P6 stated that the process of obtaining a diagnosis and a Statement of SEN was treated like an end in itself:

It feels like with his schooling, the focus is on diagnosing in order to statement or get help for children, rather than finding very tailored solutions for children. (P6, semi-structured interview).

P2 (whose child, C2, did not have one-to-one TA support or a Statement/EHC plan) considered that because her child was well-behaved, he was not thought to be a priority for extra help, while P3 was of the view that her son (C3) was not receiving the support which was stipulated in his Statement. Indeed, although C3 was described by the S2 as being in receipt of one-to-one

support, I did not see him receiving any TA support from my time in school with him (although this was limited), and his interviews with me were conducted without the presence of a TA i.e. none was offered. An extract from my research diary in which I documented the first time I met C3, substantiates a point made by P3 that the support her son needed is perhaps less evident, but nevertheless necessary:

Context: whole class (Year 4) activity of making an Easter card.

C3 was sitting on the floor with some other children (...). He was engrossed in a book. Teacher was explaining to the children sitting on the floor how to make the card. She pulled C3 up several times on the fact that he wasn't listening, and kept asking him to repeat what she had just explained, some of which he got right, some not. She wouldn't let him have a second go at the answer, opening it to the floor, and refusing to take his second attempt. (...) At one point she asked him if the bunny rabbit would look better with the cutting line showing or with it hidden – I knew what was coming. “With the line showing”, said C3. I wondered if the teacher had interpreted this as insolence. C3 was extremely co-operative throughout my visit. He seems very bright. I would have liked to have known about his book – no reference to that whatever from the teacher – she was only concerned about the card-making as far as C3 was concerned. (Research diary, 25.03.2015).

The ‘correct’ answer that the teacher was seeking was that the ‘cutting line’ should be hidden on the final version of the card, but this was almost certainly either misunderstood by C3 (who may have not known what she meant by ‘better’), or indeed he might have been of the view that the appearance of the card was enhanced by the line being visible. In addition, his deep concentration on the book – such focus being very typical of how autistic cognition functions

– is perceived by the teacher as an unwelcome distraction, which she chooses to ignore. In this case, C3 is clearly more or less coping in class, but there is a lack of understanding of how his autism might impact on his concentration, perceptions and responses, as well as how to harness this to his educational advantage.

Therefore, the negative conceptualisations of support expressed by parents were not due to its quality, but rather because of the difficulties in obtaining this input. Similarly, autistic adults AA1, AA4, AA6, AA8 and AA9 expressed the view that they received insufficient support in school, particularly if they were deemed to be coping well academically. In addition, inflexibility on the part of teachers is considered to make life more difficult for autistic children:

The worst ones were the ones who insisted I had to do things in a prescribed manner, like ‘now’. The more rigid the teacher, the more I struggled. (AA9, semi-structured interview).

As far as the children were concerned, C1, C8 and C10 were all observed by me to be experiencing their support in a negative manner at times. For C1, this consisted, for example, of not being allowed to choose, despite being taken to his ‘choosing board’, while C8 and C10 had to navigate poor planning, unclear or confused communication, lack of or too much attention, as well as insensitivity on occasions.

Examples:

1. Can’t quite hear what C10 is saying, but he is talking to TA14 about something else (think it is related to a child)

C10: *Don’t tell anyone about this* (recounts something to her in a whisper)

TA14: (loudly) *Oh the book from the library!*

C10: (putting his finger to his mouth and looking around him) *sshhh*

C10: (continues shushing her) *It's secret.* (C10, unstructured observation).

2. **Context:** C8 is engaged in a whole class activity sitting on the carpet. The TA is seated next to her and is repeating to C8 all of the questions asked by the teacher, as well as asking her supplementary questions.

C8 looks irritated by the TA because she is listening to the teacher and the TA distracts her by talking to her. (...) Mild sign of irritation from C8 towards the TA. (C8, unstructured observation, C8).

iii. Effective and Ineffective Support

Support was found to be most effective when it was accompanied by a low level of physical or verbal prompting. For example, AA9 said that she responded best to teachers who let her be herself:

When I was at school, the teachers I worked with best were the teachers who took a relaxed approach and allowed me to do things in my own way. (AA9, semi-structured interview).

Similarly, I observed the most constructive support from school staff to be when the child was able to take a certain lead and for this to be encouraged and validated:

He then chooses a red pen and guides the TA's hand again. TA1 v encouraging "beautiful" – this really is perfect support. (C1, unstructured observation).

TA4, TA7, TA9, TA13 and TA15 all showed evidence in their interviews of some strong teaching techniques as well as understanding the specific requirements of the individual children they were supporting. TA7 emphasised the importance of flexibility of support,

asserting that she would take her lead from the child in this regard: some days he required much more support than others. Meanwhile, TA13 considered, like some of the parents, that the personal relationship with the child was key. T3, unlike her colleague T4 who I had observed during the Easter card-making exercise, was firmly of the view that she should follow the lead of the autistic child in her class (who was not a participant), and she had devised a number of teaching and assessment materials which were based around his interests, a crucial point which will be explored more fully in a later theme.

On the other hand, lack of effective support on the part of school staff was observed or evidenced during interviews in relation to C1, C4, C7, C8 and C10, at least some of the time. Meanwhile, C5 and C9 appeared to have good quality support most of the time, but C2 and C3 did not have sufficient TA support. The issue of ineffective support is most fruitfully evidenced via two key observations with C1 and C10, who were seen to have the poorest support amongst all of the children in my cohort. The extent to which they might be considered ‘typical’ or ‘representative’ might be questionable, although they serve to highlight some important issues which may well be more widespread. Furthermore, the examples shown here were, to an extent, ‘typical’ of the support provided to these particular children.

Example 1: Writing activity (C10; TA14) (Year 4). Unstructured observation

Context: C10 is with the whole class, seated at a table with five other children, TA14 is next to him. The activity consists of copying some writing from their exercise book onto a ‘leaflet’ they are making. C10 is not a native English speaker, and his own language involves a different script, which during another writing activity I had observed earlier, he sometimes confuses with English script.

TA14 is sitting drawing lines onto C10's leaflet (...) C10 has nothing to do during this and waits patiently, though he is a bit fidgety. Class v noisy. (...)

TA14 then starts copying the sentences from his exercise book onto a small whiteboard. C10 rocking. TA14 continues to copy a paragraph from C10's exercise book onto his whiteboard, asking him for clarification on certain points. C10 is not given anything to do while she is doing this. C10 fidgeting. (...)

TA14 asks him for clarification on another part of the leaflet, the 'fact file', but the TA doesn't know the facts herself (they are relatively obscure). (...) They spend quite a long time trying to sort out what is true and what isn't, but they don't have the original text in front of them. (...)

TA14 finishes the few sentences on the whiteboard and asks C10 if he would like to copy them into his exercise book first. He says "yes, yes, yes, yes etc." but this is clearly not a genuine answer to her question i.e. he is bored and irritated.

Faffing about looking for pencil. (...)

C10 then expresses his confusion about having to copy from the whiteboard rather than directly from his exercise book, as the teacher had requested. The TA has also left out one of his sentences, saying it is not needed in the context, and C10 is not happy about this.

C10 makes to start writing but creates diversions such as saying he wants a break, putting his head on the table, saying he is hungry etc. (...)

C10: But I'm hungry. It will take too long. It's killing me. It's annoying. It's annoying me.

C10 continues to carry out the activity of copying sentences very slowly, stopping often and complaining.

He writes a couple of words, but stops to talk about someone coming to his house. He writes very slowly, stopping a lot. He makes verbal stims. He is completely unmotivated.

C10 (after one sentence): *I can't. I'm so hungry.*

Continued verbal stimming. Rocking. Humming and chanting lines from action hero videos.

(...)

Very slow from C10, virtually a letter every few moments. C10 turns to the video and makes an 'argh' face.

TA14: (tapping leaflet) *Excuse me. Rebecca doesn't want to see your mouth.*

After 17 minutes, C10 has copied the three sentences and so has finished.

C10 (picking up leaflet): *Here it is.*

TA14: *Full stop?*

C10: yes (he hasn't done one)

TA14: *No*

C10 writes one in.

(...)

TA14: *now what you can do is copy it into your book.*

TA14 finds a clean page in C10's exercise book and makes it clear that he has to copy the sentences he has written on the leaflet *back into* his exercise book (where C10 had written them initially).

C10: *Oh no.*

C10 complies with this request, but continues to demonstrate much frustration and boredom. TA14 offers C10 the reward of doing a drawing when he has finished, an activity he usually enjoys.

C10 writes, pauses, rocks, hums

TA14 (quite audibly to another child): *Your writing is absolutely beautiful.*

TA14 (continuing): *I like the way it flows, it's so neat.* TA14 continues to talk to the other child. *It's lovely though.*

C10 finishes – it has taken him nearly 30 minutes to copy three sentences twice.

C10: *Done.*

TA14 (to C10): *Have you finished yours?*

C10: *Yes*

TA14: *Excellent*

C10 says he doesn't want to draw

In an interview earlier in the week during which T14 was present, C10 had stated how much he liked using computers. However, during this observation I learned that while some of the children had carried out this activity on computers, C10 had not been given this option.

Example 2: Class Reading activity with C1, TA1 and T1 (Reception). Structured observation.

Context: Whole class Reading activity; the rest of the class is on the carpet with the teacher.

C1 is seated apart at a table with TA1 (C1 is on her lap), with a different book from the one T1 is using with the class. C1 does not want to comply with this activity.

Duration of activity: 2 minutes 20 seconds. This structured observation was analysed using event sampling.

| | |
|--|---|
| Number of times child attempts to leave activity | Is struggling to leave throughout. 21 = attempts to leave or reject activity. |
| Number of times staff member gives verbal prompts | 34 (Grouped prompts counted as 1 e.g. <i>wait, wait, wait</i>). |
| Specific verbal prompts if given | <i>Look, look at the book, wait, open, No, turn the page, butterfly, you need to look at the book, what's that there? one, two, shut the book, looking, put the book away.</i> |
| Number of times staff member gives physical prompts during activity | Throughout – fully physically prompted apart from when putting book away. 17 separate ones identified, although the physical control did not cease until the end. |
| Specific physical prompts if given | Picking up from behind, sitting child on her knee, stopping the child from sitting on the floor by pulling him up to standing or to her knee, moving his hands, attempting hand over hand, pointing, pushing. |
| Number of times child exhibits any signs of aversion to task | 39 (physical, verbal, non-verbal) |
| Specific signs of aversion to task if shown | Whining. Says <i>want to go out</i> (not heard/understood by TA); <i>out</i> ; shaking his head (i.e. 'No') Physically struggling, trying to close the book, trying to get away from the table, falling onto the floor (on knees), physically holding onto the book so it can't be opened, pushing TA's hand away from book, throwing head back. |
| Number of times child exhibits any approval behaviours | Only when putting book away – total independence. |

| | |
|---|--|
| Specific approval behaviours if shown | Puts book away by walking across the classroom unprompted and places it on correct pile, even re-adjusting it when it is not quite straight. |
| What follows this activity? | TA gives up after 2 mins 20 secs. Child then goes and puts the book away entirely unaided, without any physical prompting. |
| What is the child's behaviour immediately after this activity? | Child is calm. |

The ways in which support was experienced by the participants, and the children in particular, needs to be considered in the context of the extra duties the school staff had to carry out.

Code: Support given (extra duties)

During interviews, the TAs often referred to themselves as ‘the teacher’ and their activity as ‘teaching’, and indeed it was the case in a number of instances that the TA was expected to both provide the content and devise the learning techniques for the children they were supporting. One of the consequences of this was that the TA who, unlike the class teacher, did not benefit from paid preparation time, would clearly be making something up on the spot for the autistic child in order to give the appearance of a differentiated curriculum activity. This also meant that the autistic child received very little direct input from the qualified class teacher. Indeed, on the few occasions when I did observe direct attention from the teacher, it was always positively received by the child who was also seen to benefit from the superior pedagogical skill of the teacher. In addition, the TAs were often asked to support small groups at the same time as providing one-to-one support for the child to whom they had been allocated. Furthermore, during my observations, the TAs were frequently interrupted by demands from other children, or the teacher would ask them to take a small group of children with diverse needs, including the autistic child, to another location to do some focussed work. However, it

was also clear in some instances at least that the class teacher was expected to provide a very high level of differentiation in classes containing children of a range of abilities, from diverse multi-cultural backgrounds. This was particularly evident in the large community primary school (School 4), in which, according to D4, 53 languages were spoken, for example. Most lessons for the core subjects of Maths and Literacy involved the children being divided into groups according to ability, meaning that the teacher had to provide different learning materials and targets for each group.

Discussion

My findings for the theme of ‘support for children’ are represented graphically in Figure 11.

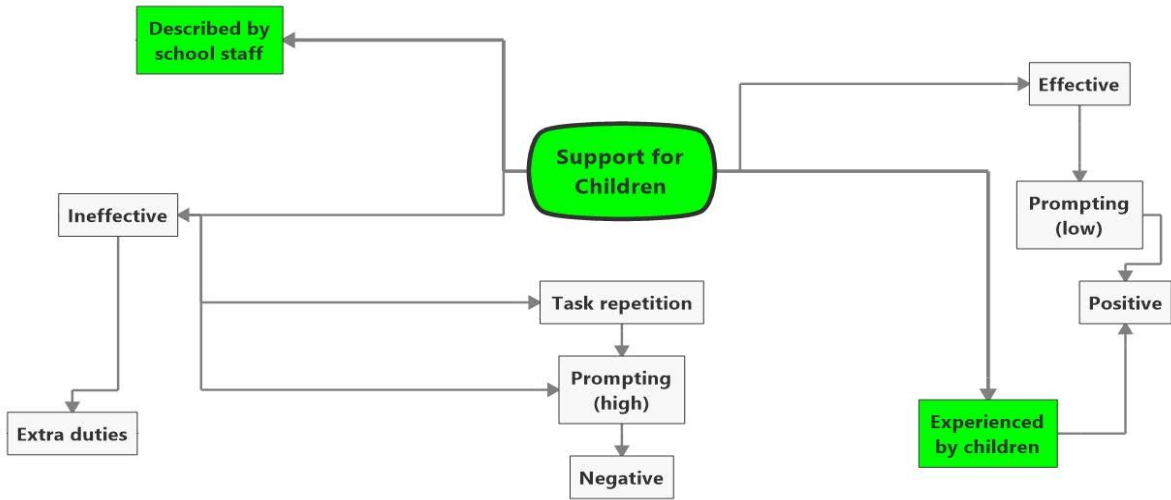


Figure 11: Support for children

In my study, there were examples of effective support which impacted positively on the children, and these appeared to be typified by flexibility on the part of the staff member, as well as enabling the child to take a certain lead in the activity. The provision of emotional support, which the availability of a dedicated TA might furnish, was also appreciated by some of the

children. It was also the case that my own data collection was facilitated considerably by TAs who had a good relationship with the child, and a sensitive understanding of their needs.

However, there are nevertheless some clear divergences between the rationale for support in relation to the autistic children as understood by school staff and the ways in which it was experienced by some of the children in my study, of which I have only been able to include a few examples here. These appear to defeat the very purposes for support as expressed by school staff. For example, while school staff identified keeping the children on task as the most important priority, the children were distracted by unnecessary, additional questions, or asked to carry out repetitive, demotivating activities. Similarly, they might be asked to complete tasks in a different way to their classmates, with no evident justification, also impacting negatively on the second most important priority identified: curriculum access. The patience – and so behaviour – of the children was tested as they were made to engage with poorly planned activities in which they are patently not interested (or even, to which they might have a justifiable aversion). The ‘material’ support identified by school staff was rarely observed to be of any real use, consisting instead of rather pointless ‘special needs’ paraphernalia and apparatus such as white boards, visual timetables and timers. These issues resulted in the children being distracted and demotivated, meaning that they required a high level of prompting, thus undermining another important priority: independence. Indeed, the ability of the children to have confidence in their own choices is contradicted by being subject to a high level of control, taking little or no account of their views.

These examples are all, to a greater or lesser extent, characterised by a lack of clarity of instructions and poor communication generally. Goals are unclear and activities at times give the appearance of teaching and supporting, when little or none is in fact taking place. Here, the school staff are highly directive and largely ignore either the spoken or non-spoken

communication of the children, overloading them instead with instructions and limiting their self-expression. The support from the school staff also serves to separate the child from the rest of the class and mark them out as different, and make it more difficult, not easier, for them to socialise. Other difficulties included the unnecessary labelling of items to give the appearance of teaching communication skills, or TAs struggling themselves with Reading or Maths activities with which they were supposed to be helping the children. Teachers and teaching assistants switched between phonetic and non-phonetic spelling of words during the same exercise, and when ‘sounding out’ words phonetically, did so incorrectly on occasions. Some school staff, while attempting to support autistic children whose first language was not English or who had speech difficulties, struggled themselves with English pronunciation, word-order and spelling. C4, who was not as advanced as the rest of his class in Writing, was given writing activities in a separate location while sitting on the floor, meaning that he was unable to sit comfortably while doing so, thus delaying further his pencil skills.

Above all, the two main difficulties observed in relation to the support the children received were over-prompting and task repetition. As the example with C1 above demonstrates, the younger children in particular could be subject to very high levels of physical and verbal prompting when they would not comply with the activity in hand. However, this non-compliance itself was at least in part due to the problem of task repetition. With the example of the bear-matching exercise carried out by C1 mentioned earlier, for example, I was informed that he would be asked to do this three times a day, for at least ten days, even though he had done it correctly the first time. If on one occasion he refused to match the bears, he would be asked to do it an extra time the following day. Similarly, C4 was provided with a ‘box activity’ once or twice a day, but he carried them out so swiftly, it was clear that he had done them a number of times before, and so their educational value was negligible. Indeed, it was in

situations where the children had been provided with especially made, differentiated materials that they were most likely to be asked to do them again and again, without them being changed or updated for weeks or even months. Moreover, while P2 expressed a concern that her son's targets had not been changed for months, P9 considered that repetition was an important and useful technique for her child. Similarly, TA5, T4, T5 and T9 all stated that repetition was a valuable teaching tool for autistic children.

Moreover, the same staff member could demonstrate both effective and ineffective support towards the same child, depending on the particular circumstances of the learning situation. Therefore, the important question does not concern the inherent abilities or lack thereof of school staff, but rather to consider what the circumstances are in which staff members are more likely to be able to demonstrate skill and to be effective in their support. As we have seen, activities invented on an ad hoc basis with little attention to their educational value or to the interests of the child were unlikely to be successful. Tasks which required a lot of repetition were especially unproductive, leading to a high level of prompting which threatened to overwhelm the child. On the other hand, well-planned, motivating activities with a sensory component appeared to work well for the autistic children, enabling them to engage independently and thus requiring little prompting. However, the demands placed on school staff could be high, with TAs expected to fulfil a multiplicity of roles, and teachers needing to prepare different activities for a diversity of learners, thus presenting a considerable barrier to the planning of accessible and intrinsically motivating learning tasks for the autistic children.

Theme 2: School Curriculum

Perhaps unsurprisingly, the support the children received in school, and the ways in which this was experienced by them, is closely linked to the second theme of the school curriculum, and how or whether the autistic children accessed this and specific issues which emerged in relation to certain subjects. As was indicated by the secondary data analysis which formed part of the literature review, autistic children in primary schools appear to be performing poorly in the subjects which are measured, and there are also indications that some do not participate in tests, meaning that it can be difficult to ascertain their progress. Consequently, I focussed on the core subjects for which data from the DfE are available: Phonics, Reading, Writing and Maths.

Subject 1. Code: Phonics

The most striking finding from the secondary data provided by the DfE was that significant numbers of autistic children are either not reaching the expected standard in Phonics or are not even present in the statistics. This finding was certainly substantiated in my own study: school staff asserted that C1, C2, C4, C7 and C10 were not able to access Phonics at all, while C5 had been delayed in starting this subject. S1 and S5 were of the view that Phonics was intrinsically difficult for autistic children because they are unable to sound out words. T6, when referring to an autistic child who was not a participant, stated the following:

He hated Phonics and he didn't learn like that at all. But he passed his Phonics test.

(T6, semi-structured interview).

TA2, TA15 and T3 pointed out that the children they supported read via 'whole word recognition', and so the sounding out of words was unhelpful and unnecessary. D5 was of the view that the stumbling block for some children is the necessity to acknowledge non-words, which he suggested not all would be able to accept. In addition, T5 asserted that because

Phonics teaching is usually delivered through carpet time, this is intrinsically exclusionary for autistic children who often struggle to sit still on the carpet. Indeed, during my time in the schools, the autistic children rarely sat on the carpet with the rest of the class during whole class teaching activities, which tended to be delivered in this way. In addition, as we have already seen, school staff – perhaps especially those who did not learn to read via Phonics themselves – were observed to be confused about the phonemes they should be using in relation to sounding-out words, which might be complicated further if the staff member had an uncertain grasp of English.

Subject 2. Codes: Reading; Support (effective); Ability; Autism; Social.

A number of difficulties were raised in relation to Reading for the autistic children and adults in my cohort. T9 and T12 stated that the reading levels of C7 and C10 were well below average. P5, S5, T4 and TA9 all considered that the autistic children struggled in Reading due to an inability to make inferences, a key requirement in the higher level Reading assessments. During my time in schools, C2 and C10 were observed to be focussing on different aspects of the narrative of a book than those emphasised by the school staff supporting them, with C10 complaining that “dinosaurs don’t exist” when reading a book recounting the adventures of a cartoon dinosaur which was somewhat personified. AA5 informed me that he had needed additional support for reading in school, while AA7 said that she had had a negative experience of reading at school due to having to read out loud in front of the class.

Despite this finding, all of the autistic children in my study either asserted that they enjoyed reading activities or were seen to be engaging positively with them during my data collection. C7 had a preference for books which did not contain too many words:

The only thing I don't like there's too much words and too much words is in the books.

(C7, semi-structured interview)

C9, who had a strong interest in numbers and Maths activities, was perhaps the most mixed in his views about Reading:

RW: *Do you like making up games with numbers?*

C9: *Yeah. I'm not so crazy about letters.*

RW: *No, numbers are better than letters are they?*

C9: *Yeah* (C9, semi-structured interview)

T11, the teacher of C9, said he only enjoyed reading if he could choose the book himself:

It (...) has to be his choice of reading. He's happy to read anything if he goes and picks it, but he's not interested if the adult has chosen. (T11, semi-structured interview)

C5 was considered to be a 'high level reader' (T7) and his mother cited an interesting example of when his reading skill had provided evidence of his general ability during his diagnostic assessment for autism:

They wanted C5 to put red blocks and green blocks in the actual boxes, but C5 was getting a bit confused, so I said to them, "look, I've got a pen" and I wrote the words red, blue, green on just random pieces of paper and put them down and I said "C5, could you put the word 'red' in the red box?" and C5 picked up the word red and put it in the red box and he done it that way and they were like "wow he can read" and I'm saying, he could read from a young age, just because he's non-verbal doesn't mean he doesn't understand. (P5, focus group 2)

P6 expressed a similar view with regard to her son, C6:

His Reading is very good – his Literacy is very high – so I think to some extent it's been an advantage – it's been a chance for him to sit down and just show what he knows and how well he understands. (P6, semi-structured interview)

C10, who was shown in the previous sub-theme to be struggling with a highly repetitive and rather dull written activity, was observed to respond much more positively to a reading exercise when the topic was one which interested him greatly. He sat reading from a newspaper for about ten minutes without any input at all from a TA, during which another child started talking to him and tried to find other articles which she thought might interest him.

AA9 had found Reading relatively easy in school, and AA2, AA3 and P3 all considered that Reading should be a priority in school. Further, as part of the process of familiarisation with all of the children, I took with me a range of books relating to common areas of interest for autistic children (dinosaurs, planets and animals), as well as with a high level of visual content. These books were very well-received, with comments such as “wow” (C7) and “that’s pretty cool” (C3) serving to exemplify this. Moreover, these books also fulfilled a secondary purpose (which had not been my original intention): to gain some insight into how the autistic children responded to Reading as a subject in school. Indeed, C1, C2, C3, C4, C5, C8, C9 and C10 were all observed to engage positively with books at different times, in all cases when they had chosen the book themselves.

Subject 3. Codes: Writing; Autism (sensory)

C1, C4, C5, C7 and C8 enjoyed Writing, while C3, C6 and C9 said that they liked it some of the time only. T10, the teacher of C8, said that she “loves her writing” and it was obvious from her exercise book that she took considerable pride in producing neat written work, decorated with drawings. However, it is helpful to distinguish between the physical act of writing – the

fine motor skills required – spelling, and the content of the written material.

AA6 stated that she had been quite delayed in comparison to her peers when learning to write and AA9 asserted that she had “terrible” hand-writing. C2 (aged five) was unable to write, while C1 and C4 (both aged 4) engaged in pre-writing activities, such as mark-making and colouring in: all were behind their peers in this respect. C3 was considered to have very poor hand-writing, and C5 was described as being slow to develop writing skills. S4 expressed the view that children can be disadvantaged if they cannot write well (in terms of demonstrating their ability), and T12, the teacher of C10 considered that he was unable to match his verbal skill in writing:

He has good ideas verbally, but he cannot implement them on paper. There is a huge gap between what he can express verbally and what he can write. (T12, semi-structured interview)

As has been seen already, the support C10 received in relation to his hand-writing was quite poor, and there were other instances when he was expected to engage with writing activities which had clearly not been planned and which lacked any kind of interest, such as asking him to repeatedly copy words randomly selected. Moreover, school staff did not appear to notice that at times C10 was mixing up the script of his native language with the English alphabet, and so he was not offered any guidance with this. Meanwhile, C9 said that he felt his hand-writing was poor, and C6 had an additional physical condition which meant that he struggled with fine motor co-ordination. Other autistic children were described as having a poor pencil grip and SENCOs considered that they lacked input from Occupational Therapists to help with these issues.

However, AA8 said that she had been particularly good at written work and she had always found spelling quite easy, meaning that a new, high ability spelling group was created for her

in class. C5 also said that he liked spelling and he demonstrated this by ‘testing’ my spelling on a couple of words during our interview, a sign of his confidence in this area. On the other hand, AA9 said that she had been very poor at spelling tests and C7 said that he didn’t enjoy them. Further, there was some evidence that Phonics can create confusion in terms of spelling, as the following example, taken from a class activity indicates:

They are writing words ending in ‘ble’ on individual white boards. C8 is struggling with writing the word ‘bible’ which she keeps writing ‘biblble’. The TA is trying to help by getting her to read out loud what she has written, but this approach doesn’t work – she keeps getting it more and more wrong, e.g. writing ‘biblbbble’. (...) The TA abandons this word and asks her to write ‘bubbles’. TA is asking her to sound out the letters/words i.e. approaching it phonetically – although at one point the TA does say ‘double b’, which C8 understands. C8 gets this word right. (TA generally mixing in phonetic and non-phonetic approach e.g. she says ‘kuh’ for ‘c’. (C8, unstructured observation)

C9 and C10 both said that they prefer typing on a computer to hand-writing, and TA9 stated that C5 was good at typing. His mother also asserted the following:

C5 is only just learning to write, and there’s the big focus in write, write, write, C5 can spell fabulous on the computer, he does everything, all his homework, all his...on the computer at home. Now I’m finding it hard with this, with mainstream is that why can’t C5 do everything on the computer? (...) ...but some teachers are no, he has to learn to write, he has to learn to write...I’m not being funny, emails, twitter, everything is done on a phone or everything is done on a laptop or an iPad. I just don’t understand why they’re always focussing on C5 to...C5 doesn’t like writing he does it at a push (...) I just find if you just let him on the computer to do his work or give him an iPad to do his

work, it would be so much quicker, he'd sit there and be a lot calmer, but it seems like with the curriculum, they have to learn to write. (P5, mother of C5, focus group 2)

An additional difficulty which some of the autistic participants experienced in relation to writing was dealing with the content of the tasks which had been prescribed. AA1 asserted the following:

Writing mini essays and accounts of school trips or what I'd done at the weekend seemed like a pointless and never-ending waste of my time. (AA1, semi-structured interview)

Similarly, AA4 said that he was good at comprehension and grammar, but “making up stories was beyond me”. Meanwhile, C9 and C10 were both described by school staff as experiencing difficulties in sticking to the topic asked for, and some teachers said that the autistic children particularly struggled with open questions, or writing at length. T10 said the following about an autistic child in her class who was not a participant:

His writing has become more and more dominated by his preoccupations and obsessions. I worry that his writing might become more and more strange, and less interesting. (T10, semi-structured interview).

Similarly, C7 was described as having an aversion to the lower case ‘d’ and so he avoided writing this. In addition, both C6 and C8 disliked crossing out their work, which they were expected to do when they made a mistake.

Subject 4. Codes: Maths; Support; Autism (sensory/zoning out)

Autistic adults AA2, AA3, AA4 and AA10 all stated that Maths should be considered a core subject in school, a view shared by P3. However, AA8 had struggled with Maths, a difficulty

she felt went unnoticed because she was generally considered to be bright. AA9 also stated that she has “a certain amount of number blindness”, and has the following memory from her time in primary school:

I know that I had a massive, massive meltdown at home because my mum bought me a times table book. I shredded it and then afterwards, I felt bad because I had shredded a book. (AA9, semi-structured interview)

P1, P2 and P8 asserted that their child’s Maths skills were weak, and T7, T9 and T12 all said that the autistic children in their class struggled in the subject. T9 said that the difficulty with C6 was his inability to estimate, and that he insists instead on trying to ascertain the precise number or amount. TA11, the TA of C6, also said the following in relation to his approach to Maths:

He has a set way of doing things, like if he’s asked to do a Maths problem a different way from the way he likes to do it. He wants to do Maths problems his way. (TA11, semi-structured interview)

T10, who had two autistic children in her class, one of whom – C8 – was a participant, said that they both would become distressed if they were unable to get the answer right, a view which was substantiated during my time with C8. Indeed, C8 was the only child who asked me to delete some of my video footage which showed her making quite a few mistakes in Maths, a request with which I complied (and so this footage does not form part of my data). C10 also struggled in Maths, a subject in which he was also not very well supported, as the following extract from an unstructured observation of a Maths activity shows:

Context: C10 is sitting with TA15 at a table in the corridor outside the main classroom. TA15 is drawing times onto some blank clock faces, asking C10 to say the time and then write this underneath the clock in his book.

Child comes out of classroom and distracts TA as she is helping C10 with the next question. She talks to the child for a bit. C10 is distracted too. Time is 7.30.

C10: *It's 8 o'clock.*

TA15 tries to explain but is again distracted by some children coming out of the class.

C10: *Half past 8*

TA corrects and then C10 gets it right.

(...)

Another child distracts in the corridor.

TA is sticking more clock faces into his book. C10 looks bored and unmotivated. TA says that they are going to do two more which will be the last ones.

C10: *Phew!*

C10 gets the next one right.

RW: *Roughly how long had you been doing this before I came?*

TA15: *About 50 minutes*

Given that telling the time is a learning activity which is first introduced in Reception and is generally repeated throughout the school for children who have not yet mastered this skill, one can only imagine how many times C10, now near the end of Year 4, must have carried out tasks

with clock faces. Indeed, in this situation, and notwithstanding the several interruptions during this activity, the TA was showing some adept teaching techniques, such as breaking down the questions and providing careful explanations and additional prompts. However, the key issue of the motivation of C10 was not addressed, especially as this repetitive and protracted task was allied with the much-disliked handwriting. Similarly C1, whose Maths activities consisted predominantly of highly repetitive shape and colour-matching, almost always refused to carry these out when I observed him, meaning that he was all the more likely to be presented with them again.

However, there were some circumstances in which some of those very children who were deemed to not enjoy Maths, or who I observed to be finding it difficult, were able to engage more positively with the subject. For example, C8 clearly enjoyed a Maths activity when she was seated on the carpet with her classmates in a session run by a skilled trainee teacher who was able to judge how to involve her. This activity was also underpinned by strong visual supports and was at a level C8 could access with relative ease. Similarly, while C1 was observed to be subject to a high level of prompting – due to his complete aversion to the task – during the bear-matching activity described in Outlier 1 (pp. 182 - 184), this was almost completely reversed in the following Maths exercise involving placing coloured plastic animals in different bowls:

| | |
|---|--|
| Total duration of the activity | 3 minutes. |
| Number of times child attempts to leave activity during 3 minutes | None. He resists when the TA tries to pull him away to go to his 'choosing' board. |
| Number of times staff member gives verbal prompts during 3 minutes | 14 |

| | |
|--|---|
| Specific verbal prompts if given | <i>Look, green, where does the green go, in here?, red, what's this?</i> |
| Number of times staff member gives physical prompts during 3 minutes | 7 |
| Specific physical prompts if given | Pointing, showing (at end – pulling away from table). |
| Number of times child exhibits any signs of aversion to task during 3 minutes | None – apart from at end when TA tried to pull him away. |
| Specific signs of aversion to task if shown | None to the physical items. The TA places a green animal in the green bowl, which he removes. When she tries to pull him away from the activity, he resists and shakes his head. |
| Number of times child exhibits any approval behaviours during 3 minutes | Very difficult to count because he is engaged contentedly throughout. During 3 minutes = 30 |
| Specific approval behaviours if shown | Child is calm, relaxed and engaged. Day dreams (i.e. seems to be zoning out/relaxing). Self-directed, self-organised, standing up to reach animals and sitting down again, readjusting position of animals, making them 'walk'. |
| Number of times child engages in a different activity (but remains in place) during 3 minutes | None |
| Number of verbal and non-verbal communication attempts during 3 minutes | None – apart from when TA tries to end activity. |
| What follows this activity? | Taken to the choosing board to 'choose' the register card. |
| What is the child's behaviour immediately after this activity? | Whining, physically resisting, flopping. |

During this activity, and unlike the Maths activity described on p. 183 and the Reading exercise on p. 205, C1 is seated at the table with the TA by his side, rather than on her lap. The physical prompting is greatly reduced, and her instructions are a guide, rather than pleas for conformity. Indeed, in marked contrast to the exercise with the matching bears, the only difficulty arises when she tries the end the activity, because C1 is evidently gaining pleasure from it, and does not wish to 'choose' the register card.

In a similar activity, C4 (who, like C1, was aged 4) was observed to engage very contentedly with an early Maths skills activity involving putting pegs in holes, which he tackled with great care, concentration and in silence, as C4 had done with the plastic bears exercise. Furthermore, C2, C5, C6 and C7 all stated that Maths was a favourite subject, and AA4 said that he had found Maths easy at school. Moreover, AA2 had been considered to be gifted in the subject. However, it was C9 who showed the most striking interest in Maths and numbers generally, which he brought into all of our conversations. Here he is describing one of the many imaginative games, predominantly of his invention, which he played with his friends during break times:

Yeah, yeah, yeah. And Harry Potter. We don't play that so often but it's on um.... every Friday. And there's another game called Croatian and if we defeat 10 zombies we get 10 more power. And, and if we defeat 20 we get um 30 more power and if we defeat 30 we get 50 more and the best...um....that's very rare, the rarest game, we do it every 18th anything, like 18th of January, 18th of May, 18th of December, 18th of...June. (C9, semi-structured interview).

C9 also told me that he particularly liked fractions:

...thing about Maths with fractions, and I really, really, really, really, really, really (pronounced 'weally') like it! (C9, semi-structured interview)

C9, who benefitted from a class teacher who had a very relaxed approach to his particular dispositions (tolerating, for example, an occasion when he changed all of the practice clock times in the classroom), would sit apart from the other children when he felt stressed and make up number puzzles in order to try to regain his sense of equilibrium. This self-calming technique, as well as his strong fascination for numbers, appeared to be understood, accepted and valued by the class teacher and his peers alike.

Discussion

The theme of School Curriculum is represented graphically in Figure 12.

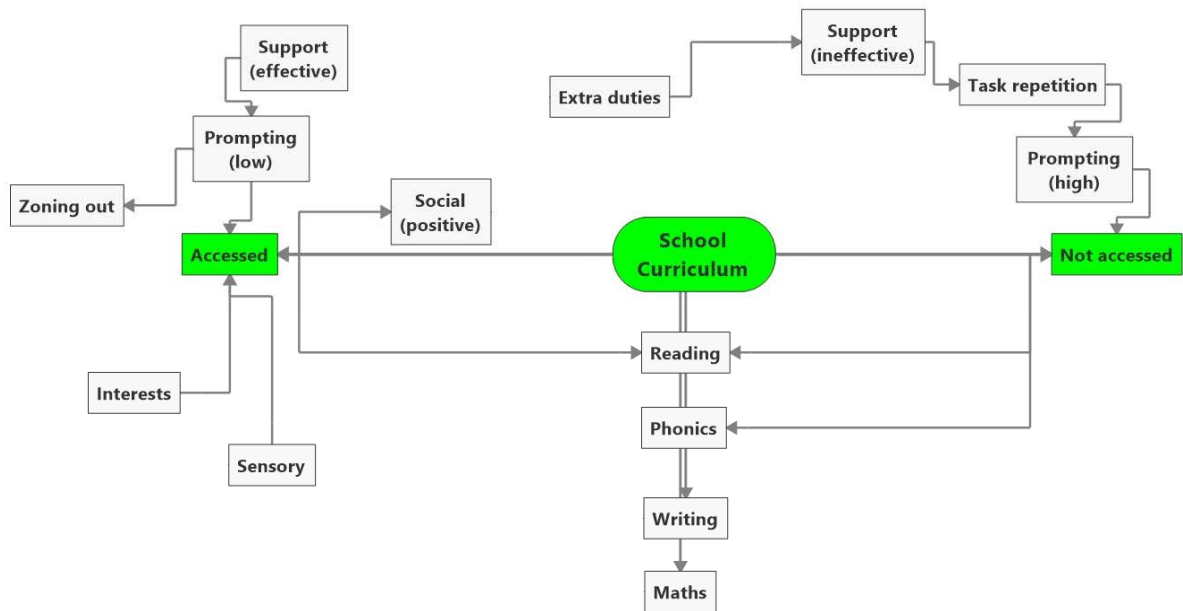


Figure 12: School Curriculum

My findings in relation to the core subjects offer explanations for why autistic children might find them difficult, as well as provide insights into the factors which typify better engagement, achievement and enjoyment. However, the very nature of Phonics, with its emphasis on sounding out words, some of which might not even be words, appears to be contrary to the ways in which some autistic children learn to read, and even create difficulties in spelling. Further, Phonics is typically taught with all children seated on ‘the carpet’, a format autistic children may find difficult, due to sensory issues which make close proximity to large groups of people uncomfortable for some. Allied to this, TAs themselves – who may well be the autistic child’s primary teacher - might have an uncertain grasp of Phonics, especially if they learned to read via another method.

Meanwhile, all of the children at some point exhibited evident pleasure from looking at books, especially those with a high visual content and linked to their interests. In these circumstances, much less prompting is needed from the TA, perhaps creating more social opportunities for the autistic child. For some, Reading was an opportunity to show their understanding and skill, while others fell foul of the requirement to make ‘inferences’ at the higher levels of the subject. In some cases, there appeared to be a genuine inability to envisage what might happen next in a narrative, but for most, however, it was more a case of using different information to make alternative, unanticipated predictions. However, these unanticipated predictions were not considered valid by school staff. In addition, problems can emerge when the adult supporting the child is over-directive with the reading activity, especially if also attempting to dictate what should be of interest and how the narrative should be interpreted. It might be the case that autistic children, especially those who have the support of a TA, are less likely to be allowed to choose their own books, as reading materials are dictated by a sense of their ‘needs’ rather than their interests, which are presented as problematic in this context.

The physical process of hand-writing seemed effortful and difficult for nearly all of the children, but only one child (C6, who had an additional physical disability) was provided with an option to use the computer instead. However, the youngest children benefitted greatly from the sensory approach to hand-writing activities, being provided with brightly coloured, thick felt-tipped pens they could pick and choose, white boards they could wipe clean at will, as well as items to colour in which corresponded with their interests. The defining characteristics of the pegs activity with C4 were the freedom to place the pegs in a pattern of his choosing, as well as the bright colours and sensory appeal of the items. These circumstances resulted in minimal input from the children’s TAs who clearly gained vicarious pleasure from the children’s enjoyment of these activities. However, there was no equivalent for the older children, who might be

presented with profoundly unmotivating copying exercises, causing genuine distress to the child. In addition, and in some cases at least, the topic the autistic child wants to write about is at odds with what is prescribed by the teacher or the requirements of the curriculum, with aversions and preoccupations creating additional hurdles at times.

Maths appeared to be easy and highly enjoyable for some of the autistic participants, while others found it difficult. In addition, T12 informed me that as the children progress through school, they are expected to demonstrate gradually less reliance on physical items such as bead strings and number lines, a situation which could put autistic children with sensory needs at a disadvantage. Just as C1 and C4 engaged well with early Maths exercises when they were presented via varied sensory items (as well as other circumstances being in place, such as low prompting), it might be the case that older autistic children could benefit from this also, without it necessarily carrying connotations of low ability. Furthermore, C9 was a particularly interesting case in this regard, as he was clearly experimenting with numbers on a level that was well beyond the demands of the curriculum. However, as he was classified as a child with ‘special needs’, he was deemed to require support for his difficulties only, and not his strengths.

While it is difficult to generalise about what might aid curriculum access for autistic children in primary schools, it seems evident that more imagination, choice and flexibility is required. When the children were able to engage with the subjects, the consequent reduction in TA prompting was very marked, leading in turn to better social opportunities for the children, amongst other benefits. Furthermore, part of the children’s enjoyment of the activities appeared to derive from being able to ‘zone out’, arguably a necessity afforded other children who are not being heavily prompted by a TA. Consequently, in some cases at least, it is not so much the school subject which might be the problem, but the circumstances under which the children are expected to connect with it.

As we have seen, the question of access to the school curriculum and different subjects for autistic children is complex. Moreover, this issue is governed, to an extent, by broader questions concerning educational priorities, what these might be, and how these decisions are reached. This is explored in the next theme.

Theme 3: Educational Priorities

Codes: Educational Priorities; Social; Future; Mainstream/Special

As explained at the beginning of Chapter 5, the parents of the autistic children, as well as a sample of parents of children with no diagnosed SEND, were issued with questionnaires at an early stage of the data collection. The aim of these, amongst other issues, was to identify what the educational priorities of the parents might be in relation to their children. Parents ranked priorities from the following pre-set list on the questionnaire:

- Making friends
- Gaining independence
- Studying a range of subjects
- Improving knowledge and understanding
- Doing well in tests

As discussed in Chapter 5 (pp. 145 – 148), the results showed both sets of parents ranked improving knowledge and understanding as the most important educational priority, while gaining independence appeared to be a slightly higher priority for parents of children with SEND than for those whose children had no SEND. Further, although making friends was quite an important priority for parents of children with SEND, none of them ranked this as the most important priority, while some of the parents of children without SEND did so.

In the subsequent phase of my data collection, parents of autistic children and the autistic adults were also asked about educational priorities: for their children, for autistic children in particular and for all children in primary schools in general. The answers of both groups of participants are summarised in Table 12.

Table 12: Educational priorities in primary school: autistic adults and parents of autistic children

| | Academic skills (core subjects) | Adapted, alternative or partial curriculum | Independence and life skills | Social skills | Well-being and happiness | Other |
|--------------------------------|---------------------------------|--|------------------------------|---------------|--------------------------|--|
| AA1 | | | | | | |
| AA2 | | | | | | |
| AA3 | | | | | | |
| AA4 | | | | | | P.E. |
| AA5 | | | | | | |
| AA6 | | | | | | Communication skills |
| AA7 | | | | | | Develop love of learning |
| AA8 | | | | | | Develop love of learning, how to learn & about their autism. |
| AA9 | | | | | | |
| AA10 | | | | | | |
| Total AAs | 6 | 3 | 2 | 4 | 5 | |
| P1 | | | | | | Communication skills |
| P2 | | | | | | |
| P3 | | | | | | |
| P4 | | | | | | Communication skills |
| P5 | | | | | | Skills-based learning Learning about differences |
| P6 | | | | | | |
| P7 | | | | | | |
| P8 | | | | | | |
| P9 | | | | | | |
| P10 | | | | | | |
| Total parents | 2 | 5 | 3 | 8 | 4 | |
| Total AAs & parents | 8 | 8 | 5 | 12 | 9 | |

As Table 12 shows, most participants considered that primary schools should provide for a range of social, emotional and educational needs. Only four of the participants - two autistic

adults and two parents - proposed a single priority: well-being and happiness for the former, and social skills for the latter group.

The greatest area of similarity between both groups is in the category of well-being and happiness, where approximately half of the autistic adults and parents considered this to be an important priority in school. Similarly, independence and life skills are not highlighted by many in either group as an area of particular priority in the primary school phase. Parents are more likely to recommend an alternative, adapted or partial curriculum, although given that all of the interviews/focus groups with the parents were conducted in person, while none of the interviews with the autistic adults were, there was more of an opportunity with the parents to explore this particular point.

The main area of divergence between the two groups is in academic skills, which are emphasised more by the autistic adults than any other category, and social skills, which are particularly underlined by the parents as an important priority. Indeed, in the interviews or focus groups, some parents stressed this point repeatedly, with P2, P3 and P6 citing this as a core reason for the educational choices they had made about their children. For P3, the decision to place her son in a mainstream school, rather than a special school, was made for social reasons. Here she describes her visit to the local special school:

We went out into the playground to see the children but they weren't like him (C3) – they weren't very sociable, they weren't playing with each other. (...) These children weren't interacting with each other. (...) The teacher told us that two of the children would be moving to mainstream, and you could pick out the two children. (...) C3 has grown up with lots and lots of friends, always. (P3, mother of C3, semi-structured interview)

P6 said that the decision of whether or not her son would continue in mainstream would be based on “social reasons”, while P7, whose son C7 was in Year 6 and so due to transfer to secondary school, said that she had decided to move her son to the nearby mainstream secondary school because “his friends are all doing so.” Moreover, it was particularly the continuity of friendships that parents considered to be important, both from pre-school to primary school, and from then on into secondary school and beyond: P1, P2, P3, P4, P5 and P7 all made this point. For P3, whose son “is very sociable” and “has a lot of friends”, the key issue was that the children had known him “since he was a baby”. Indeed, P1, P4, P5, P8, P9 and P10 all worried about how their children would cope socially as teenagers, and feared that their children would be mocked or bullied in a mainstream secondary school, “left (...), sitting on his own” (P1), if the other children didn’t know them already. Some parents considered not only that younger children are inherently more accepting, but that the ability to make friends is key to future happiness, and feared that their child’s autism might preclude this.

Consequently, the information provided in the interviews and focus groups differed from some of that derived from the parental questionnaires in relation to the importance placed on friendships. Moreover, while the autistic adults placed a stronger emphasis on core academic subjects in terms of educational priorities, some nevertheless felt that it was important that autistic children should be taught how to socialise in school. Furthermore, the responses of the autistic adults in other parts of the interviews indicated that some had experienced significant social difficulties in primary school which, it could be argued, ought to have been addressed.

Examples:

1. *Well it's not like school teaches you how to be sociable. It's just a sink-or-swim method. I think I floundered. I did well academically but floundered socially.* (AA6, semi-structured interview)
2. *I struggled with joining in social time, play time. I found it very difficult to understand team dynamics. I was very, very sensitive to any kind of criticism. I'd get very upset if my peers said something – I'd get very upset and that would make it happen more.* (AA8, semi-structured interview)
3. *At school, I would be on the edge of the playground, watching the other kids. I wanted to join in, but didn't know how to. I would be jumping up and down and flapping my hands, but I didn't know what to do. If someone approached me, I would freak out.* (AA9, semi-structured interview)

AA1 said that she had no friends at primary school due to her “inability to understand social protocol”, while AA4 referred to his “obvious social difficulties” and AA5 had one friend only throughout his time at primary school. AA10 said that she was afraid of the other children and the teachers, and that her energy was taken up just trying to cope with the noise in school, rather than working out how to make friends. Furthermore, in a similar point also made by some of the parents, AA7, AA8 and AA9 noticed a marked difference between infant and junior school, where in the latter, social relationships became more complex and difficult to navigate, and the children less tolerant.

Nevertheless, as well as emphasising the importance of the core curriculum, the autistic adults also tended to speak in more general terms in the context of educational priorities, such as the need to be taught how to “make sense of life”, “learning to stick with a task until it is completed” (AA10) and getting “the basics” in place (AA5). For AA9, the most important priority was for a child to “get through the school process with their self-esteem intact”, while AA1 felt it

essential that each child is treated an individual, with their particular talents, needs and characteristics nurtured. AA7 and AA8 both considered that primary schools should try to engender an enthusiasm for learning in children, emphasising the point that for this group of participants, the general circumstances of the learning environment and mindset of the children are central issues to address. AA2 also asserted that children should be taught about equality and to be “confident in who they are”, which exemplifies the importance placed on emotional well-being for some of the autistic adults. Moreover, P5 was the only parent participant to suggest teaching about ‘differences’ and disability is needed in schools, implying that it is the other children who need to learn and adapt:

You see the thing is I think mainstream maybe should teach about differences (...) Because I don't think schools do a lot of teaching about differences, not differences....they do a lot of differences about cultures and things like that but they don't do a lot of differences about disabilities. (...) Do you know what I mean? There's no heroes as in a disabled person. You know, you've got your Winston Churchills, but there's no-one saying, but he was fantastic, but he's a disa...do you know what I mean, it's always about typical people and not anything about people...you know...like about the Paralympics and things like that, the Paralympics was on BBC2 and the Olympics was on B...do you know what I mean? You just think to yourself well hold on a minute...this is society. (P5, focus group 2).

Similarly, P4 felt that happiness was a core requirement in school, because “they can't learn if they're not happy, that's a basic”. For P1 also, her son's happiness was the most important priority:

RW: What matters most for you in school?

P1: *Happiness, that's it. Whatever he does, he's happy, then I'm happy.* (P1, semi-structured interview)

Consequently, the category of well-being and happiness also shows some congruence between the parents and the autistic adults (some of whom were parents themselves). In addition, while some of the autistic adults emphasised the importance of children's particular interests being nurtured in school, this was also reflected in some of the parents' comments too.

With regard to the adapted curriculum, P2, P3, P4, P5 and P6 all said that they would be prepared for certain subjects to be dropped so that their child could focus on other skills such as communication, social skills, therapeutic input and subjects or activities that particularly interested them. While, in the light of their concerns about their children's future, this is understandable, they were nevertheless unclear about which subjects should be dropped, although Geography, German and P.E. were cited by P2, P6 and P4 respectively. Moreover, P2, P3 and P6 referred approvingly to a 'social skills' group which their child attended in school.

Discussion

The theme of educational priorities is summarised in Figure 13.

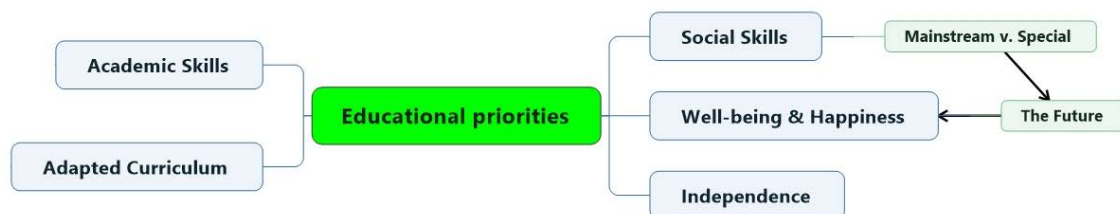


Figure 13: Educational Priorities

The theme of educational priorities is dominated by issues about socialisation and friendships from the point of view of the parents. While most of the autistic adults did not emphasise this point when asked specifically about educational priorities, other comments and anecdotes in the broader interviews highlighted the significant social difficulties some of them had experienced in school. For the parents, the need to make and sustain friendships lay behind the key educational decisions they were making about their children, as well as providing the basis of their fears for their future. Indeed, the desire for their children to make friends was key to future social acceptance and being ‘normal’, a word they used often, but always accompanied by an inverted comma, suggesting a sense of diffidence about the concept. Most of the parents had visited the local special school, but had a strong sense that the children there were less socially adept than their own children, who would be provided with more positive role models in a mainstream setting. Meanwhile, the concern of the autistic adults was tolerance and understanding, rather than – with some exceptions – being helped to learn how to make friends. Similarly, although some of the autistic adults felt that it was important that autistic children should be taught how to socialise in school, this was not only a much lesser priority for this category of participants overall, but it was expressed more as a necessity in order to be able to “function in society” (AA6), rather than a personal wish or need. Indeed, while the parents emphasised that they had chosen mainstream schools to help their children’s social skills, the autistic adults expressed a strong sense of disconnect between themselves and the other children socially. Further, it is also important to stress that while some of the autistic adults had experienced social difficulties in school, or even expressed a wish that social skills should be prioritised, this did not mean that academic skills were somehow unimportant as a result.

However, not all autistic adults problematised friendships, or the lack of them. AA2 said that the other children at primary school were “irrelevant” to her, and that she was quite content to

form friendships with the teachers instead. For her, children should be taught “how to be able to make friends”, but only “if they want”. In addition, AA5 said that although he was always the last to be picked for teams, he was untroubled by this. In addition, while most of the autistic children, at least some of the time, were observed to engage happily with other children, they did not often emphasise friendships in our discussions. Further, C3 and C6, whose parents, arguably, had placed the greatest emphasis on the need for friendships in school, both said that they preferred to work on their own. Indeed, TA8 asserted that “you have to accept sometimes that they want to be on their own.”

If parents emphasised the importance of friendships in school and later life, and autistic adults experienced social difficulties in school, it was also the case that school staff repeatedly asserted the importance of the relationship they had with the individual autistic children as being crucial to their general well-being and achievement. However, in the light of the issues already raised about the support the children ostensibly receive, which sometimes serves to segregate the autistic children and mark them out as different, questions must be asked about how successful the current methods of support are in this respect. Indeed, some children are sent to social skills groups, which might operate to remove them from their preferred choice of peers and activity. In one school, the non-autistic children were rewarded for attending the social skills group with the autistic child, with little sense that this might create an undesirable social dynamic for all. Indeed, if the autistic children wanted to select their own friendships, or showed a more positive response to children than adults, this could be problematised by school staff:

He likes reading with a child, but he makes a fuss about reading with an adult. (T3, semi-structured interview).

It may be the case, therefore, that the very measures school staff are taking to address the purported social difficulties of the autistic children, and the failure to recognise the importance of their own choices and preferences in this context, are sowing the seeds for their further alienation from their peers. Furthermore, the concerns expressed on the part of autistic adults and the parents that the older children become, the less socially accepting they are, suggests the social needs of older, primary school children require some attention, particularly before they progress to secondary school.

In addition, there seemed to be a general failure to consult with the autistic children - whose views might be at odds with those of their parents - about their educational priorities. The issue seemed to be not so much what the educational priorities for the children might be (and whether schools could fulfil the numerous expectations of them), but how those decisions were reached. Indeed, my own study provided an example of a happy confluence of educational priorities in relation to C5, who had stated in his interview that he wanted to be a chef. His mother, P5, also said that she would prefer more emphasis in the curriculum on the development of skills rather than academic subjects and cited the fact that her son wanted to be a chef as an example. The school therefore organised for C5 to spend two afternoons a week shopping for food and cooking with his TA. While the issue of an adapted or partial timetable will be explored further in the later theme of Inclusion and Exclusion, this example perhaps gives an early indication of the circumstances under which educational priorities can be agreed upon for the benefit of the child.

Theme 4: Assessment and Tests

Codes: Assessments; Maths; Reading; Writing

If, as has been seen in the previous themes, access to the academic curriculum in school is problematic and complex for autistic children, their participation in assessment and tests in school is similarly marked by complications. The secondary datasets from the DfE which were analysed prior to the primary data collection phase show that if autistic children take part in national tests, they perform poorly in them. In addition, and as discussed in Chapter 5, the qualitative responses to the questionnaires which were issued to samples of parents of children with a diagnosed SEND and those whose children did not have an identified SEND indicated that although tests were considered to be of value, their nature, purpose and form are contested in various ways. In my study, all participants, with the exception of the two youngest children and the Community Practitioner (CP), were asked about tests in schools, whether they were accessible for autistic children, and which, if any, accommodations and adaptations they either used or would recommend.

Terminology

A difficulty throughout my data collection was the use of the terms ‘assessment’ and ‘tests’, with participants either using them interchangeably or to refer to distinct activities and processes. In addition, some school staff assumed that when I used the term ‘assessment’ in relation to autistic children, I was referring to either a diagnostic assessment or a specialist form of assessment. Indeed, this assumption was in itself quite telling, given that these were all mainstream schools which, in principle at least, included all of the children in the curriculum to a greater or lesser extent. Furthermore, ‘teacher assessment’ (T/A) tends to take place with the younger children, with ‘tests’ – i.e. national tests in the form of SATs – becoming more the

norm for the older ones. Other types of tests, such as the ‘weekly spelling test’, only featured occasionally in the schools involved in my study. In this account, ‘assessment’ is used to refer to the overall process of testing within the class or school, with ‘tests’ referring to individual assessment activities in specific subjects, usually within a delineated time period. ‘Teacher assessment’ is used to describe a more fluid assessment process which might take place over a number of weeks, or a specific test set entirely by the teacher.

In addition, ‘accommodations’ in relation to tests refers to certain access arrangements made to the ways in which the test might be taken, such as extra time, taking breaks or doing the test in a separate room. In other words, there are no changes to the test itself, just how it is accessed by the child. Meanwhile, ‘adaptations’ refer to specific changes which might be made to a test, such as using employing different formats, changing the ways in which the child might tackle some of the questions, or even altering the questions themselves. At times, however, it can be quite difficult to separate ‘accommodations’ and ‘adaptations’, with participants presenting ideas which fall into both categories at different times.

i. Tests and difficulties of access

Tests were generally considered to be difficult for autistic children to access. D2, D3, D5, S2, S4, T2, T3, T5, T12, TA1, TA2 and TA12 all referred to autistic children (including C7, in Year 6) who were disapplied from school-based or national tests. Furthermore, while my school visits were arranged directly with the SENCOs, none invited me to attend during ‘SATs week’, citing the fact that this was a very busy time for the school. Therefore, I had no opportunity to observe how the autistic children might participate in school tests at any point during the six months that I spent in schools.

Table 13 sets out the reasons adult participants provided for the fact that autistic children either did not do tests, or found them difficult to access.

Table 13: Reasons why tests are difficult to access for autistic children

| Problem | Participants |
|---|-----------------------------------|
| Form of the test or circumstances in which it is taken | |
| Too long | D2; P2; P3; T4; T6; T10; TA15 |
| Wording | AA7; AA9; AA10; D3; S5; TA4; TA15 |
| Changes from classroom learning to test situation | D4; TA4; TA13; TA15 |
| Humiliation (through not doing well/public exposure) | AA1; AA3; AA6; AA7; AA9; P2 |
| Tests written from a 'neurotypical' standpoint | AA9; S5; TA5 |
| Social culture around testing | AA1 |
| Layout of test too complex | T4 |
| Unclear expectations | D4 |
| Nature of autism | |
| Child getting 'stuck' and unable to move on | P10; TA9; TA12 |
| Child can't sit still and/or focus | P3; S2; TA7; T11 |
| Inferences/abstract concepts difficult | AA2; S1; T4 |
| Not internally motivated | AA6; D3; P10; P5; S5; TA7 |
| Child's preoccupations get in the way | TA14 |
| Child 'overwhelmed' | TA6 |
| Child can't write well or at length | AA3; T4; T6; TA12 |
| Child susceptible to stress and so can't focus | AA7; AA8; AA9; P2; P8; TA12 |
| Child needs to talk | T12 |
| Fear of failure | AA10 |
| Sensory issues | AA3; AA6 |
| Proximity issues | AA6 |

Table 13 shows that the responses from participants can be divided into two broad categories: those which centred on either the form of the tests or the circumstances in which they might be taken as being intrinsically inaccessible to autistic children, and those considered to do with the nature of autism itself, deemed to be at odds with the process of testing. Even so, the differences between these categories are not stark: for example, the issue of the length of tests was considered to be a difficulty for autistic children specifically, and so a result of their autism.

The autistic adults – and to a lesser extent, parents – were far more likely to focus on social and emotional difficulties associated with testing, while the school staff were more inclined to consider the practical elements. For example, it was predominantly the autistic adults who raised the issue of stress and humiliation, especially if the child is already experiencing stress simply by dint of being in school:

It's like a thermometer. Most people are at zero, and a test situation pushes you up to 20. Someone who has Asperger's might already be at 15, and a testing situation might push them off the scale. (AA8, semi-structured interview)

Some autistic adults described the high levels of anxiety they experienced at school when they performed poorly in tests, not because of the low result, but because of the humiliation experienced when marks were read out loud, or simply because of drawing attention to themselves. Meanwhile, AA1 stated that the real difficulty in tests for her was the social culture in relation to success or failure, and the problems she had navigating these. Indeed, doing well could be equally problematic for some autistic adults:

But one thing I experienced is anything less than 10 out of 10 is incredibly difficult to quantify. Other children might be very happy with 9 out of 10 or 90% - but to someone with Aspergers it's incredibly difficult to comprehend the difference between that and 20%. (...)

For someone with Aspergers getting 9 out of 10 might lead to anxiety because they don't know if it's good or not. It can become socially difficult as well because if you're saying I'm unhappy, I've got 90% and your peers have got less than that, then it might seem like an inverted form of gloating. (AA8, semi-structured interview)

Another autistic adult stated the following:

It should also be taken into account that most autistic people are perfectionists and small mistakes in a test can feel like complete failure. (AA10, semi-structured interview)

Consequently, for these autistic adults, it was not so much the form and content of the tests themselves which created difficulties, but the social implications of dealing with the results.

Some autistic adult and staff participants considered that the difficulty lay with the wording of questions.

Examples:

1. *...it can seem like they are being tricked into thinking one thing rather than another. (...) For example, the wrong answer might be given and they have to identify whether or not it is the right answer – 14 might be given, when the answer is 41. An autistic child might wonder why the wrong answer has been given. (D3, semi-structured interview)*
2. *These tests are not written for autistic children. It's not that they don't understand, it's all the superficial wording. (S5, semi-structured interview)*
3. *The language throws them off. (TA15, semi-structured interview)*

AA2 and AA7 also considered that abstract or metaphorical language could be problematic for autistic children, while AA9 asserted that questions which either measured or relied upon social

understanding could be confusing. Moreover, AA9 felt that tests were intrinsically alien to autistic children, as they are written from a ‘neurotypical’ perspective, a point also made by some school staff members:

It’s almost like you’re expecting someone to step outside of their nature and do something completely alien to who they are. (S5, semi-structured interview)

It’s a bit like giving a child a test in German when they don’t speak German. (TA5, semi-structured interview)

AA10 stated that some questions might simply be interpreted differently by autistic children, but that this was rarely acknowledged or validated through the mark scheme. The issue of interpretation seemed to apply to Reading papers in particular, but also to other subjects, such as Maths.

However, while some participants suggested that the current format of testing is inherently exclusionary to autistic children, and P2, P9, P10 and T6 stated that they felt that the current system did not enable the autistic child’s abilities to be shown, other comments, predominantly from the non-autistic adults, implied that the core issue was the nature of the child’s autism. Some children were described as lacking focus and being unable to settle to a test, or not possessing the independence needed for a test situation, while others could not see the value of tests and so were not motivated to try to do well. Others still were considered to be heavily preoccupied by their own ideas or interests, or they were easily distracted, needing to get up and walk around or talk.

As far as the autistic children were concerned, C3, C6, C7 and C9 said they felt tests were important. However, C5 and C10 said that they didn’t like tests and C7 cited spelling tests as being particularly loathed, a view shared by AA9. Nevertheless, C5 relished spelling tests, as

had AA8. AA6 had enjoyed tests at school and for AA8, tests carry the possibility of showing both the abilities of the child and where s/he might need help. The important issue, AA8 considered, is that tests should be used to aid the progress of the child, not to shore up the school's reputation, a view shared by P5. However, as D4 asserted, "results are the first thing parents go to on the school website", and so if this is the case, it is perhaps understandable that schools have this focus.

ii. Access arrangements for tests

The DfE (2014e) permits a range of 'access arrangements' for pupils doing tests at Key Stage 2 (Year 6). This includes those who have a difficulty reading, writing, have a hearing or visual impairment, use sign language, have difficulty concentrating and who have processing difficulties (DfE, 2014e). While there are certain rules which apply in relation to the circumstances under which schools might employ access arrangements, it is useful to compare here the data from the SENCOs' questionnaires – who were answering on the part of all of the autistic children in the schools - with the specific accommodations allowed. The list below shows the permitted access arrangements which are relevant to autistic children and the number of children (shown in brackets) SENCOs said they were used for in their school:

- early opening of papers **(0)**
- additional time **(4)**
- scribes **(1)**
- transcripts **(0)**
- word processors or other technical or electronic aids **(0)**
- administering the tests at an alternative location (e.g. at home) **(0)**
- readers **(4)**

- prompts (3)
- rest breaks (a test can take as long as whole day) (0)
- apparatus for the Mathematics test (0)
- making modifications to test papers (e.g. photocopying onto differently coloured paper, enhancing diagrams, enlarging text) (0)

While the data provided by SENCO questionnaires was incomplete (because I had to discount those from S5), their responses are nevertheless an indication of the fact that schools are simply not taking advantage of the access arrangements already available for autistic (and other) children.

In addition, during interviews all participants were asked what could help autistic children to access tests in school. Their answers are summarised in Table 14 below, in which I also highlight the access arrangements permitted by the DfE (2014e). (Note: Table 14 does not include the questionnaire data).

Table 14: Recommendations for adaptations/accommodations for tests (highlighting those already permitted)

| Accommodation/adaptation recommended | Children | School staff | Parents | Autistic adults |
|--------------------------------------|----------|-------------------|----------------|-----------------|
| Being able to move around | C5 | TA9 | | |
| Use of computer/software packages | C5 | TA4; T8; T11 | P5 | |
| More visual/pictorial presentation | C5 | T1 | P4; P5 | |
| Advice/explanations from an adult | C7 | TA12; T12 | P2; P5; P6; P8 | AA7 |
| Being able to talk | | TA9; TA15; T4; T6 | | |
| Adapted or different test | | D2; D3 | P1; P2 | AA5; AA7 |
| Flexibility over timing | | | P2 | |

| Accommodation/adaptation recommended | Children | School staff | Parents | Autistic adults |
|---|-----------------|---|----------------|-------------------------------|
| Separate room/outside classroom | | D3; S4; TA4; TA5; TA8; T6; T12 | | AA1; AA6; AA8 |
| Encouragement from an adult | | TA15; T10 | | |
| A reader | | D2; D3; S3; TA5; TA7; TA9; TA11; TA15; T4; T6; T7; T8 | P9 | |
| Completing test in a small group | | D5; TA12; TA13 | | |
| Taking breaks | | D2; S2; TA4; TA12; T4; T10 | P3 | AA3; AA6 |
| Flexible approach to taking test | | D5; TA9; TA13; T7; T10; | P2; P6 | AA2; AA8 |
| A scribe | | D2; S2; TA4; T8 | P3 | |
| Extra time | | D2; S2; TA1; TA12; TA13; T4; T10 | P1; P5; P9 | AA3; AA7; AA8 |
| Using a reward | | | P3 | |
| Providing hints | | TA9; TA15 | P5 | |
| Different/simpler format | | S2 | | AA1; AA2 |
| Writing in answer if child gets stuck | | D1; S4; TA9 | | |
| Answers permitted verbally, written or with Maths apparatus | | D2; S1; TA2; TA4; TA10; TA14; TA15; T3; T4; T12 | P6 | |
| Simpler language | | TA15 | | AA1; |
| Low arousal or 'the right' environment | | TA9 | | AA1; AA3; AA4; AA6; AA7; AA10 |
| Being able to write about a subject of interest | | T3 | | AA2; AA7; AA9 |
| Having stim toys or listening to music via headphones | | | | AA1; AA3; AA4 |
| Emotional support | | | | AA1; AA8; AA10 |
| Accept different versions of answer/change marking criteria | | | | AA10 |
| Not changing seating or materials for test | | TA13; T10; T12 | | |
| Consistency of test format | | S4; T4 | | |
| Shorter tests | | S4; TA15; T4 | | |

Table 14 shows that participants provided a range of suggestions for accommodations or adaptations which could be employed to help autistic children to participate in tests. Moreover, while it is important to note that some school staff are referring to accommodations already employed, such as providing extra time and reading questions out loud to children, most participants were speaking in entirely hypothetical terms i.e. they were referring to what they felt should happen. In addition, the sections highlighted in Table 14 – which are indicative only because they do not all fit neatly with the DfE access arrangement categories – show that many of the suggested accommodations by participants in fact already exist, but that school staff (and their parents) are unaware of them. Furthermore, some of the participants' suggestions contradict each other, with recommendations for 'no change' to classroom layout, for example, at odds with the participants who proposed that autistic children should take a test elsewhere. Moreover, the issue of space was a significant one during my data collection, with rooms rarely available for interviews, and children provided with extra support in corridors, for example. This was particularly the case in School 4, which had approximately 900 pupils, still on the same site where, according to one of the parents who had attended the school as a child, it had once housed 300 pupils only. The results of this are illustrated in an extract from my research diary which describes my first visit to the school:

The school is on the street with very high green fencing. It was lunch-time when I arrived and the playground was full of kids making the most unbelievable din. I couldn't see any adults. There were so many children, and they didn't seem to have any space at all around them. My thoughts were 'this is totally non autism-friendly'. (Research diary, 03.03.2015)

Moreover, S5 told me that space was of such a premium in the school, that even corridors had to be 'booked' for visiting practitioners such as speech therapists. Perhaps in these

circumstances, it is unsurprising that schools did not provide more opportunities for children to sit tests separately.

With regard to the recommendations for accommodations or adaptations which remain i.e. those which are not already permitted by the DfE, many of these are highlighted particularly by autistic adults and they relate more to an understanding of the specific ways in which autistic children might need to tackle tests if they are to be successful. These included being able to take stim toys into an exam or being allowed to listen to music through head-phones, or being provided with confidential advice from an adult about the social aspects of the testing situation.

However, not all participants considered that autistic children required any particular assistance or accommodations for tests. Some of the autistic adults were keen to warn against a ‘one size fits all’ approach, for example, and C6 was clear that he did not want any extra help or to have any arrangements specific to him. AA5 also felt that some children should not be “marked out” as needing certain accommodations.

iii. Teacher assessment

If the question of adaptations and accommodations revealed, to an extent, differences in priority between the autistic adults, parents of autistic children and school staff, the issue of ‘teacher assessment’ (T/A) was more unifying, with a number of participants stating they were in favour of this. This is despite the fact that I did not specifically ask participants about this assessment option.

Participants in favour of T/A:

Autistic Adults: AA1; AA5; AA7; AA8; AA9

School staff: D1; D5; S1; S2; S3; TA6; TA14; T1; T2; T3; T7; T11

Parents: P2

Participants who supported T/A particularly emphasised the relationship between the teacher and child and the knowledge that the teacher has of the child as being central to the success of the assessment process. For P2, “a good teacher” would have an understanding of the child’s abilities which could not be met within national testing procedures, a view shared by a number of the autistic adults. Indeed, the most common tropes in association with T/A were ‘flexibility’ and ‘familiarity’ (with the children). Consequently, the high value placed by some participants on T/A was predicated on a somewhat idealised notion of a teacher: a person always present, who engages with all of the children in the class, and understands them on an individual basis. Furthermore, the autistic adults emphasise again the issue of ‘being understood’ which, they suggest, forms the basis of successful T/A.

iv. Alternative assessment

A number of staff members – D4, S2, S3, S4, T1, T2, T3, T5 and T9 - stated that they used different assessment schemes specifically for the autistic children. While some of these comprised of alternative methods to measure progress in alignment with the National Curriculum, others incorporated entirely different targets which school staff considered more important than those associated with the core subjects. Furthermore, even though Individual Education Plans (IEPs) were set aside in the new Code of Practice (2014), some school staff continued to use these to measure self-help, independence and social skills, for example, which were viewed as more important than the core curriculum. Moreover, even though it was the case, as was shown in the previous theme, that some parents, for example, wanted their child to have access to an adapted curriculum, there was little sense from school staff that they had consulted with parents, other school staff – or even the children themselves - when making the decision to not include the autistic children in the core curriculum and accompanying

assessment procedures. Indeed, P4 and P5 both stated that they felt it was “unfair” that their child was assessed on self-help skills, given this was an area in which they particularly lacked skill.

Discussion

The theme of assessment and tests provides arguably the most diverse, fractured and, at times, contradictory range of responses from participants, indicating that this remains an area which is highly contested for schools. While it is evident that school staff are simply not familiar with the range of access arrangements available for children, the fact that none can be deemed to be useful for autistic children specifically means there is little incentive to apply them. Furthermore, some school staff were nervous when addressing this issue, as they were concerned they might be ‘over-helping’ the child during the tests, and so, in some senses ‘cheating’. In other words, not providing enough support was considered a far lesser crime than providing too much. In addition, the range of responses from participants implies that devising ‘autism-specific’ accommodations could be problematic, with some children not requiring any at all. Moreover, the very circumstances in which some schools now find themselves, with limited space, for example, might mean that the existing access arrangements are in fact very difficult to deliver on a practical level.

In addition, as we have already seen, the autistic children were often subject to a high degree of prompting, meaning that they were not developing the independence required for test situations. Indeed, as AA1 suggested, perhaps TAs could be more fruitfully deployed in providing confidential support to the child in relation to the social implications of a low or high test result. Meanwhile, although teacher assessment was a more unifying concept for participants, teachers appeared to spend very little time engaging directly with the autistic

children in my study with, as we have seen, some children appearing to be entirely in the charge of the TA. Indeed, as will be discussed later, some of the autistic children spent limited time even in the same location as the rest of their class and teacher. This problem could be compounded further by the fact that some classes had more than one teacher, as was the case with C1, C8 and C9, or used agency staff to cover teacher absence, which occurred with C10. Consequently, the notion that teacher assessment could provide the solution to this problem is highly questionable.

Moreover, decisions about whether autistic children should take part in the school's generic testing procedures seemed to exclude parents and the children themselves, with the alternative devised on an ad hoc basis by the class teacher or SENCO. Here, the focus was on the child's difficulties and deficiencies, rather than his/her aptitudes, strengths and interests, potentially placing the child on a failure trajectory. Indeed, the question of testing and assessments could be deemed to mirror the debates between the medical and social models of disability, with some participants' responses implying that the difficulties were derived from the children's autism, rather than external factors. In addition, the practical arrangements existent or proposed would not tackle the core issue of interpretation, with the sense that the wording of current tests confuse some autistic children, and overall simply do not capture their abilities and understanding, and the ways in which they demonstrate their learning.

Theme 5: Communication

Codes: Communication; Autism; Interests; Support

Of more general concern in terms of the participation and well-being of autistic children in school, is the issue of communication. As shown in the literature review, communication difficulties form part of the medical, diagnostic definition of autism. Indeed, P1, P2, P3, P4, P6, P8, P9 and P10 all reported that their children either struggled to communicate or were late in developing speaking skills in comparison to other children of the same age. For P2, her son (C2) “can’t get his words out sometimes” and according to P3, her son (C3) “didn’t speak until he was four”. Similarly, according to D4, S5, TA1, TA5, TA6, TA9, TA15, T2 and T7, limited or delayed communication is a feature of autism, although some also asserted that this did not apply to all autistic people. For TA5, “they find communication hard – it’s hard to know what they’re thinking”, while for TA15, some autistic children “have no speaking skills”. T2 even stated that C1 had “no vocal communication”, which was patently not the case, as has already been seen. According to TA9, the problem lies with translating thoughts into words:

They have difficulty in communicating the way in which they perceive the world. (TA9, semi-structured interview)

Further, there was also a sense amongst a small number of the participants that this was in fact a question of volition, with TA9 stating that C5 “wouldn’t speak” when he was in nursery. P9 and P10 also asserted the following about their son, C9:

P10: He wouldn’t even tell us what he’d had for dinner for a long time

(...)

P10: We’d sit playing little games to try to trick the information out of him

P9: *I think they can't be bothered sometimes as well. 'It's not my interest to talk about that – I don't want to talk about that.'* (Focus group 1)

The use of 'they' from TA9 and P9 suggests they are alluding to autistic children as a general category. However, amongst the autistic adults, AA4 was the only participant to refer to communication difficulties, stating that he had problems in this area as a child.

i. Communication with children

As far as my data collection was concerned, it became evident during the time I spent with the autistic children that they all, to a greater or lesser extent, had some difficulties with spoken communication. Although not 'non-verbal', as described by school staff, C1 and C4 had a limited vocabulary, while mis-pronunciation of words was a common feature amongst the rest of the children. Here is an example with C2, aged five, who elected to conduct our interview with a friend, a non-autistic child (C2a) of the same age, as they look through a hologram book with animal pictures I had brought in (references to place names have been changed, and permission to include the words of C2a was obtained):

C2: *I ove (i.e. love) it*

RW: *So, what kind of books do you like then?*

C2: (inaudible) *in my bedroom*

C2a: *It's a cheetah, cheetah*

(...)

RW: *So, you're going on a trip tomorrow, aren't you?*

C2a: *Yeah*

RW: *Where are you going to?*

C2a: *Farm*

C2: *Farm ash...at*

RW: *Is it Ponders Farm? No.*

C2a: *No. It's...I think...oh I forgot where*

RW: *OK*

C2: *Ashtin Farm*

C2a: (laughs) *No*

RW: *No?*

C2a: *It's Thornley Farm, Thornley Farm*

RW: *Oh, OK*

C2: *No, no Ashlin*

C2a: *No, Thornley, C2....zebra*

RW: *So C2, do you like*

C2: *zeba*

RW: *going on trips?*

C2a: *It's not a zeb-a it's a zebra*

C2: (gasps) *a g'affe*

C2a: *It's not a g'affe* (C2, semi-structured interview)

C5 and C7 also experienced significant difficulties with both word retrieval and pronunciation:

1. C5: *It was...sometimes....er....er...er...um...* (C5, semi-structured interview)

2. C7: *If it's like fun test or if it's like eafy (i.e. easy) test*

(...)

And I get to crime (i.e. climb) I get the crime on the trip, outside. (C7, semi-structured interview)

Some children also struggled with narrative structure and word-order: here C2 is telling me a story about a man who he said had been sitting in the road outside of his house:

C2: *The ra, the ra...Another day (i.e. the other day) there is, there is a man sitting at the road, there's, there is a, there is a man sitting at the road and he got really rundover*

(...)

C2: *An ambulance got in and he went to hospital (a bit garbled)*

(...)

C2: (shaking head) *He didn't, he really didn't, he, he, he, he looked at the road, he didn't (down?) like that, he, he, he crashed the road, he was looking, and he went cross the road to our house. (C2, semi-structured interview)*

Other children, as some of the staff and parents had suggested, found it difficult to put their thoughts into words, or even to formulate answers. In this example, C3 (aged nine) is finding our interview quite effortful:

RW: *Do you? Why do you like that?*

C3: *I can't explain*

RW: *You can't explain. It's a difficult question, I suppose.*

(...)

C3: *It's hard to explain as well*

(...)

RW: *Ok you prefer that. And what about the whole class? Do you like work....*

C3: (head in hands) *I don't know.*

(...)

C3: (mumbles something while chewing fingers) *not sure*

(...)

RW: *Something that's made you feel really good and made you feel really happy.*

C3: *Can't explain* (C3, semi-structured interview)

As with all of the child participants, I reiterated a number of times that they did not need to participate if they didn't want to, that they could leave at any point without giving a reason etc. Unsurprisingly, given the response of C3, I interpreted this – wrongly, as it transpired – as a sign that he did not want to take part, especially as he had his back to me at this point:

RW: *C3, do you want to stop doing this? Is this not something you want to do?*

C3: *I do want to do it*

(C3 turns around)

RW: (having misheard) *You don't want to do it.*

C3: *I do want to do it!*

RW: *You do, OK.*

C3: *I said I do* (C3, semi-structured interview)

Indeed, the more time I spent with C3, the more I realised that he was frustrated at not being able to find the words to express himself: I had misunderstood and misinterpreted his fidgeting and non-committal replies as being signs of an unwillingness to take part in the interview.

ii. Communication context

Notwithstanding the real difficulties the autistic children appeared to be experiencing with spoken communication, it also became clear that these problems varied in accordance with the contexts or broader circumstances in which they found themselves. Here is a further example with C3, who is talking about his great interest, computer coding:

C3: *It's epic, Coding Club*

RW: *Why is it epic?*

C3: *Because you get to do like coding and make ga games*

RW: *Fantastic*

C3: *I made this epic game, it's called Pixel Rush. It's so cool.*

RW: *What's cool about it?*

C3: *Well it means you have to try to get to the diamond and once you fall on like a spike, you've failed the level.*

RW: *Ah*

C3: *Y...you, you, you ha you go back to the beginning again and you have to try and start again.* (C3, semi-structured interview)

In this extract, C3's answers are not only longer and more fluent, but he has no difficulty explaining why he likes Coding Club, whereas previously he had been completely unable to answer similar questions about his favourite subjects in school. He is also much more relaxed. A similar, striking example was provided by C8, who was hesitant and taciturn during interviews and learning activities, but became much more voluble in response to a book about snakes I had taken in to show her, having noticed that she liked books about animal life.

C8 has the confidence to make assertions about whether or not the TA is right. (...) She says “wow” when the TA points out to her the picture of how many people it takes to hold the snake and C8 makes further comments on this. (...) Some more reading out loud. More comments from C8 on the text and the pictures. She is v intrigued by the fact that the snake eats the egg and how this might work. (...) C8 is showing a lot of different skills: reading out loud, finding synonyms, asking questions, commenting, relating to her own experiences, making factual assertions, independent (silent) reading. (C8, unstructured observation notes)

In this extract, C8 is showing a range of skills which were not evident at other times I observed or interviewed her, becoming not only less reliant on the teaching assistant, but demonstrating the confidence to challenge her. Here, C8 is not so much the child with ‘needs’, but an equal – if not more dominant – communication partner. Similarly C5, who also tended to stumble over words and mis-pronounce them, was observed to be more confident and skilled in his spoken communication when he felt able to access the activities in which he was interested. At times, this resulted in an interview role reversal, where he would ‘test’ me or the TA with spelling or Maths questions. In other words, when the circumstances for C5 were such that he felt confident and sure of his ground, he was no longer the hesitant, receptive participant and interviewee, but the person who was actively directing the conversation.

iii. Role of support

In the theme of ‘Support for Children’, I provided an example of a protracted and tedious writing activity involving C10, with which he had struggled greatly (pp. 201 – 204). One of our interviews was scheduled to take place straight after this lesson and, although C10 was happy to take part (and had stopped complaining that he was hungry, for example), the negative impact of the monotonous writing exercise seems evident here:

C10: But I'm still...I'm still old...I'm still...I know how to...I know how to...like...use the....my sister's compers (i.e. computers) ...she didn't....she won't ask me...she always....she wants....her ones. (C10, semi-structured interview)

C10, who was not a native speaker of English, but deemed to have communication difficulties by dint of his autism, appears worn out, and is struggling to express himself verbally as a result. Moreover, his repeated assertions that he was finding the writing task difficult – e.g. “it’s killing me” – had been ignored by the TA, who felt her mission was to ‘keep him on task’ (the main purpose school staff identified for their support of autistic children). Therefore, while C10’s communication had been disregarded, his own ability to express himself verbally is apparently damaged too.

Other children also experienced similar difficulties. For example, C4 was described as ‘non-verbal’, but he would voluntarily say the words and make the sounds of animals, which he loved. He would also say “No”, “Oh no, oh no, oh no” and use other similar expressions when presented with activities he didn’t want to do, as did C1, similarly described as ‘non-verbal’. However, in all cases when I observed this, their responses were neither acknowledged nor acted upon by the school staff.

C1 was provided with a ‘choosing board’ where he was ostensibly given a choice between different activities in order to help his communication skills. However, in reality, he was often made to choose the activity which the adult had in mind, or his choices outside of the narrow possibilities of the choosing board were ignored:

The TA eventually took C1 over to his ‘choosing board’ (...). C1 said ‘no, no, no’ when she said she wanted him to choose. He kept wanting to go towards something in the

classroom, but she kept pulling him back, and insisting he ‘choose’ one of the three cards.

(...)

The TA left and so the teacher took over primary responsibility for him. She made him return a magnifying glass he had taken out of a drawer. I saw C1 stamp his foot in annoyance. Couldn’t understand why he was made to return this – wasn’t he ‘choosing’? (Research diary, 24.04.2015)

As this example shows, the children were sometimes constrained to express themselves in ways selected by school staff rather than in the manner with which they were most comfortable. Indeed, even when C1 tried to communicate using the choosing board, his actions were not always treated as legitimate:

At the visual timetable. C1 picks the ‘choosing’ card. TA: “No, we’re not choosing.”
(C1, unstructured observation)

There were numerous examples with C1 and C10 in particular, where they were communicating very clearly and in an appropriate manner, but their wishes were either ignored or treated as invalid. Furthermore, as described earlier, the communication from school staff was not always especially clear, demonstrating vague instructions, problems with word-order (e.g. “we’re going to do a puzzle numbers”), a lack of positive reinforcement when the children did as asked and a failure to explain the length and purpose of activities in some cases. Sometimes staff seemed to be going through the motions of communication support, but without actually responding to and interacting with the child, as seen in this example with C4, who is completing all of the tasks requested:

TA kept repeating words e.g. colours, animals, in a loud voice, but she completely failed to engage with him in any way. (...) She was giving him virtually no positive feedback during these activities and so I broke with protocol and issued a few ‘well done’ and ‘good boy’ comments. (Research diary, 01.04.2015)

However, some school staff supported the communication of the children in a positive and enabling manner, which also facilitated considerably the process of my data collection. For example, the TAs of C5, C6 and C7 conducted the interviews themselves, as it was evident that they had a good understanding – much better than I did - of how to engage with the children. What typified these relationships was a gentle approach and a care to avoid any kind of pressure or stress, and presenting the children with genuine choices about the different activities. These staff, as well as others at different times, showed flexibility and humour, and a sincere desire to help the children to express themselves in an unadulterated manner.

Furthermore, just as the support skills of school staff were observed to be enhanced when the children were engaged in motivating activities, their ability to interact and encourage the children’s communication improved in these circumstances too. In this example, the TA of C8, who was shown earlier to be overloading her with instructions during a Maths activity (p. 200), is much more effective when C8 is looking at the book about snakes:

The TA is interacting with her very well in this activity too – guiding her well with questions, getting her to find out information for herself, congratulating her etc. At one point the TA explains something and C8 says (confidently) – “I was going to say that”. TA and I laugh and flicker of a smile from C8. (C8, unstructured observation notes)

iv. Non-verbal communication

C10, who like C3, became frustrated when he couldn't find the words to express himself, was nevertheless highly skilled in using gesture. Here he is describing when he accidentally dropped a toy down the toilet:

C10: Yeah. It was my fault, yeah (poking at nose) I didn't mean to do that yeah plus there was too much (gestures smell) yeah, then there was a...like...the water look...like my sister was doing it and it was going higher and higher and higher (gestures water rising) (C10, semi-structured interview)

Moreover, C10 had a strong interest in action heroes, and not only did he talk about this at length, but elected to carry out kung-fu style actions, which he was keen for me to video record. Indeed, this formed the basis of our agreement: I would ask him some questions, at the end of which I would record his action hero moves. It was evident to me that C10, who was made to engage in unstimulating and repetitive activities during his school day, and who also struggled with spoken language (partly as a result of this), was developing compensatory skills in gesture and actions, at which he was particularly adept. Indeed, as a child who was subject to repressive educational activities and some bullying from his peers (which I reported to the SENCO), it is possible that his desire to emulate action heroes derived from a wish to acquire some sort of agency and control in his life.

C1 also demonstrated unspoken as well as spoken communication skills. However, here too, school staff did not always recognise or respond to his non-verbal communication. This extract is from an observation of a reading activity that C1 had enjoyed:

Shakes his head once, but otherwise communication attempts seem positive. Draws TA hand to book, says to her "finished", which she doesn't recognise. At the end, he closes the book

and puts her hand on it – he is trying to communicate that he has had enough. She seems to recognise this, but carries on anyway. (C1, unstructured observation)

In this extract, although C1 is using both spoken language and gesture in a clear and skilled way, the TA does not recognise this communication and, when she does, she chooses to ignore it.

v. Communication differences

Some of the parents expressed the concern that their child's lack of spoken communication somehow marked their child out as different or 'odd':

Because C4 can't talk, I think to us he looks completely normal, when he's in the house, because we interact with him in our own way and he's charming, he's delightful, but I suppose when you take him out, not that I've noticed people staring, but he'll start to run up to people or teachers and he'll babble at them and they're kind of like, how old is he? cos he's nearly five now so he probably does look a little odd. (P4, parent of C4, semi-structured interview)

P1, the mother of C1, was also concerned that her son's apparent lack of speech would mark him out as odd, and it is noteworthy that neither alluded to the spoken language that both children used. However, T11 valued the honest way in which C9 communicated, for example:

Every day is different. There's never a dull moment. If something's boring, he'll tell you. We had some animals come into the school recently and C9 just stood up and said it was boring. (T11, semi-structured interview)

Moreover, some of the autistic adults had an entirely different perspective on the issue of communication:

Nonautistic people have quite distinct (trying not to use language like 'odd') ways of bond making and conversational tools that I don't really get. (...) Also they spend a lot of time talking around things and not saying what they mean. Using many words and hiding answers to questions in massive amounts of speak. (AA2, semi-structured interview)

AA2 also referred to the need “to fill silences” which non-autistic people seem to require, as well as “to talk for the sake of it”:

I describe a lot of the chat as 'nicespeak' not saying what you mean, not worrying about the quality or accuracy, fluffy chat. (AA2, semi-structured interview)

For AA2, it is this sort of conversational approach which was puzzling, almost ‘odd’, while for AA5, the ‘chat’ of non-autistic people precludes activity and invention:

Society needs people like “us”, we’re the ones who sat away from the camp fire inventing the wheel, making tools, ignoring the chit chat. (AA5, semi-structured interview)

According to some of the autistic adults, therefore, it is not so much a question of communication difficulties on the part of autistic people, but of differences in style and content compared with the ways in which non-autistic people express themselves.

Discussion

While there was no doubt that the autistic children in my cohort were experiencing difficulties in speech in one way or another, this did not necessarily equate to a communication problem in all cases. Moreover, the context within which the children were expected to communicate had a marked impact on how successful they were at talking, with topics and activities of interest

having a significant, positive influence on how they could express themselves. This could result in an important shift in the power dynamic, with the child taking a more confident and assertive role in communication exchanges. Importantly, this appeared to have a reciprocal, enabling impact on the supporting TA. By contrast, while some staff demonstrated a high level of proficiency in supporting the communication of the autistic children, others were not necessarily skilled communicators themselves, and the children could be worn out by protracted, unmotivating activities, making it even more difficult to speak. Moreover, there was no evident attention or support for the autistic children who were not native speakers of English: all problems were deemed to emanate from their autism.

Some of the children had developed skills in non-verbal communication, such as gesture, but these were not often recognised or validated by school staff. Even when the children attempted to comply with the alternative communication system the school had set up, their communication might be ignored and they could be coerced into expressing the opposite of what they wanted to say. In these ways, the support for communication which the school apparently provided proved both contradictory and profoundly demotivating, where the child gained as little from failing to interact as when trying to communicate. Further, for those children who were labelled as ‘non-verbal’, staff had no anticipation of hearing words spoken, and so their words were simply not noticed at times. Indeed, some staff seemed more preoccupied with the equipment of communication support – visual timetables, ‘now and next’ boards and laminated cards – than actually listening to the child in front of them. Consequently, it seemed in some cases that the sole purpose of the communication strategies for the autistic child was to train them to express what school staff wanted to hear, in the way they felt it should be expressed. This was particularly marked in the case of C1, who was observed, for example, being taken away from an activity he was enjoying in order to ‘choose’ it on the visual

timetable, prompting anxiety on his part that he was being removed from the activity altogether. In addition, C1 was being taught, using a hand over hand method or full physical prompting, to sign 'good morning' to the class teacher and 'thank you' when he was given something. Similarly, an urgent priority had also been to get C1 - the youngest child in the school - toilet trained, a point school staff made repeatedly, even though this had been successful and so was no longer an issue. Therefore, the concern about C1 was not, it seemed to me, to help his independence, access to the curriculum and communication, but to train, tame and civilise him. Consequently, it was evident that the children were more skilled communicators than the adults appeared to realise in some cases, and that this very lack of understanding on the part of the adults had a deleterious effect on the very ability of the children to make themselves understood. It is important to note too that communication from the children was not only evidenced through words and gesture, but through silence. All of the children were observed at different times to be engaged silently and contentedly in activities they enjoyed. Indeed, children labelled as having communication impairments could be overloaded with the repetitive labelling of items and requests for responses from adults, when their silence - a clear indication of concentration and well-being - was considered to be of no communicative value. This was in a context where the class teachers employed various strategies - tapping tambourines, rhythmic clapping, asking the children to 'freeze' or sit cross-legged on the carpet with a finger placed on their lips - to gain silence in the classroom.

Furthermore, the insights provided by autistic adults suggest that in some respects at least, the issue is not so much of communication difficulties, but communication differences, with autistic people disliking the 'fluffy' chat in which many non-autistic people engage, for example. Moreover, while it was certainly the case that for both the autistic children and adults, I needed to employ a range of methods in order to be able to engage with them, there were still

misunderstandings at times, as exemplified by my conversations with C3. In instances with other children, their responses were at times quite literal, or tautological, or provided in an alternative or delayed manner, some of which I did not recognise or understand straight away. This in itself has implications for the very foundations of communication strategies for autistic children in schools, as well as their broader learning and educational assessment. Indeed, while one of the SENCOs had said that autistic people “are unable to read the non-verbal signs that other people take for granted”, my evidence shows that part of the problem, at least, lies with the inability of non-autistic people to understand the sometimes very evident verbal and non-verbal communication of autistic children and adults.

Theme 6: Interests

Codes: Interests; Support; Autism.

Over the course of the previous themes, a picture has started to emerge of the ways in which the interests of the autistic children, and the extent to which they are able to access these, has a positive impact on their time in school. As already discussed, the support they receive, their access to the curriculum and tests and their communication might all be facilitated when mediated through their areas of interest. Indeed, while it might be something of a truism that all children respond positively to activities which they find motivating and stimulating, this issue has particular relevance to autistic children, who are deemed to have strong interests in certain areas. It is the ‘monotropic’ thinking style (Murray, 2014) of autistic people which means that they tend to focus on a narrower range of topics or activities, but with intense focus and interest. Although there were some indications in my study that this tendency can have a negative impact on different aspects of school life for the autistic children, the evidence for its positive effects was in fact overwhelming. This was all the more striking as this had not formed part of the initial enquiries which prefaced my data collection: this evidence emerged entirely inductively through the process of data collection and analysis. The positive impact of enabling autistic children to access their interests, as derived from the interview and observation data, is summarised in Table 15.

Table 15: Positive impact of accessing interests

| Area of impact | Participants |
|--|--|
| Improved access to learning, curriculum & tests | AA1; AA2; AA3; AA7; C1; C2; C4; C5; C6; C7; C8; C9; D2; D3; P9; TA7; TA9; TA12; T3; T6; T7; T9 |
| Increased socialisation | AA1; C1; C2; C7; C9; C10; D3; P6; P7; T2; T3 |
| Greater independence | C1; C3; C4; C5; C8; C9; C10; |
| Improved communication | C2; C3; C4; C8; C9; C10 |
| Source of comfort | C1; C2; C3; C4; C5; C7; C8; C9; C10; TA7 |
| Better motor skills | C1; C4; C7; C10 |
| Link with expertise/future plans | AA1; AA10; C3; C5; C7; C9; C10; D4; P2; P5; P9; S5 |

As has already been seen, some of the autistic children were subject to a high level of verbal and physical prompting. Here is an extract from my research diary about C1, who was considered to have poor motor planning, during a P.E. lesson:

PE consisted of him being dragged around by the hand by the TA as well as generally excessively physically manipulated. (...) ...most of the time she was manhandling him, even to the point of lying him on top of her when they all had to lie down. (Research diary, 27.04.2015)

However, this contrasted greatly with tasks when C1 was voluntarily engaged with the activity, such as looking through a preferred book, where he was observed to show good fine motor skills (flicking backwards and forwards), or when playing outside (an activity he often selected

from his ‘choosing board’), where he ran, climbed and jumped without difficulty. These activities were also characterised by minimal TA input, or even by a role reversal, whereby C1 is prompting the TA:

C1 puts his hand over TA’s as she draws – this seems like a very gentle, sensory approach which suits C1. (...) C1 does a few circular scribbles on his own with pen in fist (...) but really he wants to guide the TA’s hand while she holds the pen. (...) TA says that now he is guiding her hand completely. It’s great that she goes along with this. TA v encouraging – “good boy” etc. He is prompting her in this activity. (C1, unstructured observation)

This activity not only shows better motor skill and independence on the part of C1, but his whole demeanour emboldens the TA to transfer control from her to him, while encouraging C1 throughout. Her language, which during a reading activity C1 had not wanted to do (see p. 205), had been negative – “no”, “wait” etc. – is now affirmative, complimentary and reassuring. Similarly, C10, who was considered to be weak at P.E., was agile and creative when it came to inventing kung-fu style moves in the name of the action heroes he admired. Further, this change of dynamic does not lead to less compliance from the child, but more, as I noted during the hand-writing activity with C1:

TA asks C1 to clean board a few times and he does this. (C1, unstructured observation)

While the fact that the child was engaged with the activity in hand led to better curriculum access and increased independence, this also augmented the social opportunities for that child. When C1 was engaged in the hand-writing activity, for example, I noted that he started transferring his interest from the TA to the child sitting next to him. C9, who had a strong interest in Maths, said that he liked “working in a three”, because three was his favourite

number. This, combined with his other deep interest of fantasy stories, led him to create, with his two friends, elaborate games during play time, which were rich and varied in their content. During a reading activity with C10, where he was absorbed in a newspaper article of interest, and had no TA input at all, another child started looking through newspapers to see if she could find similar articles which might interest him. Indeed, other children appeared to enjoy supplying some of the autistic children with items of interest, and would bring C1 dinosaurs, for example, which they knew he loved. With these activities, the omnipresent TA starts to fade into the background, leaving the child more free to interact with other children, who appear to understand, better than the adults do, how their interests can be a conduit to the forming of relationships. In these respects, the children had already worked out what many of the adults failed to see.

Moreover, for one teacher, the fact that she shared the same interests as an autistic boy in her class (who was not a participant), this reciprocity had provided, not just an important mechanism whereby she could teach and he could learn, but a sense of self-recognition on her part, whereby she perceived them both to be of a similar kind. Here she discusses their mutual interest in Disney films:

He's now my absolute favourite child I have ever taught. I have a good relationship with him. I can chat to him about The Princess and the Frog. I'm into that sort of thing too. If he comes in singing a song from a Disney film, I know what it is and I start singing with him. In some ways, we're on the same wavelength. I'm very Disneyfied. (T3, semi-structured interview).

Having described herself as “worried” when she learned he would be starting in her class that year, T3 had now found that because of their shared interest, they have an understanding and a

bond. Moreover, she explained that she was able to set the child a number of learning activities based around his interests, because she knew that this would engage him in a way other aspects of the curriculum would not. T3 also used the same technique to set tests, because the TA would not know the answers, and so she was confident that the child was completing the tests independently.

From observations and interviews, accessing their areas of interest was shown to enable nearly all of the autistic children to self-calm and regulate their emotions in situations of stress, such as a noisy classroom or being presented with unstimulating learning activities. Moreover, as was explained in the previous theme, the children were observed on a number of occasions to be more fluent in their speech when they were talking about their interests, becoming less hesitant and reserved too. In addition, while the specific areas of interest varied between the children, there were nevertheless some commonalities, such as animals and dinosaurs in the case of C1 and C4, sports for C6 and C7, and fantasy heroes for C9 and C10. However, some form of ICT or computers was by far the most frequently cited topic of interest, linking C1, C2, C3, C5, C6, C9 and C10 in different ways. For C3, ICT was his favourite subject, along with PE, while C5 stated that using computers more would make his school work easier. As seen in the Outlier 1 example, C1 was deemed to be “behind in everything”, according to his teacher, with the exception of ICT.

However, despite some clear examples of the positive impact of access to computers, there was evidence that the autistic children had less, not more access to ICT than the rest of the class. As has already been seen with C10, while his classmates did research on computers, he was given magazines instead. C9 also missed an ICT lesson to attend a ‘communication group’. Meanwhile, C1 and C4 were both provided with elaborately devised visual timetables, differentiated materials, communication boards and tokens, which could have been much better

sourced via a computer. In addition, while there was substantial evidence that the autistic children struggled with hand-writing activities, none apart from C6 (who had an additional physical disability) appeared to have access to computer programmes and typing exercises, which could have supported this aspect of their learning. Indeed, while C5, unlike some of the other children, had regular access to computers, this was used as a reward only, with some school staff considering that time on the computer was ‘play’, rather than ‘work’:

He hates doing work. He likes sitting on the computer and playing CBeebies. (TA10, semi-structured interview)

Indeed, just as P1 had been criticised for leaving her son “on the iPad all day”, P9 said that she feared that her own son’s computer use was misunderstood, as he was deemed to be playing only, whereas in her view, he was picking up important skills. Moreover, P5 and P9 both felt that their children should be able to do school tests on computers, not currently possible for national assessments.

However, despite the strong evidence of the positive impact of enabling autistic children to access their interests in school, there were also indications that the children’s preoccupations could create barriers to learning. For example, C9, who was passionate about numbers and indeed would create Maths puzzles to calm himself when stressed, might spoil Maths tests if he became distracted by a game about numbers which he had been thinking about earlier, according to his parents. C9 also told me that his attitude to tests – any test – would be dictated by which numbers it contained:

RW: What would make doing tests easier for you?

C9: um...um...make it easier? When there was four very easy questions.

TA: Four very easy questions

C9: *Yeah, just four. Actually 20, because I like 20, actually 55 cos it's my favourite number, actually 3 is. 3 and 55 are my favourite, so 58.* (C9, semi-structured interview)

Similarly, in my interviews with C2 and C10, they often digressed from the questions I asked, preferring to talk about their interests, as this example from C2 shows, again with his non-autistic friend, C2a:

RW: *So let's just talk about school a little bit more C2*

C2: *I I like Butlins, it's...it has (gestures)... at Butlins*

C2a: *C2 do you (inaudible) pantomime? Pantomime.*

C2: *He's...he...pantomime's just a silly*

C2a: (laughs) *yeah*

C2: *Yeah silly lady*

C2a: *That's why he's a boy*

C2: *Or he's a man, he's just a silly man*

RW: *OK C2, let's get back to school, just for a little bit, erm, let's talk about school just for a little bit*

C2: *I'm not talking about pantomimes, I'm talking about school*

RW: *Are you going to talk about school? Do you want to talk about school C2?*

C2: *Erm, yeah I want to talk about sold (i.e. school) not pantomime any more*

RW: *OK. Why don't you tell me what you'd like to say about school?*

C2: I like Butlins. And there's a burger king at Butlins (gestures) (C2, semi-structured interview)

P5, S1, TA8, TA10, TA14, TA15, T1, T3, T6, T10 and T11 all considered that the intensity of the interests and preoccupations of autistic children precludes their effective learning in class, while P2, P4, P9, P10 and TA8 were of the view that this phenomenon creates social difficulties too:

I'm hoping he's going to learn that he can't be so selfish. He can't just talk about what he wants to talk about, or play with what he wants to play with. (P2, mother of C2, semi-structured interview)

However, AA7 considered that the difficulty might lie with the teacher if s/he did not have the same level of expertise as the child in a particular topic. Furthermore, S5 was of the view that certain historical figures such as Mozart were probably autistic, and that their success had hinged on their ability to pursue their strong interests:

But these people were lucky to be able to pursue their interests. Not all autistic people get that. Had they been born at a different time, they might not have been so lucky. (S5, semi-structured interview)

While it is not clear what S5 means by “had they been born at a different time”, her comments do suggest that this propensity can be linked to high achievement. Similarly, as Table 15 above demonstrates, a number of school staff recognised the importance of tapping into the interests of autistic children in order to facilitate their learning and the assessment of their skills. Furthermore, P2, P5, P9 and P10 all stated that they felt their child’s future hinged in part on their ability to pursue the learning activities they enjoyed, while AA1, who had a negative

experience of primary school on the whole, found this improved when she found classmates who shared her interest, which also informed her career decisions.

Discussion

The role and impact of interests for autistic children in school can be summarised in Figure 14:

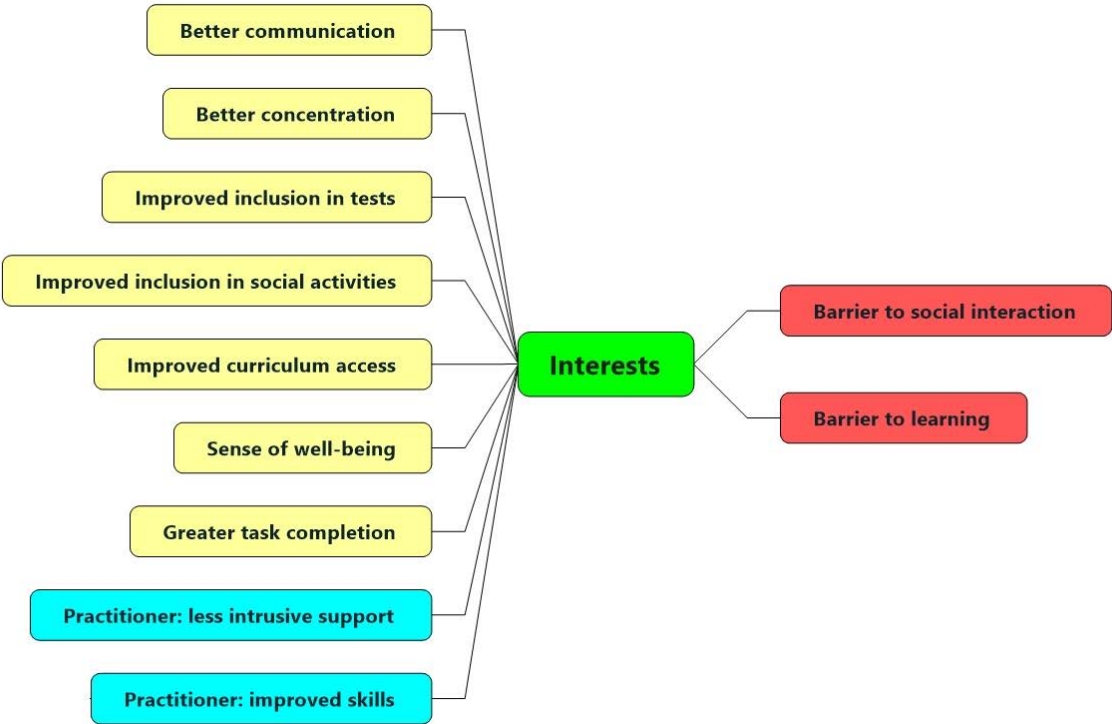


Figure 14: Summary of impact of access to interests

According to my findings, several positive outcomes can be associated with enabling the autistic children to have access to the activities which interest them. Moreover, while the children themselves were shown to be more relaxed, focussed and independent (amongst other positive attributes) in these circumstances, the skills of the school staff were observed to be better too. This reciprocity was also seen to build through activities, with the more adept support

from the TA meaning the child became calmer, more attentive and responsive. Prompting from school staff also decreased significantly, instructions became more positive and the child tended to require much less support, creating at times, a power shift from the adult to the child, which resulted in greater, not less, compliance. During these more constructive activities, other children were observed to respond more positively to the autistic children too.

In addition, some participants linked the phenomenon of intense interests with expertise and a positive pathway for the child in the future. Moreover, while for some children, their preoccupations appeared to present a barrier to learning, it seemed in some cases at least, that this was a coping strategy to deal with the stress of being in school. Moreover, while C2 talked frequently about school trips and holidays, he was, in reality, being frank about what he most looked forward to when in school: trips and out of term holidays. C7, aged ten, an active child who loved playing football with his friends, also talked a great deal about an upcoming outward-bound residential school trip, because this represented what he most enjoyed. Indeed, when I observed him playing football, his collaborative interactions with the other children, anticipatory moves, assertiveness and general level of skill contrasted sharply with his hesitance and general confusion during his solo Maths and Reading activities, at pre-school level, where he seemed rather lost. These conversations serve not only to underscore the fact that a child's preoccupations in school might be entirely different to those of adults, but that their interests are instructive about the circumstances in which they feel comfortable, happy and engaged, and able to 'be themselves'.

Furthermore, it might be the case that one of the reasons why the children valued time on computers was because of the level of control they were able to exercise, independently of the TA. Moreover, P6 explained that a computer-based Maths activity had been obtained for her son in school, which proved to be so popular, that it was now used for the whole class. In this

way, tapping into the child's interest has facilitated the engagement and education of the whole class, creating another shift in the dynamic from the child with 'needs' to the child who, in some senses, provides or aids.

Theme 7: Inclusion and Exclusion

Codes: Inclusion; Exclusion; Educational priorities; Bullying; Professional Experience

As set out in the first two chapters of this thesis, educational inclusion, which overarches all of the themes discussed so far, is a highly complex issue, with diverse and often unclear understandings of what it means and how it should operate. In addition, exclusion, in various forms, continues to be a reality for many autistic children. These difficulties and complexities were certainly apparent during my data collection, with the ideas and practices associated with inclusion and exclusion proving to be interconnected.

i. Mainstream versus special school

All of my adult autistic participants had attended mainstream primary schools as children: indeed, this formed part of the inclusion criteria for their participation in my study. Similarly, my data collection took place in mainstream schools only, where the autistic children were placed, and so in the most narrow sense, all of the participating autistic children were ‘included’ in school.

However, while it was clear that most of the parents of the children in my study had either considered a special school placement for their child or anticipated this as a possibility for the future, not all school staff fully embraced the notion of the placement of autistic children in their school. Indeed, the spectre of exclusion and placement in a ‘specialist setting’ was never far away, with T1, for example, implying repeatedly that C1 would be much better off in a special school:

We lack facilities and resources. There are many things in a special school that he would love. (T1, semi-structured interview)

According to D4, one of the deputy head teachers of School 4, children must be able to “access the curriculum” if they are to be placed in the school, and they should be without major sensory issues meaning that they are “eating the Pritstick”. For her, “high functioning” autistic children are well suited to the school: “they are totally included and this is the best place for them to be”. Such children contrasted with those who are “low functioning”:

Some low functioning children can manage in Reception, maybe into Year 1, but after that they can no longer manage – they need specialist help. We recommend that they leave. (D4, semi-structured interview)

Indeed, the notion of ‘specialist help’, considered to be within the purview of special schools or external professionals, was often evoked by school staff, who considered that they lacked the ‘expertise’ to support autistic children. Another important criterion for D4 was that the children must not need to be withdrawn from class which, given the highly crowded nature of this school, is perhaps unsurprising. D4 also told me about an autistic child in their nursery who, she said, would not progress to the primary school section, and would instead attend a special school. Similarly, staff at School 2 also referred to an autistic child in their nursery school, who they were currently trying to persuade the LA to send to the special school. This resulted in a particularly fraught discussion between the SENCO and the Head teacher, on a hot day (and so all the doors and windows were open), when I was conducting interviews with teaching assistants in the room next door:

They both sounded quite exercised (...). I could hear phrases like “detrimental to the efficient education of the other children” (the only legal basis on which a child can be rejected by a school), “we do whole class teaching here”, “he would need full time TA support” etc. although in reality, I was trying not to listen. This discussion went on

during the entire afternoon while I was interviewing TAs, and was still going on when I left. It was like an off-stage chorus of truth-tellers during a Greek tragedy. (Research diary, 20.04.2015)

The juxtaposition of my interviews with the TAs on the subject of how they supported the inclusion of the autistic children in class, with discussions from the room next door about how the senior management of the school was going to argue for the exclusion of such a child, felt deeply ironic. Indeed, the pre-school and early primary school years appeared to be a time when children were particularly vulnerable to exclusion from mainstream settings, with P2 and P4 describing very difficult experiences overall. For P4, this led to social withdrawal for her and her son:

I look back and I think because gradually we were going to toddler groups with C4 and he was struggling in them and you know getting really anxious and I just gradually withdrew and I probably kept him in the house quite a bit for six months because it was too difficult going places. (P4, focus group 2)

While it is not clear in this example how much the staff in these settings might have impacted on the difficulties P4 was experiencing, this does suggest that educational inclusion, in the broadest sense, does not just impact on the child, but on the parents too. For example, P4 also explained that because C4 now attended his local school, he was more accepted in the broader community and so she felt more confident taking him to the park, for example, where she would meet other parents of children at the same school. For her, the problem with sending her son to a special school was that it might be “an hour away”, meaning he would no longer be so well integrated locally, or that they might even have to move house altogether. She feared that under such circumstances, neither she, nor her son, would be met with such understanding or

acceptance in the local park and elsewhere. Furthermore, there was also evidence in my study that the children themselves can be negatively impacted by the threat of exclusion, as demonstrated by C5, during a discussion about what he liked and didn't like about school:

TA10: *What do you not like the most?*

C5: (pause) *I do not like...I do not like...*

RW: *Are there any subj...?*

C5: *...being expelled from (name of school)*

TA10: *C5, What? You're not going to get expelled!*

C5: *yeah*

TA10: *I won't let them. But they don't want to anyway. Why would you get expelled?*

C5: *Because if I do something, I'll get expelled*

TA10: *Oh, C5, it's not like that. Don't worry, you're not going to get expelled at all*
(rubs C5 on his back)

C5: *OK, I will?*

TA10: *Yeah. You're staying here.*

C5: *Yeah!*

TA10: *I promise, until the end of Year 6*

C5: *Oh thank you* (leans over and hugs TA10)

TA10: *You're extremely welcome, you're very, very welcome indeed.* (C5, semi-structured interview)

ii. Attendance, time in class and the curriculum

Amongst the ten children in my study, eight attended school full time. Both of the participating autistic children in School 2 (C4 and C5) were on reduced timetable. C4, who was the youngest in his Reception class, did a shorter day than the rest of the children and this was fully endorsed by his mother, P4. C5 went home for two hours over lunch-time because, I was informed, he could not cope with the noise of the dining hall. However, while C5 did indeed appear very sensitive to noise, this arrangement was highly inconvenient to his mother, P5, who complained that she was unable to work because of it. Furthermore, sensitivity to noise was the reason used to justify the fact that C5 did not attend P.E., even though he had identified this as one of his favourite activities in school. In addition, even when technically present in school, all of the children, with the exception of C8, spent some time away from the rest of the main cohort, either on the school premises or in another location entirely. The reasons provided by school staff for these arrangements are summarised in Table 16.

Table 16: Reasons for spending time away from main cohort

| Reasons | Deputy head teachers | TAs | Teachers | SENCOs |
|---|----------------------|----------------|----------------------------|------------|
| Speech and language therapy (SLT) input | | | T1; T9; T11 | S1; S2; S5 |
| Calming down | | | T2 | |
| Behavioural problems | | | T8 | S4 |
| To take part in 'low ability' group | | TA12 | | S1; S4; S5 |
| Classroom too noisy | | TA9 | T3; T4; T7 | |
| Can't access class activity | | TA2; TA4; TA12 | T1; T2; T3; T4; T5; T7; T9 | S1 |
| Sensory input | D2 | TA10; TA15 | T12 | S2; S3 |

| Reasons | Deputy head teachers | TAs | Teachers | SENCOs |
|---------------------------------------|----------------------|-----------|----------|------------|
| Social skills | | TA8 | T7; T9 | S2; S3; S4 |
| Alternative activity/community visits | | TA6; TA10 | T5 | S2; S3 |
| Interventions | D2 | | T2; T4 | |
| Life skills | | | T2; T9 | S2 |

According to school staff, time out of class enabled them to work with some of the children on the same broad curriculum targets as those of the rest of the class, either in a small, low ability group or on a one-to-one basis with a TA. However, these occasions were more often justified as providing the opportunity to focus on entirely different curriculum targets, such as life-skills, communication or socialisation, or because the child was deemed to need a break from the rest of the class. Some members of staff said that the children lacked motivation and focus, and so needed time away from the main cohort, while others felt that the class could be too noisy, or the activities themselves were somehow contrary to the child's learning style:

He struggles with noise levels, especially if it's something practical like a science experiment, art or discussion, which is when the noise levels might rise. He just runs out of the class. He can't really do Philosophy for Children – he can't cope with talking and he doesn't get the concepts. They're too abstract for him and he doesn't like hypothetical questions e.g. What if there were no adults? He can't handle it. (T7, semi-structured interview)

Another teacher referred to a child's "literal approach" and lack of emotional development, while other staff members emphasised the need for therapeutic support in some cases. Indeed, C4, C5 and C10 were taken to a therapeutic centre for sensory input one afternoon a week, while C5, as we have already seen, spent an additional two afternoons a week shopping and

cooking. Indeed, given that C5 also spent two hours a day at home over lunch-time, the amount of time he spent on the school premises, or with his class, was quite low. This point was made, with some feeling, by one of his TAs during our interview:

My focus has been on trying to reintegrate him with his class, because last year he would only spend five minutes per day with the class, when the register was taken. The rest of the time he was entirely segregated. (TA10, semi-structured interview)

Meanwhile, for C10, the trip to the therapeutic centre meant he missed a science lesson every week, and yet, according to his teacher, there was no mechanism in place to enable him to catch up on the work he had missed. Indeed, D2 stated that some children “might miss whole units of certain subjects” as a result of time out of class, and this was accepted as unproblematic by most. C9 was similarly observed to miss parts of lessons for an ‘intervention group’, meaning that he had to complete the class work set in less time, having received a partial explanation only of what he needed to do. Further, in some cases, withdrawal from class seemed almost arbitrary and to be done on a whim of the teaching assistant, who would take the opportunity to catch up on paperwork. Meanwhile, other TAs were expected to use the one-to-one support the autistic child had been allocated to run small teaching groups, juggling his or her responsibilities to that child with trying to address the learning needs of the other children in the group.

Notwithstanding these issues, it was evident that in some circumstances that spending time away from the main cohort was of clear benefit to the child. In the case of C9 and C10, for example, it provided them with the opportunity to speak confidentially to a TA who they trusted, while other children, such as C1, C4 and C5 were able to spend time on activities that interested them, away from the din of the class. Similarly C4, whose Reception class was linked

both to the nursery class and the ‘outdoor classroom’, appeared to gain greatly from this fluid, ‘free flow’ arrangement, where he seemed purposeful, usefully engaged and content, requiring little or no TA input. Therefore, it is clear is that withdrawal from class – especially self-withdrawal - can be beneficial as a method of inclusion. Moreover, only two of the autistic adults in my study stated that they had been subject to withdrawal from the class in school, although this was so they could attend a group for children considered ‘gifted’, and not because they were considered to be experiencing some sort of difficulty.

iii. Within-class inclusion/exclusion

Some children were educated separately from the other children, but within the same classroom. This was particularly the case for C1, who was placed either at a small workstation at the side of the classroom, or alone at a table, while his classmates were seated on the carpet engaged in a different activity, led by the teacher. On other occasions, he was seated on the knee of the TA (who was on a chair), on the periphery of the group seated on the floor. Therefore, although he was ‘included’ in the classroom, he was usually separated in some way. Moreover, he was also observed to be regularly distracted by the class activity, which might involve some sort of chanting of numbers, for example. Indeed, C1 often took a much greater interest in the whole class activity than the one he was ostensibly engaged in which, through his responses when the teacher noticed and decided to involve him, demonstrated his full understanding of the topic in hand. Further, while T2 felt that the reason C1 was unable to join his classmates was because his mother, P1, “didn’t implement the strategies at home”, P1 was of the view that C1 was being more included with his cohort than was the case:

Yeah, they include him in everything, they don’t leave him to his TA, they don’t leave him, let her deal with everything, they like him to be involved in the group, the reading, sitting down and listening. (P1, semi-structured interview)

However, T10, in another school, appeared to conduct within-class inclusion more successfully. She was staunchly of the view that all children should be included in all activities within the classroom if possible, not least because “the other children learn so much how to support them”. Moreover, it was her view that she should modify her planning and teaching style in order to better accommodate the two autistic children in her class. For example, during P.E. activities, she always placed them at the end of a queue, so they didn’t feel crowded. For tests, she kept the seating arrangements the same, and would hold Maths tests during the usual Maths slot on the timetable, for example, so they weren’t unsettled by a change in the schedule. For C8, she permitted a lot of flexibility during Writing tests, because she knew she would struggle to cope emotionally if she hadn’t finished. With regard to another autistic child with co-ordination difficulties, she asserted that she arranged the classroom “so there are the minimum amount of pathways for him to navigate around, and his seat in the classroom is where it will be easiest for him to get to the different places”. Indeed, T10 felt that the need to make these arrangements caused her to be better organised in her planning overall, and so a better teacher.

iv. Extra-curricular activities and break times

Only one of the children (C3) in my cohort participated in the extra-curricular activities which take place outside of the main school day, such as Breakfast Club and after-school activities. Even in the case of C3, this was only once a week, after-school, when he attended Coding Club. The main reason cited by school staff for the lack of extra-curricular activity was that the children would not be able to access these without support, and that the funding for TAs only covered the main school day. For school trips, which constituted, for some of the children, their favourite school activity, S2, S3 and S4 said that they invited parents to join them in order to support their children, without which they might not be able to attend.

In School 4, children with SEND were also expected to be able to manage without TA support at lunch-times, and this was a further defining factor in whether or not the child was considered to be suitably placed in the school. However, C10, a pupil in School 4, complained that he was bullied at lunch-times, while some of the autistic adult participants identified breaks and lunch-times as being the most difficult parts of the school days to navigate, as they were unstructured and socially complex. Indeed, AA1, AA2, AA3, AA4, AA6, AA8 and AA9 all said they were bullied at school, with break-times constituting times when they were particularly at risk. For AA6, she was always afraid that she would be “cornered”, while AA9, who enjoyed looking at the bark patterns of a willow tree in the school grounds to which she was very attached, noted that the branches “were also a cover for bullies”, who would seek her out.

v. Benefits of Inclusion

T9 was of the view that the presence of C7 in his class was highly beneficial to the other children:

Everyone accepts him, helps him. I like that he’s part of our class. The kids are sensitive towards his academic abilities. It’s nice to see the kids caring because of C7, even the nasty ones. You can’t be mean towards him – he’s just too nice. (T9, semi-structured interview).

Similarly, T1, T2, T3, T4, T8, T10, T11 and T12 were all of the view that the presence of autistic children in their class was beneficial to the rest of the children, principally because it encouraged them to ‘look after’ the autistic child, or understand ‘differences’ in some way. In other words, the sense that the autistic child had ‘needs’ and was ‘different’ was somehow absorbed by the other children – perhaps by dint of the segregation which the autistic child

experienced – and this in turn encouraged them to be more caring and understanding. However, T5 felt that the autistic children themselves don't benefit from this status quo:

I find it a bit sad for the child. You know this whole idea about it helps the other children be more understanding and maybe that works, but I don't know if the autistic child always gets a lot out of it. (T5, semi-structured interview)

vi. Educational diversity

A strong message from the autistic adult participants was that mainstream schools should aim to cater for a much wider range of pupils, with diverse presentations and needs. AA1, AA2, AA6, AA7, AA8, AA9 and AA10 all considered that there should be more individualised education programmes, with greater flexibility embedded within the curriculum to suit a variety of learning styles. AA10 raised the issue of the classroom environment, which she felt should not be too cluttered, somewhat at odds with the reality I found in some of the schools, where the walls and ceilings were covered with various decorations and pieces of art work. For AA1, the curriculum should be balanced between “developing individual interests” and “core skills”, while AA5 asserted that the idea of adapting school schedules for children with SEND only was “bonkers”, because all children need this to a greater or lesser extent.

Indeed, for AA2, acceptance extends beyond being tolerated despite deficiencies, but concerns autistic people being valued for their intrinsic worth:

Everything is set up for the majority, the majority think that they are always right (...). The majority don't accept that they misunderstand because they make the rules - their rules, their way. They think we're a problem, not the system or the environment, or the others who don't understand us. (AA2, semi-structured interview)

While the autistic adults called for greater understanding and acceptance, this can be contrasted,

to an extent, with the views of most of the parents, who hoped their children would be able to adapt to a society which wouldn't tolerate them as they currently were.

Discussion

My study shows that on the whole, inclusion operates in a rather fractured and unsatisfactory way in these schools, with autistic children subject to part-time timetables and alternative curricula, but without any consistent justification or consideration of the broader educational, social and psychological implications. While their presence in mainstream schools is still contested, some children, already considered to be educationally disadvantaged as a result of their autism, are routinely taken out of lessons, and are expected to somehow cope or catch up on their own, without any planning or support. Indeed, the fact of missing parts of the core curriculum is considered unimportant compared with the ostensible drive towards independence, life skills and communication. Meanwhile, although autistic children are taken out of lessons for 'social skills' training, they are excluded from the more natural social opportunities that after-school clubs provide. Schools also rely on their parents for day and residential trips, potentially creating an additional social barrier for those children, and placing a further burden on their parents, already negatively impacted by the part-time school attendance of their children, or the lack of availability of the extended school day, which other parents use to access work and leisure. In these ways, the educational exclusion of the children also results in different forms of exclusion for their parents, limiting their ability to make their own broader contribution to society. Moreover, if the one-to-one support the children receive is diluted by the TA being required to support other children at the same time, the potential absence of TA input during break-times is even more problematic. Already a difficult time of

the school day for some autistic children due to their unstructured nature, break-times also present opportunities for bullies, as the autistic adults, in particular, recounted.

While it was certainly the case that small group work, withdrawal from class and even alternative learning targets could be beneficial for some of the children, on the whole it was these very strategies for inclusion which formed the driver for exclusion of the children in my cohort. Indeed, even though a number of school staff cited the social and affective benefits of the presence of an autistic child in their class, the concomitant advantages of the inclusionary arrangements for the autistic child were not so obvious.

Above all, it seemed that the way in which inclusion operated was dependent on the particular circumstances of the school, such as the availability of space, or staff, or the views of whichever person considered expert. Further, it is not the action itself which appeared to define whether or not it is exclusionary or inclusive, but how the decision is reached, and whether or not it is genuinely beneficial to the child. Moreover, according to the autistic adults, inclusion concerns much more an acceptance of diversity and a recognition that all children, in some senses, have ‘needs’, rather than targeting some with a raft of inclusion strategies, which might serve paradoxically to exclude them further.

Theme 8: Descriptions of Autism

Codes: Autism; Ability; Form of diagnosis

In my final theme, I consider descriptions of autism, and reflect on the implications of these for the inclusion of autistic children in mainstream schools. All adult participants were asked how they would describe or define autism, and in this theme, I set out the various descriptions which participants provided, after which I offer a brief discussion.

Participants, including the autistic adults, found this question difficult to answer, and some said that they couldn't define autism.

Table 17.1: Autism is difficult to define

| What is autism? | Autistic Adults | Deputy head teachers | Parents | SENCOs | TAs | Teachers |
|-----------------|-----------------|----------------------|-----------------------------|--------|------------|----------|
| Can't define | AA2; AA6; AA8 | D3 | P1; P3; P4; P5; P6; P7; P10 | S2; S5 | TA10; TA11 | T7; T9 |

There was a general sense from these participants, especially the parents, that it is unhelpful to try to group all autistic people together under a single definition, as autism is so varied in its presentation. Similarly, AA8, who was the only participant to mention 'neurodiversity', asserted the following:

I'm not sure it's possible to describe autism as one thing, and I'm not sure it's helpful either. (AA8, semi-structured interview)

Furthermore, some of the school staff asserted that the autistic children in their class were not as they had expected, and these pre-conceptions were based on negative associations with autism such as inflexibility, lack of imagination, behavioural problems, lack of eye contact, poor social skills and not seeing the point of view of others. For these participants, they had not anticipated that some of the autistic children they encountered would be of high ability, for

example, or well-behaved. A small number cited autistic family members, who were reported to be experiencing various difficulties in life, as the source of this negative conceptualisation. Meanwhile, two of the parents considered their child to be much more skilled and sociable than they generally associated with the idea of autism.

Table 17.2: Autistic children not as expected

| What is autism? | Autistic Adults | Deputy head teachers | Parents | SENCOs | TAs | Teachers |
|-----------------|-----------------|----------------------|---------|--------|---------------------------------|------------------|
| Not as expected | N/A | | P2; P6 | S4; S5 | TA1; TA2; TA3; TA11; TA12; TA15 | T3; T7; T9; T10; |

Other participants used the term ‘spectrum’ to convey the notion that autism is highly varied in its presentation. For D2, “the spectrum is enormous”, while D4 said that it was the “scale or spectrum of it that blows my mind”. However, none of the autistic adults used the term ‘spectrum’.

Table 17.3: Autism is a spectrum condition

| What is autism? | Autistic Adults | Deputy head teachers | Parents | SENCOs | TAs | Teachers |
|----------------------|-----------------|----------------------|------------|------------|---|-----------------|
| A spectrum condition | | D2; D4 | P2; P3; P6 | S1; S2; S5 | TA1; TA4; TA6; TA10; TA12; TA13; TA14; TA15 | T3; T4; T7; T10 |

For the school staff, where a child might be placed on the spectrum hinged on whether they were of high or low ability and how responsive, interactive and socially skilled they were considered to be. Furthermore, while only one of the autistic adults used the term ‘high functioning’, some of the parents described their own children as such, centred on the view that their children could deal well with change, had a high level of understanding and a range of interests. On the other hand, children who were ‘low functioning’ or ‘severe’ in their autism -

the latter being the term most frequently used in this context - were at the opposite end of this 'spectrum'. Such a child, according to P2, might have the following difficulties:

...a child that needs specialist care, maybe can't communicate, you know...can't do many day-to-day things, you know, wouldn't be able queue in a queue, wouldn't be able to sit with a group of children, would really freak like, roll around the floor, and scream.

(P2, semi-structured interview)

None of the parents described their own child as 'low functioning'.

i. Problems associated with autism

For some participants - and school staff in particular - autism is inherently problematic, associated with a range of difficulties. Some staff asserted that they had been worried or fearful when they learned they would be working with an autistic child, either based on the 'reputation' of that particular child, or because of negative associations with autism more generally. Indeed, P9 was of the view that autism can ruin lives.

Table 17.4: Autism is a problematic condition

| What is autism? | Autistic Adults | Deputy head teachers | Parents | SENCOs | TAs | Teachers |
|-------------------------|-----------------|----------------------|---------|--------|----------------------|------------|
| A problematic condition | | D5 | P9 | | TA3; TA6; TA10; TA11 | T3; T4; T5 |

The specific problems associated with autism are set out in Table 17.5.

Table 17.5: Problems associated with autism

| What is autism? | Autistic Adults | Deputy head teachers | Parents | SENCOs | TAs | Teachers |
|--|-------------------------|----------------------|---------------------------------|----------------|---|--------------------------|
| Behavioural problems | AA9 | | P1; P2; P3; P8 | S4 | TA4; TA7; TA11; TA13; TA15 | T4; T5; T8 |
| Set in ways, self-directed or obsessive | AA10 | D2; D3; | P1; P2; P5; P6; P8 | S4; S5 | TA2; TA3; TA4; TA6; TA7; TA8; TA9; TA10; TA11; TA12; TA13; TA14; TA15 | T4; T6; T7; T8; T10; T11 |
| Need for a routine | AA1; AA10 | D2; D4 | | S1 | TA5; TA6; TA13 | T2; T7 |
| Social interaction difficulties | AA3; AA4; AA5; AA6; AA8 | D2; D3; D5 | P1; P2; P3; P4; P6; P8; P9; P10 | S1; S3; S4; S5 | TA1; TA3; TA6; TA8; TA13; TA15 | T2; T3; T4; T5; T7; T8 |
| Speech and communication difficulties | AA4 | D4; D5 | P2; P3; P4; P6; P8 | S4 | TA1; TA5; TA6; TA9; TA11; TA15 | T7; T12 |
| Problems in understanding | | D5 | P1; P2; P6; P7 | S1; S4 | TA3; TA4; TA5; TA8 | T2; T3; T4; T5 |
| Low ability | | | | S1; S4 | TA3; TA6; TA12; TA14 | T2; T3; T4; T5; T9 |
| Lacking concentration | | D3 | P1; P2; P3; P6 | S4 | TA3; TA4; TA5; TA9 | T3 |
| Lack of empathy | | D5 | P9 | S1; S2 | TA3; TA4; TA5; TA8; TA10 | T4; T7; T8; T11; T12 |
| Lack of eye contact | AA4 | D3 | P2 | | TA6; TA12; TA13 | T10 |
| Immaturity or developmental delay | AA9 | | P3 | | TA1; TA5 | T4 |

Table 17.5 shows that it was predominantly the school staff – and TAs in particular - who associated autism with various problems and difficulties. These especially concerned the notion that autistic people have ‘fixed’ interests, and are obsessive and set in their ways. In addition, while some members of staff had complained that the autistic children would not follow the

routine of the class, there was also a perception that a defining – and problematic - characteristic of autism is a need to follow a set routine.

The category of social interaction difficulties presented the area where most participants agreed, with most of the parents and half of the autistic adults considering that this is a problem for autistic people, as do some of the school staff. However, it is noticeable that no autistic participants at all feature in some of these categories, while none of the parents associated autism with low ability or the need for a routine. However, a number of school staff said that the autistic child in their class was “at the bottom”, while one child was described as being “even lower” than the lowest ability group. Meanwhile, some participants felt that the problems in understanding resided in a difficulty with abstract language and a tendency to think literally.

Moreover, while some non-autistic participants considered that autistic people are unable to feel empathy, or understand the point of view of others, AA4 felt that this is an appearance only of incomprehension, rather than a reality. P8 also asserted that as far as her daughter was concerned, it was more an inability to know how to react in certain situations, and not an inability to empathise. In addition, T9 stated that the presence of C7 in the class gives the other children the opportunity to “show some empathy”.

Most of the problems associated with autism described so far are characterised by a sense that autistic individuals, their ways of being and responding, are a problem for others. However, some participants highlighted the difficulties autistic people can experience instead. According to AA8, for example, autism can be accompanied by associated difficulties such as anxiety, epilepsy and sleep difficulties. P3, P8, P9, TA7, T4, T10 and T11 also associated autism with distress or anxiety. Moreover, according to AA2, for example, this distress emerges from a lack of acceptance and understanding, or being ignored or ridiculed. Indeed, AA1, AA6, AA7, AA8

and AA9 all described their time in primary school, or aspects of it, as being upsetting and difficult. However, T11 stated that for C9, his anxiety stemmed from his attachment to the placement of items in the class, which he feared might be changed, rather than any issues associated with his peers or school staff. AA9 also described her strong attachment to a willow tree in the school grounds, which she enjoyed looking at during break times. Indeed, when the tree was cut down, she was “distraught”. What is not clear, however, is whether this attachment to items is associated with autism, or a response to a stressful situation in school, where the social rules – a point highlighted by most of the autistic adults – are opaque.

ii. Different

The word ‘different’ was frequently used to describe autistic people. However, it was evident that this word carried multiple possible meanings: some were negative, others positive, and others still were relatively neutral.

Table 17.6: Different (strange)

| What is autism? | Autistic Adults | Deputy head teachers | Parents | SENCOs | TAs | Teachers |
|---------------------|-----------------|----------------------|-------------------------|--------|-----------------|----------|
| Different (strange) | | D2 | P2; P4; P5; P8; P9; P10 | S2; S4 | TA4; TA10; TA15 | T3; T10 |

Parents did not appear to consider their children to be strange, but were concerned that others would find their children’s behaviour “odd” or “weird”, especially as they got older, citing hand-flapping, making noises and limited speech as being characteristics that might mark their children out as odd, leading them to be shunned socially by their peers. According to some participants, therefore, this ‘difference’ extends to physical manifestations. In addition, TA9 and T10 highlighted a lack of co-ordination and fine motor skills of some autistic children, while AA6, AA9 and S5 were of the view that there are no outward physical signs of autism.

As we have seen previously, a number of school staff consider that autistic children lack concentration:

Autistic children are prone to drift off – they need constant reminding. (S4, semi-structured interview)

This was linked to the idea that they are somehow in a different world to others:

They live within their own world far more than they do in the world that we do. (TA4, semi-structured interview)

This apparent disconnectedness was also associated with ‘severity’ of autism:

It sits on a spectrum – at the top end there is Aspergers. At the extreme end – they’re in a complete bubble. (S2, semi-structured interview)

Meanwhile, AA1 complained that at school, she was made to feel “like an alien” and “not human” as a result of her autistic traits. Similarly, AA9 complained that it was other people who made her feel “different”, and P8 was “made to feel like an alien” when she was stared at while helping her daughter. In addition, the translator for P7, who was not in fact reflecting the parent’s view at this point, stated that the siblings of C7 were “perfect” in comparison to him.

However, some participants also felt that autistic people possess unique qualities:

Table 17.7: Different (special)

| What is autism? | Autistic Adults | Deputy head teachers | Parents | SENCOs | TAs | Teachers |
|---------------------|-----------------|----------------------|--------------------|--------|-----------|----------|
| Different (special) | AA5; AA6; AA10 | D3 | P1; P2; P4; P6; P9 | S5 | TA2; TA11 | T9 |

According to AA5 and AA10, autistic people have the necessary skills required for invention, and so have contributed significantly to the evolution of the human race, while for S5, “some have amazing skills”, which can be associated with genius.

Other descriptions, meanwhile, referenced ‘difference’ in a more anodyne fashion, without positive or negative associations in any obvious sense, although being ‘different’ was seemingly accepted or welcomed by some, and not by others. According to AA1, AA2 and AA10, autism is a “neurological difference” which impacts on how people think, process information and respond to the environment. For AA7, the problematisation of autism results from the fact that they are a minority, ‘different’ from the norm, and so subject to prejudice and exclusion. Meanwhile, AA2 was of the view that it is non-autistic people who are “odd” in certain respects. P1, P2, P6, P7 and P10 all used the term ‘different’ to describe their autistic children, while P5 was strongly of the view that all children are ‘different’, and that some should not be marked out as such. Some school staff – D5, TA9, T1, T7 and T10 – also used the term ‘different’ to describe autism, while other participants used this term to reinforce the idea that autistic people differ greatly from each other. Ultimately, the word ‘different’, which was the word most commonly used to describe autism, emerged as polysemic, and subject to multiple associations and interpretations.

iii. Autism and ability

A high number of participants commented on the abilities of autistic adults and children. While it was only school staff who referred to autistic children as being of low ability, D4, P1, P2, P4, P5, P6, P9, P10, S1, S4, TA2, TA12, T6, T10 and T11 all stated that some were able, but might struggle to manifest this, mainly due to the perceived inflexibility of the curriculum, but also because of poor communication, speaking or writing skills. Similarly, AA7 and AA9 were also of the view that their primary schools had not enabled their strengths and skills to be manifested.

Moreover, while AA9 said that she had been considered to be of low ability at school, AA2, AA4, AA6, AA8 and AA10 were all thought to be academically able during that time. Furthermore, eight of my ten autistic adult participants had a university degree, and six also had a post-graduate qualification. In addition, AA1, AA5, AA6, AA9 and AA10 considered autistic people had certain specific abilities deriving directly as a result of being autistic, a view also shared by P9, TA5 and T9. These abilities were deemed to stem in part from perfectionism and attention to detail.

Table 17.8: Perfectionism and attention to detail

| What is autism? | Autistic Adults | Deputy head teachers | Parents | SENCOs | TAs | Teachers |
|---------------------------------------|-----------------|----------------------|------------|--------|-----|----------|
| Perfectionism and attention to detail | AA2; AA8; AA10 | | P5; P8; P9 | | | T4; T10 |

Moreover, according to AA10, attention to detail, which is a positive trait on the whole, can also accompanied by an inability to filter out non-salient items. This can result in “a need for sameness and predictability and resistance to change”, an issue some of the school staff considered problematic. It was also considered to result in a high level of skill or knowledge in certain, specific areas.

Some participants also considered that autistic adults and children have a particular learning style:

Table 17.9: Autistic learning style

| What is autism? | Autistic Adults | Deputy head teachers | Parents | SENCOs | TAs | Teachers |
|-----------------|-----------------|----------------------|------------|--------|----------|----------|
| Learning style | AA6; AA8 | D2; D4 | P4; P5; P6 | S1; S5 | TA4; TA5 | T2; T6 |

Although this learning style wasn't especially defined by participants, some of the autistic adults felt that the school curriculum should be more adaptable to different types of learners (e.g. visual, kinetic etc.).

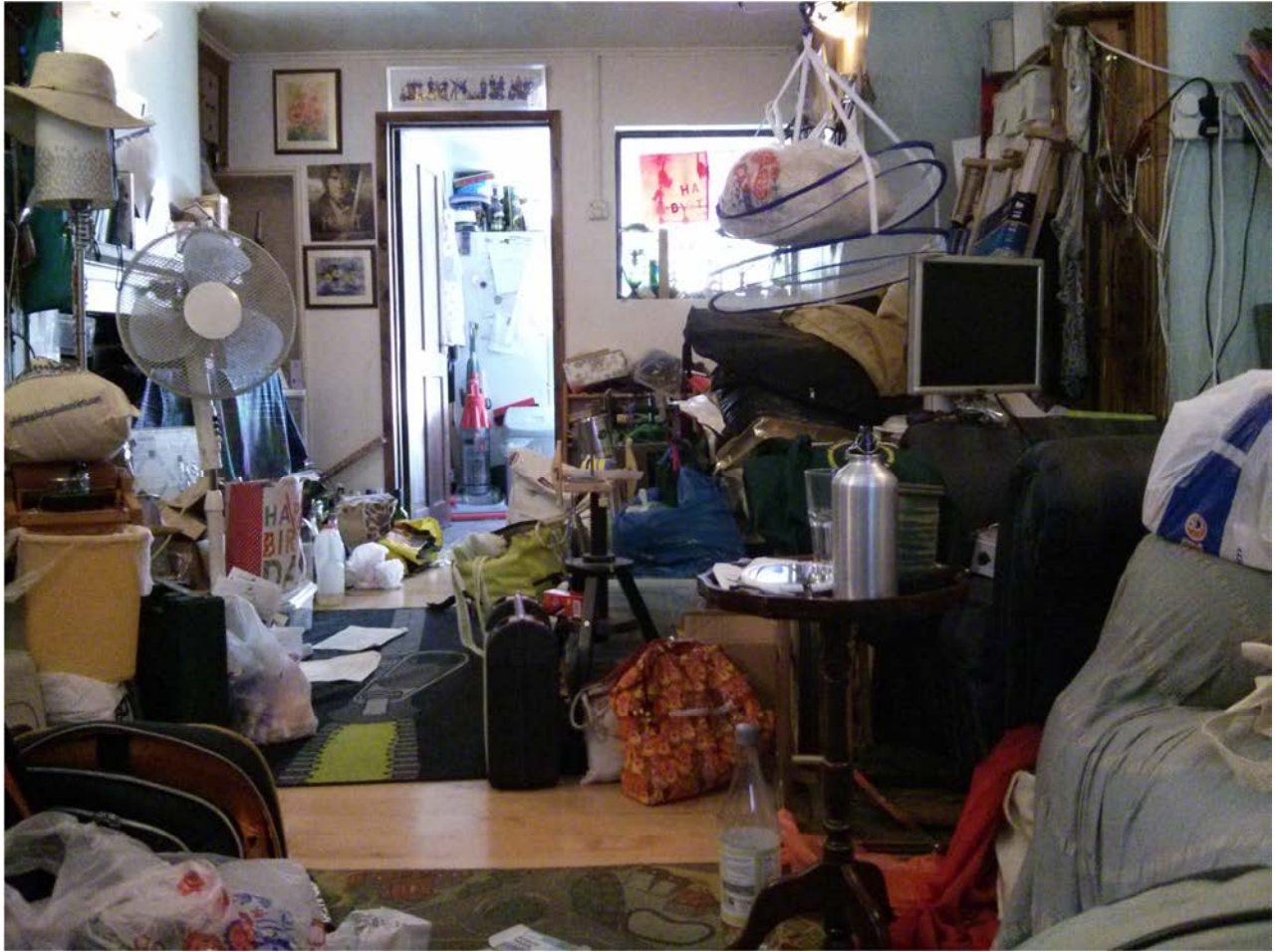
iv. Sensory issues

During my time in schools, C1, C3, C4, C5, C9 and C10 were observed to have certain sensory sensibilities. According to D4, P2, P6, S2, T1 and T5, sensory issues are a defining aspect of autism, while AA1, AA2, AA3, AA7 and AA9 asserted that autism is denoted by a varying reaction to environmental factors. For AA1, this had been an exclusionary issue, as her peers complained that she would hold their hands too tightly during games, for example. C5 stated that noise made his "ears bleed", and T7 said an autistic child could not attend school clubs because of the noise levels. TA6 said that C4 had been highly distressed by the sirens during a trip to the local fire station, while TA8 asserted the following:

They don't like noise – people need to accept this – it's stronger than them, it's the condition. (TA8, semi-structured interview)

For AA6 and AA10, the noise levels at school had created difficulties for them, while sensitivity to noise was provided as a reason to exclude C3 and C5 from certain aspects of the curriculum. AA9 was of the view that autism consists of a "multi-sensory" response to the world, and as part of her description of autism, provided a picture of her living room (Plate 1), which she described as a "clutter bomb".

Plate 1



The living room of AA9 (reproduced with permission)

Discussion

The fact that school staff, and TAs in particular, consider autism to be a condition defined by difficulties, is an indication that the inclusion of autistic children in mainstream primary schools continues to be problematised. Parents and autistic adults, on the other hand, were much less likely to consider autism to be problematic, although many participants agreed that social interaction difficulties are a common issue. In addition, while some parents considered their child to be “high functioning”, other, imagined “low functioning” children were seen as very different to their own child. Indeed, in this, the views of parents continue to demonstrate the

high value placed on social skills, and mirror their perception of special schools as places suited to ‘other’ children. Further, while all parents spoke lovingly about their children, some felt it was their autism in particular which provided them with admirable traits. For P1, for example, her son was simply “awesome”.

A striking contradiction was provided by the fact that school staff perceive their role as helping the child stay on task and follow the school routine, and the view that autistic children are routine-bound and set in their ways. Similarly, their perception of the communication difficulties of autistic children is at odds with the several ways, already described, in which the communication of the autistic children is ignored or considered invalid. Moreover, there was also evidence that everyday issues, which other school children might experience routinely, were unnecessarily problematised in the case of the autistic children. This included toilet training, which many children in Reception class need help with, but which was frequently evoked in the case of C1 and C4, both the youngest children in their schools. This point was firmly made by P3, who felt that at times, school staff confused behaviour typical of young children, with some sort of unwelcome manifestation of her son’s autism. Furthermore, AA1, AA2 and AA7 expressed the view that autistic people are simply seen as ‘a problem’, and that this creates difficulties for them. Meanwhile, the notion of ‘difference’, which ostensibly a permits tolerance and acceptance, emerges as a concept which positions others as separate and alien. This raises the question of whether the inclusion of autistic children in schools is hampered by the perception that they are both ‘a problem’ and somehow not part of the main cohort.

Noise in schools transpires as a potentially significant exclusionary factor for autistic children, predominantly as a result of sensory issues. In my own case, while I did not keep a systematic record of this, I often found the classrooms and the general environment of the schools to be

extremely noisy, both from the children (especially during break times), and from external entities such as traffic. When transcribing the video recordings, I cannot always decipher the instructions of the teacher, for example. However, none of the school staff demonstrated any awareness of how the general hubbub might impact on the autistic children, in terms of their general well-being, and the oft-cited inability to concentrate. Furthermore, a qualitative difference was ascribed to the ‘noise’ that the autistic children might make, considered by some to be a problem associated with autism, with the more typical noise of school children, which included screaming during break times, considered unremarkable and unproblematic. Indeed, C10 was not allowed to join his classmates in the school library - a place I found to be dominated by the sound of teachers loudly instructing pupils - ostensibly because of his inability to understand the need for ‘silence’. In addition, I described earlier how over-zealous attention and input from TAs can prevent autistic children from having valuable ‘zoning out’ time, which other children were observed to engage in and indeed require. Consequently this, combined with the high level of input from a TA, might also create an additional need to take mental breaks, a requirement potentially unrecognised and misunderstood by school staff.

Finally, it is also useful to factor into this analysis the input from the Community Paediatrician (CP), who oversees all childhood autism diagnoses within the LA where the schools are placed. She asserted that while autism diagnoses had increased “dramatically” and “exponentially” since the year 2000 (when the diagnostic clinic had started), no effective system of recording was in place, and so they are “almost guessing at numbers” for prevalence figures. While it is hardly surprising, therefore, that consistent and reliable national prevalence figures are impossible to obtain, the very diversity of views about the nature of autism revealed in my study underscores how complex this process is. Indeed, the CP stressed that “clinicians are now actively looking out for autism in other groups”, including children with ADHD, Prader Willi

and cerebral palsy, thus ensconcing autism diagnosis even further within a medical model. Moreover, while AA8 and AA9 both found their own diagnoses, as women, were hampered by “a male model” of Aspergers, the CP stated that three times more boys than girls continue to be diagnosed in the LA, adding a further complexity to this issue.

Chapter summary

In this chapter, I have set out, explored and discussed my findings from my interview and observation data, and have also included a few illustrative comments from my research diary. In addition, I have referenced the questionnaire data from the previous chapter where relevant. The eight, interlinked themes which emerged from the processes of coding and thematic analysis are explicated and explored, predominantly in accordance with each participant group: autistic children, their parents, autistic adults, teaching assistants, teachers, SENCOs and deputy Head Teachers. Nevertheless, I also draw on data relating to individuals when it is instructive to do so. In the next chapter, I present a summative discussion where I synthesise the core issues emerging from the eight themes, focussing in particular on descriptions of autism, curriculum access and assessment, support in school, inclusion and language and interpretation. This is followed by a short conclusion in which I consider the broader applicability of my study and its contribution to the field of autism education research.

CHAPTER 7: SUMMATIVE DISCUSSION AND CONCLUSIONS

At the beginning of this thesis, I set out, in the literature review, the ways in which the educational provision, assessment and attainment of autistic children is beset by difficulties, and how the information which is available presents a gloomy picture of their time in school and longer-term outcomes. Further, while teachers complain of stress resulting from the presence of autistic children in the classroom, no clear message emerges in relation to the benefit of a modified curriculum or the presence of teaching assistants. Indeed, there appears to be considerable uncertainty about what the educational priorities of autistic children should be, and while the legal basis for their presence in mainstream schools is formidable, they are subject to exclusion and bullying. Moreover, autism is typically diagnosed within medical contexts and is associated with various impairments, triggering a drive towards interventions and a quest to find its genetic aetiology, a mission which dominates the autism research field.

However, and in a manner evocative of the medical versus social models described in chapter two, other conceptualisations of autism exist, where the focus is not on dysfunction, but on alternative ways of thinking and responding, sometimes centred on the notion of ‘difference’. Moreover, while the idea of difference can lead to acceptance and inclusion, it can also serve to further marginalise and exclude, in ways in which some feminist writers and others have highlighted. Indeed, certain individuals can be ‘othered’ by the manner in which they are described and positioned, and the very definition of autism as distinguished by communication impairments results in a sense that they are disordered, incomprehensible and not necessarily to be believed.

Informed by an interpretivist paradigm, my aim was to provide a multi-perspective study in which the views of all the individuals involved in a child’s education are incorporated, including

also the opinions and experiences of autistic adults. Therefore, a case study format, which offers ‘a rich picture with many kinds of insights from different angles, from different kinds of information’ (Thomas, 2016, p. 21) provided the necessary research design, in which the ‘cases’ were five mainstream primary schools in England. My research questions focused on whether autistic children access the curriculum and tests and if so, with what sort of support, as well as identifying what the educational priorities were for them. I wanted to consider how they were being supported in school and to reflect on broader aspects of inclusion, such as extra-curricular activities and whether their parents had considered a special school placement, for example. In addition, I aimed to find out how the different participants conceived of autism, and if this had any sort of relevance to how the children were included, educated and supported. Overall, I hoped to draw from my findings ideas about how the participation, experience and outcomes of autistic children in primary schools could be improved.

My project incorporated diverse participants and sources of data, and so the case study design permitted the range of methods of data collection and analysis required in order to try to answer my research questions. My findings, which included quantitative data relating to educational priorities and curriculum access, as well as two instructive ‘outlier’ examples, were predominantly analysed via thematic analysis, and are discussed in detail in Chapter six. In this final chapter, I present a synthesis and summary of my findings, drawing together the different strands of my research project. I offer additional analysis in the key areas which emerged from my findings, concluding with a brief discussion concerning the broader applicability and contribution of my research.

Summary of Findings

Descriptions of autism

While at the outset of my data collection, I was not certain of the ways in which questions about descriptions of autism would prove relevant, my diverse findings indicated strongly that addressing this issue ought to be the starting point of questions about the school curriculum, access to tests, support, educational priorities and broader matters relating to educational and societal inclusion. For example, the support the children received, when it was unskilled and negatively experienced by them, was predicated on the notion that the children were dysfunctional and in need of repair, causing school staff to fail to respond to them on a human level, and perhaps contrary to their own instincts. Indeed, this very identification of needs seemed to correspond to an association of the children as alien presences, not quite in this world, subject to the ‘individualistic and pathologizing gaze’ of others (Liasidou, 2012, p. 102).

This attitude compared with other examples where school staff stated how much they valued their relationship with the autistic children, and support was based on a recognition of their individuality and particular disposition, which in turn, made staff feel more effective in their work. Meanwhile, the educational priorities for the autistic children were sometimes set according to a generalised notion of autism as a condition beset by impairments, with little consideration of the views of the children themselves, or the longer-term impact of these arrangements on their educational attainment. Indeed, while most of the children in my cohort expressed ambitions for the future, there was a sense amongst some school staff that ability, support needs and autism were somehow incompatible, as shown in this comment about a child who was not a participant:

He is very high ability and he functions perfectly well without support. I don't know how he got a diagnosis of autism. (T7, semi-structured interview)

In addition, the association of autism with repetitive behaviour, rigidity and being routine-bound (Barrett, 2014), meant that staff failed to see their own inflexibility, the repetitive nature of their instructions and the learning activities they set, and the high value they placed on the routine of the school. For example, during the unsuccessful bear-matching activity with C1 described on p. 183, the TA issued almost identical questions and instructions 73 and 53 times respectively over the course of 12 minutes, equating to 10.5 questions or instructions per minute. Some staff refused to desist from or alter learning targets which might have very little educational value, ascribing the child's failure to comply to difficulties inherent to autism, rather than the tedious or repetitive nature of the activity itself. Similarly, the identification of communication difficulties in the children, considered at times to be 'deviant or bizarre' (Emam and Farrell, 2009, p. 407), and a set idea about how they should be addressed, meant that school staff were oblivious to their own unclear communication. Meanwhile, the actual communication of the children was ignored and treated as invalid, unless it corresponded with what the adults wanted to hear. These issues are not only evocative of the 'double empathy problem' described by Milton (2012), where the putative lack of empathy of autistic people is shown to reside in those who make this assertion, but of the ways in which inclusion is shown to be anchored in the context of values and power (Allan, 2008). Indeed, communication targets were shown to be closely associated with a desire to control and somehow civilise the autistic child. However, an important shift in this dynamic would take place when the child was able to access activities which were motivating, resulting – perhaps counter-intuitively – in more, not less compliance on the part of the autistic child.

Further, if the association of autism with impairments caused school staff not to hear what the children were saying, it also meant they failed to see what the actual child in front of them was doing. One TA, for example, as we observed C4 engage in elaborate and patterned play with toy animals, commented that he was “lining things up”, because this is what she had been told to expect of autistic children. This ‘confirmation bias’ (Jonas et al., 2001), where contrary information is ignored once a decision has been made, underlines how crucial understandings of autism are in the context of school inclusion.

Therefore, my findings suggest that the ways in which autism is conceptualised should be the starting point of all other issues relating to the educational inclusion of autistic children, meaning that their participation, experience and outcomes can only be addressed if this core issue is tackled too. How autistic children access the curriculum and tests can only be understood if the support they receive is critically evaluated and implemented flexibly, which in turn must derive from how inclusion (and exclusion) operate more broadly in the school. However, none of this makes sense unless there is an informed understanding of what autism is, and how autistic children might think, learn and respond to their environment, as depicted in Figure 15.

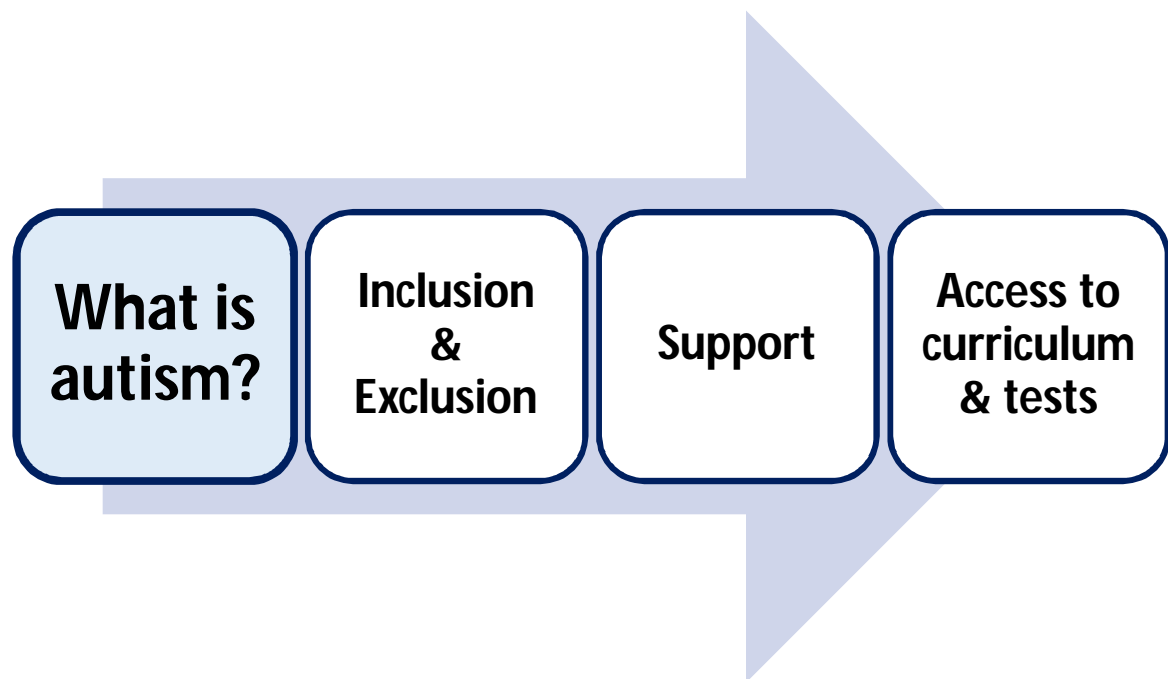


Figure 15: An understanding of autism as the starting point to educational inclusion

Inclusion which proceeds on the basis of assumptions derived from the medical model of autism may simply be setting some children up to fail. Indeed, the typical focus on the children's deficits means that 'nothing is said about the necessity to reconsider the nature of schooling, the curriculum and teaching styles, as well as the exclusionary policies and practices firmly embedded in processes and practices of current schooling' (Liasidou, 2012, p. 102).

Furthermore, Grinker (2015) asserts the following:

'...we can take the medicalized, genetic approach to autism too far, to a point at which a disease construct is so profoundly fetishized that we fail to question the validity of the construct, and to see its cultural constitution. Medicalized approaches to autism (...) also risk making a disease out of traits that are likely distributed in varying degrees among the general population, obscuring the positive characteristics of autism that contribute to human diversity and creativity, neglecting the possibility for new forms of sociality to emerge, and diminishing the role that autism can play in forming new social identities.' (p. 345)

Similarly, Kapp et al. (2013), discuss the concept of ‘neurodiversity’, and suggest that autism, whether accompanied by impairments or not, is a manifestation of human diversity, a view echoed by some of the autistic adults in my study. Meanwhile, Lawson (2011) argues against the idea of autism being narrowly defined as on ‘a spectrum’, a point also made by Happé (2015). Indeed, for AA9, autism has “a culture of its own”, while AA6, perhaps in contrast to some of the school staff who could not ‘see’ the autistic children, considers that autism “is rather like a pair of glasses which gives someone the ability to see”. Moreover, just as for the feminist writer Kristeva (1981), the oppression of women means that she cannot ‘be’, it follows that ‘a feminist practice can only be negative, at odds with what already exists’ (p. 137). Similarly, the failure to permit autistic people to simply ‘be’ has contributed to a growth in autistic activism which ineluctably opposes the status quo:

‘The cultural politics of autistic activism signify a resistance to those assumptions about autism driven by the deficit and cure ideologies.’ (Thibault, 2014, p. 79)

For Thibault (2014), autistic people are themselves ‘redefining autism’ and in so doing, they are ‘creating new spaces in the cultural landscape, shifting boundaries, changing old paradigms and altering abnormality discourses’ (p. 80).

Curriculum access and assessment

In the literature review, I set out how, according to DfE datasets, autistic children appear to be performing poorly in national tests, or are even absent from the data altogether, suggesting some might not be taking those tests. I also outlined how according to Douglas et al. (2012), more, not less monitoring of pupils with SEND is suggested. Indeed, this point was further substantiated in Douglas et al. (2016). In addition, during the course of my research project, wide-ranging reforms to both the National Curriculum and systems of testing have taken place

(DfE, 2013f), and the resultant picture for children with SEND is rather mixed. For example, following these reforms, the number of children being monitored according to ‘primary need’ in DfE datasets nearly doubled from 2014 to 2016 (DfE, 2017), meaning that more autistic children are now included in these results. However, assessment schemes for children with SEND are still under review (Standards and Testing Agency, 2016), and appear to represent a wish to remove from these datasets – apparently uncritically – children deemed to be ‘working below the level’ of national tests. Moreover, less formal monitoring and accountability are proposed for those children. However, my research suggests that the disjointed nature of the school timetables of some children, where they regularly miss lessons or parts of lessons, or are expected to complete alternative learning targets amidst numerous distractions, are important factors relating to their attainment. In addition, their education appears to rest in the hands of the teaching assistants, who are neither qualified nor remunerated to carry out this role. Consequently, there is a need to critically evaluate why autistic children might perform poorly in tests, or appear to be ‘below the level’ of the tests themselves.

Moreover, some aspects of certain subjects were shown in my study to be both presented and assessed in ways which are contrary to how autistic learn, process information and demonstrate their understanding. Phonics, for example, appears to not correspond to how autistic children learn to read. Writing causes particular difficulties, suggesting an urgent need to incorporate the vast array of current technological devices and programs available, especially as many children enjoyed – and were especially adept at using – computers (Murray and Lawson, 2007). In addition, my evidence indicates a need to recognise the value of a sensory approach to learning for all primary school age groups. Further, there is clearly a necessity to review and re-evaluate current testing procedures from the point of view of access for autistic children, and to consider whether autism-specific accommodations could be of benefit. Indeed, more

fundamental changes in layout, wording and accepted, interpretative norms need to be considered, as there may be an argument for a more, fundamental shift in the perception of autistic expression, where its inherent value and aesthetic are recognised.

In addition, the role of interests – sometimes designated as ‘special’ (Jung and Sainato, 2015) or ‘restricted’ (Gunn and Delafield-Butt, 2016) – can be problematised or perhaps pathologised, even though their role in enabling learning is increasingly recognised (Jones et al., 2008; Wittemeyer et al., 2011a; Gunn and Delafield-Butt, 2016). In my study, not only was there evidence of the ‘monotropic’ thinking style (Murray, 2014) of autistic children, but the ways in which this is aligned with strong interests was shown to result, predominantly, in a range of educational and social gains for them, as well as permitting a sense of well-being and the possibility to self-calm. Indeed, C4 in particular, who was observed to benefit greatly from the ‘free flow’ of his Reception class, evoked the ‘flow states’ described in McDonnell and Milton (2014), where the concept of autistic ‘repetitive behaviour’ is reconsidered and shown to be closely associated with a state of well-being. These factors also suggest autistic children would benefit from a more flexible and less directive teaching style in school.

Support in School

If teacher training in SEND consists of ‘a perfunctory rehearsal of the mantras of inclusion and a tour of the range of children’s deficits they are likely to see in the classroom’ (Allan, 2008, p. 19), TAs ‘are encouraged to acquire an identity as experts on children’s deficits’ (ibid., p. 22). In addition, as I found in my study, the role of TAs seems to extend significantly beyond providing one-to-one support, for example, meaning that they are ‘spread so thinly across the school that there is little impact. They can never give enough and are offered scant guidance on their uphill struggle’ (Allan, 2008, p. 22). Indeed, Cremin, Thomas and Vincett (2005) found

that not enough attention is paid to ‘the changes that might occur when these extra people move into the domain of the teacher’ (p. 415). Meanwhile, Lindsay (2007a) asks whether the TA should ‘support, supplement, extend or replace the teacher’ and cite Broer, Doyle and Giangrenko (2005), who found that the TA has four potential roles: mother, friend, protector and primary teacher (p. 14). In these descriptions, the role of the TA is potentially extensive, acquiring responsibilities far beyond his or her job description, remuneration and possibly capabilities.

Moreover, for Humphrey and Lewis (2008), and as I also found, the presence of TAs resulted in ‘little or no actual interaction with class teachers’ (p. 39), a point also highlighted in Norwich and Kelly (2004). For Dockrell et al. (2012), autistic pupils were ‘significantly more likely’ to be working with a TA in the classroom (or to be working outside the classroom) than pupils with language impairments (p. 18). Moreover, Sharples, Webster and Blatchford (2015) highlight the ways in which ‘schools have drifted into a situation in which TAs are used as an informal instructional resource for pupils with most need’ (p. 4) and recommend that teachers divide their time equally between all pupils. In addition, as my study substantiated, the tendency to assign responsibility for the education of the autistic children to the TA means that for teachers, it is implicit that the child is ‘not within their range of responsibilities’ (Emam and Farrell, 2009, p. 416).

Therefore, because of the ways they are deployed, the presence of TAs in the classroom, in some circumstances at least, emerges as a driver of exclusion, potentially impeding a child’s social integration with his or her peers, and hindering their learning, independence and agency. Nevertheless, the teachers in my cohort particularly emphasised the relationship they had with the autistic child as being the axis on which understanding and inclusion operated, a point also made in Jones et al. (2008). Moreover, while C10 was observed to experience his support quite

negatively on most occasions, and one of his TAs said she “couldn’t think of anything positive” to say about him, his teacher had a much more encouraging view:

I really enjoy teaching him – he’s a lovely boy, he makes me laugh. He’s very knowledgeable, he brings a lot to the class. (T12, semi-structured interview)

In addition, there was no particular evidence in my study that school staff who had received training in autism were more adept than those who had not. Indeed, six of the teaching assistants and four of the teachers in my cohort stated that they had never worked with an autistic child before, and some were preoccupied with the notion that ‘expertise’ lay elsewhere, as they were not ‘specialist’. This was predicated, as we have seen in the previous chapter, on the idea that the children were ‘different’. Indeed, while Jordan (2005) calls for an end to ‘the therapeutic model of education as a form of ‘treatment’’ (p. 113), Allan (2010) critiques the inclusive training manuals which offer ‘strategies for managing difference’ (p. 609). Indeed, for Thomas (2012a), the ‘relentlessly deficit-oriented history of special education’ (p. 477) has done little to further inclusive practices.

Inclusion

According to Allan (2008), ‘inclusion is and should be a struggle’ (p. 19), and this certainly seemed evident in my study, where school staff tended to problematise the presence of the autistic children, although there were, of course, some important and instructive exceptions. Moreover, even though Rioux and Valentine (2006), for example, warn against the drive to ‘normalise’ certain children and Liasidou (2012) states that inclusion should not be an ‘assimilationist process’ (p. 26), the identification of ‘special needs’ in my study was accompanied by equipment, materials, a different timetable, part-time school attendance in some cases and alternative, vaguely defined expectations, such as ‘life skills’. Indeed, the very

processes implemented to facilitate inclusion could merely serve to exclude autistic children, and the apparent availability of extra-curricular activities to all children except those with SEND, for example, caused further social marginalisation for them and their parents. Moreover, Hodge and Runswick-Cole (2008) argue that despite the language of the social model of disability, professionals in the field 'still adopt a model aimed at intervening and modifying the behaviour of children and families, rather than removing the barriers to achievement' (p. 643). Consequently, while the CRPD (2006) refers to 'attitudinal and environmental barriers' which hinder the 'full and effective participation in society' (preamble e) of disabled people, my study suggests that those barriers remain in place.

Liasidou (2012) considers that for inclusion to succeed, there is a need for 'educational systems to be radically restructured so as to provide quality education for all students (...), irrespective of their individual characteristics and diverse biographical and developmental trajectories' (p. 9). Furthermore, according to Slee and Allan (2001), 'regular schooling was never meant for all comers' and they suggest that genuine inclusive schooling 'may well imply an array of offerings' where 'authenticity of choice and destination' are key issues (p. 186). Indeed, for Allan (2008), inclusion as it was originally conceived, was intended not to be about placement only but 'increasing participation and removing barriers' (p. 9), because 'schools were never meant to be for everyone' (p. 10). Meanwhile, Thomas (2012a) proposes training school staff in mainstream schools 'to work across home-school boundaries' (p. 480) in order to facilitate inclusion.

Inclusion, therefore, would appear to imply the availability of the right educational model for individual children, rather than a system which positions some children as 'failures' (Allan, 2010, p. 609), and so in need of inclusive strategies. Similarly, Thomas (2012a) sets out an argument for a conceptual overhaul of how inclusion is to be considered, placing the issue

within a much broader, community and societal context, evocative of the descriptions offered in the CRPD (2006):

‘...it is time now for ideas and policy about inclusion to move forward once more, to fold around a range of matters concerning learning, community, identity and belonging. Inclusion has to be conceived with many surfaces—disability, certainly, and social justice, no less—but now other facets of life at school: community, social capital, equality and respect.’ (Thomas, 2012a, p. 474)

There is a strong need, urges Thomas (2012a), for a ‘new kind of thinking and policy about inclusion’ (p. 474), because, crucially, ‘inclusive education is meaningful only when embedded in understandings about community and communality, only when seen as both reflective of, and creative of, inclusion in society’ (p. 485). Similarly, for Liasidou (2012), if inclusion is to succeed, there needs to be fundamental social - as well as educational - restructuring.

For Rioux and Valentine (2006), a key issue is citizenship, because disabled people are limited by government policies and programmes, and so ‘are constructed as non-citizens’ (p. 55). In their view, ‘citizenship status is an emerging standard in which treatment, care, and allocation of resources are based in citizenship rights and equal outcome for people with disabilities’ (p. 58). Devlin and Pothier (2006) also argue that we must aim for an ‘enabling citizenship’ (p. 18), whereby disabled people are not judged according to their capacity for productivity, and their entrance into the mainstream is not conditional ‘upon their emulation of able-bodied norms’ (p. 13). It becomes clear, therefore, that to understand educational inclusion, questions about societal inclusion and citizenship must also be considered, as Thomas (2012a) argues, referencing Booth (1999): ‘inclusion is about more than ‘special needs’. It is about *participation*.’ (p. 485).

Language and interpretation

In my study, just as the identification of the ‘special needs’ of certain children was accompanied by practical paraphernalia and different expectations in school, there was also a concomitant alternative vocabulary to describe them and their educational ‘needs’. Although not in all cases, these were ‘deficit-oriented discourses’ (Liasidou, 2012, p. 99) which implied ‘dependency, inadequacy and unworthiness’ (Corbett, 1995, p. 3), where children might be unhelpfully categorised according to binary oppositions such as ‘high’ or ‘low’ functioning (Dawson, 2010), or simply ‘othered’ and considered ‘odd’. However, despite being positioned as ‘different’, there is no hesitation on the part of educators and assessors, for example, in thinking they can interpret the worlds of autistic children. Further, as we have seen in the theme of communication (pp. 251 – 266), the fact that autistic children might express themselves differently and have unanticipated ways of interpreting spoken, written and visual information has clear practical implications for the format of tests and how they are assessed educationally.

In addition, while the problem of noise emerged as a significant exclusionary factor for some autistic children, with their own ‘noise’ considered undesirable and deviant, little attention was paid to the sensory and psychological impact of repeated instructions from school staff. As seen with C8, for example, her focus on the class teacher and group participation was interrupted repeatedly by supplementary questions from the TA. In contrast, Liasidou (2012) refers to the ‘linguistic silences’ or ‘absences’ in texts in relation to ‘the ways that disabled children are positioned and constructed within legislative documents’ (p. 101), a point also made by Slee and Allan (2001). Indeed, these administrative absences and ‘silences’ can be further compared with the value ascribed to the silence of the children, which I observed to be somewhat overlooked in the quest to implement ‘communication strategies’ in schools. While some of the children were noted to be clearer and more fluent in their speech when talking about topics

that interested them, for example, others were seen to be silent, calm and concentrated when engaged with motivating activities. Indeed, Davis, Watson and Cunningham-Burley (2000), noted that the children in a special school were simply choosing when to communicate, as they must be permitted to be 'the final gatekeepers to their worlds' (p. 210), a point also made by Lewis (2008). Further, Acheson (2008), in an account informed by the work of Merleau-Ponty, challenges the notion of silence as 'a lack', 'the void in which speech occurs, the background or field that frames speech' (p. 536). Acheson cites examples from other cultures in which silence is both valued and interpreted differently, leading to the conclusion that silences are 'situated, embodied practices', which 'can be gestures' (ibid, p. 552). She argues not only that silences should be interpreted within the cultural, historical and intersubjective situations in which they are produced, but we must, she considers, 'escape the binary of speech and silence and understand the human experience of silence in its communicative fullness' (ibid, p. 552). Similarly, Humphry (2014), through an exploration of the Foucauldian notion of the 'pause', considers how silence can create the opportunity for 'a different truth' to be expressed about young people considered to be educationally dysfunctional (p. 493). According to Lewis (2008), meanwhile, researchers do not place enough emphasis on children's silences, and she considers that 'listening better includes hearing silence' and recognising that 'silence is not neutral or empty.' (p. 20). Indeed, she is of the view that research in the context of 'child voice' might benefit from the development of 'methodologies of silence' (ibid, p. 20). Further, Glenn (2004) draws out the association between silence and authority, since it concerns 'who remains silent and who silences' (p. xii), an issue of particular relevance in schools, where teachers talk, and children are expected to listen.

Conclusion

For Denscombe (1998), the value of a case study approach ‘is that it has the potential to deal with the subtleties and intricacies of complex social situations’ (p. 35), while according to Thomas (2011), it is a method which is ‘open-ended and untethered’ (p. 519). However, the extent to which it is possible to generalise findings from a case study is the subject of complex discussion and debate (Thomas, 2016). Gorard (2013), for example, asserts the following:

‘If you wish to make warranted claims about similarity, uniqueness, difference, change, cause, or anything else of real social scientific interest, then you will need more than a case study. You will need a comparator.’ (Gorard, 2013, p. 96).

Meanwhile, for Flyvbjerg (2006), the view that it is not possible to generalise from a case study ‘is usually considered to be devastating to the case study as a scientific method’ (p. 224), a goal which, according to Thomas (2016) is unnecessary and ill-founded, particularly in education research (Thomas, 2012b).

In my own study, the broader applicability of my findings is suggested by the ways in which, to an extent, they constituted further verification of issues already identified in the existing literature. Importantly, however, my findings – additionally informed by the theoretical models discussed in Chapter 2 - also provide possible explanations for the poor educational status quo and impoverished longer-term outcomes of autistic children which that literature suggested. Furthermore, despite encountering some difficulties in recruitment and sampling as explained in Chapter 3, and other limitations such as the gender bias of participant groups - with only one female autistic child, one male parent, one male teaching assistant and two male autistic adult participants, for example – I consider that I fulfilled the following prescription from Denscombe (1998):

‘...the researcher should pursue his or her investigation until the questions have been answered and things can be explained’ (p. 25).

Indeed, part of my findings could be characterised as establishing the importance of *not* generalising about autistic children in schools. In addition, just as Maclure (2002) rejects, from, a post-modernist perspective, typical binary oppositions such as theory and practice, school and work, and cites Lather (1991, p. 69), who questions the ‘victory narrative’ which can define many research projects, Armstrong and Moore (2004), in the context of action research, argue that an exploration of values and practices is more important than specific, measurable outcomes. Moreover, this was an issue I was able to consider through my feedback processes with individuals, schools and the LA. Further, as Gorard (2004) argues, it would be a mistake ‘to say some social science research descriptions are not meant to be accepted as “true”, else why should we be concerned with them?’ (p. 152).

In the light of these points, I suggest that my findings are of significance and constitute a small but important contribution to the field of autism education research, in terms of practical application, the value of theory and methodological processes. For example, I have shown how the poor results autistic children obtain in national tests in the primary phase of education might be explained by patchy access to the curriculum, a limited understanding of their needs, inconsistent support and a failure to apply permitted examination accommodations during tests. These difficulties are further compounded by issues concerning language and interpretation, where the ways in which children might respond to different aspects of the curriculum and demonstrate their understanding are not necessarily understood or validated by school staff. Furthermore, while the autistic children are considered to have language and communication impairments, the ways in which they express themselves were shown in my study to be subject to a high level of control and even censure, impacting negatively on their well-being, individual

agency and even their very ability to communicate. These findings suggest an urgent need for alternative ways of conceptualising the poor participation and outcomes in education of autistic children, setting aside the ‘within child’ model of educational failure (Terzi, 2005; Lindsay, 2007b), and embracing instead an approach where their particular dispositions and learning styles are recognised and valued.

Indeed, many of the problems faced by the autistic children in my study could be deemed to proceed from a confusion over how to perceive and describe autism, with the impairment model constituting a default understanding on which their educational priorities were predicated. However, I have shown that by incorporating the perspectives of a range of participants, a more nuanced understanding of the educational experiences of autistic children can be provided, and that while definitive descriptions of autism remain elusive, this very ambiguity underscores the importance of consulting broadly while setting educational programmes for autistic children. Furthermore, the high value provided to my study by the perspectives, views and experiences of autistic children and adults, and the range of methods required to facilitate this participation, are perhaps instructive for the autism education field more generally, which continues to focus on ‘teacher attitudes’, or to position autistic people as objects of scientific study, as if they were medical curios (Arnold, 2013). Indeed, there is a parallel between the flexibility of methods required to facilitate the participation of autistic children and adults in my study and the need to approach the educational inclusion of autistic children in a more individualised, accepting and accommodating manner.

Meanwhile, if Pothier and Devlin (2006), for example, explore the problem of the necessity of the medical model in order to access support, Terzi (2005) recommends the ‘capability approach’, as this is ‘a matter of justice’ (p. 455). Consequently, although I do not pretend to have found all of the answers to the issues described, I consider that I have provided evidence

of the significant disadvantages of the deficit model of autism, which creates limits in the understanding, agency and aspirations of autistic children in schools. Indeed, as Johnston (1985) argued in the context of reading failure, the assumption that this derives from cognitive impairment, rather than ‘the individual’s goals, motives, and situations’ (p. 154), leads to inappropriate analysis of that failure. On the other hand, a more constructive, open-minded approach, in which children can access their interests in a supportive environment, where they are provided with genuine choices and are listened to, means that they feel comfortable, and can progress and learn. Indeed, this makes life much easier for school staff too.

Furthermore, according to Lewis (2004), the UN has been critical of the UK in terms of the lack of attention paid to gathering children’s views. Similarly, the incumbent Children’s Commissioner, with reference to the UNCRC (1989), also asks ‘are we listening, and if we are, are we acting on what we hear?’ (Atkinson, in Pellicano et al., 2014, p. 3). Consequently, while it was an important aspect of the design of my project to incorporate a multiplicity of views, I consider that the inclusion of the interviews and observations of the children – which were often enhanced, explicated and supplemented by the perceptions of the autistic adults – provides my study with authenticity, insight and validity. It is therefore only fitting that I end this thesis with the words of one of the children, C2, who talked frequently about school strips, and had said previously that he liked Maths:

RW: So when you have a normal day at school, C2, what’s your favourite subject at school?

(pause)

RW: Do you have a favourite subject?

C2: Er, yes

RW: *What is it?*

C2: *Ummmmm*

(pause)

RW: *Is it Maths?*

(C2 looks distracted)

C2: *I think it is*

(...)

RW: *Anything else that you really like C2?*

C2: *Hmm er, I like er, some, s, like b burg... like burger king (smiles).*

ENDS

APPENDICES (3)

LIST OF REFERENCES

- Acheson, K. (2008) 'Silence as Gesture: Rethinking the Nature of Communicative Silences', *Communication Theory*, 18: pp. 535 – 555
- Aksu, F., Baykara, B., Ergin, B. and Arman, C. (2013) 'Phenotypic Features in Autistic Individuals: The Finger Length Ratio (2D:4D), Hair Whorl, and Hand Dominance', *Turkish Journal of Psychiatry*, 24 (2): pp. 94 - 100
- Allan, J. (2008) *Rethinking Inclusive Education: the Philosophers of Difference in Practice*, The Netherlands: Springer
- Allan, J. (2010) 'The sociology of disability and the struggle for inclusive education', *British Journal of Sociology of Education*, 31 (5): pp. 603 – 619
- Amanda Baggs Controversy (2009) *Presentation and Discussion of the Amanda Baggs Controversy*, available at <http://abaggs.blogspot.co.uk/#One> (Accessed 3 January 2017)
- Ambitious About Autism (AAA) (2012) *Schools Report 2012*. London: Ambitious About Autism
- Ambitious About Autism (AAA) (2013) *Schools Report 2013*, London: Ambitious About Autism
- Ambitious About Autism (AAA) (2016) *When will ~~they~~ we learn?* London: Ambitious About Autism
- Armstrong, D., Galloway, D. and Tomlinson, S. (1993) 'Assessing Special Educational Needs: The Child's Contribution', *British Educational Research Journal*, 19 (2), pp. 121 – 131
- Armstrong, F. and Moore, M. (eds) (2004) *Action Research for Inclusive Education: Changing Places, Changing Practices, Changing Minds*. London: Routledge Falmer, pp.1 - 16
- Arnold, L. (2013) 'The Social Construction of the Savant', *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1 (2): pp. 1 - 8
- Autism Education Trust (2011) 'Schools Training Hubs', *Autism Education Trust* <http://www.autismeducationtrust.org.uk/> Available at <http://www.aetraininghubs.org.uk/schools/training-hubs/> (Accessed 19 September 2013)
- Baggs, A. (2006) *In My Language*, available at: <https://www.youtube.com/watch?v=JnylM1hI2jc> (Accessed 12 December 2014)
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. and Charman, T. (2006) 'Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)', *The Lancet*, 368, pp. 210 – 215
- Baker, D. (2006) 'Autism as Public Policy' in Pothier, D. and Devlin, R. (eds) *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law*. Vancouver: UBC Press, pp. 177 – 194

- Barbeau, E., Zeffiro, T., Soulières, I., Dawson, M. And Mottron, L. (2012) ‘The Level and Nature of Autistic Intelligence III: Inspection Time’, *Journal of Abnormal Psychology*, 122 (1): pp. 295 - 301
- Barnard, J., Broach, S., Potter, D. and Prior, A. (2002) *Autism in Schools: crisis or challenge?* London: National Autistic Society
- Baron-Cohen, S., Leslie, A. and Frith, U. (1985) ‘Does the autistic child have a “theory of mind”?’ *Cognition*, 21(1), pp. 37 – 46
- Baron-Cohen, S. (2002a) ‘The extreme male brain theory of autism’, *TRENDS in Cognitive Sciences*, 6(6), pp. 248 – 253
- Baron-Cohen, S. (2002b) ‘Is Asperger Syndrome Necessarily Viewed as a Disability?’ *Focus on Autism and Developmental Disabilities*, 17, pp. 181 - 191
- Baron-Cohen, S., Scott, F.J., Allison, C., Williams, J., Bolton, P., Matthews, F.E. and Brayne, C. (2009) ‘Prevalence of autism-spectrum conditions: UK school-based population study’, *British Journal of Psychiatry*, 194 (6), pp. 500 – 509
- Baron-Cohen, S., Lombardo, M.V., Auyeung, B., Ashwin, E., Chakrabarti, B. and Knickmeyer, R. (2011) ‘Why are autism spectrum conditions more prevalent in males?’ *PloSBiology*, 9 (6): pp. 1 – 10 <https://doi.org/10.1371/journal.pbio.1001081>
- Barrett, S. (2014) ‘DSM-V Criteria for Diagnosing Autism’ *Autism Watch*, 25 August 2014. Available at <http://www.autism-watch.org/> (Accessed 3 January, 2015)
- Barthes, R. (1968) ‘La Mort de l’Auteur’, *Manteia*, pp. 61 – 67
- Basit, T. (2003) ‘Manual or electronic? The role of coding in qualitative data analysis’, *Educational Research*, 45 (2): pp. 143 - 154
- Batten, A., Corbett, C., Rosenblatt, M., Withers, L. and Yuille, R. (2006) *Autism and Education: the reality for families today*. London: NAS Publications.
- Beaney, J. (2006) *Reaching out, reaching in: implications for leaders of mainstream schools and their support service providers in supporting children with an autistic spectrum disorder*, London: National College for School Leadership
- de Beauvoir, S. (1949) *Le deuxième sexe I*, Paris: Gallimard
- Begley, A. (2000) ‘The educational self-perceptions of children with Downs Syndrome’ in Lewis, A. and Lindsay (eds) *Researching Children’s Perspectives*, pp. 98 - 111
- Berkeley, G. (Warnock, G.J., ed.) (1710/1981) *The Principles of Human Knowledge with Other Writings*, 10th ed., Glasgow: William Collins Sons & Co.
- Bhaskar, R. (1975) (1997) *A Realist Theory of Science*, London: Verso
- Bourgeron, T. (2015) ‘Genetics, ethics and implications for the lives of autistic people’, *Looking Forward, Looking Back: the Janus View of Autism*, Research Autism, Prince Philip House, London, 25 to 26 November, 2015.
- Boxall, K. And Ralph, S. (2009) ‘Research ethics and the use of visual images in research with people with intellectual disability’, *Journal of Intellectual & Developmental Disability*, 34 (1): pp. 45 -54

- Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3 (2): pp. 77 - 101
- Briskman, J., Frith, U. and Happé, F. (2001) 'Exploring the Cognitive Phenotype of Autism: Weak "Central Coherence" in Parents and Siblings of Children with Autism: II. Real-life Skills and Preferences', *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, 42 (3), pp. 309 – 316
- British Medical Association (2013) *Ethics toolkit for students* (online) <http://bma.org.uk/practical-support-at-work/ethics/medical-students-ethics-tool-kitth> (Accessed 1 November 2014)
- British Research Association (BERA) (2011) *Ethical Guidelines for Educational Research* (online) <https://www.bera.ac.uk/researchers-resources/publications/ethical-guidelines-for-educational-research-2011> (Accessed 3 August 2014)
- Broach, S. (2016) (8 November) Available at <https://twitter.com/SteveBroach> (Accessed 8 November 2016)
- Broderick, A.A. and Ne'eman, A. (2008) 'Autism as metaphor: narrative and counter-narrative', *International Journal of Inclusive Education* 12 (5 – 6), pp. 459 – 476
- Brugha, T., McManus, S., Meltzer, H., Smith, J., Scott, F., Purdon, S., Harris, J. and Bankart, J. (2007) *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007* The NHS Information Centre for health and social care. Available at www.ic.nhs.uk/asdpsychiatricmorbidity07 (Accessed 20 April 2014)
- Bury, M. (2000) 'A comment on the ICIDH2', *Disability & Society*, 15 (7): pp. 1073 – 1077
- Byatt, A.S. (2016) 'The gulf between words and things may be difficult – but it's also glorious', *The Guardian*, 17 December 2016, Books.
- Campbell, R. and Wasco, S. (2000) 'Feminist Approaches to Social Science: Epistemological and Methodological Tenets', *American Journal of Psychology*, 28 (6): pp. 773 - 791
- Campbell, T. (2015) 'Stereotyped at Seven? Biases in Teacher Judgement of Pupils' Ability and Attainment', *Journal of Social Policy*, 44 (3): pp. 517 – 547
- Carpenter, D. (2013) 'Generic Ethics Principles in Social Science Research. Discussion 'Stimulus' Paper for Symposium 1 (Principles)' *Academy of Social Sciences: Professional Briefings*, Issue 3: pp. 3 - 6
- Chan, J., Lang, R., Rispoli, M., O'Reilly, M., Sigafoos, J. and Cole, H. (2009) 'Use of peer-mediated interventions in the treatment of autism spectrum disorders: A systematic review', *Research in Autism Spectrum Disorders*, 3 (4), pp. 876 – 889
- Chappell, A.L. (2000) Emergence of participatory methodology in learning difficulty research: understanding the context, *British Journal of Learning Disabilities*, 28: pp. 38 – 43
- Cheslack-Postava, K. and Jordan-Young, R. (2012) 'Autism spectrum disorders: Toward a gendered embodiment model', *Social Science and Medicine*, 74 (11), pp. 1667-1674
- Children and Families Act 2014 (c. 6, 2014) Available at: <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted> (Accessed 16 August 2014)
- Christensen, P. and James, A. (2000) *Research with Children: Perspectives and Practices*, London: Falmer Press.

- Cigman, R. (ed.) (2007) *Included or Excluded? The challenge of mainstream for some SEN children*. Oxon: Routledge
- Cixous, H. (1981) 'Sorties' in Marks and de Courtivron (eds), *New French Feminisms*, Brighton: The Harvester Press Limited, pp. 90 – 98
- Coffey, A. and Atkinson, P. *Making Sense of Qualitative Data: Complementary Research Strategies*, London: Sage Publications Limited
- Colley, W. (2007) 'The road to Marrakesh: reflections on small schools and fragile children' in Cigman, R. (ed.) *Included or Excluded? The challenge of the mainstream for some SEN children*, Oxon: Routledge, pp. 51 - 56
- Committee on the Rights of Persons with Disabilities (2016) (CRPD/C/15/R.2/Rev.1) *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention*, United Nations.
- Comte, A. (Martineau, H. [trans]) (1853/2009) *The Positive Philosophy of Auguste Comte* (online) Cambridge: Cambridge University Press.
<http://dx.doi.org/10.1017/CBO9780511701450> (Accessed 15 November 2014)
- Convention on the Rights of Persons with Disabilities (2006), United Nations. Available at: <http://www.un.org/disabilities/convention/conventionfull.shtml> (Accessed 15 July 2014)
- Corbett, J. (1995) *Bad Mouthing: The Language of Special Needs*, Abingdon: Routledge
- Costley, D. (2000) 'Collecting the views of young people with moderate learning difficulties' in Lewis and Lindsay (eds) *Researching Children's Perspectives*, Buckingham: Open University Press, pp. 163 - 172
- le Couteur, A. (2003) *National Autism Plan for Children (NAPC): Plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school aged children with autism spectrum disorders (ASD)*. London: National Autistic Society.
- Cox, M., Herner, J., Demczyk and Nieberding, J. (2006) 'Provision of Testing Accommodations for Students with Disabilities on Statewide Assessments: Statistical Links with Participation and Discipline Rates', *Remedial and Special Education*, 27 (6): pp. 346 – 354
- Cremin, H., Thomas, G. and Vincett, K. (2005) 'Working with teaching assistants: three models evaluated', *Research Papers in Education*, 20 (4): pp. 413 - 432
- Croll, P. (2002) 'Social Deprivation, school-level achievement and SEN', *Educational Research*, 44 (1): pp. 43 - 53
- Crosland, K. and Dunlap, G. (2012) 'Effective Strategies for the Inclusion of Children With Autism in General Education Classrooms', *Behavior Modification*, 36 (3), pp. 251-269
- Cullen, M.A., Cullen, S., Lindsay, G. and Arweck, E. (2013) *Evaluation of Autism Education Trust Training Hubs Programme, 2011- 2013: Final Report*, Centre for Educational Development, Appraisal and Research, Warwick Institute of Education: University of Warwick
- Czarniawska, B. (2004) *Narratives in Social Science Research*, London: Sage Publications Ltd.
- Davis, J., Watson, N. and Cunningham-Burley, S. (2000) 'Learning the Lives of Disabled Children: Developing a Reflexive Approach' in Christensen, P. and James, A. (eds) *Research with Children: Perspectives and Practices*, 1st edition, Abingdon: Routledge, pp. 203 - 220

- Dawson, M., Soulières, I., Gernsbacher, M.A. and Mottron, L. (2007) 'The level and nature of autistic intelligence', *Psychological Science*, 18(8): pp. 657-62
- Dawson, M. (2010) 'Are you high or low functioning? Examples from autism research', in *autism crisis: science and ethics in the era of autism politics*, 31 August, 2010. Available at <http://autismcrisis.blogspot.co.uk/2010/08/are-you-high-or-low-functioning.html> (Accessed 06.07.2017)
- Dawson, M. (2016) (12 March) Available at: <https://twitter.com/autismcrisis> (Accessed 18 August 2016)
- Dean, M., Fox Adams, G. and Kasari, C. (2013) 'How narrative difficulties build peer rejection: A discourse analysis of a girl with autism and her female peers', *Discourse Studies*, 15 (2): pp. 147 – 166
- Denscombe, M. (1998) *The Good Research Guide: for small scale research projects*, 1st ed., Buckingham: Open University Press
- Department for Children, Schools and Families (DCSF) (2009) *Inclusion Development Programme Primary and Secondary: Supporting pupils on the autistic spectrum*. Available at: <https://www.gov.uk/government/publications/inclusion-development-programme-primary-and-secondary-supporting-pupils-on-the-autism-spectrum> (Accessed 5 August 2013)
- Department of Education and Science (DES) (1978) *Special Educational Needs: report of the Committee of Enquiry into the Education of Handicapped Children and Young People (The Warnock Report)*. London: HMSO.
- Department for Education and Skills (DfES) (2001) *Special Educational Needs code of practice*. London: Department for Education and Skills
- Department for Education (DfE) (2012a) *School and College Performance Tables: Statement of Intent – 2012* Available at http://www.education.gov.uk/schools/performance/archive/Statement_of_Intent_2012.pdf (Accessed 12 April 2014)
- Department for Education (DfE) (2012b) *Special educational needs in England: January 2012*. Available at <https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2012> (Accessed 15 May 2014)
- Department for Education (DfE) (2012c) *Children with special educational needs: an analysis – 2012* Available at: <https://www.gov.uk/government/statistics/children-with-special-educational-needs-an-analysis-2012> (Accessed 10 May 2014)
- Department for Education (DfE 2012d) *National curriculum assessments: key stage 2, 2012 (revised)* Available at: <https://www.gov.uk/government/statistics/national-curriculum-assessments-at-key-stage-2-in-england-academic-year-2011-to-2012> (Accessed 20 June 2014)
- Department for Education (DfE) (2012e) *Phonics screening check and key stage 1 assessments: England 2012*. Available at <https://www.gov.uk/government/statistics/phonics-screening-check-and-national-curriculum-assessments-at-key-stage-1-in-england-2012> (Accessed 30 November 2013)
- Department for Education (DfE) (2013a) *Special educational needs in England: January 2013*. Available at <https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2013> (Accessed 16 May 2014)

Department for Education (2013b) *Children with Special Educational Needs 2013: An Analysis* Available at <https://www.gov.uk/government/statistics/children-with-special-educational-needs-an-analysis-2013> (Accessed 17 May 2014)

Department for Education (2013c) *National curriculum assessments: key stage 2, 2013 (revised)* Available at: <https://www.gov.uk/government/statistics/national-curriculum-assessments-at-key-stage-2-2012-to-2013> (Accessed 17 July 2014)

Department for Education (2013d) *Phonics screening check and key stage 1 assessments: England 2013*. Available at <https://www.gov.uk/government/statistics/phonics-screening-check-and-national-curriculum-assessments-at-key-stage-1-in-england-2013> (Accessed 18 January 2014)

Department for Education (2013e) *Impact indicators 23, 24, 25: number of academies and free schools as a percentage of the total state-funded mainstream schools* Available at <https://www.gov.uk/government/publications/number-of-academies-and-free-schools> (Accessed 23 August 2014)

Department for Education (2013f) *National curriculum in England: Key stages 1 and 2 framework document*. Available at <https://www.gov.uk/government/publications/national-curriculum-in-england-primary-curriculum> (Accessed 23 August 2014)

Department for Education (DfE) (2014a) *Special educational needs code of practice: 0 to 25 years*. Available at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/342440/SEND_Code_of_Practice_approved_by_Parliament_29.07.14.pdf (Accessed 20 September 2014)

Department for Education (DfE) (2014b) *Special educational needs in England: January 2014*. Available at <https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2014> (Accessed 20 November 2014)

Department for Education (DfE) (2014c) *Children with special educational needs: an analysis – 2014* Available at: <https://www.gov.uk/government/statistics/children-with-special-educational-needs-an-analysis-2014> (Accessed 23 November 2014)

Department for Education (DfE) (2014d) *Phonics screening check and key stage 1 assessments – England 2014* Available at <https://www.gov.uk/government/statistics/phonics-screening-check-and-key-stage-1-assessments-england-2014> (Accessed 15 January 2015)

Department for Education (DfE) (2014e) ‘Key stage 2 tests: how to use access arrangements’ *National curriculum assessments: key stage 2 tests*. Available at: <https://www.gov.uk/guidance/key-stage-2-tests-how-to-use-access-arrangements> (Accessed 20 September 2016)

Department for Education (DfE) (2014f) *Reforming assessment and accountability for primary schools*. Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/297595/Primary_Accountability_and_Assessment_Consultation_Response.pdf (Accessed 22 July 2014)

Department for Education (2014g) *Types of school* Available at <https://www.gov.uk/types-of-school/overview> (Accessed 25 July 2014)

Department for Education (DfE) (2015a) *School Performance Tables 1994 – 2015* Available at: <http://www.education.gov.uk/schools/performance/archive/index.shtml> (Accessed 19 October 2016)

Department for Education (DfE) (2015b) *Children with special educational needs: an analysis – 2015* Available at <https://www.gov.uk/government/statistics/announcements/children-with-special-educational-needs-an-analysis-2015> (Accessed 14 December 2015)

Department for Education (DfE) (2016a) *A framework of core content for initial teacher training (ITT)*, Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/536890/Framework_Report_11_July_2016_Final.pdf (Accessed 25 October 2016)

Department for Education (DfE) (2017) *National Curriculum Assessments 2016: key stage 2 (revised)*. Available at <https://www.gov.uk/government/statistics/national-curriculum-assessments-key-stage-2-2016-revised> (Accessed 11 July 2017)

Derrida, J. (1967) *De La Grammatologie*, Paris: Editions de Minuit

Detheridge, T. (2000) 'Research involving children with severe learning difficulties' in Lewis and Lindsay (eds) *Researching Children's Perspectives*, Buckingham: Open University Press, pp. 112 - 121

Devlin, R. and Pothier, D. (2006) 'Introduction: Toward a Critical Theory of Dis-Citizenship' in Pothier, D. and Devlin, R. (eds), *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law*, Vancouver: UBC Press, pp.1 - 22

Dillenburger, K., Jordan, J., McKerr, L. and Keenan, M. (2015) 'The Millennium child with autism: early childhood trajectories for health, education and economic wellbeing.' *Developmental Neurorehabilitation*, 18 (1): pp. 37 – 46

Disability Discrimination Act 1995 (c.50, 1995) Available at <http://www.legislation.gov.uk/ukpga/1995/50/contents> (Accessed 28 July 2014)

Disability Discrimination Act 2005 (c.13, 2005) Available at <http://www.legislation.gov.uk/ukpga/2005/13/contents> (Accessed 28 July 2014)

Dockrell, J., Peacey, N. and Lunt, I. (2002) *Literature Review: Meeting the Needs of Children with Special Educational Needs*, London: Institute of Education, University of London

Dockrell, J., Ricketts, J., Palikara, O., Charman, T. and Lindsay, G. (2012) *Profiles of need and provision for children with language impairments and autism spectrum disorders in mainstream schools: A prospective study*. London: Department for Education

Downing, L. (2008) *The Cambridge Introduction to Michel Foucault*, Cambridge: Cambridge University Press

Douglas, G., Travers, J., McLinden, M., Robertson, C., Smith, E., Macnab, N., Powers, S., Guldberg, K., McGough, A., O'Donnell, M. and Lacey, P. (2012) *Measuring Educational Engagement, Progress and Outcomes for Children with Special Educational Needs: A Review*. Report no. 11. Ireland: National Council for Special Education

- Douglas, G., McLinden, M., Robertson, C., Travers, J. and Smith, E. (2016) 'Including Pupils with Special Educational Needs and Disability in National Assessment: Comparison of Three Country Case Studies through an Inclusive Assessment Framework', *International Journal of Disability, Development and Education*, 63 (1): pp. 98 – 121
- Drahota, A., Wood, J., Sze, K., and van Dyke, M. (2010) 'Effects of cognitive behavioural therapy on daily living skills in children with high-functioning autism and concurrent anxiety disorders', *Journal of Autism Developmental Disorders*, 41 (3): pp. 257 – 265
- Dunn, Y. (2014) 'Meaningful involvement in organising our own support – ethical issues', *Autism and Ethics*, Autism Rights Group Highland and National Autistic Society Scotland, Inverness, 16 May 2014 <http://www.arghighland.co.uk/ethics.html>
- Dyson, A. and Farrell, P., with Gallanaugh, F., Hutcheson, G. and Polat, F. (2007) 'But what about the others? Patterns of student achievement in inclusive schools' in Cigman, R. (ed.) (2007) *Included or Excluded? The challenge of mainstream for some SEN children*. Oxon: Routledge. pp. 115 – 127
- Eagleton, T. (1983) *Literary Theory: An Introduction*, Oxford: Basil Blackwell
- Economic and Social Research Council (ESRC) (2010, updated 2012) *Framework for Research Ethics (FRE)* (online) <http://www.esrc.ac.uk/about-esrc/information/research-ethics.aspx> (Accessed 20 August 2014)
- Education Act 1981 (1981, c.60) Available at <http://www.legislation.gov.uk/ukpga/1981/60/contents> (Accessed 2 July 2014)
- Education Act 1996 (1996, c. 56) Available at <http://www.legislation.gov.uk/ukpga/1996/56/contents> (Accessed 5 July 2014)
- Education (Special Educational Needs Co-ordinators) (England) Regulations 2008) (SI 2945/2008) Available at: <http://www.legislation.gov.uk/uksi/2008/2945/made?view=plain> (Accessed 12 June 2014)
- Education (Special Educational Needs Co-ordinators) (England) (Amendment) Regulations 2009) (SI 1387/2009) Available at: http://www.legislation.gov.uk/uksi/2009/1387/pdfs/uksi_20091387_en.pdf (Accessed 13 June 2014)
- Ellis, S., Tod, J. and Graham-Matheson, L. (2012) *Reflection, Renewal and Reality: Teachers' Experience of Special Educational Needs and Inclusion*, Birmingham: National Association of Schoolmasters Union of Women Teachers
- Emam, M. and Farrell, P. (2009) 'Tensions experienced by teachers and their views of support for pupils with autism spectrum disorders in mainstream schools', *European Journal of Special Educational Needs*, 24 (4): pp. 407 - 422
- Equality Act 2010 (2010, c. 15) Available at: <http://www.legislation.gov.uk/ukpga/2010/15/contents> (Accessed 9 July 2014)
- Equality and Human Rights Commission (2009) 'The law about disability discrimination', *Creating a Fairer Britain* Available at <http://www.equalityhumanrights.com/your-rights/equal-rights/disability/the-law-about-disability-discrimination> (Accessed 19 July 2014)

- Erevelles, N. (2002) 'Voices of silence: Foucault, Disability and the Question of Self-Determination', *Studies in Philosophy and Education*, 21: pp. 17 - 35
- Espinoza, J. (2016) 'Autism to be part of core teacher training, Government says', *The Telegraph*, 26 May, 2016.
- Fava, L., Vicari, S., Valeri, G., D'Elia, L., Arima, S. and Strauss, K. (2012) 'Intensive Behavioural Intervention for school-aged children with autism: Una Breccia nel Muro (UBM) - A Comprehensive Behavioral Model', *Research in Autism Spectrum Disorders*, 6 (4), pp. 1273 – 1288
- Feldman, E., Kim, J.-S. and Elliott, S. (2011) 'The Effects of Accommodations on Adolescents' Self-Efficacy and Test Performance', *Journal of Special Education*, 45 (2): pp. 77 - 88
- Florian, L., Rouse, M., Black-Hawkins, K. and Jull, S. (2004) 'What can national data sets tell us about inclusion and pupil achievement?' *British Journal of Special Education*, 31(3): pp. 115 – 121
- Flyvbjerg, B. (2006) 'Five Misunderstandings about case study research', *Qualitative Enquiry*, 5 (2): pp. 219 - 245
- Free, G. (1990) 'Language, Speech and Writing: Merleau-Ponty and Derrida on Saussure', *Human Studies*, 13 (4): pp. 293 - 307
- Frith, U. and Happé, F. (1994) 'Autism: beyond "theory of mind"', *Cognition*, 50, pp. 115 – 132.
- Frith, U. (2006) 'How Cognitive Theories Can Help us Explain Autism', MIND Institute Lecture Series on Neurodevelopmental Disorders. Available at: <http://www.uctv.tv/shows/How-Cognitive-Theories-Can-Help-Us-Explain-Autism-11862> (Accessed 15 February 2014)
- Gabel, S. and Peters, S. (2004) 'Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability', *Disability and Society*, 19 (6): pp. 585 – 600
- Gadamer, H.-G. (1960/2004, revised trans. [Weinsheimer, J. And Marshall, D.]) *Truth and Method*, revised 2nd ed., London: Bloomsbury Academic
- Gernsbacher, M., Dawson, M. and Goldsmith, H. (2005) 'Three Reasons Not to Believe in an Autism Epidemic', *Current Directions in Psychological Science*, 14(2), pp. 55 – 58. doi: 10.1111/j.0963-7214.2005.00334.x
- Giles, D. (2013) 'DSM-V is taking away our identity: The reaction of the online community to the proposed changes in the diagnosis of Asperger's disorder', *Health*, 18 (2): pp. 179 - 195
- Gillard, D. (2011) *Education in England: a brief history* Available at www.educationinengland.org.uk/history (Accessed 15 August 2014)
- Gillberg, C., Cederlund, M., Lamberg, K. and Zeijlon, L. (2006) 'Brief report: "the autism epidemic". The registered prevalence of autism in a Swedish urban area', *Journal of Developmental Disorders*, 36, pp. 429–435.
- Gillberg, C. (2015) 'Autism plus: new thinking about old findings', *Looking Forward, Looking Back: the Janus View of Autism*, Research Autism, Prince Philip House, London, 25 to 26 November, 2015.

- Glashan, L., Mackay, G. and Grieve, A. (2004) 'Teachers' Experience of Support in the Mainstream Education of Pupils with Autism' *Improving Schools*, 7 (1): 49-60
- Glenn, C. (2004) *Unspoken: A Rhetoric of Silence*, Carbondale: Southern Illinois University Press
- Gorard, S. (2001) *Quantitative Methods in Educational Research: The role of numbers made easy*. London: Continuum
- Gorard, S. (2002) 'The role of secondary data in combining methodological approaches', *Educational Review*, 54 (3): pp. 231 – 237
- Gorard, S. with Taylor, C. (2004) *Combining Methods in Educational and Social Research*, Berkshire: Open University Press
- Gorard, S. (2013) *Research Design: Creating Robust Approaches for the Social Sciences*, London: Sage Publications Limited
- Gould, J. and Ashton-Smith, J. (2011) 'Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum', *Good Autism Practice (GAP)*, 12 (1), pp. 34 – 41
- Graby, S. (2012) 'To be or not to be disabled: autism, disablement and identity politics', *Theorizing Normalcy and the Mundane*, University of Chester: 26 – 27 June 2012
- Grinker, R. (2015) 'Reframing the Science and Anthropology of Autism', *Culture, Medicine and Psychiatry*, 39: pp. 345 – 350
- Grue, J. (2015) *Disability and Discourse Analysis*, Farnham: Ashgate Publishing Limited
- Guldborg, K. (2010) 'Educating children on the autism spectrum: preconditions for inclusion and notions of 'best autism practice' in the early years', *British Journal of Special Education*, 37 (4), pp. 168 – 174
- Gunn, K. and Delafield-Butt, J. (2016) 'Teaching children with autism spectrum disorder with restricted interests: a review of evidence for best practice', *Review of Educational Research*, 86 (2): pp. 408 - 430
- Hakim, C. (1982) 'Secondary analysis and the relationship between official and academic social research', *Sociology*, 16 (1): pp. 12 - 28
- Happé, F. (1999) 'Autism: cognitive deficit or cognitive style?' *Trends in Cognitive Sciences*, 3 (6), pp. 216 - 222
- Happé, F., Booth, R., Charlton, R. and Hughes, C. (2006) 'Executive function deficits in autism spectrum disorders and attention-deficit/hyperactivity disorder: Examining profiles across domains and ages', *Brain and Cognition*, 61(1), pp. 25 – 39
- Happé F., Ronald, A. and Plomin R. (2006) 'Time to give up on a single explanation for autism', *Nature Neuroscience*, 9 (10), pp. 1218 – 1220
- Happé, F. (2015) 'Are we really any closer to our understanding of autism across the whole spectrum? Important headlines from autism research', *Looking Forward, Looking Back: the Janus View of Autism*, Research Autism, Prince Philip House, London, 25 to 26 November, 2015.
- Harrower, J. and Dunlap, G. (2001) 'Including children with autism in general education classrooms', *Behavior Modification*, 25 (5), pp. 762 – 784

- Harvey, J.A. (2011) *What's so special about special? Improving Inclusion for children with Autism in mainstream schools*. Doctor of Applied Child and Educational Psychology Thesis, University of Birmingham. Available at http://etheses.bham.ac.uk/3287/1/Harvey_12_Applied_Vol1.pdf (Accessed 12 November 2013)
- Hearst, C. (2016) 'Voices from the Constellation #17: Caroline Hearst on Neurodiversity and Autism Advocacy', *Learn from Autistics: Connecting Parents and Caregivers with Autistic Voices*, 27 September 2016, available at: <http://learnfromautistics.com/voices-constellation-17-caroline-hearst-neurodiversity-autism-advocacy/> (Accessed 2 January, 2017)
- Hebron, J. and Humphrey, N. (2013) 'Exposure to bullying among students with autism spectrum conditions: A multi-informant analysis of risk and protective factors', *Autism*, 18 (6): pp. 618 - 630
- Heidegger, M. (1947/2010) 'Letter on Humanism' in *Heidegger: Basic Writings*, Abingdon: Routledge, pp. 141 – 182
- Heritage, S. (2014) 'Yeah, Tristram, an oath is really going to turn a bad teacher into a good one' *The Guardian*, Monday 13 October 2014 (online)
<http://www.theguardian.com/commentisfree/2014/oct/13/oath-turn-bad-teacher-into-good-one> (Accessed 14 October 2014)
- Hesmondhalgh, M. and Breakey, H. (2001) *Access and Inclusion for Children with Autistic Spectrum Disorders: Let Me In*. London: Jessica Kingsley Publishers.
- Hesmondhalgh, M. (2006) *Autism, Access and Inclusion on the Front Line: Confessions of an Autism Anorak*. London: Jessica Kingsley Publishers
- Hertz-Picciotto, I. and Delwiche, L. (2009) 'The Rise in Autism and the Role of Age at Diagnosis', *Epidemiology*, 20 (1), pp. 84 – 90.
- Ho, A. (2004) 'To be labelled, or not to be labelled: that is the question' *British Journal of Learning Disabilities*, 32 (2): pp. 86 - 92
- Hodge, N. and Runswick-Cole, K. (2008) 'Problematising parent-professional partnerships in education', *Disability & Society*, 23 (6): pp. 637 – 647
- Hodge, N. (2014) 'Emancipatory disability research' *Seminar series on conducting and publishing disability research, department of Disability, Inclusion and Special Needs*, University of Birmingham, 4th December 2014.
- Holub, R.C. (1984) *Reception Theory: A critical introduction*, London: Methuen and Co. Ltd.
- Howlin, P., Mawhood, L. and Rutter, M. (2000) 'Autism and Developmental Receptive Language Disorder - a Follow-up Comparison in Early Adult Life. II: Social, Behavioural, and Psychiatric Outcomes', *Journal for Child Psychology and Psychiatry*, 41 (5), pp. 561 – 578
- Hughes, B. (2009) 'Disability activism: social model stalwarts and biological citizens', *Disability & Society*, 24 (6): pp. 677 - 688
- Hu-Lince, D., Craig, D., Huenteleman, M. and Stephan, D. (2005) 'The Autism Genome Project: Goals and Strategies', *American Journal of Pharmacogenomics*, 5(4), pp. 233 – 246

- Humphrey, N. (2008) 'Including pupils with autistic spectrum disorders in mainstream schools', *Support for Learning*, 23 (1): 41-47 DOI: 10.1111/j.1467-9604.2007.00367.x
- Humphrey, N. and Lewis, S. (2008) 'Make Me Normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools', *Autism*, 12 (1): pp. 23 - 46
- Humphrey, N. and Symes, W. (2011) 'Inclusive education for pupils with autistic spectrum disorders in secondary mainstream schools: teacher attitudes, experience and knowledge', *International Journal of Inclusive Education*, 17 (1): pp. 32- 46
- Humphry, N. (2014) 'Disrupting deficit: the power of 'the pause' in resisting the dominance of deficit knowledges in education', *International Journal of Inclusive Education*, 18(5): 484-499
- Hurst, R. (2000) 'To Revise or Not to Revise?', *Disability & Society*, 15 (7): pp. 1083 – 1087
- Huws, J. and Jones, R. (2010) 'Missing voices: representations of autism in British newspapers, 1999 – 2008', *British Journal of Learning Disabilities*, 39: pp. 98 – 104
- Irigaray, L. (1981) 'The Sex Which Is Not One' in Marks and de Courtivron (eds), *New French Feminisms*, Brighton: The Harvester Press Limited, pp. 99 – 106
- Jansson, B., Miniscalco, C., Westerlund, J., Kantzer, A-K., Fernell, E. and Gillberg, C. 'Children who screen positive for autism at 2.5 years and receive early intervention: a prospective naturalistic 2-year outcome study', *Neuropsychiatric Disease and Treatment*, 2016 (12), pp. 2255 – 2263 doi: <https://dx.doi.org/10.2147/NDT.S108899>
- Johnston, P. (1985) 'Understanding Reading Disability: A Case Study Approach', *Harvard Educational Review*, 55 (2): pp. 153 - 177
- Jonas, E., Schultz-Hardt, S., Dieter, F. and Thelen, N. (2001) 'Confirmation bias in sequential information search after preliminary decisions. An expansion of dissonance theoretical research on selective exposure to information', *Journal of Personality and Social Psychology*, 80 (4): pp. 557 - 571
- Jones, G. (2002) *Educational Provision for Children with Autism and Asperger Syndrome: Meeting their Needs*. London: David Fulton Publishers
- Jones, G., English, A., Guldberg, K., Jordan, R., Richardson, P. and Waltz, M. (2008) *Educational provision for children and young people on the autism spectrum living in England: a review of current practice, issues and challenges*. London: Autism Education Trust
- Jones, G., Baker, L., English, A. and Lyn-Cook, L. (2011) *National Autism Standards*, London: Autism Education Trust
- Jordan, R. (2005) 'Autistic Spectrum Disorders' in Lewis, A. and Norwich B. (eds) *Special Teaching for Special Children? pedagogies for inclusion*, Berkshire: Open University Press, pp. 110 – 122
- Jung, S. and Sainato, D. (2015) 'Teaching games to young children with autism spectrum disorder using special interests and video modelling', *Journal of Intellectual and Developmental Disability*, 40 (2): pp. 198 - 212
- Jurkowski, J. (2008) 'Photovoice as Participatory Action Research Tool for Engaging People with Intellectual Disabilities in Research and Program Development', *Intellectual and Developmental Disabilities*, 46 (1): pp. 1 – 11

- Kapp, S., Gillespie-Lynch, K., Sherman, L. and Hutman, T. (2013) 'Deficit, Difference, or Both? Autism and Neurodiversity', *Developmental Psychology*, 49 (1): pp. 59 - 71
- Kelly-Gadol, J. (1987) 'The Social Relation of the Sexes: Methodological Implications of Women's History', in Harding, S. (ed.) *Feminism and Methodology*, Bloomington: Indiana University Press, pp. 15 - 28
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. And Pellicano, E. (2015) 'Which terms should be used to describe autism? Perspectives from the UK autism community', *Autism*: pp. 1 – 21. doi:10.1177/1362361315588200
- Kim, H. (2012): 'Autism across cultures: rethinking autism', *Disability & Society*, 27(4), pp. 535-545
- Kim, YS., Leventhal, B., Koh, Y., Fombonne, E., Laska, E., Lim, E., Kim, SJ., Kim, YK., Lee, H., Song, D and Grinker, R. (2011) 'Prevalence of autism spectrum disorders in a total population sample.' *American Journal of Psychiatry*, 168 (9): pp. 904 – 912 doi: 10.1176/appi.ajp.2011.10101532
- Klar-Wolfond, E. (2008) 'The Mismeasure of Autism: The Basis for Current Autism 'Advocacy'' in Lawson, W. (2008) *Concepts of Normality (The Autistic and Typical Spectrum)*, London: Jessica Kingsley Publishers, pp. 104 - 129
- Kovshoff, H., Hastings, R.P. and Remington, B. (2011) 'Two-Year Outcomes for Children with Autism After the Cessation of Early Intensive Behavioral Intervention', *Behavior Modification*, 35 (5), pp. 427 – 450
- Kristeva, J. (1981) 'Woman Can Never Be Defined' in Marks and de Courtivron (eds), *New French Feminisms*, Brighton: The Harvester Press Limited, pp. 137 - 141
- Lawson, W. (2008) *Concepts of Normality (The Autistic and Typical Spectrum)*, London: Jessica Kingsley Publishers
- Lawson, W. (2011) *The passionate mind: how people with autism learn*, London: Jessica Kingsley Publishers
- Lawson, W. (2014). 'Autism spectrum conditions (ASC), ethics and issues of gender', *Autism and Ethics*, Inverness, 16 May 2014. Scotland: Autism Rights Group Highland and National Autistic Society Scotland. Available at <http://www.arghighland.co.uk/ethics.html>
- Lewis, A. and Lindsay, G. (eds.) (2000) *Researching Children's Perspectives*, Buckingham: Open University Press.
- Lewis, A. (2001) 'Reflections on interviewing children and young people as a method of inquiry in exploring their perspectives on integration/inclusion', *Journal of Research in Special Educational Needs*, 1: no. doi:10.1111/j.1471-3802.2001.00146.x
- Lewis, A. (2004) 'And when did you last see your father?' Exploring the views of children with learning difficulties/disabilities, *British Journal of Special Education*, 31 (1): pp. 3-9
- Lewis, A. and Porter, J. (2004) Interviewing children and young people with learning disabilities: guidelines for researchers and multi-professional practice, *British Journal of Learning Disabilities*, 32: pp. 191-197
- Lewis, A. and Norwich, B. (eds) (2005) *Special Teaching for Special Children? Pedagogies for inclusion*. Berkshire: Open University Press

- Lewis, A. (2009) 'Methodological issues in exploring the ideas of children with autism concerning self and spirituality', *Religion, Disability and Health*, 13: pp. 64 - 76
- Lewis, A. (2010) 'Silence in the Context of 'Child Voice'', *Children & Society*, 24: pp. 14 - 23
- Liasidou, A. (2012) *Inclusive Education, Politics and Policymaking*, London: Continuum International Publishing Group
- Lilley, R. (2013) 'It's an absolute nightmare: maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia', *Disability & Society*, 28 (4): pp. 514 - 526
- Lindsay, G. (2007a) 'Educational psychology and the effectiveness of inclusive education/mainstreaming', *British Journal of Educational Psychology*, 77: pp. 1 - 24
- Lindsay, G. (2007b) 'Rights, efficacy and inclusive education' in Cigman, R. (ed.) (2007) *Included or Excluded? The challenge of mainstream for some SEN children*. Oxon: Routledge. pp. 15 - 22
- Linton, K., Taylor, E., Sensui, L. et al. (2013) Opinions of People Who Self-Identify With Autism and Asperger's on DSM-5 Criteria. *Research on Social Work Practice*, 24 (1): pp. 67 - 77
- Lloyd-Smith, M. and Tarr, J. (2000) 'A Sociological Dimension' in Lewis, A. and Lindsay, G. (eds), *Researching Children's Perspectives*, Buckingham: Open University Press, pp. 59 - 70.
- Locke, J. (Phemister, P., ed.) (1689/2008) *An Essay Concerning Human Understanding*, Oxford: Oxford World Classics
- Loveland, K., McEvoy, R., Tunali, B. and Kelley, M. (1990) 'Narrative story telling in autism and Down's syndrome', *British Journal of Developmental Psychology*, 8 (1): pp. 9 - 23
- Lundström, S., Reichenberg, A., Melke, J., Råstam, M., Kerekes, N., Lichtenstein, P., Gillberg, C. and Anckarsäter, H. (2015) 'Autism spectrum disorders and coexisting disorders in a nationwide Swedish twin study', *The Journal of Child Psychology and Psychiatry*, 56(6), pp. 702 - 710.
- Macfarlane, B. (2010) 'Values and virtues in qualitative research' in Savin-Baden, M. and Howell (eds) *New Approaches to Qualitative Research: Wisdom and Uncertainty*, Abingdon: Routledge, pp. 18 - 27
- Mackay, T. (2016) 'Autism Practice Today. Where are the Gaps?' *XI Autism-Europe International Congress 2016*, Edinburgh, 16 - 18 September 2016
- MacLeod, A., Lewis, A. And Robertson, C. (2013) 'Why should I be like bloody Rain Man?!' Navigating the autistic identity', *British Journal of Special Education*, 40 (1): pp. 41 - 49
- Maclure, M. (2002) 'Postmodernism: a postscript' in Day, C., Elliott, J., Somekh, B. and Winter, R. (eds), *Theory and Practice in Action Research: some international perspectives*, Oxford: Symposium Books, pp.61 - 73
- Matthews, B. and Ross, L. (2010) *Research Methods: a practical guide for the social sciences*, Harlow: Pearson Education Ltd.
- Mawhood, L., Howlin, P. and Rutter, M. (2000) 'Autism and Developmental Receptive Language Disorder - a Comparative Follow-up in Early Adult Life. 1: Cognitive and Language Outcomes', *Journal for Child Psychology and Psychiatry*, 41 (5), pp. 547 - 559

- May, T. (1997) *Social Research: Issues, Methods and Process*, 2nd ed., Buckingham: Open University Press
- McCartney, E. Ellis, S., Boyle, J., Turnbull, M. and Kerr, J. (2010) 'Developing a language support model for mainstream primary school teachers', *Child Language Teaching and Therapy*, 26 (3): pp. 359 – 374
- McColl, M. A., James, A., Boyce, W. and Shortt, S. (2006) 'Disability Policy Making: Evaluating the Evidence Base' in Pothier, D. and Devlin, R. (eds) *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law*. Vancouver: UBC Press, pp. 25 - 43
- McConnell S. (2002) 'Interventions to Facilitate Social Interaction for Young Children with Autism: Review of Available Research and Recommendations for Educational Intervention and Future Research', *Journal of Autism and Developmental Disorders*, 32 (5), pp. 351 – 372
- McDonnell, A. and Milton, D. (2014) 'Going with the flow: reconsidering 'repetitive behaviour' through the concept of 'flow states'', in Jones, G. and Hurley, E. (eds), *Good Autism Practice: Autism, Happiness and Wellbeing*, Birmingham: BILD, pp. 38 - 47
- Mesibov, G. and Howley, M. (2003) *Accessing the Curriculum for Pupils with Autistic Spectrum Disorders: Using the TEACCH Programme to Help Inclusion*, London: David Fulton Publishers Limited.
- Miles, M. and Huberman, A. (1994) *Qualitative data analysis: an expanded sourcebook*, 2nd ed., London: Sage Publications Ltd.
- Milgram, S. (1963) 'Behavioral study of obedience', *Journal of Abnormal and Social Psychology*, 67, pp. 371-378.
- Millar, R., McCann, J., Scott, L., Doherty, K., McSorley, G., O'Hara, C. and Hunter, J. (2002) *Autistic Spectrum Disorders: A Guide to Classroom Practice*, Dublin: Department of Education
- Millman and Moss Kanter (1987) 'Another Voice: Feminist Perspectives on Social Life and Social Science', in Harding, S. (ed.) *Feminism and Methodology*, Bloomington: Indiana University Press, pp. 29 – 36
- Millward, L. (2012) 'Focus Groups' in Breakwell, G., Smith, J.A. and Wright, D. (eds) *Research Methods in Psychology*, 4th ed., London: Sage Publications Ltd., pp. 411 - 438
- Milton, D. (2012) 'The ontological status of autism: the 'double empathy problem'', *Disability & Society*, 27 (6): pp. 883 - 887
- Milton, D. (2014a) 'So what exactly are autism interventions intervening with?' *Good Autism Practice*, 15(2): pp.6-14.
- Milton, D. (2014b) 'Autistic expertise: A critical reflection on the production of knowledge in autism studies', *Autism*: 1 – 9, DOI 10.1177/1362361314525281
- Milton, D. (2014c) 'What is meant by participation and inclusion and why it can be difficult to achieve?' *Participation and inclusion from the inside out: seeing autism from an autistic perspective*, National Autistic Society, London, 28 April 2014.
- Milton, D. and Sims, T. (2016) 'How is a sense of well-being and belonging constructed in the accounts of autistic adults?' *Disability & Society*, 31 (4): pp. 520 - 534
- Moi, T. (1985) *Sexual Textual Politics: Feminist Literary Theory*, London: Methuen & Co. Ltd.

- Molloy, H. and Vasil, L. (2002) 'The social construction of Asperger Syndrome: The pathologising of difference?' *Disability and Society*, 17, pp. 659-669
- Molloy, H. and Vasil, L. (2004) *Asperger Syndrome, Adolescence and Identity: Looking Beyond the Label*, London: Jessica Kingsley Publishers
- de Montaigne, M. (1580) (1993) *The Complete Essays*, London: Penguin Classics
- Mottron, L., Dawson, M., Bertone, A. and Wang, L. (2007) 'Cognitive versatility in autism cannot be reduced to a deficit', *Cognitive Neuropsychology* 24: pp. 578 - 580
- Moyes, R. (2002) *Addressing the Challenging Behaviour of Children with High Functioning Autism/Asperger Syndrome in the Classroom: A Guide for Teachers and Parents*, London: Jessica Kingsley Publishers
- Murray, D. and Lawson, W. (2007) 'Inclusion through technology for autistic children', in Cigman, R. (ed.) *Included or Excluded? The challenge of the mainstream for some SEN children*, Oxon: Routledge, pp. 151 - 157
- Murray, D. (2014) 'Participation and scope', *Participation and inclusion from the inside out: seeing autism from an autistic perspective*, National Autistic Society, London, 28 April 2014
- Nader, A.-M., Courchesne, V., Dawson, M. and Soulières, I. (2016) 'Does WISC-IV Underestimate the Intelligence of Autistic Children?', *Journal of Autism and Developmental Disorders*, 46 (5): pp. 1582 - 1589
- Nash, T. and Norwich, B. (2010) 'The initial training of teachers to teach children with special educational needs: a national survey of English Post Graduate Certificate of Education programmes', *Teaching and Teacher Education*, 26 (7): pp. 1471 - 1480
- National Autistic Society (2016) 'Every Teacher' <http://www.autism.org.uk/> 2016. Available at: <http://www.autism.org.uk/everyteacher> (Accessed 15 November 2016)
- Nind, M. (2008) *Conducting qualitative research with people with learning, communication and other disabilities: methodological challenges*, NCRM/012, ESRC National Centre for Research Methods, University of Southampton
- Nind, M. (2011) Participatory data analysis: a step too far? *Qualitative Research*, 11 (4): pp. 349 - 363
- Norbury, C. and Bishop, D. (2003) 'Narrative skills of children with communication impairments', *International Journal of Language and Communication Disorders*, 38 (3): pp. 287 - 313
- Norwich, B. and Kelly, N. (2004) 'Pupils' Views on Inclusion: Moderate Learning Difficulties and Bullying in Mainstream and Special Schools', *British Educational Research Journal*, 30 (1): pp. 43 - 65
- Norwich, B. and Lewis, A. (2005) 'How specialized is teaching pupils with disabilities and difficulties?' in Lewis, A. and Norwich, B. (eds) (2005) *Special Teaching for Special Children? Pedagogies for inclusion*. Berkshire: Open University Press, pp. 1 - 14
- Norwich, B. and Lewis, A. (2007) 'How specialized is teaching children with disabilities and difficulties?' *Journal of Curriculum Studies*, 39 (2): pp. 127 - 150
- Norwich, B. (2008) *Dilemmas of Difference, Inclusion and Disability: International perspectives and future directions*, Abingdon: Routledge

- Norwich, B. (2014) 'Government Policy and Where Pupils with SEN/Disabilities go to School' *Respecting Children and Young People: Learning from the Past, Redesigning the Future*, British Educational Research Association (BERA), 11 July 2014. Available at <http://berarespectingchildren.wordpress.com/2014/07/11/government-policy-and-where-pupils-with-sen-disabilities-go-to-school/#more-257> (Accessed 14 July 2014)
- Oakley, A. (1998) 'Gender, methodology and people's ways of knowing: some problems with feminism and the paradigm debate in social science' *Sociology*, 32(4): pp. 707 – 731
- Office for Disability Issues (2011) *Equality Act 2010 Guidance: Guidance on matters to be taken into account in determining questions relating to the definition of disability*. London: Office for Disability Issues.
- Office for National Statistics (2011) *2011 Census* Available at <http://www.ons.gov.uk/census/2011census> (Accessed 17 July 2013)
- Office of Qualifications and Examinations Regulation (Ofqual) (2012) *Ofqual Equality Objectives 2012 – 2013*. Coventry: Ofqual
- Office of the Children's Commissioner (2012) *"They never give up on you": Schools' Exclusions Inquiry*. London: Office of the Children's Commissioner
- Oppenheim, A. (1992) *Questionnaire Design, Interviewing and Attitude Measurement*, London: Pinter
- Pantelis, P. and Kennedy, D. (2016) 'Estimation of the prevalence of autism spectrum disorder in South Korea, revisited', *Autism*, 5: pp. 517 - 527
- Papadopoulos, C. (2016) 'Stigma towards individuals diagnosed with autistic spectrum disorder: a comparison of UK-based Nigerians and English attitudes' *XI Autism-Europe International Congress 2016*, Edinburgh, 16 – 18 September 2016
- Parker, I. and the Bolton Discourse Network (1999) *Critical Textwork: an introduction to varieties of discourse and analysis*, Buckingham: Open University Press
- Parsons, S., Guldberg, K., Macleod, A., Jones, G., Prunty, A. and Balfe, T. (2011) 'International review of the evidence on best practice in educational provision for children on the autism spectrum', *European Journal of Special Educational Needs*, 26 (1), pp. 47 - 63
- Pellicano, E., Dinsmore, A. and Charman, T. (2013) *A future made together: shaping autism research in the UK*. London: Institute of Education
- Pellicano, E., Hill, V., Croydon, A., Greathead, S., Kenny, L. And Yates, R. (2014) *My Life at School: Understanding the experiences of children and young people with special educational needs in residential special schools*. London: Institute of Education
- Pickles, A., le Couteur, A., Leadbitter, K., Salomone, E., Cole-Fletcher, R., Tobin, H., Gammer, I., Lowry, J., Vamvakas, G., Byford, S., Aldred, C., Slomins, V., McConachie, H., Howlin, P., Parr, J., Charman, T. and Green, J. (2016) 'Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial', *The Lancet*, 388 (10059): pp. 2501 - 2509
- Popper, K. (1953) 'Science: Conjectures and Refutations', *Developments and trends in contemporary British philosophy*, British Council, Peterhouse, Cambridge.

- Pothier, D. and Devlin, R. (2006) (eds) *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law*. Vancouver: UBC Press
- Pfeiffer, D. (2000) 'The Devils are in the Details: The ICIDH2 and the disability movement', *Disability & Society*, 15 (7): 1079-1082
- Pring, R. (2000) *Philosophy of Educational Research*, London: Continuum
- Prizant, B., Wetherby, A., Rubin, E. and Laurent, A. (2003) 'The SCERTS Model: A Transactional, Family-Centred Approach to Enhancing Communication and Socioemotional Abilities of Children With Autism Spectrum Disorder', *Infants and Young Children*, 16 (4): pp. 296 - 316
- Rajendran, G. and Mitchell, P. (2007) 'Cognitive theories of autism', *Developmental Review*, 27, pp. 224 – 260
- Ravet, J. (2011) 'Inclusive/exclusive? Contradictory perspectives on autism and inclusion: the case for an integrative position.' *International Journal of Inclusive Education*, 15 (6): pp. 667-682
- Remington, B., Hastings, R., Kovshoff, H., degli Espinosa, F., Jahr, E., Brown, T., Alsford, P., Lemaic, M. and Ward, N. (2007) 'Early Intensive Behavioral Intervention: Outcomes for Children With Autism and Their Parents After Two Years', *American Journal of Mental Retardation*, 112 (6), pp. 418 - 438
- Research Autism (2016) *Alphabetic List of Interventions, Treatments and Therapies*. Available at: <http://researchautism.net/autism-interventions/alphabetic-list-interventions> (Accessed 30 August 2016)
- Richards, L. (2005) *Handling Qualitative Data: A Practical Guide*, London: Sage Publications Ltd.
- Rioux, M. and Valentine, F. (2006) 'Does Theory Matter? Exploring the Nexus between Disability, Human Rights and Public Policy' in Pothier, D. and Devlin, R. (eds) *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law*. Vancouver: UBC Press, pp. 47 - 69
- Roberts, V. and Joiner, R. (2007) 'Investigating the efficacy of concept mapping with pupils with autistic spectrum disorder', *British Journal of Special Education*, 34 (3), pp. 127 – 135
- Robson, C. (2002) *Real World Research*, 2nd ed., Oxford: Blackwell Publishers Limited
- Robson, C. (2011) *Real World Research*, 3rd ed., Oxford: Blackwell Publishers Limited
- Rosenthal, M., Wallace, G. L., Lawson, R., Wills, M. C., Dixon, E., Yerys, B. E. and Kenworthy, L. (2013) 'Impairments in Real-World Executive Function Increase From Childhood to Adolescence in Autism Spectrum Disorders', *Neuropsychology*, 27 (1), pp. 13 – 18
- Rousseau, J.-J. (1762) (1993). *Emile*, London: Everyman
- Runswick-Cole, K. and Hodge, N. (2009) 'Needs or rights? A challenge to the discourse of special education' *British Journal of Special Education*, 36 (4): pp.198 – 203
- Runswick-Cole, K., Mallett, R. and Timimi, S. (2016) *Re-Thinking Autism: Diagnosis, Identity and Equality*, London: Jessica Kingsley Publishers

- Rutter, M., Andersen-Wood, L., Beckett, C., Bredenkamp, D., Castle, J., Groothues, C., Kreppner, J., Keaveney, L., Lord, C., O'Connor, T.G. and the English and Romanian Adoptees (ERA) Study Team (1999) 'Quasi-autistic Patterns Following Severe Early Global Privation', *Journal for Child Psychology and Psychiatry*, 40 (4), pp. 537 – 549.
- Ryan, G. and Bernard, H. (2003) 'Techniques to Identify Themes', *Field Methods*, 15 (1): pp. 85 - 109
- Ryan, S. and Runswick-Cole, K. (2008) 'Repositioning mothers: mothers, disabled children and disability studies', *Disability & Society*, 23 (3): pp. 199 – 210
- Sacco, R., Gabriele, S. and Persico, A. (2015) 'Head circumference and brain size in autism spectrum disorder: A systemic review and meta-analysis', *Psychiatry Research: Neuroimaging*, 234 (2): pp. 239 – 251
- Saldaña, J. (2016) *The Coding Manual for Qualitative Researchers*, 3rd ed., London: Sage Publications Ltd.
- Schlosser, R., Balandin, S., Hemsley, B., Iacono, T., Probst, P. and von Tetzchner, S. (2014) 'Facilitated Communication and Authorship: A Systematic Review', *Augmentative and Alternative Communication*, 30 (4): pp. 359 - 358
- Schuelka, M. (2016) 'The Limits of Attitude: Why Teacher Attitude Surveys on Inclusive Education are Looking in the Wrong Direction' in *Research in Practice Seminar*, University of Birmingham, 24 February 2016.
- Schultz, P and Searleman, A. (2002) 'Rigidity of Thought and Behavior: 100 Years of Research', *Genetic, Social and General Psychology Monographs*, 128 (2): pp. 165 - 207
- Shah, A. and Frith, U. (1982) 'An Islet of Ability in Autistic Children: A Research Note', *Journal for Child Psychology and Psychiatry*, 24 (4), pp. 613 – 620
- Shakespeare, T. (2014) *Disability Rights and Wrongs Revisited*, 2nd ed., Abingdon: Routledge
- Sharples, J., Webster, R. and Blatchford, P. (2015) *Making Best Use of Teaching Assistants: Guidance Report*, London: Education Endowment Foundation
- Silverman, D. (2001) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*, London: Sage Publications Limited
- Silverman, C. (2008) 'Fieldwork on another planet: Social Science Perspectives on the Autism Spectrum', *BioSocieties* 3: pp. 325 - 341
- Sinclair, J. (1993) 'Don't Mourn for Us' *Autism Network International*, 26 June 2002. Available at: http://www.autreat.com/dont_mourn.html (Accessed 13 June, 2014)
- Sinclair Taylor, A. (2000) 'The UN Convention and the Rights of the Child: giving children a voice', in Lewis, A. and Lindsay, G. (eds) *Researching Children's Perspectives*, Buckingham: Open University Press, pp. 21 – 33
- Slee, R. and Allan, J. (2001) 'Excluding the included: A reconsideration of inclusive education' *International Studies in Sociology of Education*, 11(2): pp. 173 – 192
- Smith, D. E. (1987) 'Women's Perspective as a Radical Critique of Sociology' in Harding, S. (ed.), *Feminism and Methodology*, Bloomington, Indiana: Indiana University Press, pp. 84 - 96

- Smith, E. (2008) *Using Secondary Data in Educational and Social Research*. Buckingham: Open University Press
- Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*, London: Sage Publications Ltd.
- Smith, J. and Osborn, M. (2007) in Smith, J. (ed.) *Qualitative Psychology*, London: Sage Publications Ltd, pp. 53 - 80
- Soulières, I., Dawson, M., Gernsbacher, M. And Mottron, L. (2011) 'The Level and Nature of Autistic Intelligence II: What about Asperger Syndrome?', *PLoS ONE*, 2011; 6 (9): e25372 DOI: 10.1371/journal.pone.0025372
- Special Educational Needs and Disability Act 2001 (2001, c. 10) Available at: <http://www.legislation.gov.uk/ukpga/2001/10/contents> (Accessed 18 July 2014)
- Standards and Testing Agency (2016) *The Rochford Review: final report Review of assessment for pupils working below the standard of national curriculum tests*. Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/561411/Rochford_Review_Report_v5_PFDA.pdf (Accessed 23 October 2016)
- Stewart, C. (2016) 'Cygnets to swans – supporting girls on the spectrum in the education setting from primary school onwards', *From Exclusion to Inclusion: How to Transform Autism Education*, Birmingham, 13 October 2016, Transforming Autism Education project.
- Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research Techniques and Procedures for Developing Grounded Theory*, 2nd ed., London: Sage Publications Ltd.
- Sweileh, W., Al-Jabi, S., Sawalha, A. and Zyoud, S. (2016) 'Bibliometric profile of the global scientific research on autism spectrum disorders', *SpringerPlus*, 5: 1480 DOI: 10.1186/s40064-016-3165-6
- Syriopoulou-Delli, C., Cassimos, D., Tripsianis, G. and Polychronoulou, S. (2012) 'Teachers' perceptions regarding the management of children with autism spectrum disorders', *Journal of Autism Developmental Disorders*, 42(5): pp. 755 – 768
- Tager-Flusberg, H., Rhea, P. and Lord, C. (2005) 'Language and Communication in Autism' in Volkmar, F., Rhea, P., Klin, I. and Cohen, D. (eds) *Handbook of Autism and Pervasive Developmental Disorders*, volume 1, 3rd ed., pp. 335 – 364
- Tarr, M., Tsokova, D. and Takkunen, U.-M. (2012) 'Insights into inclusive education through a small Finnish case study of an inclusive school context', *International Journal of Inclusive Education*, 16 (7): pp. 691 - 704
- Taylor, S. (2001) 'Locating and Conducting Discourse Analytic Research' in Wetherell, M., Taylor, S. and Yates, S. (eds) *Discourse as Data: A Guide for Analysis*, London: Sage Publications Limited, pp. 5 - 48
- Terzi, L. (2005) 'Beyond the Dilemma of Difference: The Capability Approach to Disability and Special Needs Education' *Journal of Philosophy of Education*, 39(3): pp. 443 – 459
- The Secret Teacher (2016) 'We end up hindering the pupils we're meant to help' *The Guardian* (12 November 2016)

- Thibault, R. (2014) 'Can Autistics Redefine Autism? The Cultural Politics of Autistic Activism', *Trans-Scripts* 4. Available at: https://www.academia.edu/7234120/Can_Autistics_Redefine_Autism_The_Cultural_Politics_of_Autistic_Activism (Accessed 13 October 2015)
- Thomas, G. and O'Hanlon, C. (2005) 'Series editors' preface' in Lewis, A. and Norwich, B. (eds) *Special Teaching for Special Children? Pedagogies for inclusion*. Berkshire: Open University Press. pp. xi – xii
- Thomas, G. (2011) 'A Typology for the Case Study in Social Science Following a Review of Definition, Discourse, and Structure', *Qualitative Inquiry*, 17 (6): pp. 511 - 521
- Thomas, G. (2012a) 'A review of thinking and research about inclusive education policy, with suggestions for a new kind of inclusive thinking' *British Educational Research Journal*, 39 (3): pp. 473-490
- Thomas, G. (2012b) 'Changing Our Landscape of Inquiry for a New Science of Education'. *Harvard Educational Review*, 82 (1): pp. 26 - 51
- Thomas, G. (2013a) *How to do your Research Project: A Guide for Students in Education and Applied Social Sciences*, 2nd ed., London: Sage Publications Limited
- Thomas, G. (2013b) 'A review of thinking and research about inclusive education policy, with suggestions for a new kind of inclusive thinking', *British Educational Research Journal*, 39 (3): pp. 473-490
- Thomas, G. (2016) *How to do your Case Study*, 2nd ed., London: Sage Publications Ltd.
- Turner, J., Beeghley, L. and Powers, C. (2012) *The Emergence of Sociological Theory*, 7th ed., London: Sage Publications Limited
- United Nations Convention on the Rights of the Child (1989), London: UNICEF UK
- United Nations Educational, Scientific and Cultural Organization (UNESCO) (1994) *The Salamanca Statement and Framework for Action on Special Needs Education*. Spain: Ministry of Education and Science
- Ward, (2012) 'Complicating actions and complicated lives: raising questions about narrative theory through and exploration of lesbian lives' in Hackstaff, K., Kupferberg, F. and Négroni, C. (eds) *Biography and Turning Points in Europe and America*, Bristol: Policy Press
- Warnock, M. (2005) *Special Educational needs: a new look*, London: Philosophy of Education Society of Great Britain
- Wengraf, T. (2009) *Qualitative Research Interviewing: Biographic Narrative and Semi-Structured Methods*, London: Sage Publications Ltd.
- Wetherell, M., Taylor, S. and Yates, S. (eds) *Discourse as Data: A Guide for Analysis*, London: Sage Publications Ltd.
- Whitaker, P. (2007) 'Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say - and what parents want', *British Journal of Special Education*, 34 (3): pp. 170 - 178
- Wilkinson, K. and Twist, L. (2010) *Autism and Educational Assessment: UK Policy and Practice*. Slough: National Centre for Educational Research.

- Williams, J. and Mavin, S. (2012) 'Disability as Constructed Difference: A Literature Review and Research Agenda for Management and Organization Studies', *International Journal of Management Reviews*, 14: pp. 159 - 179
- Wing and Gould (1979) 'Severe impairments of social-interaction and associated abnormalities in children: epidemiology and classification', *Journal of Developmental Disorders*, 9(1), pp. 11 – 29
- Wing, L. (1980) 'Childhood autism and social class: a question of selection?' *The British Journal of Psychiatry*, 137 (5), pp. 410-417; DOI: 10.1192/bjp.137.5.410
- Wing, L. (2007) 'Children with autistic spectrum disorders' in Cigman, R. (ed.) *Included or Excluded? The challenge of the mainstream for some SEN children*, Oxon: Routledge, pp. 23 – 33
- Wittemeyer, K., Charman, T., Cusack, J., Guldberg, K., Hastings, R., Howlin, P., Macnab, N., Parsons, S., Pellicano, L. and Slomins, V. (2011a) *Educational provision and outcomes for people on the autism spectrum*. London: Autism Education Trust
- Wittemeyer, K. English, A., Jones, G., Lyn-Cook, L. and Milton, D. (2011b) *AET Professional Competency Framework*, London: Autism Education Trust
- World Health Organization. (1980) *International Classification of Impairments, Disabilities, and Handicaps*. Geneva.
- World Health Organization. (2001) *International Classification of Functioning, Disability and Health*. Geneva.
- Woronko, D. and Killoran, I. (2011) 'Creating inclusive environments for children with autism' in Williams, T. (ed.) *Autism Spectrum Disorders – From Genes to Environment*, InTech, DOI: 10.5772/21136. Available at:
<http://www.intechopen.com/books/howtoreference/autism-spectrum-disorders-from-genes-to-environment/creating-inclusive-environments-for-children-with-autism> (Accessed 3 July 2013)