UNIVERSITY OF WINCHESTER

“They really didn’t get to see me”:

Towards an Interactive Bioecological Model of Autism – Education, Understanding and Relationships

Miriam Ruth Walker

ORCID Number: 0000-0002-7331-3003

Doctor of Education

December 2019

This Thesis has been completed as a requirement for
a postgraduate research degree of the University of Winchester.

OPEN ACCESS / EMBARGO AGREEMENT FORM

DECLARATION AND COPYRIGHT STATEMENT

Declaration:

No portion of the work referred to in the Thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

I confirm that this Thesis is entirely my own work.

I confirm that no work previously submitted for credit or published in the public domain has been reused verbatim. Any previously submitted work has been revised, developed and recontextualised relevant to the thesis.

I confirm that no material of this thesis has been published in advance of its submission.

I confirm that no third party proof-reading or editing has been used in this thesis.

Copyright:

ACKNOWLEDGEMENTS

The completion of my EdD thesis is the result of a fascinating journey. It does not end here but is a marker in the road to a variety of new pathways and experiences yet to come.

First of all I would like to thank my two supervisors, Wayne Veck and Caroline Stockman for their knowledge, their advice, but especially for their support and belief in me during this phase in my journey. Their faith in this project and my ability to bring it to fruition has never wavered and I am extremely grateful for this.

I also want to thank my family for all the love and support I have had through the whole of life's journey so far. Particular thanks go to my Mum, who has painstakingly proofread the whole of this thesis, and to my daughter Kezia who patiently worked through several adaptations of my scribblings to create the visual creations for the diagrams in Chapter Two.

Finally, I want to give my sincere thanks to the participants who willingly told me their stories and shared their experiences with me. Without them there would have been no research. I feel honoured to have been given an insight into part of their personal journeys and to have had the opportunity to walk a tiny step of the way together.

UNIVERSITY OF WINCHESTER

ABSTRACT

“They really didn’t get to see me”:

Towards an Interactive Bioecological Model of Autism –

Education, Understanding and Relationships

Miriam Ruth Walker

ORCID Number: 0000-0002-7331-3003

Doctor of Education

December 2019

This thesis proposes an exploratory model of autism that has been created by combining Bronfenbrenner’s *Bioecological Systems Theory* with Shakespeare’s *Interactive Model of Disability*. The *Bioecological Systems Theory* highlights the impact on the individual from their surrounding ecosystem, with a particular focus on bi-directional communication between the individual and those within their microsystem. The *Interactive Model of Disability* emphasises the value of information regarding autism from both the social and medical models of disability. Drawing on the work of Erving Goffman, additional consideration is given to how individual perception of autism might influence the flow of information that is filtered through his or her ecology. Using a qualitative methodology, this study positions the voices of five pupils with autism who experienced a mainstream primary education alongside those of other writers in the fields of education and autism. This synthesis clarifies the importance of understanding the individual and complex experience of autism.

The following themes arose from the data: perspectives of autism and the lived experience in education; understanding autism in education through reciprocal communication; and finally, the need to develop better pupil/teacher relationships. The first theme considers how perspectives of autism are continuously influenced through the individual’s lived experiences. This in turn, can have an impact on their communication, which can in turn enhance their perspectives. The second and third themes are combined to highlight the potential for teachers and pupils with autism to base their understanding of the other on first-hand experience through reciprocal communication in order to develop their relationship. It is proposed that this process could create a deeper, more reliable understanding for both individuals, decrease anxiety for the pupil in the classroom, and form a better basis for the flourishing of future relationships.

An *Interactive Bioecological Model of Autism* is proposed as an exploratory model that could demonstrate the components that autism needs to be considered with if better relationships founded on mutual understanding between pupil and teacher can be actualised.

Keywords: Autism, Ecosystem, Communication, Perspective, Understanding, Relationships

LIST OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Chapter 1 Introduction

> Understanding grows from personal experience that enables a person to see and feel in ways so varied and so full of changeable meanings that one's self-awareness is the determining factor. Here one can admit more readily that the substances of a shadowy world are projected out of our personal thoughts, attitudes, emotions, needs. Perhaps it is easier to understand that even though we do not have the wisdom to enumerate the reasons for the behaviour of another person, we can grant that every individual does have his private world of meaning, conceived out of the integrity and dignity of his personality (Axline, 1964: 15).

These words describe the development of self-awareness and understanding, emphasising the importance of recognising that every individual has their own 'private world of meaning' (Axline, 1964: 15). They are written by a psychotherapist and chart the development of a five-year-old boy called Dibs. From the first meeting with Dibs in school, Axline was able to witness his minimal, aggressive and confused communications with others. The pages that follow depict the young boy's journey towards developing the capacity to embrace a life he could enjoy. Through her gentle and professional encouragement, and by giving Dibs time and space, Axline (1964: 7) enabled him to understand that 'the security of the world was not wholly outside of himself, but that the stabilising centre he searched for with such intensity was deep down inside that self'. The book is a powerful example of how external manifestations of individuality are not always accurate mirrors of internal experience. What is so incredible about Dibs is that by the age of five and before he met Virginia Axline, he had already built a wall to protect his inner fragile world. A wall so high that no one could get close; occasional glimpses were the only opportunities his parents and teachers had that gave them any idea of what lay within.

One key area of focus for this thesis is the consideration of information that is communicated and interpreted between individuals, as it was between Dibs and those who came into contact with him. The other key area to be developed alongside this, is the impact such communication and interpretation has on an individual's perspective and understanding within a relationship. This includes considering how an individual's outward manifestations may belie what is consciously and/or unconsciously hidden from others, and how the assumptions and judgments formed by others may therefore have little in common with the intentions of the communicator. In focusing such a pattern on the experience of disability, Shakespeare (2018: 54) proposed that 'how one is regarded by others and how one feels about oneself are often, usually perhaps, different things', thus highlighting how someone classified as disabled may not feel disabled or even wish to identify as such. With regard to the 'disability' of autism, the necessity for seeking a better understanding of the individual's lived experiences through direct communication with them, rather than forming judgements based on assumption and generalisation is explored in this study.

This thesis develops an original concept that aims to advance an area of practice in education through combining the ideas of Bronfenbrenner, Shakespeare and Goffman in creating an exploratory and holistic model that it is proposed would develop a better understanding of autism. Shakespeare promotes the need to consider an individual's experience of disability and the importance of this aspect if a greater understanding is sought. Bronfenbrenner adds an awareness of the impact on the individual of both macro and micro levels, and how independent exchanges or proximal processes will be influenced by an individual's personal ecosystem. Goffman problematises and deepens the relationship between individual and society, demonstrating outcomes that arise from interconnections between the two, and emphasising how self and society are linked and therefore shape and diminish stigma. Combining considerations from the literature with the reflections of five pupils with a diagnosis of autism regarding their mainstream primary school experiences, this thesis aims to explore and promote a better understanding of autism in education using the following research questions:

1. Could Shakespeare's *Interactive Model of Disability* and Bronfenbrenner's *Bioecological Systems Theory* be used in conjunction to develop a better understanding of pupils with autism?
2. Do pupils with autism consider there is a need for a greater reciprocal understanding between teachers and themselves of the diversity within autism?
3. Might a new model have potential to guide understanding and the development of more respectful and reciprocal relationships between pupils with autism and their teachers in educational settings?

In accepting that autism is currently diagnosed as a disability (American Psychiatric Association, 2013 and World Health Organisation [WHO], 2018) it is necessary to investigate the impact of such a term on individual perspective, and how such perspective could thus affect understanding within relationships. Through considering the opportunities and limitations that arise from interpreting disability through the social and medical models of disability, an alternative model is proposed that could act as a tool to increase understanding in autism through an improved two-way communication will become transparent. The new model, which aims to advance practice in an area of education, is composed of two parts: the *Interactive Model of Disability*, as proposed by Shakespeare (2006, 2014); and the *Bioecological Systems Theory*, as proposed by Bronfenbrenner (1979, 2005). In generating a new, *Interactive Bioecological Model of Autism*, this study aims to illuminate the necessity of amalgamating Bronfenbrenner's (1979, 2005) ecological dimensions of human experience with Shakespeare's (2006, 2014) emphasis on an interactive approach to disability to better grasp the complexity of autism.

My personal connection with autism began in my teaching career over three decades ago. From having no awareness or understanding of autism within mainstream education, my curiosity was sparked when a six-year-old girl at risk of exclusion from her infant school because of her autism became a member of my class for two years. Thus began an intense desire to deepen my knowledge of the difference of autism; to develop a better understanding of how certain individuals view the world in a different way and respond accordingly. Reading the experiences of other autistic writers, becoming a Special Educational Needs Co-ordinator and then completing a Master's dissertation with a focus on autism and playtime in mainstream schools began to enrich my understanding. A year spent working in a special secondary school then led to my current position as Senior Lecturer in Education with a focus in Special Educational Needs. This role has provided me with the opportunity of spending time in various mainstream and special primary schools whilst keeping up to date with legislative changes in SEND and further specific reading around autism. Such a combination of factors has also highlighted the gap identified by the pupils with autism regarding the understanding of their teachers. It is possible to see the frustrations and misunderstandings that this leads to from both sides and recognise how this could lead to a lack of confidence within the relationship, a wariness in communication and many other potential and possibly long lasting negative outcomes. It was this that led to the design of this thesis and from which I wish to continue in the future.

The writings of Bronfenbrenner (1979, 2005), Shakespeare (2006, 2014) and Goffman (1959, 1963) have been big influencers in the design of this research to actively include the voices of autistic pupils. The methods selected for gathering and analysing their stories enabled me to work with the memories they shared with me from their primary education. The key themes that arose of perspective, and the need for a greater level of understanding in order to develop the teacher/pupil relationship through reciprocal communication corroborated with the creation of a model as an exploratory tool that could be used in the future to deepen understanding and accept difference. Although the focus for this thesis is on autism in primary mainstream education, as that is where most of my experience lies, I believe the outcomes could have potential implications for ITE and CPD within both primary and secondary mainstream and special school settings.

A careful consideration of the language and terms to be used throughout this thesis is necessary to be outlined and justified from the outset, particularly because of the impact that language has on individual perception. Firstly there is the choice of whether to consider autism as a disorder, condition or difference. I consider that the first two options suggest a more medical focus with the latter option of difference being perhaps more accurate but less frequently used. Considerations of terminology will continue and further changes are inevitable, as was demonstrated in the most recent publication of the diagnostic manuals: the *International Classification of Diseases Version 11* (ICD11) (WHO, 2018) and the *Diagnostic and Statistical Manual Version 5* (DSM5) (American Psychiatric Association, 2013) when the diagnosis of Asperger's Syndrome became subsumed into the diagnosis of autism. Many authors have chosen the most widely used term of Autism Spectrum Disorder (ASD), which is the label given at diagnosis (Baron-Cohen, 2000; LeBlanc *et al*., 2009; Huws and Jones, 2010; Campbell, 2018). When quotations are taken from authors who make this choice, it is this term of reference that will occur. A shift from 'disorder' to 'condition' has been more recently mooted (Ravet, 2011; Bargiela *et al*., 2016, Hebron *et al.*, 2017) as a preferable descriptor with less of a focus on a deficit model, but it has not yet become widespread. Where possible, I have chosen to use the term difference to draw attention to the fact that this is what technically autism is - a different way of viewing the world (Prizant, 2015). How much the difference of autism becomes a condition or disorder is often dependent on other factors, which will be considered throughout this thesis.

The second language consideration is whether person-first, for example 'pupil with autism' or identity-first, such as 'autistic pupil', language should be used. There has been much written about this dilemma, with many writers (Sinclair, 1999; Goodall, 2015; Prizant, 2015) asserting their choice for one option being a more accurate or reasonable descriptor than the other. In 2015 results were published from research undertaken by the *National Autistic Society* (NAS) into people's preferences for terms to describe autism (Kenny *et al*., 2015). These findings indicated that 'there is no single way of describing autism that is universally accepted and preferred by the United Kingdom's autism community and that some disagreements appear deeply entrenched' (Kenny *et al*., 2015: 442). As a consequence of these findings, the NAS chose to use the term 'autistic person' (NAS: online). A writer from *The Spectrum*, a magazine published by autistic people for autistic people, wrote strongly in defense of this language stating that 'autism is evident in every facet of my life and personality, and taking away my autism would produce a stranger with my face' (Ametrine, 2018: 4). In this article, Ametrine draws attention to the third point from Sinclair's essay entitled *'Why I dislike "person-first" language'* (Sinclair, 1999). Here, Sinclair suggests that the reason some people wish to distance themselves from the term 'autistic person' is if they consider autism as something bad. He compares the term 'autistic person' with the ease of which people refer to a 'blue-eyed person' or an 'active person' thus indicating individual perspective (1999: online). Using this example Ametrine (2018: 4) proposed that use of identity-first language would therefore confirm that 'autism isn't a monster, rather it is a natural part of human variation, but forcing person first terms on autistic people seems to confirm there is shame to be had in identifying with it'.

A further consideration with regard to this aspect is highlighted in a review of literature by Jared Reser (2011) into the etiological and comparative evidence regarding autism and natural selection. This led him to suggest that the reason autism exists today is because of its success in the past, proposing therefore that autism 'should not be thought of as something to be ashamed of, but as something that represents individuality, self-determination and autonomy' (Reser, 2011: 230). This corresponds with Ametrine's (2018) point regarding the need to embrace the term 'autistic person' as an accurate descriptor rather than considering it as something shameful to be dissociated from, as could be inferred from person-first language choices. Yet another example of how a change in terminology could alter perspective was indicated by Happé and Frith (2010), who proposed that potential might exist to develop unique and special skills in all people with autism. Instead of negatively viewing an individual's obsessive and narrow interests as limiting, they should be viewed positively as providing the opportunity for the growth of talent. However, they also highlighted that recognising such potential was largely dependent on the attitudes of parents and teachers. Happé and Frith (2010) suggested that the obsessive desire to sort, classify and systemise, which is a characteristic of autism and not generally experienced as a positive activity by the majority of society, could lead to exceptional skill. This particular characteristic of autism, which Frith (2003: 77) originally labelled 'mind-blindness', had been viewed as a deficit, an inability to consider another person's mental state. However, with a change in terminology from 'mind-blindness' (Frith, 2003: 77) to that of 'exceptional focus' (Happé and Frith, 2010: ix), there is potential to change perspective. Instead of viewing the sorting, classifying and systemising characteristic of autism as negative and limiting, it could be recognised as a positive attribute with the opportunity to lead to the development of a particular skill. Taking this a step further, Treffert (2010: 8) proposed that nurtured talent in individuals with autism had the potential to become a 'conduit towards normalisation' and that 'rather than seeing the special abilities as frivolous, they can be used as a form of expression with the goal of channelling those abilities more usefully' (p.8). This indicates a change in perspective regarding a characteristic of autism that had previously been considered a deficit, towards a characteristic that should instead be recognised and celebrated.

As there is currently no universal agreement regarding autistic terminology (Kenny *et al.*, 2015), and wanting to remain respectful of the importance of language in defining self with the impact such choices can have on perspective, I decided to take a consensus from the pupils I worked alongside for this research as to whether they preferred person-first or identity-first language. Interestingly, they were not concerned with either and had no preference for one over another. Therefore I have deliberately chosen to fluctuate between identity-first and person-first language for the writing that follows. However, there will be times when the language choices of other authors are voiced through excerpts of their own writing.

Finally, in setting this thesis in its geographical context, it is important to provide some basic information about the organisation of state education in England. This is compulsory for all children between the ages of four and sixteen and takes place in what for the majority of pupils is recognised as a mainstream education that follows *The National Curriculum* (DfE, 2014). However, some children with a special educational need and/or disability (SEND) as specified in the *Special Educational Needs Code of Practice: 0-25 years*

(DfE and DoH, 2015) can receive an education within a special school environment. In these establishments, the focus of learning will not necessarily follow that of mainstream schools but may instead be tailored to the needs of the pupil.

The following chapter of this study investigates literature in relation to the main concepts that will be considered throughout this thesis in presenting a proposal for the adoption of a new model of autism. The chapter will begin by considering the history of the medical and social models of disability thus highlighting the current dichotomy in education between the two. The history of autism is also briefly covered here and linked to the developments with the two models of disability. The *Interactive Model of Disability* is then introduced as an alternative to the medical and the social models. Shakespeare (2006, 2014) proposed this model would eliminate the dichotomy by demonstrating that the medical and the social models of disability could work in tandem rather than be considered in opposition. The second independent aspect to be considered is that of Bronfenbrenner's (1979, 2005) *Bioecological Systems Theory* which is introduced as a theory that recognised all individuals as operating within and having impact on a framework of ecological systems. Goffman's (1963) work on the concept of stigma is added in as the third contributing factor to be considered with regard to the need for a more holistic model of disability. The final two sections of Chapter Two propose that by combining Shakespeare's *Interactive Model of Disability* with Bronfenbrenner's *Bioecological Systems Theory* a new model could be created that could be particularly significant in developing a richer understanding of autism. The impact this could have within education is considered and linked to the three key authors. Chapter Three presents the methods used for gathering empirical research that would add greater emphasis to the need for change within the current educational environment. The overarching method of inclusive research will be discussed within this chapter and linked to its particular relevance with the theory covered in Chapter Two. Specific considerations relating to methodologies and ethical issues will also be covered. The chapter will conclude with a justification of thematic analysis as the method that was chosen for analysing the data, supported by narrative as the means for portraying the information that was gathered from the analysis. Chapters Four and Five take the key themes from the data analysis and synthesise the findings from the empirical data with proposals from the literature. Both of these themed chapters conclude with a consideration of how the themes have particular significance in exploring the use of an *Interactive Bioecological Model of Autism* as a step in developing a more rounded and respectful view of autism. The final chapter will conclude by returning to the research questions, considering the limitations of the research carried out and providing both implications for practice and considerations for future research.

At the start of each main section within the following chapters, a quotation is provided to emphasise a particular viewpoint. Excerpts from the pupils' voices provide the sources for these quotations within the two themed chapters; the voices of other writers are used in Chapters Two and Three. This was a deliberate action to create a balance, as both sets of voices need to be emphasised with equal value and pertinence; this has also been the intention throughout the writing within this thesis.

Chapter 2 Literature Review

Although the prevalence of autism remains controversial (Grinker, 2009; LeBlanc, 2009), figures from the United Kingdom's (UK) 2011 census estimate that 1.1% of the population is affected by the condition (NAS, 2016). The current situation in primary education within the UK is that more than seventy per cent of children with autism are being taught in mainstream schools (NAS, 2019: online). Research published in 2016 by the NAS discovered that two-thirds of the eighty-five young people with autism who participated in their survey stated their experience of school would be better 'if more teachers understood autism' (NAS, 2016: 17); and of the 980 parents and carers of children with autism who completed the survey, 58% believed schools' knowledge of autism was 'the single most important factor in meeting their child's needs'. This lack of awareness and understanding within education is also often stressed in autobiographies from adults with autism who indicate the impact of a lack of teacher knowledge and understanding regarding their particular needs (for example Williams, 1992; Sainsbury, 2000; Robison, 2007). Painful details of journeys through the education system paint pictures of largely negative experiences and their on-going effects in adulthood. Admittedly, these adult writers would have experienced the education system at a time when less was known about autism, and it is also possible that other adults with autism who had a more positive school experience chose not to write about it. However, the research from the NAS (2016) survey indicates that this situation is current and with greater emphasis now on the necessity to seek and value pupil voice as a vital component in making positive progress (Department for Education [DFE] and Department of Health [DoH], 2015), time is ripe for change.

The quick fix solution to improve this lack of understanding about autism in education may simply be to provide more information to fill the gaps. However, this has previously been tried through online learning programmes (*Autism Education Trust* [DfE: online, 2009], *Inclusion Development Programme* [DfE: online, 2009]), and the gap remains. Although additional information will inevitably provide some improvement in understanding at a superficial level, issues of a more fundamental nature and at a more basic level need to be considered first. Adding information and developing skills that are likely to be based on shaky foundations will not generally result in a positive long-term outcome. To prepare for sustained and valuable progress, an initial step back is necessary to consider and challenge some basic concepts and actions that lead to certain outcomes in educational establishments. It is hoped that the input from this thesis and any subsequent work will add to development towards a greater understanding of autism in the future.

The publication of *A Guide for Ensuring Inclusion and Equity in Education* (*United Nations Educational Scientific and Cultural Organisation* [UNESCO], 2017: 13) urged educators to view individual difference as 'opportunities for democratising and enriching learning … recognising the benefits of student diversity, and how to live with, and learn from, difference'. If this positive view has a chance of realisation, explicit consideration during Initial Teacher Training will be necessary alongside a challenge of pre-held beliefs in current practice through Continuous Professional Development. Several authors (for example Moon, 1999; Hart and Drummond, 2014, Shakespeare, 2014) support the notion of an inextricable link between the thoughts of an individual and their actions. This relationship is described and connected to disability by Shakespeare (2014), as a link between factors that are intrinsic and those that are extrinsic. Intrinsic factors are depicted as those existing *within* the individual, such as the nature and severity of the impairment and the individual's attitude to their impairment coupled with their own personal qualities and attributes. Factors which are extrinsic or contextual include how enabling or disabling the environment is, attitudes of others and various particular societal issues concerning disability linked to culture and economics. To neglect or overlook these theoretical fundamentals concerning both intrinsic and extrinsic aspects of disability and inclusion at an early stage of teacher training risks the development of skills, and the resulting practice in school being founded on pre-held assumptions from the past (Illeris, 2006, Mezirow, 2006; Cranton and Taylor, 2012).

The purpose of this thesis is to propose that in order to develop a 'greater understanding' of autism (NAS, 2016: 17), there is a fundamental need to consider the inter-relations between the intrinsic and extrinsic factors of inclusion. This will involve an investigation into views regarding disability, and a consideration of how the condition of autism is incorporated within that term. It is hoped that the result of this may have a positive impact on the interaction between pupils and teachers within their educational environment

(WHO, 2002; Shakespeare, 2014, Booth and Ainscow, 2016). Through an exploration of these issues, the aim of this research is to highlight some of the steps that schools need to consider in their quest for real and meaningful inclusion for pupils with autism. It is necessary to start from this basic and foundational level if the theoretical drive towards understanding within effective inclusion is to have the positive outcome that it should.

In order to investigate some of these aspects in more detail through the literature, this chapter is divided into three main sections. The first section will start by providing a brief history of autism. Within this section, an overview of the medical and social models of disability will be provided alongside a consideration of the benefits and limitations of viewing autism through these models. The dichotomy between the two models, and the impact this has on autism within education will then be highlighted. The second section will introduce three key authors: Tom Shakespeare, Urie Bronfenbrenner and Erving Goffman, whose writing will be drawn on throughout this thesis. Tom Shakespeare, an academic and disability activist, proposed an alternative model of disability in 2014 and termed it the *Interactive Model of Disability*. Links between this model and the *Biopsychosocial Model* from the *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2002) will be highlighted, and the implications of Shakespeare's alternative model will be considered for pupils with autism. Urie Bronfenbrenner (1917-2005), a developmental psychologist, is the second author who exerts a serious influence on this study. His 1979 publication of *The Ecology of Human Development*, where the *Ecological Systems Theory* as it was originally termed was first introduced, is of particular relevance and significance. Finally, Erving Goffman (1922-1982), a sociologist and social psychologist and the writer of *Stigma: Notes on the management of spoiled identity* will be introduced. With an awareness of the valuable contributions from each of these authors, it will then be possible to investigate the combination of Bronfenbrenner's theory with Shakespeare's model to create a new model termed an *Interactive Bioecological Model of Autism* that might lead to a greater understanding of autism and a lessening of the negative connotations of stigma around this difference. Other writers have already made strong assertions regarding the role of social ecology in development (Cairns and Cairns, 2005; Connolly and Gersch, 2016), and many studies have used Bronfenbrenner's theory as a framework to emphasise the connectedness between individuals and their bio-ecologies (Swick and Williams, 2006; Gabbard and Krebbs, 2012; Guckin and Minton, 2014). However, what is distinct about this study is the suggestion that the *Interactive Model of*

Disability (Shakespeare, 2006; 2014) could be combined with the *Bioecological Systems Theory* (Bronfenbrenner, 1979, 2005), and that used together they could emphasise aspects of individuals' differences and connectedness in a challenge to what are the currently held more traditional views of disability. This is not to be considered as a deviation from the independent value of both Bronfenbrenner's and Shakespeare's work, but rather a development. It is also important to note that at this stage, this model is an exploratory tool that has derived from an engagement with the literature and has not been researched empirically as part of this study. The final section will consider the value of an *Interactive Bioecological Model of Autism* for pupils with autism and their teachers in mainstream primary education and return to the contributions to this model from the three key authors. Through considering an *Interactive Bioecological Model of Autism* within education at a foundational level, it is hoped that opportunities to further skills and knowledge could have a deeper and more sustained long-term impact on both personal and professional expertise. Although this study is specifically concerned with the effects of this alternative model on pupils with autism, in the future the outcomes could be considered more widely for pupils with other needs within mainstream education.

2.1 Autism and the impact of the current dichotomy between the Medical and Social Models of Disability

> The Nobel Prize-winning physicist Paul Dirac identified how light appears to be a particle if we ask a particle-like question, and a wave if we ask a wave-like question. A similar duality obtains in this matter of self. Many conditions are both illness and identity, but we can see one only when we obscure the other. Identity politics refutes the idea of illness, while medicine short-changes identity. Both are diminished by this narrowness (Solomon, 2014: 5).

The opening quotation for this section from Andrew Solomon highlights the danger of narrowing vision by considering characteristics that only fit a particular model of understanding at the expense of considering alternatives. In the case of disability, the proposition would be that rather than limit understanding of oneself, or that of the lived experience of others with a disability as interpreted through one model of disability alone, vision needs to be kept broad if disability is to be viewed from more than one angle. However, before it is possible to start considering a view that uses more than one model of disability, it is important to clarify the remits of the medical and social models of disability as separate entities. Therefore, this section will provide an outline of autism before turning to an exploration of the benefits and limitations of the medical model. What follows is a similar consideration of the social model with a final consideration of the dichotomy between the two.

Autism has been described as 'mysterious' (McGuire and Michalko, 2011: 163) and 'a little understood condition' (Ravet, 2011: 667). However, at least one in one hundred pupils are on the autism spectrum and it is now recognised as one of the most common types of Special Educational Needs (SEN) (NAS, 2016). In order to comprehend how society has reached its understanding of what is currently considered to be the disability of autism, it is necessary to investigate its history from when it first became a diagnosable condition in the 1940s. Considering these developments alongside views of the medical or social model of disability that was held at the time will illuminate how this dichotomy between the two models in the current educational situation in mainstream primary schools can affect pupils with autism. It is necessary to appreciate from the outset that for a current diagnosis of autism a child must present with preoccupations, repetitive behaviours and social and communicative needs (American Psychiatric Association [APA], 2013). Characteristics of this nature prior to the late 1900s would have received a different diagnosis, which would have resulted for many in a very different outcome.

In 1943 Leo Kanner, a highly regarded child psychiatrist in the United States first identified the condition of autism. A child named Donald Triplett had been brought to his attention and through this connection and in consideration of eight other similar childhood cases known to him, Kanner invented the term 'autistic disturbances of affective contact' (1943: 217) to better describe their characteristics. Initially he focused on children with little or no verbal communication and it was from these children that he defined the two traits of this condition: the extreme preference for aloneness, and the extreme need for sameness. Although these were not new characteristics, Kanner determined that children who exhibited them would previously have been diagnosed with 'childhood schizophrenia'. A year after the publication of Kanner's paper, Hans Asperger, a Viennese clinician also published a paper concerning his discovery of several similar unifying factors with four young patients he had come into contact with, although these children differed from Kanner's by being verbal as well as having precocious abilities in science and maths.

Both Kanner and Asperger worked alongside innovative practitioners who shared the vision of advocating the necessity of viewing the child as an individual within his or her own unique system of ecologies in order to gain a fuller understanding (Donovan and Zucker, 2016). Asperger worked in a ward within a children's clinic founded by Erwin Lazar. Lazar's approach to special education was that instead of seeing the children as patients with flaws, it was necessary to view their potential as a variety of future professionals: rather than being viewed as broken and sick, the children were 'suffering from neglect by a culture that had failed to provide them with teaching methods suited to their individual styles of learning' (Silberman, 2015: 84). The approach to diagnosis in Lazar's Children's Clinic was based on a method of intensive observation which he had developed and founded on a belief that it was 'only by watching a child in the course of his or her daily life - in class, at play, at the dinner table, and at rest - could the true dimensions of the child's condition be gauged' (Silberman, 2015: 87). Although in some respects there was enlightenment through a refusal to view these children through a deficit model, this aspect is particularly interesting when considered alongside the criticism by Oliver (1996) several decades later of the inadequate awareness of medical professionals regarding the reality of impairment. It could be said that a greater awareness of autism was provided in Lazar's clinic through careful observation in a variety of real life situations, however it is important to note that no mention is made by Lazar of actually seeking the voice of those observed. It is now recognised that observation alone can only reveal so much as it neglects to query the actual experience of those being observed (Shakespeare, 2014; 2018). Therefore, the subjective experiences of the impairment of autism at that early stage of its recognition remained untapped.

Similarly, Kanner during the early stages of his career, worked under Adolf Meyer who was then the president of the *American Psychiatric Society* in the *John Hopkins Department of Psychiatry* . It was Meyer's argument that 'no aspect of human behaviour could be understood in isolation: neurology, genetics, family background, and social dynamics all had to be considered to properly evaluate a patient's mental state' (Silberman, 2015: 156). These interpretations of human behaviour link strongly with the suggestions made by Shakespeare regarding the *Interactive Model of Disability* which incorporates both the medical and social models of disability. It also resonates with Bronfenbrenner's *Bioecological Systems Theory* where the theory is based on the impact of an individual's ecosystem. Proposals from both of these authors and their significance to this study will be looked at in more depth in the second section of this chapter.

During these early developments in the understanding of autism, most general medical professionals would have begun to recognise the condition by its specific characteristics. The model used to define and label disorders or conditions later became recognised as the medical model of disability. A few decades later this view was challenged and thus formed the social model of disability. To understand the current dichotomy that exists between the medical and social models and besets many educationalists, it is necessary to explore their separate histories considering the benefits of both models and highlighting their limitations when used independently. This will provide the background for a better understanding of some of the outcomes that have arisen and had an impact on the understanding of autism, and will highlight a root of the dichotomy.

2.1.1 Autism and The Medical Model of Disability: benefits and limitations

The medical model of disability was defined by the ICF (WHO, 2002: 8) as describing 'a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals'. This definition depicted the result of many medical and scientific developments that continue to provide a greater understanding for diagnoses and new medical terms for specific disorders and conditions. Sometimes the outcome from such a diagnosis presented opportunities for treatment that would enable individuals to benefit from greater integration into society without being as negatively affected by the limitations of their disorder. However, although for many who experienced this as a positive step (Bailey, 1998), such developments also presented counter effects. For example, whereas diversity had previously been more readily accepted as a part of being human (Silberman, 2015), the growing emphasis on active involvement in the workplace through the industrial revolution and advances in medical knowledge provided greater opportunities for treatments and cures. Thus the concept grew that a specialist's diagnosis for a particular condition or disorder was one step closer to 'recovery' (Anastasiou and Kauffman, 2012) and therefore something of value (Imrie, 2004). For those with no diagnosis and/or cure, the resulting segregation of their undiagnosed or 'untreatable' impairment or disorder often placed them in a position of being considered humans of lesser value and/or greater need (Lawson, 2008). The view of disability began to shift from 'the discovery of a better depiction of reality based on scientific investigation' towards the position of a 'changing moral sensibility' (Gallagher *et al*., 2014: 1126).

The effect of this on pupils with autism in education meant that once autism became recognised as a specific condition in 1980 (APA, 1980), the aspects of their individuality that made them different could be diagnosed or labelled. Although for many this could have been positive and resulted in the education and care that was necessary, it also had the potential for others to focus on differences that were 'pathologised as difficulties inherent *within* students' (original italics, Ainscow, 2005: 116). In other words, although the diagnosis provided the opportunity for a greater understanding of the condition or disorder, the label also began to be considered potentially limiting. Perceptions of 'difficulty' or 'disability' became 'constructed around and within discourses of comparison - around normality and abnormality, success and failure, the functional and the dysfunctional' (Thomas, 2013: 482). A writer with autism named Donna Williams (1996) suggested there could be further negatives with potentially defining specific characteristics of a condition and measuring their severity:

> The observation of these "symptoms" might have been fairly harmless except that people stopped looking at them as observations of symptoms and started taking them to be "facts". Instead of noticing all the people who did seem to get jokes or show curiosity or be emotionally expressive or express "normal" intelligence, these people were considered "exceptions" to the "rule" and only those who fitted the outlined symptoms were considered the "true" "autistics". However, this may not have singled out one subgroup among the "autistic" population, it may have created one (Williams, 1996: 12).

Considering conditions through the medical model is by necessity to view the deficits of the individual and to focus on their resulting problems and inabilities. This outcome was highlighted by Sacks (2007) who proposed that:

> Our tests, our approaches, … our "evaluations", are ridiculously inadequate. They only show us deficits, they do not show us powers; they only show us puzzles and schemata, when we need to see music, narrative, play, a being conducting itself spontaneously in its own natural way (Sacks, 2007: 191).

Indeed, considering autism through the lens of this deficit model provides some explanation as to how several decades ago, children were often considered by medical practitioners as defective human beings. The advice then given to many parents was to send them to institutions with the expectation that if an education was considered, they would attend separate special schools and not be eligible for the mainstream education that their peers received. Theories were suggested regarding the root of autism, including that of Kanner's 'refrigerator-mother' (Silberman, 2015: 188) that proposed the condition stemmed from a lack of parental warmth. As a result of autism's medicalisation, huge arrays of varying treatments were advocated alongside an increase in behaviourism.

An inherent danger of the medical model is to view individuals with autism on a bell curve of normativity (Fendler and Muzaffar, 2008); to sort human beings into two groups comprised of those who fit into the category of 'normal' and those who do not, or in this instance have autism and are therefore outliers. One example of this can be seen in Baron-Cohen's consideration of the theory of mind and his comparison between things that 'normal children' can do, as opposed to 'children with severe autism' (2000: 183). Whilst it is accepted that there are certain aspects of life that are more of a challenge for some than others, is there such a thing as a 'normal child' with which to reliably compare, or is Baron-Cohen referring to a child who does not have the diagnosis of autism, but is no more or less 'normal' than the other? Goffman (1963: 17f/n) suggests that 'the notion of "normal human being" may have its source in the medical approach to humanity or in the tendency of large-scale bureaucratic organisations, such as the nation state, to treat all members in some respects as equal'. This would seem to apply to Baron-Cohen's use of the word, but the outcome of using language to categorise in medical terms results in those who consider themselves as 'normal' often and unthinkingly reducing the life chances of those who do not fit that category (Goffman, 1990). This may explain another insight into the medical model's influence on Baron-Cohen, which can be seen in his extreme deficit definition of autism as a condition that is:

> diagnosed on the basis of abnormal development of social behaviour, communication and imagination, often in the presence of marked obsessional, repetitive or ritualistic behaviour. Such children find it hard to be part of a social group and dominate their families by insisting on their own preoccupations and bizarre routines (Baron-Cohen, 2000: 181).

By reducing considerations regarding another human being to medical language alone, normality would technically exist within the majority of the population who reacted or behaved in a similar way in certain given situations. It is worth pointing out here the reminder provided by an adult writer with autism that ‘who we are is normal for us’ (Lawson, 2008: 15). The danger of limiting the view and therefore the consideration of individuals to what is known about the medicalisation of their condition, considers only their deficits, the dominant identifying factors being those of abnormalities, inabilities and differences. Indeed, in a more recent article from Baron-Cohen *et al*. (2009), the mention of the word ‘difficulties’ occurs fourteen times. If this deficit and medicalised view is the only one considered valuable, it is not difficult to see why parents receiving a clinical diagnosis that explained their child’s specific characteristics often became desperate to find a ‘cure’ to make the autism go away. Or to seek a different outcome, as explained by Katrine (2019: 15): ‘I want to be liked by everybody and to be liked requires normality’.

The limitations caused by viewing autism through the medical model alone, and not considering other factors of disability and individuality, continue to be experienced. In considering this effect on children with autism and therefore proposing the need for a greater balance in outlook, Wolfond (2008) enjoins professionals to be wary of the dangers of:

> diagnosing anything and everything that comprises the human condition, rather than evaluating the circumstances around autistic experience - the good and the painful - and asking what that means and feels like. We can and are pathologising human experience, and we do so by adding in our bias our mismeasures. We should not misread the disability as a medical condition, but take a look at how we can assist the disability while dealing with some medical aspects that can result in any human being (p.118).

It would be wrong however, just to consider the medical model in a negative light, as the need for and value of a medical diagnosis often seems to be directly linked to the environment in which the person is operating and the interpretation from those within the environment. For example, Silberman (2015) wrote about a mathematician and engineer named John McCarthy who entered the *Massachusetts Institute of Technology* as an undergraduate in the late 1950s. He discussed his unusual and sometimes ‘unnerving’ (p.248) behaviour, but also highlighted his groundbreaking work in computing and artificial intelligence. McCarthy belonged to an age where autism had not yet been diagnosed, however according to Silberman, even if a diagnosis had been possible it would not have been necessary because McCarthy ‘was able to carve out a niche in an emerging field that was perfectly suited to his strengths while being tolerant - indeed, appreciative - of his many eccentricities’ (Silberman, 2015: 251). A diagnosis for McCarthy, were it possible, would not have deepened his understanding of who he was and how he fitted in to society; but, if he had been placed in a different environment it could have been a very different story. Bailey (1998) on the other hand became convinced from working with the case of Billy Gates, a child with ADHD, 'that categorisation is necessary for appropriate services to be provided' (p.172). Bailey considered that inclusion for Billy would have resulted in him 'being in an ordinary school with other students, following the same curriculum at the same time, in the same classes, with full acceptance by all and in a way which makes the student feel no different from any other student' (p.173). Through working with Billy, his mother and the school, it became clear to Bailey that in order for this to be possible, Billy's Attention Deficit and Hyperactivity Disorder needed to be identified in order to receive the support he needed to fully participate.

There are also frequent accounts by writers in the magazine *The Spectrum* of the value of their diagnosis and therefore label of autism. One writer, diagnosed with autism at the age of forty-one, wrote how his diagnosis 'answered many questions, filled in gaps and helped me to move on and understand myself and others better' (Andrew, 2019: 17). His ability to understand himself better through being able to read about what his label meant provided affirmation and relief that:

> No longer did I need to try to fit in and try to be someone else because I could not and cannot be that person. I can only be me. I don't need to try anymore I can relax and let the things I cannot control go and concentrate on the things I can do (p.17).

Another article by an adult who received her diagnosis of Asperger syndrome at the age of ten wrote about how her diagnosis, like that of Billy Gates, had meant that her education was able to be more tailored to her needs. For her, the outcome of a diagnosis had been that she was able to attend a special school where she recalled the relief of finally finding friends in this new environment. Her opinion was that the label of autism is particularly useful for deepening the understanding of others, stating that 'Mum and Dad understand that it helps me to cope better when others are aware that I'm autistic' (Siobahn, 2018: 15).

It seems that the medical model is useful in defining some aspects of autism and other conditions, which may lead to an increase in understanding. However, it is also necessary to be aware of the danger that a label from a diagnosis can result in causing stereotype and assumption regarding that particular human being, as though the characteristics of the label explained their entirety. The next part of this section will consider the impact on autism of the arrival of a new model of disability in the form of The Social Model.

2.1.2 Autism and the Social Model of Disability: benefits and limitations

Due to the sometimes-limiting outcome of viewing symptoms and deficits as creators of labels and in defining disability, an alternative view of disability was created in the 1970s by the *Union of the Physically Impaired Against Segregation* (UPIAS). This group of disabled activists formed as a result of their growing concern that medical professionals were regarded by many as the major players in decisions regarding interventions for the disabled individual (UPIAS, 1976). What they proposed as an alternative was that it was not the individual who needed to be altered in order to 'fit', but the physical and attitudinal aspects of barriers erected by society that required changing. Their model highlighted the fact that the degree of disability was imposed upon them by the social and environmental context (Cummings *et al*., 2006) and that the view of disability presented by the medical model was a call for 'medical or other treatment or intervention to "correct" the problem within the individual' (WHO, 2002: 8). This alternative model gained the term 'the social model' and was considered by many with a physical disability as a positive addition to the previous unilaterally held view, which then became known as 'the medical model' (Oliver, 2009).

The origins of the social model are explained by Mike Oliver, who was one of its key authors, in updating the second edition of his book *Understanding Disability: From Theory to Practice* (Oliver, 2009). His explanation for the first edition was that he had 'formulated [the social model] as a possible aid to social work practice [he] had no idea that it would also crucially become the slogan for the newly emerging disabled people's movement' (Oliver, 2009: 10). Initially Oliver worried that a new edition of his book would waste everyone's time, including his own, but came to accept that in the fifteen years that had elapsed since the first edition much change had taken place and an update was timely. He reminded readers that the purpose of a model was to create a way 'of translating ideas into practice' (Oliver, 2009: 43). From his perspective the need for an updated model originated from his understanding of the individual (or medical) model being underpinned by personal tragedy. His newly proposed social model instead drew attention to 'externally imposed restriction' (p.43). However, reflecting on the previous fifteen years, Oliver (2009) believed the model had become 'a sacred cow that has been viciously fought over' and went on to remind critics that 'if it is any good, use it and share your gains with the rest of us; if it is useless … invent something else' (p.11). Indeed, thirty years after Oliver's original publication that introduced the social model, he re-defined it as 'a tool to improve people's lives' (Oliver, 2013: 1025) and chided those who had spoken out against the model whilst failing to provide an alternative.

Another key author for the social model was Vic Finklestein, who suggested that the medical model of disability had created an oppressed minority group from the assumption that disabled people were 'socially passive, inadequate and helpless' (Swain *et al.*, 2014: 6). In order to further draw attention to the necessity for a change in outlook that the alternative model provided, and to highlight that much that was experienced by those with a physical disability had been caused by attitudes and decisions made by society, he wrote a powerful fable to highlight the issue (Finklestein, 1981). The fable depicts a village where all occupants were wheel-chair users with full management and democratic rights. Their environment had been created to perfectly suit their needs. Able-bodied people were seldom seen in the village, and therefore little understood. When some arrived to settle in the village they experienced particular difficulties within the environment that they needed to seek assistance for. These problems also resulted in an inability for them to hold down employment. In order to try and incorporate these able-bodied arrivals, the wheelchair users created societies and money was raised in order to make some necessary changes. The able-bodied individuals were not consulted on the ideas that were raised and realised over time that the wheelchair users may have overlooked several proposed solutions because of their inability to see the problems from the same perspective as the able-bodied newcomers. Finkelstein concluded the fable with a warning: 'the able-bodied disabled even argued that perhaps, just perhaps, their disabilities could be overcome (and disappear!) with changes in society' (Finklestein, 1981: 36). This clever fable highlights the assumptions that Finkelstein proposed were so often made by the 'able-bodied' in their regard as to what is necessary to 'solve the problems' of the disabled. The effects of not involving those who should have had a major voice are highlighted, shedding a light on the limitations of 'development' through basing change on the assumptions of others. In seeking to avoid a similar occurrence within this study, it has been essential to work directly with pupils who have autism in order to seek their voice. Further considerations regarding this will be covered in later sections.

A significant aspect of the social model was the clear definition between the terms impairment and disability as proposed by UPIAS:

> Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression (UPIAS, 1976: online).

It was believed that the separation of these two terms was necessary for society to have a better awareness of the changes that needed to be made. A further expectation of the social model was that disabled people themselves would be included in the decisions made about them and that progress would be made *with* them not *for* them, as had so often been the case (UPIAS, 1976). Thus the empowering maxim of 'Nothing About Us Without Us' (Aspis, 2000: 84) became popularised several years later. Certain factors of the social model were considered fundamental if society was to accommodate this change in perspective. Its foundations were based on the understanding that 'disability is a situation caused by social conditions' (UPIAS, 1976: 3) and in order for these to be eliminated three principles needed to be agreed:

> (a) that no one aspect such as incomes, mobility or institutions is treated in isolation,
> (b) that disabled people should, with the advice and help of others, assume control over their own lives, and
> (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people (UPIAS, 1976: 3).

The original focus of the social model as set out in 1976 was echoed in 2002 by the WHO in their definition of disability as 'a socially created problem and not at all an attribute of an individual' (WHO, 2002: 9). This clearly emphasised a political response to disability, as the root of its cause was the unaccommodating environment and attitudes of others. As highlighted by Paul Hunt, another disabled activist involved from the start of UPIAS, 'if everyone were disabled as we are, there would be no special situation to consider' (Swain *et al*., 2014: 3). In embracing this new model of disability, views of medical intervention being the *only* solution in enabling as many people as possible to have the opportunity to fit into structures that suited the majority, be they workplace, education based or regarding general opportunities in life were challenged. If social exclusion had primarily occurred because of the responses of society to people with impairments, as defined by the medical model, society now needed to be the target for change (Oliver, 1996).

Within education, the publication of *The Warnock Report* (DES, 1979) marked a definite change for many aspects of SEN and was heralded as a major player in considerations regarding inclusion. *The Disability Discrimination Act* (Gov.uk, 1995) and *The Education Act* (Gov.uk, 1996) that followed legislated alterations that were necessary to be made within organisations to minimise any disabling effects of the environment. However, the proposal from UPIAS (1976) to ensure the involvement of individuals with disabilities in the control of their own lives without professionals making decisions on their behalf seemed largely to be overlooked in the alterations that followed. The long-term outcome of this in education was that the pupils, who were then welcomed into what was considered by those who had created it as a more inclusive educational environment, had not been an active part of the change. If they had been, they might have questioned the replacement of one model with another; understanding through their own experiences that neither model used independently could provide the complete picture.

Educational professionals began to view the medical, or traditional view of disability as depicting situations that were 'fixed and unchangeable' (Hollenweger, 2014: 10). It began to be recognised as a 'one-dimensional landscape' (Thomas, 2013: 474) often comprising pre-held deterministic beliefs about disability and difficulty (Hart and Drummond, 2014) and tending to incorporate a bell-curve notion of ability (Fendler and Muzaffar, 2008). The medical model of disability became negatively recognised as summing up 'everything which [was] backward looking and reactionary' (Shakespeare, 2014: 11). As its replacement, the social model of disability was instead valued as being 'synonymous with progressive approaches to disability' (Shakespeare, 2014: 11). Inclusion, as depicted by the social model was welcomed as a 'three-dimensional terrain' that incorporated 'a more extensive spectrum of concerns and discourses about the benefits that come from valuing diversity' (Thomas, 2013: 474). Through shunning the medical model, thus the root of the current schism between the medical and social model began: explained by Shakespeare (2006: 10) as evolution into a ‘rigid ideology claiming that disability was everything to do with social barriers, and nothing to do with individual impairment.’ This evolving situation highlights the dilemma raised by the quotation from Solomon (2014) at the start of this section, which provides a reminder of the possibility of altering a view through limiting vision.

Even though its primary focus had been for those experiencing physical disability, the advent of the social model brought welcome change to attitudes regarding autism. The shift that occurred from considering disability as something that was ‘intrinsic to the person and one-dimensional, to reflecting an interaction between the individual and contextual factors’ (Alves *et al*., 2012: 159) presented challenges to those who had previously viewed autism as a problem of the individual. Now the possibility had to be confronted that society might have placed unnecessary limitations and barriers on people at the edges of the bell curve of ‘normality’ (Fendler and Muzaffar, 2008). New interpretations of disability and impairment for pupils with autism that were founded in the social model began to develop from the 1981 *Education Act* (Gov.uk, 1981). Its focus was primarily on changes to the environment within schools and classrooms in order for them to become more inclusive towards children with SEN. The necessity for a more proactive, rather than reactive consideration of some of these aspects was highlighted to minimise behaviours often viewed as challenging or disruptive. However, although these alterations were often based on good intentions, as changes made were only connected to the environment they frequently tended to be superficial and transient. Many teachers in the eighties and nineties would have previously been pupils in schools when autism was either not diagnosed, or when children who had an autism diagnosis would be sent to different institutions. This inevitably would have influenced their views on disability. The outcome of this for pupils with autism within mainstream education at this early stage of the social model’s introduction was that the real concept of inclusion, with all its connotations, had not gone far enough. Despite some physical changes to the learning environment, long lasting effects on mind-set from the previously held understanding of disability based on the medical model view could not be instantly replaced with those of the social model.

One example of this was indicated in research by Gallagher *et al*. (2014) that highlighted the tendency of adults to regard the drawing of attention to difference or exceptionality as possibly inappropriate. The result of this was that despite a possible well-intentioned verbal silence, adult attitudes could still be implicitly and inadvertently communicated to children, thus creating an aura of secrecy or shame around these concepts. As Gallagher *et al*. (2014) pointed out, it is important to note that one of the aspects of being human is that observations are not value free, instead they are 'prepossessed by cultural values and individual beliefs … observation and interpretation are inseparable: to have one is, simultaneously, to have the other' (p.1124). Indeed, earlier research conducted by Cummings *et al*. (2006) suggested that children recognised difference from an early age and had varying responses to it dependent on their environment and upbringing. Therefore, the danger of underestimating this ability is that without careful exploration into the root of an individual adult's view of disability, subconscious reactions can be passed on to the next generation.

2.1.3 Autism and the dichotomy in education between the medical and social models of disability

In this final part of the first section of Chapter Two, which has considered the two separate models of disability and their effects on pupils with autism, attention now turns to the dichotomy that currently exists between them. This is in preparation for the proposal of an alternative model of disability with a focus on autism in the second section.

Although the social model brought welcome change for many physically disabled people and had undeniable 'emancipatory significance' (Gallagher *et al*., 2014: 1120) questions were posed suggesting there were errors in the model that ignored certain aspects of disability (Anastasiou and Kauffman, 2011). Five main criticisms of the social model were suggested from within the disabled people's movement (Oliver, 1996). These will be explored here in more depth and linked specifically to outcomes for pupils with autism. However, it is important to note that since the 1940s pupils with autism have had much variability in categorisation and represent a unique set of the population (Castro *et al*., 2013). What is considered 'normal' has always been socially defined (Gallagher *et al*., 2014) and that currently a diagnosis of autism sits within the category of being disabled.

The first criticism of the social model that was rebutted by Oliver (1996: 37) focused on suggestions that the model represented an inadequate awareness of the 'experience of impairment': the second criticism proposed that subjective experiences of impairment were ignored. Both of these criticisms resonate with the missed opportunity within the ICF to consider and include an individual's response to their experiences of impairment. This omission will be considered further in section 2.2.1. In considering these two criticisms in light of this study, it is important to highlight that this 'inadequate awareness' within education for pupils with autism has had both a negative and a limiting impact. Through embracing the social model as a replacement to the medical model and thus creating a binary situation, educators focused on issues they felt were within their control that concerned the minimisation of the disability of autism. For example, by making adaptations to the environment and through attempting to improve the attitudes of society, assumptions were made that the difference and therefore 'disability' of autism would be managed or even eliminated. The alterations made focused on extrinsic factors (Shakespeare, 2014). However, as highlighted by Able *et al*. (2015: 45) following research into the inclusion of pupils with autism into mainstream classrooms: 'physical integration does not necessarily equate to full inclusion'. The situation for many people with autism is that the characteristics outlined within the medical model, which provide medical personnel with the ability to diagnose autism, will still be experienced by individuals despite the changes made to the educational environment. Experiences of 'navigating peer relationships and other classroom social situations' (Able *et al.*, 2015: 44) for example, will continue to be more difficult for pupils with autism as it is the difficulties negotiating the social world that lie at the core of autism (Hebron *et al.*, 2015). Links between the first criticism highlighting the lack of awareness of the experience of impairment and the second, proposing that subjective experiences of impairment are ignored are clear. Without gaining an awareness of the individual's experience of impairment and their lived experience of the condition, knowledge is severely limited; without seeking to better understand subjective experiences, their significance can easily be overlooked. Susan Lawson, an adult with Asperger's, wrote that 'the very term that defines me as an individual with autism states that I am disabled due to deficits in three areas of functioning: social understanding, communication and imagination' (2008: 95). She continued by considering her subjective human experience and raised the query 'are there not many individuals, with or without autism, who have these difficulties?' (p.95). Although there have been several studies into autism by authors who have sought and valued pupil voice (for example: MacLeod *et al*., 2014; Hebron, *et al*., 2015; Dillon *et al*., 2016; Parsons *et al.*, 2020), according to Philpott and Poultney (2018), it would seem that seeking subjective experiences from individuals with autism remains an aspect that is largely overlooked in autism research. Therefore, in order to ensure that the same criticism cannot be made of this study, careful considerations regarding the seeking, hearing and acting upon pupil voice are discussed in Chapter Four with the overarching method itself also highlighted as a vital component in the process towards positive change.

The third criticism of the social model from within the disabled people's movement that Oliver (1996) considered regarded its limitations, proposing that it was not possible to incorporate the model into other social divisions of race, gender, etc. This is an interesting proposal and could explain why for people with autism, the social model that was originally focused on physical disability, has not been especially helpful. The fourth criticism centred on the positioning society gave to disabled people as 'other' which links with the previous criticism and the connotations that arise from this sense of 'otherness', particularly for people with autism whose 'disability' is sometimes referred to as a 'hidden disability' (Leedham *et al*., 2020) as there are often no visible physical characteristics. This criticism demonstrates the need to look more deeply for a connection between the views of the individual and the views of society and how one can affect the other. The section to follow that considers Goffman's writing regarding stigma (section 2.2.3) will explain this concept in more detail. The final criticism was that of the inadequacy of the social model as a social theory of disablement. The reality as proposed by Oliver (1996) was that in the everyday lives for people with disabilities even if all social barriers and limitations were removed, some restrictions would remain. This concept was further developed by Shakespeare (2014) who considered the lack of neutrality of impairment that had been proposed by the social model. He suggested that impairment would often involve some form of 'intrinsic disadvantage', and raised awareness that 'disabling barriers make impairment more difficult, but even in the absence of barriers, impairment can be problematic' (Shakespeare, 2014: 33).

Gallagher *et al*. (2014: 1122) proposed that the dichotomy of the medical and social models should not have arisen: it should never have been 'one versus the other'. Further to this, they suggested that the outcome of the distinction made in the social model between impairment and disability, had actually created 'a conceptual muddle of some consequence among several scholars' (p.1129). Rather than question whether people differed from one another, Gallagher *et al*. (2014: 1124) preferred a consideration of 'how do those differences come to make a difference as a consequence of the way others interpret and subsequently respond to them'. The binary situation between the two models resulted in attempts within education to reject the stance of the medical model and adopt the view of inclusion of the social model through an act of will. For pupils with autism, the dichotomy that arose then remains active today, and continues to affect the way many are treated and how therefore have an impact on how they might feel about themselves within their educational environment. It returns to the point made earlier by Gallagher *et al*. (2014) who highlighted the effect on children of the explicit and implicit views of adults around them and the resulting impact this can have on their views of themselves.

This study seeks to emphasise the need to reconsider the restrictions of previous independent and contrasting standpoints and propose instead the adoption of an alternative model of disability that combines aspects from both the medical and social models in a move towards a greater awareness of inclusion and disability in all its connotations. If it can be accepted that no human being is totally capable in every environment and in all contexts, then this provides the possibility of viewing disability as a much more fluid entity. Therefore, having briefly explored some of the history behind autism and the effects of the medical and social models of disability, it is necessary to return to the statement from UNESCO (2017: 13) proposing that 'individual differences' be viewed 'not as problems to be fixed, but as opportunities for democratising and enriching learning … recognising the benefits of student diversity, and how to live with, and learn from, difference'. Difference within the human race has long been accountable for its success. Although there is a slow departure from the belief that the medicalisation of conditions such as autism are the only way to progress, and a greater awareness is developing of the major part that society plays in its acceptance of diversity, the acceptance of autism and many other conditions still has a long way to go. The need to view individuals with autism as more than a set of characteristics to be interpreted through either the medical or social models of disability, to consider their 'complex challenges' (Sciutto *et al*., 2012: 178) and to consider how they are influenced by their systems of ecology, and in turn influence their ecologies will be considered in the second section of this chapter.

2.2 Introducing Shakespeare's *Interactive Model of Disability*, Bronfenbrenner's *Bioecological Systems Theory* and Goffman's concept of Stigma

> If you've got a camel which is finding it hard to walk under the weight of all the straws on its back, the easiest way for making it easier for the camel to walk is to take as many straws off its back as possible. Management is about training the camel to walk or appear to walk whilst carrying the straws. Cure is about taking the straws off the camel's back. The two can work together (Williams, 1996: 87).

In this quotation, Williams (1996) is providing an analogy to highlight the considerations necessary when working effectively alongside a person with autism. Autism viewed through the medical model, as discussed in the previous section, focuses on the deficits within the condition and invites considerations of its management: thus how the camel can better walk with its existing load. Viewed through the social model, there is an implication that through minimising some of the deficits of autism, by making alterations to the environment and the mindset of society, the person may be less disabled by their autism. In other words, some of the straws will have been removed from the camel's back making it easier for it to walk. Ideally, both options would work simultaneously.

Through considering the journey of autism in education, the need for a change in mindset in order to depart from the awkwardness and inappropriateness of the dichotomy of the social and medical models of disability has already been highlighted. The second part of this chapter will explore the potential for a proposed alternative model through a consideration of literature. The relevance of this new model will be considered as an opportunity to improve outcomes for pupils with autism in mainstream primary education through challenging the current view of functioning and disability that is founded on either the social or medical model. The new model for autism is developed from the *Interactive Model of Disability,* which was originally proposed by Tom Shakespeare in 2006 and is combined with Bronfenbrenner's *Bioecological Systems Theory* (1979, 2005) and considered alongside Goffman's (1963) writing on stigma. Although the focus for change has arisen from an awareness of a gap identified in the UK regarding teachers' understanding of pupils with autism, the suggestion of a new model has much wider implications both for aspects of Special Educational Needs and Disabilities (SEND) within the UK and internationally through its similarities to the *Biopsychosocial Model* as presented in the ICF (WHO, 2002).

The first part of this section will begin by exploring Shakespeare's proposal for the *Interactive Model of Disability* and will consider its similarities to the *Biopsychosocial Model*. Secondly, Bronfenbrenner's *Bioecological Systems Theory* will be outlined. Before demonstrating how these two models could be combined to create a new model, considerations will be given to Goffman's (1963) concept of stigma that will further highlight the need to value the interrelationship between views of disability from society and views of disability from the individual. Finally, Bronfenbrenner's theory will be combined with Shakespeare's model to introduce a new model as an exploratory tool, termed an *Interactive Bioecological Model of Autism,* that is hoped would further develop understanding of the diversity and individuality of autism in education.

2.2.1 Shakespeare's *Interactive Model of Disability* and the *Biopsychosocial Model* in the *International Classification of Functioning, Disability and Health* (WHO, 2002)

In reflecting on attitudes to disability, Shakespeare proposed that 'it is often easier to fit a ramp or provide screen reader software than to change the prejudices which are so often associated with disability' (Shakespeare, 2018: 16). This highlights the outcome of the current situation that remains grounded within deep-rooted views of disability; a mindset that has remained unchallenged for several decades. The outcome of this for those with disabilities has been and remains a prejudice from many within society that requires education and then eradication. Although recognising that much positive change had occurred as a result of the introduction of the social model, Shakespeare (2014) proposed that the concepts of impairment and disability were linked rather than viewed as separate entities, which was a concept of the social model. He recognised that even if environments were potentially fully enabling to all, some individuals would still be impaired, as the experience of impairment is a universal phenomenon experienced by everyone in some form at various life stages. Impairments were not conditions that could be viewed in a positive light as they all caused some form of predicament for individuals and acted as limiters to opportunity. From his perspective as a non-reductionist and critical realist, Shakespeare (2014) suggested that however accessible the world was made to be, there would be many who would still experience disadvantage.

In proposing the *Interactive Model of Disability*, Shakespeare (2006, 2014) acknowledged other authors' prior considerations of the necessity for a balance between social and medical models. He accepted that his model of disability was not wholly original and that there were continuities between the *Interactive Model of Disability* and that of others through identifying three unifying elements. These elements that consisted of: individual factors, societal factors, and factors within the system of support, he believed would more reliably influence integration between the medical and social models. Shakespeare's view of disability was that it was made up of 'the combination of a certain set of physical or mental attributes, in a particular physical environment, within a specified social relationship, played out within a broader cultural and political context' (Shakespeare, 2014: 78). He therefore proposed that the level of disability the impairment caused was dependent on the outcome of the interaction between these three elements, and that this could vary:

> We cannot reduce the complexity of disability to either a biological problem, a psychological problem, or a social problem. We need to take account of all the factors and intervene at all the different levels to benefit and include disabled people (Shakespeare, 2018: 21).

In other words, by combining the separate elements of the social and medical models, as discussed in the previous section, it was possible for them to act as one model thus providing a broader view of disability, providing all elements were equally considered.

There are particular similarities with Shakespeare's model and the *Biopsychosocial Model* originally proposed by the *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2002) and recognised as beneficial by Shakespeare for its ability to highlight 'the complexity of disability' (Shakespeare, 2014: 78). Emphasis within the ICF was placed on the need to consider how rather than isolating and alienating an individual or creating an 'other' through factors which emanated from the medical model alone, the focus would be on providing a wider view of humanity through incorporating additional factors arising from the social model. Thus the ICF proposed a balance between individual aspects of functioning, disability and health, and that a potential outcome for *all* human beings was that everyone would experience health decline and disability. Considerations were added to concepts of management and reduction 'in the incidence and severity of disability in a population … by enhancing the functional capacity of the person and by improving performance by modifying features of the social and physical environment' (WHO, 2002: 5).

Although recognising the partial previous validity of the medical and social models of disability within this context, the ICF recognised that independently they were inadequate. They proposed that a better model would be one that 'synthesises what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects' (WHO, 2002: 9). Therefore, through synthesising the medical and social models of disability, the *Biopsychosocial Model* approached disability from a 'multi-dimensional perspective' (Castro *et al*., 2013: 321). Instead of viewing disability and functioning as two separate entities, they were depicted as 'the ends of a continuum of human functioning' that was the result of 'complex interactions between the person and the environment' (Hollenweger, 2014: 11). Disability within the ICF was recognised as 'a social relationship between personal characteristics and the extent to which society is able to take them into account' (Alves *et al*., 2010: 14). Within this international model, 'disability and functioning are viewed as outcomes between *health conditions* (diseases, disorders and injuries) and *contextual factors*' (original emphasis, WHO, 2002: 10). Instead of the previous static nature of diagnosis from the medical model, or the implication of the social model that changing the environment alone could eliminate disability, this model depicted a continuum of functioning and disability on which *all* individuals existed depending on various factors.

There are clear links between this model and Shakespeare's (2006, 2014) *Interactive Model of Disability*. Most notable is the departure from the dichotomy between the medical and social models of disability with an emphasis instead on the value of both. The medical aspect imparts necessary detail that could better explain the symptoms and characteristics of the disability to the individual and society, and equates to the intrinsic factors of disability (Shakespeare, 2014). The social model of disability adds essential considerations regarding aspects of the environment, the impact of the mindset of others that includes societies attitudes to difference and disability, and equates to the extrinsic factors of disability (Shakespeare, 2014). These factors are combined within both models to increase awareness of the potential for greater functioning and a lessening of disability within an adapted environment and open-minded society.

However, although many researchers have used the *Biopsychosocial Model* as the basis for their work (see Chapireau, 2005; Gentry *et al*., 2018; Baria *et al*., 2019), it has certain limitations. An area of particular relevance to this study was raised by Alves *et al*.

(2010: 132) who proposed that by ‘having participation as a key concept, the ICF does not capture the notion of social inclusion that is central for the life of every individual, especially those with disabilities, who are often excluded’. Imrie (2004) also raised concerns about the theoretical efficacy of the *Biopsychosocial Model*. Despite accepting that the ICF provided new considerations regarding the nature of disability, his proposal was that the *Biopsychosocial Model* needed to be more explicit about its ontological claims ‘in order to provide the basis for a defence against viewpoints that are dismissive of the potency of the biological body in enframing life experiences’ (Imrie, 2004: 295). He suggested that this lack of boldness was a potential problem for those who sought to utilise the *Biopsychosocial Model* and required a theoretical basis for its justification. Indeed, in the introduction to a training manual entitled *Human Rights, Persons with Disabilities, ICF and the UN Convention on the rights of persons with disabilities* (Alves *et al*., 2010), it was suggested that in order to create ‘a better understanding of the condition of persons with disabilities’ (p.12), the ICF was not used independently, but rather in conjunction with the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006). It is also interesting to note that despite international recognition of the ICF and its aim of encouraging a common language in the areas of functioning and disability, it has been little used to date in education within the UK (Moretti *et al*., 2012; Norwich, 2016). Even in the most recent changes for the updated *Special Educational Needs and Disabilities Code of Practice* (DfE and DoH, 2015) there is still no mention of the ICF and/or a mention of the *Biopsychosocial Model*. In considering this situation, Norwich (2016) proposed it could be due to a lack of connection between professionals in the field and researchers in SEN; or the prospect of negative implications in viewing classification as reverting back to the more deficit based medical model. Norwich’s first suggestion regarding the outcome of a lack of connection between researchers and practitioners when considering a more informed practice had already been highlighted by Fielding (2000: 377) who warned that: ‘without philosophy education policy is more likely to be muddled and inconsistent, overly concerned with the tangential or the trivial, and so tremendously busy with getting things done that the possibility of foolishness outweighs the likelihood of wisdom’. This thesis attempts to bridge such a gap in proposing Shakespeare’s updated model of disability and linking it with theory in order for it to be more confidently actualised in practice.

In responding to later critics of the social model, Oliver’s (2009: 89) proposal was that all social theory should be judged on three interrelated elements: ‘its adequacy in describing experience; its ability to explain experience; and, finally, its potential to transform experience'. Using these elements as judgments for the *Biopsychosocial Model* it seems that although attempting to attain a holistic overview, it is lacking in the first element, that of 'describing experience'. This was highlighted in Söder's (2009: 72) considerations of the *Biopsychosocial Model*: 'the biological is taken for granted as objectively given and at the risk of being essentialised in much the same way as in the social model'. It was also a concern raised by Shakespeare regarding assumptions of the lived experience of the person with the disability (Shakespeare, 2018: 45), preventing those that form such assumptions from being able to see that 'people disabled from birth are likely to feel that disability is part of their identity, they cannot imagine life without it'. Shakespeare (2018: 47) proposed that the experience for disabled people was that through a process of adapting, coping and accommodating, 'even if life is sometimes hard, we are used to being the way we are'. The danger of others making assumptions by taking the biological element for granted as proposed by Söder (2009), results in a tendency to 'exaggerate, project, and mistake what life is really like for people with disabilities' (p.48). Therefore, in returning to Oliver's three interrelated elements for the judgement of social theory, if there is inadequacy in describing experience, then the relationship of the inadequate description to the resulting explanation and transformation of experience will not be effective. Each interrelated step of the process of judging a social theory, as proposed by Oliver (2009), needs to be examined in its own right if the theory can be regarded as worthy for adoption.

Similarly to the ICF's definition of disability as outcomes of both health conditions and contextual factors (WHO, 2002), Shakespeare's *Interactive Model of Disability* considered the elements of disability as an interaction between both intrinsic factors to an individual and those that are extrinsic to them. These terms were outlined at the start of this chapter (page 17). Disability therefore was described as the 'interplay of impairment with particular contexts and environments', with the emphasis being that 'people are disabled by society *and* their bodies' (original emphasis, Shakespeare, 2014: 75). Shakespeare disputed the proposal that disability was a 'natural phenomenon' as posed by the social model, and suggested instead that disability was 'always influenced by social relations and cultural values' (Shakespeare, 2018: 24) which would change over the course of history. His belief was that it was only in accounting for the combination of all the elements that disability was composed of: biological, psychological and social, that the most appropriate level of intervention could be maximised.

It is important to note that some of Shakespeare's work is also criticised for its limitations. For example, Gallagher *et al*. (2009) proposed that Shakespeare's writing could be read quite selectively due to it drawing on a variety of conceptual frameworks. This, they suggested could result in confusion and misunderstanding, proposing that the result of Shakespeare's 'plurality of approaches' entailed a 'shifting from one conceptual framework to another that some might mistake as incoherence and others find difficult to decipher' (Gallagher *et al.*, 2009: 1130). It is therefore the proposal of this thesis in consideration of the criticisms above, to further develop Shakespeare's *Interactive Model of Disability* as one part of the creation of a new model that would enable a better understanding of autism. In strengthening the proposition that Shakespeare's *Interactive Model of Disability* has potential as a major component in this new model of autism that would replace the dichotomy between the social and medical models and add a greater focus on the individual, the next section within this chapter will introduce Urie Bronfenbrenner as the author for the other key component of this new model, and the creator of the *Bioecological Systems Theory.* By combining the *Interactive Model of Disability* with Bronfenbrenner's *Bioecological Systems Theory*, this study seeks to realise the necessary 'depth and dimension to theoretical understanding' (Donmoyer, 2011: 64) that might enable a greater sense of the possibility for a global adoption of an *Interactive Bioecological Model of Autism* for use within education in the future.

2.2.2 Bronfenbrenner's *Bioecological Systems Theory*

In a similar way to Shakespeare's emphasis on the need to seek the lived experience of disability in the creation of his *Interactive Model of Disability*, so too was the focus on the individual within Bronfenbrenner's theory. A key emphasis of the *Bioecological Systems Theory* was that 'the characteristics of the person function both as an indirect producer and as a product of development … the relations between an active individual and his or her active and multilevel ecology constitute the driving force of human development' (Lerner, 2005: xix). This explanation of the theory demonstrates the power of realising human functioning as a two-way process, describing Bronfenbrenner's *Bioecological Systems Theory* as one where individual development is affected by and simultaneously affects the 'multilevel ecology' of which they are a part. In this section, an explanation of the history and central tenets of Bronfenbrenner's theory will be outlined before moving to consider the potential of its connection with Shakespeare's *Interactive Model of Disability.* It is hoped that combining the two will firstly add the necessary theoretical rigour that an *Interactive Bioecological Model of Autism* requires for consideration within education and more broadly within society. And secondly, that highlighting the concepts of individuality whilst accepting the influences from their surrounding ecosystem will act as a reminder of how all individuals within societies are both influenced by and have influence upon other individuals and their environments.

Bronfenbrenner (2005) based his *Bioecological Systems Theory* on a powerful two-way process, emphasising that:

> Human beings create the environments that shape the course of human development. Their actions influence the multiple physical and cultural ties of the ecology that shapes them, and this agency makes humans - for better or for worse - active producers of their own development (p.xxvii).

He considered the theory as 'an evolving theoretical system for the scientific study of human development over time' (Bronfenbrenner, 2005: xxviii), and proposed that 'the recognition that developmental processes are profoundly affected by events and conditions in the larger environment accords major importance to public policies and practices that influence the nature of the environment and as a result have significant effects, often unintended, on the development of children growing up in families, classrooms, and other settings' (p.xxviii). His developing theory drew heavily on the work of Lewin (1943) amongst others, and he spent sixty years of his life considering aspects of reciprocal relationships and the influences between individuals and their ecology (Bronfenbrenner, 2001). His original proposal in 1979 suggested that social development applied to the individual as well as to the social organisation in which s/he belonged (Bronfenbrenner, 1979). Here, he proposed the existence of 'an interplay between the psychological characteristics of the person and of a specific environment', stating that 'one cannot be defined without reference to the other' (Bronfenbrenner, 2005: 146). In setting out the origins of his theory, he stated that:

> Consistent with an ecological view of organism-environment interaction, the orientation takes its point of departure *a conception of the person as an active agent who contributes to his or her own development. Correspondingly, personal characteristics are distinguished in terms of their potential to evoke response from, alter, or create the external environment, thereby influencing the subsequent*

> *course of the person's psychological growth* (original emphasis, Bronfenbrenner, 2005: 121).

This interplay was described by Cummings *et al*. (2006: 195) as a view of individuals who are 'embedded in an ecological framework of family and peer relationships, nested within neighbourhood, schools and other institutions, operating within communities, various levels of government, and society'. Bronfenbrenner's theory can thus be visualised as a series of concentric rings with each ring representing a separate ecological layer that exists and operates independently around the biology of the individual.

The individual exists within the first ring known as the microsystem, where the closest and most significant interactions occur. This ring contains significant others to the individual, including family, peers and school and consists of various environments where the individual will spend most of their time. The second ring, named the mesosystem, surrounds the microsystem and depicts the inter-relations between two or more elements of the microsystem 'in which the developing person actively participates' (Bronfenbrenner, 1979: 25). The exosystem, or third ring, refers to 'one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by what happens in the setting containing the developing person' (p.25). The outermost ring named the macrosystem, although not interacting directly with the individual, will affect the settings and communities of which the individual is a part, and was outlined by Bronfenbrenner as 'consistencies in the form and content of lower order systems (micro-, meso-, and exo-) that exist, or could exist at the subculture or the culture as a whole along with any belief systems or ideology underlying such consistencies' (Bronfenbrenner, 1979: 26).

An interesting example of how effects from the macrosytem level can be observed at an individual level was documented in comparative research into different approaches to autism across three different countries (Kim, 2012). Through interviewing parents of children with autism, Kim investigated how autism was considered in the cultures of Korea, Canada and Nicaragua. For example, in Korea the attitudes of the public towards disability were that of 'indifference, neglect and hostility' (Kim, 2012: 539). Kim then followed a family from Korea who had emigrated to Canada specifically because their child had autism. The recommendation of a Korean specialist to the parents had been that in Canada or the United States of America there were 'better services and less discrimination against people with disabilities' (Kim, 2012: 540). This turned out to be true as society seemed more accepting, however the imprint of previous Korean cultural messages proved hard to eradicate from the parents' cultural identities. In comparing the two cultures or macrosystems, Kim noted that in Nicaragua, autism existed but was not well known. It was acknowledged that in general the community embraced people both with and without disabilities, which perhaps resulted in a lesser need to define autism as a difference. Kim concluded that culture had great significance in defining the attitudes of individuals, and proposed that 'culture imprints deeply and perhaps permanently into our identities' (Kim, 2012: 541). Although a consideration of bioecological systems was not a part of this study, it clearly identified the significance of the macrosystem on the views and attitudes of individuals. Another example of the effect of culture on individuals can be taken from research involving a policy analysis of Portugal's inclusive education (Alves, 2019). Through analysing the cultural and historical context to the policies developed through three legislative frameworks spanning almost thirty years, Alves (2019: 863) proposed that the ecological system that each policy exists within 'reflects different international, national, regional and local dynamics … created by policymakers and subsequently rewritten, restated and turned into practice at the school level'. This demonstrates the implications for individuals at microsystem level from policy decisions made at macrosystem level and highlights the need for a bi-directional flow of information through all levels of the ecosystem both ascending to the policymakers as well as descending from them.

In considering the powerful effects of the multiple systems surrounding the individual, Bronfenbrenner proposed that many earlier studies of child development were likely to be inaccurate in their portrayal, as children had often been viewed in settings other than their natural environments. Through analysing a variety of earlier childhood studies, he concluded that 'children become isomorphic with their social environment, their ecological setting, as a function of the interaction that takes place among the participants in that ecological setting' (Bronfenbrenner, 2005: 30). Bronfenbrenner considered the reciprocity of the interactive process, believing that 'individuals influence the people and institutions of their ecology as much as they are influenced by them' (Bronfenbrenner, 2005: ix). Such interactions between a person and aspects of their immediate external environment, which included other people, he termed 'proximal processes' and although the significance of these interactions varied over time, Bronfenbrenner viewed their relevance as 'the primary engines of development' (Bronfenbrenner, 2005: 6). He described this series of interactions as an opportunity for how:

> the external becomes internal and becomes transformed in the process. However, because from the very beginning the organism begins to change its environment, the internal becomes external, and is transformed in the process … The realisation of human potentials requires intervening mechanisms that connect the inner with the outer in a two-way process that occurs not instantly, but over time (Bronfenbrenner and Ceci, 1994: 572).

It was the two-way process that Bronfenbrenner highlighted; proposing that one of the most basic units of analysis at the 'innermost level of the ecological schema' was that of 'the *dyad* or two-person system' (original emphasis, Bronfenbrenner, 2005: 52). In an earlier explanation he suggested that developmental changes could be better understood between the child and a primary caregiver as dyadic data revealed that 'if one member of the pair undergoes a process of development, the other does also' (Bronfenbrenner, 1979: 5). An ideal dyad was recognised as one of 'reciprocity, progressively increasing complexity, mutuality of positive feeling and gradual shift in balance of power' (Bronfenbrenner, 1979: 60).

As the *Bioecological Systems Theory* is a clear demonstration of the interactions between an individual and their environment and the links that exist between different elements of both, many studies have used it as a theoretical framework to emphasise the connectedness between individuals and their bio-ecologies. For example, a study by Gabbard and Krebbs (2012) into the environmental influence on motor development in children promoted Bronfenbrenner's framework as indicating that 'to change developmental status and foster positive future behaviours, one must identify and understand direct and indirect influences on human development' (p.146). Other examples are that of Swick and Williams (2006) who looked at how microsystems are affected by an individual's drug dependency; Guckin and Minton (2014) who considered how school bullying might be better understood using Bronfenbrenner's ecological model; and a study by Connolly and Gersch (2016) which used the theory to explore the experiences of parents whose children with autism were starting primary school.

Other applications of Bronfenbrenner's *Bioecological Systems Theory* have commented on its ability to uniquely support understanding of development 'as a joint function of environmental influences (i.e. parents, teachers, neighbours) and the child characteristics'

(Sontag, 1996: 321). For example, a study by Chipuer (2001) into a young person's need to belong, investigated ecological environments within the microsystem and their interactions within the mesosystem ring. In summarising the findings, Chipuer proposed that 'dyadic attachments to best friends, more so than to parents, were more significantly associated with their experiences of emotional and social loneliness' and that 'both school and neighbourhood connectedness were significantly associated with youths' loneliness experiences' (Chipuer, 2001: 443). Another study conducted in America that applied Bronfenbrenner's theory to the integration of immigrant children and their families highlighted the aspect of peer interaction and how 'through socialisation and experiences with school personnel and classmates, immigrant children form a belief system and a frame of reference about American society' (Paat, 2013: 958). These studies clearly demonstrate how Bronfenbrenner's (1979, 2005) *Bioecological Systems Theory* has great potential for research into the connectedness between individuals and their environment.

However, before considering how aspects of this theory could be connected to Shakespeare's *Interactive Model of Disability* as the other key component of an *Interactive Bioecological Model of Autism*, it is important to consider some critics of Bronfenbrenner's theory. One such example comes from Rogoff (2003) who proposed that a negative implication of the nested systems constrained relations between individuals and their cultural processes through their separateness. A later proposition that counteracted Rogoff's concern was that the concentric rings around the individual should be networked and not nested (Neal and Neal, 2013). However, the significance of the content of who and/or what is in each proximal ring is an important aspect for consideration in this case study. The nested rings of Bronfenbrenner's *Bioecological Systems Theory* rather than the networked rings, as proposed by Neal and Neal (2013), will be used to demonstrate the importance of combining an understanding of the individual as a pupil and the teacher as a component within the individual's microsystem and the outcome of this within their shared environment and their understanding of each other. Another critic of Bronfenbrenner's original theory is Christensen (2010) who proposed that an additional dimension of resilience was necessary in order to further enhance it. Christensen (2010) proposed that:

> Some individuals, to a very high extent, see possibilities while some individuals primarily see difficulties and obstacles. The surrounding environment related to a societal framework (local, national and international) and / or organisational context (family, friends, personal network, workplace) in relation to the individual's capacity plays a key role in development as a whole (p.123).

In countering this suggestion, it is necessary to remember that the individual was added as a clearly defined entity to the construct of what was originally termed the *Ecological Systems Theory* by Bronfenbrenner several years into the development of the theory. It was through returning to his original definition of the microsystem as 'a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical and material features' (Bronfenbrenner, 2005: 147) that Bronfenbrenner recognised what he described as his 'glaring omission'. His explanation was that although 'the definition recognises other human beings as existing in the setting, it is solely in terms of their social roles and relationships: that is, they have no existence as persons possessing distinctive characteristics of temperament, personality, or systems of belief' (Bronfenbrenner, 2005: 147). In order for Bronfenbrenner's theory to be generic, specific aspects of the character of the individual, both genetic and psychological were left open. However, the aspect of resilience of character, as proposed by Christensen, is a concept that was considered by Shakespeare (2014). Through his explanation of the intrinsic factors of disability Shakespeare's *Interactive Model of Disability* highlights how the individual's view of their own disability is an important aspect in their overall outlook.

Having outlined the *Interactive Model of Disability* and the *Bioecological Systems Theory*, the next section within this chapter will introduce the final key author whose writing is significant for the purpose of this thesis. Erving Goffman's (1963) considerations regarding the impact of stigma both on the individual and society play a central role in demonstrating the need for a holistic model of autism that encompasses both aspects and appreciates the significance of the flow of information in its many forms between the two.

2.2.3 The Concept of Stigma

Although Goffman did not produce a model or a theory, his considerations regarding the impact of stigma on individuals provides a valuable contribution when considering an *Interactive Bioecological Model of Autism* (IBMoA). In this section the concept of stigma will be explored before the new model is introduced in the next section, returning in the final section to demonstrate the impact of the three key authors on the proposed model and its potential value as an exploratory tool for better understanding autism.

Goffman (1963: 12) reasoned that every individual carries within them a set of 'normative expectations' that he located in the workings of society rather than the subconscious. His explanation was that:

> Society establishes the means of categorising persons and the complement of attributes felt to be ordinary and natural for members of each of these categories. Social settings establish the categories of the persons likely to be encountered there (1963: 11).

Goffman (1963: 12) used the term 'virtual social identity' to denote the unexamined assumptions that are carried by every individual and that only become conscious when a stranger is met who unsettles them. The discomfort in this process occurs when this stranger defies the other's anticipated or 'virtual' identity and thereby causes 'a discrepancy between virtual and actual social identity' (Goffman, 1963: 12). Goffman further explored these complexities by proposing that there are two sub-groups of stigmatised persons: those who are '*discredited',* whose 'difference is known about already or is evident on the spot'; and those who are 'the *discreditable'*; whose differences are 'neither known about by those present nor immediately perceivable' (original emphasis, Goffman, 1963: 14).

If it is accepted that every human being personally creates and experiences these constructs, or 'virtual social identities' (Goffman, 1963: 12) in everyday life to a certain degree, it is because all humans exist somewhere on what could be considered an invisible continuum. For example, from the perspective of someone with autism, Lawson (2008: 63) proposed that the accuracy of the labels 'condition' or 'disorder' are very much dependent on the individual's experience at the time, which in itself can vary throughout the day and is dependant on a variety of factors. From her perspective, Lawson (2008: 15) believed that as disability presents itself in a variety of ways it is worth remembering that 'for most of us living with disability, who we are is normal for us'. This variation is also a concept considered by Connor (2013), who through discussions with autistic students in secondary schools discovered that:

> All students saw themselves as neurodiverse. However, for one segment of the population, this signified their difference was merely that, a "difference" incorporating strengths and weaknesses that did not interfere with academic self-

> esteem or career ambition. In contrast, for those who saw themselves through the "medical/deficit" view, their neurodiversity was seen as a disadvantageous medical condition (p.114).

In a similar light, the aspect of normality was emphasised by Milton and Bracher (2013). They identified two concerning trends in research into autism: 'the failure to explore and engage fully with the lived experiences of participants in the production of knowledge on autism'; and the 'imposition of problematic narratives on autistic experiences, linked to partial or complete absence of engagement with the diverse work of autistic authors' (Milton and Bracher, 2013: 61). Their findings led them to suggest that:

> While problems with social and environmental aspects of the everyday world are common features of life for people on the spectrum, "being autistic" should not be framed purely through a deficit model lens … for many people, autistic experiences are central to their wellbeing and sense of self, and social and cultural constraints mediate the extent to which they can freely experience these ways of being (Milton and Bracher, 2013: 62).

All of this highlights the previously considered danger of narrowing vision through the assumption that it is only possible to use either the medical or social model of disability in developing understanding of another, and points towards the need for change. It resonates with the findings from research carried out by Hull *et al.* (2017) into the act of camouflaging where most of the ninety-two autistic individuals described 'a social expectation from the general population that individuals with ASC need to change in order to be accepted by others' or to 'blend in with the normals' (p.2523). This research focused specifically on the act of camouflaging, a term conceptualised by Lai *et al*. (2017: 692) to define 'using learned social communicative behaviours (e.g. imitation, gestures, and conversation skills) to mask underlying difficulties related to autism'. Other recent research with autistic women has demonstrated that this behaviour may be particularly prevalent in autistic females who are currently estimated at a ratio of 15:1 for high-functioning autism, and yet 2:1 for low-functioning autism (Bargiela, 2019). Bargiela's (2019) research proposes that this ratio is likely to be due to differences in some of the criteria that are currently used for diagnosis and focus more heavily on the male phenotype. The outcome of this is that many women have been told they were not autistic and several have received a different medical diagnosis. For many, this has resulted in confusion and a stronger desire to change themselves - to camouflage, in order to fit in and be like other women or girls as they have been unable to make sense of why they felt different.

Goffman (1963: 57) termed the process of camouflage more generically as 'managing information' and explained it as involving an ongoing set of actions made by the stigmatised individual with regard to whether 'to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where'. Such decisions need frequent reconsidering dependent on changes within certain variables. The term camouflaging is often used with regard to autistic behaviour because of the desire to '*blend into* their social environment' through imitation of others' interactions (original emphasis, Dean *et al.*, 2017: 678). This concept will be considered in more depth in the next chapter (section 3.3.2).

The danger of assuming the right to consider another individual as 'normal' or not can be overlooked when individual voices are afforded little value. However, with recognition of the fact that 'the seemingly benign category "normal" is, in fact, a powerful notion that defines who is inscribed within and who is positioned outside of its circle' (Gallagher *et al.*, 2014: 1125) comes a greater degree of acceptance of difference and normality which in time may lead to social change. As mentioned on page 24, Goffman (1963: 17f/n) proposed that it was the medical approach that led to the notion of 'a normal human being'. However, Gallagher *et al*. (2014: 1124) suggest that a critique of the notion of normality forms the core of the social model, proposing that:

> The social model does not treat normalcy as "given" but instead, like disability, as socially defined, context specific, and subject to change. Indeed, it is the symbiotic relationship of normalcy and abnormalcy - and how each defines the other - that forms the core of the social model.

If it is agreed that in theory no one can define 'normal' for another, as the concept is an individual construct that varies depending on the individual's experience at the time, then the gathering of voice from the pupils themselves, who will be the ones most affected when changes to policy and practice are implemented, is vital. This is an area that will be explored in more depth in the next chapter.

Conclusions from research by Davis and Watson (2001: 685) into disabled children's notions of normality and difference in both mainstream and special schools led them to believe that 'full inclusion is only likely to be achieved when policy decisions are built on disabled children's own lived experiences as articulated directly to policy makers or collected within empirical studies'. This has long been a particular issue for autism with much of the past research, presenting an '"outsider" looking-in stance' (Harvey, 2018: 28). Limiting understanding to assumption from outward manifestations of autism is likely to result in an inaccurate perspective. An example of this can be read in an article that appeared in *The Spectrum* emphasising that many of the problems the adult writer had experienced from her past stemmed from people not understanding about how her autism affected her. Her consideration of this from their perspective was that 'their desperation has been to treat me normally, but by doing that they have caused me upset, and have made me feel inadequate and inferior' (Siobahn, 2018: 15).

A further fundamental aspect to be considered within the concept of stigma and in relation to an individual within society was the process for its development, which Goffman (1963: 45) termed the 'moral career' of the stigmatised individual. This phrase was used to describe certain processes in an individual's learning experiences and the impact these had on their self-conception. The first two phases of the 'career' were those that set the foundation for later development. Phase one was 'that through which the stigmatised person learns and incorporates the stand-point of the normal, acquiring thereby the identity beliefs of the wider society and a general idea of what it would be like to possess a particular stigma' (Goffman, 1963: 45). Phase two was in learning 'that he possesses a particular stigma and, this time in detail, the consequence of possessing it' (p.45). Following on from these two initial phases, Goffman (1963) separated four patterns of stigma, consisting of: first, those who become socialised into their disadvantaged situation and have an inborn stigma; second, those who have a congenital stigma yet are protected within the capsule of family and / or neighbourhood during early development; third, those who become stigmatised later in life or who learn that they have always been 'discreditable'; and finally, those who have been 'initially socialised in an alien community … and who then must learn a second way of being that is felt by those around them to be the real and valid one' (Goffman, 1963: 49). The relevancy of the phases within each individual's 'moral career' will be returned to in section 3.3.2 of the next chapter.

> The import of theories and perspectives from other fields has been carried out rather uncritically. This seemingly paradoxical situation has consisted of openness for ideas, but isolation from the context and special circumstances in which they have been developed as well as a lack of critical examination of how these ideas apply to disability studies (Söder, 2009: 68).

The point made by Söder in the quotation above resonates with warnings already discussed by Oliver (2009) about rigour in proposing new theories: it emphasises the need to ensure that new perspectives on disability are critically examined. This section will focus on the necessary critical examination of the proposal to combine Shakespeare's *Interactive Model of Disability* with Bronfenbrenner's *Bioecological Systems Theory* to create an *Interactive Bioecological Model of Autism*.

So far in this chapter, the dichotomy within education that has arisen between the medical and social models has been described. Through examining the history of autism and the ongoing need to develop a greater understanding of its difference, this dichotomy has been highlighted as a limiting issue for those involved in updating policy and practice. Shakespeare's *Interactive Model of Disability* has been proposed as a viable alternative in proposing that better outcomes would arise if both models were considered together rather than seen as exclusionary. Bronfenbrenner's *Bioecological Systems Theory* was introduced because of its focus on how the individual is both affected by and has effect on their ecosystem. This theory is not focused on disability but could equally be applied to someone who considers they are disabled as to someone who considers they are not. Goffman's considerations of stigma have been outlined to demonstrate the connections and the impact of information flow between an individual and society. Having looked at all of these components in turn, this thesis will now demonstrate how the combination of the *Interactive Model of Disability* with the *Bioecological Systems Theory* has the potential to produce a new model that could be used to create a better understanding of autism.

2.2.4 An *Interactive Bioecological Model of Autism*

As mentioned in section 2.2.2, the basis of Bronfenbrenner's belief was that 'genetic material does not produce finished traits but rather interacts with environmental experience in determining developmental outcomes' (Bronfenbrenner and Ceci, 1994: 571). The two-way process of such on-going interactions depicts individuals as both 'producers' and 'products' and demonstrates the flow existing between the multilevels of ecology as the 'driving force of human development' (Lerner, 2005: xix). The *Interactive*

Model of Disability is founded on the same principles. The micro- and meso-system rings that are made up of direct relationships with others for example through peer interaction, time spent in school, being part of a family, etc., constitute the intrinsic factors, as suggested by Shakespeare (2014) that affect the individual's view of disability. Views held by all parties regarding disability would continuously be filtered in the on-going and two-way communication between the individual and 'others' existing within their microsystem. This process would have direct outcomes on each member's view of disability and therefore on the psychological aspect of the actual lived experience, as interpreted by all parties within the microsystem and the individual. This is emphasised by Bronfenbrenner (1986: 723) who proposed that:

> Although the family is the principal context in which human development takes place, it is but one of several settings in which developmental processes can and do occur. Moreover, the processes operating in different settings are not independent of each other … events at home can affect the child's progress at school, and vice versa.

The intrinsic factors depicted above would jointly function with extrinsic factors, explained by Shakespeare (2014) as the attitudes and reactions of others that are linked to the environment and the wider cultural, social and economic issues. These extrinsic factors relate to the rings of the exosystem and macrosystem as proposed by Bronfenbrenner's *Bioecological Systems Theory.* The layers or rings that encircle these systems are comprised of other organisations and groups of people who although do not have a direct link with the individual are impacted by the attitudes and ideologies of the culture. This was explained by Bronfenbrenner (1986: 723) who proposed that 'the psychological development of children in the family is affected not only by what happens in the other environments in which children spend their time but also by what occurs in the other settings in which their parents live their lives'. This explanation of the two-way process of interpretation as a fundamental aspect of Bronfenbrenner's theory has clear links with Shakespeare's clarification that disability should not be explained by extrinsic factors or intrinsic factors alone, but rather through a connection of the two. A similar proposal was made by Bronfenbrenner shortly before his death in 2005 suggesting that there should be 'corresponding integrated empirical systems for research in human development' precisely because 'the biopsychological system that a human being is and the socioeconomic-political system that an environment is … for human beings to flourish there must be an interplay between these two systems' (Bronfenbrenner, 2005: 64). This resonates strongly with Shakespeare's proposal that 'disability is a complex interaction of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision' (2014: 26). It also highlights the opportunities that could arise from combining the *Interactive Model of Disability* with the *Bioecological Systems Theory* in future empirical research into areas of disability and the 'interplay' between the individual and their environment.

An *Interactive Bioecological Model of Autism* has been created from two main components as highlighted in the diagrams on the next two pages. Diagram 1 depicts the concentric rings that provide the visual element of Bronfenbrenner's *Bioecological Systems Theory*. Breaks in the lines that separate each ring demonstrates their interconnectedness through the opportunity for a two-way information exchange. The increase in colour from light on the outer rings to dark on the inner rings represents the intensity of the effect of the issue that is being considered, in this case that of disability. Diagram 2 represents the interaction between the social and medical models, demonstrating that both models have an impact on the individual and the wider society, as proposed through Shakespeare's *Interactive Model of Disability*. The blue circle that represents the social model is both affected by and has an effect on the individual and society, as is demonstrated by the alteration in colour within the intersection. The same applies to the red ring that depicts the medical model. In relation to both the social and medical models, not all the information they offer will have an impact on particular individuals and organisations within their ecosystem. Hence, some of the circles remain red and blue. Likewise, there remain aspects of the individual and society that are not affected by input from either model, which is demonstrated through some of the central circle remaining yellow. Diagram 3 represents the combination of diagram 1 depicting Bronfenbrenner's *Bioecological Systems Theory* with diagram 2 representing the effects of Shakespeare's *Interactive Model of Disability* on the individual and society. Intersecting the medical model and the social model with the concentric rings of the *Bioecological Systems Theory* demonstrates clearly how all of the 'interconnected systems' (Bronfenbrenner, 2005: 1) that affect an individual and on which the individual can cause a direct or indirect effect, are influenced by both the social and the medical models of disability, as proposed by Shakespeare's *Interactive Model of Disability*.

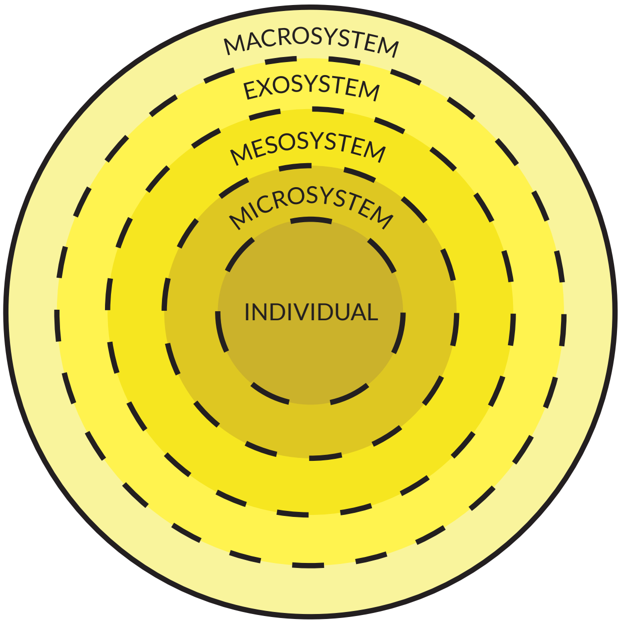


Diagram 1: Bronfenbrenner's Bioecological Systems Theory

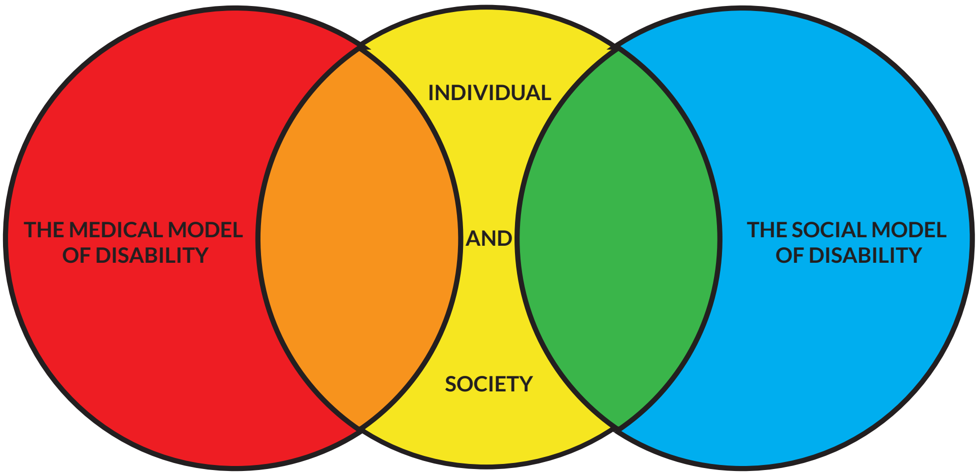


Diagram 2: The influence of Shakespeare's Interactive Model of Disability on an individual and society

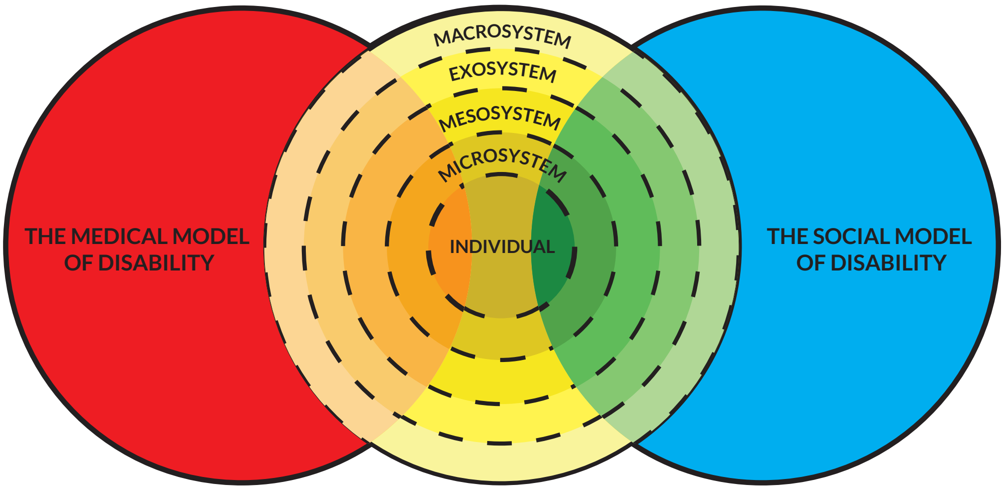


Diagram 3: An Interactive Bioecological Model of Disability: Combining Bronfenbrenner's Bioecological Systems Theory with Shakespeare's Interactive Model of Disability

The final section of this chapter will consider the connections to the three key authors within this proposed model, and highlight its potential value within education.

2.3 An *Interactive Bioecological Model of Autism* in education and its connections with Shakespeare, Bronfenbrenner and Goffman

> After the family, school represents the most dominant social context for children, and the overt and covert messages that children and youth receive determine their feelings of self-worth and identity as they move towards adulthood
> (Cummings *et al*., 2006: 194).

The quotation from Cummings *et al*. (2006) emphasises the role that educators play in the determination of pupils' self-view. The importance of this, particularly for pupils with autism, will be considered within this section through proposing an *Interactive Bioecological Model of Autism* which would demonstrate the need for interaction between both models of disability and the impact this could have on the individual within their ecology.

Before continuing, it is worth a brief reminder of the changes made in education in the 1990s prior to considering how this new model could currently be adopted to create a better understanding of pupils, specifically with autism. Shortly after the publication in

England of the first *Code of Practice* (DfE, 1994), Tony Booth suggested what was required instead of a code was:

> a single set of policies that support communities, schools, and education systems in reaching out and responding to the full diversity of learners … The separation of special and general policies on education perpetuates the exclusion of disabled learners from education … It fosters the notion that all marginalised groups will be looked after by special interventions (Booth, 1999: 165).

This position is also supported by Messiou (2017: 147) who proposed that the focus in education should be on *all* pupils, rather than on particular groups, as 'labelling individuals has the potential dangers of stigmatisation and damage'. Indeed, research conducted by Dillon *et al*. (2016: 228) proposed that 'an inclusive ethos in schooling can significantly improve the experience of all students'. However, this single set of policies never materialised and England is now on its third edition of legislation for SEND, outlining policy that is specific to pupils with various needs and disabilities. By its very existence with its focus on deficits, this legislation from the outset created segregation as a by-product whilst also providing what some considered useful labels and categories for specific children. Despite the positive intentions, and the increase in training on autism for both trainees and teachers in school since the first *Code of Practice* (DfE, 1994), the information from the NAS survey provided at the start of this chapter (see page 16), clearly identified that some aspects regarding the development of a greater understanding of autism remains ineffective for pupils with autism who are educated in mainstream schools. Many teachers are now of the opinion that the best outcome for inclusion is achieved through optimising the environment and providing the necessary interventions to 'remove barriers to learning' (DfE and DoH, 2015: 25). This often leads to individual categorisation resulting in the grouping of individuals thus reinforcing the potential connection between categorisation and assumption and thus creating stigma (Goffman, 1963).

Even the term SEN, as it was first known from its introduction in 1981 from recommendations in the *Warnock Report* (DES, 1978), had positive intentions of departing from the previous focus on a child's deficits and needs but has complications (Norwich, 2016). Originally, the driver was that the new term would replace others considered as stigmatising under the social model, with the intention of focusing instead on an identification of functioning and the needs of the child in a more holistic manner. Similarly, the goal of an SEN assessment was that it '*could* be holistic by taking account of a child's other personal characteristics, their strengths, and difficulties, which deficit diagnosis might overlook' (original emphasis, Norwich, 2016: 2). However, now there exists a contrast between 'a framework of thinking' and 'how it is put into operation and used' (p.2). Both of these issues that link concepts and ideas with resulting practice are based on social constructions of language within definitions and their interpretations that largely depend on an individual's mindset within their context (Messiou, 2019a).

Considering these issues and their particular impact on autism, one autistic adult writer proposed that at a fundamental level, views of autism need to change to that of recognising individuals on the autistic spectrum as 'atypical, as opposed to "wrong", and autism as a different and valuable way of being' (Wolfond, 2008: 115). Similarly, many participants in research by Sciutto *et al.* (2012: 179) highlighted the necessity for teachers to 'look beyond the problem behaviours to understand the inner experience of the individual child and the strengths he or she brings to the classroom'. This resonates with the views of Booth (1999) and Messiou (2017) in recommending that a healthier mindset would be one that recognised and valued diversity rather than singling out marginalised groups for a specific set of policies that are different to what is 'general'. In considering marginalisation as an outcome, Charmaz (2008) outlined particular negative experiences around aspects of difference. She defined these as 'boundaries or barriers, distance or separation, and division or difference' (Charmaz, 2008: 9) and proposed that they were often founded on societal assumptions as to what is normal, which was then reflected through institutional values. These terms regarding marginalisation resonate with Goffman's (1963) examination of the impact of stigma on an individual and society and link closely with Shakespeare's *Interactive Model of Disability,* which combines considerations of both the individual's intrinsic and extrinsic experiences of disability. They also connect with Bronfenbrenner's (1979, 2005) theory regarding the bi-directional flow of information from the individual through their ecosystem to the outermost ring of the macrosystem, comprising the belief systems and ideology belonging to the culture. Charmaz (2008: 9) suggested that the outcome for the individual experiencing marginalisation was likely to be a negative experience of 'disconnection, devaluation, discrimination, and deprivation' and described the opportunity of others to gather real insight into all types of marginalisation as the chance to experience a 'view from the margins' (p.9). Through her own experiences in working with marginalised groups, she proposed that such an alternative view had the potential to provide several valuable opportunities that would offer 'significant differences in knowledge, meanings and priorities - a distinctive view, another course of action …

another way of being in the world and, taken collectively, a source of institutional change' (Charmaz, 2008: 9-10).

In considering the concept of marginalisation within education, Messiou (2019a) suggested that positive change could occur through a greater engagement in dialogue between colleagues and their students. Dialogue was described as 'the various reciprocal interactions between participants that lead to an authentic engagement with one another's views, that subsequently lead to the creation of new meanings and the creation of further questions' (Messiou, 2019a: 311). The term 'dialogue' rather than 'listening' was deliberately chosen as:

> when authentic forms of dialogue take place, they can lead to transformation in thinking and practices …. Moving away from deficit ways of viewing students, therefore, simply because they belong in a category, and, at the same time, neglecting others, simply because they do not belong in any category that are deemed to be of concern, opens up possibilities for transformation and the creation of more inclusive schools (Messiou, 2019a: 315).

Messiou (2019a) proposed that in order to create a more positive and inclusive outcome, the use of dialogue between pupils and their teachers could enhance 'understanding marginalisation and consequently lead to positive actions to facilitate inclusion' (p.308). Indeed, Veck and Hall (original emphasis, 2018: online) suggest it is the *process* of the interaction between individuals that has the opportunity to be educational, proposing that 'inclusive research in education privileges neither the researcher nor the researched, since it privileges the dialogue that brings *both* the researchers and the researched together in an *educative* relation'. Such an outcome was demonstrated in research conducted by Parsons *et al*. (2020) that involved 240 participants from a range of backgrounds including autistic individuals who took part in a series of quarterly seminars over two years. Participants indicated that the value for them had been 'the processes and experience of engagement' (Parsons *et al*. 2020: online), possibly even more so than the formal outcomes of the research. Thus it seems that through engaging in dialogic processes, opportunities could be created that would be valuable for all participants. In returning to the concept of marginalisation, this process could involve departing from the understanding that this concept can only be experienced by those belonging to a certain group and lead instead to the consideration that *every* student has the potential to experience marginalisation at school. It could limit a further potential negative outcome of certain pupils getting overlooked because they were not considered to belong in a particular category (Messiou, 2019a). This shift in view was an aspect also emphasised by Bronfenbrenner (2005) when he drew attention to the connection between individuals who could be identified as belonging to a particular group, and their environment, or the ecosystem that surrounded them. His proposition was that 'instead of regarding social class, ethnicity, and religion as attributes of the person, we shall come to see them for what they are, namely, structured aspects of the environment that function to enhance or inhibit the processes of making human beings human' (Bronfenbrenner, 2005: 47). In other words, potential categorisations that could result in the marginalisation of an individual or the group they are assigned to should be recognised as labels and structures that have been provided by others which may or may not be of benefit to the individual.

This is particularly vital in the community of a school, as Murray (2008: 82) suggested that autism is 'by definition a condition in which society plays a role … value judgments involved depend on one's point of view'. A reminder of the impact that society or culture plays in informing individual mindset was presented earlier in Kim's (2012) research into perceptions of autism in three different countries. Another example proposed by Murray (2008) on a smaller scale, although connecting to the bigger picture concerning society, suggested that the difference in terminology between autism spectrum disorder (ASD) and autism spectrum condition (ASC), was actually the outcome of 'inappropriate behaviours perpetuated by Others [that] contribute to the social climate which turns autistic spectrum conditions into disorders' (Murray, 2008: 82). This concept of 'othering' was proposed by Hall (2014) as a process that created difference between the norm and 'the other', with 'the other' being recognised as inferior and provides a clear link with the significance of Goffman's (1963) concept of virtual and actual social identities. Empirical research by Huws and Jones (2010) into lay perceptions of autism further emphasised this point by highlighting the minimal knowledge such classifications are often founded on. Their data concerned the responses from ten adult non-autistic participants with minimal knowledge about autism to certain questions. Specific themes arose from the data that indicated the participants' beliefs about autism, such as: people with autism often contravene accepted societal norms; they are incapable of functioning and living independently; they are trapped in their own bodies. However, what was particularly striking from the ten interviews was how confidently these views were held despite each participant openly admitting to having very little knowledge on autism. Fortunately, other research into the influence of autism training sessions on a group of new teachers conducted by LeBlanc *et* *al*. (2009) indicated that even a small amount of teacher training on the inclusion of a child with autism in a mainstream setting can increase teacher knowledge and confidence, and thereby potentially create more positive outcomes.

Within the previous initiatives that have already been trialled for increasing the understanding and confidence of teachers in autism and other areas of SEN (*Autism Education Trust* [DfE: online, 2009], *Inclusion Development Programme* [DfE: online, 2009]), the various conditions have largely been considered through the lens of the social model. Their focus has been on adaptations that could be made to the environment and/or teaching methods and learning opportunities. Although they were informative for those who accessed them, many teachers continued to practice their profession with a limited understanding of the lived experience of the condition resulting in the continuation of normative assumptions being made regarding some autistic behaviours (Ravet, 2011). More recently, *The Carter Review* (DfE, 2015: 3) stated that 'what really matters most in a child's education is the quality of the teaching'. It is important to point out that 'quality teaching' demands a combination of both knowledge and understanding. Therefore, in order for it to make a significant and lasting impact, time needs to be set aside for individual and collegial reflection within learning communities as well as providing opportunities for knowledge based information exchange. With regard to SEND and autism in particular, it is vital that as well as providing information both at the Initial Teacher Training stage and throughout Continuous Professional Development in schools, the foundations of inclusion and considerations of disability are openly and explicitly discussed in order to respectfully challenge when necessary. This vital collegial process was highlighted through a three-year study conducted by Ainscow (2005) into developing inclusive education systems. His conclusion was that inclusion 'involves social learning processes within a given workplace that influence people's actions and, indeed, the thinking that informs these actions' (Ainscow, 2005: 113). This was also the outcome from research by Davis and Watson (2001) into discriminatory notions of 'normality' and 'difference' in both mainstream and special schools, which proposed that:

> The discourses which disabled children encounter are interrelated with subjective notions of essential difference based on judgments of cognitive, physical and social ability. Once a child is considered to have a physical or sensory impairment other diagnosis of academic, cultural and social deficits are but a short step away. Judgments of ability are not value free because they are interlinked with the structural organisation of schools, and the beliefs and actions of different adults and children (Davis and Watson, 2001: 684).

This concept returns to Wenger's (1998: 48) considerations of social learning and the proposition that within every educational establishment, or 'community of practice' deep-rooted individual views of society and place of self in society will vary. If it is also conceded that marginalisation, which is an outcome of stereotyping based on assumptions and a 'fluid process that relies in part on the person's interpretations and situations and includes internalised ideals and standards' (Charmaz, 2008: 12), then through a process of individual reflection alongside a communal sharing of views, such positive diversity of individuals would be demonstrated. Rather than pursuing the potential individual perception of difference linked to deficit, this would provide healthy opportunities for consideration and discussion (Wenger, 1998; Messiou, 2012; Opertti *et al*., 2014); including the topic of the currently existing dichotomy between the medical and social models of disability within education, and the direct and indirect negative affects this has on individuals, environments, communities, and in particular on pupils with autism.

What seems to have occurred in education within the UK over the last few decades has stemmed from an initial positive change with the adoption of the social model. However, due to its limitations as an independent model this has since levelled out and there is now little measurable progress (Shakespeare, 2006; 2014). Viewing autism through either the medical or the social model of disability has often limited the possibility of a deeper understanding. This situation was highlighted by Elliman (2011: 117) who proposed that 'it seems likely that rather than the experiences of those with [Asperger Syndrome] AS being directly caused by their neurology, as the medical model has been much criticised for implying, or being entirely socially constructed, as strict interpretations of the social model would argue, there is an interaction between impairment and social environment'. Taken independently, the medical and social models of disability each provide a lens of the disability, disorder, condition or difference of autism, thus providing the possibility to better understand that aspect of the individual. An advance on this would be to consider an interaction between the two models that would take into account the intrinsic and extrinsic factors of disability as highlighted in the *Interactive Model of Disability*. This model can be viewed as providing a wider-angled lens to seek a clearer and more holistic picture of the effects of the disability on the individual. However, the knowledge gained from considering autism through the *Interactive Model of Disability* (Shakespeare, 2006; 2014) will not provide sufficient information to understand and appreciate the wider picture and its implications on that individual's lived experience. Combining this information with that which is provided by the *Bioecological Systems Theory* (Bronfenbrenner, 1979; 2005), enables a more holistic consideration. The view is extended to not only how the individual is shaped independently and in connection with their autism or disability, but also how they in turn can be shaped by and create shape on the view and attitudes of those around them through the impact that originally arises from the 'proximal processes' (Bronfenbrenner, 2005: 6) that occur within the microsystem. By adding the *Bioecological Systems Theory* to the *Interactive Model of Disability* richness is added to perspective. The uniqueness of the manifestations of autism can be combined with an awareness of the uniqueness of the individual who is directly and indirectly active in both shaping and being shaped by their ecologies: knowledge of the condition and awareness of the person are essential for perspective.

Finally, the coloured intersections of an *Interactive Bioecological Model of Autism* as seen in diagram 3 (p.57), demonstrate a link to the impact of stigma (Goffman, 1963). The gradations of colour and the breaks in the lines illustrate the flow of information between the individual and those they come into contact with in their microsystem. The direct interactions or proximal processes that take place within the myriad of varied communities that exist at this level of an individual's ecology have an indirect effect on society with regard to information that originates from the medical model and social model regarding their autism. This emphasises the need to consider factors relating to autism in a wider context, recognising that there is a flow between the understandings of self and that of society, which will influence and affect the relationships that take place within the microsystem.

2.4 Conclusion

This chapter has proposed that if change and development towards a greater understanding of autism within education is to occur it needs to be driven from foundational level, through openness, challenge and discussion both within communities and at an individual level. Throughout the different sections of this chapter, various factors have been investigated: the history and difference of autism; the separate concepts of the models of disability; the combination of the social and medical models through the *Interactive Model of Disability*; an outline of the *Bioecological Systems Theory* with its emphasis on the individual within their ecosystem; the value of interpreting individual viewpoints and the impact of society through Goffman's interpretation of the concept of stigma; an introduction of an *Interactive Bioecological Model of Disability*; and finally, a consideration of its potential value in education. This process has provided a reminder that seeking to understand another individual is a journey of discovery, and that if potential arose for a model that could provide better access in gaining knowledge and/or understanding then it should be shared. To echo again the words of Oliver, 'if it is any good, use it and share your gains with the rest of us; if it is useless … invent something else' (Oliver, 2009: 11). Far from saying any of these previously considered concepts are 'useless', the value that all separately mentioned developments have brought and continue to bring to current understanding has been highlighted. However, with regard to potential development for future improvement in the understanding of autism, it is possible to see that there may be an advantage in combining some of these factors.

An *Interactive Bioecological Model of Autism* adopts the combination of an updated model of disability combining both the social and medical models with the structure of a theory that represents a reciprocal flow of information between human beings and their ecosystem. If individuals are prepared to challenge their previous concepts of autism by considering them through a new model, then the adoption of an *Interactive Bioecological Model of Autism,* that is proposed in this chapter as an exploratory tool through an analysis of the literature, has the potential for growth of a two-way process of understanding; for those with autism communicating with others, and for others communicating with them. At this early stage in the process of considering whether this model has relevance as a potential tool in developing understanding of autism, time needs to be spent alongside those for whom it has been designed to assist. The long-term aim is that there will be a bi-directional impact, that its adoption might enable a greater understanding between pupils with autism and their teachers. Therefore the next step within this thesis is to consider the model's potential from the pupils' perspective before being able to consider its potential from the teachers' perspective, which is an area for future research and is anticipated will be completed in a post-doctoral study. The next chapter will turn to a consideration of inclusive methods for gathering empirical research with pupils who have autism that was conducted for this thesis. The two chapters that follow the focus on methodology will consider whether there is synthesis between what is discovered empirically with the pupils and what is at present proposed from the literature as a model for better understanding autism.

Chapter 3 Methodology

This chapter will begin with a consideration of how the methodology of inclusive research corresponds with the theoretical focus of this study as outlined in the previous chapter. The second section will link inclusive research with the search for the lived experience of autism. The third section will introduce how the process of inclusive research could enable the hearing of autistic voices. It will also include considerations of who is listening to whom and why, and how specific decisions are made with regard to the listening process. The final section will investigate ethical and methodological considerations that are specific to this study, including some of the decisions made with the pupils once they had chosen interview as their preferred method for sharing their memories and with regard to collaboratively organising and grouping the main themes that arose. It will justify the use of thematic analysis of the data and explain why the findings were written in narrative form including an explanation of how the final themes were organised into the two chapters that follow this one.

Throughout this chapter, the quality of the research will be measured against criteria specific to qualitative research. These are encompassed within the 'big tent' model suggested by Tracy and Hinrichs (2017), which proposes that high-quality qualitative research should be founded in a worthy topic; one that challenges assumptions on aspects of practical, theoretical and/or methodological aspects that may have been taken for granted, therefore 'catalysing new contributions and understandings of the social world' (p.4). The worthiness of this study has previously been considered in earlier sections through clarifying that its focus originated from the responses of two-thirds of the young people who had completed a survey by the NAS (2016: 17) and believed their experience of school would be better 'if more teachers understood autism'. It is hoped that the proposal of an *Interactive Bioecological Model of Autism* will make a significant contribution in developing a greater understanding of autism and thereby achieve the outcome of being considered worthy (Tracy and Hinrichs, 2017). Further 'big tent' criteria for ensuring the quality of qualitative research are that the data must be investigated with a rich rigour whilst demonstrating sincerity, credibility and resonance with the reader. The research must be ethical, have a meaningful coherence and make a significant contribution (Tracy and Hinrichs, 2017). As each criterion is considered within this chapter in relation to this research, a more detailed explanation of the meaning of the term will be offered. What follows in the next section is an outline of inclusive research that was developed by Melanie Nind (2014, 2017).

3.1 What is inclusive research and how does it link to this study?

> Every human observation, including a scientific one, is influenced by our selected methods and tools of inquiry as well as our personal background and dispositions. What is out there in the world cannot be known separately from what we believe about it: none of our knowledge is mind-independent or value-free
> (Gallagher *et al*., 2014: 1124).

In the quotation above, Gallagher *et al*. (2014), highlight how the experiences of each individual are filtered through a personal and unique set of values. This acts as a reminder to consider the exploratory *Interactive Bioecological Model of Autism* not just for use in schools in order to develop understanding between the pupil and their teacher, but also as a potential tool for future research. Individuality is also a factor of inclusive research, which emanates from an inclusive starting point (Nind and Vinha, 2012). It remains respectful of all participants throughout and is described in metaphorical terms as ‘a bridge to other worlds’ (p.105). This visual image encapsulates how using inclusive methods can create the possibility of a greater understanding among varying perspectives from all those involved. This approach to research was created to ‘disrupt’ what Nind (2014: 20) considered ‘the perceived hierarchy and the powerless researched’. Highly valued features of inclusive research are specified as those of ‘asking for help, facilitating, enabling, making things accessible, checking things out and being honest’ (Nind and Vinha, 2012: 106). Its flexible approach was further highlighted by Nind (2014: 83) when she explained her preference for the term ‘*doing research inclusively’* over the alternative descriptor of ‘*inclusive research’* (original emphases), which carries with it more fixed connotations. Emphasis within this methodology is placed on equality and mutual respect between all participants through a process of listening and learning from each other; research that 'generates opportunities for researchers and researched to be realised as unique persons and to be educated about how the world is now and how it might be changed for the better' (Veck and Hall, 2018: online). Rather than seeking to impose previously considered research designs on participants, 'doing research inclusively' proposes the better option would be ensuring that all research participants are involved in 'a collective act to solve a public problem' (Hall, 2014: 388).

Black-Hawkins and Amrhein (2014: 370) suggest that inclusive research has the potential to provide 'a framework that welcomes open and exploratory methodological approaches and has at its heart a deep respect for the experiences of the people who are at the start of the study'. This shift in emphasis towards equality is the basis of research 'with' rather than research 'on' (Black-Hawkins and Amrhein, 2014; Nind, 2017) and seeks an outcome of 'a practical wisdom' (Nind, 2017: 284). For this study, it is a methodology for research that has been chosen because of its potential to develop a better understanding of the condition of autism 'from the inside' (Charmaz, 2008: 15). It is also hoped that an outcome of using inclusive methods for this research will indicate the future value of considering autism through the wider angled view that is proposed by an *Interactive Bioecological Model of Autism*. Reflecting on aspects of autism that are explained through first-hand experience may lead to questioning the origins of previously accepted knowledge, and therefore highlighting the need to search for understanding from the source directly. As highlighted by a writer for *The Spectrum*, 'what you see on the outside of me isn't true - but what you don't see on the hidden side is the truth' (Bruce, 2019: 15).

Although inclusive research is a form of participatory research, Walmsley (2001: 188) suggested that inclusive research as a term has an advantage over other terms in being easier to explain to people who are 'unfamiliar with the jargon and nuances of academic debate, including people with learning difficulties'. The concept and activity of participation can reside in research at many levels; inclusion suggests a more deliberate attempt to involve participants in ways that they are able to most fully participate. This has particular relevance when considering that inclusive research describes research in which 'those (such as learners and teachers) who tend to be the objects of other people's research become agents in the conduct of research, ensuring that such research addresses issues that are important to them and includes their views and experiences' (Seale *et al.*, 2014: 347). It is a type of research used particularly when working with people who have learning difficulties as a way of involving them further than considering them simply as subjects or respondents in research (Walmsley, 2001). In creating opportunities for social change through dialogue, purposes for both academic and lay researchers to work together can be provided. This results in the mutual benefit for both from the perspective of the other, and in so doing develops the opportunity for a greater 'democratisation of the research process' (Nind, 2014: 1).

Two basic questions underpin this study, and many other studies that have used inclusive methodology. The first considers whom the research is for, in terms of its purpose in hoping to improve a current situation; the second considers those who might access the information resulting from the research (Nind, 2014). The first of these two questions will be covered in greater depth in the following sections within this chapter, but it is important to consider here the second question, which for this study concerns the value for educational practitioners in terms of credibility that the methodology of inclusive research will provide within the dissemination of this study. Credibility is one of the 'big tent' criteria for qualitative research and is described as 'significant in creating confidence that people can act upon data and findings to make decisions in their own lives, work, and families, or in future research settings' (Tracy and Hinrichs, 2017: 6). In considering how to bridge what has been identified as a current gap in understanding between educators and their pupils with autism (NAS, 2016), it needs to be recognised that some of what may be proposed might come as a challenge to some practitioners' currently held beliefs. Pring (2015: 189) proposed that such an outcome could be borne of a natural tendency 'to defend cherished beliefs, not to question too deeply, not to suffer the discomforts of doubt'. If such discomforts are to be reflected on and hopefully embraced by practitioners, it is vital that assurance is provided that the inclusive method for research expects transparency and an open honesty throughout the research process (Nind, 2014). This process of inclusive research should indicate to the reader that each step, including its dissemination, is part of a journey that all professionals involved in the education of children take *together*. It removes a culture of superiority of the researcher, and instead accepts the fragility of research, openly admitting that instead of researchers being fearful of 'getting it wrong' (Nind, 2014: 80); such a concept can be embraced. Nind (2014) encourages researchers to view their position as being 'immature researchers in development' thus proposing that 'as researchers are honest about the compromises they make and the pragmatic decision making that is needed … they challenge the aura that perfect inclusion is necessary or possible' (p.80). Indeed, a tangible aspect of inclusivity will be established through the language with which the information is disseminated. In considering this essential step in the process of knowledge exchange, Pring (2015) proposed that on occasions 'the gulf, which creates a barrier to the dissemination of research, between the language of teachers (whose practice, research must ultimately relate to) and the technical language of the researcher may be the fault of researchers - cut adrift from the common-sense language of those who practice (Pring, 2015: 9-10). It is important to note however, that not only is common-sense (Pring, 2015) and honesty (Nind, 2014) necessary in writing about the research for intended readers, but also in creating a relationship with the participants in the earlier data gathering and analysis stages.

3.2 Using inclusive research to understand the lived experience of autism

> Academics who want to make comments about the impact of impairment might do well to base their analysis on empirical evidence about how disabled people feel about their embodiment (Shakespeare, 2014: 67).

Drawing on Shakespeare's guidance, this section will investigate how inclusive research can be a powerful tool in attempting to better understand the lived experience of disability. Suggestions will be posed relating to possible reasons as to why voice has been often overlooked in the past (Batchelor, 2006; Messiou, 2019b). This missing factor might explain the response to the NAS (2016) survey where pupils with autism felt that their teachers lacked understanding about autism. It might also answer the question posed by Silberman in 2015 that asked: 'after seventy years of research on autism, why do we still seem to know so little about it?' (p.15).

Despite Article 12 of *The United Nations Convention on the Rights of the Child* (UNCRC) (UNICEF, 1991: online) stating that

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, the views

> of the child being given due weight in accordance with the age and maturity of the child.

the reality of seeking and then giving 'due weight' to the voice of the child has been slow in actuality within UK education. One suggestion for this is that it stems from a lack of awareness of its legally binding obligation, another suggestion being that of a lack of commitment by the adults in its activation (Lundy, 2007). A third possible factor was identified by Fielding (2001) through a three-year collaborative research and development project with two schools. The outcome of this study suggested that the drive in the past for pupil voice had often been based on fear from the teachers and 'the attendant desire to control' (Fielding, 2001: 123). In considering this barrier, Fielding (2001: 137) outlined the term 'radical collegiality' that emphasised the different views held by pupils and teachers. This was an aspect he proposed that needed to be reflected in teaching. Rather than teachers fearing the involvement of pupil voice in aspects of education, Fielding (2001) suggested that it should be seen as an opportunity to enable and enhance mutual learning through expectations of interdependency and therefore a shared responsibility for success. His original proposal was that through embracing students as researchers, a commitment to teaching and learning would be demonstrated as 'a shared responsibility' (Fielding, 2001: 137).

Later research by Rudduck and Fielding (2006) highlighted another potential reason regarding missed opportunities for the potential of pupil voice. Outcomes from their study proposed that pupil voice within democratic education was more often about preparing pupils as future citizens than demonstrating how their voices could affect democracy within their present educational experience. Findings from their research suggested this stemmed partly from a lack of time within the curriculum but primarily from educators' concerns about disrupting the traditions regarding boundaries and power dynamics: that in giving so much emphasis to the voice of students, the teachers' role in change would be overlooked. If the impact of pupils' inputs into their current situations is afforded little or no value, then their actual life experiences are overlooked. This would be a denial of who they are as individuals; denying them power to develop an active agency over their lives as encouraged by Bronfenbrenner (2005); and offering no opportunity to deepen others' understanding of them through sharing their lived experience, as recommended by Shakespeare (2014).

Nearly forty years ago a fascinating study of primary aged children was undertaken by Michael Armstrong (1980) who spent a year observing in a classroom whilst working alongside the teacher in a supporting capacity. His findings led him to acknowledge the children's 'seriousness of purpose' within their play and through their interactions, recognising this as 'a significance of performance rather than a course of training' (p.206). Through the time he spent with the children he was able to witness first-hand what he later described as 'the quality of seriousness that permits us to describe the life of reason as beginning at or close to, the beginnings of learning' (Armstrong, 1980: 206). Armstrong's observations highlighted the need for seeking and embracing pupil voice as opportunities to appreciate and understand authentic views of the pupil with regard to their current situation. They also clarified the children's ability to provide this knowledge. If fear of disruption or an imbalance of power are the overriding factors within educational environments, then opportunities for improvement, particularly for pupils with autism cannot be maximised and an understanding of the value of an *Interactive Bioecological Model of Autism* in leading to a greater holistic understanding of the individual will not be embraced.

It is important however, within all considerations regarding the gathering of voice that adults give due recognition to the fact that not all voices are equal in volume or tenacity and some will take greater encouragement and/or creativity to be heard. An interesting finding from Batchelor's (2006) research in this area led her to suggest there is a risk of the dismissal of vulnerable voices by others who judge vulnerability as weakness or failure. She highlighted a difference in terminology between 'a condition *of* vulnerability' (original emphasis), which suggests a state from which no further progress can be made with 'a condition *for* vulnerability' (original emphasis, p.790) which has more open connotations, therefore suggesting possibilities for change and growth. Batchelor proposed that the term vulnerability should offer positivity, signifying 'an opening up, rather than a closing down, of possibilities for having a voice' (Batchelor, 2006: 790). In considering this potential outcome for pupils with autism, it would seem that when they are viewed by professionals from a 'condition *of* vulnerability', decisions are more likely to be based on limited empirical knowledge. An example of this was provided by Messiou (2019c: 199-200) from a collaborative exercise between teachers within an action research project that considered 'responding to learner diversity through an engagement with students' voices'. The example demonstrated a transition in a teacher's way of thinking about some of his students through working and reflecting collaboratively with another colleague. Initially, he observed his colleague teach a lesson they had planned together to his class. His observations caused him to reflect on his own practice and begin therefore to query his expectations for his class. The outcome for this teacher from the collaborative exercise was a realisation as to 'how deficit ways of thinking about students, such as perceived low ability and assumptions about what they might be able to do, affected the specific teacher's way of behaving in the class' (Messiou, 2019c: 203).

Connected to these more generic assumptions of learner diversity are the personally created constructs of 'difference' and 'usual', or 'normal' and 'abnormal' within the context of ability and disability. An investigation into these constructs within education was considered by Alves *et al*. (2016) with regard to student identity within the educational SEN systems of Sweden and England. What they discovered was that despite boundaries between special and mainstream education within these two countries being more 'fluid and permeable' (Alves *et al*., 2016: 152) than several other national educational systems, other boundaries were still being 're-created on a daily basis, as teachers respond to student diversity within their classrooms, and construct notions of who is different and who is "normal" through their practice' (p.152). Their research led them to acknowledge a profound impact from the knowledge and expectations of the teachers on the expected outcomes for their students (Alves *et al*., 2016).

To conclude this section, it is essential to remember that when researching inclusively 'there is more than one way of knowing something, and therefore more than one way of researching something, so the research design must reflect the worldview of those at the centre of the research' (Hall, 2014: 381). Potential pitfalls recognised from previously published research involving inclusive methods have been indicated from a scoping review entitled *The influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders* by Jivraj *et al*. (2014). Their review of research carried out under the auspices of being inclusive, uncovered a spectrum of involvement from non-academic participants. Some partners were only involved in one stage of the research and were labelled 'consultants' or 'collaborators' (Jivraj *et al.,* 2014: 782), whereas other studies used collaborative decision-making throughout. Both benefits and challenges to partner involvement were outlined from the seven research reports examined and three key themes were further explored.

The first of these considered the lack of clarity regarding the role of the partner during the research process; the second was how the multiple perspectives between researchers and partners were integrated when decisions were made; and finally, the question of how a 'partner' was differentiated from the role of a research assistant was considered. Two of the seven reports which had previously been selected by Nicolaidis *et al*. (2011, 2013) were highlighted by Jivraj *et al*. (2014: 789) as a demonstration of participatory research (PR) excellence for providing 'a feeling of authenticity and relevance of the research and exemplifying the necessity of adults with ASD or other neurodevelopmental disorders to be included as partners in PR'. In aspiring to such an outcome, whilst being mindful that my position as a lone researcher is different to that of Nicolaidis *et al*. (2011, 2013) who were operating from an academic-community partnership, some of the considerations that they highlighted as concerns will be returned to in the next section.

3.3 How inclusive research methods enable the hearing of autistic voices

> Autism isn't something a person *has* or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colours every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate autism from the person - and if it were possible, the person you'd have left would not be the same person you started with (original emphasis, Sinclair, 1993: online).

In order to understand autism as Sinclair (1993) described above, as 'a way of being', inclusive research methods are proposed as an approach with the potential of gaining a better insight into how experience and existence is individual. From the outset, it has to be recognised that when research participants are selected because of their special educational needs they are already seen as 'categorically different' and 'primarily interesting, therefore, because of a perceived *difference*' (original emphasis, Clough, 1998: 129). This dimension needs to be added to other generic issues of voice such as '*who* is listening to *whom*, *why* and - above all, perhaps - *in whose interests*?' (original emphasis, p.129). Concepts of normality and difference have already briefly been considered in the previous section, but it is necessary to highlight here the need for particular sensitivity in providing opportunities to gain a greater awareness of how the impact of difference affects specific individuals through pupil voice.

This section examines a consideration of voice and the significance of listening directly to those who experience autism first-hand, to consider the relevancy of an *Interactive Bioecological Model of Autism*. The need for direct communication between individuals in the development of understanding was highlighted by Williams (1996: 14), an adult writer with autism, who proposed that 'from the time someone came up with the term "autism", the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced … that has big implications for how people try to deal with the condition and big implications for "success" or lack of it'. Shakespeare (2014, 2018) enjoined researchers to seek direct knowledge of disability in order to better understand the lived experience, as was discussed in the previous chapter, reminding researchers of the maxim 'nothing about us without us' (Aspis, 2000: 84). Bronfenbrenner (1979) also highlighted his concerns with the reliability of earlier research that had been carried out in unfamiliar environments with children. Although the proposal for an *Interactive Bioecological Model of Autism* is as a model with potential to deepen understanding between pupils with autism and their teachers, it also has the possibility of highlighting the need for a broader consideration of SEND. It encourages practitioners to engage in small-scale inclusive research in their own educational environment and with their own pupils to deepen awareness of the lived experience of disability. Reasoning behind the decisions made throughout the process of gathering the data in order to present this proposal will be covered in this section.

Bines *et al*. (2007: 65) proposed that a key question for the researcher should be 'in whose interests is this story being told?' In the case of this research it seeks an outcome of developing understanding between pupils with autism and their teachers, therefore methods to be considered should provide opportunities to gather voices of pupils with autism; methods that would seek 'a view from the inside' (Charmaz, 2008: 15). In desiring authenticity in highlighting the need to adopt an *Interactive Bioecological Model of Autism*, any selected methods for gathering empirical research should correspond with the theoretical proposals considered in the previous chapter from Shakespeare's *Interactive Model of Disability* and Bronfenbrenner's *Bioecological Systems Theory*. These methods would then guide the process of seeking, analysing and sharing stories from the pupils who have lived with the experience of autism during their journey through their primary mainstream education. By placing the voice of the participant at the fore, and through providing enough detail it should be possible for readers to come to their own conclusions from the data rather than being told what to think (Tracy and Hinrichs, 2017).

In reflecting on previous writing regarding the use of voice, Fielding (2004: 296) proposed that its theoretical underpinnings had not always been fully considered, finding it surprising 'that only a very small proportion of the literature has taken us back to theoretical foundations that underpin both the advocacy and the emerging realities of student voice in school and community renewal'. An emphasis on the significance of voice in education and research corresponds with Bronfenbrenner's (1979; 2005) *Bioecological Systems Theory* and is consistent with his ecological view of organism-environment interaction. Enabling children as 'active participants' or 'active agents' (Bronfenbrenner, 2005: 121) in contributing to their own development, he considered a vital aspect within a healthy development that could provide the potential to positively influence future psychological wellbeing. It is also a key aspect within the *Interactive Model of Disability* with Shakespeare's proposal of the principle of 'expertise by experience' (Shakespeare, 2018: 160): exonerating user involvement or coproduction within research through suggesting that 'rather than experts determining what is best for people, people should use their own lived experience' (p.160). Such user involvement should be an expectation of participation within inclusive societies thus ensuring that 'the people included are protagonists in the process of inclusion, as experts on the way in which society must treat them' (Alves *et al.*, 2010: 19). Indeed a positive bi-product can result from such collaborative participatory processes, as they 'are more likely to facilitate the development of inclusive contexts, on the one hand, and empower participants who take active roles in research studies, on the other hand' (Messiou, 2019b: 770). Therefore, within this section, two main questions will be considered with regard to gathering voice through inclusive methods: firstly, who is listening to whom and why? and secondly, how are decisions made in the process of gathering voice?

3.3.1 Who is listening to whom and why?

The mark of sincerity as one of the 'big tent criteria' for qualitative research is achieved through researchers demonstrating 'self-reflexivity, vulnerability, honesty, and transparency' (Tracy and Hinrichs, 2017: 5). Such an outcome can be demonstrated in this study through seeking a balance between the pupils' voices and that of my own in my role as researcher. In embracing the role of researcher as that of a 'change agent' (Gray, 2014: 328), it is necessary to take care that I do not view myself as some kind of beneficiary or, as described by Riddell *et al*., (2007: 79) as being in a position of '"giving disabled people a voice" suggesting an act of generosity' as though they would not have a voice without me. I need to be mindful of any possible implications of a learnt helplessness through identifying difference as in any way lesser, or viewing characteristics of autism through a deficit lens. It is essential that the pupils do not believe that they have been identified because of what is 'wrong with them' (Clough and Barton, 1995: 2), but rather valued for their ability to expose what it is really like to be different in a specific way from the majority of the population: thereby providing a view of autism that is 'from the inside according to how it is experienced' (Williams, 1996: 14).

An aspect of sincerity, as considered by Tracy and Hinrichs (2017) is that the researcher conveys honesty about their biases and considers how these may impact the data collection and analysis through self-reflexivity. Indeed, as the research journey is one of reciprocity, it is imperative that I remain self-reflexive throughout the process, and mindful that the role of researcher is 'a learning experience involving crucial changes in one's own ideas and intentions' (Barton, 2007: 33). I consider that I am as vital an 'active agent' (Bronfenbrenner, 2005: 121) within the research process as those whose voices I seek. It is not possible for me to remain detached during this process, but rather to recognise the importance through my involvement regarding the potential of highlighting a different interpretation of a social experience from the perspectives of the pupil participants. It needs to be clarified that this interpretation is inevitably one that will be filtered through my own perspective, as a participant involved in the research and through the choices made during the process of probing the memories of the pupil participants (Potts, 2007).

One of the purposes of qualitative enquiry is to consider 'how humans engage in meaning making - in essence, making sense of the world' (Patton, 2015: 4). This is a focus for this research, to develop a greater understanding of how pupils with autism make sense of the environment or the world they inhabit during their primary education; to consider their lived experience. However, it is essential to remain aware that each view has independently stemmed from a particular personal perspective, and that each participant will have his or her own concept of what they consider reality is. Pring (2015: 65) described such essence of reality as 'something not entirely "created" or "constructed" or "negotiated" but constraining and limiting - something which is independent of us, which shapes the standards of what we can *justifiably* say, and which constricts the conclusions that can be *correctly* drawn from the evidence given' (original emphasis). It is important therefore to remember that individual voices will demonstrate particular views of reality: all will stem from individually filtered memories. The outcome of this for research purposes is that it is essential to recognise that 'there is no way that one could step outside this world of ideas to check whether or not they accurately represent a world existing independently of the ideas themselves' (Pring, 2015: 65).

In considering another 'big tent' criterion for qualitative research of 'rich rigour', described by Tracy and Hinrichs (2017: 4) as research that is 'marked by a rich complexity of abundant descriptions and rich explanations', it is vital to accept that what is provided as illustration by taking an idea from one or more voices, connecting it to a theme by the writer, in order for it to be read by a third party attempts to be as accurate a portrayal of what was originally meant as possible. This process can be made more rigorous through close and open communication from the outset. The outcome of a lack of close involvement between participants in research into autism was one of the three key themes investigated by Nicholaidis *et al*. (2012) and developed by Jivraj *et al*. (2014). It concerned research where the role of the partner was highlighted as having a potential lack of involvement during the early stages of planning and decision-making and in general had a lack of clarity in the research process. In the particular case provided, the partner had been hired one year into the study due to a late award for funding. The conclusion from the review of this research was that 'the study did not conform to an ideal type of PR [participatory research], as it was neither initiated directly by people with ID [intellectual disability], owned by them, nor reflective of their interests and experience' (Jivraj *et al*., 2014: 785). A similar situation was highlighted by Hall (2014) who proposed that outcomes from research on decisions emanating originally from the researcher or their institution and not within the partnership was often 'perceived by the communities as disconnected and lacking any relevancy to them, and they felt excluded from any kind of agency over the research process' (p.380).

In further considering the outcome of 'rich rigour' (Tracy and Hinrichs, 2017: 4) through the respectful process of gathering research inclusively (Nind, 2014) and thereby gaining descriptions and explanations from a variety of perspectives, the expectation of truth needs to be eliminated (Pring, 2015). That is not to say that the participants are not to be believed but rather that it is necessary to accept that there will always remain multiple realities. This has an outcome on the qualitative research gathered and the need therefore to state clearly that it is not possible to generalise from the results. Instead what is gained as a positive outcome from inclusive methods of research is the departure from the ability to generalise with its temptation to use the findings as the basis for assumptions that form stereotypes. The value of this research in gathering pupil voice on individual experience lies in the acceptance that generalisability is not desirable: instead its naturalistic focus considers the similarities and differences within each individual which are specific to their setting and for which recognition is essential if understanding is to be developed.

The term resonance was used by Tracy and Hinrichs (2017) to embrace the concept of naturalistic generalisation. They proposed that in qualitative research:

> rather than using their findings to predict, generalise, and control future interactions and contexts, qualitative researchers conduct in-depth, situated analyses of contexts, rhetorical situations, and embodied experiences in such a way that readers can appreciate the study's findings and then intuitively apply, or transfer, those findings to their own situations (Tracy and Hinrichs, 2017: 7).

Therefore through the voices of the five participants, it is possible to draw plausible inferences but with no claim to causality. In seeking a naturalisitic generalisation, this enquiry is developing 'an ideographic body of knowledge that describes individual cases' (Gray, 2018: 28). Indeed, the fact that 'phenomena can only be understood within their environment or setting; they cannot be isolated or held constant while others are manipulated' (Gray, 2018: 28) is vital in the choice of methodology that underpins the theory of this study. Despite Pring's (2015: 50) proposal that 'there would seem to be certain aspects of being human which enable us to make tentative generalisations about how individuals will perform or react, while at the same time recognising that there will inevitably be exceptions to the rule', when considering disability specifically, Shakespeare (2018: 163) suggested:

> There is rarely one problem or one explanation or one solution that applies for everyone. People understand themselves and affiliate in different ways, and this may change as their lives continue. It seems to me that openness to these possibilities - to letting a thousand flowers bloom - is the only way forward.

Bronfenbrenner (1979: 33) proposed that 'like frictionless motion, ecological validity was a goal to be pursued, approached, but never achieved' as the scope between the view of the investigator and the subject was just one of the aspects to be considered. Further to that was the need to take into account 'the complex interplay between the developing human organism and the functionally relevant aspects of its physical and social environment' (Bronfenbrenner, 1979: 33). Indeed, highlighting the outcome of involving subjects of research as participants in the construction of knowledge, Dyson (2007: 6) proposed a necessity to 'think in terms, not of alternative pathways to "the truth", but of pathways to *alternative* truths' (original emphasis). This is a vital factor within this research, as it is hoped that through listening to and then sharing the voices of pupils with autism through the process of inclusive research, others, and in particular their teachers, can better understand the existence of a 'pathway to alternative truths'. Considering a 'pathway to an alternative truth' has previously been proposed as an often-overlooked element in previous research into autism. For example, in reviewing the literature regarding healthcare experiences for adults with autism, Nicolaidis *et al*. (2012) proposed that despite the fact that adults with autism had an enormous amount of information they *could* offer about their experiences, none of the studies involved the adults directly. They concluded that 'autistic adults have rarely been included as partners in autism research' (p.762). Milton and Bracher (2013: 63) made a similar suggestion, explaining that research in the past had viewed autistic people as 'objects of inspection, rather than active participants in the creation of knowledge relating to their own experiences'. Their proposal was that through the inclusion of autistic people in research, and by viewing them as equal participants, the research process would be enriched and the danger of 'overly deterministic designs and interpretations' (Milton and Bracher, 2013: 63) could be subverted. Such active participation was an element highlighted by both Bronfenbrenner and Shakespeare, as previously discussed, and clearly emphasises why inclusive research methods are ideal when working directly and sensitively with pupils with autism. If a greater understanding of 'alternative pathways' through seeking rich description from a range of voices, and a departure from a view of autism as a deficit within 'normality' is sought, then listening respectfully to autistic voices instead of forming assumptions based on stereotypes could provide the opportunity to develop a greater awareness of interrelations or 'multiple realities' as acceptable concerning particular events.

Despite recognising that listening to the voices of those with autism is an imperative in understanding their ‘pathway to *alternative* truth’ (original emphasis, Dyson, 2007: 6), the method of ‘how’ decisions were made during the listening and analysis process needs explanation and will be covered in the next section.

3.3.2 How are decisions made in the process of inclusive research?

There have been several suggestions that more transparency is necessary in considering how decisions are made when complex relationships are a major aspect of the research to be undertaken (e.g. Barton, 2007; Nind and Vinha, 2012; Tracy and Hinrichs, 2017). As Corbett (2007: 55) proposed, the issue of voice is ‘complex and multi-layered’:

> Firstly there is the struggle over which discipline (e.g. psychology or sociology) or specific model (e.g. social model of disability) gains prominence in setting the tenor of the research framework and key issues. Secondly there is a dilemma over selecting a sample and deciding how to listen and what to hear. Finally, and most challenging, there is the need to provide a means of expression beyond the conventional which most accurately conveys the perceptions and experiences of vulnerable people whose apparent ideas are open to interpretive distortion and abuse.

Therefore, it is necessary for clarification regarding how decisions are made at various points with regard to how voice is gathered within this research and to ensure that the process connects with the values that form the theory driving the study (Pring, 2004). As proposed by Maguire (2005: 3) ‘ethical decisions and methodological choices in working with children are embedded in ontological perspectives and epistemological assumptions about how policy makers and researchers understand child development or any other phenomenon related to children, their communicative and decision-making competence and human potential, and how this can and should be respected and represented’. In considering previous research using inclusive methods, Nind (2014) warned that all too often, details regarding how the research was conducted inclusively were not clear and that the challenges of inclusive research had been inadequately considered and reflected upon. This would have a negative impact on the transparency of the qualitative research, and in neglecting a consideration of the dissemination of information involving the processes of researching inclusively, opportunities will have been lost for further development from an honest reflection on practice.

A fundamental consideration regarding the methods selected for this study is to minimise the danger of assumption through maximising direct communication with the participants (Nicholaidis *et al*., 2012; Silberman, 2015; Messiou, 2019b). Despite all the progress that has been made so far within inclusive education, the fact that pupils with autism are still wishing their teachers understood more about the way their autism affects them (NAS, 2016), justifies its necessity. This on-going need seems to originate in a communication block that stems from a difficulty for teachers understanding the alternative subjective experiences of pupils with autism which they are only able to experience from the outside (Williams, 1996), whilst the pupils who are internally experiencing their autism are equally unaware of the alternative view interpreted from their external communications that are experienced by their teachers. It is useful at this point to consider this situation in accordance with the phase of the pupils' 'moral careers' (Goffman, 1963: 45) (mentioned earlier in section 2.2.3). At this stage of their educational journey, they would most likely be experiencing phase two of the process and following the second pattern of stigma development which was explained by Goffman (1963) as a development in understanding for 'those who have a congenital stigma yet are protected within the capsule of family and / or neighbourhood during early development'. This correlates with information from Attwood's (2007) experiences in diagnosing autism where he reflected that adults receiving a diagnosis of autism usually stated that it was when they started school that they began to feel different. His description of this is that they felt 'able to understand and relate to family members … but when they were expected to play with their peers at school and relate to a teacher, they recognised themselves as being very different from children that age' (Attwood, 2007: 15).

It is important to recognise that the reasons for particular reactions to all types of difference are rooted in systems that individuals are a part of, as emphasised by Bronfenbrenner, Shakespeare and Goffman: for example, their social group, their family, the religious beliefs they hold and so on (Goffman, 1963; Bronfenbrenner, 2005; Shakespeare, 2014; Patton, 2015), and that these are also influenced by communications filtered through their surrounding ecosystem. Acknowledgement of this ensures a greater awareness to extend considerations of not only how the pupil data is collected, but also how it is analysed, and at a later date, how practitioners could read and interpret the data. Milton and Bracher (2013: 64) warned of the danger of assumptions made by third party observers imagining they could understand the parameters of another's wellbeing and what 'makes life liveable and every day worlds inhabitable for different autistic people'. They stressed how crucial it was that 'researchers explore the subjective significance of AS related experiences in relation to wellbeing, as this may not be immediately apparent to non-AS observers' (Milton and Bracher, 2013: 64). Therefore, in asking pupils with autism to reflect on experiences of their primary school for this research, it is imperative that I avoid making decisions based on my own assumptions or behave with the same closed perspective that they may have experienced in their previous education.

Clough and Barton (1995) warned potential researchers into areas of SEN and inclusion of the possibility that without due care and consideration, research could be linked to the viewpoint and ideology of the researcher. They highlighted the danger that without a careful consideration of the 'how?' and instead following a rigid adherence to a particular framework for gathering data, filters could be inadvertently placed by the researcher 'between their perceptions and the objects under study' (Clough and Barton, 1995: 4). A further consideration regarding how to gather data was highlighted by Söder (2009). He proposed that many disability researchers 'tend to be divided into empirical researchers, and their need to identify persons with disabilities, on the one hand and on the other hand theoretically oriented researchers criticising the individual focus this leads to, but uninterested in developing an alternative approach' (Söder, 2009: 74). His warning was that a result of this divide was inconsistency when relating theory to empirical research. However, choosing inclusive research as the methodology for this study aligns the 'why' that resulted from considering the theory covered in the previous chapter with the 'how' concerning the gathering of data for this research. This framework encapsulates considerations necessary for joint decisions regarding the gathering and analysis of data (Nind and Vinha, 2012) whilst also encouraging a careful consideration of the researcher position within this process.

Some examples of recent research conducted with autistic participants include that of Parsons *et al*. (2020). Their aim was to create an inclusive research process that considered the concept of technology and autism. Their method involved several seminars over a two-year period and the collection of post-it notes for comments thus negating the expectation for oral contribution. Another example is that of MacLeod *et al*. (2014) who worked with ten autistic students to investigate how they made sense of their achievements. The options that were offered to the participants for this research consisted of face-to-face, telephone or online interview. The intention of providing these options was 'to avoid making generalised presumptions but rather to engage with individual preferences as far as possible (MacLeod, 2014: 409). A final example to be considered here is that of Hebron *et al*. (2015) whose research focused on the vulnerability to bullying of young people with autism in English mainstream schools. They used semi-structured interviews to maximise pupil voice for the five pupil participants and clarified that the pupils they worked with had no complex communication difficulties and that as researchers they had ensured flexibility within the interview schedule.

In considering the process of the co-production of research, Seale *et al*. (2014) proposed that although a balance of power when using inclusive research methods was necessary, the questioning of benefits that arose from the process of co-production may be of more importance. They suggested that within the process of co-production, inclusive research could still be researcher-initiated as researchers have an important part to play in the inclusion of voices that are sought, often through the provision of some initial suggestions and ideas as a starting point. This point was also raised by Riddell *et al*. (2007: 86), who proposed that 'there may be aspects of research in which not everybody has the necessary knowledge and skill to play a role'. Therefore rather than anticipating that everything needs to be equally balanced in all aspects of inclusive research, it is more realistic to anticipate that 'if people with learning difficulties are to be involved in the research, then it should be in ways which draw on their expertise and specialist knowledge, with accountability remaining a guiding principle' (Riddell *et al*., 2007: 86). The advantage of this was clarified in research undertaken by adults with learning difficulties for the *Department of Health* (DoH) (2006). Their recommendations to future researchers considering this type of involvement was that:

> Researchers with learning difficulties have the advantage of knowing what it feels like to have a learning difficulty. This expertise can change research (DoH, 2006: 84).

Two further key themes yet to be explored that were highlighted by Jivraj *et al*. (2014) for consideration in future research involving participants will now be considered. The first concerned limitations in reporting on the involvement of partners, the second highlighted a lack of clarity into how multiple perspectives were involved in the decision making process. Jivraj *et al*. (2014) proposed that in general there had been a lack of explicitness into the reaching of a consensus when there were varying views from those involved, including that of the researcher, with the outcome being a limitation in the acknowledgement of the various unique contributions from all the partners. This lack of clarity in the process of creating a common story has also been highlighted in inclusive research more specifically by Nind (2014) who proposed that charting the process of moving from individual stories to a common story is valuable as 'a means for validating different voices, narratives and narrators' (p.49). The second key theme was how the involvement of 'partners' in inclusive research processes was different to that of the involvement of 'research assistants' (Jivraj *et al*., 2014). Authenticity is a vital component of this study and the ability to provide authentic knowledge can only come from those involved as partners rather than assistants. As proposed by Nind (2014), inclusive research 'can and does produce more authentic knowledge … when grounded in the experiences and values of those concerned … one's identity brings with it a particular view of the world based in the identity, which in turn produces a particular kind of knowledge' (p.24). In responding to both of these considerations, it is necessary once again to clarify the importance of the role of the partners involved and to highlight how respectful and reciprocal relationships will be developed through this process. Pring (2015) proposed a connection between individual interpretation and the ongoing collaborative agreement related to the construction of social rules, suggesting that:

> Although the rules which constitute social life and social facts … are inherited and not dependent on the subjective meanings of each individual, they are none the less socially constituted and their continued existence depends on social agreement. Such meanings change as people come to interpret things differently ... Agreement on interpreting things differently recreates social reality (Pring, 2015: 122).

In seeking to maximise objectivity as an outcome of successful research, Pring (2015) proposed that it should be sought through checking interpretations against the evidence and considering which interpretations are the most appropriate when all participants are involved in considering the data. Objectivity is therefore maximised through 'taking the necessary steps to eliminate bias or subjective interpretations of the evidence, and that is ensured by seeking wide and continuous criticism of the conclusions provisionally reached' (Pring, 2015: 157). This emphasises the importance of collaborative processes within the social construction of knowledge and resonates strongly with Goffman's (1963) writing on stigma. It is also a reminder of the need to recognise the bi-directional flow of information between the ecosystem, as suggested by Bronfenbrenner (2005) and a vital component of an *Interactive Bioecological Model of Autism*. In considering past examples of objectivity in research, Patton (2015) highlighted the theorists Piaget and Freud as examples where closeness and empathy with individuals had not negatively affected the value of the insights they provided and their objectivity. In short, Patton's proposal was that 'closeness does not make bias and loss of perspective inevitable; and distance is no guarantee of objectivity' (Patton, 2015: 57).

In considering these highlighted areas for this study, it is necessary to state that firstly, its success depends entirely on the willing voices of others. It is therefore essential that from the outset, the research is recognised by all participants as 'by', 'with' and 'for' them (Nind, 2017: 279) rather than 'on' or 'about' them. Secondly, it is pertinent to remember that it would be unwise to make assumptions on the meaning of, or assume interpretations regarding what motivates the voices of these individuals who are likely to hold a very different view of the world to that of my own. Therefore, at every stage of the research process I hope to demonstrate how the multiple perspectives between myself as researcher, and the partners involved were integrated when decisions were made. Accuracy in this is of extreme importance when working alongside pupils on the autism spectrum whose input and particular way of viewing the world is a crucial aspect of this study in the development of knowledge and understanding of autism (MacLeod *et al.*, 2014). It is hoped that a positive outcome from presenting reflections from the five pupil participants with autism on aspects of their primary education will be that 'alternative ways of understanding what society perceives as disability, normality, and reality' will 'troubl[e] the "truth" about human difference' (Connor, 2013: 124). This is a crucial step in a process towards real optimisation of the potential for the inclusion of pupils with autism in mainstream schools through the adoption of an *Interactive Bioecological Model of Autism*.

Relationships are the cornerstone of effective inclusive research as the research processes from beginning to end are negotiated between all participants. As proposed by Nind (2014: 50) 'it is important to examine the dynamic between the researcher and the researched, who do not become merged or transformed in this kind of inclusive research but do come closer together with potential for reciprocity'. The positive outcomes from a reciprocal and empowering inclusive research process also demonstrate the potential for developing a deeper understanding when autism is considered through an *Interactive Bioecological Model of Autism*. Diagram 3 on page 57 demonstrates that an individual in the centre of their concentric rings is separate from another individual, for example a teacher or parent, who is situated within their microsystem. What is proposed through the adoption of the new model is a greater awareness of the bi-directional flow of information between the individual within their ecosystem and those they have direct contact with who exist within their microsystem. This would include recognition of the impact of information that filters through the layers of each individual's ecosystem and the awareness that every level is affected by the interpretation of autism through both the medical and social models of disability. Considerations regarding some of these matters alongside other ethical and methodological decisions will be covered in the next section.

3.4 Ethical and methodological choices for this research

> The imagination is a dangerous tool when it comes to disability: we tend to exaggerate, project and mistake what life is really like for people with disabilities. We wrongly assume that difficulties for people result in misery for people (Shakespeare, 2018: 48).

As implied in Shakespeare's quotation above, imagining what life might be like for someone else is not useful especially when they are disabled in some way. Care therefore must be taken throughout research into aspects of disability that opportunities for imagination and therefore assumption and stereotype do not occur. It is hoped that the process of inclusive research involving the close partnership with the pupils will minimise this risk. However, it is necessary to highlight that researching inclusively demands a specific set of ethical and methodological values. Although many are inseparable from the practice of inclusive research per se, and therefore have been generically covered in earlier sections of this chapter, there are some aspects that will be pertinent to this research that will be further considered here. In addition to the ethical and methodological decisions made about the process regarding data gathering and analysis, is the awareness that the role of researcher also needs careful scrutiny. The act of inquiring using inclusive qualitative methods is inevitably a personal one and an important step is that of outlining the journey and the reasons for undertaking an enquiry.

For this particular study on autism, it was also necessary to be mindful of a further range of potential ethical problematic issues highlighted by Nicholaidis *et al*. (2011) from their investigation into various research studies that had attempted to involve people with autism as partners. These included a potential 'misalignment between researchers' priorities and those of the autistic community; a lack of inclusion of autistic individuals in the research process; use of demeaning or derogatory language and concepts; threats to study validity derived from miscommunication between researchers and participants; and the use of findings to advance agendas that opposed community values' (p.143). These correlate with findings from Milton and Bracher (2013) and re-emphasise the necessity for the researcher to be alert to the need for sensitivity within an inclusive research approach and to take care to avoid assumptions.

The first part of this section will return to the 'big tent criteria' for qualitative research (Tracy and Hinrichs, 2017) in order to consider ethical considerations, before moving on to justify the reasoning behind the selection of the participants. A section outlining why interviews were selected by the pupils as the method for gathering the data will follow and will include a discussion of other methods that were considered and why they were discounted. This will then lead to an explanation of decisions made on how the data was recorded and transcribed, with the final section clarifying why narrative was chosen as a framework for presenting the thematically analysed data.

3.4.1 Ethical considerations

Whilst being aware of the many positives arising from the flexibility of inclusive research, in this study it was essential that time was given to examining the ethical considerations necessary within that flexibility that were necessary for all participants. Many of these have been covered through the writing in earlier sections but a few aspects still need greater focus. The proposal by Tracy and Hinrichs (2017) was that full coverage of ethical issues should be categorised in four different ways, each of which will be considered within this section, with the first being 'procedural ethics' (p.8) or those considered universal for participants' protection. For this study all data gathering was carried out in accordance with the *British Education Research Association's* (BERA) ethical guidelines (2018) and those of the *University of Winchester* (2015). General principles of anonymity and confidentiality were stressed from the outset, in the Project Information Sheets (appendix 1) provided for the pupils, parents and gatekeepers, and on meeting the pupils. It was clarified that no person would be mentioned by name, but would instead be given a pseudonym, and no school could be identified. All notes in the form of gathered data would be kept securely in a locked filing cabinet and all orally recorded data would be kept on a password encrypted device (appendix 2).

The second ethical category was that of 'situational ethics' which refers to the 'in-the-moment enactment of upholding rules and standards of ethical behaviour' (Tracy and Hinrichs, 2017: 9). This therefore necessitates a constant examination and re-examination of ethics and methods as an on-going process, whilst remembering that 'there is rarely a clear-cut and context free, set of rules or principles which can be applied without deliberation' (Pring, 2015: 174). What Pring urged of the researcher was 'the clarification of principles which then need to be applied to particular situations, in the full knowledge that other principles might also be evoked which would lead to different decisions' (p.175).

The third category termed 'relational ethics' (Tracy and Hinrichs, 2017: 9), which encourages an awareness of impact on others and in particular the treating of participants with dignity not just as subjects for observation, has been largely covered in previous sections within this chapter regarding inclusive research. However, the aspect of power imbalance between researcher and participants needs highlighting here as a vital consideration in mitigating the outcome of the 'powerless researched' (Nind, 2014: 20). The methodology of inclusive research 'represents an interest in the people outside of academia being active and credible producers of knowledge' (Seale *et al*., 2014: 347). It disrupts the hierarchy (Nind, 2014) and through its focus on equality embraces methods that involve working 'with' participants rather than 'on' them (Black-Hawkins and Amrhein, 2014; Nind, 2017). In seeking a process within this research that would enable the pupils to be 'active participants' (Bronfenbrenner, 2005: 121) it is necessary to return to Fielding's (2001, 2004) concept of 'radical collegiality', first mentioned in section 3.2 and its potential for transforming the relationships of teachers and pupils through an 'intermingling and interdependence of both' (p.296). Fielding's proposition was that if the recognition of *both* perspectives, teacher and pupil or in this case researcher and participant, could be acknowledged as having equal value, the power and potential of all voices could then be maximised within a respectful partnership: 'each depends on both the acknowledged legitimacy of difference and the manifest reciprocity of its articulation for its practical energy and drive' (Fielding, 2001: 131).

'Asymmetries in power' was a concept considered more widely by Lensmire (2010: 272) who focused on situations where dominant groups tended to have the advantage and others found themselves 'in continuing conflict with the dominant meanings and values of society' (p.272). This is a situation that may have been experienced by some of the pupils with autism in their relationships with particular teachers during their primary education, and will therefore demand particular care by myself in the role of researcher. In considering such standpoint epistemology, Söder (2009) proposed that as researchers 'our thinking and the research we do cannot be predicated on the grounds that have to do with our personal characteristics or our position in a stratified social system' (p.69). This was an aspect also emphasised by Nind and Vinha (2012) who specified that their role as inclusive researchers consisted primarily of listening, reflecting and transforming, and that through this they 'positioned everyone involved in the research, including [themselves], as learners' (p.103). Working from this standpoint within participatory research provides the potential for empowerment of all participants, thus mitigating the negative outcome of a power imbalance. Therefore processes should be sought that provide opportunities for developing 'power with' rather than 'power over' young people, a outcome of the use of power that Rodrìguez and Brown (2009) suggest is 'both necessary and educative' (p.28).

For the purposes of this research therefore I need to be recognised by the pupils as a learner about autism, putting them in the position of experts (Bourke, 2009). Our roles are clearly defined within this as they own information they are aware that I require. By opting in as participants to this research they will have initially agreed to share their insights and thus provide me with an education that will enable me to better understand their autism. Therefore, the choices about the methods that will be used to gather the information, as well as the specific areas we will cover in my education about their autism, will be placed in the hands of the participants. It will also be necessary to work together in locations within their school environment that they will feel comfortable in and where I, through the nature of being a visitor, will be seen as the outsider. At every point of working directly with the pupils, and then with their reflections, they need to be involved to ensure they never lose ownership of the information they supply. This process is designed to disrupt the hierarchy of much previous research (Nind, 2014) and should empower the pupils as participants, as in this situation I am the pupil and they are the teachers. Further details are provided about these aspects in the section that follows.

The final ethical category is that of 'exiting ethics' which refers to the departure from the site and the sharing of results. The sharing of results will be discussed in a later section within this chapter on narrative analysis. However, considerations regarding departure from the site will be returned to in the final chapter of this thesis with regard to future implications for this research.

3.4.2 The participants

From the outset a careful consideration regarding where to search for voices that could provide useful insights was necessary. It was decided that pupils with a diagnosis of autism who would be in their first year of secondary school would be approached as a homogenous and purposive sample in the hope that they might be able to provide recent memories of their mainstream primary school whilst currently attending another school that could provide some kind of comparator. A special school and a mainstream secondary school were selected as both admitted pupils with autism who had attended mainstream primaries. This search resulted in five consenting pupil participants consisting of two males and three females; all pupils attended different mainstream primary schools and had received a diagnosis of autism at some point during this time. The pupils came from supportive families consisting of both birth parents and a variety of siblings. This purposive sampling resulted in a small number of participants, but provided the opportunity within the time limitations of this study to consider information-rich cases from a particular subgroup (Patton, 2015). The provision of rich data in conjunction with careful analysis can provide opportunities to 'reach below the surface, and allow the researcher to gain a deep understanding of the topic of interest' (Braun and Clarke, 2013: 34). In this way, a thick description, necessary for credibility, can be produced (Tracy and Hinrichs, 2017).

Although as previously highlighted, the nature of this research is such that it will not be possible to generalise from the data (Patton, 2015), and nor is it required as an outcome, it is instead hoped that it will provide new possibilities for developing future insights into a better understanding of autism. Other examples of potent outcomes in research from small samples include that of Connor (2013) and Baron *et al*. (1999). Connor's research looked in depth at one particular participant with AS called David whom he labelled a 'college survivor' (2013: 121). In considering David's responses, Connor (2013) demonstrated: his reactions to his college environment; some of the problems he had in fitting in; and, how important the Asperger community became to him. The research by Baron *et al*. (1999) into the dynamics of identity formation covered ethnographic case studies of three adults with Down's Syndrome. From their reflections, Baron *et al*. (1999) highlighted that post-war assumptions on youth being considered a transition from the stable state of childhood to the stable state of adulthood, was not the case for all individuals. The four key markers of adult status they drew from the experiences of the three participants led them to propose 'the possibility of politics of identity and of redistribution for people with learning difficulties' (p.484). Both of these examples provide valuable outcomes from small samples, thus demonstrating that where detailed reflections are required regarding a specific focus, small numbers of participants can be valuable in the provision of rich detail.

Explanations to the potential participants who were met as a group or a class, as to what would be taking place and why their involvement was invaluable, were presented through visual and oral methods using a PowerPoint. The steps to be taken within the research and analysis process were revisited using pictures and a timeline on occasions, to ensure continued understanding and to check that the pupils' consent in participation was still freely given. Using visual methods as well as oral and written descriptions for pupils with autism is recommended good pedagogical practice by the *National Autistic Society* (online). Consent was also gained from the head teachers of the two schools involved and subsequently from both the pupils and their parents (appendix 4). The three essential criteria for participant selection as mentioned earlier, were: that the pupils were in their first year at secondary school; they had a diagnosis of autism; and that they had attended mainstream primary school. The teachers highlighted specific pupils who met these criteria and letters were sent via the pupils to the parents, which included the information regarding the project and the necessary, consent forms for the parent/guardians and the pupils. Only one form was returned from the special school from the fifteen that were sent out to potential participants. This could have stemmed from the nature of secondary schools having less direct parental involvement than at a primary school. It was also possible that the parents were wary of my involvement, especially if there had been particular problems during the pupils' previous primary education. In retrospect, it might have been better to invite the parents to a meeting rather than providing the information in the form of a letter. The mainstream secondary school that had been selected had a base where pupils with identified specific needs could attend for structured teaching and return to as a quieter place during break and lunch times if necessary. Four pupils were selected as potential participants by the head of the base, and it was with those pupils that I had my first meeting.

Brief details are provided of the pupils here, but a more rounded profile of each will be developed through their own words in the following two chapters. For ease of reference, the pupil information provided below has been tabulated and can be found in appendix 3.
Ben was diagnosed with autism at the age of four. He currently attends all classes within the mainstream secondary school, only using a support base within the school on occasions during lunchtimes.
Roger received his autism diagnosis at the age of ten after moving to a different primary school in Year Six after a SENCo suggested it as a possibility. Like Ben, Roger spends the majority of his time in the mainstream school, only attending the support base for time out if necessary during break and lunchtimes.
Alice was diagnosed with autism at the age of ten. Her parents however had recognised that she might have autism from the time she was approximately seven years old, but chose to seek a diagnosis when she was ten in the hope that it would provide more help for her in her education. She spends the majority of her time in the mainstream school although is timetabled to attend the support base during specific language lessons as she also has dyslexia. Similarly to Ben and Roger, she is able to spend time in the base during break and lunchtimes.
Esther received her diagnosis for autism and epilepsy at the age of three and attends the same secondary school as Ben, Roger and Alice. At the start of this academic year, a specific room within the school was set up for particularly able pupils with high levels of anxiety. She is granted access at any time to this calm environment to get on with her work when the classroom environment becomes too stressful. She also attends the same support base as the other pupils for occasional tests.
Meg moved from her mainstream education to attending a specialist secondary school at the time of transfer between Year Six and Year Seven. Her autism was diagnosed when she

was nine years old. She has attended two different primary schools, but spent the majority of time in the second, which is the one she refers to during the interviews.

Once the pupils and their parents/guardians had given their consent, decisions of how to gather voice were placed in the hands of the pupils. I believed this to be an important initial step in our relationship as it would be one of the first decisions that would be made by the pupils in the research process. It was fundamental that mutual respect and open collaboration existed within our partnership from the outset. The importance of this was outlined by Maguire (2005: 12) who proposed that an aspect of children's engagement with the world and significant others involved:

> Negotiating multiple discourses of value and intertwined significance in the contexts in which they find themselves … it requires a new epistemology of childhood and positive view of children as social actors who have a sense of agency to choose and decide rather than incompetent view of children who need to be protected.

This concept was also recognised by Shakespeare (2018: 51) who expressed concern about the fact that it was during the early years of education that children realised they were different but that 'most of the research is not done with the children themselves, it is done by their parents, carers and professionals'. It was important to acknowledge that the pupil participants may not have experienced a 'sense of agency' for choice and decisions within their primary school education. It was also possible that some may have experienced previous misunderstanding from practitioners in their primary education and this research process needed to reassure them from the outset that professional relationships could be different. Therefore, the respectful and collaborative aspect of decisions was particularly important if the pupils were to recognise their value as individuals and participants with agency from the start. As proposed by Parsons and Cobb (2014: 437) researchers need 'to be clear about the extent to which users may or may not be involved in decision-making and to ensure they understand the reasons why/why not'. Therefore, it was vital that I did not elevate my position or set myself apart from them in assuming responsibility for a process that relied on their willing co-operation and needed to be rooted in respectful reciprocity.

The aspect of choice and design within a naturalistic inquiry design was outlined by Patton (2015: 50) who proposed that although some aspects will be specified at the start of data gathering there are other parts that by necessity need to remain unspecified and will ‘unfold[s] or emerge[s] as the fieldwork unfolds’. Indeed, the very heart of any inclusive research process is in ‘addressing the power relationship between the researcher and researched’ (Nind, 2014: 73). Patton (2015: 57) proposed that the researcher’s aim should be to achieve a state of ‘empathic neutrality’. In unpicking these two words that seem diametrically opposed, Patton suggested that empathy developed from ‘interpersonal connection with the people interviewed and observed during fieldwork’ and involved ‘being able to take and understand the stance, position, feelings, experiences, and worldview of others’ (Patton, 2015: 59). Neutrality on the other hand he proposed could ‘actually facilitate rapport and help build a relationship that supports empathy by disciplining the researcher to be open to the other person and non-judgmental in that openness’ (p.59). This state of ‘empathic neutrality’ could therefore lead to the opportunity of ‘understanding a person’s situation and perspective without judging the person – and communicating that understanding with authenticity to build rapport, trust and openness’ (Patton, 2015: 57).

When considering various methods for gathering the view of the participants, it was vital that I was seen as an equal participant in the process. This precluded then the option of questionnaires or structured interviews, as I would have had to prepare the focus for these methods in advance and thus move away from enabling the pupils to decide what to cover in the moment. Online or telephone interviews were also discounted as I believed it was important to come alongside the pupils and work with them on their memories where we had the opportunity to be in each other’s company and see each other face to face. I was also aware that too much choice for people with autism could make a decision hard to reach (NAS, online). Therefore, a small range of possible methods were proposed and explored at the start with the pupils in order for them to make an informed choice. Individual or group interviews were one of the methods suggested and it was hoped that with consent, these could be audio recorded. Although individual interviews would be easier to transcribe, an advantage of group interviews could be that the pupils might be reminded of experiences they had encountered through the memories of their peers. In trying to keep a state of ‘empathic neutrality’ I decided not to make prior judgments on whether a group situation or a one-to-one situation might afford less stress to the participants and left that decision to them. Another alternative method was provided for any pupils who preferred a less direct method of communication. They were offered a notebook to write or draw memories that could be discussed later if necessary either with me or through being orally recorded. The pupils were presented with these options at our first meeting and then left to decide before we met again. They all chose to be interviewed and the advantages and limitations of this method for sharing their stories will be discussed in the next section.

3.4.3 Interviews: Pupil voice in inclusive research

The nature of all qualitative inquiry is that it takes the researcher 'into the world to experience and document the world, and the world being multidimensional, multi-layered, complex, dynamic and enveloping, will take you to places both planned and unplanned' (Patton, 2015: 37). This dimension of qualitative inquiry is a particular strength of inclusive research*,* and in attempting to remain non-judgmental and in a state of 'empathic neutrality' it was constantly necessary to be prepared for 'places both planned and unplanned'. The formation of assumptions, judgments and stereotypes was deliberately avoided in order to actualise the inclusive research approach and remain true to the principles with Shakespeare's *Interactive Model of Disability* and Bronfenbrenner's *Bioecological Systems Theory*.

During the initial discussions with the pupils, options were outlined for capturing what they chose to share from their memories of primary school. All pupils chose to be interviewed and gave consent to being audio recorded as they appreciated why this would be helpful during post-interview analysis. Although all participants chose this method to share their stories, I wanted to take care not to be considered as the one who was leading our time together. Therefore I only brought as prompts to open the discussion, the response from the NAS (2016) survey and the quotation from Williams (1996: 14) proposing that autism is more often judged 'from the outside, by its appearances, and not from the inside according to how it is experienced'. These were to act as reminders of why we were working on this area of understanding autism together. I had to be confident that my earlier explanation and the provision of the project information sheets had possibly sparked some memories from their primary education, but it was not for me to plan the topics we would cover; the pupils would lead those decisions during our journey together. I needed to take care that it was *their* memories of events that were pertinent to them and not those invoked by others in their family, which is why I chose not to provide them with suggestions ahead of our discussions. Whether undertaken individually or as part of a group, interviews would provide opportunities for a semi-structured approach where specific areas could be included at their request, but with the pupils predominantly leading the flow of conversation. This method could also include observational notes in the resulting narrative, as facial expressions, body language and overall demeanour could be recorded whilst we were together which would add to the creation of a more rounded narrative. For this research, the individual pupil from the special school was interviewed on her own in an empty classroom, or on one occasion an office, whilst the other four from the mainstream secondary school chose to be interviewed as a group with their support base used as the venue for these sessions, thus ensuring they felt as relaxed as possible within their environment. Following the initial introductory visit where the process was explained, there were two group interviews, which were followed by a third interview conducted with their consent as individual interviews. This was deemed necessary during the data gathering process, as I had become aware of some details that one pupil in particular seemed reluctant to talk about in front of the others. Spending time with them individually also provided the opportunity to delve deeper into some of their previous answers, to check with them that they were in agreement with my interpretation of what had been said by them in previous interviews and, to consider emerging themes. This process has been set out on the following page in the form of a table (Table 1).

Meetings and preparation	Content
First meeting	Initial sharing of ideas with pupils and a discussion of information from the NAS survey. The proposed collaborative process was shared and consent forms were left for pupils and parent/carers for consideration. The pupils were asked to consider how they wanted to share information if they wished to participate that we would return to next time.
Interview 1	Pupils' responses to the NAS survey and Williams' quote were considered as a group. Ideas were raised for future discussions and were noted on post-it notes. An empty journal was left for the pupils to note any further ideas they had for discussion while I was not with them if they wished.
Preparation for interview 2	Post-it notes were considered and grouped by MW in preparation for interview 2. Interview 1 was transcribed and coded.
Interview 2	The post-it notes from Interview 1 were returned to with the pupils to analyse the concepts in more detail together and consider any further ideas arising from this discussion or related to interview 1. Discussions took place in other areas as the conversation flowed. The pupils' consent was requested and given for an individual interview to be the next step.
Preparation for Individual Interviews / Interview 3	Interview 2 was transcribed and coded by MW. Individual ideas previously discussed in interviews 1 and 2 were considered by MW in preparation for the individual interviews / interview 3 which were to focus on the pupil's own specific experiences from their primary school education.
Individual Interviews / Interview 3	Previous individual responses from Interviews 1 and 2 were checked with the pupils for clarity and interpretation and individual themes were developed further where necessary. An initial mention of the emerging themes from previous interviews was shared with the pupils to see if they agreed with them.
Preparation for final analysis discussion	Individual interviews / interview 3 transcribed and coded by MW. All transcripts were returned to and codes were placed initially on an electronic mind-mapping tool followed by transference onto paper and post-it note mind-maps for the visualisation of connections and themes with the pupils for the final analysis discussion.
Final analysis discussion / Interview 4	Pupils were involved in considering the emerging themes from the paper and post-it mindmaps to check that they agreed with the process of grouping their initial ideas into themes. These themes

Final theme decisions	The final themes that were agreed with the pupils were then considered by MW and the supervisors in order to amalgamate them into the titles for the two chapters that would include the findings and analysis of the empirical data.

Table 1: interview and analysis process with pupils

Not only was the process of how the data was gathered important, but also the method of transcription leading to data interpretation and then analysis that needed careful consideration within the process of inclusive research. An interesting study by Welikala and Atkin (2014) into the involvement of university students in the analysis of their own data about their university experiences across three different geopolitical contexts, reported that 'one of the most significant aspects of co-inquiring with the students was the ability to make meaning of student experience through the eyes of the students themselves' (p.401). Welikala and Atkin's belief was that too often the students acted in the role of passive informants whilst the researchers gathered the data. Their proposal was that if instead a greater involvement for students' engagement in the project was created, the students were then encouraged to 'rethink and re-engage with their identities' (p.397). This positive outcome was also highlighted by Shakespeare (2018: 161) who proposed that it should be 'the process of doing research, not just the results of doing research, [that] should be empowering to participants and beneficiaries'. Similarly, Nicholaidis *et al.*, (2011: 145) stressed the possibility of mutual benefit being an outcome from the empowering process of analysis by the combination of both professional and personal expertise within a project where 'academic and community members serve as equal partners in all phases of the research'. This is a fundamental aspect of inclusive research (Nind, 2014, 2017) and another reason for its selection as the methodology for this thesis. With this in mind, it is important for the researcher to recognise their role as 'a tool through which "voice" can variously be released, distorted or inhibited' (Corbett, 2007: 59). This was highlighted by Corbett as vital during the interview phase, but there is an equal importance in ensuring the on-going active involvement of pupils in the later stages of analysis as well. Without their continued involvement, the pupils' released and recorded stories could equally run the risk of being distorted through another's interpretation. Every interview was transcribed in full and initially coded immediately afterwards on an excel spread sheet, an example of which is provided in appendix 5.

In transcribing the interviews, my role within the partnership was to write accurately and in a way that would transport the reader as if they were there when the interviews were taking place: a process of providing what Patton (2015: 54) described as a 'thick description with contextual details'. This is an outcome also emphasised by King *et al*. (2019: 194) in proposing that 'approaches that seem to examine personal experience in depth … will require full verbatim transcription, probably involving a level of detail beyond the basic'. Here it is important to remember the link already made between observation and interview, as skilful interviewing must also include considerations of the setting, reading of non-verbal messages and other nuances of interaction between the interviewer and interviewee (Patton, 2015). The words and their tone, as well as the gaps and pauses from the interviews, were transcribed to be as accurate a portrayal of what happened during our time together as possible (King *et al*., 2019). Working with these transcripts from the recordings of memories from pupils whose view of the world was likely to be different to mine for many reasons, meant that the analysis process needed to provide assurance that I would not be the only participant who would interrogate the data to provide interpretations. Patton (2015: 12) warned researchers that 'the dirty little secret in much of research and evaluation is that the designs do not give serious attention to the emergent and unexpected because those who design studies are primarily interested in testing their predetermined hypotheses and analysing established indicators rather than openly inquiring into the complex and dynamic ways in which the real world unfolds'. This further emphasised the requirement within the process of inclusive research to work as equal participants, involving all partners in decisions made during the analysis stage as well as in earlier decisions regarding data gathering. By means of involving the participants in analysing the empirical data through its written representation, the potential of limiting the outcome through only 'testing their predetermined hypotheses and analysing established indicators' (Patton, 2015: 12) would be minimised.

Latent coding was chosen for working with the transcribed interviews, as it involved a more conceptual or theoretical interpretation of the data (Braun and Clarke, 2013). It is explained as a coding that 'is extended to an interpretive level in which the researcher seeks to find the underlying meaning' (Bengtsson, 2016: 10). However, for all types of complete coding, Braun and Clarke (2013) stressed inclusivity; ensuring that if there was any question over the relevance of an utterance, it should be coded and considered later. Themes could be developed from the codes, which would later be narrated as illustrations.

This was particularly important when returning to discuss the developments with the participants as within this fluid process nothing uttered was removed. Through sharing the process of analysis with the participants from the initial latent coding of the data to the development of the themes, it was hoped that they would feel affirmed in the stories they had shared and that a joint agreement could occur regarding the themes that had arisen from the data. As highlighted by Lensmire (2010: 268): 'advocates of critical pedagogy assert that the affirmation of students' own experiences, languages, and stories is crucial … traditional pedagogies belittle and alienate students by not respecting and working with the ways that they make sense of their worlds and themselves'. This was a crucial aspect within this project as one of the key tenets was 'making sense of their worlds'. In this case the 'world' was that of the pupils with autism and how their active involvement during all stages of the research might provide a better understanding for others of their lived experience of autism within a mainstream primary setting. Therefore, respecting voice and involving the participants throughout the whole process was vital if the resulting proposals drawn from the synthesis of theory and data were able to provide the strong foundations on which to more reliably consider change.

At the start of each new session with the pupils, the transcripts and their initial coding were returned to in order to check my interpretation of what had been discussed and to follow up on some of the main areas if necessary. This provided a more continuous style of analysis and ensured that the pupils were involved in considering what they had already said (Nind, 2011) and building on it or explaining it further when the need arose. After the individual interviews, all the codes were considered through a mind-mapping tool (appendix 6). This highlighted particular areas of information that ultimately, and through the involvement of all participants using paper and post-it notes (appendix 7), resulted in the selection of the themes. This process will be covered in more depth in the next section.

Despite the initial decision by the pupils to use interviews for data collection, it was necessary to continue to be cautious in considerations regarding any personal involvement throughout this process in trying to ensure equality in the partnership. Patton (2015: 3) proposed that decisions made by the researcher are affected by 'who you are, what's going on in your life, what you care about, how you view the world, and how you've chosen to study what interests you'. The same has to be said of the pupils. Their initial reasoning behind their consent to be involved and then in subsequent decisions taken individually about what to share and how to share it were all made independently. Although one of the criteria for sample selection was a diagnosis of autism, it would be wrong to assume that the pupils should therefore represent all pupils with autism, as only some who were eligible had chosen to take part. In addition to this the ratio of males to females of 2:3 in this study does not represent the ratio of males to females with autism in the population, which currently stands at 4:1 (Eaton, 2018). The individuals within this group were already motivated for reasons that they might have been aware of, but I was not, therefore potentially confirming Nind's suggestion that 'it is those who want to be a good citizen or who are "emotionally literate" who become heard within inclusive research' (2014: 76). Inevitably there exists 'a dichotomy between the public and the private, between the objective and the subjective' (Pring, 2015: 54), and although openness and honesty was sought in the information provided by the pupils, it would never be possible to know what the pupil had already filtered before utterance. As pointed out by King *et al*. (2019: 287) 'this version of events is not necessarily accurate in a realist sense; rather we have edited our lives in ways that make sense to us, that have value, possibly enhancing our understandings of who we are'. Pring (2015: 82) defended this limitation in contrast to the potential precision within the world of the laboratory, by proposing that 'the social world we are dealing with in educational practice has such a complicated set of interacting causal factors that we cannot isolate the events under consideration from this complex reality'. It is essential when considering the validity and reliability of this research to note these limitations regarding the data gathered.

The next section will consider these aspects in more detail through outlining how inclusive steps were taken within the method of thematic analysis to guide the joint development of themes from the voices of the participants. Finally, the decision to explore and retell the stories through a narrative approach will be justified.

3.4.4 Synthesising the results of inclusive research through thematic analysis with narrative form

In considering how best to progress from inclusive methods of gathering voice to inclusive methods of analysing voice, the stepped process of thematic analysis as suggested by Braun and Clarke (2006) was demonstrated in a visual and participatory way to the participants. The opportunity was provided for participants to group and re-group codes as themes and sub-themes were considered through on-going reciprocal communication. Braun and Clarke (2006: 79) described thematic analysis as a ‘method for identifying, analysing and reporting [themes] within data’ and proposed six phases from familiarisation with the data to producing the final report. They emphasised that the process was not a linear one and that the six phases should be recognised as having a fluid order rather than a set rigidity. Both Braun and Clarke (2013) and Nind (2011) emphasised the importance of clarifying the *process* of the formation of themes. They proposed that the method of analysis should illuminate the processes worked through as well as considering their final outcomes, and as such this method lends itself to the expectations of inclusive research.

Once the first phases of thematic analysis were completed and the zig-zag motion that wove between the data collection process and its initial analysis with the pupils had come to an end, discussions followed regarding themes that had been raised with the pupils with my two doctoral supervisors. This led to the fourth and final session that included all the pupils who wanted to be involved in the final analysis stage (Table 1). The discussions that followed with a group of three of the original four pupils in the mainstream school and with Meg from the special school were also recorded, transcribed and analysed. In order to make the final analysis process more visual and interactive, the themes and sub-themes were provided on large pieces of paper with post-it notes that could be manipulated by the pupils if necessary (appendix 7). This was important, as the pupils had not wanted to read through the transcripts verbatim, although they were presented at the next interview after each one was transcribed. Instead they agreed to the on-going process of checking and drawing conclusions both independently and collaboratively through our discussions.

My position within this process was to respect the trust that the pupils, their parents and the staff within the schools placed on me that the stories shared that would be honoured and respected. My role was ‘to understand the world as it unfolds, be true to complexities and multiple perspectives as they emerge, and be balanced in reporting both confirming and disconfirming evidence with regard to any conclusions offered’ (Patton, 2015: 58). The initial gathering of voices, as recognised by Corbett (2007: 63), would only arise from an emotional climate of ‘trust, respect and sincerity, without which sounds from the margins can remain unheard or ridiculed as defective’. But the following participatory stages of analysis and narrative within this climate were of equal importance. I could not disconnect my role in this process, and nor should it have been necessary, although it was important for it to be acknowledged and to ensure I remained aware of my own limitations. With this in mind, Braun and Clarke (2013: 36) reminded qualitative researchers that 'we as researchers bring our own histories, values, assumptions, perspectives, politics and mannerisms into the research - and we cannot leave those at the door … in qualitative research, our humanness, our subjectivity, can be used as a research tool'.

Once the themes had been agreed upon with the pupils, the actual act of narrative and the situation of my own voice within this needed to be considered. A cautionary tale was provided by Drake (2010) when reflecting on her first attempt at considering data from stories gathered through formulaic analysis. On returning to her unfinished project several years later, she recognised that the results of not taking a reflexive stance had rendered her unable to position herself as storyteller through either the recordings or analysis. Her reflections on this outcome identified the error of placing herself as a scribe rather than an author, the outcome of which she believed diminished the text rather than enhanced it. This process of authorship was described by Braun and Clarke (2013) as an interweaving through the narrative between my story as a writer regarding the content and meaning of the data, providing descriptions and interpretations of the themes from the data provided, but also illustrated throughout by extracts from the transcripts which were used as examples of the points being made. They likened this process to the development of a patchwork quilt. The data was there in the form of fabric shapes, but the organisation of the shapes needed to be given due time and care if the final effect was to have the most positive outcome. This final phase before the writing process began was completed with my supervisors through looking at the themes that had been decided in collaboration with the pupils and seeking to avoid any potential overlap or confusion with regard to the presentation of the research. This resulted in the initial themes of anxiety, being 'normal', understanding and relationships, as seen in Appendix 6, becoming two chapters. Within the chapters entitled 'Perspectives of autism and the lived experience in education' and 'Understanding autism in education through developing better pupil/teacher relationships built on reciprocal communication' the four themes from Appendix 6 have been covered. The justification for narrative as the form of exchange for this process is provided below.

Narrative is a form of looking at meaning through what Patton (2015: 128) described as 'translucent windows'. The flow of each story is part of the process of making sense of individual communications within a social world, which can be further examined through narrative. Not only can narrative reproduce the experience of another, but it can also assist in providing structure and meaning for the individual with whom it is shared (Elliott, 2005). A particular strength is that the provision of narrative accounts from respondents can 'help to redress some of the power differentials inherent in the research enterprise and can also provide good evidence about the everyday lives of research subjects and the meanings they attach to their experiences' (Elliott, 2005: 17). Therefore as a method of knowledge exchange, narrative fits well with the expectations of inclusive research as proposed by Nind (2014).

In considering the difference between story and narrative, Patton (2015: 128) proposed that a distinction would be 'to treat the story as data and the narrative as analysis, which involves interpreting the story, placing it in context and comparing it with other stories'. A master of this was the writer Oliver Sacks who provided many wonderful descriptions of some of the people he worked with as a psychologist. His definition of narrative was that it formed an individual's on-going life story that was deliberately constructed to make sense of what is happening. Sacks (2007: 116-117) proposed that 'each of us constructs and lives a "narrative", and that this narrative is us, our identities … biologically, physiologically, we are not so different from each other; historically, as narratives - we are each of us unique'. His plea for other writers was 'to restore the human subject at the centre - the suffering afflicted, fighting, human subject - we must deepen a case history to a narrative or tale: only then do we have a "who" as well as a "what", a real person, a patient, in relation to disease - in relation to the physical' (Sacks, 2007: x). This resonates strongly with the theory behind Bronfenbrenner's *Bioecological Systems Theory* (1979, 2005) and his epiphany several years into its development when he recognised that his previously named *Ecological Systems Theory* had overlooked the presence of the person:

> With the sobering wisdom of hindsight, I find myself struck by what now appears as a glaring omission in this formulation. To the extent that the definition recognises other human beings as existing in the setting, it is solely in terms of their social roles and relationships: that is, they have no existence as persons possessing distinctive characteristics of temperament, personality, or systems of belief (Bronfenbrenner, 2005: 147).

Keeping the individual at the centre of the process also resonates strongly with Shakespeare's *Interactive Model of Disability* (2006, 2014) and his plea to seek the lived experience of disability by communicating directly with the individual rather than judging or forming opinions based on assumptions or stereotypes. The necessity for focusing on the 'human subject at the centre' (Sacks, 2007: 116) through all aspects of the research process was borne out in research by Seale (2010) whose research involved working with students with disabilities that impacted on aspects of their university learning. Having gathered their voices, the students were then involved in analysing the data and finally worked together towards creating materials that could be used by staff with the aim of reducing barriers to inclusion. What transpired through this process of sharing and analysis was that rather than wishing to be viewed as disabled persons, the students wanted to be able to express themselves as learners and to define the difficulties they might experience as 'functional difficulties' (Seale, 2010: 1009). This highlights the need to ensure that if the retelling of a story is to be as true to the subject(s) as possible, they need to be involved in the *whole* process and not only regarded as vessels from which to capture data. It emphasises again the need to ensure that the process of researching inclusively in this study remains true to the theory behind Shakespeare's *Interactive Model of Disability* and that of Bronfenbrenner's *Bioecological Systems Theory*, thereby avoiding assumptions being made through the formation of stereotypes or jumping to conclusions regarding specific utterances.

Being open to direction at every stage from those who are involved in research as partners is critical as caution is required when interpreting meaning. Seale *et al*. (2014: 351) highlighted this aspect and termed it 'the troubling of roles in inclusive research', thus drawing attention to the care that is necessary in decisions concerning 'who does what, whose voice is heard and who has the final say' (p.351). This was particularly important when taking care to respect the involvement of the pupils with autism in this project. Pring (2015: 13) proposed that the research process, from initial query all the way through to analysis stemmed from thinking philosophically which:

> often begins with puzzlement about what someone means. It requires further explanation, often where others find no grounds for puzzlement at all. Therefore, philosophy requires close attention to the meaning of what is said, seeing the different possible meanings, and probing more deeply the significance of those different meanings.

This resonates strongly with both Shakespeare and Bronfenbrenner who both stressed the need to probe meaning through seeking a deeper understanding of the individual thereby avoiding assumptions and judgments through respectful reciprocal communication. It highlights the need to explicate how all involved in this research are equal partners who are trying to make sense of their perspective regarding a specific concept: avoiding a prescriptive process, but instead enabling an unfolding through joint decisions when the need arises along the journey. Indeed, one of the concepts of inclusive research, expressed by Nind (2014: 56), was its flexibility in enabling academics to 'launch a project and allow this organic development for participation to grow'.

The final 'big tent' criteria yet to be addressed for this study are those of making a 'significant contribution' and the seeking of 'meaningful coherence' (Tracy and Hinrichs, 2017: 9). It is not possible to consider how significant this study's contribution might be until reaching the end of the writing, therefore this aspect will be returned to in the final chapter. However, meaningful coherence within qualitative research, which is described as 'the overall consistency, soundness and rationality of a study' (Tracy and Hinrichs, 2017: 9), can be examined here. Tracey and Hinrichs (2017) propose that this criterion for quality in qualitative research is achieved through linking the literature with the research questions; addressing the research questions through the use of appropriate methods; fitting the data with the literature and research questions; achieving the goals of the study in the analysis; and thereby speaking to issues identified by making connections within the study. Thus meaningfully coherent studies 'achieve their stated purpose, accomplish what they are about, use methods that partner appropriately with the espoused theories and paradigms, and connect current literature with the research foci, methods and findings' (Tracy and Hinrichs, 2017: 9). It is hoped that this has been achieved through the explanations within the previous sections, the connections that have been highlighted between this chapter and the literature examined in Chapter Two, and that the meaningful coherence of this study will continue through the chapters that follow.

3.5 Conclusion

This chapter has considered the methodology and process of inclusive research and how it connects to concepts raised within in the previous chapter. The methods therefore for gathering the data, analysing the findings and sharing the outcomes have been justified in line with ethical and methodological considerations and with the concepts of inclusive research. Particular emphasis has been placed on considering the quality of this study through the ‘big tent criteria’ (Tracy and Hinrichs, 2017) that provides a specific measure for qualitative research.

The next two chapters will consider the three main themes of perspective, understanding and relationships that were identified through thematic analysis. Reflections from the pupils’ primary school experiences will be synthesised with elements from literature that has been previously considered regarding the aspects of autism, the *Interactive Model of Disability* and the *Bioecological Systems Theory.* It is hoped that both of the themed chapters will advance conclusions that reinforce the research aim to highlight the need for the creation of a new model of autism to develop a better understanding between teachers and their autistic pupils.

Chapter 4 Perspectives of autism and the lived experience in education

This chapter considers how perspectives of autism affect both pupils and teachers, how this is connected to feelings of anxiety and 'being normal', which were themes identified by the pupils (Appendix 6), and how this might be perceived within the school environment.

Bronfenbrenner considered 'the *dyad*, or two-person system' (original emphasis, Bronfenbrenner, 1979: 5), as the innermost connection within the ecological schema. In a school environment dyadic exchanges between an individual and others within their microsystem are frequently occurring, and therefore will be a communication pattern that is often referred to. The focus of this chapter is the origin and impact of these exchanges, and the effect they have on perspectives of autism that are implicitly and explicitly shared through such communications. Data gathered from the pupil conversations suggested that the formation of patterns of behaviour and the development of positive or negative relationships seemed to originate from the reciprocal understanding gained from these interactions. Goffman's (1963) consideration of stigma and its effects will be widely drawn upon in the analysis within this chapter to emphasise the difference in perspective with regard to concepts of normality and difference, which will have an effect on the lived experience in education for the pupil with autism.

It is essential that the pupils' voices can be accessed in their entirety as can all other references within this thesis, therefore the complete interview transcripts with the pupils' verbatim responses have been appended (appendices 8-18). Where the speakers have referred to another participant, that participant's initial has been used. Names of friends or pets have been replaced by pseudonyms. A dash indicates a pause in the conversation, or where the comment trailed off at the end, and any additional information, for example with regard to tone of voice, is supplied in brackets. Within the excerpts taken from the transcripts for the following three chapters, ellipses have been used to indicate an abbreviated version of the original text. Quotations from the transcripts have been referenced as follows: the four interviews with Meg have been numbered M1 - M4; the three group interviews with the pupils at the mainstream secondary have been numbered as AC1, AC2 and AC4, and the speaker has been indicated at the start, for example E, AC4; the third set of interviews that were completed at the mainstream school individually with the pupils are referenced with the person who was interviewed followed by the number three. All references are completed with the page number that links to the appended transcript.

This chapter is divided into two sections. The first section will examine how dyadic exchanges between individuals can affect perceptions of difference and normality regarding autism. The second section will outline the decision by some pupils to 'act normal' through altering their responses at times in order to better fit in and be considered 'normal'. Throughout both sections, the impact that an *Interactive Bioecological Model of Autism* could have in developing perspective of both self and others and how such a perspective could relate to an individual's perceptions and experiences of difference and normality will be considered.

4.1 The effect of dyadic exchanges on perspectives of difference and normality within autism

> I don't know how they'll react to me, like some people will be fine, some people might think I'm weird but even if they don't show that I'm weird, I always panic that they think I'm weird (Esther, E3: 258).

This comment from Esther demonstrates the anxiety she experiences in most social situations. She was very aware during our discussions of how other people might perceive her, and their accuracy and reliability in reading her for who she was mattered to her. Esther was not the only one of the five pupils with a strong reaction to the perception of others. Experiences relating to difference and perceptions of autism were frequently referred to during the interviews; thus highlighting the possibility that what seemed to be lacking through many interactions, was the awareness that individuals interpret events differently (Bronfenbrenner, 2005; Shakespeare, 2014) and this is a natural outcome. A particular example of this was provided by Meg who regularly referred to her current special school as a 'problem school' (Meg, M1: 292), a term she used as an accurate descriptor rather than with any negative connotations, considering mainstream secondary schools as ‘normal’ (Meg, M1: 292). Here she recollected a pattern of interaction regarding detentions she received in response to the choices she made in responding to particular situations. She outlined some of the negative sequences of communication between herself and her teachers, explaining that the teachers’ reactions to her communications made her want ‘to be more naughty’ (Meg, M4: 316). The word she gave for her frequent response to these patterns of behaviour was that of ‘payback’ where she would do something else, that from her perspective righted the balance. She was well aware though that this was not the end; it simply resulted in the teachers ‘being angry … and then the end of the day, it just goes on and on’ (Meg, M4: 316). Her perception of the teachers’ reactions to her was that they were unfair. Rather than resolving the specific situation, it worsened as Meg’s response was:

> Then I would fight after - that’s what I mean. It wouldn’t be over after that, I would get angry still. It’s not over until I get my, until I get pay back (Meg, M3: 310).

This provides one example of the negative outcomes of entrenched perspectives where dyadic communications, in this case between pupil and teacher, evidence the formation of assumptions based on an individual’s perspective without seeking an understanding of the lived experience of the other (Shakespeare, 2014). It demonstrates what is missing when the process of dialogue is not engaged in (Messiou, 2019a) or where policy is adhered to with no consideration for its value and resonance with the individual (Alves *et al*., 2016; Dillon *et al.,* 2016). Meg viewed these experiences from the centre of her ecology; the dyadic communication between her and the teacher occurred because the teacher was situated within Meg’s microsystem. If Meg was able to envisage a reverse of the positions, with the teacher in the middle of his/her ecosystem, and with Meg situated in his/her microsystem, she might be able to see that a different perspective could be formed from the interaction. She might come to recognise that, as each individual is influenced by their own experiences, this will have an impact on their perspective of themselves and others.

In comparing this sequence of interactions with reflections on her new environment, Meg explained that although she still got angry, the response from the teachers was different:

> They’ve calmed me down. In that school they didn’t know how to calm me down, they’d just say I’d got a detention … I do get angry but what I mean is I copes more and it’s gone, where in my old school that would ruin the whole day (Meg, M3: 306).

This outcome may be because the special school environment provides a more fluid perspective on concepts of difference and normality. This possibility corresponds with Goffman's (1963) understanding of stigma, which he described as a social process which sets the individual apart from others as being different, 'less desirable … thus reduced in our minds from a whole and usual person to a tainted, discounted one' (Goffman, 1963: 12). The concept of stigma was introduced in section 2.2.3, but it is the outcome of a clash between an individual's virtual social identity, or 'the character we impute to the individual … an imputation made in potential retrospect' (Goffman, 1963: 12) with what is perceived as their actual social identity, one that is made up of 'the category and attributes he could in fact be proved to possess' (p.12) that is particularly pertinent here. Goffman stressed that it was not that all undesirable attributes were an issue, but only those that linked to an incongruity with stereotypes, or what he described as 'normative expectations' (Goffman, 1963: 12). Therefore the concept of stigma is more closely linked to 'a language of relationships not attributes' (Goffman, 1963: 13). The example of this that Goffman supplied concerned the information applicants might provide for a specific job. For some roles the choice would be made to conceal the lack of a college education; whilst other roles might require applicants who *had* received a college education to conceal *that* fact lest they get marked out as 'outsiders' (p.13). In relating this to the contrast between the teachers' reactions in Meg's two schools, the negative memories of her primary experiences focused heavily on Meg being forced into a mould that diminished the characteristics of what was perceived by others as her discrediting stigma. However, in her secondary special school, the teachers' communications with her were instead focused on diminishing her reactions to events that caused her discomfort. The potential for the latter outcome is clearly linked to the need to listen to the pupil, an aspect highlighted by Meg when she was asked what was different about her current school where this negative sequence was not occurring. Here she replied:

> I don't know … like the first ever thing to start detention and me getting angries was not letting stuff really get in my way when it actually helps me, like blu-tac. That would help me in lessons, *but they didn't listen* (author's emphasis, Meg, M4: 317).

The lack of listening that Meg experienced in her primary school could be attributed to teachers fearing a possible loss of control, as indicated in Fielding's research (2001, 2004). His proposal that 'radical collegiality' (2004: 296) could develop relationships between pupil and teacher might have positively influenced the situation for Meg who regarded her primary teachers' reactions to her 'naughtiness', as uncaring by letting her 'go in the trash' (Meg, M4: 316). She did not perceive herself as different from her peers and therefore felt no stigma or need for normalisation. Thus, she interpreted her primary school experiences through a perception that reinforced her beliefs that within that environment she had little or no value. This interpretation of self echoes research by Charmaz (2008) who considered the negative experiences regarding aspects of difference, suggesting the outcome for the individual was often that of 'disconnection, devaluation, discrimination and deprivation' (p.9). The situation for Meg and her teachers was not one that was fulfilling for either party and the implicit reference perceived by Meg was that if you 'had problems' you needed to be in 'a problem school' (Meg, M2: 302).

Alice also referred to negative interactions between herself and a particular teacher whilst in her final year at primary school. This teacher was part of a job share but although she only taught the class for two out of the five school days, her input had a serious negative impact that coloured many of Alice's primary school memories. She described this teacher as 'really horrible' (Alice, AC1: 220), and it seemed to Alice that after her autism diagnosis at the age of ten, the teacher's attitude to her worsened: 'before she knew, it was ok, and when she knew it just went terrible' (Alice, AC1: 223). This situation, which contributed to Alice's decision to become mute for several months, corresponds with the suggestion made by Lawson (2008) regarding how different environments or attitudes of others could have a direct impact on whether autism be considered a 'condition' or a 'disorder' (p.63). It was also emphasised in research by Davis and Watson (2001) regarding notions of normality and difference. Their findings suggested that children with disabilities were affected by 'subjective notions of essential difference' that were founded on 'judgments of cognitive, physical and social ability' (p.684). This echoes Shakespeare's view of disability as composed of 'the combination of a certain set of physical or mental attributes, in a particular physical environment, within a specified social relationship, played out within a broader cultural and political context' (2014: 78). It also emphasises the impact of perspective, thus highlighting the possibility of the erection of a barrier by an individual with negative and limiting views of disability (Sciutto *et al*., 2012; Shakespeare, 2018).

Teachers shouting created reactions experienced by all pupils of heightened anxiety. Other less obvious interactions tended to revolve around teachers misinterpreting an outcome such as the pupil's ability to do their work. Several pupils explained that if too much was occurring in the environment, this increased the pressure they felt and made concentration more difficult. The reaction of some teachers who then misinterpreted the lower than expected work output was explained by Esther: ‘sometimes they put me on the lower tables because they thought I struggled with the work, but really I was only struggling with the environment’ (Esther, AC1: 223). Another misinterpretation was recalled by Roger: ‘I got tasked with things that other people got tasked with - I sometimes found, found it hard to do - and then I would get in trouble for not doing the work, just because I didn’t understand it and they didn’t know that’ (Roger, AC1: 229). Alice explained another anxiety provoking occurrence concerning a teacher’s reaction to a misunderstood action: ‘like when I can’t help something and they don’t understand that I can’t help it … and I do it and they get angry with me’ (Alice, AC1: 229). Ben’s more outspoken and reactive reactions to teachers, which had often got him into trouble in his primary school, had begun to become more tempered now in his secondary school environment. He had realised that some responses might be better kept to himself, demonstrating a development that could assist him in avoiding misinterpretation, although this was dependent on his mood:

> I make people laugh sometimes, like the work’s boring and I know it, and the teachers know it, and yeah, I don’t say what I think in my head sometimes … If I’m in a happy mood I don’t say, but if I’m in a bad mood, I’ll say it (Ben, AC1: 226).

Many of the pupils’ experiences recounted here, demonstrate their awareness that their teachers’ perspectives of autism may have been formed from an ‘”outsider” looking-in stance’ (Harvey, 2018: 28). For example, the teachers’ views on the pupils’ work outputs could have been influenced by assumptions regarding the label of autism rather than considering the pupil’s actual cognitive ability. The danger with this, as proposed by Davis and Watson (2001: 684) is that:

> Once a child is considered to have a physical or sensory impairment other diagnosis of academic, cultural and social deficits are but a short step away. Judgments of ability are not value free because they are interlinked with the structural organisation of schools, and the beliefs and actions of different adults and children.

The pupils’ experiences also highlighted the possibility that such perspectives may have been based on views of normality that were founded in societal assumptions. These views then become reflected through the values of the institution, thus perpetuating and exonerating their existence (Goffman, 1963; Charmaz, 2008; Lai *et al.*, 2017). This was also a concept raised by Bronfenbrenner (1979) in proposing that although the understanding of individuals is directly influenced by dyadic connections with others within their microsystem, other aspects within their ecology will also have an impact. Therefore, there must be recognition that:

> Environmental events and conditions outside any immediate setting containing the person can have a profound influence on behaviour and development within that setting. Such external influences can, for example, play a critical role in defining the meaning of the immediate situation to the person (Bronfenbrenner, 1979: 18).

This correlates with the choice made by some autistic individuals to camouflage in certain environments in order to blend in (Hull *et al.*, 2017; Lai *et al.*, 2017; Bargiela, 2019). It also resonates with Lawson's (2008) suggestion that depending on the interaction and the environment, autism is sometimes experienced by those with the diagnosis as a disorder and at other times better described as a condition.

When the implication of perspective is considered through the medical and the social models of disability, and therefore through *The Interactive Model of Disability*, it can be recognised that one of the functions is that of serving the person with the disability whilst educating others. However, although developing greater knowledge has value regarding individual perspective, it may also result in re-emphasising considerations of the concept of normal by separating out the viewer from the viewed: of 'who is inscribed within and who is positioned outside of its circle' (Gallagher *et al.*, 2014: 1125). This is an aspect of marginalisation considered by Messiou who proposed that 'such conceptualisations though, focus on the assumption that there is a distinction to be made by others, amongst those inside and outside the margins, without giving sufficient emphasis to the subjective experiences of individuals' (Messiou, 2019a: 307).

By placing *The Bioecological Systems Theory* in the centre of *The Interactive Model of Disability* (diagram 3, p.57), a reminder is provided of wider considerations that need to be made regarding individual perspective. One individual's perspective will be experienced from their position within their central ring, thus affecting their communication with others who operate within that individual's microsystem. A very different perspective on the other hand will arise when the event is viewed from the other's perspective through reversing the positions of those involved. This is because of the process through which information is filtered between an individual's ecosystem, as well as the impact on such information through their responses to the social and medical models of disability. An

Interactive Bioecological Model of Autism clarifies the need for the consideration of wider factors on perspective that will have implications both on the pupils with autism and those who form relationships with them, including their teachers. The model reminds individuals that communications are both influenced by and have influence on other individuals, the wider society and the environment. It highlights the necessity, when considering interactions that occur within relationships, to look more deeply at their origins from both perspectives.

The experiences more often referred to by Ben, Esther, Alice and Roger focused on interactions with peers which were more explicitly based in perspective that related to concepts of normality and difference, rather than interactions with their teachers, as had been the case with Meg. Apart from Ben, all the pupils currently attending a mainstream secondary school had often and deliberately chosen to hide their identities, preferring to mask what they considered might be interpreted by others as autistic responses. Their reason was to avoid being negatively judged or perceived as 'weird'. Masking, camouflaging or 'acting normal' is a concept that will be discussed in more depth in the next section as a possible outcome from varying perspectives of the concepts of normality and difference. In considering this situation regarding peer interaction, the three pupils who took part in the final interview were asked if they felt it necessary that pupils should learn more about autism. Alice had already explained in an earlier interview that fellow pupils, rather than teachers, could be forgiven for their lack of understanding

> because they don't know enough about it. And they're kids to be honest. They don't know, they're not doctors or anything like that (Alice, 3: 251).

However, all pupils agreed that learning more about autism in a lesson or an assembly would help everyone. This result relates to research by Gallagher *et al.* (2014) in considering the potential negative outcomes of adults' beliefs regarding the highlighting of difference as inappropriate. Their research indicated that even when adults were not explicit with their pupils in considering difference, their attitudes were still communicated. This corresponds with earlier research by Cummings *et al.* (2006), which indicated that children of an early age were able to recognise difference. Thus it seems that through attempting to bury the concept of difference rather than openly and explicitly embracing it, an aura of secrecy or shame is developed. This resonates with Goffman's considerations over the 'control of identity information' and his proposal that 'the more time the individual spends with another the more chance the other will acquire discrediting information about him' (1963: 108). What seems to be implied by all five pupils involved in many of the discussions is that the outcome of their teachers trying to hide the *difference* of autism, however well intentioned, has forced some of them to mask their identities in order to be regarded normal. If instead, their peers and teachers were educated regarding the difference of autism alongside more general aspects of neurodiversity within a respectful culture that demonstrated such values through actions as well as values and policies (Booth and Ainscow, 2016), the pupils might be better accepted for who they are. As indicated in the research by Parsons et al. (2020), the process of engagement and participation from this could be valued by all participants. If this then led to a greater understanding and acceptance of difference combined with a focus on similarities between individuals, then pupils with autism might experience fewer communications based on assumption and stereotype, thus perpetuating the concept of a perceived normality. The process of education could provide the opportunity to better understand such difference in perspective so that all individuals might become more aware of the influences of the others' ecosystem.

4.2 'Acting Normal'

> I just act like how any other person would act. But it's just a front to hide what's inside (Roger, 3: 266).

Similarly to Roger's explanation above, the phrase 'putting on my best normal' (Hull *et al.*, 2017: 2519) was used by an adult with autism to explain the act of social camouflaging. This deliberate behaviour creates a distinction between the individual's 'true' or 'automatic behaviours' and what they present to others in their environment (Hull *et al*., 2017: 2525). It seems to be a strategy learnt during childhood and although not ideal, as implied in the quotation, with the alternative option being potential ridicule, the decision to camouflage is often regarded as the lesser of the two evils. Current research (Bargiela *et al*., 2016; Hull *et al*., 2017; Lai *et al*., 2017) seems to indicate that camouflaging is a more predominantly female autistic behaviour, however if the camouflage is too effective it may impact the accuracy of the sample as effective camouflage may result in non or mis-diagnosis as signs of autism are less likely to be spotted by families and professionals (Lai *et al*., 2017). Camouflaging, or 'acting normal' was often referred to by Alice, Esther and Roger in our discussions, with the reason for the choice explained by Esther:

> Esther: Well, when I'm out I would want to be more fun, sociable, but when I'm out I'm just kind of quiet, cos when every time I try to be, as I would see it, a 'normal' kind of fun, it doesn't work.
> Miriam: And what happens then?
> Esther: I get over excited and I think people don't like me and then I go home and regret it.
> Miriam: Yeah, so when you're 'acting normal' is it hard?
> Esther: Um, yeah.
> Miriam: And is it something that you wish you didn't have to do, or are you ok about it?
> Esther: Um, I wish I didn't *have* to do it obviously, but you know (trailing off).
> Miriam: And do you think you do it because you've learnt (E affirming) that you need to do it - you think you need to do it?
> Esther: Yeah, because otherwise people are gonna - laugh at me, people are gonna be like that cos you know (trailing off) (Esther, 3: 257-258).

Once the pupils had reached the second stage in their 'moral career' (Goffman, 1963: 45), and had become aware of a difference between them and their peers, personal decisions ensued: should they continue as someone who openly reacted differently; or change aspects of themselves in order to be perceived by their peers, as 'normal'? What followed might best be described as an on-going discomforting process as all of the pupils apart from Meg and Ben chose to try and fit in by discovering which responses to certain occurrences were different from those around them and then masking or hiding their initial reactions through a variety of methods.

Although the process of camouflaging, or the more generic term of masking, to a greater or lesser degree is widespread, Goffman (1963: 12) proposed that for some individuals it was likely to feel more necessary as their stigma highlighted 'a failing, a shortcoming, a handicap'. In these cases, the individual might choose to employ 'defensive and protective practices' in order to 'safeguard the impression fostered by an individual during his presence before others' (Goffman, 1959: 25), or in any way being considered discreditable. In reaching the second phase of their 'moral career' (Goffman, 1963: 45), and through considering themselves in the vulnerable position of being 'discreditable', the pupils with autism who chose to camouflage sought the 'protective practice' (Goffman, 1959: 25) of masking. Goffman explained such tension regarding social contact as resulting from on-going decisions regarding whether 'to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie, and in each case, to whom, how, when, and where' (1963: 57). Here, Goffman's contribution to an *Interactive Bioecological Model of Autism* is clear: understanding the lived experiences of people with autism means engaging with the lived experience of being discreditable. The standards set by the wider society provide feedback to the stigmatised individual as to whether or not their social group could accept them as an equal, or the possibility that instead the individual might run the risk of 'fall[ing] short of what he really ought to be' (Goffman, 1963: 18). This outcome directly correlates with the findings from Hull *et al*. (2017) that highlighted the respondents' awareness of the need to change in order to be accepted by others.

The process of information exchange across different ecosystems was considered in Chapter Two in relation to the impact it could have on one individual's interpretation of another (Bronfenbrenner, 2005). It was also highlighted through Kim's (2012) research into perceptions of autism across different cultures, and considered through Hall's (2014) research which proposed that the process of selection between those existing within the 'norm' group and those who better fitted in the 'other' group created a divide with the 'other' being considered inferior. The awareness of such a divide may have been the basis for Alice's explanation of why she would not highlight her difference to her peers: 'because they would treat me differently, or they would assume things, that's like not true' (Alice, 3: 251). She considered that other's perceptions of her were likely to negatively affect her. Indeed, Goffman (1963: 18) proposed that an awareness of the perception of inequality by the stigmatised individual was likely to result in shame 'arising from the individual's perception of one of his own attributes as being a defiling thing to possess, and one he can readily see himself not possessing'. This explanation might shed some light on the possible origins of camouflaging in certain social situations and demonstrate how it could become a useful tool that might diminish some of the anxiety experienced by Esther, as indicated in the quotation at the start of this chapter.

Esther was able to reflect on the fear that stemmed from interactions with peers in both her primary and secondary mainstream schools and her panic over being perceived by others as weird. She considered that other people would not understand her and therefore would be more likely to interpret her reactions negatively or as something that did not fit their perspective of what a 'normal' reaction might be. The potential anxiety of this for Esther meant that the reactions of others were constantly being calibrated in order to inform her as to whether it might be safe to trust the person with who she really was, thus becoming an actual anxiety. This behaviour was considered by Hull *et al*. (2017: 2527) who reported that successful camouflaging involved 'a constant mirroring of the situation, as if training oneself in self-monitoring, self-awareness and monitoring others' reactions both during and after the interaction had occurred'. These actions equate to the 'decoding capacity' outlined by Goffman (1963: 68) that he proposed needed to occur before the individual was able to decide how visible it was possible to be with the audience. The increase in Esther's anxiety is one that is recognised to be widely experienced as a result of camouflaging practices and acknowledged as a concern with regard to mental health (Hull *et al.*, 2017; Lai *et al.*, 2017, Eaton, 2019). Fortunately for Esther, her current option is that she can relocate to a specific room within her mainstream secondary school when her anxiety gets too much. This has provided her with the opportunity to compare the communications she has with others within that environment to those in the mainstream school. She was able to acknowledge that in the specific room there was no need to 'act normal', because 'I'm around everyone who is kind of different, like me, but when I'm in the main school I kind of feel the pressure to act normal because - I don't want to be laughed at' (Esther, 3: 257). Although Esther recognised that it was her choice to camouflage, she believed that 'you should be able to act the way you can - the way you do act in front of people, as long as it's not being mean or being horrible, I think you should act whoever - who you are' (Esther, AC2: 241). She was also aware of the cost to herself in making that choice recognising that she felt 'uncomfy and tired when I have to do that, and then I end a school day - I kind of think, well they really didn't get to see me' (Esther, 3: 260). The negative outcomes experienced by Esther, as a result of camouflaging, were also felt by many of the respondents in a study by Hull *et al*. (2017: 2528) which discovered that many people with autism 'wanted to be happy as they were, but felt that the pressures of the typical social world meant this was not possible'.

Roger was also aware of occasions when he masked his initial reactions despite being unhappy with that decision. He had attended two different primary schools, moving to his second at the age of ten, and it was his second primary school experience that provided him with a difference in the reactions he received from others. Rather than feeling anxious in lessons, as he had done previously, with teachers who responded to him in ways he found hard to understand, he felt liked by the teachers in his second primary school environment. He explained that there 'it was much better, every teacher loved me' (Roger, AC1: 221). This significant change in interaction between Roger and his teachers in the two primary schools has had a positive impact on Roger's self-esteem. What still remains a reason for his masking is spending time with people he does not know, where he fears that 'they'd probably make fun of me - I just feel that if I'm going to be myself then everyone will just stare at me' (Roger, 3: 269).

Alice was the pupil who initially mentioned the phrase 'acting normal' and seemed to be the one who chose to do it most often, stating that 'the only place I act myself is probably home - that's it, and when somebody comes round, I "act normal"' (Alice, AC2: 240). There was however one exception to this, which was her friendship with Sarah. When they were together, Alice was able to drop the mask but this level of trust had taken time: 'when I first met Sarah, I acted like everyone else, then I told her, and I still acted - I remember showing a video of what I did and then um then we just started being silly and now we're crazy with each other' (Alice, 3: 253). Being 'crazy' seemed to be an outward response to something that Alice believed needed to be kept hidden, as when asked what it was that she did when she was not with other people, her response was 'act crazy' (Alice, 3: 251). However, she like Esther was aware of the process she had learnt of learning to mask, but also the negative consequences experienced from such a choice:

> Miriam: Is it hard to have to act normal?
> Alice: Mmm, not any more.
> Miriam: So it's getting easier?
> Alice: Well, not really. It's because I know how to act normal.
> Miriam: Yeah, so how do you learn to act normal?
> Alice: Err, copying other people.
> Miriam: Are you happy doing that, or would you rather you didn't?
> Alice: Mmm, sometimes - sometimes I want to be myself but sometimes I don't, but sometimes, in here, I'm myself - (trailing off).
> Miriam: So it's when you are with other people who just accept you for who you are - then you can be normal - yes? (A affirming) Great. And is it tiring then when you have to not be like that, when you have to try and remember to be someone else?
> Alice: Mmm, - well - I don't mind any more - but I would want to be myself.
> Miriam: If you could choose?
> Alice: Yeah - and then they won't stare at me. Because if I did just go in the corridor and start being crazy, I think everyone would stare at me (Alice, 3: 252).

All pupils who chose to mask were aware of the increased anxiety levels that occurred in deciphering situations and communications in order to recognise when it was acceptable to react spontaneously and when it was safer to mask reactions and copy perceived 'normal' responses. The necessity for such caution by the autistic person could explain why a greater anxiety is experienced around people whose behaviour is more erratic, as this is likely to necessitate a higher level of alertness in order to be able to respond in a way that is deemed appropriate and safe at the time (this is considered in more depth in section 5.1). Indeed, reports from both clinical observations and autobiographical descriptions by Lai *et al*. (2017: 691) often suggested that ‘camouflaging unfortunately comes at a cost: it often requires substantial cognitive effort, can be exhausting and may lead to increased stress responses, meltdown due to social overload, anxiety and depression, and even a negative impact on the development of one’s identity’. This is particularly important to be considered within a school context, as this is the environment where children will spend most of their waking hours and therefore experience most of their social interactions (Hebron *et al*., 2015).

A final complication of camouflaging or masking certain responses to be considered here is that it requires certain individuals to be able to see through it at times; it is not necessarily wished by the individual who is employing this behaviour to be interpreted by all in the same way. Research by Dean *et al*. (2017) into gender different social behaviours demonstrated that the social challenges of boys during play were more obvious than those of girls. This highlights the negative outcome of effective camouflage as their observations indicated that ‘from the perspective of untrained observers, such as recess aides and many teachers, male social groups were as conducive to exposing the social challenges of boys, as female groups were to camouflaging girls’ social challenges’ (Dean *et al*., 2017: 685). This potential outcome also emphasises the significance in differentiating between what constitutes participation and what constitutes social inclusion. As proposed by Alves *et al*. (2012: 161), a limitation of participation as a performance qualifier in the biospsychosocial model is that although it ‘could be used to capture the individual perspective on any given activity or participation … this would still not include the notion of equal opportunity, which is vital to the concept of social inclusion’. The act of participation rather than the experience of social inclusion can be masked through effective camouflage, and although able to deceive many adults, the research by Dean *et al*. (2017) indicated this deception did not extend to peers.

Alice provided an example of masking at school through copying the reactions of others that occurred during the movement of people between lessons. She stated that ‘if it was busy and I didn’t like it, I would act like it’s fine’ (Alice, AC1: 227). This deliberately chosen action normalised Alice with her peers, whom she perceived as having no anxieties regarding this situation, but simultaneously clashed with her internal feelings of anxiety which required an understanding individual to appreciate and come to her aid. The advice she wished to be passed on to other teachers reflected this when she explained the need for them to recognise that sometimes pupils with autism ‘might seem ok - when they're not’ (Alice, AC4: 277). The personal choices made regarding the potential perceptions of others were also outlined by Roger who reflected that ‘sometimes I mean when I’m round people that I know - and it’s just them, I feel like I can relax and be how I am normally, but when I’m in a crowd of people I don’t know - because I want to be someone I’m not, and I don’t like that’ (Roger, AC2: 240). The outcome of masking or camouflaging demonstrates the importance of teachers looking beyond what is visible on the outside and entering into constructive dialogue with the pupil in order to gain their perspective of the pupil’s lived experience with autism (Scuitto *et al.,* 2012; Shakespeare, 2014; Messiou, 2019a; Messiou, 2019b). It also resonates strongly with Bronfenbrenner’s definition of the microsystem including the critical term *experienced*: a term deliberately chosen to indicate that ‘the scientifically relevant features of any environment include not only its objective properties but also the way in which these properties are perceived by the persons in that environment’ (Bronfenbrenner, 1979: 22).

Meg and Ben were the two pupils who did not choose to try and mask their autism by ‘acting normal’. They were also the two pupils who had a more reactive and physical response to others in their primary school when they felt misunderstood. This may correlate with the consideration provided by Goffman (1969) relating to an interaction within the presence of others where there is potential for discredit: rather than feeling shame leading to the ‘protective practice’ (Goffman, 1959: 25) of masking identity, they chose a ‘defensive practice’ (p.25). For a variety of reasons that will be discussed within the next chapter, Meg did not feel the need to ‘act normal’. Similarly, Ben’s advice to others with autism was to ‘be yourself, don’t like - be like the sad one because you have autism, it’s like fine to have it, ‘cos other people around the world and around the school probably have it’ (Ben, AC1: 233). However, it was interesting to note that although this may have been what he wished was possible, he was also very cautious about who he told about his autism, giving the explanation that it was better to ‘keep it in’ (Ben, AC2: 239). These two different types of reactions from the pupils to their autism when within social situations correspond with the suggestion by Hull *et al.* (2017: 2529) that masking is related to ‘the motivations of fitting in and forming connections respectively’. This finding correlates with the fact that both Ben and Meg who did not camouflage their identities through masking, seemed more confident with who they were as individuals and appeared to feel less of a need to fit in in comparison to Esther, Alice and Roger. Rather than demonstrate the impact of another's perspective that was deemed unfair or inaccurate by reacting defensively as Ben and Meg chose to, Roger, Alice and Esther internalised their reactions and proceeded to try and adapt themselves to fit in.

For most individuals, the trajectory of their 'moral career' (Goffman, 1963: 45) will move them through a growing awareness of normality in phase one, to a consideration of their individual differences from others in phase two by identifying characteristics they themselves hold that do not match those of their peers. Instead of these being minor or perhaps more fleeting concepts of difference as experienced by all individuals, it would seem that pupils with autism become aware that it is their experience of life and their reactions to these experiences that do not match their growing awareness of the experiences of others. Therefore, if characteristics of autism are not spotted before the onset of phase two, the choice to mask or camouflage can result in a diagnosis being overlooked (Hull *et al*., 2017; Lai *et al*., 2017). The complication is to work out when masking starts and at what point people start to create their 'virtual identities' (Goffman, 1963: 11) through forming perceptions of others and categorising individuals with whom they come into contact.

Without valuing the impact of the bi-directional flow of information across an ecosystem, communication patterns that form from repeated interactions founded on misinterpretation through a lack of understanding are likely to cause all social actors anxiety and confusion. Not only did some respondents to the research by Hull *et al*. (2017) state that their camouflaging was causing them to lose a sense of their true identity, there were others who felt that they were being deceptive in their relationships with the result that the relationship itself was false. This resonates with the proposal by Alves *et al*. (2010) that participation in an activity is not necessarily the same as social inclusion. This is all the more likely when knowledge of the individual with autism is limited to a more generic consideration of information about difference and normality that stems from the social and medical models of disability. The danger of only considering and valuing characteristics that could be diagnosed without 'evaluating the circumstances around autistic experience' was highlighted by Wolfond (2008: 118). For example, an inaccurate perception of Meg caused her teachers to react to some of her responses in a way that Meg considered unfair.

For Alice, it highlighted the difference in perspective between the two teachers that she experienced in her final year of primary school. For two days every week, despite being in the same environment with the same peers, a particular teacher had a greater negative impact on her autism and on her ensuing communication.

By failing to investigate the origins of perspective, much useful information is never discovered, resulting in interpretations often based within the limited framework of a diagnosis (Sciutto *et al.,* 2012; Milton and Bracher, 2013). Such a limitation was emphasised in research by Gallagher *et al*. (2014) into lay perceptions of the difference of autism, which led them to conclude that the best question to ask regarding difference was 'how do those differences come to make a difference as a consequence of the way others interpret and subsequently respond to them' (p.1124). This re-emphasises the value of interpreting autism through *The Interactive Model of Disability*, rather than restricting the view to the dichotomy between the social or the medical model, or overlooking the impact of the bi-directional flow of information within a person's ecosystem. Challenge at this fundamental level is particularly important when research indicates that adult conceptions of difference and normality can be passed sub-consciously through actions and reactions to the next generation (Cummings *et al*., 2006). Whatever the origins are of limiting perspective, the result is a situation that limits openness to possibility and growth - to the opportunity of 'letting a thousand flowers bloom' (Shakespeare, 2018: 163).

4.3 Conclusion

An *Interactive Bioecological Model of Autism* demonstrates in theory that there is much that will impact on the origins of interactions and that perspectives of autism do not always equate to the lived experience. Considering autism through the model sheds more light on why masking or camouflaging behaviours may occur in order to protect an individual's fragile sense of self (Hull *et al*., 2017, Lai *et al*., 2017) and highlights that performance for every human being is 'a delicate, fragile thing that can be shattered by very minor mishaps' (Goffman, 1959: 63).

As the ecological rings from Bronfenbrenner's (1979; 2005) *Bioecological Systems Theory* illustrate, the individual's perspective from the centre of their ecology is both affected by and has an effect on the bi-directional flow of information between the different ecosystems and on which microsystem level interactions will be most greatly influenced. Added to this is the impact of the individual's considerations of autism through the medical or social model of disability, both on their view of themselves and their perceptions of others. The need therefore to develop understanding not just of the perceived difference of autism, but of the individual's experience of it, whilst at the same time remaining aware and respectful of differing perspectives, is vital for effective communication. How to assist the perspective of both autistic pupil and their teacher through seeking reciprocal understanding in order to develop a better relationship is the focus of the next chapter.

Chapter 5 Developing understanding relationships in education through reciprocal communication

The word 'understanding' was frequently mentioned throughout the pupil interviews. It was identified as one of the main themes by the pupils and connected with that of relationships (Appendix 6). They wished that their teachers understood them better, as was highlighted in the NAS (2016) survey, but also that their peers better understood them, and that they better understood themselves. They sought that is, both the understanding of others and better self-understanding. This chapter will propose that in order to develop a better relationship with another, it needs to be founded on understanding that is developed through reciprocal communication and situated within an awareness of individual ecology and the acceptance of different perspectives. It is important to remind the reader here that this research did not involve any direct communication with any of the teachers; therefore the views of the relationship that are represented in this thesis are only those of the pupils.

The first section will consider the reciprocal process involved in understanding another before turning in the second section to look at the impact this has on the understanding of oneself. The final section will combine these two elements and connect them with the previous chapter's consideration of perspective to focus on the teacher/pupil relationship. Throughout all the sections, the pupils' voices will be interwoven with Shakespeare's *Interactive Model of Disability* and Bronfenbrenner's *Bioecological Systems Theory*. In so doing, the chapter will highlight the potential value of an *Interactive Bioecological Model of Autism* in its capacity for demonstrating the need for, and the possibilities of, developing a more proactive and functional two-way process of communication within education to develop understanding of autism.

5.1 The reciprocal process of understanding others

> So being with people with autism, you all understand each other, like in a certain kind of way. So it makes it easier just to be yourself I guess with everyone. Um, but if like you're with people who don't have autism, they don't fully understand you (Esther, AC2: 240).

These words spoken by Esther, shed some light on her perception that it is easier to 'be yourself' with similar people who understand you, and is a concept echoed in many communities (Goffman, 1963; Solomon, 2013). The situation however for the majority of pupils with autism is that often the community they find themselves having to interact within is largely alien to them, thus exacerbating their difference and thereby increasing their anxiety (Lawson, 2008). This is particularly the case in early stages of communication and the formation of relationships with others, outside of the family at school (Williams, 1992; Sainsbury, 2000; Robison, 2007). Esther's words above suggest how vital the teacher's role is in being able to develop confidence for the pupil in this area, through the interactions that occur in this different environment. Many incidents were recalled by the pupils of occasions where they believed others had misunderstood and misinterpreted them. This may have originated from that individual's perspective of autism, as considered in the previous chapter, or in a lack of mutual understanding between themselves and their peers or teachers. The result of this outcome for the pupils with autism was often a mixture of sadness and confusion or anger and aggression.

Meg's recollections of relationships with her primary school teachers demonstrate a series of negative interactions. These often created a negative downward spiral stemming from her reaction to a lack of understanding from a teacher, which was followed by a detention founded in an equal lack of understanding. As she explained: 'in that school, they didn't know how to calm me down, they'd just say I'd got a detention' (Meg, 3: 306). She considered that the teachers' responses in her mainstream primary education, in comparison to her new setting of the secondary special school, had been based on a lack of understanding, recollecting that:

> In my old school they don't - they don't really understand what I'm like and why this has happened. They would, like if they just noticed a girl being really naughty you'd probably think "she's being really naughty - that's an un-nice girl - being really naughty over there". And even if you tell them, they don't understand - what that girl is actually got, and in this school they do. I don't even has to tell them - I got problems. They all know - I've got something wrong with me (Meg, 4: 317).

This demonstrates Meg's awareness that it was her responses that were being acted upon by the teachers in her primary school, rather than seeking to understand their origins. If a deeper understanding had been sought for Meg's 'naughtiness' it might have provided both parties with the opportunity to view what they were experiencing from the other's perspective. The result of neglecting this was that the negative spiral of actions and reactions continued which, as Meg stated would often 'ruin the whole day' (Meg, 3: 304). When Meg was asked whether she thought her primary teachers had been unfair in their reaction to her, she responded: 'hmmm no not really - I don't know, but they didn't really understand did they?' (Meg, 3: 306). In comparing her primary experiences to her current situation in her special secondary school, she explained that now these teachers are different: 'they understand when you're angry' (Meg, 2: 302). Although Meg recognised that she still got angry in her new school, she was now able to appreciate that she was helped to cope with the outcomes she experienced from the emotion. When asked if she could explain why these teachers were different, she attributed their more enlightened responses towards her to the fact that 'they've got teached - how to understand - cos there's all different problems - like when they get angry - you need to learn how to cope and that when they get there' (Meg, 3: 308). Having teachers who are better able to understand her has had major and positive implications on her perceptions of her current school and on her perspective of her previous one:

> I don't get as angry as in that school. In that school I was really naughty. In this school I don't ever, hardly ever get angry really … because really all it was, was that I didn't really like it (Meg, 3: 306).

Meg also often mentioned in our discussions having to 'beg' and 'fight' for things in her primary school, which if they were taken away from her added an even greater sense of injustice:

> You'd like fight for stuff and then they'd take it away from you and then you'd have to fight again, so it was lots of fighting. All the time. Which also affected me getting angry. So I might be angry just because of something, because I just know there's been fighting going on to get something (Meg, 3: 308).

The greatest injustice recalled by Meg was when the school removed her one-to-one in Year Four, which she considered her only support. When asked if there were other things apart from her one-to-one that the school did that helped her, she replied:

> No, not really. Cos, cos they done that before, moving up to Year Four, and I had a terrible life and then in Year Five they had to put a like different one-to-one back,

> cos, cos, cos that was one of the worst years what I've had cos of that situation (Meg, 2: 299).

The relationship she had with her one-to-one was mainly recalled with happy memories. In general, Meg appreciated the understanding and assistance this person provided with her work. However, the negative outcome she experienced as a by-product of understanding being pivotal on one person was that her relationships with the other staff did not often seem to develop positively. Meg felt the need to defend herself from being forced to fit into a system that struggled with individuality. This included relationships with her primary school teachers who appeared to Meg as having an inability to accept her for who she was, and recognise her autism as an integral aspect of her individuality.

Meg's recollections of the relationships she had with friends in her primary school were positive, as has already been mentioned in the previous chapter. In her new environment at the special secondary school, she once again quickly made new friends. Her response to the question 'so why do you think you've got more friends here?' was to explain 'well, I did have different friends in my other school, but - these friends are more like me - a little bit more' (Meg, 2: 302). However, when asked whether it was because more of her new friends had autism that they might be able to better understand her, she replied: 'it don't make its different, because my friends are kinder in my old school, which also gives me a clue that they might have problems too which is why I think they should have changed that school into a problem school' (Meg, 3: 310). Meg seems to be implying here that kind friends were likely to be ones similar to her 'with problems'. Forming friendships did not seem as difficult for her as it had been for the other four pupils. How much this was the result of her acceptance of who she was, or her friends' acceptance of who she was is impossible to ascertain, but the result for her was a confidence in forming relationships with her peers.

Similarly to Meg, Ben also tended to react more instantly and physically to others' misunderstandings of him. Advice to the other three pupils involved in the group interviews regarding troubling experiences within relationships was periodically given, with suggestions like 'you should have punched him in the face' (Ben, AC1: 227). Ben, like Meg had also not felt the need to 'act normal' and was generally confidant in considering how others perceived him. This was differentiated though between his relative ease in time spent with those he knew, and the discomfort of being with people who were unknown entities. An example he provided of this was that:

> So, if I'm in a lesson - and I know most people, so I don't normally feel really anxious before, and I think "oh I know loads of people and I'll just join in the conversation" and I know it's like easy and that, if there's loads of people chatting around me. But when it's like going into London, with people that I really do not know, it's a bit weird, confusing. Like, what are they on about? I don't know these people (Ben, 3: 261).

Ben also recalled a particular memory from previous peer relationships where he has now become more aware of the vulnerability of his younger self. His explanation of this situation, which he linked to his autism, was that:

> What I struggle with autism is like when people tell me to do stuff and I do it, and sometimes it kind of doesn't work so, so when they tell me to do something naughty and I do it, I get in trouble, which I can't blame it on the other person, because I done it instead of them done it, so I can't really say, "euhhh I got dared" because teachers wouldn't really like it, like "oh well don't blame it on other people for your own actions", so that's why I kind of find really hard cos I know, I listen to people and I do it, which I know I shouldn't and I still do it, but I don't know why (Ben, AC1: 230).

This response indicated a growing awareness of a previous area of difficulty but also an on-going lack of understanding regarding some of his reactions, a situation he continues to find difficult to deal with. Although not feeling the need to hide his autism by masking or camouflaging, Ben had decided that apart from his one ally in junior school, the safest option was not to tell peers about his autism, despite receiving his diagnosis before starting primary school. The reasoning behind Ben's caution over personal revelation was proposed by Goffman (1963: 108) who suggested that 'control of identity information has a special bearing on relationships'. Indeed, Goffman (1963) might have labelled this friend of Ben's as 'wise'. Such a descriptor was given to individuals 'before whom the individual with a fault need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as an ordinary other' (p.41).

Alice, Esther and Roger on the other hand chose to retreat when relationships were confusing, rather than confront, as was the modus operandi of Meg and Ben. This vulnerability experienced from the requirement to understand others, resulted in new relationships being cautiously approached for fear of rejection or worse. Roger outlined his hesitancy in this area by explaining that 'with people who I don't know, it's just difficult to tell if they're friend or foe' (Roger, 3: 268). The difficulty in reading and understanding another's intentions was one that caused many of the pupils considerable anxiety. Discussions around this topic revealed that discovering how to socially communicate with others had been learned the hard way. The conclusion drawn by all the pupils was that people on the whole were unpredictable, which thereby tended for most to heighten their anxiety around individuals that were disliked and/or unknown. They explained that careful navigation at the start of a relationship was therefore necessary to protect their own vulnerability, as many previous negative experiences had highlighted the prospect of relationships as a potential minefield. Their memories from primary school correspond with other accounts from autistic adults regarding the complications of forming and maintaining relationships, which often resulted in the realisation that a trusting relationship for someone with autism was hard to find (see Williams, 1992; Sainsbury, 2000; Robison, 2007). The pupils' journeys through their primary mainstream education had surrounded them with a host of potential peer relationships, and as their choices took them down a variety of different pathways, so their aspirations and fears for what was possible in future relationships began to be shaped.

Alice had experienced great difficulties in forming relationships with her peers during her primary education. A lack of recognition as to what is acceptable in a relationship can create a sea of misunderstandings, and a frequent anxiety that Alice experienced, similarly to Ben, was the concern over how to respond to another's demands. Her anxiety and vulnerability had made her a target and she recalled being forced by another pupil into a relationship she did not want and from which she was only released when the other pupil moved to a different location. Alice's protective practice rather than Ben's defensive practice (Goffman, 1959) and more speedy resolution, resulted in an unhealthy relationship with a peer that continued for several years. When she was questioned about the potential usefulness of talking to an adult regarding some of the problems in the relationships she had had with other pupils, even this seemed problematic:

> I don't want to keep telling too. If it keeps happening I will tell my parents once. If I don't do anything about it, they'll tell the teacher and I just won't tell them - until it gets to a serious stage (Alice, AC4: 284).

This situation for Alice may have arisen because of her previous experiences with adult relationships in primary school that taught her to have little faith in teachers.

Esther, who had received her diagnosis at the age of three, and by the age of ten had a one-to-one Learning Support Assistant (LSA) and a therapy dog in school because of her epilepsy and anxiety, was able to contrast the understanding she received from her LSA to that of the teachers. Her LSA, who also experienced extreme anxiety, and therefore Esther believed had a greater understanding of her, 'just got how I worked kind of, how I thought and how I learnt' (Esther, AC1: 220). This understanding was compared to that of other teachers who 'would try and teach me in a way that didn't work for me' (Esther, AC1: 220). However, in a similar magnanimous response to Meg's, Esther reflected that she did not perceive the teachers as 'mean', as had been described by Alice, it was that 'they just didn't understand' (Esther, AC1: 220). When asked if the opportunity had ever been taken by the teachers to find out from her directly, Esther's reply was: 'umm not - not the teachers … I think it would have helped but they were quite busy as well' (Esther, 3: 256).

Esther was the only pupil participant who on transfer to mainstream secondary education had the opportunity to attend a specific room when her anxiety levels got too high in the mainstream school. Here she felt able to form relationships with other pupils who experienced similar anxieties, as well as being able to relax and be herself. In this environment, she was surrounded by 'sympathetic others' (Goffman, 1963: 31). However, elsewhere in the mainstream school Esther found the navigation of relationships much more complicated. Fears of being thought 'weird', of being misunderstood and laughed at were high and added to the anxiety she experienced from other factors within her environment. Her descriptor of a friend was someone who 'would keep secrets they're always supportive of you' (Esther, AC4: 273). This need for trust in a relationship, for the keeping of secrets, was one that was mentioned many times by several of the pupils. From this and other discussions with Esther, her comment about keeping secrets could also imply that she considered her autism as something negative. This would add further explanation regarding her choice in certain social situations and within some relationships, to mask aspects of her identity. Without her mask she was aware that if peers were considering forming a relationship with her, she would be more likely to be misunderstood. Time to develop an understanding of who she was, and not to jump to conclusions in how she was perceived was another aspect within a relationship that Esther wished for. In the comfort she received from adhering closely to rules, she believed that for others 'to make a snap judgment on something that you don't really know much about, it's not really - fair' (Esther, 3: 259). Esther accepted that at times inaccurate perceptions of her by others were likely to stem from a lack of knowledge. She believed that judgments made by peers were often based on their perceptions of normality: ‘because they can see what we’re doing and it doesn’t fit their social kind of - what everyone else is doing … if everyone else is doing what you are doing that would be normal, if no one else is doing what you’re doing that’s not normal’ (Esther, AC4: 275). When asked whether she thought the basis for this awareness of normality was the media, Esther answered ‘I think it has to do with people around them, so their environment’ (Esther, AC4: 275). This response demonstrates the onus on adults within school who have more responsibility over the creation and culture of the environment within the classroom and the activities taking place, to demonstrate effective relationships.

Listening, as part of communication, was highlighted as a vital component in the process of understanding, and resonates strongly with Messiou’s concept of the mutually beneficial process of dialogue (2019a). Most pupils responded to questions about their primary school experiences with teachers as lacking opportunities to listen. In comparing the two different primary schools that Roger had attended, his instant response to the question ‘so what did they do that was really good in the second school?’ was that ‘they listened to me’ (Roger, AC1: 224). Ben had a similar recollection, stating that the best teachers at his primary school ‘would sit down and talk to me more and say if I have any issues then come to talk to me and that’ (Ben, AC1: 224). By talking things through together it may have been that these teachers would have understood that some of Ben’s anxieties and struggles centred on his difficulties concentrating in certain environments. He may have been able to communicate to his teachers that ‘they could have made my life a lot easier instead of like putting like more pressure on me than I already had’ (Ben, AC1: 222). Esther proposed that a step towards a better relationship and one that led on from the listening was that of creating a connection between individuals, finding factors that could deepen the relationship through similarities that could be shared. This had a powerful and positive outcome as she explained:

> Because when teachers can relate to you, you feel more comfortable around them, and - and they have understanding. They can help you teach - teach you in a better way (Esther, 3: 256).

However, many of the teachers’ responses recalled by the pupils seemed to be based on assumptions thus stereotyping those with autism into one homogenous group, rather than seeking knowledge directly from the pupil that would develop a better understanding. For some of the primary teachers the five pupils had experienced, opportunities had been missed in developing a better reciprocal understanding in order to be able to make the necessary adaptations for their learning that may have made a difference. For example, when Esther was asked what she would have told her teachers if they had talked to her about her autism, her reply was:

> Well, I would have told them that the classroom gets really loud and that if you set me a lot of work in a very loud classroom, I won't get it all done - It's not that I wasn't focused all the time, it was just because of the environment - Yeah, I didn't struggle with the work, I struggled with the environment (Esther, 3: 256).

Her response to becoming over stimulated by her environment was to shut down or on extreme occasions, run away. Both of these outcomes might have been avoided if opportunities had been taken for sharing information. A limitation of this research is that without talking directly to the teachers, it is only possible to interpret their responses to the pupils through the memory and experiences of the pupils themselves. However, from the pupils' recollections, it seems that if information were sought by the teachers about how autism might affect an individual, it was not sought from the individual themselves. The outcome of this limitation was highlighted by Ainscow's (2005) research into the collegial process of developing inclusive education systems where his results demonstrated the connections between 'social learning processes' (p.113) and people's actions and thinking. It also links to Messiou's suggestion that 'inclusion and student voice are interconnected ideas, inclusion referring to the presence, participation and achievement of all learners … listening to children's voices is a manifestation of being inclusive' (2019b: 769). Both these authors demonstrate the need for teachers to nurture a reciprocal form of communication between themselves and the pupil with autism if understanding is to be based on knowledge that is focused on the individual rather than founded in a perspective that is based on assumption or stereotype.

In considering how understanding between pupils with autism and their teacher can be developed, it is worth considering here the use of information from a diagnosis. All the pupils who were interviewed had received a diagnosis of autism either before starting their primary school or during their time there. Without talking to the parents, the reason for seeking the diagnosis remained unknown, apart from some insight through Alice's recollections. Her explanation was that her parents sought a diagnosis because 'they just wanted the paperwork … to help me in primary school' (Alice, 3: 249). This hope for better help once a medical diagnosis had been procured has resonance with the reasoning presented in Bailey's (1998) reflection on his case study of Billy Gates. Here Bailey highlighted the vital role of Billy's diagnosis, both for Billy, his mother, and in being able to add to the understanding of others who were situated within his microsystem. It can also be related to the positive response to diagnosis mentioned by some writers in *The Spectrum* (see Siobhan, 2018 and Andrew, 2019) regarding its use in developing their own understanding and acceptance of who they were as well as in being able to help others to understand them better. However, the reaction of others to the individual with the diagnosis once it is divulged is dependent on how the information is interpreted. This will be affected by preconceived ideas of disability and difference that have already formed from previous information that has been filtered between the individual's ecosystem.

Although the emphasis on understanding is through dyadic communication with others in the individual's microsystem, Gallagher *et al*. (2014) highlighted the necessity to remain aware that interpretations will have been subjected to an individual's specific set of values and beliefs, and that these will have been impacted over the course of a lifetime from a variety of different sources. Bronfenbrenner also proposed further reaching effects from this most basic and fundamental interaction, suggesting that:

> The ecological environment is conceived as extending far beyond the immediate situation directly affecting the developing person – the objects to which he responds or the people with whom he interacts on a face-to-face basis. Regarded as of equal importance are connections between other persons present in the setting, the nature of these links, and their direct influence on the developing person through their effect on those who deal with him first hand (Bronfenbrenner, 1979: 7).

It is possible that in educational establishments, a diagnosis and resulting label of autism, which corresponds with information from the medical model, may have given some teachers a false belief that they understand the pupil in their entirety. Some teachers may have assumed that they need only to absorb information on the diagnosed condition to suffice. This potential limitation was highlighted by Shakespeare (2014) in proposing that 'there is undoubtedly the tendency for "identity spread" or "diagnostic overshadowing", whereby the diagnosis becomes the most important thing, and the individuality of the child or adult is ignored or lost' (p.58). A further danger with such an assumption is that once medical information from the diagnosis had been considered it might lead to a focus on seeking 'the solution', aiming to minimise the various deficits from the diagnosis by considering the pupil with autism through the social model of disability. This suggests that a model of autism is needed that would emphasise the value of developing knowledge and understanding of the individual through various sources, including the medical and social models of disability, rather than being dependent on one type of knowledge alone.

A key aspect of *Bronfenbrenner's Bioecological Systems Theory* (Bronfenbrenner, 2005) is its emphasis on mutuality, highlighting the need for information exchange to occur through a two-way process and emphasising the equal importance of one participant in this process to the other. For example, in returning to Esther's comment at the start of this section, it would seem that the individual with autism needs to seek information about those existing within their microsystem who do not have autism but with whom they have a relationship in order to better understand their perspective. The other individual in the relationship would be likewise reminded that they too could be misunderstood by the autistic individual to the detriment of the relationship if they were not prepared to both seek and share information with those operating within their microsystem. If the positive outcome from a bi-directional flow of information is recognised, this then can provide the potential for the development of a mutual understanding to deepen a relationship established through reciprocal communication. As mentioned in Chapter Two, Bronfenbrenner (1979) stressed that dyadic communications have an effect on the development of both parties. Examples of this were apparent in talking with the pupils who provided examples demonstrating exchanges between themselves and their teachers. The depth of understanding these communications indicated linked directly to the amount of anxiety the pupil experienced within the relationship. The teachers who gave them time to talk and listened to what they had to say were the ones with whom the pupils felt the most comfortable: the teachers who misunderstood the pupils and reacted in ways that were considered unreasonable were the ones they wished to avoid being in the company of. A positive dyadic exchange would result in a process of mutual understanding where it was not that one individual had a greater need for it than the other, but that in seeking to develop a better understanding, there would be recognition of equal value: 'what A does influences B and vice versa' (Bronfenbrenner, 1979: 57). Without accepting the need for mutuality through a dyadic exchange of information between individuals existing within their separate but connected ecosystems, a more helpless and less equal outcome can arise. If the assumption is that people with autism need to help another individual to understand them better, without recognising the same understanding is equally valuable the other way around, they are placed in a subordinate position that lacks reciprocity and balance. This could potentially further the belief that autism is something that needs investigating by those who do not have it in order to better understand it (Milton and Bracher, 2013).

Although the three main rings that make up the *Interactive Bioecological Model of Autism* (diagram 3, p.57) were originally formed independently to develop understanding of self and of others, it is the combination of the three that makes the model more useful. This can be demonstrated initially by deconstructing that combination and considering the concept of understanding through each of the three rings separately. The medical model, as one of the side rings to the concentric circles, originated and continues to be updated as medical understanding about diagnoses are challenged and created anew. As discussed in the previous chapter, the information this medical model can supply is useful in developing knowledge and understanding of some of the concepts of the diagnosed disability. The social model, as the ring on the other side of the *Interactive Bioecological Model of Autism*, was proposed to develop awareness and an understanding of the limitations that can be imposed on people with disabilities by ‘a disabling society’ (Oliver, 2009: 9). Information considered through this model of disability balances the deficit view described in the medical model and swings the focus away from the individual with the disability and out to their immediate environment and the mindset of those with whom they have the greatest impact through dyadic interactions. Shakespeare’s *Interactive Model of Disability* (2006, 2014), which combines concepts from both the social and medical models, and therefore is incorporated within an *Interactive Bioecological Model of Autism*, indicates that awareness of information provided from *both* the social and medical models must be considered in creating a better understanding of an individual’s lived experience of their disability.

In relating the focus of these two rings to the pupils’ experiences in school, it was interesting to note that they were all able to list examples of some of the adaptations or specific resources that had been put in place to support them in their learning. These included extra time for writing, thus enabling breaks in a test; a specific LSA during lessons; and a box of fiddle toys to calm feelings of anxiety. As stated in England’s *SEND Code of Practice* (DfE and DoH, 2015) considerations need to be made regarding any pupil needing extra support to access their learning that is ‘different from or additional to that normally available to pupils of the same age’ (p.94). It would seem that an understanding of what was legislative had been put into operation to some degree at each of the pupils’ schools.

However, it is clear that knowledge derived from adopting the medical and social model approach to disability alone cannot be assumed to provide all of the information necessary to understand an individual. Without spending time with the pupil to gain a greater awareness of other aspects of their individuality, the plethora of additional factors that exist within the central rings of an *Interactive Bioecological Model of Autism*, and make up the complexity of the autistic individual will have been overlooked. By placing the *Bioecological Systems Theory* in the intersection of the *Interactive Model of Disability*, these additional considerations are highlighted and a greater breadth for understanding is made apparent.

The central concentric rings of Bronfenbrenner's *Bioecological Systems Theory* (1979; 2005) emphasise the recognition of individuality. They highlight the need to deepen understanding regarding the diversity of human beings through appreciating the impact of the bi-directional flow of information between the different systems that surround each individual. The implication of combining Bronfenbrenner's *Bioecological Systems Theory* with Shakespeare's *Interactive Model of Disability* demonstrates that although both theory and model have indisputable value, when used in isolation they do not supply all of the information that could lead to the development of a more rounded understanding of an individual with autism. Placing the individual in the centre of an *Interactive Bioecological Model of Autism* serves as a reminder that individuality is more than the sum of the descriptions provided through the medical or social models alone, and that no person's identity can be divorced from the ecosystem that surrounds them.

Batchelor's (2006) research into vulnerable voices highlighted a potential negative result of limiting understanding that could further impact the teacher/pupil relationship. Here she suggested that a lack of understanding could lead to assumptions that had the potential to become stereotypes through interpreting a condition as one '*of* vulnerability' in contrast to the more open connotations arising from a condition ' *for* vulnerability'. Her proposal was that instead of viewing vulnerability as a weakness, it should offer potential for 'opening up, rather than closing down' opportunities (Batchelor, 2006: 790). This was a sentiment echoed by many of the pupils, but summed up by Esther when she explained that:

> When people find out you have autism they might just make a snap judgment of you and not fully understand the whole thing … "she finds noise difficult, doesn't like crowded places", stuff like that. But sometimes autism is very different from person to person, like it can vary (Esther, AC2: 237).

The dangers of not developing an understanding of an individual through direct communication was also highlighted in research by Nicholaidis *et al*. (2012). Their literature search revealed that none of the studies they investigated regarding autism involved the adults who had autism directly, there had been no dyadic exchange between the individual and the researcher(s). This is more likely to create the effect of Chinese whispers, where information becomes misinterpreted, leading therefore to an inaccurate analysis, which is then further filtered through the writer, resulting in the presentation of information that has a greater possibility of being based on assumption. This was also highlighted by Alice who stated that '[teachers] need to know that everyone's different and just know things that they *could* not like … learn before they assume things' (pupil's emphasis, Alice, 3: 253). The danger of basing understanding of an individual through a single viewpoint, as highlighted in Chapter Two, is that vision is blinkered (Solomon, 2014), or by not developing knowledge through a mutual process of dyadic communication or dialogue (Messiou, 2019a), it has little reciprocity and risks becoming one-sided (Bronfenbrenner, 1979).

Without direct communication, positive and lasting progress in understanding is limited. Communities will remain where conversations between those with autism are focused on 'the difficulties of navigating and surviving in a world not built for them' (Silberman, 2015: 15). Therefore, understanding remains obscured from those within the wider community that many of the challenges faced by people with autism are not '"symptoms" of their autism, but hardships imposed by a society that refuses to make basic accommodation for people with cognitive disabilities' (Silberman, 2015: 15). Individuals with autism will continue to believe that they are less significant than those who do not have autism, an outcome voiced by Esther in our final conversation: 'the world wasn't built for you, so it's not your fault that you're like this' (Esther, AC4: 285).

5.2 Understanding oneself

> I was just being myself and someone laughed at me - and - I was sad about that (Roger, AC1: 227).

Roger's words here demonstrate his sadness when another's response to something he communicated had not matched his expectations. They serve as one example of many provided by the pupils that highlighted how interactions between individuals were intricately bound together and largely responsible for perspective and the formation of stereotype, a concept considered in the previous chapter. Roger's words also suggest how in a social community, the most secure relationships are those that are created through a process of mutual and respectful understanding. The focus of this section is a consideration of how the understanding or misunderstanding of others through dyadic communication can affect the interpretation and understanding of oneself.

Each of the five pupils had their own personal history affecting the language they used, thus providing potential insights into their self-belief. For example, Meg often referred to a regular pattern of behaviour at her primary school that resulted in her experiencing what she described as 'so much chapters of each angriness' (Meg, 3: 307). If she interpreted an action from the school or teacher as unfair, such as not allowing her to use blu-tac, which was something she usually had during our interviews and which she would roll out on the table or create shapes with while we were talking, she would often respond with a demonstration of her anger. This frequently resulted in a detention, which then made her more cross. Such a spiral of negativity would continue with detention after detention often resulting in her running away from the classroom. At this point in Meg's socialisation process or 'moral career' (Goffman, 1963: 45) where she had moved beyond the confines of her family and into other social networks, she was no longer protected by their influence and was thus having to 'face the view which the public at large takes of [her]' (Goffman, 1963: 47). The interpretation she made of this new view would have an impact on how she viewed herself.

Much of understanding of oneself is built on a matrix of filtered verbal and non-verbal communications with others (Goffman, 1959 and 1963). Phrases, initially mentioned by others tend to be subsumed into this creation of self, which may have been the origin of Meg's statement 'I've got problems' (Meg, 2: 299). This was a particularly pertinent comment, because in her current special secondary school environment, Meg generally felt understood by others. She commented that here she was able to relate easily to her peers, as everyone 'had a bit of problems' (Meg, 1: 292). She believed that her friends from her mainstream primary school also 'had problems' and it was clear from how she talked that she had a strong and loyal bond with them, albeit against the establishment in this case. The tight-knit friendship group in her primary school that she had been a part of had a united sense of purpose, which on reflection caused Meg to feel sad that she was no longer able to be with them. She explained that 'that's why I feel a little bit sorry because - I don't know, that I protected myself so I could protect other people (Meg, 3: 312). In developing her understanding of herself, Meg had become aware that there were others around her who were equally 'struggling' (Meg, 1: 292).

Research from Cummings *et al*. (2006), that has previously been considered, highlighted that children become aware that they are perceived to be different from an early age as a step in the development of their understanding. For children with autism this carries a plethora of additional nuanced complications to add to a world that already seems confusing (Sainsbury, 2000), where the majority of 'others' seem to be interacting by different and unspoken rules through effortless interpretation. This experience was explained by Goffman (1963: 110):

> What are unthinking routines for normals can become management problems for the discreditable. These problems cannot always be handled by past experience, since new contingencies always arise, making former concealing devices inadequate. The person with a secret failing, then, must be alive to the social situation as a scanner of possibilities, and is therefore likely to be alienated from the simpler world in which those around him apparently dwell.

Both Esther and Alice were able to pinpoint the occurrence of this epiphany at around the middle of their primary school education. Their dawning awareness of a perception of difference between themselves and their peers became clarified through conversations with friends whence it became clear that the way 'others' reacted to a particular event did not match their reactions. Having a diagnosis of autism at this point did not seem significant within this understanding of oneself. This was explained by Roger who received his autism diagnosis at the age of eleven. When asked whether he was expecting things to change because of this, his reply was:

> I thought everything might seem clearer to me. Now that I think about it, nothing seems clearer … everything just feels so strange. Like, what I'm feeling is that everybody is doing different things to what I'm doing. And I'm thinking I'm a weirdo and everybody else thinks I'm a weirdo, so I'm going to get bullied (Roger, AC4: 276).

In this instance, it seems that the diagnosis just furthered his sense of the injustice of difference and his perception of the divide between those who have autism and those who do not. Such awareness might explain the decision to camouflage his autism through masking aspects of his identity, by ‘putting on a mask to cover your real face’ (Roger, AC4: 277). When asked exactly what he meant by this, Roger explained that he changed his personality in order to try to create and maintain a relationship. A friend for him was therefore ‘just the right person for you … because they understand just how you’re feeling’ (Roger, AC4: 281): someone with whom he would be able to be himself.

Even if the description of the specific characteristics of their condition could have helped the pupils to recognise that they were part of a particular community of people who had greater similarities with themselves than those around them, it did not eradicate the need to understand who they were as an individual. For example, Alice explained the confusion she experienced over differentiating what was autism and what was part of who she was, when considering whether it was better to tell people about her autism or not:

> Alice: I mean, I’ve told Sarah and Amy, but some people don’t even know what it is and I don’t know how to explain it ‘cos I don’t know what it is really.
> Miriam: It’s just you isn’t it?
> Alice: Yeah - it’s like explaining yourself (A, 3: 252).

Similarly for Meg, knowing what was her and what was her autism, and whether the two were the same was confusing. She was not sure about what ‘having autism’ really implied, stating: ‘it’s all a bit confusing for me, I just know that I’m autistic’ (Meg, 3: 309).

The four pupils currently attending a mainstream secondary school also recalled an on-going struggle through their primary education of trying to understand who they were and how they fitted in. The problem was that once they had recognised that they were different from their peers, highlighting it to others was avoided by all through fear of negative response. In most cases they chose not to confide in their peers, preferring to hide many elements of themselves in order not to draw attention to what they perceived as their difference. Ben found one ally in his primary school that remained a loyal and trusted friend throughout his junior school education. However, there had been other occasions with peers where Ben had learnt from experience that it was better to keep concerns to yourself and proffered the advice:

> Don’t tell anyone that will probably judge you or like, anyone else about it, … the worst thing to do is tell someone “I got autism” and they judge you or tell everyone you’ve got autism, which is probably the mean - the worst thing that could happen (Ben, AC1: 231).

Others had not been so fortunate with friends, recalling that once some of their peers from primary school became aware of their difference they started acting unfavourably towards them. Similarly to Ben, this resulted for the pupils with autism in a decision to mask their initial responses and 'act normal' in order to better fit in. 'Acting normal' was a concept considered in the previous chapter and linked to perspectives of normality and difference, but here Alice explains the phrase and how she feels about making such a choice:

> Miriam: Yeah - so it's just this thing about being different and what you'd change when you feel you need to act normal. Is it hard to 'act normal'?
> Alice: Not any more.
> Miriam: So, it's getting easier?
> Alice: Well, not really. It's because I know how to act normal.
> Miriam: Yeah, so how do you learn to act normal?
> Alice: Err, copying other people.
> Miriam: Are you happy doing that, or would you rather you didn't?
> Alice: Mmm, sometimes - sometimes I want to be myself but sometimes I don't, but sometimes in here, I'm myself (A, 3: 251).

When asked if it was tiring having to remember to behave in a different way, she replied in a more wistful tone than her previous factual account:

> Alice: Mmm - well - I don't mind any more - but I would want to be myself.
> Miriam: If you could choose?
> Alice: Yeah - and then they won't stare at me (A, 3: 252).

By this point in her development, Alice had enough self-awareness and understanding to realise that it was easier to act in a different way with most people, thus sacrificing her initial and more natural responses in order to be better accepted by others. This was a strategy also echoed by Esther and Roger, who frequently and deliberately made the decision to mask their initial reactions by copying other learnt behaviours from their peers. This would have resulted in the juxtaposition between their virtual and actual social identities. Meg however felt differently. In general, she seemed to have an understanding and acceptance of who she was as an individual, and of her relationships with her peers. Because of this confidence, she did not appear to have experienced the complication of trying to hide or mask her identity. She felt no need to mirror herself on the behaviour of others and her reaction to being anything other than who she was was incredulity. When asked if she felt comfortable in her primary school, which had been an environment she struggled in, or whether she had tried to hide any of her responses to better fit in, her reply was:

> Yeah, I was still myself. Why would I has to put an act on? It wouldn't really work, can't get rid of it. Can't get rid of it for a few seconds, cos if I could then what's the point? I don't have it then, if I could get rid of it, then I'm just acting (Meg, 3: 312).

In considering this different response in developing understanding of oneself, it is useful to return to the research conducted by Connor (2013) who looked at the differences between groups of students identified as neurodiverse. Some viewed their neurodiversity as a difference that did not interfere with their self-esteem or ambition and incorporated their strengths and weaknesses. Others, who focused on the deficit or medical view of their neurodiversity, considered it a disadvantage. If Meg had been part of this research it is likely that she would have placed herself in the former group. Although she recognised her difference, and accepted that she 'had problems', she was also aware that many people 'had problems' and felt no sense of shame or the need for secrecy as a result of this. She was amongst 'sympathetic others' (Goffman, 1963: 31) with whom she shared understanding and experienced support and comfort. Alice, Esther, Ben and Roger on the other hand might have identified more strongly with the latter group. If they viewed their autism as a disadvantage to them, this could explain why they felt the need to hide or mask some of their responses in order to be better understood and accepted by others. The result of these two different outcomes is likely to have had an impact on the pupils' understanding of themselves.

The ecosystem rings that surround the individual, as depicted in *The Bioecological Systems Theory* (Bronfenbrenner, 2005; diagram 1 p.56) demonstrate every individual as existing within their own ecosystem and therefore being affected by concepts that flow between the factors within the rings and from one ecosystem to another. In extending this further through an *Interactive Bioecological Model of Autism* by adding Shakespeare's *Interactive Model of Disability* (diagram 3, p.57), the effect of an individual's view of disability also becomes highlighted as a consideration thus demonstrating that their understanding has been affected by their ecology. For example, if autism is viewed as a deficit and this is compounded and experienced by similar views from others within the individual's microsystem, it is likely that additional information will be selectively filtered through their outer interconnected systems from the media or cultural attitudes that further strengthen these views. Although a variation of responses towards autism can be recognised in the attitudes of others, it is necessary to appreciate the impact that the ecosystem has in the development of individual understanding regarding autism. For example, for someone *with* autism, the question could be how much would they perceive their difference as a deficit or just as part of neurodiversity? This would have an impact on their lived experience of autism, and is a further reminder of the intrinsic and extrinsic aspects of disability. On the other hand, for someone who does not have autism, the question could be how do they respond to the characteristics and diagnosis of autism in another?

The final section within this chapter turns to focus on how an *Interactive Bioecological Model of Autism* could be used to develop better teacher/pupil relationships through encouraging the development of understanding through reciprocal communication, thus assimilating the effect of individual perspective with knowledge and understanding.

5.3 The development of an understanding teacher/pupil relationship

> The teachers I trusted like the most … well, they like understood me and like, they found something to relate to me (Esther, AC1: 225).

Esther's words here suggest the need for connection through understanding in a teacher/pupil relationship. The themes covered earlier in this chapter of understanding others (section 5.1) and understanding oneself (section 5.2) will be linked in this section to the theme of perspective that was considered in Chapter Four to consider within this section the potential for the development of a mutually beneficial teacher/pupil relationship.

At the start of this section, it s necessary to return to Bronfenbrenner's description of a microsystem which he outlined as 'a pattern of activities, roles and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics' (1979:22). It is within this level of the individual's ecosystem that the teacher/pupil relationship will take place. It is also necessary to return here to the significance of the developmental step of attending school in the children's moral career as they move from the initial protective embrace of the family and into a wider environment (Goffman, 1963) (previously mentioned in section 2.2.3). The communications therefore that take place within this new setting have an impact on the current and future relationships the pupils make as they navigate their way through the understanding and perspective of others and the implications this has on the understanding and perspective of themselves. Bronfenbrenner (1979: 6) proposed that: ‘the environmental events that are the most immediate and potent in affecting a person’s development are activities that are engaged in by others with that person or in her presence’. He noted that despite there being a familiarity and universal acceptance in the statement ‘human development is a product of interaction between the growing organism and its environment’ (1979: 16), research in the past had not focused enough on the person *and* their environment, and especially the interaction between both. His proposal was that ‘human development is the process through which the growing person acquires a more extended differentiated, and valid conception of the ecological environment, and becomes motivated and able to engage in activities that reveal the properties of, sustain, or restructure that environment at levels of similar or greater complexity in form and content’ (1979: 27). It is clear from this proposal that aspects of perspective and understanding from those within the individual’s environment are both contributors to and producers of aspects of the development that takes place. For pupils with autism therefore, the relationship between them and their teacher is of profound significance.

It is fitting that relationships should be a theme that has arisen from the data, as it has been a major thread throughout this thesis. This includes the relationship between the social and medical models of disability, as indicated through *The Interactive Model of Disability*; the relationship between intrinsic and extrinsic factors of disability as proposed by Shakespeare (2014); the direct and indirect relationships between the individual and their ecosystem as suggested by the *Bioecological Systems Theory* (Bronfenbrenner, 1979; 2005); the relationship created in combining these aspects through an *Interactive Bioecological Model of Autism*; and finally, the relationship between the pupil with autism and their teacher, which was the starting point for the research. Through considerations that link these concepts with an *Interactive Bioecological Model of Autism*, the need for developing a greater understanding of the pupil’s individuality through the process of reciprocal communication has been emphasised. It has also been proposed that gaining knowledge of the pupil’s perspective concerning aspects of their primary education could have a reciprocally beneficial outcome. The pupil would benefit in developing their understanding and acceptance of themselves as individuals thus instilling the confidence to embrace the difference of others with the guidance of a safe and trusted adult. The teacher would benefit from creating a culture that reflected inclusive values and fostered a deeper awareness of neurodiversity, thereby lowering pupils' anxiety levels and focusing on the positives of individuality. Recommendations from Goffman, Bronfenbrenner and Shakespeare regarding the value of taking an interactive and bioecological approach towards informing a greater understanding within relationships will be synthesised with the voices of the pupils, whose voices illuminate such a necessity.

It seemed through the discussions with the participants, that all the pupils experienced strong negative or positive feelings towards specific teachers. For example, Ben stated that 'I probably could talk to three, maybe four teachers about [his] autism, but no one else, because they would probably yeah, not understand, or probably hate me for it' (Ben, AC1: 224). Alice made a clear distinction between the two different teachers within the job share she encountered whilst in her final year at her primary school, enjoying the relationship with one whilst struggling with the other (section 4.1). And Roger experienced two very different emotions to causing laughter from his teachers in the two separate primary schools he attended. He outlined that in his first primary school he felt hurt by their laughter, explaining that 'sometimes I can be really stupid, but people don't have to laugh at it' (Roger, AC1: 227). But when considering the same scenario in his second school, he was able to reflect that 'I just remember being in the classroom and every time I said something, like, I would always make the teachers laugh, and I loved it - they just found everything I said funny, not in a horrible way' (Roger, AC1: 220). The basis of this change for Roger was that of relationships. He was aware that in the second school 'I felt comfortable … I just felt like I was being respected' (Roger, 3: 266). These examples from the pupils demonstrate a link between their perceptions of a lack of understanding from the teachers, and the resulting feeling of insecurity that led to a heightened level of anxiety or confusion. As already considered in section 5.1, relationships in which there was raised anxiety seemed more likely to cause 'protective practices' such as masking of identity for Roger, Esther and Alice, or the more active 'defensive practices' as with Ben and Meg (Goffman, 1959: 24). For the pupils, this had become a learnt response in order to protect themselves from teachers' misunderstandings that might have been based on an 'imposition of problematic narratives on autistic experiences' (Milton and Bracher, 2013: 61).

The excerpts from the pupils' discussions demonstrate the impact of relationships within the school environment. They clarify the need for relationships to be built on an understanding of the individual and not just their difference or their diagnosis. They highlight that it is not just alterations regarding the physical arrangements that make a difference to them, although these are of significance. How much their autism could negatively or positively affect them was greatly dependent on *both* their surroundings and the relationships they had within that environment. This aspect was also highlighted in the pupils' considerations as to whether the effects of autism could best be described as a disability, difference or something else. Esther's reply was: 'it's not a disability if you're in the right environment, but it is a difference as you need to be in the right environment' (Esther, AC4: 286). Alice on the other hand, believed the word disability better described her autism as she felt a curtailment of what she could do as she was so greatly influenced by the environment. These themes are consonant with prior research into this area which highlighted that teacher characteristics of 'consistency and fairness' (Hebron *et al*. 2015: 189), having personnel who were 'open to differences and who were child centred' (Sciutto *et al*., 2012: 182) and staff who placed emphasis on 'feeling comfortable' (Dillon *et al*., 2016: 225) that created good relationships between pupils with autism and the adults they came into contact with in school.

The significance of this for pupils with autism demonstrates the need for teachers to actively seek out the subjective significance of autistic related experiences in relation to wellbeing (Milton and Bracher, 2013): to be aware of the variety within autism, appreciating that it is 'not like a text book kind of thing' (Esther, AC4: 277), 'autism is so much, like, bigger, than just one, like mental problem' (Esther, 3: 259). It is also important to remember that the original intention of an SEN assessment from *The Warnock Report* (DES, 1978) as depicted by Norwich (2016) was that rather than focusing on the pupil's need and deficits, it '*could* be holistic by taking account of a child's other personal characteristics, their strengths, and difficulties, which deficit diagnosis might overlook' (original emphasis, Norwich, 2016: 2). Overlooking this can also result in missed opportunities to maximise potential as highlighted by Happé and Vital (2010) who proposed that if the obsessive and narrow interests of those with autism were only considered as deficits and hindrances to socialisation, there would never be the opportunity for these to be developed into areas of positive potential, or the nurtured talents providing a focus for 'normalisation' (Treffert, 2010: 8).

Fielding used the term 'radical collegiality' (2004: 296) to explain the ideal relationship between pupil and teacher that was based on an acceptance that their views *would* be different from each other. Indeed, acknowledging the skills and understanding from all stakeholders is a vital component of successful collaboration (Parsons, *et al.*, 2020). Through embracing this concept within the teacher/pupil relationship, it could become possible that rather than teachers fearing the active involvement of pupils in their education, the pupils' voices would be welcomed by their educators as an opportunity to create a shared responsibility for success based on a positive acknowledgment of their differing skills. The educational journey could then be recognised as one to be maximised through the acknowledgement of both perspectives holding a 'legitimacy of difference' (p.131). Such legitimacy of individual perspective also acknowledges Armstrong's (1980) proposal that children should be regarded as key people in their own lives, rather than being considered apprentices in training for what they will become in their future; and that of Maguire (2005: 12) who proposed that children should be viewed as 'social actors who have a sense of agency to choose and decide rather than an incompetent view of children who need to be protected'. A consideration of an active involvement in relationships also resonates with the expectations of inclusive research (Nind, 2014). In the case of a teacher/pupil relationship instead of researcher/participant, the knowledge sought would be gathered by educators and their pupils within their own environment to further their respective understandings; the focus being on 'multiple realities' rather than truth (Pring, 2015: 77). The gathering of such information would be a respectful process, with everyone positioning themselves as learners (Nind and Vinha, 2012) and thus creating a state of 'empathic neutrality' (Patton, 2015: 59). From either side there would be a connection with the individual and an understanding of their 'stance, position, feelings, experiences, and worldview of others' (Patton, 2015: 59). This would develop through neutrality, a discipline of openness and the deliberate decision to be non-judgmental.

This greater awareness could be developed by considering autism through Shakespeare's (2006, 2014) *Interactive Model of Disability.* By integrating information from both the medical and social models, the interaction between the three elements of disability: individual factors, societal factors, and factors within the system of support would be clarified. Shakespeare's proposal was that if one or more of these elements is missing, an inaccurate view is more likely to be formed of the individual and the level of disability experienced by them will be negatively affected (2014). This also highlights the connection between: intrinsic factors of disability, which are linked with individual attitude, personality and ability; and extrinsic factors, which constitute the environment and the attitudes of others (Shakespeare 2014). The varying relationships the pupils recalled with their teachers indicates the delicate balance required between intrinsic and extrinsic factors concerning autism. It is a balance that was emphasised in *The Bioecological Systems Theory* (Bronfenbrenner, 1979; 2005) through its focus on 'the relations between an active individual and his or her active and multilevel ecology' (Lerner, 2005: xix). This highlighted the relationship between the individual and their ecology thus emphasising the two-way process of shaping and being shaped through their influences. The danger is that without developing opportunities for communication to deepen understanding, even well intentioned teachers might base their decisions on a limited understanding that is affected by their own perspective of autism and thus risk the outcome depicted in Finkelstein's fable (1981) (on page 28 of this thesis). This was highlighted in research conducted by Sciutto *et al*. (2012), which indicated that the teachers who were child centred and open to difference were the ones who had the greatest positive impact. The lived experience of autism needs to have the opportunity to be communicated in order for it to be better understood (Shakespeare, 2014, 2018) as the foundation for a positive and productive relationship. Developing an understanding through valuing reciprocal communication has positive implications for both parties in the creation of a mutually beneficial relationship. As recommended by Esther:

> I think there should be like - I think there's like a trust thing. If a teacher shouts at you - you're more likely to hide your feelings. If a teacher is open and honest with you, I think you'd be open and honest with them (Esther, AC4: 277).

5.4 Conclusion

This chapter has synthesised the voices of pupils with proposals from Shakespeare's *Interactive Model of Disability* and Bronfenbrenner's *Bioecological Systems Theory* to demonstrate the need to consider an exploratory model of autism with potential for enhancing understanding by developing relationships that are founded in reciprocal communication. The understanding that could develop would be both effective for the person with autism in their understanding of others, whilst at the same time assisting others in better understanding the person with autism. Acknowledging the two-way process in the development of knowledge and understanding through dyadic communication, the reciprocal dimension of an effective relationship has been emphasised. The impact of additional information from the interaction between the social and medical models of disability, and how this will also be filtered through each individual's ecosystem further highlights the need to take all three elements into consideration through an *Interactive Bioecological Model of Autism*.

Chapter 6 Conclusion - Joining all the Voices

Although an awareness of the characteristics of autism is necessary, and physically altering elements within the environment is likely to be useful for the autistic pupil, it is the climate of trust and respect that is developed through understanding relationships that are fostered within this environment which carries the greatest significance (Sciutto *et al.*, 2012; Dillon *et al*., 2016). This will be effective both in the present for pupil and teacher, and in preparing the groundwork for future relationships. It is important that all parties involved accept and embrace the variety of experience that arises from neurodiversity understanding that it is often the similarities that draw people together, and the differences that can cause problems for both individuals if not understood and/or accepted. Through seeking and then focusing on the similarities rather than the differences, as well as accepting that perspectives are formed from previous experience and understanding, the foundations of a good relationship can be built (UNESCO, 2017).

When pupils are accepted by their teachers for who they are, the risks of their feeling 'discredited' are greatly minimised leading to reduced feelings of uncertainty and ambiguity (Goffman, 1963:57). Encouraging pupils to express their views enables a greater awareness of the impact of differing perspectives. This in turn could lead to fresh understanding and enable schools to enhance their functioning through reflecting on their current practice with autism (Dillon *et al.,* 2016). In addition to this it is possible that increased collaboration that leads to a greater acceptance of individuality within one environment can have an impact on another. As Bronfenbrenner proposed in his *Bioecological Systems Theory,* information can flow from one ecosystem to another, as well as between different units within ecosystems therefore, 'events at home can affect the child's progress at school, and vice versa' Bronfenbrenner (1986:723).

After spending four decades working alongside parents and children with autism, Dr Prizant decided that a challenge of perspectives about autism was necessary. He proposed that:

> Autism isn't an illness. It's a different way of being human. Children with autism aren't sick; they're progressing through developmental stages as we all do. To help them, we don't need to change them or fix them. We need to work to understand them, and then change what we do. In other words, the best way to help a person with autism is to change ourselves … by listening (Prizant, 2015: 4).

The focus of his book, as is indicated from the quotation above, is that instead of viewing autism with anxiety or perplexity, autism should simply be accepted as 'a different way of being human' (2015: 4). His message is clear: it is not people with autism that need to change to fit our expectations; it is instead our perspective on autism that needs to be challenged, and that will happen through listening to people with autism. This proposal resonates strongly with the major elements from an *Interactive Bioecological Model of Autism*. For example, seeking the lived experience of the person with the disability was fundamental to Shakespeare's *Interactive Model of Disability*. Thus the uniqueness of the individual with autism would be understood, rather than a focus on a list of deficits from the medical model, or on the need for change within society and the environment, as is the focus for the social model. The impact of combining Shakespeare's model with Bronfenbrenner's *Bioecological Systems Theory* highlights the necessity for recognising the bi-directional influence on perspective from the ecosystem that surrounds each individual.

As proposed in Chapters Four and Five, there is a connection between the concepts of perspective and understanding that must be considered in the context of relationships. As information about one individual is considered by another, it is both consciously and sub-consciously sifted and sorted to minimise challenge and therefore discomfort to their original perspective. This highlights the need to respect that interpretations made with regard to external manifestations of behaviour and appearance in order to better understand another person are likely to be embraced in a way that matches and validates the perspective of the viewer, thus strengthening their original viewpoint. In other words, perspective influences understanding, but understanding only has the potential to influence perspective. This link between perspective and understanding needs to be recognised and where necessary circumvented through the process of developing a reciprocal understanding in the development of positive relationships. This is particularly important when autism is considered as a different way of viewing the world (Prizant, 2015) and is therefore more likely to challenge the original perspectives of others. Through embracing another's perspective as being different, and accepting such a difference through 'radical collegiality' (Fielding, 2004: 296) as healthy, the way becomes open for a more productive and mutually beneficial and understanding relationship. Instead of the potential for disparity, a new opportunity could be achieved through developing a better understanding and appreciation of another's perspective. Then it would become possible to develop a relationship that accepts and embraces difference, for each individual to subsume another's perspective within his or her own ecology. Thus there would be no need for one individual's perspective to be more prominent than the other as both can co-exist and be respected as different.

The next section of this chapter will return to answer the research questions that were mentioned in Chapter One. The limitations of this research will then be considered, and this will be followed by two further sections covering implications for practice and potential developments for the future.

6.1 A return to the research questions

This thesis aimed to explore and promote a better understanding of autism in education. The first research question that was introduced in Chapter One and linked to this aim was whether Shakespeare's *Interactive Model of Disability* could be used in conjunction with Bronfenbrenner's *Bioecological Systems Theory* to develop a better understanding of pupils with autism. From an analysis of the literature considered in Chapter Two, it was clear that both the theory and the model provided valuable viewpoints regarding individuality that could be connected with a deeper understanding of autism. Considering autism through Shakespeare's (2006, 2014) *Interactive Model of Disability* would enable a greater awareness of the condition, its potential and its limitations. It would demonstrate the need for seeking a greater understanding of the difference of autism through the medical model with its focus on the condition as a disability, alongside knowledge of what could be adapted within the environment and in relation to the mindset of individuals from information considered through the social model of disability, thus limiting the disabling effects and celebrating difference and individuality. Connecting this information about autism with a consideration of what was understood about the pupil through

Bronfenbrenner's (1979, 2005) *Bioecological Systems Theory* would provide a more holistic view. It would demonstrate the need to look beyond the information about autism provided through the *Interactive Model of Disability* and to see the pupil as a whole. It would indicate to both parties within the relationship that their considerations of each other as unique beings had been impacted by previous information and experience that had been filtered through their ecosystems. These considerations suggest that an *Interactive Bioecological Model of Autism,* which is currently at an exploratory stage, could have potential for a greater understanding of autism.

The second research question to be returned to in this concluding chapter was whether pupils with autism considered there was a need for a greater reciprocal understanding between teachers and themselves of the diversity within autism. The empirical research undertaken with the five pupils who took part has clearly indicated their desire for a greater reciprocal understanding between pupil and teacher. The themes of anxiety, 'being normal', understanding and relationships that arose from the collaborative analysis of the data were discussed within the two themed chapters of this thesis. Here the pupils' personal experiences of themselves as autistic individuals within their mainstream educational environments were synthesised with the literature and then considered alongside the proposed new model of autism. Their responses stressed that although they wished their teachers understood more about the diversity of autism and the different challenges it can create in the school environment for each individual autistic pupil, they also wanted to be considered as individuals in their own right. If the focus of teacher understanding remained on individuality rather than on the diagnosis of autism considered through the medical and social models of disability, it might have the potential to diminish the pupil's anxieties regarding 'being normal' as all pupils within their class would be considered as unique individuals.

The final research question for this thesis was whether a new model might have potential to guide understanding and the development of more respectful and reciprocal relationships between pupils with autism and their teachers in educational settings. In answer to this question, it is proposed within this thesis that an *Interactive Bioecological Model of Autism* has the potential to create an explicit connection between the different influences that will have an impact on the individual through the direct and indirect links with his or her ecosystem. It indicates how the understanding of information from both the social and the medical models of disability will be filtered through the individual's ecosystem thus having an impact on their perspective, as is demonstrated in diagram 3 (page 57). A clearer image is therefore provided of how that individual is both affected by and has an effect on considerations of disability, and specifically in this case, autism. Combining Bronfenbrenner's *Bioecological Systems Theory* with Shakespeare's *Interactive Model of Disability* demonstrates that it is not just those with autism who are affected by the perspectives of others. Rather the emphasis is that individual understanding needs to be recognised as a reciprocal process. It is hoped that an *Interactive Bioecological Model of Autism* will demonstrate that the expectation should not be that one individual should be moulded into an acceptable form by another, but rather that both individuals can co-exist and equally enrich each other through appreciating and understanding the varying perspectives within a reciprocal and respectful relationship.

What has been produced is an original concept that has connected together two valuable tools for considering disability and individuality. It is hoped that the proposed model, which is at an exploratory stage, creates a coherent and holistic structure that could be used by teachers and pupils with autism in forming relationships that are based on a reciprocal understanding and respect of each other's perspective.

6.2 Limitations of the research

The first limitation to this research is that although all of the pupils attended different primary schools, they were all located within the same county. It is possible that the primary education experienced by pupils with autism in other counties could be different which may cause a different outcome in their reflections. However, as the original focus for this research came from the responses to a national survey by the NAS (NAS: 2016), the lack of understanding from teachers about pupils with autism, which this survey highlighted, would seem to be a national problem. What this research has done is to focus on one geographical area in more depth to develop a deeper awareness of what some pupils consider is missing in their teachers' understanding regarding autism, which was one of the issues raised from the original survey.

A more pertinent limitation of this research has been its focus on only one side of the teacher/pupil relationship. The pupils' reflections and their perspectives of the experiences they recalled within their primary education have been considered. This has been a useful starting point, but needs to be balanced through seeking the teachers' voices concerning their relationships with autistic pupils within the mainstream primary school setting. Therefore, this will be the focus for further research. A further limitation has been that despite emphasising that many factors within an individual's ecosystem will have an impact on their perspective and understanding of other individuals, it has only been the relationships within the school environment that have been considered, and particularly that of the teacher/pupil relationship. It is likely that other relationships experienced in other environments within the pupil's microsystem will have an effect on their relationships with their teachers. Similarly, it has been suggested that information that is filtered through the layers of each individual's ecosystem, for example the attitude of the culture regarding autism from the macrosystem as well as the impact of the views from the social and the medical models, will have relevance. How great an impact this could have on the teacher/pupil relationship has also not been considered within this research.

6.3 Implications for Practice

The implications for practice of an *Interactive Bioecological Model of Autism* are currently proposed in theory as this model is still at an exploratory stage. It is suggested that its use within education is as a tool that could develop a more holistic understanding of autism. Viewing autism through Shakespeare's (2006, 2014) *Interactive Model of Disability* emphasises the different components that make up the condition that the diagnosis recognises. The incorporation of Bronfenbrenner's (1979, 2005) *Bioecological Systems Theory* within the new model demonstrates how the understanding of the condition can be connected to the perspective of an individual. It creates awareness that the view of one individual from the centre of their ecosystem will not be the same as that of another individual who is surrounded by their own ecosystem. The new model highlights how perceptions of disability will have been filtered through each individual's ecosystem and how this will have an impact on both their view of themselves and others. This is an important consideration in the formation of respectful and reciprocal relationships.

If in the future, this model is seen to have potential in replacing the dichotomy between the medical and social models in assisting teachers to understand autism, it could be incorporated into Initial Teacher Training and used within Continuous Professional Development regarding further training on autism for teachers already in the profession. It is hoped that the model would deepen educators' awareness of the need for a more holistic view and demonstrate the value of creating respectful and reciprocal relationships with their autistic pupils so that both parties are able to better understand each other. 'Radical collegiality' (Fielding, 2004: 296) would be an outcome of the improved relationship where both parties accepted a difference in view that enriched their understanding of the other as both legitimate and valuable, accepting with 'empathic neutrality' (Patton, 2015: 296) that individual experience is subjective and related to wellbeing (Milton and Bracher, 2013).

6.4 Potential future developments

Through analysing the literature and gathering empirical data, the focus for this research has been on the pupils with autism in their mainstream primary schools. They have been placed in the centre of their ecosystem and consideration has been given to their relationships with others from their perspective, and selected from the memories they recalled of the dyadic communications they had with others within their microsystem. The next step therefore is to consider whether the *Interactive Bioecological Model of Autism* has value from the teachers' perspective, thus placing the professional in the centre of their ecosystem and considering the pupil within the teacher's microsystem.

Other potential developments would be to consider this reciprocal process from the parents' perspective, or that of other professionals involved with the pupil with autism such as doctors, social workers or educational psychologists. There is a growing need to look more closely at the effectiveness of the mesosystem in considering relationships between different aspects within the individual's microsystem, especially now the concept of *Education and Health Care Plans* (DfE and DoH, 2015) in England necessitates a more joined-up approach to health, care and education. It would also be interesting to trace the effects from the outer two rings of the exosystem and macrosystem through to the inner rings of an individual's ecosystem in order to consider the impact of culture and the expectations from wider society on the pupil with autism and their teacher. Finally, the opportunity to investigate the impact on the individual of Shakespeare's *Interactive Model of Disability* through all the layers of their ecosystem would be useful in order to emphasise its effectiveness as a model of disability.

In this, the final chapter of this study, it is now possible to reflect on the last 'big tent' criterion for the quality of qualitative research and consider whether this study has made a 'significant contribution' (Tracy and Hinrichs, 2017: 7). This judgment turns on 'whether or not the findings extend, transform, or complicate existing bodies of knowledge, theories or practices, in new, important and insightful ways' (Tracy and Hinrichs, 2017: 7-8). Within this context, it is proposed that the outcome from this research has international significance through its creation of a new model of autism that could have relevance in other countries. Although this research has been focused on proposing a model that could create a better understanding of autism, it also has the potential of wider implications for developing a better understanding of other conditions, which could be developed in the future. However it is important to note that in the UK, it is widely accepted that the education profession is under increasing pressure. Therefore, it must be highlighted that in proposing this model as a development of a better and more reciprocal understanding between pupils with autism and their teachers, there is no expectation that it is necessary for teachers to do more than they are already doing. Rather the focus of this model is on considering how perspectives about autism have already been formed, and challenging these if necessary through the process of dialogue between pupil and teacher with a view to deepening understanding thus creating a more reciprocal and beneficial relationship.

This thesis began with a quotation from Axline (1964) and will end with another from the same author that highlights the impact of valuing and respecting the child as an equally valuable partner within a relationship. This emphasises the importance of considering the individual within their ecosystem as proposed by Bronfenbrenner, and valuing the individual's lived experience of disability as highlighted by Shakespeare. If through effective communication and understanding, the child is able to experience themselves as capable and responsible, two basic truths can be communicated:

> That no one ever really knows as much about any human being's inner world as does the individual himself; and that responsible freedom grows and develops from

> inside the person. The child must first learn self-respect and a sense of dignity that grows out of his increasing self-understanding before he can learn to respect the personalities and rights and differences of others (Axline, 1964: 58).

Reference List

Able, H., Sreckovic, M., Schultz, T., Garwood, J. and Sherman, J. (2015) Views from the trenches: Teacher and Student Supports Needed for Full Inclusion of Students with ASD. *Teacher Education and Special Education*, 38, (1), 44-57.

Ainscow, M. (2005) Developing Inclusive Education Systems: What are the levers for change? *Journal of Educational Change*, 6, 109-124.

Alves, I., Fazzi, L. B., Griffo, G. (2010) *Human Rights, Persons with Disabilities, ICF and the UN Convention on the rights of persons with disabilities: Training toolkit*. Available at: https://www.academia.edu/1279003/Human_Rights_Persons_with_Disabilities_ICF_and_the_UN_Convention_on_the_rights_of_persons_with_disabilities_-_Training_toolkit [Accessed 10 December 2019].

Alves, I., Fazzi, L. and Griffo, G. (2012) Human Rights, UN Convention and the International Classification of Functioning, Disability and Health: collecting data on persons with disabilities? *American Journal of Physical Medicine and Rehabilitation,* 91, (13), (suppl), S159-S162.

Alves, I., Andreasson, I., Karlsson, Y. and Miles, S. (2016) 'Constructions of student identity in talk and text: A focus on special educational needs in Sweden and England'. In: Beach, D. and Dyson, A. (eds) *Equity and Education in cold climates.* London: Tuffnell Press, 137-153.

Alves, I. (2019) International inspiration and national aspirations: inclusive education in Portugal. *International Journal of Inclusive Education*, 23, (7-8), 862-875.

American Psychiatric Association. (1980) *Diagnostic and statistical manual of mental disorders: DSM-3*. Arlington, VA: American Psychiatric Association.

American Psychiatric Association. (2013) *Diagnostic and statistical manual of mental disorders: DSM-5*. Arlington, VA: American Psychiatric Association.

Ametrine (2018) The language of autism: on whose terms? *The Spectrum*, 95, 4-5.

Anastasiou, D. and Kauffman, J. (2011) A Social Constructionist Approach to Disability: Implications for Special Education. *Exceptional Children*, 77, (3), 367-384.

Anastasiou, D. and Kauffman, J. (2012) Disability as Cultural Difference: Implications for Special Education. *Remedial and Special Education*, 33, (3), 139-149.

Andrew (2019) Alexithymia – a personal journey. *The Spectrum*, 99, 16-17.

Armstrong, M. (1980) *Closely Observed Children the diary of a primary classroom*. London: Writers and Readers.

Aspis, S. (2000) 'Researching our own history: Who is in charge?' In Brigham, L., Atkinson, D., Jackson, M., Rolph, S. and Walmsley, J. (eds.) *Crossing Boundaries: Change and Continuity in the History of Learning Disabilities*. Kidderminster: BILD, 1-7.

Attwood, T. (2007) *The Complete Guide to Asperger's Syndrome*. London: Jessica Kinglsey.

Axline, V. (1964) *DIBS In Search of Self: The moving story of an emotionally lost boy who found his way back*. Middlesex: Penguin.

Bailey, J. (1998) Australia: Inclusion through Categorisation? In: Booth, T. and Ainscow, M. *From Them To Us: An International Study of Inclusion in Education*. London: Routledge, 171-186.

Bargiela, S., Steward, R. and Mandy, W. (2016) The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autistic Developmental Disorders*, 46, 3281-3294.

Bargiela, S. (2019) *Camouflage: the hidden lives of autistic women*. London: Jessica Kingsley.

Baria, A., Pangarkar, S., Abrams, G. and Miaskowski, C. (2019) Adaption of the Biopsychosocial Model of Chronic Noncancer Pain in Veterans. *Pain Medicine*, 20, (1), 14-28.

Baron-Cohen, S. (2000) Autism and ‘theory of mind’. In: *The Applied Psychologist*. Hartley, J. and Branthwaite, A. (eds). Buckingham: Open University Press, 181-194.

Baron-Cohen, S. Golan, O. and Ashwin, E. (2009) Can emotion recognition be taught to children with autism spectrum conditions? *Philosophical Transactions of the Royal Society*, 364, (1535), 3567-3574.

Barton, L. (2007) ‘Developing an emancipatory research agenda: possibilities and dilemmas’. In: Clough, P. and Barton, L. (eds.) *Articulating with Difficulty Research Voices in Inclusive Education*. London: Paul Chapman, 29-39.

Batchelor, C. (2006) Vulnerable Voices: An examination of the concept of vulnerability in relation to student voice. *Education Philosophy and Theory: Incorporating ACCESS*, 38, (6), 787-800.

Bengtsson, M. (2016) How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, 2, 8-14

Black-Hawkins, K. and Amrhein, B. (2014) Valuing Student Teachers’ Perspectives: Researching Inclusively in Inclusive Education. *International Journal of Research and Method in Education*, 37, (4), 357-375.

Booth, T. (1999) Viewing Inclusion from a Distance: Gaining Perspective from Comparative Study. *Support for Learning*, 14, (4), 164-168).

Booth, T. and Ainscow, M. (2016) *Index for Inclusion: Developing Learning and Participation in Schools*. Cambridge: Index for Inclusion Network.

Bourke, L. (2009) Reflections on doing participatory research in health: participation, method and power. *International Journal of Social Research Methodology*, 12, (5), 457-474.

Braun, V. and Clarke, V. (2006) Using Thematic Analysis in Psychology. *Qualitative Research in Psychology,* 3, 77-101.

Braun, V. and Clarke, V. (2013) *Successful Qualitative Research a practical guide for beginners*. London: Sage.

British Educational Research Association (BERA). (2018) *Ethical Guidelines for Educational Research*. 4th edn. Available at: *https://www.bera.ac.uk/publication/ethical-guidelines-for-educational-research-2018-online*. [Accessed 9 October 2019].

Bronfenbrenner, U. (1979) *The Ecology of Human Development: Experiments by Nature and Design*. London: Harvard University Press.

Bronfenbrenner, U. (1986) Ecology of the family as a context for human development: Research Perspectives. *Developmental Psychology*, 22, (6), 723-742.

Bronfenbrenner, U. and Ceci, S.J. (1994) Nature-Nurture Reconceptualised in developmental Perpsective: A Bioecological Model. *Psychological Review*, 101, (4), 568-586.

Bronfenbrenner, U. (2001) The Bioecological theory of Human Development. In: Smelser, N. and Baltes, P. (eds.) *International Encyclopaedia of the Social and Behavioural Sciences*, 10. New York: Elsevier, 6963-6970.

Bronfenbrenner, U. (2005) *Making Human Beings Human*. London: Sage.

Bruce (2019) The Asperger's Syndrome Victim. *The Spectrum*, 97, 13-15.

Cairns, R.B. and Cairns, B.D. (2005) Social Ecology over Time and Space. In: Bronfenbrenner, U. (ed.) *Making Human Beings Human: Bioecological perspectives on human development*. London: Sage, 16-21.

Campbell, M. (2018) Finding Your Tribe. In: Cook, B. and Garnett, M. (eds) *Spectrum Women Walking to the Beat of Autism*. London: Jessica Kingsley, 21-32.

Castro, S., Ferreira, T., Dababnah, S. and Pinto, A. (2013) Linking autism measures with the ICF-CY: Functionality beyond the borders of diagnosis and interrater agreement issues. *Developmental Neurorehabilitation*, 16, (5), 321-331.

Chapireau, F. (2005) The Environment in the International Classification of Functioning, Disability and Health. *Journal of Applied Research in Intellectual Disabilities*, 18, 305-311.

Charmaz, K. (2008) Views from the Margins: Voices, Silences, and Suffering. *Qualitative Research in Psychology*, 5, 7-18.

Chipuer, H. (2001) Dyadic attachments and community connectedness: links with youths' loneliness experiences. *Journal of Community Psychology*, 29, (4), 429-446.

Christensen, J. (2010) Proposed Enhancement of Bronfenbrenner's Development Ecology Model. *Education Inquiry*, 1, (2), 117-126.

Clough, P. (1998) Differently articulate: Some indices of disturbed / disturbing voices. In: Clough, P. and Barton, L. (eds.) *Articulating with Difficulty Research Voices in Inclusive Education*. London: Paul Chapman, 128-145.

Clough, P. and Barton, L. (1995) Introduction: self and the research act. In: Clough, P. and Barton, L. (eds). *Making difficulties: research and the construction of special educational needs.* London: Paul Chapman, 1-5.

Connolly, M. and Gersch, I. (2016) Experiences of parents whose children with autism spectrum disorder (ASD) are starting primary school. *Educational Psychology in Practice*, 32, (3), 245-261.

Connor, D. (2013) Kiss my Asperger's: turning the tables of knowledge. *International Journal of Inclusive Education*, 17, (2), 111-129.

Corbett, J. (2007) ”Voice” in emancipatory research: imaginative listening. In: Clough, P. and Barton, L. (eds.) *Articulating with Difficulty Research Voices in Inclusive Education*. London: Paul Chapman, 54-63.

Cranton, P. and Taylor, E. (2012) Transformative Learning Theory: Seeking a more unified Theory. In: Taylor, E., Cranton, P. and Associates (eds.) *The Handbook of Transformative Learning: Theory, Research and Practice*. San Francisco: Jossey-Bass, 3-20.

Cummings, J., Pepler, P., Mishna, F., Craig, W. (2006) Bullying and Victimisation among students with exceptionalities. *Exceptionality Education*, 16, (2/3), 193-222.

Davis, J.M., and Watson, N. (2001) Where are the Children’s Experiences? Analysing Social and Cultural Exclusion in “Special” and “Mainstream” Schools. *Disability and Society*, 16, (5), 671-687.

Dean, M., Harwood, R. and Kasari, C. (2017) The art of camouflage: Gender differences in the social behaviours of girls and boys with autism spectrum disorder. *Autism*, 21, (6), 678-689.

DES (1979) The Warnock Report. Available at: *http://www.educationengland.org.uk/documents/warnock/warnock1978.html*. [Accessed 9 October 2019]

Department for Education and Skills (DfES). (2001) *The Special Educational Needs Code of Practice*. Available at: *https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/273877/special_educational_needs_code_of_practice.pdf*. [Accessed 26 March 2018].

DfE (2009) *Autism Education Trust*. Available at: *https://www.autismeducationtrust.org.uk/*. [Accessed 4 October 2019].

DfE (2009) *Inclusion Development Programme*. Available at*: http://www.idponline.org.uk/*. [Accessed 4 October 2019].

DfE (2014) The National Curriculum. Available at: https://www.gov.uk/government/publications/national-curriculum-in-england-framework-for-key-stages-1-to-4/the-national-curriculum-in-england-framework-for-key-stages-1-to-4 [Accessed 30 May 2020].

Department for Education and Department of Health (DfE and DoH). (2015) *The Special Educational Needs and Disability Code of Practice: 0 – 25*. London: DfE and DoH.

DfE (2015) The Carter Review. Available at: *https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/399957/Carter_Review.pdf*. [Accessed 9 October 2019].

Department of Health (DoH). (2006) *Let me in – I'm a researcher*. London: Crown.

Dillon, G., Underwood, J. and Freemantle, L. (2016) Autism and the UK Secondary School Experience. *Focus on Autism and other Developmental Disabilities*, 3, (3), 221-230.

Donovan and Zucker (2016) *In a Different Key.* London: Penguin.

Donmoyer, R. (2011) Generalisability and the Single-Case Study. In: Gomm, R., Hammersley, M. and Foster, P. (eds.) *Case Study Method*. London: Sage, 45-68.

Drake, P. (2010) Grasping at methodological understanding: a cautionary tale from insider research. *International Journal of Research and Method in Education*, 33, (1), 85-99.

Dyson, A. (2007) Professional intellectuals from powerful groups: wrong from the start? In: Clough, P. and Barton, L. (eds.) *Articulating with Difficulty Research Voices in Inclusive Education*. London: Paul Chapman, 1-15.

Eaton, J. (2018) *A guide to mental health issues in girls and young women on the autism spectrum: diagnosis, intervention and family support*. London: Jessica Kingsley.

Elliman, L. (2011) Asperger's Syndrome – Difference or Disorder? *The Psychologist*, 24, (2), 114-117.

Elliott, J. (2005) *Using Narrative in Social Research*. London: Sage.

Fendler, L. and Muzaffar, I. (2008) The History of the Bell Curve: Sorting and the Idea of Normal. *Educational Theory*, 58, 1, 63-82.

Fielding, M. (2000) Education policy and the challenge of living philosophy. *Journal of Education Policy*, 15, (4), 377-381.

Fielding, M. (2001) Students as Radical Agents of Change. *Journal of Educational Change*, 2, 123-141.

Fielding, M. (2004) Transformative approaches to student voice: theoretical underpinnings, recalcitrant realities. *British Educational Research Journal*, 30, (2), 295-311.

Finkelstein, V. (1981) To Deny or Not to Deny Disability. In: Brechin, A., Liddiard, P. and Swain, J. (eds.) *Handicap in a Social World*. London: Open University Press. p. 34-36.

Frith, U. (2003) *Autism Explaining the Enigma*. 2^{nd} edn. Oxford: Blackwell.

Gabbard, C. and Krebbs, R. (2012) Studying Environmental Influence on Motor Development in Children. *The Physical Educator*, 69, 136-149.

Gallagher, D. J., Connor, D. J. and Ferri, B. A (2014) Beyond the far too incessant schism: Special education and the social model of disability. *International Journal of Inclusive Education*, 18, (11), 1120-1142.

Gentry, K., Snyder, K., Barstow, B. and Hamson-Utley, J. (2018) The Biopsychosocial Model: Application to Occupational Therapy Practice. *Open Journal of Occupational Therapy*, 6, (4), 1-22.

Goffman, E. (1959) *The Presentation of Self in Everyday Life*. London: Penguin.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin.

Goodall, C. (2015) How do we create ASD-friendly schools? A dilemma of placement. *Support for Learning*, 30, (4), 305-325.

Gov.uk (1981) *The Education Act*. Available at: *http://www.legislation.gov.uk/ukpga/1981/60/enacted* [Accessed 1 May 2019].

Gov.uk (1995) *The Disability Discrimination Act.* Available at: *http://www.legislation.gov.uk/ukpga/1995/50.* [Accessed 1 May 2019].

Gov.uk (1996) *The Education Act*. Available at: *https://www.legislation.gov.uk/ukpga/1996/56/contents* [Accessed 1 May 2019].

Gray, D. (2014) *Doing Research in the Real World*. London: Sage.

Grinker, R. (2009) *Unstrange Minds: Remapping the World of Autism*. New York: Basic Books.

Guckin, C. and Minton, J. (2014) From theory to practice: two ecosystemic approaches and their applications in understanding school bullying. *Australian Journal of Guidance and Counseling*, 24, (1), 36-48.

Hall, L. (2014) “With” not “about” - emerging paradigms for research in a cross-cultural space. *International Journal of Research and Method in Education*, 37, (4), 376-389.

Happé, F. and Frith, U. (2010) Introduction: The beautiful otherness of the autistic mind. In: Happé, F. and Frith, U. (Eds.) *Autism and Talent.* Oxford: Oxford University Press, xi.

Hart, S. and Drummond, J. (2014) Learning Without Limits: Constructing a Pedagogy Free from Deterministic Beliefs about Ability. In: Florian, L. (ed.) *The Sage Handbook of Special Education. Volume 2*. 2nd Edn. London: Sage, 439-458.

Harvey, C. (2018) *Difference Not Disorder: Understanding Autism Theory in Practice*. London: Jessica Kingsley.

Hebron, J., Humphrey, N. and Oldfield, J. (2015) Vulnerability to bullying of children with autism spectrum conditions in mainstream education: a multi-informant qualitative exploration. *Journal of Research in Special Educational Needs*, 15, (3), 185-193.

Hebron, J., Oldfield, J. and Humphrey, N. (2017) Cumulative risk effects in the bullying of children and young people with autism spectrum conditions. *Autism: International Journal of Research and Practice*, 21, 3, 291-300.

Hollenweger, J. (2014) *Definition and Classification of Disability*. Available at: [https://www.unicef.org/northmacedonia/reports/inclusive-education-definition-and-classification-disability.](https://www.unicef.org/northmacedonia/reports/inclusive-education-definition-and-classification-disability) [Accessed 16 April 2019].

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, M., Lai, M-C. and Mandy, W. (2017) “Putting on My Best Normal”: Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders*, 47, 2519-2534.

Huws, J. C. and Jones, R.S. (2010) ‘They just seem to live their lives in their own little world: lay perceptions of autism. *Disability and Society*, 25, (3), 331-344.

Illeris, K. (2006) What is Special about adult learning? In: Sutherland, P. and Crowther, J. (eds.) *Lifelong Learning: Concepts and Contexts*. Abingdon: Routledge, 15-23.

Imrie, R. (2004) Demistifying disability: a review of the *International Classification of Functioning, Disability and Health*. *Sociology of Health and Illness*, 26, (3), 287-305.

Jivraj, J., Sacrey, L-A., Newton, A., Nicholas, D. and Zwaigenbaum, L. (2014) Assessing the influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review. *Autism*, 18, (7), 782-793.

Kanner, L. (1943) Autistic Disturbances of Affective Contact. *Nervous Child*, 2, 217-250.

Katrine (2019) I stim. *The Spectrum*, 99, 14-15.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., Pellicano, E. (2015) Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism: The International Journal of Research and Practice*, 20, (4), 442-463.

King, N., Horrocks, C. and Brooks, J. (2019) *Interviews in Qualitative Research*. 2nd edn. London: Sage.

Kim, H. U. (2012) Autism across cultures: rethinking autism. *Disability and Society*, 27, (4), 535-545.

Lai, M-C., Lombardo, M., Ruigrok, A., Chakrabarti, B., Auyeung, B., Szatmari, P., Happé, F., Baron-Cohen, S., MRC AIMS Consortium (2017) Quantifying and exploring camouflaging in men and women with autism. *Autism*, 21, (6), 690-702.

Lawson, W. (2008) *Concepts of Normality The Autistic and Typical Spectrum*. London: Jessica Kingsley.

LeBlanc, L., Richardson, W., and Burns, K. (2009) Autism Spectrum Disorder and the Inclusive Classroom: Effective Training to Enhance Knowledge of ASD and Evidence-Based Practices. *Teacher Education and Special Education*, 32, (2), 166-179.

Leedham, A., Thompson, A., Smith, R. and Freeth, M. (2020) 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism: The International Journal of Research and Practice*, 24, (1), 135-146.

Lensmire, T. (2010) Rewriting Student Voice. *Journal of Curriculum Studies*, 30, (3), 261-291.

Lerner, R. (2005) Urie Bronfenbrenner: Career Contributions of the Consummate Developmental Scientist. In: Brofenbrenner, U. (ed.) *Making Human Beings Human: Bioecological perspectives on human development*. London: Sage, ix-xxvi.

Lewin, K. (1943) Defining the “field at a given time.” *Psychological Review*, 50, (3), 292-310.

Lundy, L. (2007) “Voice” is not enough: conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *British Educational Research Journal*, 33, (6), 927-942.

MacLeod, A. G., Lewis, A. and Robertson, C. (2014) “CHARLIE: PLEASE RESPOND!” Using a methodology with individuals on the autism spectrum. *International Journal of Research and Method in Education*, 37, (4), 407-420.

Maguire, M. (2005) What if You Talked to Me? I could be interesting! Ethical Research Considerations in Engaging with Bilingual / Multilingual Child Participants in Human Inquiry. *Forum: Qualitative Social Research*, 6, (1), 1-16.

McGuire, A. and Michalko, R. (2011) Minds between us: Autism, Mindblindness and the Uncertainty of Communication. *Educational Philosophy and Theory*, 43, (2), 162-177.

Messiou, K. (2012) Collaborating with children in exploring marginalisation: an approach to inclusive education. *International Journal of Inclusive Education*, 16, (12), 1311-1322.

Messiou, K. (2017) Engaging with the views of students to promote inclusion in education. *Journal of Educational Change*, 19, 1-7.

Messiou, K. (2019a) Understanding marginalisation through dialogue: a strategy for promoting the inclusion of all students in schools. *Educational Review*, 71, (3), 306-317.

Messiou, K. (2019b) The missing voices: students as a catalyst for promoting inclusive education. *International Journal of Inclusive Education*, 23, (7-8), 768-781.

Messiou, K. (2019c) Collaborative action research: facilitating inclusion in schools. *Educational Action Research*, 27, (2), 197-209.

Mezirow, J. (1978) Perspective Transformation. *Adult Learning*, 28, 100-110.

Mezirow, J. (2006) An overview of transformative learning. In: Sutherland, P. and Crowther, J. (eds.) *Lifelong Learning: Concepts and Contexts*. New York: Routledge, 24-38.

Milton, D. and Bracher, M. (2013) Autistics speak but are they heard? *Medical Sociology Online*, 7, (2), 60-69.

Moretti, M., Alves, I. and Maxwell, G. (2012) A systematic literature review of the situation of the International Classification of Functioning, Disability and Health – Children and Youth version in education: a useful tool or a flight of fancy? *American Journal of Physical Medicine and Rehabilitation*, 91, (13/1) 103-117.

Moon, J. (1999) *Reflection in Learning and Professional Development*. Abingdon: RoutledgeFalmer.

Murray, D. (2008) 'Whose normal is it anyway?' In: Lawson, W. (ed.) *Concepts of Normality The Autistic and Typical Spectrum*. London: Jessica Kingsley, 82-94.

National Autistic Society (NAS) (online). *The language we use to describe autism*. Available at: *https://www.autism.org.uk/about/what-is/describing.aspx*. [Accessed 10 October 2019].
National Autistic Society (NAS) (2016). *School Report 2016*. London: The National Autistic Society.

National Autistic Society (NAS) (2019). *Autism and Education: Good Practice Guide Supporting Autistic Children in Your Area.* Available at: https://www.autism.org.uk/professionals/teachers/education-guide.aspx. [Accessed April 2019].

Neal, J. W. and Neal, Z. P. (2013) Nested or Networked? Future directions for ecological systems theory. *Social Development*, 22, (4), 722-737.

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Ashkenazy, E., Boisclair, C., Robertson, S. and Baggs, A. (2011) Collaboration strategies in Nontraditional Community-Based Participatory Research Partnerships: Lessons from an Academic-Community Partnership with Autistic Self-Advocates. *Progress in Community Health Partnerships: Research, Education and Action*, 5, (2), 143-150.

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, C., Ashkenazy, E. and Baggs, A. (2012) Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: a cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*, 28, (6), 761-769.

Nind, M. (2011) Participatory data analysis: a step too far? *Qualitative Research*, 11, (4), 349-363.

Nind, M. and Vinha, H. (2012) Doing research inclusively: bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, 42, 102-109.

Nind, M. (2014) *What is Inclusive Research?* London: Bloomsbury.

Nind, M. (2017) The Practical Wisdom of Inclusive Research. *Qualitative Research*, 17, (3), 278-288.

Norwich, B. (2016) Conceptualising Special Educational Needs Using a Biopsychocosocial Model In England: The Prospects and Challenges of Using the International Classification of Functioning Framework. *Frontiers in Education*, 1, (5), 1-12.

Oliver, M. (1996) *Understanding Disability: from theory to practice*. Basingstoke: Macmillan.

Oliver, M. (2009) *Understanding Disability: from theory to practice*. 2nd edn. Basingstoke: Palgrave Macmillan.

Oliver, M. (2013) The social model of disability: thirty years on. *Disability and Society*, 28, (7), 1024-1026.

Opertti, R., Walker, Z. and Zhang, Y. (2014) Inclusive Education: From Targetting Groups and Schools to Achieving Quality Education as the Core of EFA. In: Florian, L. (ed.) *The Sage Handbook of Special Education. Volume 1*. 2nd edn. London: Sage, 149-170.

Paat, Y-F. (2013) Working with Immigrant Children and their Families: an application of Bronfenbrenner's Ecological Systems Theory. *Journal of Human Behaviour in the Social Environment*, 23, (8), 954-966.

Parsons, S. and Cobb, S. (2014) Reflections on the role of the 'users': Challenges in a multi-disciplinary context of learner-centred design for children on the autism spectrum. *International Journal of Research and Method in Education*, 37, (4), 421-441.

Parsons, S., Yuill, N., Good, J. and Brosnan, M. (2020) 'Whose agenda? Who knows best? Whose voice?' Co-creating a technology research roadmap with autism stakeholders. *Disability and Society*, 35, (2), 201-234.

Patton, M.Q. (2015) *Qualitative Research and Evaluation Methods*. 4th edn. London: Sage.

Philpott, C. and Poultney, V. (2018) *Evidence-based Teaching*. St Albans: Critical.

Potts, P. (2007) Knowledge is not enough: an exploration of what we can expect from enquiries which are social. In: Clough, P. and Barton, L. (eds) *Articulating with Difficulty Research Voices in Inclusive Education*. London: Paul Chapman, 16-28.

Pring, R. (2004) *Philosophy of Educational Research*. 2nd edn. London: Continuum.

Pring, R. (2015) *Philosophy of Educational Research*. 3rd edn. London: Bloomsbury.

Prezant, B. (2015) Uniquely Human: *A different way of seeing autism*. London: Souvenir Press.

Ravet, J. (2011) Inclusive/exclusive? Contradictory Perspectives on autism and inclusion: the case for an integrative position. *International Journal of Inlcuisve Education*, 15, (6), 667-682.

Reser, J. (2011) Conceptualising the Autism Spectrum in Terms of Natural Selection and Behavioural Ecology: The Solitary Forager Hypothesis. *Evolutionary Psychology*, 9, (2), 207-238.

Riddell, S., Wilkinson, H. and Baron, S. (2007) From Emancipatory Research to focus group: people with learning difficulties and the research process. In: Clough, P. and Barton, L. (eds). *Articulating with Difficulty Research Voices in Inclusive Education*. London: Sage. p.78-95.

Robison, J. E. (2007) *Look me in the Eye: My life with Asperger's*. London: Ebury Press.

Rodrìguez, L. and Brown, T. (2009) From voice to agency: Guiding principles for participatory action research with youth. *New Directions for Youth Development*, 123, 19-34.

Rogoff, B. (2003) *The Cultural Nature of Human Development*. Oxford: Oxford Univeresity Press.

Rudduck, J. and Fielding, M. (2006) Student Voice and the Perils of Popularity. *Educational Review*, 58, (2), 219-231.

Sacks, O. (2007) *The Man who Mistook his Wife for a Hat*. London: Picador.

Sainsbury, C. (2000) *The Martian in the Playground*. London: Paul Chapman.

Sciutto, M., Richwine, S., Mentrikoski, J. and Niedzwiecki, K. (2012) A Qualitative Analysis of the School Experiences of Students with Asperger Syndrome. *Focus on Autism and other Developmental Disabilities*, 27, (3), 177-188.

Seale, J. (2010) Doing student voice work in higher education: an exploration of the value of participatory methods. *British Educational Research Journal*, 36, (6), 995-1015.

Seale, J., Nind, M. and Parsons, S. (2014) Inclusive research in education: contributions to method and debate. *International Journal of Research and Method in Education*, 37, (4), 347-356.

Shakespeare (2006) *Disability Rights and Wrongs*. London: Routledge.

Shakespeare, T. (2014) *Disability Rights and Wrongs Revisited*. 2nd Edn. London: Routledge.

Shakespeare, T. (2018) *Disability the basics*. London: Routledge.

Silberman, S. (2015) *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*. New York: Avery.

Sinclair, J. (1993) 'Don't mourn for us' Our Voice, 1, (3), Syracuse, NY: Autism Network.

Sinclair, J. (1999) *Why I Dislike "Person-First Language".* Available at: *web.archive.org/web/20090210190652/http://web.syr.edu/~jisincla/person_first.htm*. [Accessed: 15 August, 2019].

Siobahn (2018) My life as I see it through a different lens. *The Spectrum*, 96, 13-15.

Söder, M. (2009) Tensions, Perspectives and Themes in Disability Studies. *Scandinavian Journal of Disability Research*, 11, (2) 67-81.

Solomon, A. (2014) *Far From the Tree: parents, children and the search for identity*. London: Vintage.

Sontag, J. C. (1996) Towards a comprehensive theoretical framework for disability research: Bronfenbrenner revisited. *The Journal of Special Education*, 30, (3), 319-344.

Swain, J., French, S., Barnes, C. and Thomas, C. (2014) (eds.) An Historical Overview. In: Swain, J., French, S., Barnes, C. and Thomas, C., *Disabling Barriers – Enabling Environments.* London: Sage, 3-8.

Swick, K. and Williams, R. (2006) An analysis of Bronfenbrenner's Bio-Ecological Perspective for early Childhood Educators: Implications for working with families experiencing stress. *Early Childhood Education Journal*, 33, (5), 371-378.

Thomas, G. (2013) 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), 473-490.

Treffert, D. A. (2010) The Savant Syndrome: an extraordinary condition. A synopsis: past, present, future. In: Happé, F. and Frith, U. (eds.) *Autism and Talent*. Oxford: Oxford University Press, 1-12.

UNESCO. (2017) *A Guide for Ensuring Inclusion and Equity in Education*. Paris: UNESCO.

UNICEF (1991) *United Nations Convention on the Rights of the Child*. Available at: *https://www.unicef.org.uk/what-we-do/un-convention-child-rights/.* [Accessed 2 May 2019].

United Nations (2006) *Convention on the Rights of Persons with Disabilities*. Available at: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf. [Accessed 10 December 2019].

University of Winchester. (2015) *Research and Knowledge Exchange Ethics Policy and Procedures*. Available at: *https://intranet.winchester.ac.uk/information-bank/research-and-knowledge-exchange/Documents/Ethics%20Policy%20and%20Procedures%20_Final%20Sep2015.pdf.* [Accessed 8 November 2017].

Union of the Physically Impaired Against Segregation (UPIAS) and The Disability Alliance (1976) *Fundamental Principles of Disability*. Available at: *https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf.* [Accessed 22 October 2018].

Veck, W. and Hall, M. (2018) Inclusive research in education: dialogue, relations and methods. *International Journal of Inclusive Education*, DOI: 10.1080/13603116.2018.1512659. Available at: https://www.tandfonline.com/doi/full/10.1080/13603116.2018.1512659. [Accessed 11 December 2019].

Walmsley, J. (2001) Normalisation, Emancipatory Research and Inclusive Research in Learning Disability. *Disability and Society*, 16, (2), 187-205.

Welikala, T. and Atkin, C. (2014) Student Co-Inquirers: the challenges and benefits of inclusive research. *International Journal of Research and Method in Education*, 37, (4), 390-406.

Wenger, E. (1998) *Communities of Practice: Learning, Meaning and Identity*. Cambridge: Cambridge University Press.

WHO (2002) *Towards a Common Language for Functioning, Disability and Health ICF*. Available at: *http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1.* [Accessed 22 November 2017].

WHO (2018) *International Classification of Diseases (ICD 11).* Available at: *https://icd.who.int/en.* [Accessed 10 October 2019].

Williams, D. (1992) *Nobody Nowhere: The Remarkable Autobiography of an Autistic Girl*. London: Bantam.

Williams, D. (1996) *Autism An Inside-Out Approach*. London: Jessica Kingsley.

Wolfond, E. (2008) The Mismeasure of Autism: The basis for current autism "advocacy". In: Lawson, W. (ed.) *Concepts of Normality The Autistic and Typical Spectrum*. London: Jessica Kingsley. pp.104-129.

Appendices

Appendix 1 Project Information Sheets for head-teachers, parents and pupils

Project Information Sheet: Secondary Head Teacher

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

I am a Senior Lecturer in the Faculty of Education, Health and Social Care (EHSC) and the Department of Education at Winchester University and I am studying for a Doctorate in Education. I have a current and relevant DBS that you are welcome to see. The research project described below forms the basis of my thesis and may be the foundation for future development in the area of autism, inclusion and mainstream education including journal articles and in-service training for teachers and students. I would very much appreciate it if you were prepared to take part in a project that involves collecting and analysing the memories of some secondary pupils with autism who attended mainstream primary schools. Before you decide whether you would be happy to provide consent, it is important you understand what the project involves and what will be undertaken. So, please read the following information and let me know if anything is unclear either by emailing me or if possible we could arrange to meet. Your participation in this study is entirely voluntary and you are free to withdraw at any time without giving reason and without penalty.

I was fascinated by some information from a survey by the *National Autism Society* published in 2016. They found that of the 980 parents and carers of pupils with autism who completed the survey, 58% believed schools' knowledge of autism was 'the single most important factor in meeting their child's needs'. Two-thirds of the 85 young people who took part in the survey stated that their experience of school would be better 'if more teachers understood autism' (NAS, 2016:17). I would therefore like to spend time talking with any pupils with autism who attended a mainstream primary school who would be happy to discuss some memories from their primary education and to consider what they wish their teachers had understood better about their autism.

As I am aware that working directly with me may cause some pupils anxiety, I would like to talk initially with the pupil about the best way they would like to share this information with me. Ideally I would like to audio record our discussions in order to keep an accurate record and be able to engage more fully in the time we share together. This would be done in a non-intrusive manner and the data would be stored anonymously on a password protected device. However I will only use audio recording if the pupil is happy to give consent for this after discussing it with their parents. It is possible that some of the data gathered may also be used anonymously as the basis for future projects and that this project and future projects that may use this data will lead to publications for readership by academic as well as wider audiences.

All results from the study will be confidential and no school, teacher or pupil will be able to be identified should the work be published. All audio recordings will be stored in an encrypted file and destroyed once the transcripts have been completed. If you require further information please email me at Miriam.Walker@winchester.ac.uk

This study has been approved by the Ethics Sub-Committee for the Department for EHSC. If you feel at any time that there is something wrong about the study, then please contact me or the Chair of the RKT Ethics Committee.

If you are happy to give consent, then please complete the consent form overleaf. Please ensure you keep a copy of this sheet for future reference.

Yours sincerely,

Miriam Walker
Senior Lecturer in Teacher Development
Faculty of Education, Health and Social Care
University of Winchester
Room 29, St Grimbald's
Sparkford Road
Winchester
SO22 4NR
Direct dial: 01962 826366

Project Information Sheet: Parent / Guardian

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

I am a Senior Lecturer in the Faculty of Education, Health and Social Care (EHSC) and the Institute of Education at Winchester University and I am studying for a Doctorate in Education. I have a current and relevant DBS that you are welcome to see. The research project described below forms the basis of my thesis and may be the foundation for future development in the area of autism, inclusion and mainstream education including journal articles and in-service training for teachers and students.

I would very much appreciate it if you were prepared to provide consent for your son / daughter to take part in a project that involves collecting and analysing the memories of some secondary pupils with autism who attended mainstream primary schools. Before you decide whether you would be happy to provide consent, it is important you understand what the project involves and what will be undertaken. So, please read the following information and let me know if anything is unclear by emailing me at the address at the end, or we could arrange to meet up. The participation of your son / daughter in this study is entirely voluntary and you or they are free to withdraw at any time without giving reason and without penalty. I will also be requiring them to give their consent to take part too if they are happy to do so.

As a previous teacher, I was fascinated by some information from a survey by the *National Autism Society* published in 2016. They found that of the 980 parents and carers of pupils with autism who completed the survey, 58% believed schools' knowledge of autism was 'the single most important factor in meeting their child's needs'. Two-thirds of the 85 young people who took part in the survey stated that their experience of school would be better 'if more teachers understood autism' (NAS, 2016:17). I would therefore like to spend time talking with your son / daughter about their memories from their primary education and to consider what they wish their teachers had understood better about their autism.

As I am aware that working directly with me may cause some pupils anxiety, I would like to talk initially with them about the best way they would like to share this information with me. Ideally I would like to audio record our discussions in order to keep an accurate record and be able to engage more fully in the time we share together. This would be done in a non-intrusive manner and the data would be stored anonymously on a password protected device. However I will only use audio recording if the pupil is happy to give consent for this after discussing it with you. It is possible that some of the data gathered may also be used anonymously as the basis for future projects and that this project and future projects that may use this data will lead to publications for readership by academic as well as wider audiences.

All results from the study will be confidential and no school, teacher or pupil will be able to be identified should the work be published. All audio recordings will be stored in an encrypted file and destroyed once the transcripts have been completed. If you require further information please email me at Miriam.Walker@winchester.ac.uk

This study has been approved by the Ethics Sub-Committee for the Department for EHSC. If you feel at any time that there is something wrong about the study, then please contact me or the Chair of the RKT Ethics Committee.

If you are happy to give consent, then please complete the consent form overleaf. Please ensure you keep a copy of this sheet for future reference.

Yours sincerely,

Miriam Walker
Senior Lecturer in Teacher Development
Faculty of Education, Health and Social Care
University of Winchester
Room 29, St Grimbald's
Sparkford Road
Winchester
SO22 4NR
Direct dial: 01962 826366

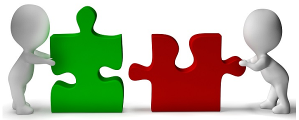
Project Information Sheet: Pupil

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

Dear Pupil,

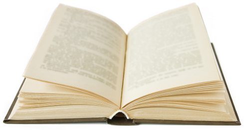
I work at Winchester University and was hoping that you would be interested in helping me with a research project I am doing that seeks to hear the views of some secondary pupils with autism who attended mainstream primary schools.

If this sounds interesting to you and you would like to take part, before you decide to provide consent, it is important you understand what the project involves and what will be undertaken. So, please read the following information and ask if anything is unclear either by emailing me or asking when we meet.



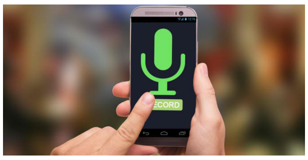
Your participation in this study is entirely voluntary and you are free to withdraw at any time without giving reason and without penalty, at which point any data held about you will be erased.

If you are happy to be involved in this, I would like to work with you in a way that you find comfortable so we can talk about how this might be when we meet.



I hope to use the information that you provide for me by typing some of it up which eventually will be made into a book. It is possible that later some writing may be used for other projects that could be read by other people.

So, it is really important that everything is anonymous, which means that you and your school will not be able to be identified.



It would be great if you are happy for me to audio record our discussions as I will be able to keep a more accurate record of what we talk about.

If you require further information please email me at Miriam.Walker@winchester.ac.uk

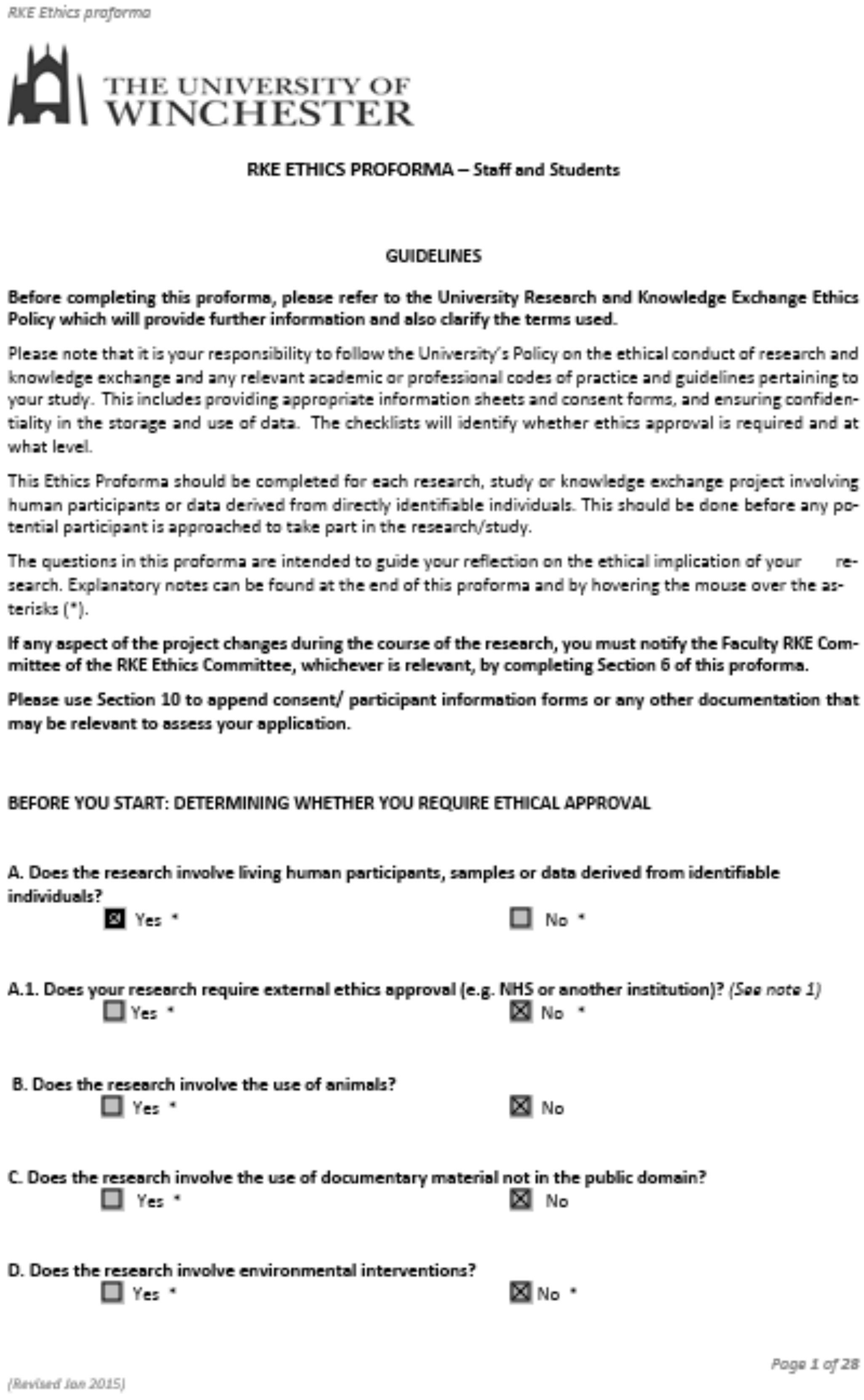
If you are happy to give consent, then please complete the consent form overleaf. Please ensure you keep a copy of this sheet for future reference.

Yours sincerely,

Miriam Walker

Miriam Walker
Senior Lecturer in Teacher Development
Faculty of Education, Health and Social Care
University of Winchester
Room 29, St Grimbald's
Sparkford Road
Winchester
SO22 4NR
Direct dial: 01962 826366

Appendix 2 Ethics Proforma



RKE Ethics proforma

THE UNIVERSITY OF
WINCHESTER

RKE ETHICS PROFORMA – Staff and Students

GUIDELINES

Before completing this proforma, please refer to the University Research and Knowledge Exchange Ethics Policy which will provide further information and also clarify the terms used.

Please note that it is your responsibility to follow the University's Policy on the ethical conduct of research and knowledge exchange and any relevant academic or professional codes of practice and guidelines pertaining to your study. This includes providing appropriate information sheets and consent forms, and ensuring confidentiality in the storage and use of data. The checklists will identify whether ethics approval is required and at what level.

This Ethics Proforma should be completed for each research, study or knowledge exchange project involving human participants or data derived from directly identifiable individuals. This should be done before any potential participant is approached to take part in the research/study.

The questions in this proforma are intended to guide your reflection on the ethical implication of your research. Explanatory notes can be found at the end of this proforma and by hovering the mouse over the asterisks (*).

If any aspect of the project changes during the course of the research, you must notify the Faculty RKE Committee of the RKE Ethics Committee, whichever is relevant, by completing Section 6 of this proforma.

Please use Section 10 to append consent/ participant information forms or any other documentation that may be relevant to assess your application.

BEFORE YOU START: DETERMINING WHETHER YOU REQUIRE ETHICAL APPROVAL

A. Does the research involve living human participants, samples or data derived from identifiable individuals?

☒ Yes * ☐ No *

A.1. Does your research require external ethics approval (e.g. NHS or another institution)? *(See note 1)*

☐ Yes * ☒ No *

B. Does the research involve the use of animals?

☐ Yes * ☒ No

C. Does the research involve the use of documentary material not in the public domain?

☐ Yes * ☒ No

D. Does the research involve environmental interventions?

☐ Yes * ☒ No *

Page 1 of 28

(Revised Jan 2015)

SECTION 1: PERSONAL DETAILS

1.1. Your name: **MIRIAM WALKER**

1.2. Your Department: EDUCATION

1.3. Your status:

☐ Undergraduate Student	☒ Staff (Academic)
☐ Taught Master	☐ Staff (Professional Services)
☒ Research Degree student	☐ Other (please specify):

1.4. Your Email address: **Miriam.Walker@winchester.ac.uk**

1.5. Your Telephone number: **01962 826366**

For students only:

1.6. Your degree programme: **EdD**

1.7. Your supervisor's name: **Wayne Veck (DoS)**

1.8. Your supervisor's department: Education Studies

SECTION 2: YOUR RESEARCH

2.1. Project title: Towards an Interactive Model of Autism: Bronfenbrenner's Ecological Systems Theory and the Celebration of Difference in Schooling

2.3. Expected start date: January 2018

2.4. Expected completion date: June 2021

2.5. Expected location: [7] University of Winchester and Hampshire Schools, UK

2.6. If outside the UK, state country: [7] N/A

2.7. Has ethical approval been obtained at the host country? * ☐ Yes ☐ No

2.8. If not, why not?

2.9 If the research is taking place outside the UK, is it covered by the University's insurance, or has the researcher obtained an appropriate insurance (e.g. travel insurance)? ☐ Yes ☐ No

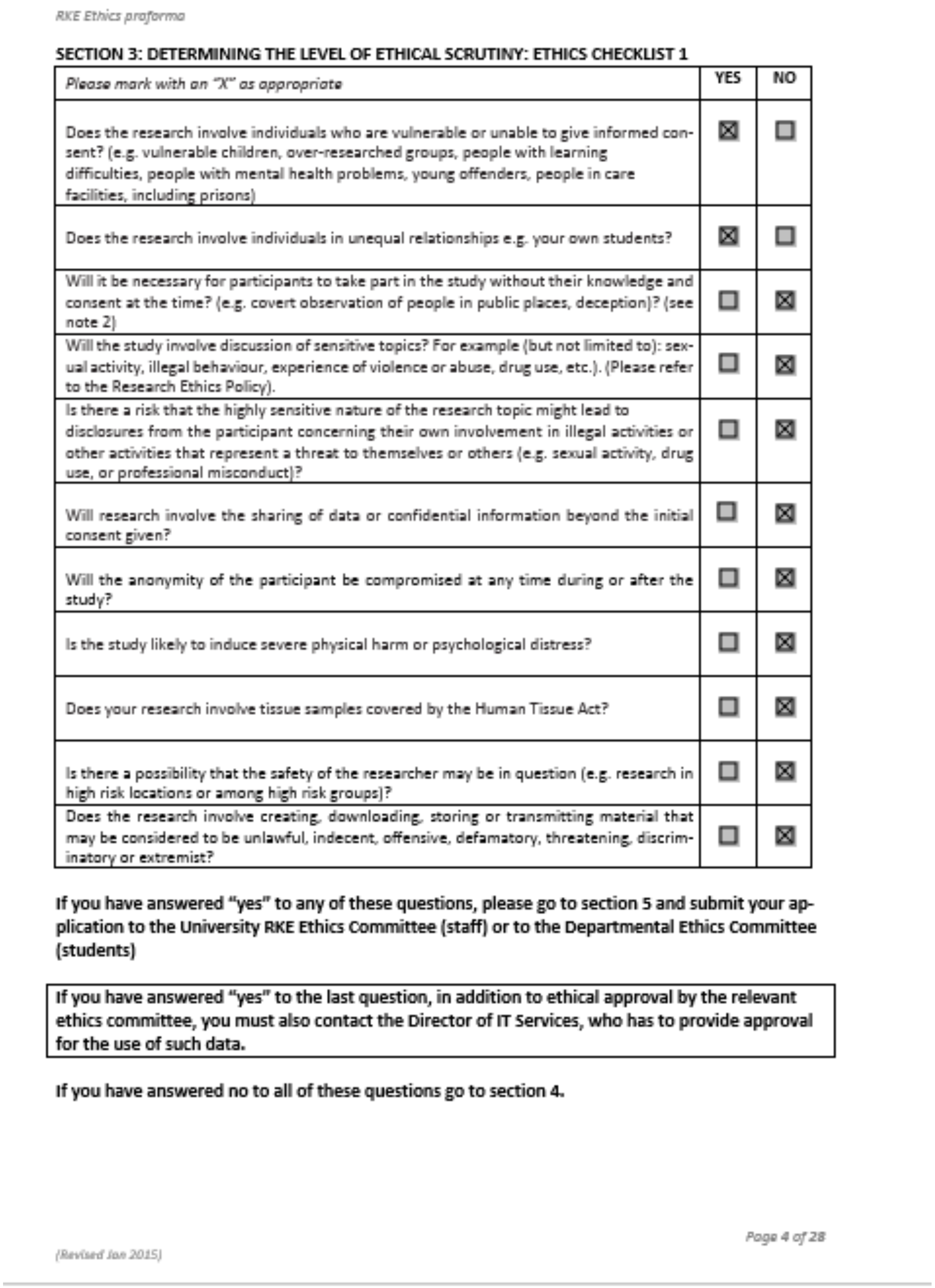
2.10. Does the research include risks or other factors that might cause it to be excluded from coverage by the University insurers? (see note 5) ☐ Yes ☒ No

2.11 Has funding been sought for this research? ☐ Yes ☒ No

2.12. If so, where have you applied for funding?

2.13. Has the funding been granted? ☐ Yes ☐ No ☐ Pending

2.14. Other collaborators *



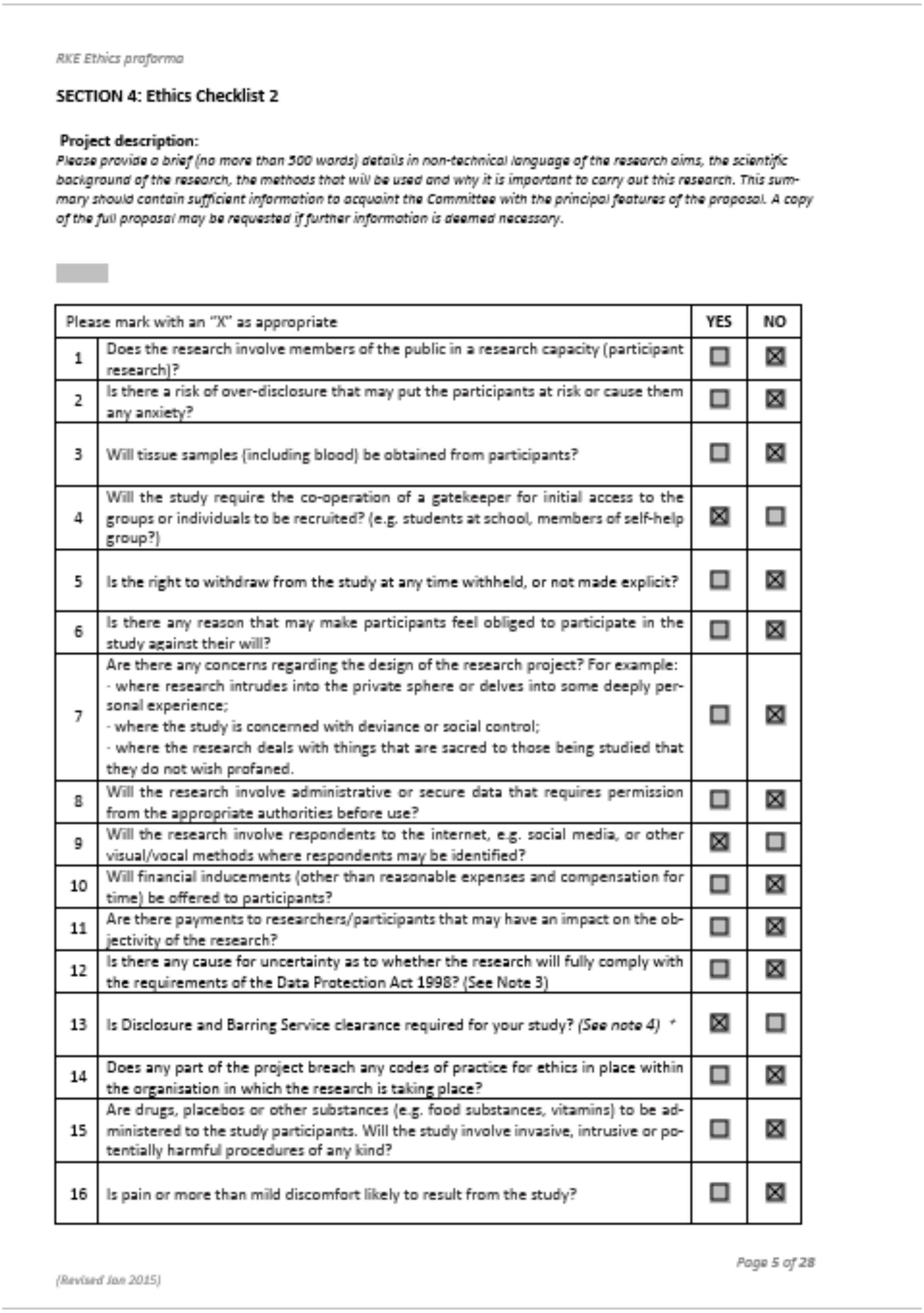
SECTION 3: DETERMINING THE LEVEL OF ETHICAL SCRUTINY: ETHICS CHECKLIST 1

Please mark with an "X" as appropriate	**YES**	**NO**
Does the research involve individuals who are vulnerable or unable to give informed consent? (e.g. vulnerable children, over-researched groups, people with learning difficulties, people with mental health problems, young offenders, people in care facilities, including prisons)	☒	☐
Does the research involve individuals in unequal relationships e.g. your own students?	☒	☐
Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (e.g. covert observation of people in public places, deception)? (see note 2)	☐	☒
Will the study involve discussion of sensitive topics? For example (but not limited to): sexual activity, illegal behaviour, experience of violence or abuse, drug use, etc.). (Please refer to the Research Ethics Policy).	☐	☒
Is there a risk that the highly sensitive nature of the research topic might lead to disclosures from the participant concerning their own involvement in illegal activities or other activities that represent a threat to themselves or others (e.g. sexual activity, drug use, or professional misconduct)?	☐	☒
Will research involve the sharing of data or confidential information beyond the initial consent given?	☐	☒
Will the anonymity of the participant be compromised at any time during or after the study?	☐	☒
Is the study likely to induce severe physical harm or psychological distress?	☐	☒
Does your research involve tissue samples covered by the Human Tissue Act?	☐	☒
Is there a possibility that the safety of the researcher may be in question (e.g. research in high risk locations or among high risk groups)?	☐	☒
Does the research involve creating, downloading, storing or transmitting material that may be considered to be unlawful, indecent, offensive, defamatory, threatening, discriminatory or extremist?	☐	☒

If you have answered "yes" to any of these questions, please go to section 5 and submit your application to the University RKE Ethics Committee (staff) or to the Departmental Ethics Committee (students)

If you have answered "yes" to the last question, in addition to ethical approval by the relevant ethics committee, you must also contact the Director of IT Services, who has to provide approval for the use of such data.

If you have answered no to all of these questions go to section 4.

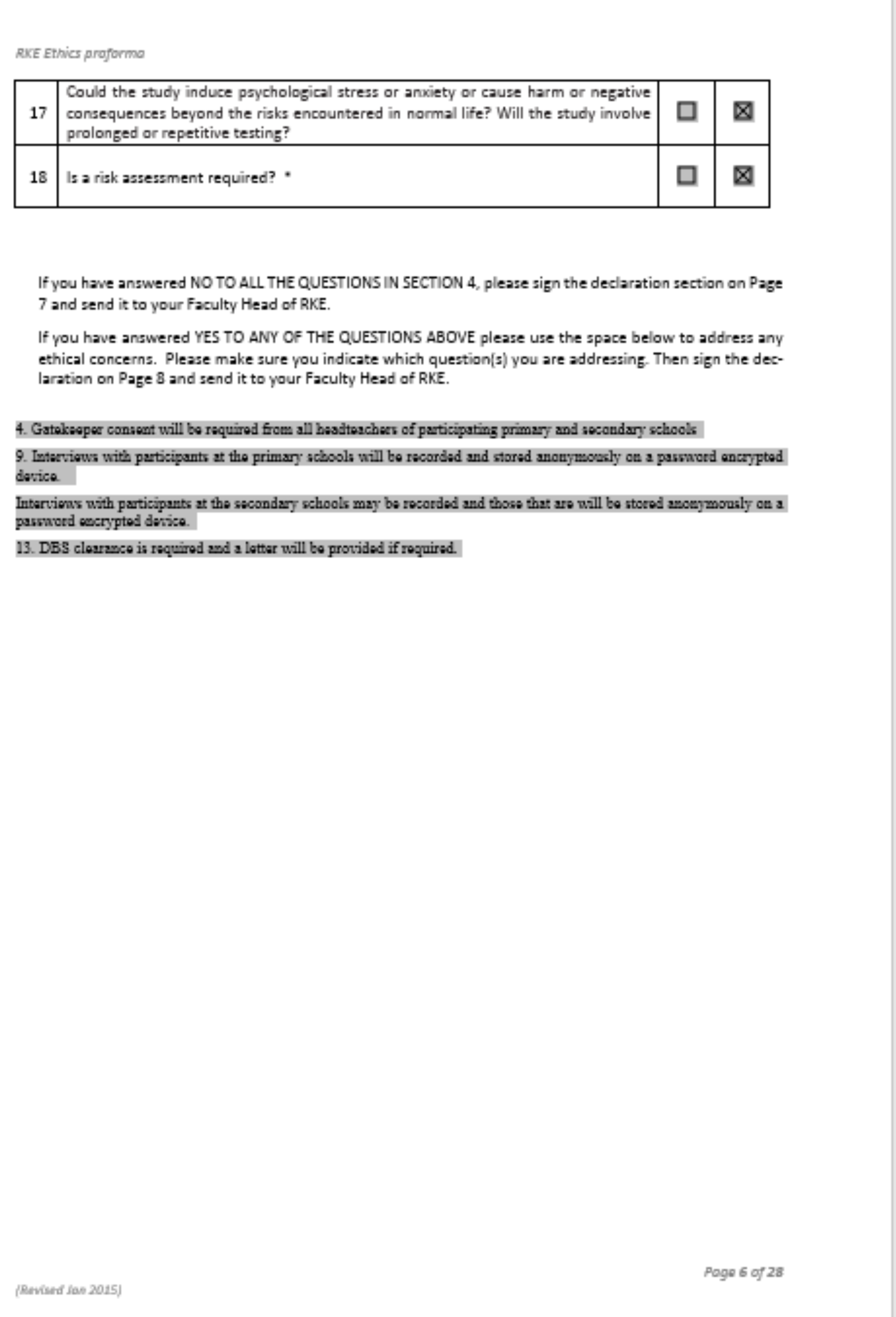


SECTION 4: Ethics Checklist 2

Project description:

Please provide a brief (no more than 500 words) details in non-technical language of the research aims, the scientific background of the research, the methods that will be used and why it is important to carry out this research. This summary should contain sufficient information to acquaint the Committee with the principal features of the proposal. A copy of the full proposal may be requested if further information is deemed necessary.

Please mark with an "X" as appropriate		YES	NO
1	Does the research involve members of the public in a research capacity (participant research)?	☐	☒
2	Is there a risk of over-disclosure that may put the participants at risk or cause them any anxiety?	☐	☒
3	Will tissue samples (including blood) be obtained from participants?	☐	☒
4	Will the study require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited? (e.g. students at school, members of self-help group?)	☒	☐
5	Is the right to withdraw from the study at any time withheld, or not made explicit?	☐	☒
6	Is there any reason that may make participants feel obliged to participate in the study against their will?	☐	☒
7	Are there any concerns regarding the design of the research project? For example: - where research intrudes into the private sphere or delves into some deeply personal experience; - where the study is concerned with deviance or social control; - where the research deals with things that are sacred to those being studied that they do not wish profaned.	☐	☒
8	Will the research involve administrative or secure data that requires permission from the appropriate authorities before use?	☐	☒
9	Will the research involve respondents to the internet, e.g. social media, or other visual/vocal methods where respondents may be identified?	☒	☐
10	Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?	☐	☒
11	Are there payments to researchers/participants that may have an impact on the objectivity of the research?	☐	☒
12	Is there any cause for uncertainty as to whether the research will fully comply with the requirements of the Data Protection Act 1998? (See Note 3)	☐	☒
13	Is Disclosure and Barring Service clearance required for your study? *(See note 4)* *	☒	☐
14	Does any part of the project breach any codes of practice for ethics in place within the organisation in which the research is taking place?	☐	☒
15	Are drugs, placebos or other substances (e.g. food substances, vitamins) to be administered to the study participants. Will the study involve invasive, intrusive or potentially harmful procedures of any kind?	☐	☒
16	Is pain or more than mild discomfort likely to result from the study?	☐	☒



17	Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life? Will the study involve prolonged or repetitive testing?	☐	☒
18	Is a risk assessment required? *	☐	☒

If you have answered NO TO ALL THE QUESTIONS IN SECTION 4, please sign the declaration section on Page 7 and send it to your Faculty Head of RKE.

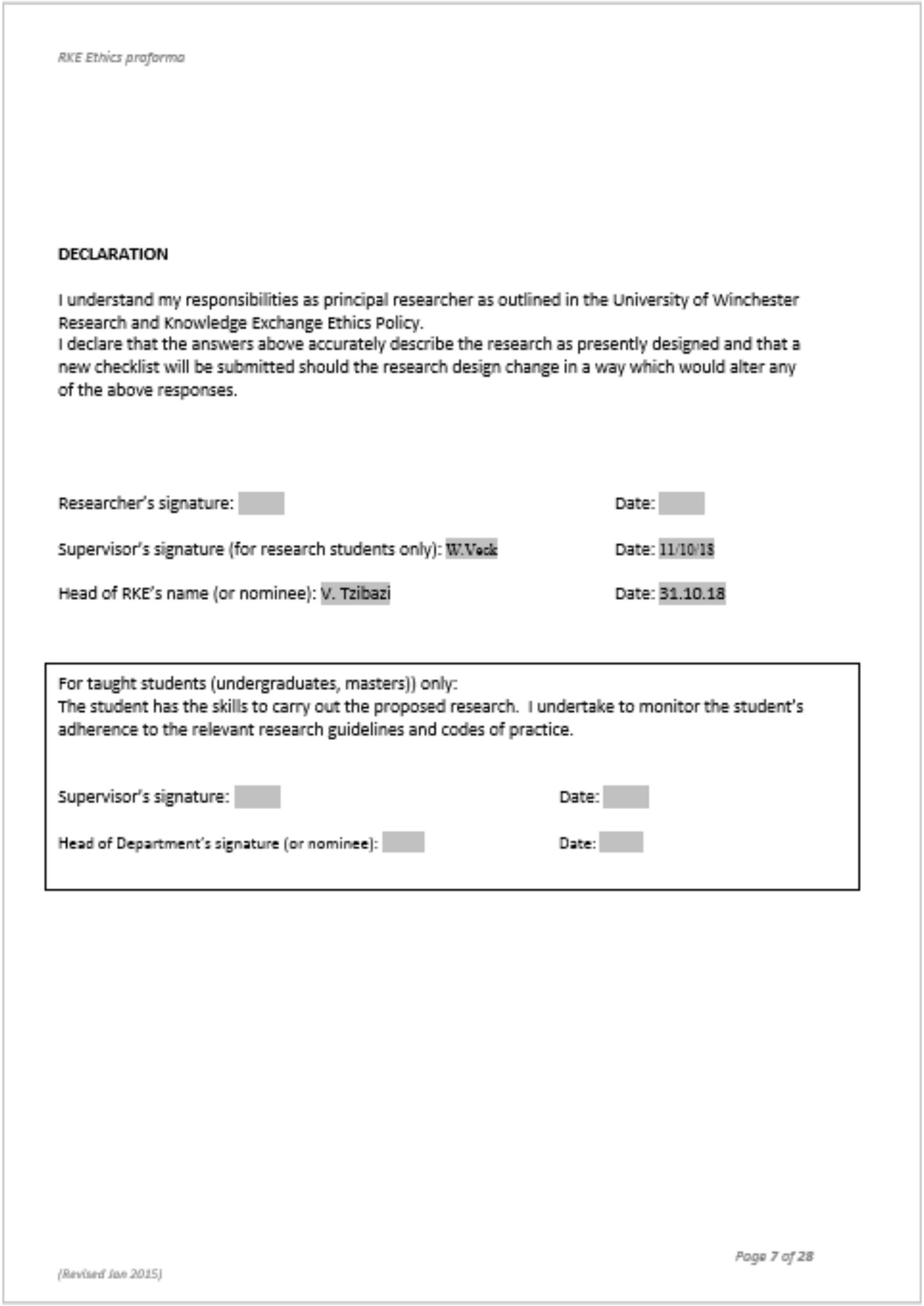
If you have answered YES TO ANY OF THE QUESTIONS ABOVE please use the space below to address any ethical concerns. Please make sure you indicate which question(s) you are addressing. Then sign the declaration on Page 8 and send it to your Faculty Head of RKE.

4. Gatekeeper consent will be required from all headteachers of participating primary and secondary schools

9. Interviews with participants at the primary schools will be recorded and stored anonymously on a password encrypted device.

Interviews with participants at the secondary schools may be recorded and those that are will be stored anonymously on a password encrypted device.

13. DBS clearance is required and a letter will be provided if required.



DECLARATION

I understand my responsibilities as principal researcher as outlined in the University of Winchester Research and Knowledge Exchange Ethics Policy.
I declare that the answers above accurately describe the research as presently designed and that a new checklist will be submitted should the research design change in a way which would alter any of the above responses.

Researcher's signature: Date:

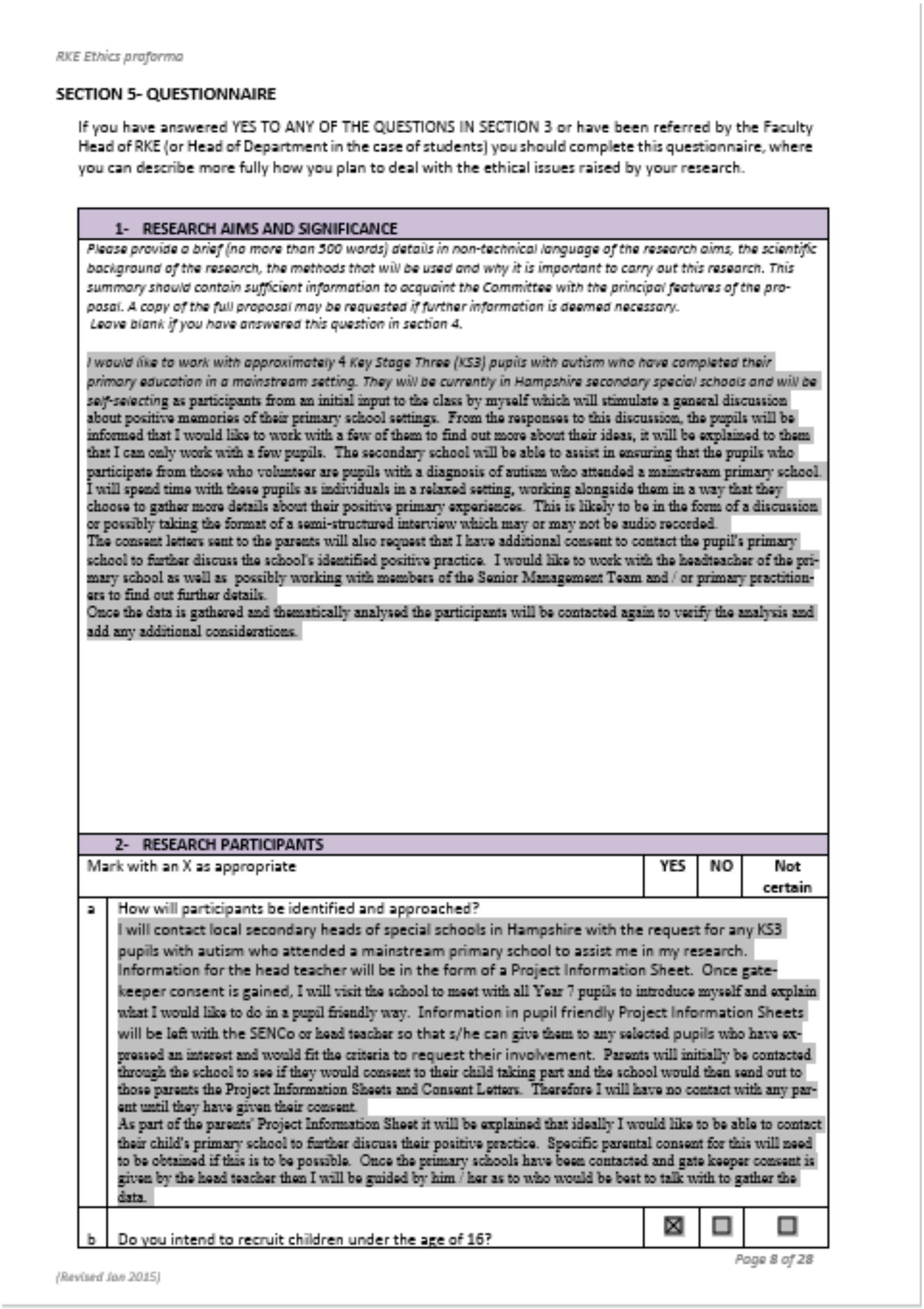
Supervisor's signature (for research students only): W.Veck Date: 11/10/18

Head of RKE's name (or nominee): V. Tzibazi Date: 31.10.18

For taught students (undergraduates, masters)) only:
The student has the skills to carry out the proposed research. I undertake to monitor the student's adherence to the relevant research guidelines and codes of practice.

Supervisor's signature: Date:

Head of Department's signature (or nominee): Date:



SECTION 5- QUESTIONNAIRE

If you have answered YES TO ANY OF THE QUESTIONS IN SECTION 3 or have been referred by the Faculty Head of RKE (or Head of Department in the case of students) you should complete this questionnaire, where you can describe more fully how you plan to deal with the ethical issues raised by your research.

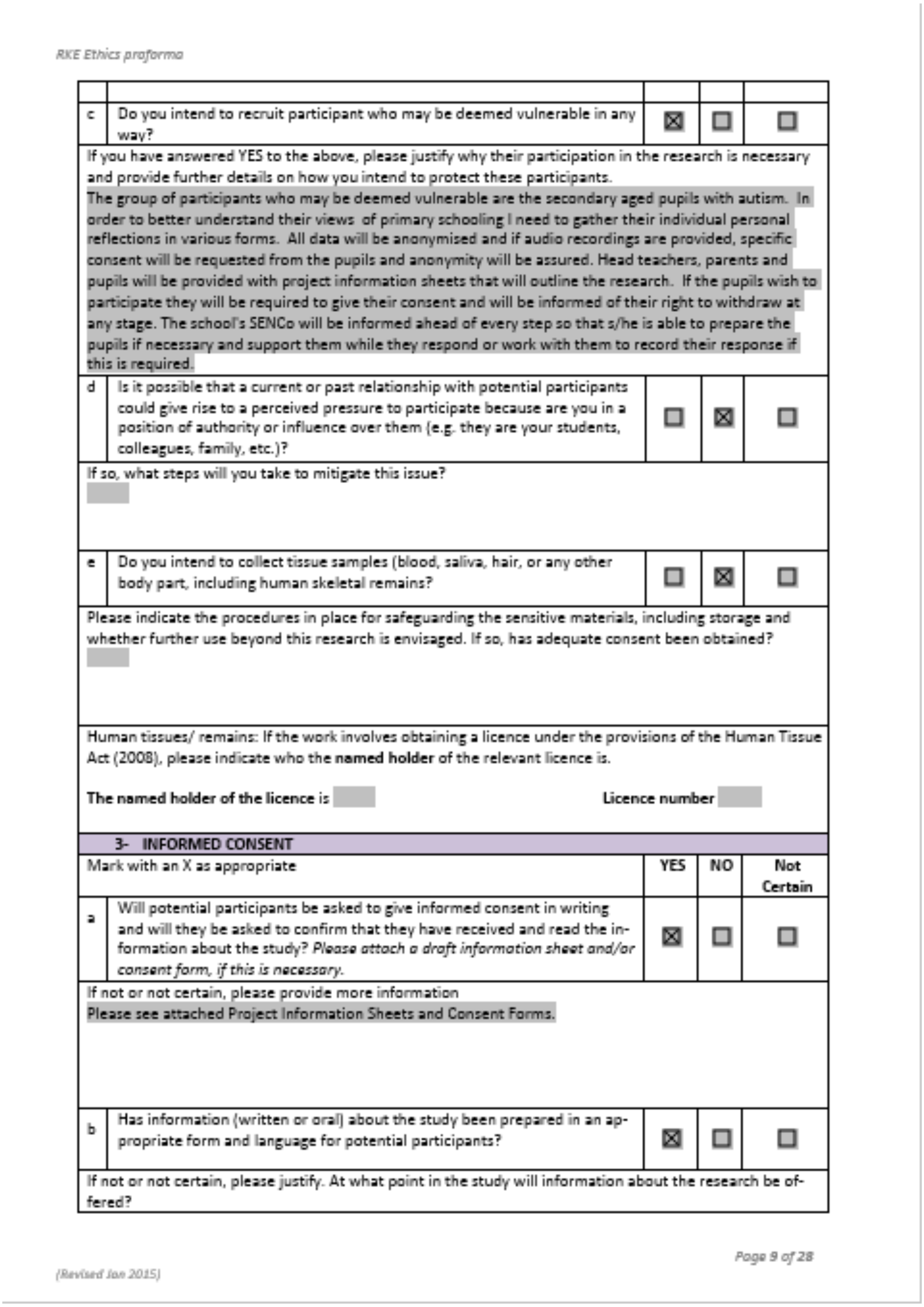
1- RESEARCH AIMS AND SIGNIFICANCE

Please provide a brief (no more than 500 words) details in non-technical language of the research aims, the scientific background of the research, the methods that will be used and why it is important to carry out this research. This summary should contain sufficient information to acquaint the Committee with the principal features of the proposal. A copy of the full proposal may be requested if further information is deemed necessary.
Leave blank if you have answered this question in section 4.

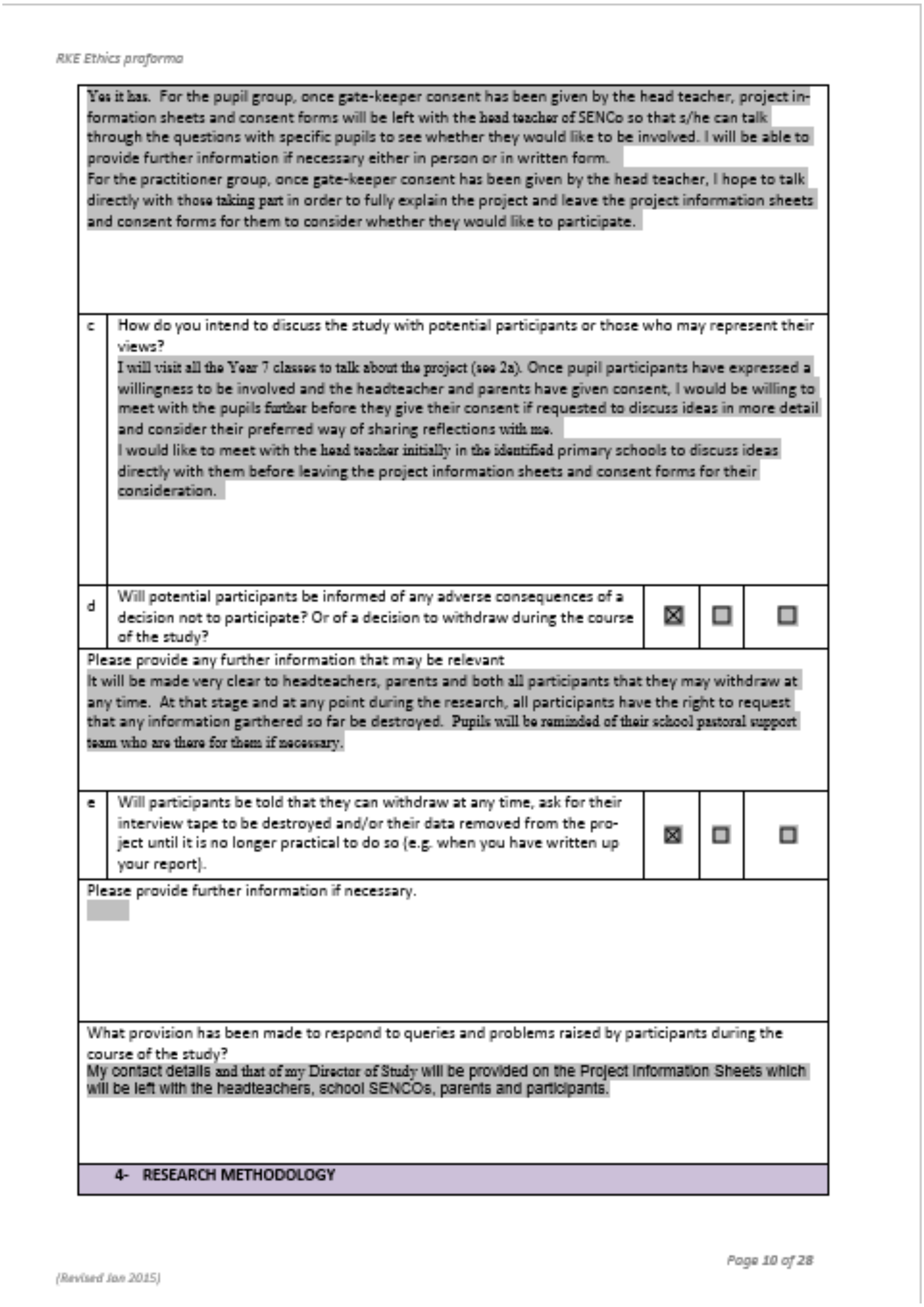
I would like to work with approximately 4 *Key Stage Three (KS3) pupils with autism who have completed their primary education in a mainstream setting. They will be currently in Hampshire secondary special schools and will be self-selecting* as participants from an initial input to the class by myself which will stimulate a general discussion about positive memories of their primary school settings. From the responses to this discussion, the pupils will be informed that I would like to work with a few of them to find out more about their ideas, it will be explained to them that I can only work with a few pupils. The secondary school will be able to assist in ensuring that the pupils who participate from those who volunteer are pupils with a diagnosis of autism who attended a mainstream primary school. I will spend time with these pupils as individuals in a relaxed setting, working alongside them in a way that they choose to gather more details about their positive primary experiences. This is likely to be in the form of a discussion or possibly taking the format of a semi-structured interview which may or may not be audio recorded.
The consent letters sent to the parents will also request that I have additional consent to contact the pupil's primary school to further discuss the school's identified positive practice. I would like to work with the headteacher of the primary school as well as possibly working with members of the Senior Management Team and / or primary practitioners to find out further details.
Once the data is gathered and thematically analysed the participants will be contacted again to verify the analysis and add any additional considerations.

2- RESEARCH PARTICIPANTS

	Mark with an X as appropriate	YES	NO	Not certain
a	How will participants be identified and approached? I will contact local secondary heads of special schools in Hampshire with the request for any KS3 pupils with autism who attended a mainstream primary school to assist me in my research. Information for the head teacher will be in the form of a Project Information Sheet. Once gatekeeper consent is gained, I will visit the school to meet with all Year 7 pupils to introduce myself and explain what I would like to do in a pupil friendly way. Information in pupil friendly Project Information Sheets will be left with the SENCo or head teacher so that s/he can give them to any selected pupils who have expressed an interest and would fit the criteria to request their involvement. Parents will initially be contacted through the school to see if they would consent to their child taking part and the school would then send out to those parents the Project Information Sheets and Consent Letters. Therefore I will have no contact with any parent until they have given their consent. As part of the parents' Project Information Sheet it will be explained that ideally I would like to be able to contact their child's primary school to further discuss their positive practice. Specific parental consent for this will need to be obtained if this is to be possible. Once the primary schools have been contacted and gate keeper consent is given by the head teacher then I will be guided by him / her as to who would be best to talk with to gather the data.			
b	Do you intend to recruit children under the age of 16?	☒	☐	☐



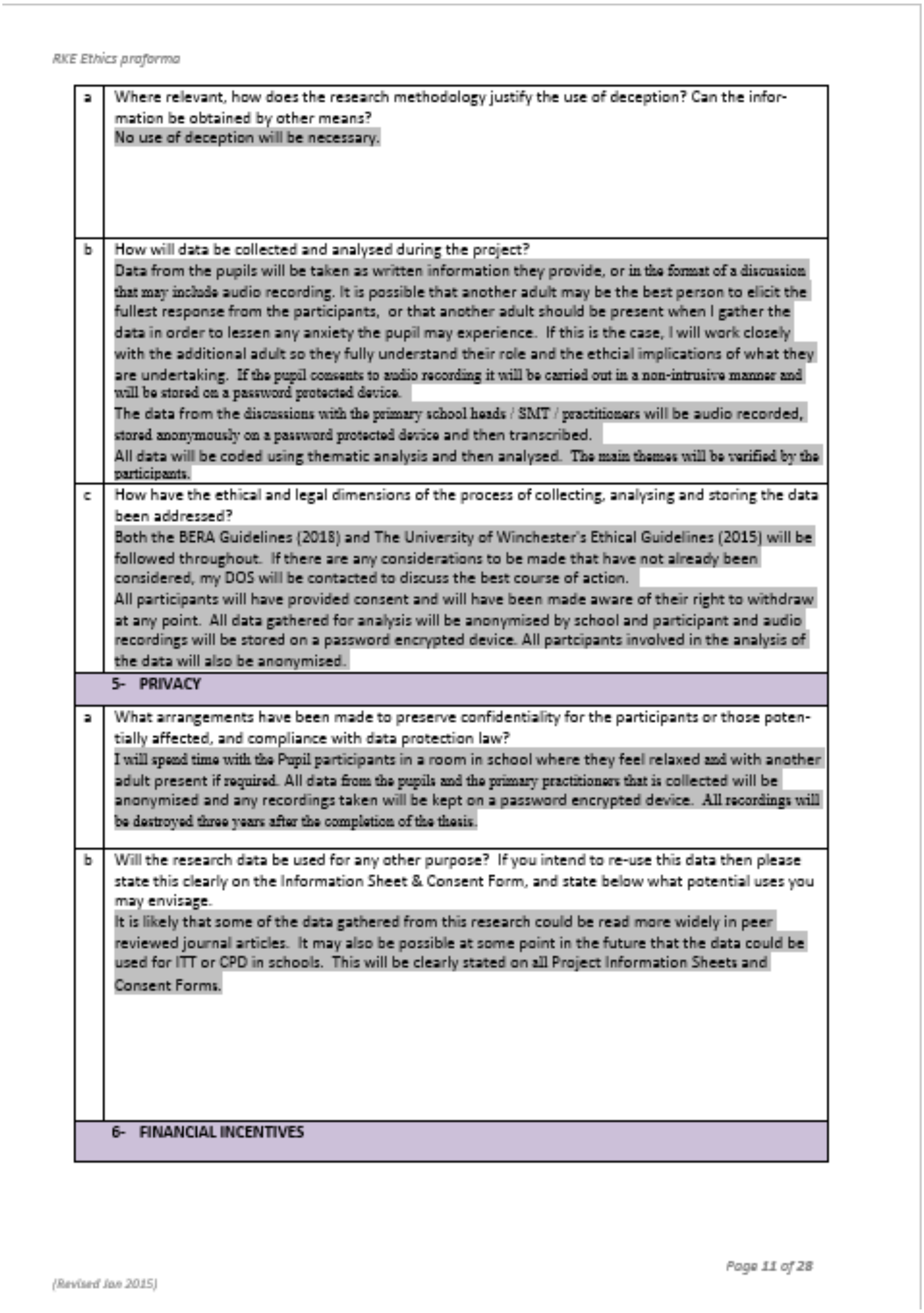
c	Do you intend to recruit participant who may be deemed vulnerable in any way?	☒	☐	☐
If you have answered YES to the above, please justify why their participation in the research is necessary and provide further details on how you intend to protect these participants. The group of participants who may be deemed vulnerable are the secondary aged pupils with autism. In order to better understand their views of primary schooling I need to gather their individual personal reflections in various forms. All data will be anonymised and if audio recordings are provided, specific consent will be requested from the pupils and anonymity will be assured. Head teachers, parents and pupils will be provided with project information sheets that will outline the research. If the pupils wish to participate they will be required to give their consent and will be informed of their right to withdraw at any stage. The school's SENCo will be informed ahead of every step so that s/he is able to prepare the pupils if necessary and support them while they respond or work with them to record their response if this is required.				
d	Is it possible that a current or past relationship with potential participants could give rise to a perceived pressure to participate because are you in a position of authority or influence over them (e.g. they are your students, colleagues, family, etc.)?	☐	☒	☐
If so, what steps will you take to mitigate this issue?				
e	Do you intend to collect tissue samples (blood, saliva, hair, or any other body part, including human skeletal remains?	☐	☒	☐
Please indicate the procedures in place for safeguarding the sensitive materials, including storage and whether further use beyond this research is envisaged. If so, has adequate consent been obtained?				
Human tissues/ remains: If the work involves obtaining a licence under the provisions of the Human Tissue Act (2008), please indicate who the **named holder** of the relevant licence is. **The named holder of the licence is** **Licence number**				
3- INFORMED CONSENT				
Mark with an X as appropriate		**YES**	**NO**	**Not Certain**
a	Will potential participants be asked to give informed consent in writing and will they be asked to confirm that they have received and read the information about the study? *Please attach a draft information sheet and/or consent form, if this is necessary.*	☒	☐	☐
If not or not certain, please provide more information Please see attached Project Information Sheets and Consent Forms.				
b	Has information (written or oral) about the study been prepared in an appropriate form and language for potential participants?	☒	☐	☐
If not or not certain, please justify. At what point in the study will information about the research be offered?				



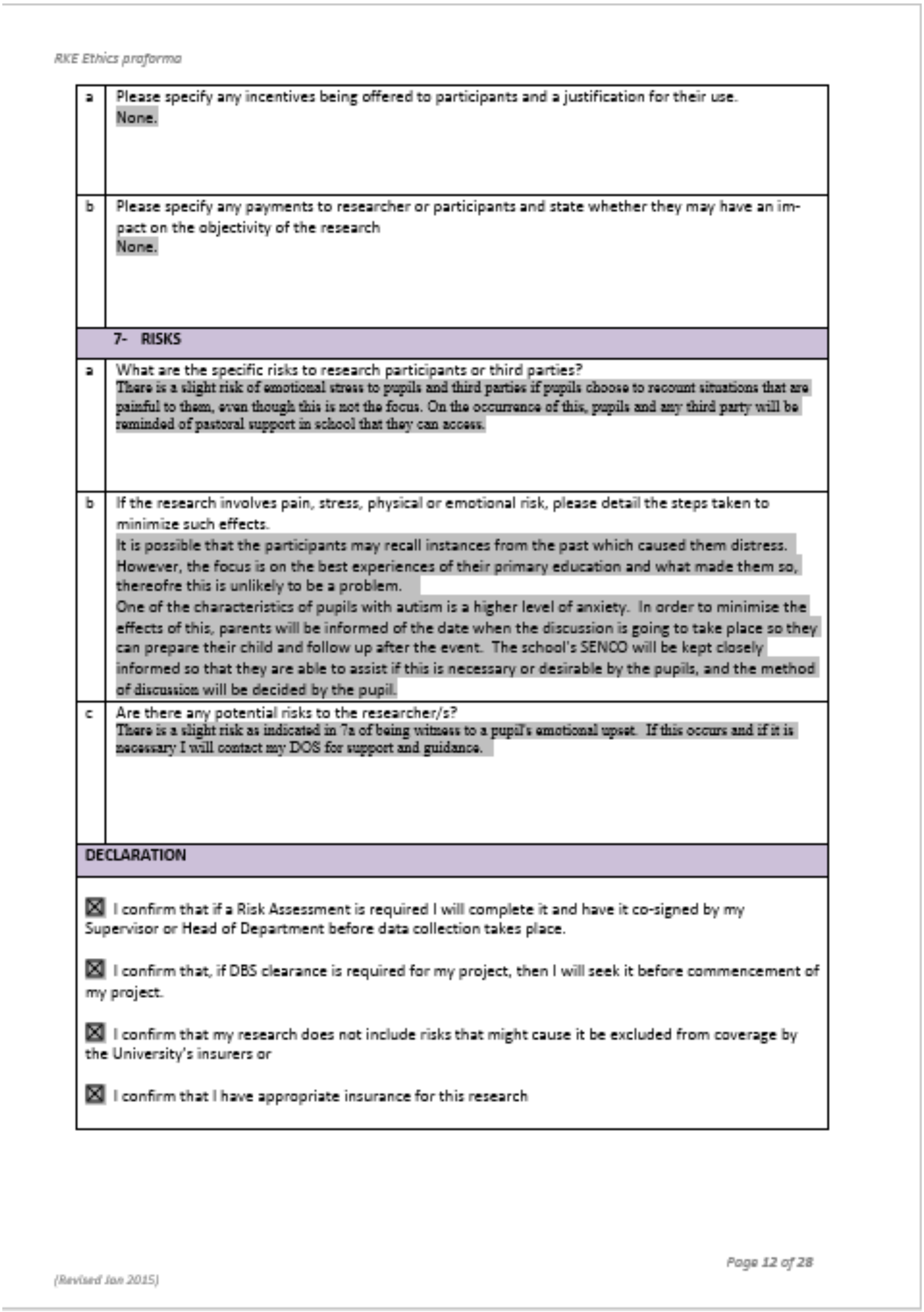
Yes it has. For the pupil group, once gate-keeper consent has been given by the head teacher, project information sheets and consent forms will be left with the head teacher of SENCo so that s/he can talk through the questions with specific pupils to see whether they would like to be involved. I will be able to provide further information if necessary either in person or in written form. For the practitioner group, once gate-keeper consent has been given by the head teacher, I hope to talk directly with those taking part in order to fully explain the project and leave the project information sheets and consent forms for them to consider whether they would like to participate.	
c	How do you intend to discuss the study with potential participants or those who may represent their views? I will visit all the Year 7 classes to talk about the project (see 2a). Once pupil participants have expressed a willingness to be involved and the headteacher and parents have given consent, I would be willing to meet with the pupils further before they give their consent if requested to discuss ideas in more detail and consider their preferred way of sharing reflections with me. I would like to meet with the head teacher initially in the identified primary schools to discuss ideas directly with them before leaving the project information sheets and consent forms for their consideration.

d	Will potential participants be informed of any adverse consequences of a decision not to participate? Or of a decision to withdraw during the course of the study?	☒	☐	☐
Please provide any further information that may be relevant It will be made very clear to headteachers, parents and both all participants that they may withdraw at any time. At that stage and at any point during the research, all participants have the right to request that any information garthered so far be destroyed. Pupils will be reminded of their school pastoral support team who are there for them if necessary.				
e	Will participants be told that they can withdraw at any time, ask for their interview tape to be destroyed and/or their data removed from the project until it is no longer practical to do so (e.g. when you have written up your report).	☒	☐	☐
Please provide further information if necessary.				
What provision has been made to respond to queries and problems raised by participants during the course of the study? My contact details and that of my Director of Study will be provided on the Project Information Sheets which will be left with the headteachers, school SENCOs, parents and participants.				

4- RESEARCH METHODOLOGY



a	Where relevant, how does the research methodology justify the use of deception? Can the information be obtained by other means? No use of deception will be necessary.
b	How will data be collected and analysed during the project? Data from the pupils will be taken as written information they provide, or in the format of a discussion that may include audio recording. It is possible that another adult may be the best person to elicit the fullest response from the participants, or that another adult should be present when I gather the data in order to lessen any anxiety the pupil may experience. If this is the case, I will work closely with the additional adult so they fully understand their role and the ethcial implications of what they are undertaking. If the pupil consents to audio recording it will be carried out in a non-intrusive manner and will be stored on a password protected device. The data from the discussions with the primary school heads / SMT / practitioners will be audio recorded, stored anonymously on a password protected device and then transcribed. All data will be coded using thematic analysis and then analysed. The main themes will be verified by the participants.
c	How have the ethical and legal dimensions of the process of collecting, analysing and storing the data been addressed? Both the BERA Guidelines (2018) and The University of Winchester's Ethical Guidelines (2015) will be followed throughout. If there are any considerations to be made that have not already been considered, my DOS will be contacted to discuss the best course of action. All participants will have provided consent and will have been made aware of their right to withdraw at any point. All data gathered for analysis will be anonymised by school and participant and audio recordings will be stored on a password encrypted device. All partcipants involved in the analysis of the data will also be anonymised.
	5- PRIVACY
a	What arrangements have been made to preserve confidentiality for the participants or those potentially affected, and compliance with data protection law? I will spend time with the Pupil participants in a room in school where they feel relaxed and with another adult present if required. All data from the pupils and the primary practitioners that is collected will be anonymised and any recordings taken will be kept on a password encrypted device. All recordings will be destroyed three years after the completion of the thesis.
b	Will the research data be used for any other purpose? If you intend to re-use this data then please state this clearly on the Information Sheet & Consent Form, and state below what potential uses you may envisage. It is likely that some of the data gathered from this research could be read more widely in peer reviewed journal articles. It may also be possible at some point in the future that the data could be used for ITT or CPD in schools. This will be clearly stated on all Project Information Sheets and Consent Forms.
	6- FINANCIAL INCENTIVES



a	Please specify any incentives being offered to participants and a justification for their use. None.
b	Please specify any payments to researcher or participants and state whether they may have an impact on the objectivity of the research None.
	7- RISKS
a	What are the specific risks to research participants or third parties? There is a slight risk of emotional stress to pupils and third parties if pupils choose to recount situations that are painful to them, even though this is not the focus. On the occurrence of this, pupils and any third party will be reminded of pastoral support in school that they can access.
b	If the research involves pain, stress, physical or emotional risk, please detail the steps taken to minimize such effects. It is possible that the participants may recall instances from the past which caused them distress. However, the focus is on the best experiences of their primary education and what made them so, thereofre this is unlikely to be a problem. One of the characteristics of pupils with autism is a higher level of anxiety. In order to minimise the effects of this, parents will be informed of the date when the discussion is going to take place so they can prepare their child and follow up after the event. The school's SENCO will be kept closely informed so that they are able to assist if this is necessary or desirable by the pupils, and the method of discussion will be decided by the pupil.
c	Are there any potential risks to the researcher/s? There is a slight risk as indicated in 7a of being witness to a pupil's emotional upset. If this occurs and if it is necessary I will contact my DOS for support and guidance.

DECLARATION

☒ I confirm that if a Risk Assessment is required I will complete it and have it co-signed by my Supervisor or Head of Department before data collection takes place.

☒ I confirm that, if DBS clearance is required for my project, then I will seek it before commencement of my project.

☒ I confirm that my research does not include risks that might cause it be excluded from coverage by the University's insurers or

☒ I confirm that I have appropriate insurance for this research

SECTION 10: ADDITIONAL INFORMATION

Please use this section to append consent forms, information sheets, questionnaires or any other documentation that may be relevant to your application. Please do this by copying and pasting from your original document.

You may also use this section to address any issues not covered in the previous sections.

Project Information Sheet: Secondary Head Teacher

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

I am a Senior Lecturer in the Faculty of Education, Health and Social Care (EHSC) and the Department of Education at Winchester University and I am studying for a Doctorate in Education. I have a current and relevant DBS that you are welcome to see. The research project described below forms the basis of my thesis and may be the foundation for future development in the area of autism, inclusion and mainstream education including journal articles and in-service training for teachers and students. I am therefore, inviting you to take part in a project that involves collecting and analysing the positive memories of some secondary pupils with autism who attended mainstream primary schools. I also hope to spend time with some identified primary schools to discuss their positive practice. Before you decide to provide consent, it is important you understand what the project involves and what will be undertaken. So, please take time to read the following information and ask if anything is unclear either by emailing me or asking during our meeting. Your participation in this study is entirely voluntary and you are free to withdraw at any time without giving reason and without penalty.

I was fascinated by some information from a survey by the National Autism Society published in 2016. They found that of the 980 parents and carers of pupils with autism who completed the survey, 58% believed schools' knowledge of autism was 'the single most important factor in meeting their child's needs'. Two-thirds of the 85 young people who took part in the survey stated that their experience of school would be better 'if more teachers understood autism' (NAS, 2016:17). I would therefore like to spend time with some of your pupils with autism who attended a mainstream primary school and can identify some positive memories from their primary education in order to consider elements of good practice. If the pupil's parents are happy to provide consent for me to contact their child's primary school, then I would like to see if it is possible to further investigate these elements of good practice with either the head teacher or Senior Management Team.

As I am aware that working directly with me may cause some pupils anxiety, I would like to talk initially with the pupil about the best way they would like to share this information with me. Ideally I would like to audio record our discussions in order to keep an accurate record and be able to engage more fully in the time we share together. This would be done in a non-intrusive manner and the data would be stored anonymously on a password protected device. However I will only use audio recording if the pupil is happy to give consent for this after discussing it with their parents. It is possible that some of the data gathered may also be used anonymously as the basis for future projects and that this project and future projects that may use this data will lead to publications for readership by academic as well as wider audiences.

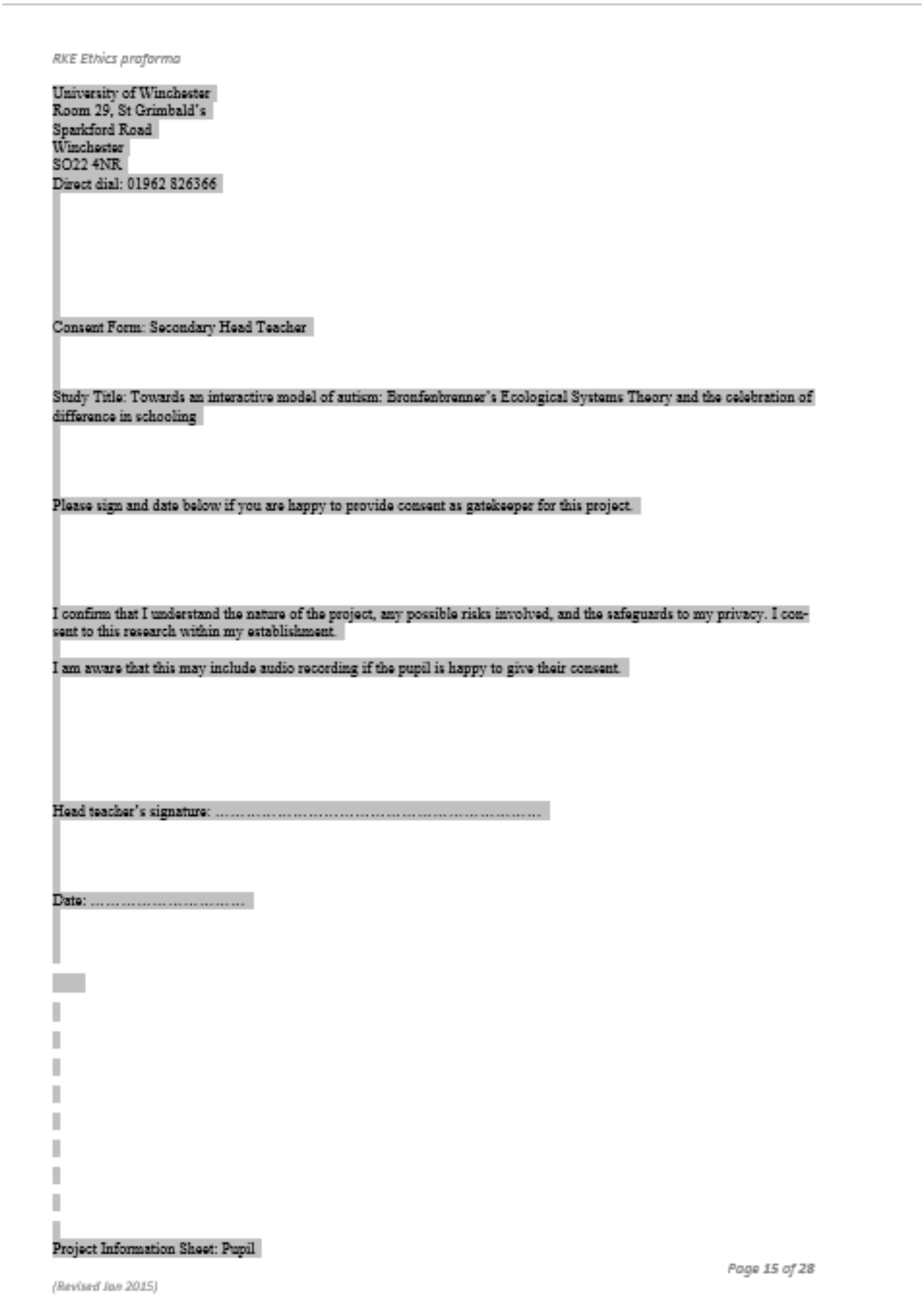
All results from the study will be confidential and no school, teacher or pupil will be able to be identified should the work be published. All audio recordings will be stored in an encrypted file and destroyed once the transcripts have been completed. If you require further information please email me at Miriam.Walker@winchester.ac.uk

This study has been approved by the Ethics Sub-Committee for the Department for EHSC. If you feel at any time that there is something wrong about the study, then please contact me or the Chair of the RKT Ethics Committee.

If you are happy to give consent, then please complete the consent form overleaf. Please ensure you keep a copy of this sheet for future reference.

Yours sincerely,

Miriam Walker
Senior Lecturer in Teacher Development
Faculty of Education, Health and Social Care



University of Winchester
Room 29, St Grimbald's
Sparkford Road
Winchester
SO22 4NR
Direct dial: 01962 826366

Consent Form: Secondary Head Teacher

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

Please sign and date below if you are happy to provide consent as gatekeeper for this project.

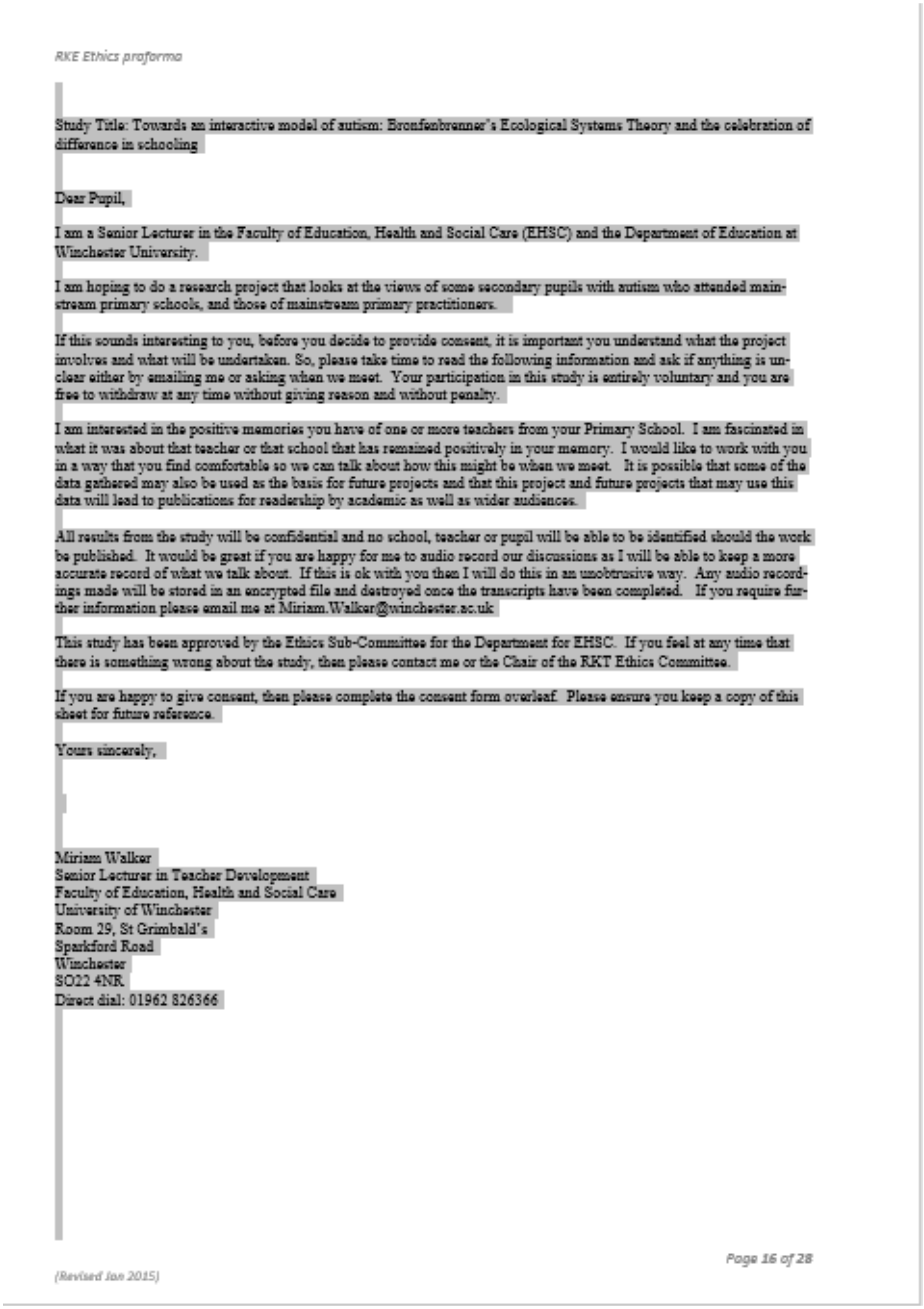
I confirm that I understand the nature of the project, any possible risks involved, and the safeguards to my privacy. I consent to this research within my establishment.

I am aware that this may include audio recording if the pupil is happy to give their consent.

Head teacher's signature: ……………………………………………………………

Date: ……………………………

Project Information Sheet: Pupil



Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

Dear Pupil,

I am a Senior Lecturer in the Faculty of Education, Health and Social Care (EHSC) and the Department of Education at Winchester University.

I am hoping to do a research project that looks at the views of some secondary pupils with autism who attended mainstream primary schools, and those of mainstream primary practitioners.

If this sounds interesting to you, before you decide to provide consent, it is important you understand what the project involves and what will be undertaken. So, please take time to read the following information and ask if anything is unclear either by emailing me or asking when we meet. Your participation in this study is entirely voluntary and you are free to withdraw at any time without giving reason and without penalty.

I am interested in the positive memories you have of one or more teachers from your Primary School. I am fascinated in what it was about that teacher or that school that has remained positively in your memory. I would like to work with you in a way that you find comfortable so we can talk about how this might be when we meet. It is possible that some of the data gathered may also be used as the basis for future projects and that this project and future projects that may use this data will lead to publications for readership by academic as well as wider audiences.

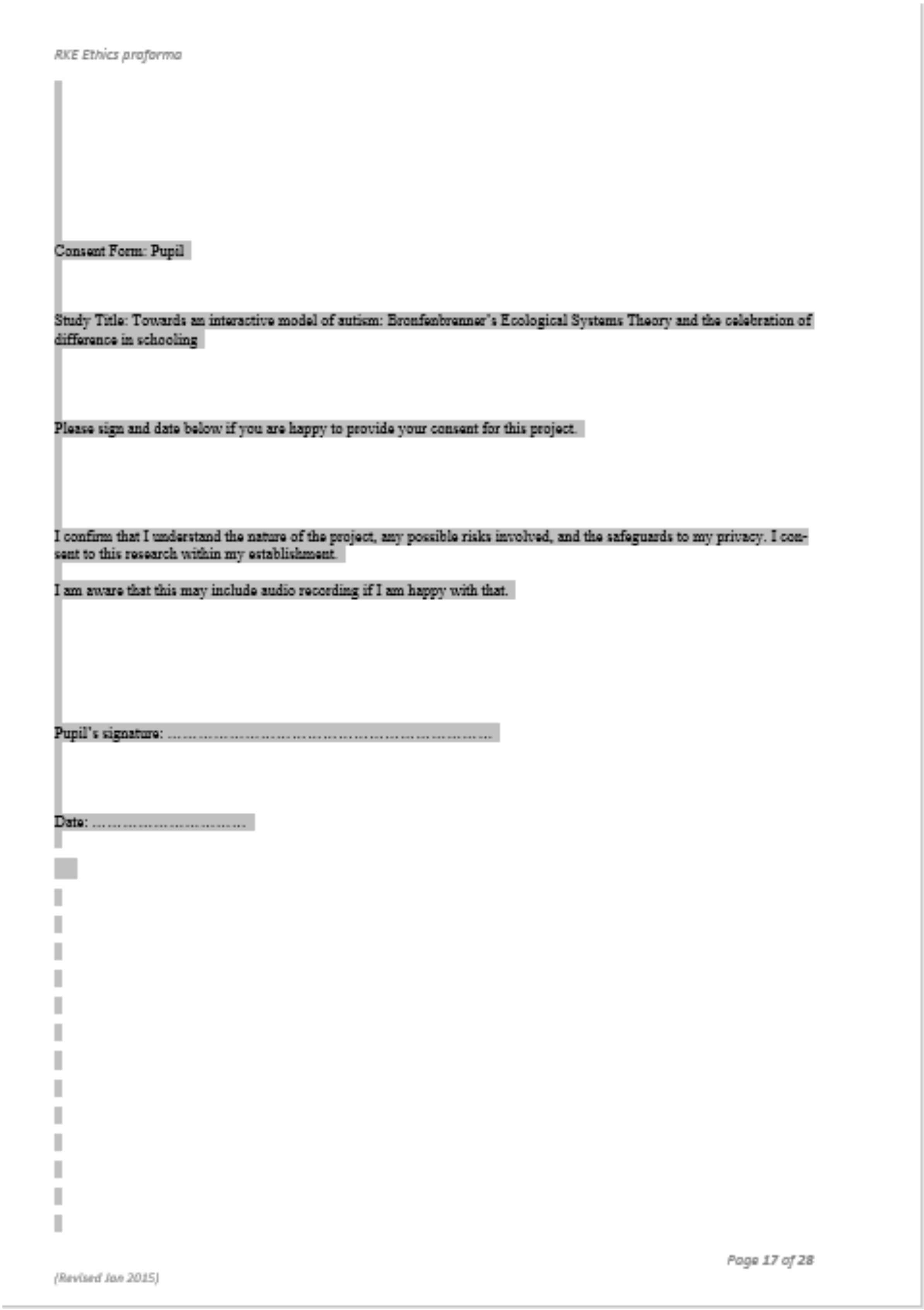
All results from the study will be confidential and no school, teacher or pupil will be able to be identified should the work be published. It would be great if you are happy for me to audio record our discussions as I will be able to keep a more accurate record of what we talk about. If this is ok with you then I will do this in an unobtrusive way. Any audio recordings made will be stored in an encrypted file and destroyed once the transcripts have been completed. If you require further information please email me at Miriam.Walker@winchester.ac.uk

This study has been approved by the Ethics Sub-Committee for the Department for EHSC. If you feel at any time that there is something wrong about the study, then please contact me or the Chair of the RKT Ethics Committee.

If you are happy to give consent, then please complete the consent form overleaf. Please ensure you keep a copy of this sheet for future reference.

Yours sincerely,

Miriam Walker
Senior Lecturer in Teacher Development
Faculty of Education, Health and Social Care
University of Winchester
Room 29, St Grimbald's
Sparkford Road
Winchester
SO22 4NR
Direct dial: 01962 826366



RKE Ethics proforma

Consent Form: Pupil

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

Please sign and date below if you are happy to provide your consent for this project.

I confirm that I understand the nature of the project, any possible risks involved, and the safeguards to my privacy. I consent to this research within my establishment.

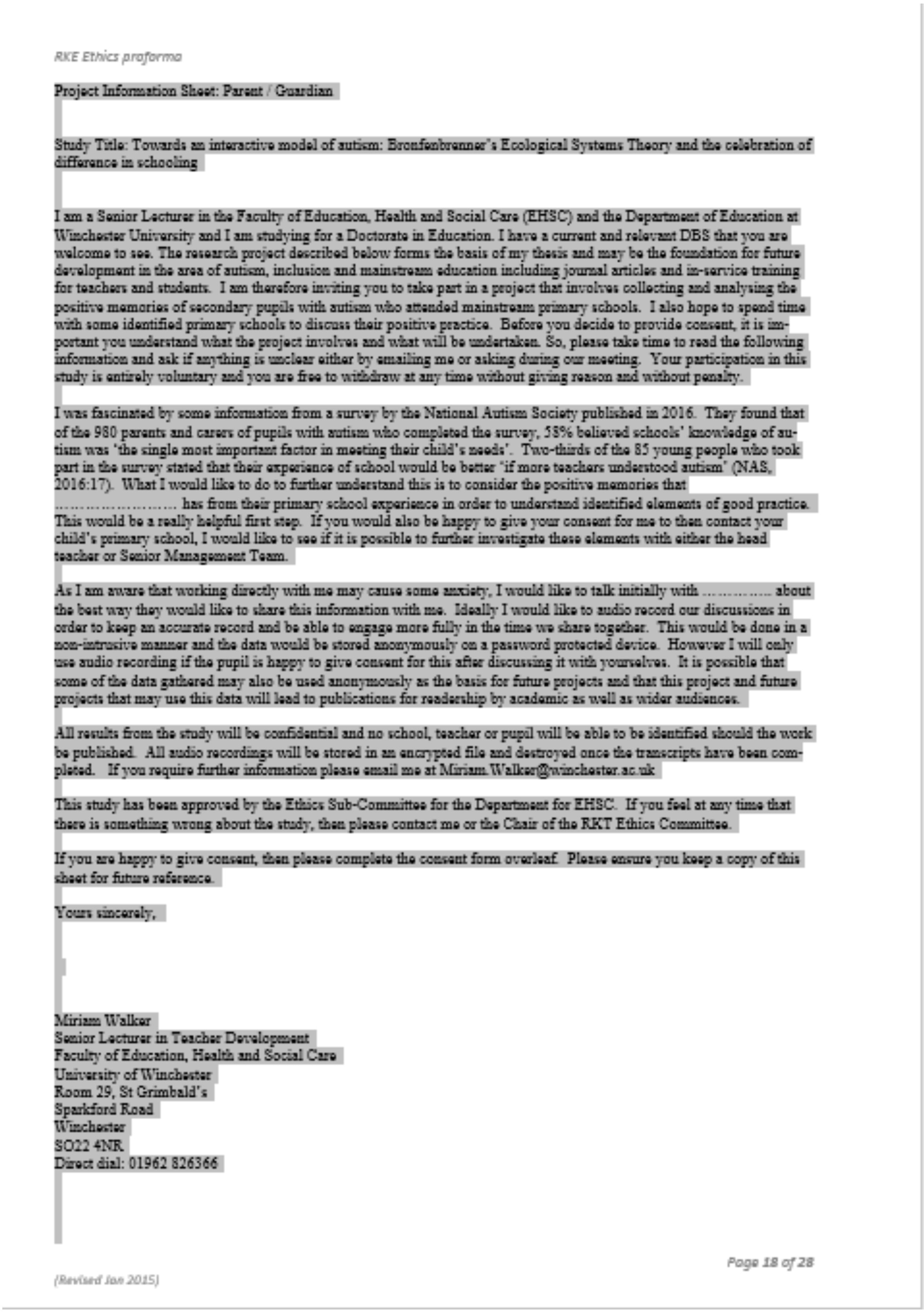
I am aware that this may include audio recording if I am happy with that.

Pupil's signature: ……………………………………………………………

Date: ……………………………

Page 17 of 28

(Revised Jan 2015)



Project Information Sheet: Parent / Guardian

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

I am a Senior Lecturer in the Faculty of Education, Health and Social Care (EHSC) and the Department of Education at Winchester University and I am studying for a Doctorate in Education. I have a current and relevant DBS that you are welcome to see. The research project described below forms the basis of my thesis and may be the foundation for future development in the area of autism, inclusion and mainstream education including journal articles and in-service training for teachers and students. I am therefore inviting you to take part in a project that involves collecting and analysing the positive memories of secondary pupils with autism who attended mainstream primary schools. I also hope to spend time with some identified primary schools to discuss their positive practice. Before you decide to provide consent, it is important you understand what the project involves and what will be undertaken. So, please take time to read the following information and ask if anything is unclear either by emailing me or asking during our meeting. Your participation in this study is entirely voluntary and you are free to withdraw at any time without giving reason and without penalty.

I was fascinated by some information from a survey by the National Autism Society published in 2016. They found that of the 980 parents and carers of pupils with autism who completed the survey, 58% believed schools' knowledge of autism was 'the single most important factor in meeting their child's needs'. Two-thirds of the 85 young people who took part in the survey stated that their experience of school would be better 'if more teachers understood autism' (NAS, 2016:17). What I would like to do to further understand this is to consider the positive memories that …………………… has from their primary school experience in order to understand identified elements of good practice. This would be a really helpful first step. If you would also be happy to give your consent for me to then contact your child's primary school, I would like to see if it is possible to further investigate these elements with either the head teacher or Senior Management Team.

As I am aware that working directly with me may cause some anxiety, I would like to talk initially with ………….. about the best way they would like to share this information with me. Ideally I would like to audio record our discussions in order to keep an accurate record and be able to engage more fully in the time we share together. This would be done in a non-intrusive manner and the data would be stored anonymously on a password protected device. However I will only use audio recording if the pupil is happy to give consent for this after discussing it with yourselves. It is possible that some of the data gathered may also be used anonymously as the basis for future projects and that this project and future projects that may use this data will lead to publications for readership by academic as well as wider audiences.

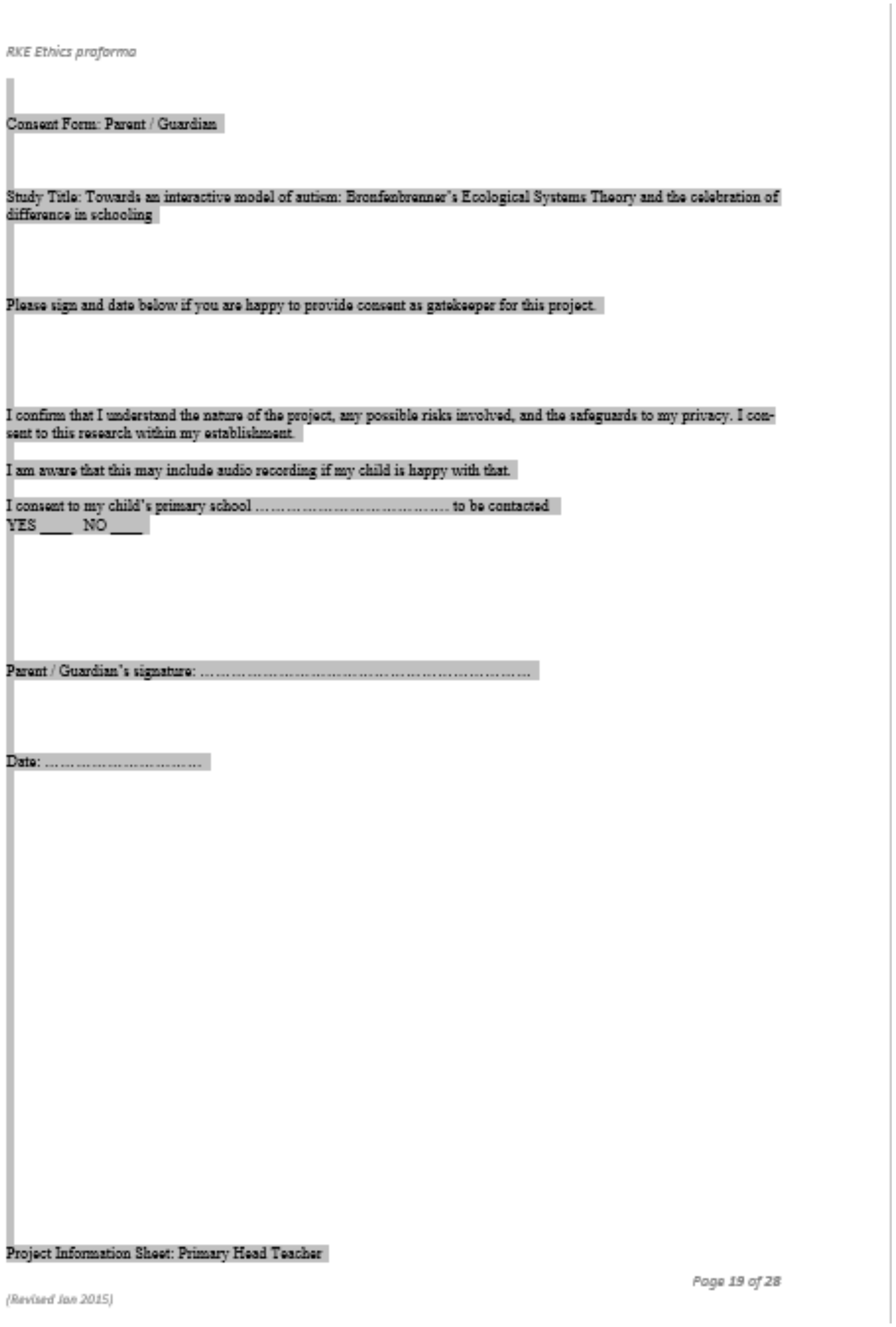
All results from the study will be confidential and no school, teacher or pupil will be able to be identified should the work be published. All audio recordings will be stored in an encrypted file and destroyed once the transcripts have been completed. If you require further information please email me at Miriam.Walker@winchester.ac.uk

This study has been approved by the Ethics Sub-Committee for the Department for EHSC. If you feel at any time that there is something wrong about the study, then please contact me or the Chair of the RKT Ethics Committee.

If you are happy to give consent, then please complete the consent form overleaf. Please ensure you keep a copy of this sheet for future reference.

Yours sincerely,

Miriam Walker
Senior Lecturer in Teacher Development
Faculty of Education, Health and Social Care
University of Winchester
Room 29, St Grimbald's
Sparkford Road
Winchester
SO22 4NR
Direct dial: 01962 826366



Consent Form: Parent / Guardian

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

Please sign and date below if you are happy to provide consent as gatekeeper for this project.

I confirm that I understand the nature of the project, any possible risks involved, and the safeguards to my privacy. I consent to this research within my establishment.

I am aware that this may include audio recording if my child is happy with that.

I consent to my child's primary school ……………………………………. to be contacted
YES ____ NO ____

Parent / Guardian's signature: ………………………………………………………………

Date: ……………………………

Project Information Sheet: Primary Head Teacher

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

I am a Senior Lecturer in the Faculty of Education, Health and Social Care (EHSC) and the Department of Education at Winchester University and I am studying for a Doctorate in Education. I have a current and relevant DBS that you are welcome to see. The research project described below forms the basis of my thesis and may be the foundation for future development in the area of autism, inclusion and mainstream education including journal articles and in-service training for teachers and students. I am therefore, inviting you to take part in a project that involves collecting and analysing the views of secondary pupils with autism who attended mainstream primary schools, and those of mainstream primary practitioners. Before you decide to provide consent, it is important you understand what the project involves and what will be undertaken. So, please take time to read the following information and ask if anything is unclear either by emailing me or asking during our meeting. Your participation in this study is entirely voluntary and you are free to withdraw at any time without giving reason and without penalty.

I was fascinated by some information from a survey by the National Autism Society published in 2016. They found that of the 980 parents and carers of pupils with autism who completed the survey, 58% believed schools' knowledge of autism was 'the single most important factor in meeting their child's needs'. Two-thirds of the 85 young people who took part in the survey stated that their experience of school would be better "if more teachers understood autism' (NAS, 2016:17). In order to find out more about this I have already been working with some KS3 pupils who have been discussing positive memories from their time in mainstream primary schools.

Your school was one of those identified through some of these discussions and consent was given by the parent of the pupil for me to contact you. I would be very interested if it was possible with you to come in and talk about the elements of good practice that have been remembered by the pupil in order to find out more detail. I am aware that an informal discussion may be necessary first so that you can find out a few more details. If you are happy to progress then consent will need to be given and then ideally I would like to audio record our discussions in order to keep an accurate record and be able to engage more fully in the time we share together. This would be done in a non-intrusive manner and the data would be stored anonymously on a password protected device.
It is possible that some of the data gathered may also be used as the basis for future projects and that this project and future projects that may use this data will lead to publications for readership by academic as well as wider audiences.

All results from the study will be confidential and no school, teacher or pupil will be able to be identified should the work be published. All audio recordings will be stored in an encrypted file and destroyed once the transcripts have been completed. If you require further information please email me at Miriam.Walker@winchester.ac.uk

This study has been approved by the Ethics Sub-Committee for the Department for EHSC. If you feel at any time that there is something wrong about the study, then please contact me or the Chair of the RKT Ethics Committee.

If you are happy to give consent, then please complete the consent form overleaf. Please ensure you keep a copy of this sheet for future reference.

Yours sincerely,

Miriam Walker
Senior Lecturer in Teacher Development
Faculty of Education, Health and Social Care
University of Winchester
Room 29, St Grimbald's
Sparkford Road
Winchester
SO22 4NR
Direct dial: 01962 826366

Consent Form: Primary Head Teacher

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

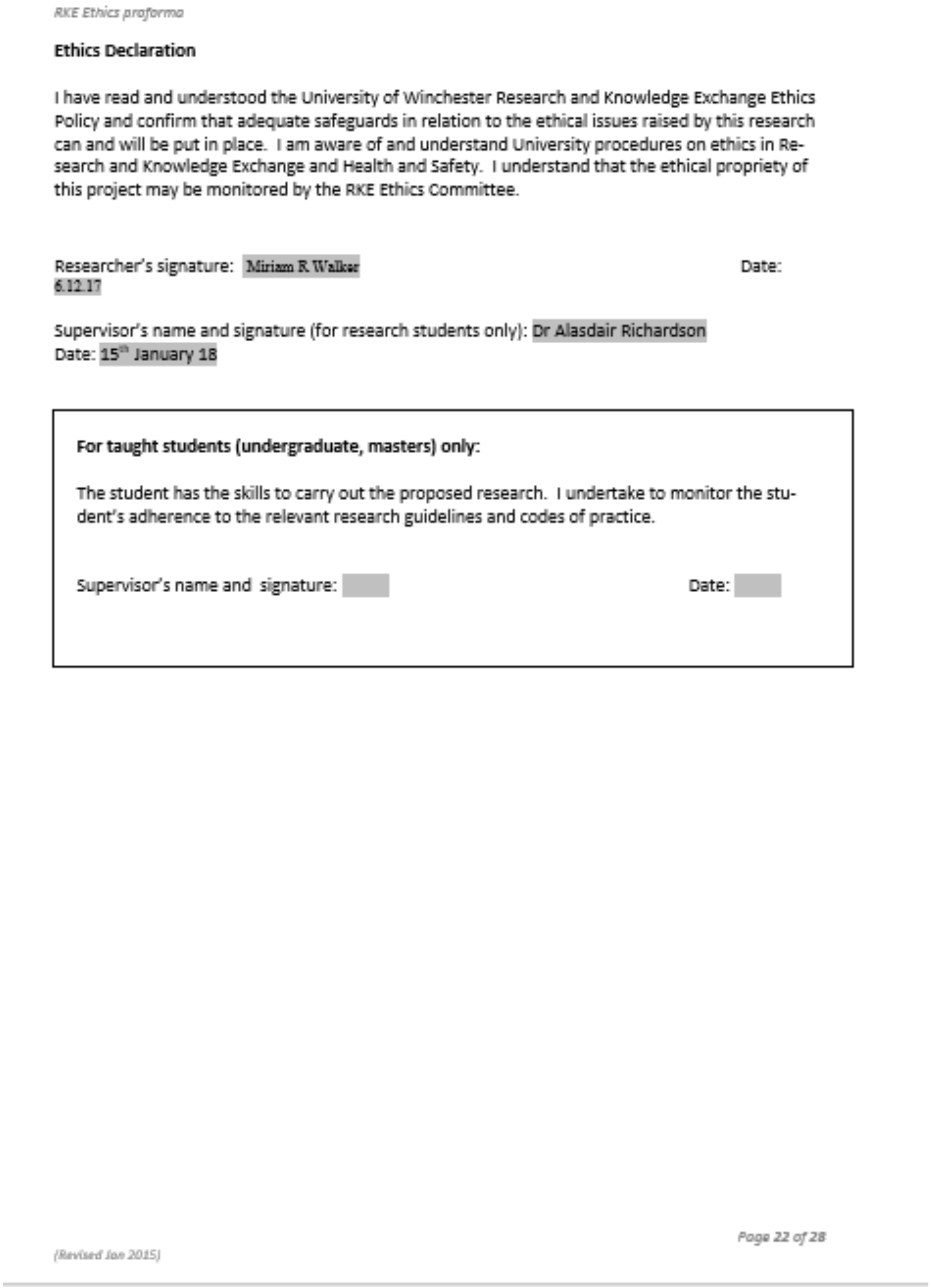
Please sign and date below if you are happy to provide consent as gatekeeper for this project.

I confirm that I understand the nature of the project, any possible risks involved, and the safeguards to my privacy. I consent to this research within my establishment.

I am aware that this may include audio recording.

Head teacher's signature: ………………………………………………………

Date: ……………………………



Ethics Declaration

I have read and understood the University of Winchester Research and Knowledge Exchange Ethics Policy and confirm that adequate safeguards in relation to the ethical issues raised by this research can and will be put in place. I am aware of and understand University procedures on ethics in Research and Knowledge Exchange and Health and Safety. I understand that the ethical propriety of this project may be monitored by the RKE Ethics Committee.

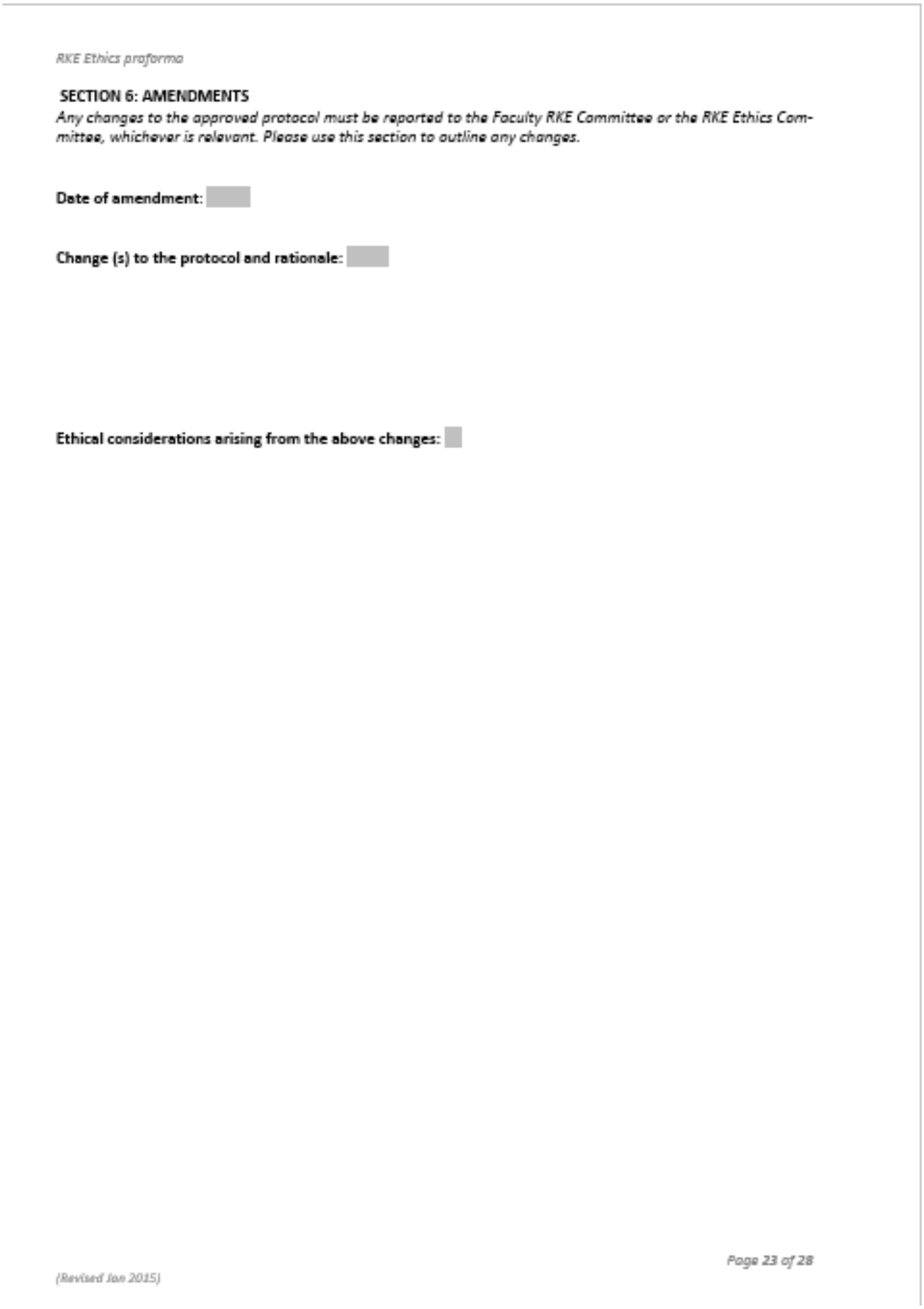
Researcher's signature: Miriam R Walker Date:
6.12.17

Supervisor's name and signature (for research students only): Dr Alasdair Richardson
Date: 15th January 18

For taught students (undergraduate, masters) only:

The student has the skills to carry out the proposed research. I undertake to monitor the student's adherence to the relevant research guidelines and codes of practice.

Supervisor's name and signature: Date:



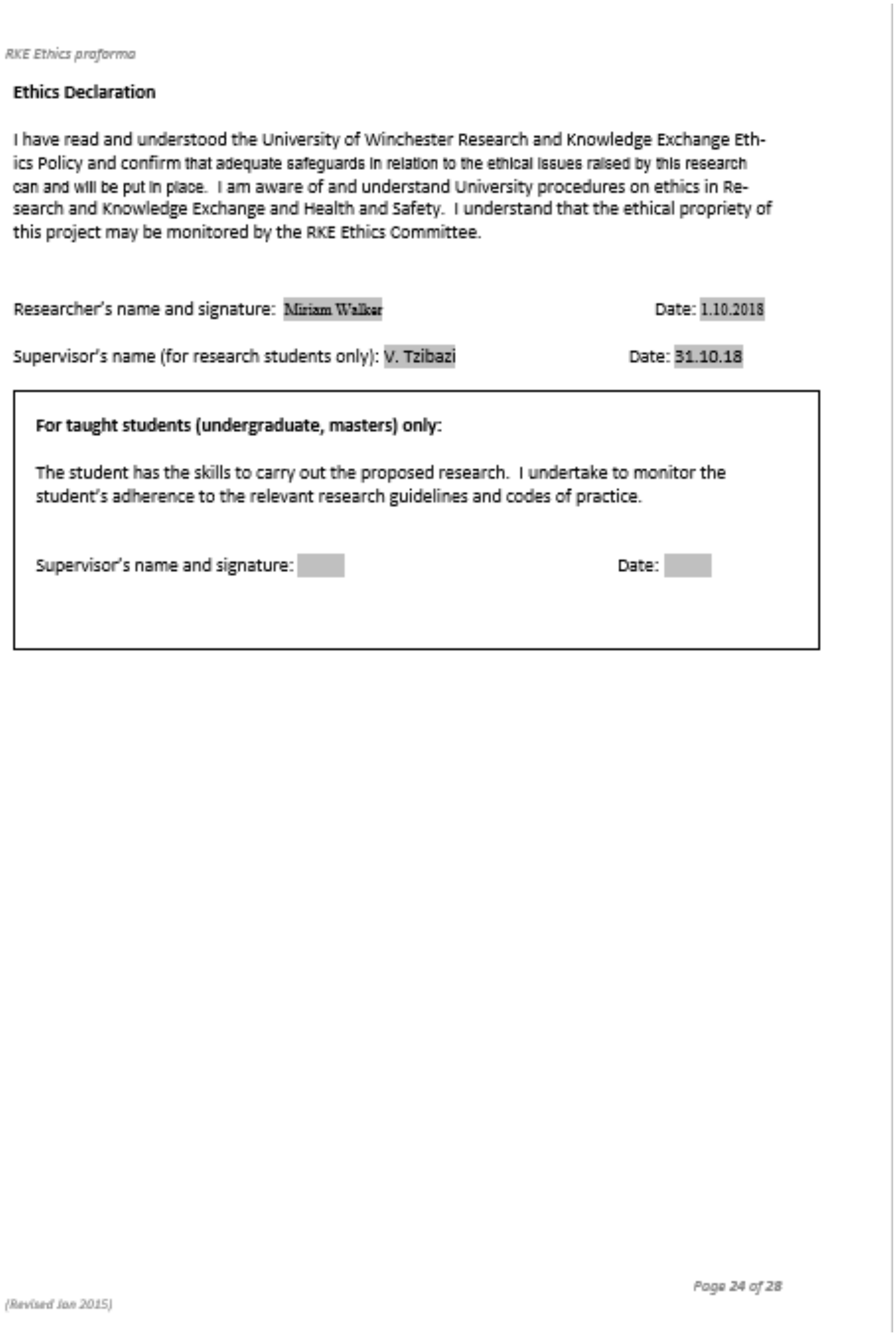
SECTION 6: AMENDMENTS

Any changes to the approved protocol must be reported to the Faculty RKE Committee or the RKE Ethics Committee, whichever is relevant. Please use this section to outline any changes.

Date of amendment:

Change (s) to the protocol and rationale:

Ethical considerations arising from the above changes:



Ethics Declaration

I have read and understood the University of Winchester Research and Knowledge Exchange Ethics Policy and confirm that adequate safeguards in relation to the ethical issues raised by this research can and will be put in place. I am aware of and understand University procedures on ethics in Research and Knowledge Exchange and Health and Safety. I understand that the ethical propriety of this project may be monitored by the RKE Ethics Committee.

Researcher's name and signature: Miriam Walker Date: 1.10.2018

Supervisor's name (for research students only): V. Tzibazi Date: 31.10.18

For taught students (undergraduate, masters) only:

The student has the skills to carry out the proposed research. I undertake to monitor the student's adherence to the relevant research guidelines and codes of practice.

Supervisor's name and signature: Date:

Appendix 3 Table of information about the five pupil participants

Pupil	Secondary School	Age at diagnosis	Diagnostic Information
Ben	Mainstream	4	Autism
Currently attends all classes within the mainstream secondary school, only using a support base within the school on occasions during lunchtimes.			
Roger	Mainstream	10	Autism
Moved to a different primary school in Year Six after a SENCo suggested it as a possibility. Spends the majority of his time in the mainstream school, only attending the support base for time out if necessary during break and lunchtimes.			
Alice	Mainstream	10	Autism and dyslexia
Her parents however recognised that she might have autism from the time she was approximately seven years old, but chose to seek a diagnosis when she was ten in the hope that it would provide more help for her in her education. She spends the majority of her time in the mainstream school although is timetabled to attend the support base during specific language lessons as she also has dyslexia. She is able to spend time in the base during break and lunchtimes.			
Esther	Mainstream	3	Autism and epilepsy
At the start of this academic year, a specific room within the school was set up for particularly able pupils with high levels of anxiety. She is granted access at any time to this calm environment to get on with her work when the classroom environment becomes too stressful. She also attends the same support base as the other pupils for occasional tests.			
Meg	Special	9	Autism
Has attended a specialist secondary school from Year Seven. Attended two different primary schools, but spent the majority of time in the second, which is the one she refers to during the interviews.			

Appendix 4 Letters of consent

Consent Form: Secondary Head Teacher

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

Please sign and date below if you are happy to provide consent as gatekeeper for this project.

I confirm that I understand the nature of the project, any possible risks involved, and the safeguards to my privacy. I consent to this research within my establishment.

I am aware that this may include audio recording if the pupil is happy to give their consent.

Head teacher's signature: ……………………………………………

Head teacher's name in capitals please: ………………………………

Date: …………………………

Consent Form: Parent / Guardian

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

Please sign and date below if you are happy to provide consent for your son / daughter to take part in this project.

I confirm that I understand the nature of this project, and the safeguards to the privacy of my son / daughter.

I am aware that this may include audio recording as long as my son / daughter is also happy to give their consent.

Parent / Guardian's signature: …………………………………………

Parent / Guardian's name in capitals please: ……………………………

Date: …………………………

Consent Form: Pupil

Study Title: Towards an interactive model of autism: Bronfenbrenner's Ecological Systems Theory and the celebration of difference in schooling

I confirm that:	**Initial**
I have been informed about the purpose of this study and have had the chance to ask questions	
I understand that my participation is voluntary, and I have been made aware of my right to withdraw my consent to taking part in the study, with no consequences, at any time without giving a reason and ask for any data collected about me to be erased.	
I understand that interviews may be audio recorded.	
I have been made aware of how my data will be stored, shared and reported and agree to my data being used in this manner	
I would like the findings of this study to be made available to me when the final summary report is complete	
I agree to take part in this study	

Please sign and date below if you are happy to provide your consent for this project.

Pupil's signature: ………………………………………………………

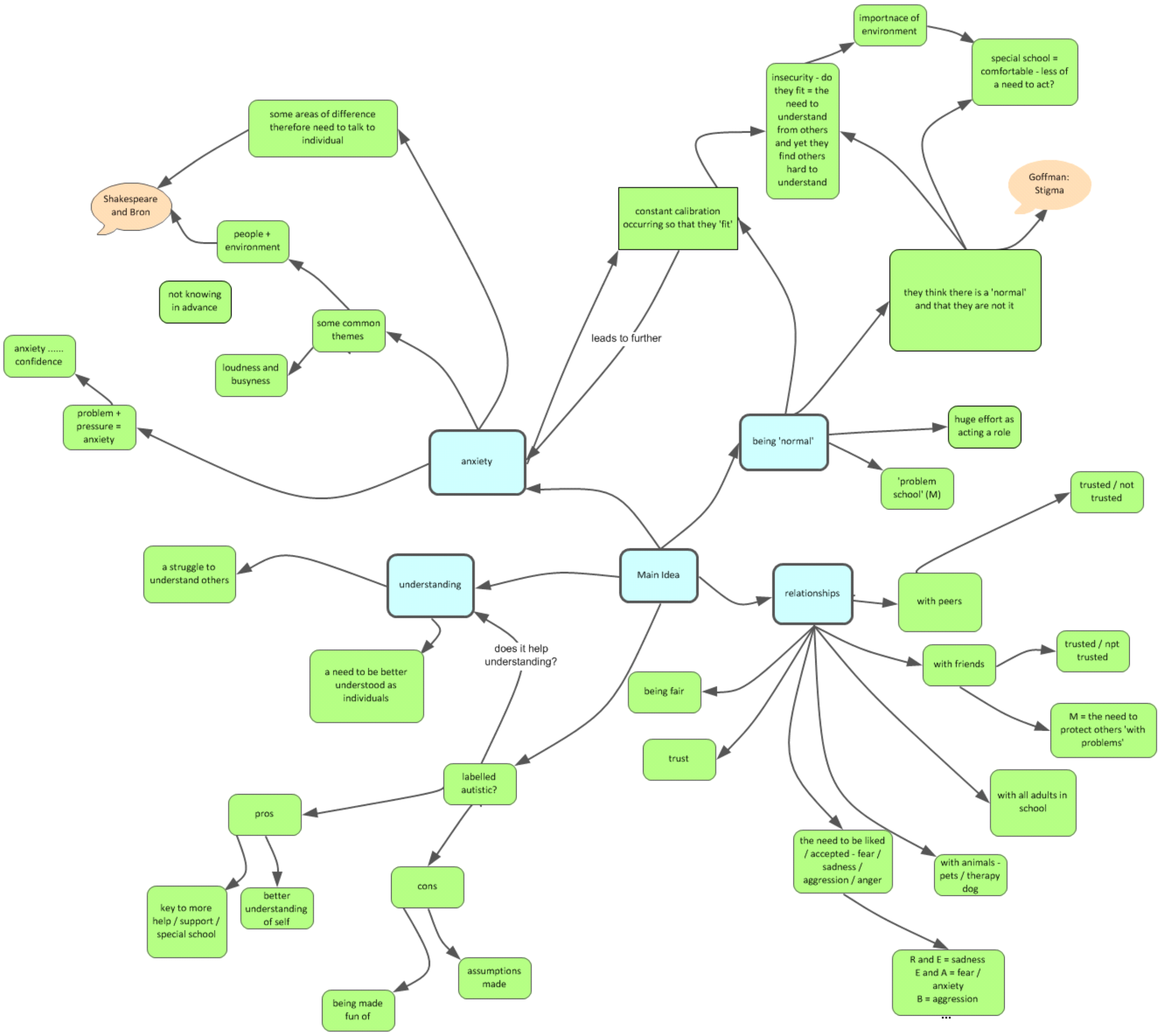
Pupil name please (in capitals): ………………………………………...

Date: …………………………

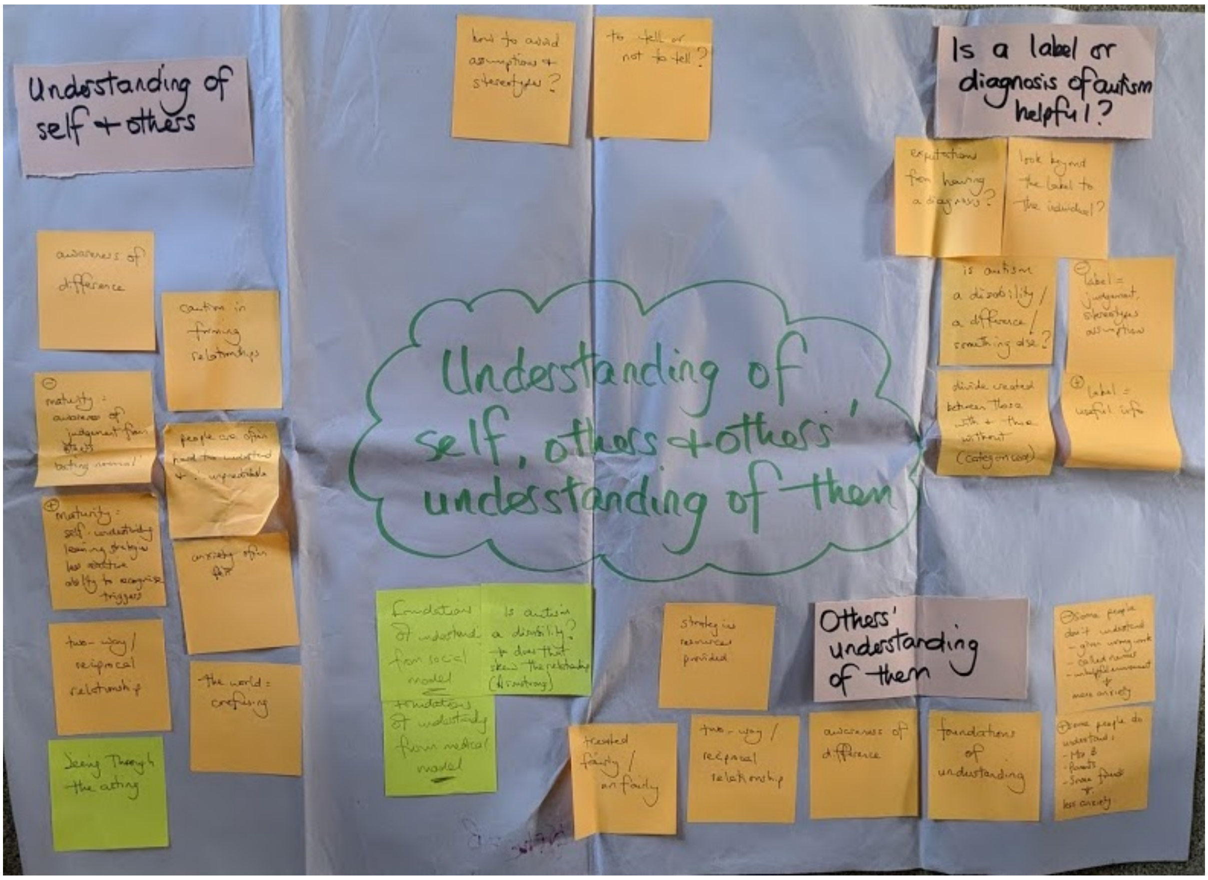
Appendix 5 An excerpt from the process of thematic analysis

Speaker		Code	Possible Theme
E	Because when teachers can relate to you, you feel more comfortable around them, and - and they have understanding. They can help you teach - teach you in a better way.	the importance of positive teacher / pupil relationships = better understanding + better teaching	understanding / relationships
MW	Mmm … one of the interesting things that we've also talked about which is also going to be a theme, is this thing about 'acting normal' (E affirming). And, you said that you didn't really need to when you were in AL.		
E	When I'm in AL, no because I'm around everyone who is kind of different, like me, but when I'm in the main school I kind of feel the pressure to act normal because - I don't want to be laughed at, I don't want to be … you know.	being with similar people + acting normal	perspective / normality

Appendix 6 Initial electronic mind-mapping of themes



Appendix 7 Example of mind-mapping process with pupils in final interview



Appendix 8 AC Interview 1

AC 1	
Name	**Comment**
MW	It's Wednesday 13th March and in this room we have - Miriam,
B	B
R	R
A	A
E	E
MW	Fabulous. Right, so what I would like to know is, tell me - two or three things about you, anything at all. Are you starting B?
B	Yaerh, I like watching Ben Phillips and he's a u-tuber and I also like um playing um Fortnight.
MW	Oh, Fortnight, yeah. Okay, thank you. R?
R	To be honest, I like loads of songs, um I like the subject music, and drama is just my thing.
MW	Okay, thank you very much. A?
A	I have two sisters, three cats and a leopard gecko - (trailing off).
MW	A leopard gecko did you say?
A	Yeah, um it's a type of gecko.
E	(Interjecting) Cute!
MW	You've seen it have you E? It's cute? Has it got fur?
E	It's like a lizard.
A	I can show you a picture.
MW	Yeah, I'd like to see a picture of it. A gecko! How big is it?
E	(Indicating with hands) Not that big.
MW	That's quite big. Ok, it's got a tail? (E and A nodding) What's it called?
A	Izelda (names gecko).
MW	Izelda? I've got a niece called Izelda, I'm going to tell her now there's a leopard gecko with the same name. (Being shown a picture on A's mobile phone). Oh I see. Have you seen it you two? (Asking two boys on other side of the table).
R and B	No.
A	I'll get a closer picture.
MW	Ok, so, E, just tell us about you? While A gets the picture.
E	I have two sisters and my favourite colour is pink and I enjoy science.
MW	Ok, ooo, lots of interesting things. I haven't played Fortnight, I'm not very good at drama but I do like it, I definitely don't have a leopard gecko, and Science - I'm not sure. What is it you like so much about Science?
A	I like Biology.
MW	Oh yeah, I do. I did zoology for my A 'level and I really enjoyed it.
B	I like Chemistry because you get to use the bunsen burners.

MW	Yup, that's good fun as well (laughing). Right, ok, so tell me - what do you remember about your Primary school? So, you're in Year 7 now and it was a year ago that you left, just under, wasn't it? What do you remember about it?
B	Umm, I just remember being in the classroom, listening and doing my work and that. That's all I can remember.
MW	Ok, what about you R?
R	Well, to be honest, I had two, um, two primary schools, but the one that I left to come here, I just remember being in the classroom and every time I said something, like, I would always make the teachers laugh, and I *loved* it.
MW	So, you did it on purpose to make them laugh?
R	Not really, they just found everything I said funny, not in a horrible way.
MW	Yeah, yeah (reassuring).
R	But they always just - just liked me. Um, um the teacher I had in Year 6 she said that, well, I made her laugh and then she said, "oh, every class needs a R".
MW	Oh, ahhh, that's nice. What about you A?
A	I didn't like it.
MW	You didn't like it, ok, why not?
B	(Interjecting) I don't blame you!
A (3.27)	It was just horrible to be honest.
MW	Was it, was it - what was horrible about it?
A	The teach-, one of the teachers.
MW	Yup, and was that a recent teacher, so when you were in -? (trailing off).
A	It was my Year 6 teacher.
MW	Ok, and what was so difficult, can you remember?
A	She was just mean to me to be honest.
MW	Yeah, ok, but the other teachers, were they better?
A	Well, I only had one, oh I had two, one was really nice and one was really horrible. I had one on Thursday and Friday, and one on Monday, Tuesday and Wednesday.
MW	Oh, I see, so there was a job share?
A	Yeah, the one I liked was on a Monday, Tuesday and Wednesday. The one I disliked was on Thursday and Friday.
MW	And do you know what it was that you liked about the one you had at the beginning of the week?
A	She was understanding, she understanded things.
MW	Yeah, um, what then was not so good about the other teacher?
A	She didn't - (trailing off)
MW	She just didn't understand?
A	(Shaking head)
MW	That's very interesting isn't it? We'll come back to that in a minute. E what about you?
E	Umm, I found it ok. It was - I had a couple of teachers I really enjoyed, and some I didn't enjoy, but they were never mean, they just didn't understand.
MW	Yeah, so the ones that you enjoyed, why, why did you like them more than the others do you think?

E	Um, I had a teacher called Mrs F she was my LSA and she, um and she just got how I worked kind of, how I thought and how I learnt. The other teachers they would try and teach me in a way that didn't work for me.
MW	Yeah, ok. And R, you said you went to two schools, so what - was one better than the other?
R	Yeah one was better than the other. The first school that I went to, it was just terrible. There was some good teachers and there was some bad teachers. There was this one teacher that um, he got so angry that what he did, cos he had a ruler in his hand, he literally banged it on the table to get everybody's attention, but he snapped the ruler.
B	(Interjecting) That's what happened to one of my teachers. When, like, you were calling him names and that, he used to grab this like really long wooden ruler and you used to put up your two hands put up like that (indicating with hands) , right in our faces, and I remember like a bit of wood flying at us.
MW	Mmm (returning to R) So, was that why you left your first school because you weren't happy there?
R	Yeah.
MW	And was the second school better?
R	It was much better, every teacher loved me - yeah. There was also a dinner lady that I just didn't like. She was horrible; she kept on shouting and shouting and shouting.
MW	Do you think, well, why do you think she was shouting?
R	I honestly don't know.
B	(Interjecting) Cos she was probably a pixie.
R	She was shouting at everybody.
MW	Ok, so it wasn't just you, it was lots of people?
R	Yeah.
MW	B, you said, when A said about school, it wasn't easy or something - did you understand that?
B	Yeah (thoughtfully).
MW	Was that the same for you then?
B	Well - sort of, like most of the time like, it was a bit hard and that - (trailing off).
MW	Can you remember what was making it hard?
B	Not really - (trailing off).
MW	Was it the work?
B	Yeah, sort of, and all of the like, the concentrating and that.
MW	Yeah.
B	Yeah (affirming).

MW (7.32)	Do you remember that, uh, do you remember when I came in last time and I showed you on the big screen, those pictures, we went through that powerpoint, didn't we (nods of agreement), and one of the things that I said at the beginning was something that had been taken from a survey of pupils like you. And the thing that they said that they wanted - 58%, so more than half of all the pupils that answered this survey said that 'the single thing that would make school better for us would be if teachers understood more about autism". (Nods) Is that something that you all agree on?
ALL	Yeah.
MW	A, you would as well, you've already mentioned teachers not understanding you quite a bit. So, if you could err, add things (stopped in tracks by picture shown by A on phone of the gecko) oh my goodness, that's Izelda. Hello Izelda! (Laughing) She is amazing, is she fully grown?
A	Yeah, um, she's up to there, she'll probably grow up to this size.
R	I want to see.
MW	Ok, we'll have to show you R in a minute. Um, so, if you're thinking about writing things - if you could write to your teachers from your primary school and say "if you'd have understood this then it would have helped me do something, what sort of information would you like to give to your teachers
B	(Unintelligible) Probably something like I wish you understood my autism more like, not like being like, shouting at me all the time and all giving us like the death looks and that, because that's what most of my teachers did.
MW	Giving you a what look?
B	Death look like - like that (demonstrating)
MW	Oh, I see yeah. And when you say you wish you could understand more. What would you want them to know that you think they didn't know?
B	That I had it.
MW	So, ok, so you had it, and do you think they should have made - they should have been different because of that?
B	Yeah.
MW	In what way?
B	They could have made my life a lot easier there instead of like putting more like pressure on me than I already had- pressure, yeah.
MW	Mmm, ok, interesting. Well done thank you. What about you R?
R	Well, I was kind of thinking the same; um - I honestly don't know what to say.
MW	So think about those teachers maybe in your first school. If you could say to them "look I need you to understand that - " what would you want them to understand that might have made them be different to you?
R	Well, they just kept on shouting and shouting, and - I was just about to say that I can only focus on one thing at a time - (trailing off).
B	(Affirming quietly) I kind of agree with you.
R	I, um, with all these like things there's one thing going on and then there's another thing going on but I'm still processing it in my head and I just can't go on to other things without knowing the other thing.
MW	Thank you.
B	(Interrupting) I was 100%

MW	You were? Mmm, did you feel there were too many things being expected of you?
B	Yeah, so from you get the teacher talking about the subject and then you get people talking about a load of other things, then you get the odd person calling out and then you got the um people walking in and out the classroom, which - kind of confusing.
MW	Mmm, what about you A?
A	I don't know what I would say to them to be honest.
MW	You wouldn't say something?
A	(Shaking head)
MW	No, but you must have wished sometimes when you went home from school, "if only they understood, my life would be easier".
A	Only one teacher knew, and she didn't tell any others, and then she knew she made it harder for me.
MW	She made it harder?
A	Yes.
B	That's a bit mean innit?
MW	Well how, what do you mean, how did that happen?
A	Um, well, before she knew, it was ok and when she knew it just went terrible
MW	What was it particularly, can you remember anything?
A	Oh, she was shouting at me, and stuff like that. I would just sit there and doing *nothing* and then she would shout at me for *nothing*, and stuff like that.
B (11.29)	Yeah, but some of the famous people, they like probably have autism and stuff like that as well.
MW	Oh absolutely, there are loads of famous people who have got autism, and they are - probably famous because of the way their brain works, which is really quite exciting (R's hand goes up). Hang on let me just go to E and then I'll come back to you R. Go on E, what about you then, what would you say about understanding? Maybe your teacher needs to understand you better - (trailing off).
E	That sometimes they put me on the lower tables because they thought I struggled with the work, but really I was only struggling with the environment.
MW	And what was it in the environment that you were struggling with?
E	The loudness and the constant movement in the room.
MW	Movement of other people?
E	Yeah, movement of other people in the room.
MW	And how did that affect you?
E	Um I couldn't focus, urrr but the thing is the work was always really easy because - (smiling) so I got through the work really quickly.
MW	Did anyone else find that (asking the rest of the group), did anyone have easier work do you think because of the fact that you were struggling with other areas but it wasn't really the work?
B	No not really.
MW	(A nodding) So you are saying yes A, (turning to B) and you say no. Go on A, what happened to you?

A	Cos I struggled in English and because of that they put me in the lowest one for maths when I needed to be higher and then I used to go over to the high table and used to look at their work (smiling).
MW	(Laughing) aaah yes - that must have been frustrating - hmm.
B	They did the same for me. Like I was meant to be lower in maths but they shoved me high in maths and low in English like, do they have a brain or what?
MW	And did you think it should be the other way round then?
B	Yeah, and I told them but they said "oh no B, your work is amazing in maths, so they were giving me like algebra and stuff and all the letters and all the alphabet and that.
MW	Yeah, and did you, did you find that difficult then or did you manage?
B	Well, I had to get on with it, I mean you can't just give up you're just going to have to learn.
MW	Yeah, ok, well what about you R then?
R	Well, with me in maths, I'm amazing at maths, but with Mr S (names teacher), the one that um works - (interrupted by B).
B	(Interjecting) The head of maths.
R	Yeah, he works in maths, we were doing algebra this one day and he said that they were, they were easy equations but they were actually hard equations and everybody got on well with them.
MW	Corrr, what because you think he said they were easy, people thought they could do them and so they did them?
R	Yeah, but um - (trailing off).
MW	Huh, that's clever isn't it?
R	Yeah, but originally, even if the questions um are hard, I'm actually good at them, yeah, it's only some questions that I get wrong.
MW	So, just thinking about your primary school again, what did the *best* teachers do that helped you?
B	They would sit down and talk to me more and say," if I have any issues then come to talk to me and that".
MW	Ok, so they gave you time really?
B	Yeah, so I kind of did that sometimes, not all the time, but sometimes.
MW	Good, did you think you could talk to any of them, or was it only that you thought you could talk to the ones who -? (B interrupting).
B	I could talk to them - I probably could talk to three, maybe four teachers about it, but no one else, because they would probably yeah, not understand, or probably hate me for it, yeah.
MW	R, what about you?
R	In my first school, the teachers didn't know about my autism, I didn't even know about my autism, but it was only in my second school, when I went to CAMHS I found out I had autism and everything was just easier for me in the second school.
MW	And so, was it because you had changed? But you hadn't changed, you had autism before, all you knew was that it had a name, after you'd gone to CAMHS, was that right (R nodding). So, was it you who had changed or was it the teachers that were different that made it easier?

R	The teachers were different.
MW	So what did they do that was really good - in the second school?
R	They *listened* to me.
MW	(Turning to B) So, that's the same as you (B nodding).
R	And they would give me easier work. So, when I was doing SATs, um I had people to read the questions for me.
MW	Yeah, and that meant that you could answer them without having to process the - (trailing off).
R	It was because I am a slow reader and they actually gave me the people to read the questions.
MW	Ok. What about you A or E?
A	What was the question again?
MW	So it was the - the teachers who understood you the most, what was it, what do you think they understood?
A	Mmm, I'm not sure cos one of the things - what I liked about one of the teachers when they found out they treated you the same.
MW	(Questioning) they treated you the same as -? (trailing off).
A	They didn't do things much different that I liked, and then if I need them to, like - I don't know.
MW	So, did you want to be treated the same, or did you want to be treated differently?
A	The same, I didn't want to get treated - (trailing off)
MW	(Confirming) You didn't want to get treated differently. Ok, but did you feel that maybe some things needed to be different in order for you to be able to manage in your classroom? What sort of things needed to be different?
A	Mmmm, the loudness, cos - and also the hallway cos it got really busy.
MW	The hallway? Do you mean going to and from your classroom?
A	Yeah, because there was a coatroom there for the year fours and threes and then our um, like coats and stuff was like in the um hallway. So you had to stop in the middle of the hallway and then it got really busy and no one can actually - no one can move (M laughing) So, you had to just stand there.
MW (17.46)	What about you E?
E	Umm, - well, the teachers that I trusted like the most - well, they like understood me or like, they found something to relate to me. My LSA was really good because she used to suffer with um, extreme anxiety which is what I suffered with, and she could kind of relate to me.
MW	Mmm, so, so the teachers who you felt understood you more, what was, what did they do that made you realise that they understood you?
E	Err, tell me experiences similar to mine or tell me something if I like you know, dogs, so tell me about a dog or something like that.
MW	(Pause) Mmm, it's interesting isn't it, thinking about school and how it's different, and the experiences that you've all had. So, how old you were you when you found out R you'd got autism?
R	Umm, I think I might have been nine or ten.
MW	Ok, what about you B?
B	Um maybe about four.

MW	Ok, so you'd gone all the way through your school knowing that you have autism. What about you A?
A	Um, well my parents were pretty sure I had it, but I didn't like got a definite answer until year six.
MW	Ok, so you didn't - (trailing off).
A	They couldn't - they tried to find out exactly what type, and stuff like that.
MW	Ok, and was it your year six teacher that you found the hardest? (A nodding) Yeah, and it was in year six that you had that diagnosis as well (A nodding). What about you E?
E	Err when I was three.
MW	When you were three, so you two were the younger ones weren't you (looking at B and E), that you'd come all the way through school - yeah. And what's fascinating about autism I think, is tha -, I can't get inside your heads and neither can other teachers. And so I know that you think things in a different way and - you can't get inside my head or you can't get inside other people's heads who don't have autism who think things in a different way, so sometimes there can feel like a wall in between can't there? Because you don't understand me and I don't understand you, so what I'm trying to do is trying to find a way of creating like a hole in the wall so we can understand each other better (R's hand goes up). Go on R.
R	I think I know why I'm good at maths, because I can visualise things in my head. Like if we had a cube made out of loads of other cubes and we got told, um we got told to count the faces and the squares, I can visualise um, I can visualise it in my head and I can actually count the, the um faces and squares.
MW	So I think you are able to do that *because* of your autism, there are certain things that you find difficult but there are also things that you are better at, than people who don't have autism. Because of the way your brain works differently. What, what do you think is good about having autism?
B	I make people laugh *sometimes* (pause) like - the work's boring and I know it, and the teachers know it, and yeah, I don't say what I think in my head *sometimes*.
MW	You *don't* say what you think in your head sometimes (checking meaning)?
B	Yeah sometimes. It depends on what mood I'm in. If I'm in a happy mood I don't say, but if I'm in a bad mood I'll say it.
MW	And then what will happen?
B	Well, I don't want to find out the consequences.
MW	(Laughing) Alright, so is there something good about your autism then do you think?
B	Yeah like - in a way yeah.
MW	Because - you are more unique which is lovely.
B	What's that?

MW	It means that there are more people who don't have autism than people who do. So it means that if we put you in a room of um one hundred people, there might be one or two people who'd have autism in that room and the rest wouldn't. And although in some ways that makes things sometimes for you sometimes more complicated, it's also really important for teachers to realise that actually it's also of enormous benefit sometimes because you *think differently*. And as you said I think R, there are famous people who've got autism, and there really are, people who've got amazing brains because they think differently - than the majority - you know than a lot of other people. So, what's good about your autism A?
A	I don't know because not a lot of people know. I don't know about teachers, but only these guys and three other people?
MW	Three other people - what outside of your own family?
A	Yeah.
MW	Ok. Do you feel different than other people in this school?
A	(Pause) *Sometimes*. I try to act normal.
MW	You try to act normal? And what does that mean?
A	Oh just - I don't know. Like - if it was busy and I didn't like it, I would act like it's fine.
MW	But you wouldn't feel it inside? (A shaking head) Ahh, that's interesting.
A	And then Miss B (names teacher of unit), like once it's, like we had this fayre thing, and it's really loud in the hall and I was just standing there and then Miss B knew. And I was just standing there and she just knew
MW	So, she understood how you were feeling, even though you were trying not to show it?
A	Yeah. cos I never show things really, but then Miss B knows. And then she said um "you can stay behind" and then I didn't go in the hall.
MW	So have either of you two (looking at R and B) do you think you have to 'act normal', like A was saying?
B	Yes and no.
R	I think yes because um, there was this one lunchtime, I was just being myself and someone laughed at me - and - I was just sad about that (sounding subdued).
MW	Yeah, so you felt then that you couldn't act then the way you would normally act because you might be laughed at in that situation? Is that right? (R affirming)
B	(Interjecting) You should have punched him in the face.
MW	So have you had experiences then B where you have felt you needed to 'act normal'?
B	Well, yes because, when I'm not acting myself people think I'm being a weirdo, and when I act myself they think I'm really funny and I like make people laugh and all that, so they think I'm better off acting normal than acting like different to everyone else - no, I agree.
MW	Mmm, what about you E, does that happen to you? Do you feel you have to be somebody different sometimes?

E	Ummm, not really, I don't really try to hide it. I mean I'm a part of VU (names specific unit within school), so as I'm around, as I'm around lots of people, with autism, um and they never try and hide it so - (trailing off)
MW	Mmm, and does that help being around other people with autism?
E	Yeah.
MW	Does it help you A, to know that you are one of four in this situation for example?
A	Mmm, yeah.
R	Ok, what about you R, does it help to know you are in a group? (R nodding).
MW	Yeah, what were you going to say (as he had his hand up previously)?
R	I was going to say, sometimes I can be really stupid, but people don't have to laugh at it.
MW	Mmm, and - and you're probably not meaning to be really stupid. I mean sometimes you choose to be because you like it, it makes people laugh sometimes. But when you're not trying to be, that's not right is it then? Is that what you're saying?
R (25.36)	Mmm, kind of.
B	(Interrupting) I remember I got laughed at once - in year five someone laughed at me he was in year 6, I remember punching them around the face and then they'd never laugh at me again because they knew I was tougher than them.
MW	But do you know remember what it was that they did that made them laugh at you?
B	I guess I was missing - I took a shot at football and I missed, and they were laughing and saying I was rubbish so I got up and punched them in the face.
MW	Ok, so it wasn't something that you'd done on purpose it was just something that happened?
B	Yeah.
MW	E, what's good about your autism then?
E	Um (long pause) I got a dog out of it.
MW	Did you - how did that happen?
E	Um, an assistance dog. I got an assistance dog; he came into school with me all through my primary school - that helped me.
MW	So that primary school made quite a difference - for you, they did something especially to help you?
E	Yeah.
MW	Ok - that's amazing (R's hand going up). Go on R.
R	I wish I could have a dog that would just know how I was feeling.
MW	Yeah, so how did this dog work then E?
E	Um so, one day I came home and we were looking after my cousin's dog and my parents realised that I was so much calmer around him. So they looked into buying one from a company - yeah.
MW	How lovely. So what's difficult about being autistic then, do you think?

E	Um (long pause) probably um (long pause) having to act, to be around lots of other people who don't struggle with the same things as you do. And then you feel kind of weird - like you know, I'm the only one going through this, so I must just be - (trailing off)
MW	(Leaving gap in case more information would come) Yeah, so it's being, being with people who might not understand you? (E affirming) And do you think they don't understand you?
E	I think they don't understand me.
MW	Mmm, ok, what about you A? What's difficult?
A	(Pause) I'm not sure - well, like when I can't help something and they don't understand that I can't help it.
MW	Mmm, so can you give me an example?
A	(Long pause) I don't know - (trailing off).
MW	So when you can't help something, do you mean how - (trailing off).
A	(Interrupting) So when I do something and I can't help it, and then I do it and they get angry with me.
MW	Are these things you do to calm yourself down sometimes? If you're feeling stressed or anxious?
A	(Sounding reluctant and unsure) Mmm - I don't know.
MW	Well, if you can think about that it would be really interesting, because again, if you think about, um where we could be going with this - it's going to kind of give teachers some really interesting and helpful information. So although it won't make a difference to you because you've come through your primary education, there will be loads of other children who will be going through exactly what you have gone through and we want to try and stop having such a difficult time for some of them don't we. (Affirmation from group). So, if there's any examples, that can actually be really helpful for other teachers. So if it comes back to you A, I'd really be interested. R what about you? (R's hand gone up).
R	What was the question?
MW	Well, do you want to say what you were going to say first?
R	Yeah, um - well, coming back to the dog thing - I absolutely love dogs and I have a cousin and I think I can't remember what it was, and I think she said she has depression, and she has a dog that um is her dog for the depression and I wish that I had a dog for my autism.
MW	Well, maybe when you're an adult and you have your own house, perhaps then?
R	Maybe.
MW	So the question R was, err, what sometimes is difficult about being autistic? So we said what was good, what's difficult?
R (29.48)	(Long pause) I think it was the learning really - I just, I got tasked with things that other people got tasked with - I sometimes found, found it hard to do - and then I would get in trouble for not doing the work, just because I didn't understand it and they didn't know that.
MW	So it was getting into trouble unfairly. Is that what you felt, that it wasn't fair?
R	Yeah.

MW	And do you think that was because - you said they didn't understand? (R nodding). Mmm, go on E what were you going to say? (E's hand up)
E	Um so it's social situations. Um, I'm not the best at talking, with new people. And also, people breaking the rules - that's a big thing. I hate - I like - love following rules, I like rules, um and when people break them, it's annoying.
MW	Mmm. Even if that doesn't affect you, it's still - (trailing off).
E	(Interrupting) Even if it doesn't affect me and it's still annoying. And that some teachers tell me "but E, it's not affecting you - this person breaking the rules", but they don't understand - it *does***!**
MW	Mmm (B's hand up). Go on B.
B	I think also like, what I struggle with autism is like when people tell me to do stuff and I do it, and sometimes it kind of doesn't work so, so when they tell me to do something naughty and I do it, I get in trouble, which I can't blame it on the other person, because I done it instead of them done it, so I can't really say, euhhh I got dared because teachers wouldn't really like it like "oh well don't blame it on other people for your own actions", so that's why I kind of find really hard cos I know, I listen to people and I do it, which I know I shouldn't and I still do it, but I don't know why.
MW	Even now?
B	Yeah.
MW	But do you think - because you're getting older - it's getting easier - or not?
B	Yeah.
MW	What about you (turning to A) do you think it's getting easier because you're getting older? (A shakes head) No, not for you A. What do you think E?
E	Yeah, I think it is, I yeah, I think it has got easier. Social situations because I've learnt techniques and how to cope with my anxiety and stuff like that. I've learnt so many techniques it's just got a lot easier.
MW	Ok, what about you R? Do you think it is getting any easier because you are getting older?
R	No, I don't think it is getting easier as I am getting older, um, like when I'm getting older, I'm just um gaining independence and sometimes, independence just doesn't work for me.
MW	So are you a bit worried - about stuff in the future?
B	(Interjecting) I can remember last year when I went to the shops and I had to buy something and I really felt it hard like paying by myself cos it was like cos of my autism like, I couldn't like, like process what was going on and what I had to do and that, but now I can do it like go to the shops and something, come back on my own without like thinking about stuff like last year when I couldn't do it.
MW	So that bit is definitely getting easier isn't it?
B (33.05)	Confidence.

MW	Exactly that, and confidence is kind of the other end to anxiety isn't it? (Indicating a spectrum line with hands). So as your anxiety is lessening maybe a little bit because you know you can do it, your confidence is building, (B nodding and agreeing) which is great. Do you remember there was another thing that I read to you, um when I saw you last time, a tiny little bit on a slide that said this. And this was written by a lady who didn't realise that she'd got autism until she was a grown up - um and she wrote this, and you have heard it before: "right from the start, from the time someone came up with the term 'autism', the condition has been judged from the *outside* by its appearances and not from the *inside* according to how it is experienced". And I remember you R were kind of nodding like mad when I like read that to you. So do you think that still happens? That it is judged from the *outside* rather than the *inside*?
R	Yeah.
MW	Can you give any examples of that - anyone? What do you think they see on the outside, other people?
B	Oh, anxious, when someone's anxious to do something that's when they think 'oh, they've probably got autism' or someone's a bit angry like they show it, or they're a bit of a show-off or a nutcase and that.
MW	Ok (R's hand is up). Go on R.
R	Sometimes, I hesitate to do things, and um, well I just wish that people could um like say, "it's um ok, it won't hurt"
MW	So you want that reassurance?
R	Yeah.
B	As long as it's your business then - and don't tell anyone that will probably judge you or like anyone else about it, then don't tell them because - the worst thing to do is to tell someone 'I got autism' and they judge you or tell everyone you've got autism, which is probably the mean - the worst thing that could happen. You can tell someone that you can trust that won't tell anyone or make fun of you.
MW	Mmm ok. (E's hand up) What about you (turning to E)?
E	Umm like anxious and unresponsive. Cos when I get anxious like I kind of like go blank and everything, um, and everything - all the noises just block out and everything about - and, yeah, so that's what people see.
MW	So they see - Um, if they could see inside you, what this lady is saying is 'if only they could see how I'm experiencing it on the inside', what would you be able to tell them about how you are feeling inside?
E	That I'm, that all the noise level is too high so I just block myself out of it.
MW	Mmm. A, anything from you?
A	Mmm, (pause) like if you do something they might think you are weird, they don't know like why you did it or something.
MW	Mmm, can you think of anything in particular that you might do - that people might think is weird?
A	Mmm, (pause) don't know.

MW	Do you know, I went to a conference in Birmingham last week, on autism. And there was a man who came onto the stage and he was about thirty-five probably, and he was a professional, he worked in something to do with computer programming. And, he came on carrying a big, like this sort of size (indicating with hands) stuffed lion that had obviously been a toy from when he was a child. And in this conference, it was in a massive Birmingham International Conference Centre which has got a bit err, a great big area for people to sit. So, there could have been about a thousand people, there weren't a thousand people there were about four hundred people looking at him sitting on these raised banks of seats, and he came onto the stage with his stuffed lion that was not attractive, it was well cuddled. It was kind of a beigy colour and he just sat it on the chair so that the chair was - the back of the chair was facing the audience so that the lion had its paws over the edge of the chair and he then just talked to us and the lion was just there, all the time. The other slightly unusual thing was that he was wearing a tail. This man - had a tail - because he identified with the lion (B laughing a little but seeming to identify) and he was telling us about stuff to do with autism from his perspective as an adult and how he felt about it. And certainly, if you'd seen him walking down the road, a thirty-five year old man with a lion under his arm, you know, a cuddly toy lion, that is quite unusual isn't it? (B agreeing) But he'd got to the stage where he didn't really care. And I think that's quite interesting.
B	I wouldn't care, I'd just be like - it looks cute, I don't really care like. There's nothing to make fun of cos like when you were probably his age you probably would do something like that.
MW	Mmm (R's hand is up). Go on R.
R	I have a - I have a stuffed snow leopard - and I love it. I got it for Christmas from my brother. But I also have um three teddies, a mickey mouse, a power ranger and a hippo - that I sleep with, and I just can't get to sleep without them.
MW	No, and they're important to you aren't they?
R	Yeah.
MW	(E's hand has gone up) Go on E.
E	This is an unrelated question, but when I was in school, a place to go when I was anxious - was really helpful.
MW	Ah, that's useful to know. So where was that, can you remember?
E	Um it was the ELSA room, we had an ELSA in our school, named Mrs T (names ELSA, and we had two hours with Mrs T (names one ELSA) and Mrs P (names other ELSA). Um I saw Mrs T, um and I got to go there if I was anxious.
MW	So, a useful thing, I'm going to write this down - we'll just finish off ok now, but we'll just write down a list of useful things. So, somewhere to go- (trailing off).
E	Yeah, a place to go.
MW	(Writing down) Somewhere to go, and you went there when you were feeling anxious?
E	When I was feeling anxious yeah and I had a card that I'd just show to the teacher so I could go there.

MW	Alright. Anyone else got any useful things? (Pause) Don't shout? (B agreeing). Yup, would you agree with that? I mean you've mentioned that already (writing it down after nods from the others) (R's hand up) Go on R.
R	I was thinking like when you're feeling like, a little bit down, kind of like a room that has a dog in that you can just snuggle up with.
MW	You've got something going there E! Alright, (turning to E) so what did you call your dog - what's your dog -? (trailing off).
E	Brandy.
MW	So, but was it called a - ? (trailing off).
E	An assistance dog.
MW	An assistance dog, yeah.
B	Be yourself.
MW	Be yourself?
B	Yeah.
MW	(Muttering while writing) be yourself. So when you say be yourself, are you talking to other primary aged children who have autism?
B	Yeah - just be yourself, don't like - be like, the sad one because you have autism, it's like fine to have it, cos other people around the world and around the school probably have it - yeah.
MW	And your differences, although sometimes they can make things difficult for you, actually in other ways, as I said before, you are different in a good way, because your brain thinks things differently. If we were all the same, our world wouldn't be anywhere near as exciting as it is now. We wouldn't have Facebook; we wouldn't have all sorts of things. Yeah, because people who have autism have a way of thinking that is very, um - uh, focused. And that can be really really good. So you can practice things again and again, much more than people without autism.
B	There's a man - famous man called Elon Musk and yeah, he had autism - (trailing off).
MW	Yup, yeah and the person - I don't know if you saw but there was a film called 'The Enigma Variations' or something but there was a man, an incredible man who unblocked coding in one of the wars. And he spent ages on this huge machine trying to work out spy coding that was going on, and he had autism, and he was absolutely amazing.
B	What was his name?
MW	I'll bring the book along cos I've got this book about famous people who were autistic and I'll bring the book when I come in next time and then we can see. I can't remember what his name was. (E's hand is up) Go on E.
E	Um, another useful thing is that I used to have two boxes and they were full of fiddle toys. One was in the classroom, so it was like putty and like fiddle toys like that, and then one was then in the ELSA room where I could go when I was anxious and I could fiddle with it, so that was really helpful.
MW	(Writing) Ok, fiddle toys, that's really useful. We're getting a good list here. (R's hand is up) Go on R.

R	I just really just say, you know um famous people with autism, I got told by Mr H, the head teacher of the school, he said that um there was this person that um, well he was doing something, I can't remember what it was, but he got a piece of paper and started drawing and it turned out to be amazing.
MW	Mmm there is um - if you look on u-tube and you Google autistic savants, so I'll write it down on a post-it note in a minute, autistic savants, they are people who have extreme levels of ability in something specific. So some of them are amazing at urr, let me think, what I have seen, urr music, people can be amazing at memorising things. There's a man called Daniel Tammet who learnt a whole new language, a difficult language called Flemish in a week and he has autism, and because of his autism he was able to do it.
R	(Incredulous) What!
MW (43:47)	One of the people you've just reminded me of R, was a boy - a man now, who um had err, he was a savant, he was autistic - he was able to be shown photographs of like New York, or fly over New York and in his head he could remember absolutely everything. And then he would draw with a pencil what he'd seen, and it was absolutely accurate. He also drew, I think it was the Tower of London or something - it's incredible. So, if I find any pictures that he's done - let me write myself a note. So I need to remember um, the book about famous people, and I'll look that up as well - the person who was drawing. Were you going to say something A or was it you E?
E	Um I'll go first - Also another thing it's just keeping everything the same - as much as possible the same. Like you have to change teachers every year, or in my school you have to change teachers and you have to change rooms every year, but the things you don't have to change is like my LSA every year, so you keep as much as possible - I understand you have to change *stuff*, if you keep as much as possible the same.
MW	And why does that help?
E	Because I struggle with change a lot, and change you know - sets a big thing - in my brain, and it's really hard for me to concentrate for the rest of the day if something's changed. Or just giving me warning if like a seating arrangement is going to change or the seating - the room look is going to change, if you give me like warning that - so I can prepare myself.
MW	Ok. A were you going to say something?
A	Um well when I was little I had like this Barbie and this Barbie dog and - because you can't get leads for them I got a piece of string and I made this like um lead. And it had a collar and you could attach the lead to it. Cos I found this like plastic thing that I wrapped it round so you could like clip it on.
MW	Yeah, and did you - was that useful to you? Did you bring it into school?
A	(Shaking head) No, it's like for when I play at home.
MW	Ok, so have you got a useful thing that you could tell a teacher that would help maybe other pupils in the primary school with autism?
A	Mmm, not sure.
MW	(R's hand has been up for a while) I'll come back to you before R's arm falls off shall I? Go on R.

R	Umm, I um don't know why but I like playing with girl toys like Barbies and that, and um, people - some people they just um laugh at me and some people they don't. And I also say that sometimes I can be very creating. I have these magnetic things, and I can do patterns with them and I - I can create 3-D art. I mean, once I did the top of the Statue of Liberty, can I show you?
MW	In a minute, yeah - let's finish off with - I'll write it down so we remember ok? (Writing) Statue of Liberty. Cos I have remembered (turning to A) that you've also got to show B Izelda (pet gecko picture), oh was it you R - sorry. Um, B have you got anything that you want to add to this list?
B	Not really.
MW	Well, if you think of anything before I come back, (indicating book for the pupils to write in) then we can do that. Is there anything else that you want to say before we stop (looking at everyone)? No?
B	No, not really.
MW	Right, (to A) do you want to quickly get your phone out then? And (to R), do you want to quickly show me that picture - have you got it on your phone? Fabulous. Right I'm going to turn this off now (indicating voice recorder) - thank you very much everybody.
	[End of interview: 47:07]

Appendix 9 AC Interview 2

AC 2	
Name	**Comment**
MW	Do you remember at the end last time I said let's see if we can make a list of things that would be useful to teachers. Do you remember that? (Affirmation from all in group). And you came up with a list, which I've written down here - but actually when I went back through everything that we said - all of that stuff there (indicating typed up transcript), there were so many more things. So what I've done is I've written them all down here (indicating many post-it notes) and I'm wondering if there is a way that we could sort them into like, maybe three groups? I don't know if we can or not? (Reading out the post-it notes to check I had interpreted their ideas correctly and then preparing to sort into groups)
MW	Please do' or 'Please don't' to the teachers, then let's have 'the environment' - so that means not the teacher necessarily, but things that are going to change, so that one can go there (indicating post-it note) - Shall we have another one for friends?
	(Sorting activity)
MW (7:14)	What about 'allow me to be myself?' - do you think your friends should allow you to be yourself (group nodding and answering Yes), and what about your teachers? Do I need to do another one for that as well? (Group agreeing) Allow you to be yourself? (Writing new post-it).
MW	What about 'be trustworthy'? (Placed on friends section) Do we need it here as well for the teachers? (Group agreeing) - (more sorting) 'I find change difficult' - shall we put that in the environment? Go on R - that's yours. I suppose that means just don't make too many changes.
R	(Reading from the post-it) I find change difficult - yeah 'cos your environment sometimes changes. Too many changes I can't handle.
MW	No and I know you're not the only one.
R	The change in teacher, I have to get to know them.
MW	Yeah, I agree. So have we got anything else? These are the messages then to your friends ok? Keep things fair, yeah? Be yourself, so you want your friends to be themselves and then do you think you would be able to be yourself? (Group agreeing). Be trustworthy? (Group agreeing)
R	Cos your friends can trust you.
MW	And then 'understand me', so you need your friends to understand who you are - yeah? Is there anything else to add on to the friends one then? (group shaking heads and saying no) Shall we leave that one just for the moment then? We've got masses on that one (indicating the teacher one), we won't do that one 'cos we've kind of done it loads. In 'the environment' what have we got here then?
R	Umm, boxes of fiddle toys, avoid crowded places, I find change difficult, assistance dog, I can't cope when there's too much happening.
MW	Ok. And then, you've got quite a lot on there B (indicating paper with post-it notes headed 'Please don't'), do you think we need to go through that or do you think we should leave it just as it is?

B	I don't mind.
MW	Do you want to read it?
B	Yeah sure. Help me not to be manipulated by other children, make things different when necessary, don't make assumptions about my work because of my autism, don't give me too much pressure with an arrow to anxiety (drawn on post-it note) and don't judge me.
MW	Right, are there any other things for the 'please don't' for the teachers?
E	I don't think so.
MW	Right let's leave that there. I have a complication here, when I was trying to work out everything on here (indicating transcript), I wasn't quite sure when it was *good* that people knew you had autism and when it was *not good*? Can anyone explain?
B	In what way?
MW	Well, sometimes you said it was good that people knew you had autism…
B	Yeah.
MW	Because then they might make changes and they understood you, but then, A (turning to A) I remember you saying that when your teacher found out you had autism, it wasn't good. So, can you explain? (E's hand goes up) Go on E, you start us off.
E	I think when people find out you have autism they might just make a snap judgement of you, and not fully understand the whole thing.
MW	Ok, so what sort of snap judgement do you think that could be?
E	Oh like, 'she finds noise difficult, doesn't like crowded places', stuff like that. But sometimes autism is like very different from person to person, like it can vary.
MW	So you think that maybe they'll think "oh you've got autism and therefore you're going to behave in a certain way?" And they won't bother to find out? (E agreeing). It would be very interesting. Ok, so that would be a *bad* thing. Right, anyone else got any ideas about why it might be *good* that people know you've got autism? (R's hand goes up) Go on R.
R	Well, with my autism, I strangely enough like having fun and sometimes, when I have school trips they - it's just so fun that um I just get so excited.
MW	Um, um so is it *good* that people know you have autism because of that?
R	I think so.
MW	Why?
R	Oh, it's hard to explain - (trailing off).
MW	Do you think - do you think your friends feel differently, - your friends *would* be excited for those things as well?
R	Yeah, but I literally, I literally sometimes get over excited.
MW	(Laughing) Then people wouldn't - wouldn't be worried about the things you do, they'd think 'that's just R'.
R	Yeah, that's what happened in __ (mentions name of school). In __ when I did anything like silly or anything, they'd think, they thought I was just being me.
MW	And was it, was that your second school or your first?
R	Second.
MW	So that was after your diagnosis when they *did* know you had autism

R	Mmm yeah, but it was my um SENCo teacher that um thought I had um ADHD but it turned out to be autism.
MW	And when you knew you had autism did it make you feel different?
R	A little bit - (trailing off).
MW	Better - or not good?
R	Uhh I think it was better, yeah
MW (14:32)	Better. (Turning to A) Cos you found out later as well didn't you A? These two (indicating B and E) knew when they were very small didn't you really (E agreeing). When you found out did it make you feel different?
A	Mmm, (pause) kind of.
MW	In what way?
A	Err, I don't really know, I didn't really think about it.
MW	Mmm cos you're still the same person aren't you?
A	Cos my parents always thought I had it.
MW	Mmm, and then you just had the diagnosis, which said "yes she does".
A	They took me to get the diagnosis, then I could get help - (trailing off).
MW	Yeah - ok. B what about you? What's good about people knowing you've got autism?
B	Well they probably think - cos now when I was naughty when I was younger, they thought "oh, why is he doing that? Is he doing that for attention?" And they thought "Is he got like - is he acting stupid?" Cos when I was younger I crashed my Mum's and Dad's car, and so I pulled on the thing and it crashed it, and um, since then, when on that day, my Dad thought there's something wrong. So they took me out and then they found out that "oh" - then they took me out to this place, I don't know where it was, somewhere in __ (names place) and they went - they said I had autism.
MW	Oh, ok.
B	(Interjecting) It might have been called CAMHS because that's where I went.
MW	Yeah, I expect it probably was. Ok, so they probably, I mean it would have been more than the thing with the car wouldn't it. There would probably have been a few things - (B interrupting).
B	I used to be really naughty as well like, - and I used to get in a lot of trouble at school, like pre-school and all that like.
MW	Yeah, but then you were quite young when you got your diagnosis weren't you?
B	Mmmm.
MW	And, um, are you happy that people know you have autism?
B	Well, I don't really tell them.
MW	Ok, right - let's - why do you not tell them then?
B	Don't know.
MW	Cos I think, some of you have said this the last time I was here. That sometimes it's *not* good. So when is it not good that people know?
E	When they make fun of you?
MW	And do you think they would do that?
E	I think they would do that.

B	(Interjecting) Cos that's why you keep it in, it's cos like - (trailing off).
E	Because kids don't have the full understanding like, that adults would.
MW	Yeah - ok, what about you A?
A	Yup, I agree with E and also when my cousin found out, she started saying I'm mean and stuff like that when actually I wasn't mean.
MW	And, she thought that *because* you had autism you were then going to be mean?
A	Yeah - but I don't think she understood.
MW	No. What about you B? You said that people might make fun of you. And has that happened to you?
B	Not really. I told one friend in my primary school who I really, really trusted and he never told anyone and he never made fun of me for it
MW (17:37)	Have we got that? (Looking at list of post-it notes) being trustworthy? Yeah we have (pointing to post-it note) Be trustworthy, so you would definitely say that for your friend, and he was.
B	Yeah, really trustworthy. Some of my teachers were too.
MW	Yeah - so actually 'being trustworthy' we've put in the teachers' thing - as well (indicating teachers sheet) so you would tell teachers who you trusted would you? (Group affirming) Yeah, and would you agree with that R - you would tell teachers you trusted?
R	(Nodding)
MW	How would you know you could trust them though?
B	With their eyes obviously, with their brains.
MW	Yeah.
B	That's if they have a brain.
MW	(Laughing with group) Hopefully they would do - they should do. What about you A? How would you know you could trust somebody?
A	I don't tell people, even if I do trust them.
MW	Why?
A	I just don't. Just in case.
MW	Just in case. Because you had that bad experience in Year 6 and that's made you feel anxious a bit about it yeah?
A	I only told - two people - (unintelligible).
MW	And you would prefer it that way?
A	Yeah. I told S and E (E sitting next to her).
MW	And are these your friends? (A nodding) Oh obviously E's your friend! And were they ok about it? (A nodding) Yeah, and what about you E?
E (18:43)	Um - if I had like a bond with someone - um I think I would be more likely to tell them than just a random person.
MW	Mmm, ok, yeah. And you mentioned actually that um sometimes it was easier to be yourself when you're in VU (names school section) (E affirming) Or like with each other as you all - have autism, rather than being with people who haven't. Can you explain a bit more? (R's hand has gone up) Hang on R.

E	So, being with people with autism, you all understand each other, like in a certain kind of way. So it makes it easier just to be yourself I guess with everyone. Um, but if like, with people who don't have autism, they don't fully understand you.
MW	Yeah, and I know that um, A, you said something about 'needing to act normal' - yeah? And is that when you're with - you don't need to act normal - well, I mean you're being yourself hopefully here, but there are some places that you feel you have to a - (A interrupting).
A	The only place I act myself is probably home - that's it. And when somebody comes round, I act normal. But when Sarah comes round, I don't.
MW	Then you can be yourself? (A nodding) With Sarah and with E you can be yourself. Ok, but home is the safest place to do that? (A nodding) Because that's another question that I want to go onto in a minute. What about you (turning to B) when do you think you - do you need - are you trying to 'act normal' - whatever 'normal' is?
B	Nope.
MW	Good, so you're just, you're just who you are?
B	Yeah.
MW	I mean everybody has to be slightly different when they're in (B interrupting).
B	When people come round I just go off and like "oh, sorry you'd better go because I'm bored stiff" and then when like one of my brother's or sister's friend comes round I'm like "just come, can't be arsed, don't come in the room, leave me alone'.
MW	Yeah, and you know you just need space at times.
B	Yeah, it's just cos they're really annoying and like - (trailing off).
MW	Do you think you've got better at that now you've got older again?
B	Yeah.
MW	Because before would you just have got cross and not known why?
B	Yeah, I would have just belted them out of the room.
MW	Whereas now, you know what things to avoid? (B affirming) And that's a bit like you A, and E saying about learning techniques for social situations (A and E agreeing), so you've learnt a technique haven't you then B - to take yourself away. What about you R - do you feel you've got to "act normal", which was something that A said, and I thought it was a really interesting phrase.
R	Sometimes, I mean when I'm around people that I know - and it's just them, I feel like I can relax and be how I am normally, but when I'm like in a crowd of people - I don't know - because I want to be someone I'm not, and I don't like that.
MW	No, (pause) because that doesn't seem very fair does it? We've got something about being fair - there - (finding it on one of the sheets of paper) here - "keep things fair". Do you think it's fair A that you've got to try and be somebody who you are not?
A	(Shaking head)

MW	It's not really is it, and you've said that then R. (Turning to B) You're not too fussed about being different (referring to B) but you know that there are sometimes (B agreeing) times that can lead to you just needing to take yourself away. And E, what do you think? Do you think is it fair?
E (22:12)	I don't think it is fair (long pause)
MW	So it's not fair because -? (trailing off).
E	Because, you know, you should be able to act the way you can - the way you do act in front of people, as long as it's not being mean or being horrible, I think you should act whoever - who you are.
MW	So one of the things we said, I meant to do one strip of paper - Oooh you had your hand up R, what were you going to say? Sorry.
R	I was going to say that when um, when I do, um like, when I have - uh, how am I going to say this? (Long pause) Right - when I know true that I can trust someone, I feel like, I feel like a really big connection with them. Yeah.
MW	That's a really nice way of putting it.
R	Also, I just want to say another thing, when I - when I'm in public with my parents, sometimes I act like I, like I normally, normally act. And my parents tell me not to be stupid and I *honestly* can't help it.
B	I'm the same. I'm actually like - when I'm in __ (names city), like and you know, by __ (names shopping area) they have this shoe thing - (trailing off).
MW	I really hate __ (names shopping area).
B	Same - I really hate __ (names shopping area) it's boring.
E and A	(Interjecting) I love shopping.
B	You know when you walk in and there's like these sofa things, I just walk straight along it and just jump up and walk along, and Mum and Dad are like "get off there" and I look down and all of a sudden I see my football marks have gone through the sofa.
MW	Uh - oh, that's not good. Go on R.
R	Um, this is a story from long, long ago, before I was even in school, but I was at this hairdressing stand in a shop and, and um my mother put me to the side and there was a cables thing dangling down, holding onto a thing that was turned on, and obviously I was curious what - what it led to, cos I didn't know. I pulled the wire, what happens is, this thing came right down on me and um, it was a really hot - and it gave me a scar on my arm.
MW	Was it a - was it some sort of hair drying - oh, it was probably tongs that people use to curl their - (R interrupting).
R	It wasn't tongs.
A	Straighteners?
MW	Yeah, was it flat?
R	I don't know, I can't remember, but it gave me a really bad scar.
MW	You know the interesting thing is - just thinking about you jumping on those sofas, I think there are a lot of people who would want to do exactly the same, and they try and act normal and so they don't. And so you are yourself and you are doing what everyone else wants to do.
B	But my football boots went right through.
MW	Yes, that's unfortunate.

R (25:42)	That reminds of something when I was really little (laughing), me and my dad were playing about and he kept on chucking me onto the sofa and every time that he did it, I got up and said "again, again, again!" (Laughing)
MW	Right, one of the things you said last time were that there were things that made you feel anxious, and then you B said "it's good to feel confident". I can't remember, you just mentioned confident - I can't remember, but it was just really interesting. So I thought right ok, so anxious is one end and confident is the other, where do you feel most confident (turning to A)? Is that in your house when you're being yourself?
A	Yeah, and sometimes in VU (names special unit) when it's just me and Frances, if I'm on my own, it's in here.
MW	So, is it called VU (names special unit) did you say?
E	It's VU (names special unit).
MW	(Writing a post-it note for A) VU, (spells out special unit) and your house, that's where you feel most confident?
R	That's the same for me.
MW	Ohhh - hang on, ok, (turning back to A) let me just find out where you feel most anxious.
A	Um, in crowded areas, when I'm like going to someone's house.
MW	When you go to someone's house that you don't know yeah?
A	No, just on the way, even when I do know them.
MW	Ok yeah.
A	Walking on your own.
MW	Walking on your own makes you feel anxious - yeah?
A	Yeah.
MW	(Writing) I can start another one (meaning another post-it note), have you got loads of other things? (A shaking head) So we've got crowded areas, at someone's house, walking on your own.
A	Class.
MW	All classes?
A	Yeah.
B	Some classes really wind me up.
MW	But you said *some* whereas A said *'all'*. So hang on, we might come back to that in a minute. Hang on to that B, don't forget.
A	Especially with the language class.
MW	Loud? (Writing loud) Loud.
B	That might be Jack (names pupil)?
MW	Anything else? (A shaking head) No. Ok, go on then B, let's get yours. Where's your best place?
B	Right, get this all down, might have to start a hundred.
MW	Oh my goodness, ok, just give me a few - not too many.
B	Right, shops.
MW	Shops? You feel confident in shops? (Sounding amazed)
B	Yeah. Me house.
MW	Own house, yeah.

B	Not Mr S's classroom for a start.
MW	Not some classes. And what's the matter with that one in particular?
B	Oh, he's just weird.
MW	Ok (others laughing).
R	Everybody calls him a pervert.
B	He is so.
MW	So is there is something that makes you feel a bit unsettled, about some people, and that's when you don't feel comfortable.
B	(Ignoring question) And um, what else? (Pause) Restaurants.
MW	You feel confident in restaurants?
B	Oh yeah.
MW	Ok, what else?
B	Phwah - my nan's house?
MW	That's where you feel confident? Yup. (turning to R as recognising the others might be getting bored) Can you remember yours, can you write them down?
R	Um I think so.
MW	Do you want to use this pen? You can start just while I do this. Nan's house (writing on B's post-it). Yup?
B	Um sleeping.
MW	Sleeping? (Slight laughter) Well, do you feel confident when you are sleeping A?
A	No.
MW	No? Well, how do you know? How do you know - if you're asleep?
A	I don't know.
MW	Right, that's all of yours. What about this other one then. Do you want to start writing some of yours on here E? (indicating post-its) Oh, hang on, let me just take out - how many am I going to need? I'm going to take out three. So you carry on with that.
B	Can I put Charlie as mine?
MW	No, R. Actually why am I writing this down for you? There you go. What colour do you want?
B	Don't mind.
MW	(Passing B a pen and then picking up post-its that are arriving from others on the table) Right, I just need to know which end to stick these (indicating confidence scale). So, these are the good confident places, yeah? So we've got VU (names special unit), your own house.
B	Mr G's (names teacher) classroom.
MW	Ok, so school *sometimes* makes you feel anxious. Can you think about particular times that that's particularly that way. Because this is school as well (indicating another post-it that says school but is on the confident end of the spectrum). And that, that makes you feel calm, or confident.
B	(Handing over completed post-its)
MW	Good job I didn't give you hundreds or whatever it was that you said! Right, what have we got here?
B	Mr D's (names teacher) class.

MW	So this is going to go down this side yeah? (Indicating anxious end of spectrum).
B	Yeah.
MW	But nobody else is going to understand about that unless they've been here, so you need to try and think about, if I was to say to other people "try and avoid this", what is it about *this* class? Is it noisy, is it the teacher?
B	Oh, it's the teacher definitely.
MW	Ok, so it's just that you don't feel relaxed with the teacher. Yeah?
B	He gets on my nerves.
MW	Ok, so what happens with that teacher? So is this going to be a 'please don't" for the teacher here? (Indicating list on large paper previously created with others) So what, what am I going to say then? (Getting ready to write on the sheet).
B	Just don't come near me ever again Sir.
MW (30:51)	So some people - just need to keep away a bit.
B	Yup.
MW	Yeah, ok, so that one needs to be down there.
B	We need to put Mr D (names teacher) class - I always feel anxious in there, he makes me feel so scared I feel like skipping the lesson.
MW	Really? So what makes you feel confident, have you done those ones?
B	Yeah.
MW	So where are they?
B	On here (indicating post-its already on confident spectrum)
MW	Oh yeah, that's yours - sorry.
R	I've done my 'anxious'. Can I tell you?
MW	Yup, go on.
R	School, a-k-a tests, in public and sometimes in class.
MW	Ok, (taking post-its) thank you, so that's your anxious one.
A	(Unintelligible)
MW	Oh yeah, let's look.
B	(Talking to R) I'm not anxious about tests I just do it, I just are really confident.
MW	Right, we're getting on, we're nearly done actually, I think. Right, hang on, let me just see what else I've got to see about - I've done that one. Oh, (taking post-it note from pupil) which way is it going to go on there? (Indicating spectrum for post-its). Thank you. (Consulting notebook) Favourite place, we've done that - done that. Right, two things I've got left. What about - (B holding post-it note up) one of the things, have you got more to add B? Yes. Um - (trailing off).
R	(Interjecting) Oooh, I've got another thing to add.
MW	Ok, you just carry on. Would people know, and this is one of the things you mentioned right at the beginning and it is really interesting because it is one of my questions, I've written down here 'would people knowing or understanding more about autism be good, or would it make them make assumptions?'
B	Make them make assumptions.

E	Make assumptions.
MW	And you feel the same B?
B	Yep.
MW	And what about you A? Do you think it would be good if they understood more or would it make it more complicated?
A	Depends. Sometimes it, like, if they, um it said just like one thing, they might make assumptions - (unintelligible).
MW	Ok, so sometimes it wouldn't be good because they will make assumptions. And they've done that to you in the past haven't they? With your previous teacher, and you (indicating E) with your work, yup, and B what about you then? You said it wouldn't be good because they would make assumptions. Can you explain a bit more?
B	So, if they made assumptions about me having autism, or thought he's so dumb I couldn't do anything well they'll get hit around the face.
MW	Because why?
B	Well, I don't like being called dumb and autistic - it's just not fair.
MW	No, because you could equally say things back couldn't you, but then that would be, that would be making assumptions about you wouldn't it. And as we know from that book (indicating book on Asperger's and famous people) there are many other people we know - you can have enormous talents in many areas as well as finding things complicated in many areas, and that's the same as anyone else.
R	I've got another one for - it's bowling and in a ball pit place a-k-a Frankie's Fun Factory.
MW	Ok, thank you very much. Go on E.
E	Um, understanding autism is very good, but if - if they start treating us differently from other people um and letting us use our autism as kind of an excuse to get out of stuff, it can kind of turn into a habit.
MW	Mmmm interesting. What do you mean 'turn into a habit'?
E	Like, if you shout at someone and just say 'sorry, it's my autism', and don't get punished, you can just keep on doing that, and it wouldn't be fair for anyone.
MW	So is this one of those occasions where you need to be treated the same?
E	Yeah.
MW	And when would be an occasion where you need to be treated differently?
E	Well, if you shout at someone but like for no reason at all you should be treated the same. But if you shout at someone because they are actually winding you up you should be treated differently.
MW (35:06)	Ok. (Turning to B) Can you think of any times that you would want to be treated differently?
B	(Misunderstanding) In my face, cos they would get a good old - (MW interrupting).
MW	No, I'm saying you would *want* them to treat you differently.
B	In what way?
MW	Well, so R I think one way you were helped one time was because somebody wrote stuff for you, that's what I mean. Any time where something could be different that would help you.

B	Bribing me.
MW	Like what? Explain?
B	Like going on roller coasters. Well there's roller coasters at __ (names theme park). There's stealth I think it is. Mum wouldn't go on it. My Dad forced me to go on it so I had to sit on it. And he bribed me money to go on it and then - (trailing off).
MW	Did you enjoy it?
B	I loved it. Almost had a heart attack, but it was good.
MW	E, you had your hand up did you?
E	Oh no, I didn't.
MW	Oh sorry, go on then R (R's hand up).
R	Um, I don't know why, but people keep on telling me to go on haunted house rides, but I'm scared of them and I'm scared of everything - (trailing off).
B	Going to Alton Towers this year.
MW	I wouldn't. I'd be too scared as well. Um, is there anything else that you want to talk about?
B	Yeah I'm going to __ (names theme park).
MW	With school?
B	No.
MW	With people at home?
B	With Mum and Dad and my little sister. Cos my younger brother and my older sister are little babies.
MW	And now having been on some of these scary things you might be able to feel better about them?
B	Yeah I'll definitely feel better. Have you been there?
MW	Urr, yeah a long time ago.
B	There's one called __ (names ride). And I'm definitely doing that. And the smiler.
MW	I went on that corkscrew thing. Is that still there?
B	Yeah.
MW	Mmm that was scary. Go on R (R's hand up).
R	Well, it might be next year, I don't know, but if my parents allow me, I'm going to Disneyland with my sister.
MW	How old's your sister?
R	Umm, she's an adult now, she's married and everything.
MW (36:59)	My goodness, that would be really really exciting. Right, anything else that you want to talk about? (Group shaking heads). So what I might do, if it's ok with Mrs B, is come back once more after Easter and catch up with each of you separately, just to find out a little bit more about everything that I haven't found out about - because I think - (R interrupting).
R	(Sadly) Is this our last session?

MW	Well, I think it might be our last session as we are together like this, but I was just going to say to Mrs B when she comes back in, I wondered whether I could come back after the Easter holidays and just catch up with you one at a time, just to find out a little more. Because I think you might be bored if I spent ages talking to E, and you were just listening, and then if I spent ages to talking to you (R) and everybody else was just listening, they'd be a bit bored. So would that be alright with you?
All	(Agreeing)
MW	Thank you very much. Right, how much time have I got to type up? Quite a lot.
B	Thirty-seven thirty.
	[End of recording: 38:01]

Appendix 10 A 3 Individual Interview with A

A 3	
Name	**Comment**
MW	Ok, let me just go through checking some of these things with you (indicating notes from previous interviews). How is Izelda [pet gecko] first of all?
A	Good.
MW	Is she? Do say hello to her for me.
A	She shedded last night.
MW	Ohhh. Does that hurt do you think?
A	No. Um, she pushed everything around her cage with her head to try and get the skin, um, it's moving all the stuff off her head.
MW	So does she kind of have to rub her head to get it off? I suppose she can scratch other bits to get it off.
A	So, she's going around the cage pushing the coconut around. She used to go in it, but now she pushes it around the cage.
MW	Why, why is she supposed to go in it then - I don't understand that?
A	Cos the water helps it - if it's dry, it's harder for her to get it off.
MW	Mmm, I suppose that's like when we have sunburn, and we peel - that's the same sort of thing isn't it?
A	Yeah, and then water helps it go soggy because it's wet, so it just comes off.
MW	So it comes off in one - (A interrupting).
A	And she eats it!
MW	Uhhhh that's disgusting!
A	(Laughing) So I didn't have to feed her last night. When I went to feed her, she was shedding so I couldn't. And she was eating it - they always do.
MW	Uhh -does she look different when she's shed?
A	Um, no she's a bit brighter, then she goes darker, then she goes white and then she sheds.
MW	And how often does she do that?
A	Um, once a month.
MW	Quite a lot, is that because she's growing and when she's stopped growing she won't need to do it any more?
A	She'll always do it. It also cleans herself.
MW	There's a lot you know about lizards, or geckos.
A	And in the summer, they do it more often.
MW	Why?
A	Like once every two weeks.
MW	How long have you had her for?
A	Um, since September.
MW	And did you have one before that? (A shaking head) So this is the first time you've really ever seen - (A interrupting excitedly).
A	It's my first ever pet. I've got three cats

MW	You've got three cats and two sisters (A affirming). You've got a fairly full house haven't you? And how old are your sisters?
A	Um one's ten and the other's twelve.
MW	Oh, so you're the oldest?
A	Yeah.
MW	And have either of those two sisters got autism?
A	No, no one in the family has.
MW	No one?
A	I'm the only one.
MW	That's quite unusual isn't it?
A (2:42)	Well, my sister, well we're pretty sure she doesn't.
MW	Interesting. But your parents recognised it didn't they? So even though your diagnosis, you said, didn't happen until Year 6, they knew (A affirming). Yeah.
A	They knew - they just wanted the paperwork.
MW	Yeah.
A	To help me in primary school.
MW	Yes, so that was why you needed that diagnosis, to help you. But interestingly, and you're a particularly interesting one, because you didn't like your primary school did you? (A affirming) And even when you had that diagnosis, which your parents hoped would help you - (A interrupting)
A	Cos the teacher didn't tell anyone.
MW	No, but should - do you think she should have done?
A	Yeah.
MW	Who do you think she should have told?
A	Um, well all my teachers - that knows me, cos none of them knew but her.
MW	And why do you think she didn't?
A	I don't know.
MW	But that teacher who knew, you still didn't like her did you? (A affirming). So even when she knew - (A interrupting).
A	I wanted the other one to know if anyone was allowed to know.
MW	Yeah, but even when she knew it didn't get better?
A	It got worse.
MW	It's just bizarre. What, what happened? What got worse?
A	Um - she shouted at me more, like she would tell me off for moving my leg or something like that - very silly reasons.
MW	Yeah, but the other teacher - because this was a job share wasn't it? - the other teacher, you thought didn't know?
A	But she - I think she thought I did, but she didn't know.
MW	And she didn't change - for the better or for the worse - she just didn't change?
A	She was the same.
MW	And was that ok? Was that ok because she was already a good teacher? (A affirming). Ok. Um, you also said that 'sometimes you were given work that was too easy'.

A	In maths, and then they would give me hard in English and it needed to be the other way around.
MW	Mmm. And sometimes, do you think it was given to you, and it was too easy, because they thought you couldn't do it?
A	Cos I struggled with English, so they put me in the lower set for everything.
MW	Ok. Yeah, that's never a good idea is it? That happens to a lot of people actually. Um, now the interesting thing again - this is why I'm a bit confused - you said that you liked it that when teachers found out 'they treated you the same'. Do you mean the same as they did before, or the same as everybody else?
A	The same as before, and they treated me only a bit differently, like if I didn't want to go on stage, they wouldn't force me, where the other teacher did.
MW	Yeah - ok.
A	She just tried to keep it all the same.
MW	Mmm, the same for everybody?
A	Yeah, but like when I needed it treated differently, she would.
MW	Ok, so what do you think teachers could do that would be useful about treating someone differently?
A	Umm, I think they should keep - treat you the same, unless you need to be treated differently.
MW	Mmm. And when might you need to be treated differently?
A	Like, umm, if like you don't want to go on stage they won't force you, or something like that.
MW	Yeah, ok. And is that to do with anxiety?
A	What like when I don't go on stage?
MW	Just generally, is it, is it difficult when things are happening that make you feel anxious?
A	Mmm (agreeing).
MW	Ok, because anxiety is one of the themes that has come out from these previous interviews. So what sort of things, apart from being on stage, would make you feel anxious?
A (7:21)	If my Mum said 'we're going somewhere' and she won't tell me, and she doesn't know what they're going to do and stuff like that. I ask questions, and if she can't answer it I get like upset.
MW	So you don't like surprises?
A	It's because she doesn't know. She'll tell me enough information.
MW	Ok. So that makes you feel anxious. What else makes you feel anxious?
A	Umm, going to like new schools and stuff like that.
MW	(Long pause) And I remember you mentioned something about a coat room being squished - do you remember?
A	I don't like crowded areas.
MW	No, crowded areas - I don't like them either.
A	In this school, um, the hallways aren't so busy. Sometimes it can be on the stairs, and you have to just go to the other stairs or just wait a few minutes.
MW	Yeah. So I suppose as you've got older as well, you've got more aware of the things that make you fell uncomfortable and anxious, and you can avoid them?

A	Cos there's two stairs and if it's really crowded on that one, it means that it's nearly empty, so I just go to that one.
MW	(Laughing) That's a good idea. Um, you said that only three people know, outside of your family, about your autism.
A	Yeah, Sarah, E - although I don't include teachers - Sarah, Lois knows - I think. Well, I told more people - in this school, then I did. But only three people in my primary school know.
MW	And why were you so careful not to tell people?
A	(Instant response) Because they would treat me differently. Or they would assume things, that's like not true.
MW	Mmm, yeah - why do you think they do that?
A	Because they don't know enough about it. And they're kids to be honest. They don't know, they're not doctors or anything like that. They don't - (trailing off).
MW	So are adults generally safer to be known - to be told?
A	Well, my parents just tell them - I have no choice (laughing together at this).
MW	Cos you came up with this phrase, which has been so interesting. And actually, I found a whole load of other people's research that's been typed up and in other magazines, and there's some stuff about adults saying - the phrase that was used was 'putting on my best normal' - and I thought, "that's A - that's exactly what she said!' So fascinating what you said.
A	So, if I'm in a crowded area, and I don't like it, I will just do what everyone else does - stand there, try to walk through it.
MW	So, do you think you copy what other people do, when you're acting normal?
A	Well, if it's - I don't know - like - sometimes I'll be myself. Like around some people, like D, but no one else really. I just try to act normal.
MW	So, what do you not do when you're with other people?
A	Mmm, act crazy (smiling).
MW	(Laughing) So, so when you're being just yourself, you'll just do whatever you want as crazily as you wish to be.
A	Yeah, like roll off the bed (M affirming). When my friend has sleepovers, we'll roll off the bed and onto the mattress.
MW	Oh, that sounds good fun. I can remember ages ago, when I was probably about your age, I stayed with a friend and she'd got a bed which had a mattress standing up on its side, and we would take it in turns to lie on the mattress - it was only about that wide, and then we would just roll off and bounce onto the bed.
A	Once me and my cousin got really told off for doing this, but her and her sister were staying round too, but her sister was in my sitting room because she has the same amount of sisters, and um, they're all two years older than one of us.
MW	Ok.
A	We got all the mattresses from around the house and piled them on top of my bed (laughing).
MW	Oh my goodness!
A	And we were jumping on top of them, and then one fell off and we rolled off of it, because it fell off like that (indicating a slope) - and we rolled down it! And then my Dad came in and told us off.

MW (11:58)	Well, I think he probably would have quite liked to have had a go before he made you put them all back! Um. Yeah - so it's just this thing about being different and what you'd change when you feel you need to act normal. Is it hard to have to act normal?
A	Mmm, not any more.
MW	So, it's getting easier?
A	Well, not really. It's because I know how to act normal.
MW	Yeah, so how do you learn to act normal?
A	Err, copying other people.
MW	Are you happy doing that, or would you rather you didn't?
A	Mmm, sometimes - sometimes I want to be myself but sometimes I don't, but sometimes, in here, I'm myself. Cos like R's in here at lunchtime.
MW	So it's when you are with other people who just accept you for who you are - then you can be normal - yes? (A affirming) Great. And is it tiring then when you have to not be like that, when you have to try and remember to be someone else?
A	Mmm, - well - I don't mind any more - but I would want to be myself (sounding wistful).
MW	If you could choose?
A	Yeah - and then they won't stare at me. Because if I did just go in the corridor and start being crazy, I think everyone would stare at me.
MW	Mmm, they might.
A	Well, in my primary school they definitely did, but in this school they don't do it as much. I mean, at lunchtime I just opened the door and said hello to everyone who goes past.
MW	(Laughing) Oh, you sound like great fun - I think that sounds lovely. Hmmm, now then where were we? I can't even read my own writing - just a minute!
A	Did you write up four of these?
MW	Mmm, and another one. Yes I did. Hard work (reading from notes), maybe it's feeling weird. One thing you don't like is being judged.
A	Like people stare at me, I tell them and they assume 'Oh she doesn't like this, she doesn't like that', when actually I might like it.
MW	Mmm, and do you think they're making assumptions because of autism? (A agreeing) Mmm, they're putting you into a box. Ok, um, let me see, yeah - you're very cautious I would say about who you tell, because you said you don't tell anyone, even if you trust them.
A	Yeah - I sometimes don't tell them.
MW	Mmm, and you've learnt that it's safer that way?
A	I mean I've told Sarah, and Amy, but some people don't even know what it is and I don't know how to explain it cos I don't know what it is really.
MW	It's just you isn't it?
A	Yeah - it's like explaining yourself.
MW (15:25)	Yeah, you know the really interesting thing that's come out of this is that working with all four of you together, you've all got autism, and so that's a similarity between all four of you, and yet you're all completely different aren't you?
A	I think everyone is (unintelligible).

MW	Mmm, so, so when - do you remember that survey that I read that thing out from? So this is from the National Autistic Society - this survey, do you remember I told you right at the beginning when I first came in - and what the people said was that 'the single thing that would make school better for us would be if teachers understood more about autism'. But there's a danger isn't there? (A talking over the top) What do you think the danger is?
A	Yeah - thinking that other people - (trailing off).
MW	Well I would say the danger could be - (trailing off).
A	That they assume things?
MW	Yeah. That they'll think - (trailing off).
A	They need to know that everyone's different and just know things that they *could* not like.
MW	Exactly.
A	And just learn them and then - (trailing off).
MW	I think I think they need to know, I definitely think that's true that teachers do need to know more about autism don't they, but that shouldn't be the end. They need to know about you within that.
A	Yeah, and like learn before they assume things.
MW	Absolutely.
A	And like watch what I'm doing or something.
MW	Yeah, and talk to you - I think if they actually talked to you, they would find out stuff. And it doesn't matter.
A	That might be a lot of meetings with the teachers! (Laughing). You could tell one and they could tell the whole - (trailing off).
MW	Exactly, that would work wouldn't it? You wouldn’t have to have a meeting with every teacher - that would take a year wouldn't it - but in your primary school, that would have been quite a good thing wouldn't it? (A agreeing). Yeah, ok, let me just go to this page here because yes - you're right yeah, I did do a page for everybody.
A	How do you know what one's what?
MW	I just put at the top E, A, R B, and all. So some of these are things that I kind of thought 'Oooh that's interesting - you know lots of people have said that' and then, things like shouting, you and R really don't like shouting, in fact I think E mentioned it as well, it makes you feel anxious.
A	When teachers just suddenly shout. (MW agreeing) Like, in my maths class, in Mr J's, everyone's so naughty, and then he'll suddenly shout and then it's all - like (trailing off).
MW	Mmm, so these themes that are coming out are to do with trust - trusting people. And if you trust people, it's usually because you understand people, or you think they're going to understand you. And then you've got stuff to do with confidence. And confidence is really important isn't it, because if you have trust and you're confident with somebody, then you can relax with them - is that right? And then anxiety kind of goes away.
A	Cos when I first met Sarah, I acted like everyone else, then I told her, and I still acted - I remember showing a video of what I did and then um then we just started being silly and now we're crazy with each other.

MW	Because you've probably, by you being you, you allow her to be her - and that's really important. Then we've also got this thing about acting normal and being me. But then the thing that's really fascinating is this difference thing. The fact that having autism makes you different, that's definitely true. That's because there are fewer of you than people who don't have autism, it means that there are fewer people who understand that, but there's also the part that you are an individual, and there are so many things about you, that are really important.
A	And also, normally about things like illnesses. Everyone's the same, but with autism - (trailing off).
MW	Say that again.
A	Other things like other illnesses, everyone will have the same symptoms, but then with autism, it's all completely different.
MW (20:00)	Yeah, so if you had a cold, you'd normally have sore throat, runny nose, cough, you feel rough but if you've got autism - (trailing off in the hope that she would complete the sentence).
A	So not everyone's - (trailing off).
MW	So there are some things I say that are similar in autism - but even within that, the fact that B likes to go shopping, that's quite a surprise. Do you like to go shopping? (A shaking head) No, so you know even within that, you're one end and he's down the other end.
A	And, and stuff like, everyone doesn't like crowded areas, but someone might like - like only if there's five people then they feel crowded or if there's loads more, they feel bad.
MW	Mmm, mmm. So, is there anything else do you think that you want to add that we haven't already talked about?
A	In this school, my confidence has improved.
MW	Why do you think that is?
A	Because I talk to people now. In my primary school I didn't talk at all.
MW	Even to your friends you didn't talk?
A	I didn't talk to anyone.
MW	So, how did you manage that? It must have made you feel really sad - didn't it?
A	I just didn't want to talk to them.
MW	Well, I'm very glad you've changed. You've only got one more term left in Year 7, and then - (A interrupting)
A	I even talk loudly.
MW	Good for you - keep that up. Yeah, be brave, because it does make a difference. The more you do it the easier it gets doesn't it? (A agreeing) Yeah. What I'll do then is type everything up, spend some time thinking about it, and then probably come back in June. The reason that I'll come back is just to check that the things that I'm thinking are ones that you agree with. Because what I don't want to do is think I've found something and you would go "No! That's not us at all" or "that's not me at all!" So would you be happy if I just saw you once more?
A	Yes.

MW	I'll probably work with you altogether, and it'll be a bit like having lots of post-it notes, but it will probably be something that I need to show you on the board or something because it will be quite a big thing. And then you'll see what I'm going to write about. Go on, what were you going to say?
A	Um, I know in July at some point, we're going on a France trip - I think it's July.
MW	Oh, ok, I'll check it out.
A	Me, E and I think R is going, and B I think.
MW	Yeah, ok. So the whole of Year 7 might be going to France - well some people will.
A	Yeah - some people yeah.
MW	Nice. Are you learning French?
A	No (laughing).
MW	Oh, ok (laughing).
A	I just wanted to go.
MW	Ok, well then you'd better learn a few quick phrases.
A	I don't do Spanish either. I do here - this is my time when everyone else is doing French and Spanish.
MW	Oh, ok I understand.
A	I do typing in RBS and stuff like that.
MW	That's quite nice isn't it; because it gives you time to come out of the busy-ness of the other classes. Cos how many people are usually in here when you come in?
A	Sometimes two (M agreeing) most of the time, or just me on my own. Sometimes B's here and then sometimes six, once every two weeks, or something.
MW	And then how many people in your normal classes in the normal school?
A	About 30.
MW	So, quite a lot more isn't it. So this is calm isn't it - usually? (A affirming) Yeah. Ok, we should stop now - can you press stop on there.
	[End of recording: 23:28]

Appendix 11 E 3 Individual Interview with E

E 3	
Name	**Comment**
MW	So, you've got two sisters, are they older than you, younger than you?
E	Umm, no - I only have one sister; she's younger than me.
MW	Ok. And you like science?
E	I like Science.
MW	And the colour pink.
E	Yup.
MW	So, your school uniform is a bit of a pain.
E	Yeah (laughing).
MW	And you said about your primary school, that it was ok but some teachers didn't understand.
E	Yeah.
MW	Now, understanding, or people not understanding is one of those themes that I have picked out. So can you just explain a bit more, when you said that 'some teachers didn't understand'?
E	Some teachers, when they taught you know, their teaching styles, you know, didn't really work with, you know, uhh, didn't really work, they were teaching quite fast paced - yeah (MW affirming). And they didn't really keep control of the classroom - as much. So they would kind of let people run around and be noisy.
MW	Yeah, ok. I understand that. So it wasn't that they were mean to you or unpleasant - (E interrupting).
E	No, they weren't mean, they weren't - they just didn't really understand.
MW	Ok, did, did they ever ask you about you?
E	Umm, not - not the teachers, but I used to have an LSA and she asked me quite a lot which was good
MW	I wonder why - do you think the teachers should have talked more to you, would it have helped?
E	I think it would have helped but they were quite busy as well.
MW	Mmm, and if they had talked to you and asked you questions, what would you have said to them?
E	Well, I would have told them that the classroom gets really loud, and that if you set me a lot of work in a very loud classroom, I won't get it all done.
MW	Yeah.
E	It's not that I wasn't focused all the time; it was just because of the environment.
MW	Yeah, I can remember you said, umm, that sometimes the work was not right, because they thought you struggled with the work and actually - (E interrupting).
E	Yeah, I didn't struggle with the work, I struggled with the environment.
MW	Yeah, so you would have preferred somewhere quiet and calm?
E	Yeah - yeah.
MW	And is that what you have when you are working in VU? (E affirming) So the environment is the way you would like it to be?

E	Yeah, the environment is right.
MW	Because, the environment does make a big difference doesn't it?
E	Yeah.
MW (3:10)	Mmm, ok. Also another theme that keeps coming up is this one of anxiety, and I know that you said that you have anxiety (E affirming). What is it that causes that to be particularly bad?
E	Well noise again is a big one - I don't like noise. Um - when there's like surprises (MW affirming) I don't like surprises. I will get used to surprises on birthdays, when it's a person's birthday there'll always be like a surprise then, and the class loved it, but I really don't (laughing).
MW	That means that you would have had about thirty days of things that you didn't like (E affirming). Yeah, ok. Ok, so noise and surprises, and I know another thing you said was about following the rules. So if people don't follow the rules, does that make you feel - (E interrupting).
E	That makes me feel anxious.
MW	(Long pause) Umm - you said that some teachers were able to relate to you, so that was important?
E	That was important.
MW	Why?
E	Because when teachers can relate to you, you feel more comfortable around them, and - and they have understanding. They can help you teach - teach you in a better way.
MW	Mmm - one of the interesting things that we've also talked about which is also going to be a theme, is this thing about 'acting normal' (E affirming). And, you said that you didn't really need to when you were in VU.
E	When I'm in VU, no because I'm around everyone who is kind of different, like me, but when I'm in the main school I kind of feel the pressure to act normal because - I don't want to be laughed at, I don't want to be - you know.
MW	So what changes when you have to 'act normal'?
E	Um - being excited, um I'm quite shy when I - yeah.
MW	So do you mean you would hide your excitement in that sort of - (E agreeing)? You would feel it, but not let it show.
E	No.
MW	But in VU you would let it show?
E	Oh yeah.
MW	Ok. And then, when you're at home, you're ' acting normal aren't you? (E affirming) Are there any other places where you're not acting normal?
E	If I go out - if I go out to town, yeah, anywhere where like people apart from - anywhere with people that don't really know about my autism.
MW	Ok, yeah. So how would you be different when you are out from the way that you would want to be?
E	Well, when I'm out I would want to be more fun, sociable, but when I'm out I'm just kind of quiet, cos when, every time I try to be, as I would see it, a normal kind of fun, it doesn't really work.
MW	And what happens then?
E	I get over excited and I think people don't like me, and then I go home and regret it.

MW	Yeah, so when you're acting normal, is it hard?
E	Um yeah.
MW	And is it something that you wish you didn't have to do? Or are you ok about it?
E	Um, I wish I didn't *have* to do it obviously, but you know - (trailing off).
MW (6:30)	And do you think you do it because you've learnt (E affirming) that you need to do it - you think you need to do it?
E	Yeah, because otherwise people are gonna - laugh at me, people are gonna be like that cos you know - (trailing off). People in my unit don't, don't always hide their autism when they go out into many lessons and people do laugh at them, which is wrong, but you know, that's why I don't do that.
MW	Yeah. And do you think if people understood more it wouldn't happen?
E	(Pause) Yeah. I think if they understood that - Yeah. Some people it would still happen I think, but you know if you understood, if you understood more about it - (trailing off).
MW	Mmm, and do you think that your peers - so other sort of teenagers really now we are talking about aren't we, are worse, or are adults worse, or are they the same?
E	Teenagers are worse. Adults usually have, you know, even if they don't really understand it, they kind of have the common sense not to - yeah - be mean or something like that.
MW	Mmm, so it's just kind of a stage of growing up (E affirming) that's difficult for you. But it should get better as you get older shouldn't it (E affirming). Mmm interesting. Ok, thank you. Ummm. You said you don't like talking with new people, I suppose that's because you don't know - (trailing off).
E	Yeah, I don't know how they'll react to me, like, some people will be fine, some people might think I'm weird but even if they don't show that I'm weird I always panic that they think I'm weird (laughing).
MW	It's complicated isn't it? You're, you're probably trying to think all the time, what is that person thinking. Is that what you're doing? (E affirming) trying to work out what you think they're thinking?
E (8:30)	Yeah, about me.
MW	Yeah - that, that, that must be quite hard work (E agreeing). Um, and that also links to something else you said where you think people don't understand you (E agreeing). Not everybody - (E interrupting).
E	Not everybody - some people, you know, some people, they just wouldn't get it, you know - (trailing off).
MW	(Wanting to clarify the point) If you *were* acting normal - they wouldn't get it?
E	Yeah.
MW	Mmm, ok. - Um, one of the things that you said which was really interesting. Sometimes you said 'people can make a snap judgement about you'.
E	Yeah.
MW	Where do they get these ideas from then, do you think?
E	So I think they just kind of like uh, when they hear someone's got autism, they kind of you know, whatever they've heard in the news or anything they just kind of link it with you, even if its not always - (trailing off).

MW	So do you think that's assumptions that are from stereotypes? (E agreeing) And does that mean it’s not good for you -if they make a snap judgement? It could be good, couldn't it? (E agreeing) But do you think normally it's not good?
E	I think normally it's not good because - to make a snap judgement on something that you don't really know much about. It's not really - fair.
MW	Mmm, one of the problems that I really am struggling with is, is it better for people to know, because if they know that you've got autism, they might make this snap judgement, mightn't they? (E agreeing) And that won't necessarily be good. If they *don't* know, would that be better?
E (10:46)	Well - the thing is if they - if everyone knows and they're well educated on it, everyone kind of knows about, about autism and they know that it, you know - so if they know, and I tell someone I've got autism, and then I explain what it is, I think that'll be good. Because then they know what it is, know how I suffer from it and then you know - (trailing off and M agreeing) But if someone just says I have - if I say I have autism and leave it at that, I think that would probably be worse, because they haven't had it explained to them.
MW	You know, this is really interesting because one of the things that I am finding more and more is - do you remember that survey in 2016 from the *National Autistic Society, t*hat started all of this research for me - the thing that the pupils said was 'the single thing that would make school better for them would be if teachers understood more about autism'. But they also need to understand about you don't they (E agreeing), as an individual. Because, what's been fascinating working with the four of you, is that you've all got autism (E agreeing), and yet you're all completely different. So, it's kind of that two parts isn't it? (E agreeing). You're a human being, you're a daughter, a sister, you're here at this school / college, you've got autism, and all of those things plus many others, make you an individual, don't they? (E agreeing). Do you think it's possible that people make assumptions just because you've got autism? (E agreeing). They think that you *must* be like this - (trailing off).
E	Yeah - they think probably you know, well - autism is this, kind of like, say diabetes, it's kind of just that, and then autism - but autism is so much, like, bigger, than just one, like mental problem.
MW	Yeah, I think it would be like if you put everybody who was in a wheelchair together and kind of made the assumption that they were all there because they'd got a broken leg, that would be ridiculous wouldn't it (E agreeing), but that is what I think people are doing aren't they - lots of people. Ok, um - let me just see (looking back through notes). Yes, because you said 'autism's very different' (E agreeing) and I think that's a very useful thing to point out. Um, one of the things you said in the second interview was that 'I think you should act whoever you are'. (E agreeing) That would be your ideal then would it?
E	Oh yeah.
MW	And that would be advice you would give to other people with autism?
E	Well - yeah, but I also know that it's very hard to do that - I would tell them to do that, but it's very - I know it would be very hard for them to do that, because I find it very hard for me to do that.
MW	Mmm, but if everything was equal and sorted and fair, that would be best (E agreeing). Because when you're having to act in a different way, does that make you feel tired?

E	Yeah, uncomfy and tired when I have to do that, and then I end a school day, or I end when I leave, I kind of think, well they really didn't get to see me. Like, you know - (trailing off).
MW	Mmm, and the real you is who you are isn't it? (E agreeing) So, what's happening with this (showing paper with previous ideas on from interviews), these are the themes coming out from all of these interviews, um, (reading from created themes) something to do with trust (E agreeing). So it's trusting people isn't it (E agreeing). And that links with understanding, and that also links with confidence, and then the other end of that, we've got anxiety, when it goes wrong, or the environment doesn't um, fit with the way that you need it to be, there's a greater anxiety isn't there? (E agreeing) And then there's this acting normal or being me - that's really important, and then the last one is this difference - difference *of* autism, which is what they wanted in the survey, people to know, but also, what you're saying, and I completely agree, is a difference *within* autism isn't it (E agreeing). They need to find out about that. (E agreeing) Can you think of anything else at the moment that you think you need to add that we haven't mentioned already?
E	Ummm, I don't know of anything - no.
MW	Because, I think we've covered a huge amount, and I'm really grateful for you being so open and honest because it has helped enormously. What I want to do is come back once more, so I'll type all of these up and then I'll carry on picking out these themes. It's a bit of a complicated process, um, it's a bit like having lots of post-it notes and then arranging them and then grouping them together and then moving that group to work with that one, but what I'd like to do, is before I then start to do my final analysis of the themes, i want to just come in once more and check with you all, or it doesn't have to be everybody, it could be just one - it doesn't matter, but I just want to check that I haven't made assumptions about these themes. That you agree about these themes, because you might not. I might be doing something completely wrong and I don't want to do that. So would you be happy to come back and just check that with me?
E	Yeah.
MW	It will probably be after half term, because it will take me quite a while to type all of this up and then start my analysis, but that will be really useful. (E agreeing) E - thanks enormously, I am really grateful. If you come back at break time - when is break time? - Do you know when break time is? Anyway, there are some doughnuts - I've brought some doughnuts - just to thank you as well. But do you need to go back to your class now?
E	Um, yes - I've got French.
M	If you press stop.
	[End of recording: 16:50]

Appendix 12 B 3 Individual Interview with B

B 3	
Name	**Comment**
MW	What this is (indicating transcripts from previous interviews) is this is all the information I've taken from these interviews, which you've said about you, and things I just want to check up.
B	Yeah.
MW	So, I know you like playing 'Fortnight'.
B	Yup.
MW	And that sometimes you find school hard because - (trailing off).
B	(Interrupting) And boring - (trailing off).
MW	Because of concentrating as well, yeah?
B	Mmm (affirming).
MW	Because if there's too much happening at once, it makes you feel anxious.
B	Mmm, not all the time.
MW	Ok, can you explain a little bit more about that?
B	So, if I'm in a lesson, I normally - and I know most of the people, so I don't normally feel really anxious before, and I think "oh I know loads of people and I'll just join in with the conversation" and I know it's like easy and that, if there's loads of people chatting around me. But when it's like going into London, with people that I really do not know, it's a bit like weird, confusing. Like, what are they on about? I don't know these people.
MW	Mmm, so you are better in a - in an environment with people you know - you feel happy. You feel less happy with people you don't know?
B	Yeah.
MW	Ok, and do you know why that is?
B	No - not really.
MW	Mmm, I mean to be honest, that's what a lot of people feel as well, it's not anything just to do with the autism. I feel really much more comfortable in a meeting when I know people, than in a meeting where I don't know people. Cos I don't know quite what they are thinking.
B	Yeah.
MW	Um, you said that sometimes teachers had been helpful to you because they had listened, and then some of them would understand, and then you also said that some of them didn't understand and would hate you for it. What do you mean?
B (2:04)	Like, some teachers at primary school, if I like told them I'd got autism, they would hate me for it. They would just do really, really (unintelligible word). And just do stuff that I didn't want to do.
MW	Like what?
B	Like, making fun of me and that.
MW	The teachers?
B	Yup.
MW	Mmm, ok. So later on you said, this was on the second interview we had, that you don't tell people about your autism (reading from transcript) 'cos that's why you keep it in'. Do you think it's because of that then, because of your

	primary school, that you don't tell people?
B	Yeah. (Long pause). I'll probably never tell anyone about it?
MW	You'll never tell anyone?
B	Well, apart from my Mum and Dad. Yeah.
MW	Because are you worried about what would happen then?
B	Yeah.
MW	And why do you think people would change if they knew?
B	I don't know - cos they think it's like a disability or something?
MW	And you don't see it that way?
B	No.
MW	No - because it doesn't stop you doing anything does it?
B	No.
MW (3:12)	Ok, and you were diagnosed when you were four, and you've got better at (reading from transcript) 'not always saying what's in your head' and not getting so angry, because you said - (trailing off).
B	(Interrupting) Oh, when my brother plays 'Fortnight' I'm always angry.
MW	Yeah, maybe at home, but in school you've got better haven't you?
B	Yeah.
MW	Cos you used to get into trouble didn't you? (B affirming) And how, why do you think you've got better?
B	I don't know. Cos I'm higher up in years. I still get told off but not as much as I used to do.
MW	Mmm (long pause). So, when we were talking with the others, all four of you here, was it good to be with them because you knew that all them had autism. Did you feel different?
B	No.
MW	Hmm, exactly the same?
B	Yeah.
MW	Yeah, I was just wondering whether that made you feel more relaxed because you knew that they would all understand you. Do you think people do understand you?
B	Not all the time, but sometimes.
MW	Who, who doesn't understand you?
B	Some of my friends and - my primary school, and some other people.
MW (4:30)	Yeah, cos you mentioned that you had a friend who you told and he was absolutely fabulous wasn't he? (B affirming) He didn't tell anybody, and you felt completely that you could trust him couldn't you?
B	Yeah.
MW	And so - (trailing off).
B	(Interrupting) (Unintelligible).
MW	Sorry?
B	He's at __ (names school) now.
MW	Where's that? I've never heard of that.
B	It's in __ (names place)
MW	Oh ok, do you still see him?

B	Yeah sometimes.
MW	Um, one of the other things that you said was that (reading from transcript) you don't want to be judged. Do you think people do judge you?
B	Yes (firmly spoken) - sometimes.
MW	In what way?
B (5:02)	Like "I don't want to be your friend no more", "ha ha you have autism" "why do you actually act like, like - I don't think they would know, because if they had autism they would actually act like idiots.
MW	Mmm, do you think adults are safer or not?
B	Yes (firm answer).
MW	Why?
B	Because they're adults, they can't (unintelligible word) they don't really care. They probably know someone who's got autism.
MW	That's interesting, so it's a lack of knowing, a lack of understanding from people of your age and younger about autism? (B affirming) I think you're absolutely spot on there. You said, which was lovely, when we were talking about what you might say to somebody else who had autism, you said "just be yourself".
B	Yeah.
MW	Mmm, that's really nice. So, do you think you're yourself?
B	Yeah.
MW	All of the time, or most of the time?
B	Most of the time.
MW	And, when are you not yourself?
B	When I'm annoyed or bored, I just get a bit stressed out.
MW	And then what happens when that happens?
B	Mmm - I get told off.
MW	Oh, ok, and that's when you are not yourself?
B	Yeah.
MW	Ok. I was amazed that you like going shopping.
B	Yeah, not clothes shopping though.
MW	Oh no, but any shopping, I hate all shopping. Why do you like shopping?
B	Cos I get to buy stuff for myself.
MW (7:05)	(Laughing) But you don't mind then being with people who you don't know, because you are aren't you? (B affirming) And that's ok is it? (B affirming) Interesting. And you also said that you thought that, which actually goes back to what you said just now, that people knowing about autism would make them make assumptions - about you.
B	Yeah.
MW	And those assumptions, would they be good or not good?
B	Not good.
MW	People need to understand more don't they.
B	Yeah.

MW	So, what I did - I picked out themes, from all of that (indicating transcripts and showing other piece of paper), these themes that at the moment might be the ones that I work on - to do with trust, people trusting you, and how confident that makes you feel. Things that make people feel anxious, which is like the other end to confidence isn't it (B agreeing) Um, people understanding you. But then also people understanding autism.
B	Yeah.
MW (8:35)	Because the really interesting thing is that the four of you, you, R, E and A - you're so different from each other, and yet you've all got autism. And what people do, wrongly, is they think that they can put you into like a, a box because you've got autism. And they'd put R (from previous interview group) into the same box, but that's not right because R is R and you're not R. (B affirming) So, I think that's another thing that I want to pull out, the fact of autism being different, but you being different within that.
B	Yeah.
MW	Can you think of anything else that you want to say that you haven't already, or that we could add to these pieces of paper up here?
B	No not really.
MW	We did a massive amount. I just wanted to catch up to make sure there wasn't anything else that you had that we hadn't covered already.
B	No, I can't think of anything else.
MW	Fabulous, that was nice and quick then. It won't take me too long to type up then will it?
B	No.
MW	Do you want to press stop then?
B	Where's stop?
	[End of recording: 9:02]

Appendix 13 R 3 Individual Interview with R

R 3	
Name	**Comment**
R	Do you recognise this bottle? (Showing water bottle).
MW	I've got one, very similar, slightly smaller; I use it for when I go running.
R	Yes, this is a running bottle.
MW	Have you brought it in before? I haven't seen it?
R	I have brought it before, but not when this is happening.
MW	No, it's nice to have isn't it, and they're useful to carry because they won't slip out of your hand.
R	Literally, it's come out of my phone because I have this thing on my phone here, it slips through my finger (demonstrating attached clip on phone with loop for finger to go through).
MW	Ah, that's a very clever idea, is it magnetised - onto the phone?
R	It's a sticky pad.
MW	That's clever, so you're not likely to drop that. Now, I know you said you like songs and drama - (R interrupting).
R	Yeah, I do.
MW	You went to two primary schools?
R	Yeah. As a matter of fact they just pulled me out of music.
MW	Oh, I'm sorry. (Feeling very guilty).
R	It doesn't matter.
MW	Oh, I feel really bad.
R	We're playing, we're playing the song 'stay with me'.
MW	Stay with me' - I know that one. Who sang that one?
R	I have no clue (singing) Stay with me - (trailing off).
MW	Is that a musical?
R	Don't know.
MW	Um (looking at notes) - you like making people laugh - is that right?
R	Yeah.
MW	And do you think you do that on purpose?
R	Sometimes, sometimes not.
MW	Yeah, because interestingly, sometimes what you said was, it was something in the first interview that you said about acting normal - you were acting normal - (R interrupting).
R	(R interjecting) Like I usually do.
MW	And then someone laughed at you, and you didn't like that.
R	No I didn't.
MW	So, how does that work then?
R	Umm, hard to explain. I don't know how to say it (long pause to see if he could work out a way of verbalising it).
MW	So, when you are acting normal, do people find that funny?
R	Yes - I think so.
MW	And is that good or is it not good?

R	Not good, because it is just offensive.
MW	Mmm, so there, you - you - you make people laugh, but you don't *want* them to - Sometimes?
R	Yeah. And when I want to make them laugh, it, um, I do.
MW	Yes, it's probably really easy for you isn't it?
R	I don't, I don't, I mean there was this one time I was on like a bus thing, it was a coach, a trip to Ypres and there were some people sat next to me - they're both my friends now, but I made them laugh.
MW	Mmm, and it's nice to be able to make people laugh.
R	I actually liked it, because then we became best friends.
MW	Ah, that's nice. But when people laugh at you when you *don't* want them to, does that stop you then 'acting normal'?
R	Mmm, yeah.
MW	And so what do you do then?
R (3:26)	I just like act like how any other person would act. But it's just a front to hide what's inside.
MW	And is that hard?
R	Yeah.
MW	Because I think somewhere you said something - (looking back at previous interview transcript) where was it - oh yeah, you said, this is when you were talking about being excited when you were going on a school trips, and you felt that it was important that you were accepted for "just being me" (reading from transcript).
R	Did I (looking pleased)?
MW	Yes, you did, and I thought that was lovely.
R	I do say some things don't I?
MW	You do, but I think that is absolutely right. I - I want to feel the same; I want to be accepted for just being me.
R	Yeah.
MW	But do you think that's happening to you? You are accepted for just being you?
R	Yeah, like with my school (names school), Mrs E, my teacher, she was the one who diagnosed me with ADHD but it turned out to be autism. So she actually knew because she was my teacher at the time.
MW	And was that - did you feel that you could just be you there, with Mrs E?
R	Yeah, I felt comfortable.
MW	That's interesting - you felt comfortable - do you know why?
R	I just felt like I was being respected
MW	And was that just by Mrs E, or was that by your friends in that school as well?
R	It was by every teacher.
MW	Mmm, and that was the second school you went to wasn't it?
R	Yeah.
MW	Another thing that you mentioned was that sometimes you've had problems with people being angry. You had an angry teacher in your first school, and a difficult dinner lady. So angriness - does that make you feel anxious?

R	A little bit. There was this one time in the first school that I went to, the teacher was trying to get the classes attention and what happened was that he grabbed a ruler and banged it on the table. He banged it so hard that the ruler snapped.
MW	I guess he wasn't angry with you, it was everybody, but it affected you.
R	Yeah, I was literally the only one listening, I felt like he was getting angry at me.
MW	Mmm and how does that make you feel?
R	I honestly don't like it.
MW	No (pause). And another thing you said that you don't like, and I don't know if this makes you feel anxious, maybe it does, but if there's lots of things going on? In the classroom?
R	Yeah, I can't move onto one thing without doing the thing that I'm doing.
MW	Mmm (pause to see if more would be explained). And so, if you're in the situation where you're being in that sort of pressure, does it make you feel anxious or how does it affect you?
R	Um (thinking), if there's too much work to do I can't think, cos I'm focusing on one thing, and the teacher says another thing and it just gets rambled up in my head.
MW	Mmm, I understand that.
R (7:07)	Am I talking a bit too quietly?
MW (End of E1)	I hope not - shall we check it (pointing to recorder and then turning off recorder to check sound).
R (Recording E2)	(After sound check) They both say two.
MW	Ok, where was I up to? Umm, oh yeah. One of the things you said about your second school was that the teachers listened to you.
R	Yeah, they did.
MW	Mmm, so how did that, how was that different to the other one?
R	Well, the first one, they didn't even know about my autism, but the second school, well, it was just a better place.
MW	So, did they listen to you because, do you think, they knew you had autism, or was it just that the school was different?
R	I think it was that the school was different. Every teacher um liked me, and every teacher here likes me.
MW	Mmm, and how does that make you feel?
R	I feel happy, very happy.
MW	That's really important isn't it?
R	Yeah. Do you know, I was the first one to finish my project in DT, woodwork?
MW	What were you making?
R	I was making a thing called an Ugly Bug.
MW	An ugly bug?
R	Yeah, it's an anatomic bug made out of wood.
MW	So, you can make it move can you?
R	Yeah?
MW	Oh my goodness - that's very clever. I would like to see a picture of that.

R	I have a photo on my phone strangely enough.
MW	Oooh fabulous, you find it because I would like to see it. Right so, when you said actually, umm can you talk at the same time or not?
R	Say what?
MW	Can you talk at the same time (laughing)? I'm just asking you while you are looking for the photo.
R	Yeah, I can probably talk at the same time.
MW	So you said, that you sometimes got into trouble for not doing the work in your primary school.
R	(No answer as scrolling on phone) I think (long pause). I can't remember (showing photo to me of Ugly Bug). There's supposed to be a lever there so when you twist it the bug goes up and down cos of the spinning wheel and then the plate.
MW	That is very clever. And then you had to paint all the background?
R	No, the background is made out of plastic.
MW	Plastic? So you had to stick it on?
R (2:24)	Yeah, we used a laser cutter and there was this like super sticky cement, it was a liquid cement, and it could stick plastic together really tight.
MW	Sounds fun. Right hang on, so. You said that you sometimes got into trouble for not doing the work and I wondered if that was because you were in one of those situations where too much was happening?
R	I just couldn't do it.
MW	But was it, that it was too hard or was it just that you could have done it if they had gone about it in a different way?
R	I think I could have done it if they had helped me but I just, I just couldn't do it. It was too difficult.
MW	Mmm, another thing that you said was that trust for you is really important isn't it? You want your friends to trust you. (R looking quizzical, so direct reference found). Interview 2 page 1. Actually, (showing entry on transcript) about being yourself. So I'd asked a question about being yourself, and I said 'so you want your friends to be themselves and then do you think you would be able to be yourself?" and you said because your friends can trust you.
R	They can - they can trust me to be me. Oh, Joel can, my friend Joel, but Joel can be a real dope head sometimes, if you catch my drift.
MW	So, are you *you* with your friends?
R	Yeah.
MW	Good. And who are not you with?
R	People I don't know.
MW	And why is that do you think?
R	Because, with the people that I don't know, it's just difficult to tell if they're friend or foe.
MW	Mmm, and if they're foe, what would happen, if you were you do you think?
R	They'd probably make fun of me, and also I didn't mean to make that rhyme.
MW	(Laughing with R) One of the things you said, on page seven in here (indicating transcript) "when I'm in a crowd of people, I want to be someone I'm not and I don't like that" - is that what you mean from what you've just said?

R	A little bit. It's kind of people, I just feel, I just feel that if I'm going to be myself then everyone will just stare at me.
MW (5:21)	So, what do you stop yourself doing in that situation?
R	Well, my parents say I'm just being silly, but it's not exactly like I can help it.
MW	But do you know what you change then? So, when you're not yourself do you know what you do?
R (5:38)	I change my personality.
MW	That must be tough!
R	Mmm, well I can handle it - kind of.
MW	Well, because you like drama, you are able to do that aren't you?
R	Yeah.
MW	But you would rather be you I assume?
R	Yeah. The last drama I had yesterday, I was pretending to be a clown (laughing).
MW	(Laughing) And did that work nicely?
R	I was a killer clown.
MW	Another thing you said was that trusting someone makes a bit connection. So you know the people you can trust, like Mrs E and your friend Joel, and your family.
R	I know that they can trust me because - well - (long pause) I know that I can trust them because - there's this thing that I feel inside me that just - I just know that I can, because they're kind of - they're kind to me most of the time. Well, Joel is, and my family.
MW	So they can trust you and you can trust them?
R	Yeah.
MW	Yeah - ok. One of the themes that keeps on coming up, so with everybody in the interviews that we've done when we're altogether, there are a few things that keep on happening, that keep on being talked about, one of them is this anxiety thing and I just wanted to find out a bit more about that. What is it that makes you feel anxious?
R	But, didn't I already say that just a minute ago?
MW	You might have done. But is it people or places or both?
R	I like places but I like going to different places. I mean not last year but the year before, I um went to Bulgaria and made a friend named Peter. I keep in touch with him because he phones me. Also, when I went to Turkey last year, I made two friends, they were brothers.
MW	Yeah, so you make friends quite easily do you?
R	Yeah, I just start chatting to them and then it just clicks.

MW	So, what I have to do, is I have to go through all this stuff on here (indicating recorder) which is on here (indicating transcript) and I have to try and work out what are the main things that everybody is saying, and at the moment, I think that the main things are to do with trust and confidence, to do with anxiety and people understanding you, acting normal, and also, one other thing that I think is going to be really interesting is about autism itself, in the fact that *because* you have autism you are different, so one in I don't know, about seventy people have autism, so that means that 69 people don't, so you are different in the same way that if you, um, I don't know, if you'd broken your leg or something, you'd be different because not everyone else would have broken their leg (R interrupting).
R	I've broken this arm before.
MW	It hurts doesn't it?
R	But you can see on the hand at the side. But the person who did it said that it would go back to normal in time.
MW	Well, how long ago did you have that done then, or did you break it?
R	Um, I think it might have been last year.
MW	Oh not that long then. It takes a long time for bones to sort themselves out. But the interesting thing is that I think that people think you have autism therefore you will do something or behave in a certain way. But that's not true, because I think the four of you (from previous interview sessions) are so different from each other, don't you?
R	Yeah.
MW	And so the fact that you have got autism, there's a huge difference within that isn't there, that people need to find out about.
R	(R yawning) I just yawned (looking embarrassed).
MW	You did, did you have a late night?
R (10:18)	Errr, a little bit (laughing).
MW	Do you think there's anything else that you want to add to what we've already got, on here (indicating recorder), or on paper (indicating notes from previous group interview), or that we’ve talked about.
R	I was just thinking - talking about confidence, there was this trip that I went to, a trip that this place set up and there was this activity that we did, that we had to climb up a pole, a giant pole, taller than the size of this room, yeah, and I got to the top. I was that brave that I got to the top.
MW	So you felt confident in that situation didn't you?
R	Yeah. I also helped the other people up.
MW	That's lovely. So you were able to give them confidence.
R	Literally. That pole was almost two storeys up.
MW	Yeah, there are a lot of people who wouldn't have liked that.
R	Yeah, it sure was fun. There had to be four people on it. First we had to hold each others' shoulders, then arms, then this part of the arms (indicating wrists).
MW	(Interrupting) so you didn't fall off? So you were holding each other on?
R	Basically, but when we was holding each other’s hands we fell off.
MW	But then, how far down did you go? Were you strapped on to something?
R	We was, it was, we were strapped on. We had the harness, the rope and that.

MW	Mmm, I've seen something like that when I was working in school. We went to __ (names activity camp), where did you go for that then, can you remember?
R	I can't remember.
MW	What I think I'm going to do R is I'm going to come back once more, um (R interrupting).
R	(Excitedly) I can bring in my ugly bug then!
MW	I would like to see that. What I have to do is type up all of these, and then work out all the themes. I think that these are the themes I will probably end up keeping, but I don't want to make an assumption. I want to check these themes with you. But I don't need necessarily everybody. Would you be interested in helping or not? You don't have to.
R	I like helping, so it's a definite yes from me.
MW	Oh good. So, what I'll do is when I have a date, I'll get in touch with Mrs B and then, hopefully you'll remember to bring your thing in that you can show me, I'd really like that.
R	But Mrs B will have to tell me the day before.
MW	Oh yeah, I'm sure she will. Do you want to press stop on that (indicating recorder)
R	Which one is that?
	[End of recording: 13:09]

Appendix 14 AC Interview 4

AC 4	
Name	**Comment**
MW	And then this is the third one - relationships - with relationships being the most important thing. So if the relationship is working well, this (pointing to other piece of paper) - actions and reactions - will go this way (pointing in a spiral upwards) and it will get better, and it’s built on a solid understanding. This doesn't mean that I'm sorted, and I know what I'm doing. That's why I have come back to check with you that these three things are what you agree with as well. Because I'm kind of doing your writing. I can't do this - do you remember I said "I can't do this without you" and I need teachers to understand better, so what you tell me, I can write and the teachers can read. That's the point, so I don't want to get this wrong. So, having done that, I think we need to move these out of the way because otherwise we are going to run out of space (moving cookie packets to side of table). Yes R (R's hand has gone up).
R	I just wanted to say, that I have a friend that is really good to me and I'm really good to him back. Every week, um he comes round for tea and then he might come round for a sleep over.
MW	Every week?
R	Yup, every week he comes round for a sleepover.
MW	That's amazing! He must be a very good friend.
R	He is.
MW	Now then (arranging large sheets of paper on the table with post it notes), E do you want to sit over there because then you can read it, I don't know that I can read it upside down. Right, ok, so what will happen is each of these areas will be a chapter of a book and so this will be the first main chapter, and each chapter will have its subheadings, so that will be most probably the title of the chapter (pointing to title at the centre of the paper). So we've got this bit here - 'understanding of you and other people', and these are the sorts of things that I'm going to put in. (Reading from post-it notes) 'awareness of difference' - so at some point, you all became aware of feeling different. Am I right? Do you remember that (all nodding), can you remember how old you were, because it wouldn't have happened when you were a baby?
E	No, um, I was about six.
MW	You were about six when you felt different from other people. Can you remember was there something specific that made that change?
E	I do - like the hallways, when they were transitioning between lessons. And I don't like certain teachers - the way they talked, ummm - (trailing off).
MW	How did you know that was different from your friends?
E	Because my friends - when I asked my friends about the teachers, they thought they were fine.
MW	Ok, so it was early school for you. A, can you remember?
A	Year 4?
MW	So, about the same time. And was there something specific that made you think "Oooh hang on a minute"? Or was it lots of reasons like E was saying?

	Can you remember any of those things in particular?
A	Like the hall reasons.
MW	Yeah, and how did you know that that wasn't the same as everyone else thought?
A	Nobody else seemed to mind.
MW	So, everybody else seemed to be fine, you thought, and you weren't. R what about you?
R	When I was around five years old.
MW	And can you remember what it was that made you feel different?
R	Not - really, because it's kind of faint - I don't really remember my childhood.
MW	Mmm, ok. But there must have been something, or lots of things maybe like E and A were saying.
R	Yeah.
MW	Ok, so that was one - what does that say? 'Caution in forming relationships'. So, I think you're all very careful about who you can trust, and you take time to get to know people, am I right?
All	Yes.
R (4:18)	To get to really know them - if they're friend or foe.
MW	Yeah, now friend or foe I've written down somewhere I think, it might not be on this page, but I think that's a really good way of finding out. And what is it - how do you know if they're a friend?
E	Um, they would keep secrets they're always supportive of you.
R	Just like my friend that I told you about.
MW	And I know B, in a previous interview, he said he had a friend who he really trusted, because he'd told him that he'd got autism, and this friend never said anything about it to anybody.
R	My friend is dyslexic and a bit of autism.
MW	Mmm, so - do you think he has a better understanding of you because of that?
R	Probably.

MW	Mmm can't ready this upside down (reading from post it note). 'People often hard to understand, and unpredictable' - that's something that came out - would you agree with that? (Group agreeing). Ok. I mean, there might be things you don't agree with and then we can just take them off, and I've got post-it notes so we can add more things on. 'Anxiety often felt' - this is really important because if people don't understand you, it makes you feel more anxious - yeah? (Group agreeing). What's that say? Oh - 'maturity'. So as you've got older - as you've grown up so far, you've got better at certain things, so you're better at understanding yourself - do you agree with that? (Group agreeing). You're better at learning strategies - do you remember that list we came up with, with all the different things that you knew you could get help with? (Group nodding) You're less reactive, I'm thinking particularly of B maybe, who got cross quite a lot when he was younger, and now he's is less cross, or can control it better, he maybe isn't' less cross. And also 'the ability to ...' what does that say, I'm going to have to come round here (moving to other side of table) oh yes, 'the ability to recognise triggers' so you know the sorts of things that make you get anxious and feel stressed. Ok, but then there's some things that are not so good as you've got older, and I think that might be, that you're aware sometimes that people judge you (group agreeing). And is that not good - when people judge you, do they judge you negatively?
E	I think so.
R	Yeah - sometimes.
MW	Sometimes, ok. And do you know that people can judge you negatively?
R	Pardon.
MW	Do you know the types of people who might judge you negatively - why might they do it?
E	They're interested.
MW	They're not interested?
E	No, they're interested. Maybe.
MW	Ok - interested in you?
E	Yeah, interested in why I'm doing that.
MW	Yeah.
E	They think it's weird maybe.
MW	Mmm, being weird is something quite important isn't it - you don't want to be weird.
E	No.
R	I have one positive side to having autism. Thanks to autism, I can make voices - different voices.
MW	Really? Have you heard these before (asking others at the table who shook their heads).
R	I can do Donald Duck's voice; I can do a chipmunk's voice from "Alvin and the Chipmunks'.
MW	Oh my goodness - do that one, cos I love that.
R	What the chipmunk?
MW	Yeah.
R	Ok, I'm going to do one of their songs (singing).

MW (7:58)	Ok R, can we just press pause there - that's absolutely fabulous. I used to watch that with my children when they were little.
R	Can I do Donald Duck?
MW	Do it in a minute. Let me just carry on with this or I will lose my track. Um, so 'sometimes the world is a bit confusing' isn't it - because you have to work out who's friend and who's foe, whose judging you and who is not judging you. Another thing to look at is this thing here (pointing to new sub heading). This is how you think other people understand you. The trouble is that I can't go and talk to these people, so what you're thinking might not be true, but we don't know do we? (Group agreeing). Umm what does that say - can anyone tell me?
R	Strategies?
MW	Oh yes, 'strategies, resources', 'two-way reciprocal relationships'. So if you trust someone, they'll usually trust you won't they, and it gets better. Umm, what does that one say?
R	Foundations of understanding'.
MW	Yeah, so so where do you think these people, when they go wrong, and judge you negatively, where does that information come from?
R	Brain - in their brain?
MW	Yeah, but how do they understand something? What gives them the ability to make a judgement about you?
E	Because they can see what we're doing and it doesn't fit their social kind of - what everyone else is doing.
R	It doesn't fit their social life.
MW	It doesn't fit. That's really interesting isn't it? And what - how do you think they think that what something's normal.
E	Because everyone else is doing it. So, you know, if everyone else is doing what you are doing that would be normal, if no one else is doing what you're doing, that's not normal.
MW	And then, because of that, people will judge you?
E	Yes.
MW	And do you think that has anything to do with things they see on television or anything like that or not?
E	I think it has to do with people around them. So their environment.

MW	Yeah, ok. So that's quite interesting isn't it? And then we've got, what does that say 'give work'? So quite a few of you actually have mentioned about teachers giving you the wrong work, because they haven't understood. I don't know if it's happened to you R, but it's definitely happened to you A, and it's happened to you E, and I know it happened to B as well. Um, what does that say? Oh yeah, some of you have been called names. And don't forget that when I did this, there's another girl in a special school who've I've also been working with, so some of this stuff might have come from her. And all of this stuff gives you anxiety. But when people do understand you, like Mrs B - you mentioned A haven't you that she kind of came to, not quite rescue you, but she understood how you were feeling. And parents, and some of your friends give you less anxiety (group agreeing). And then, this is about a' label and a diagnosis' (pointing to final sub-heading). It's really interesting isn't it! I've got here, what does that say? 'Expectations from having a diagnosis'. So, not so much for you E, because you had your diagnosis really early, but A and R, your diagnosis came quite late, when you were already near to the end of your primary school.
R	When I was in Year 6 I got my letter that said I was autistic.
MW	Yeah, did you think something was going to change because of that?
R	I thought that everything might seem clearer to me. Now that I think about it nothing feels clearer.
MW (12.09)	Why not?
R	Everything just feels so strange. Like, what I'm feeling is that everybody else is doing different things to what I'm doing. And I'm thinking I'm a weirdo and everybody else thinks that I'm a weirdo so I'm going to get bullied.
MW	Mmm, so having a diagnosis hasn’t changed that, it's just given a name to why you think you're different to other people. I mean we're all different aren't we - would that be right? (R agreeing). We can carry on with that in a minute. A, what about you? Did you think something was going to change?
A	Well, in Year 3 my parents was like 99% sure that I had it, but then the only reason that they got the diagnosis is so then I would get more help.
MW	And has that happened? (A agreeing) Yeah. But it didn't happen straight away. So can I just check actually - one thing I just need to check - (R's had goes up) Hang on R. What school did you go to in primary? I need to write this down actually. Right - E?
E	So I went to junior and infants. So my infant school was __ infant school, and my junior school was __.
MW	A. I think I have asked you this ages ago, maybe in the beginning interview. Um, A?
A	Um, __ (names school).
MW	Oh - was that infants and junior?
A	Yeah.
MW	Ok. And R?
R	I went to two schools.
MW	Yup, I remember that.

R	The first one was __ primary school and the second one was __ primary school. But I noticed a difference between the two because in __ everything was just so nasty and that. The dinners were terrible, the teachers were a bit mean, and there was this one dinner lady that I didn't like.
MW	(Recalling past interview) Yeah - I remember that.
R	And in __, everything just flipped around and all the teachers were nice, the dinners were good and everything about it was just really really good. I mean, there was this club on Friday, a drama club, where I could just let my feelings out and be myself.
MW	Mmm, and drama for you I know is really important isn't it? Ok, do you know which school B went to? I'll ask Miss B later. And none of these schools - your names won't appear with your names, because that's really important because you have to be anonymous, this school has to be anonymous, so no - no names of any schools, all of these schools are going to be anonymous. I just need to know because then I can say 'all five of the pupils - ' that's you four plus the girl in the special school, have come from different schools, and I'm pretty sure you all have. So don't worry that anything is going to come from that because it's not. Um, what were you going to say R - can you remember? (R thinking) Oh, I shouldn't have stopped you should I!
R	Oh, was that about the voices?
MW	No no it was about something else. What about - with this bit here (pointing to section on large paper) - if teachers are going to understand you, as well as possible, they need to know you've got autism - yes?
All (16:00)	Yes.
MW	Is there anything else that you would like to tell them?
E	That everyone with autism is different, it's not like a textbook kind of thing.
MW	Yup, and that’s really going to come out strongly E in my writing, so I think that's really important and I'm really grateful that you've said that. A, have you got anything that you think needs to be said to teachers?
A	Urr, they might seem ok - when they're not.
MW	The pupils? (A agreeing) Yes, so it's looking beyond what you're showing, because it's interesting - if you put on 'you being normal' - you're pretending to be 'normal' - actually it's really hard then for the teachers to work out 'is that really what you're thinking or is it not what you're thinking?" So yeah I completely agree - going beyond, looking beyond. R, what about you?
R	It's basically, basically just putting on a mask to cover your real face.
MW	Yeah, that's helpful in some ways, because you want to fit in. But if you want people to understand you, then how do they know which is the real you?
R	(Long pause) They wouldn't.
MW	No, so sometimes that could be more complicated couldn't it? What were you going to say E?
E	I think there should be like - I think there's like a trust thing. If a teacher shouts at you - you're more likely to hide your feelings. If a teacher is open and honest with you, I think you'd be open and honest with them.

MW (17:49)	Mmm, so when it comes to that final thing about relationships, that's really important isn't it. Because it's very much a two-way thing. Let me get the other thing up (bringing new paper to the table). We can add to this, but let's just look at the others, because there's two more. Is this right (checking heading) - Yes. Right, so that was this one here (taking title on paper and putting it in middle of large paper). These sort of 'actions and reactions' to people really. So when things go well, you've got like a (reading from post-its on paper) 'a calm environment', like in here isn't it?
E	Yeah.
MW	You all feel comfortable in here don't you, you feel comfortable in VU (referring to E), more than you do? Do you spend any time E in mainstream school?
E	Err yeah, I do.
MW	How does that work?
E	So VU is always there if I'm in mainstream lesson and I need to come out, VU is always there, if I can't go to a mainstream lesson that day, VU is always there, if I just can't do any mainstream lessons, I can always be back in there and do the work there.
MW	And so you try and go to mainstream classes?
E	Er, yeah, the aim is to get everyone there into mainstream classes, but that doesn't always work.
MW	So you would go there, but you wouldn't really come here?
E	Err, no.
MW	No, so you're here really just for this session.
E	Err, yeah.
MW	So would there be any time that you would come here?
E	Tests sometimes and for lunch I used to.
MW	Ok ok. And what about you A, you spend most of your time in mainstream, but there are some lessons that you come here - yes?
A	Yeah, I don't do languages, I come here, but any other lesson I'll be in mainstream.
MW	And are you able to come here whenever you feel a bit like E that she needs to go to VU, (A's face indicating not knowing) or are you not sure?
A	No.
MW	But it hasn't happened then that you feel so anxious that you need to escape, has it?
A	(Thinking) Mmm - sometimes, but I just stay there.
MW	What about you R? So you go to mainstream and you come here - ?
R	What does that mean?
MW	Well you're in main __ (names school) for lessons.
R	Yes, but there is these, these lessons that I do, they're with this person called Mr P. And I heard that Mr P does lessons for kids that have autism and stuff like that.
MW	Ok, what here?
R	No, like in other mobiles.
MW	Ok, so do you have any lessons in here?

R	No.
MW	But, how often do you come here?
R	I come in here mostly every lunchtime.
MW	And then, could you - if you needed to escape from lessons, come here or not, or are you not sure?
R	I don't know.
MW	Ok. I mean hopefully you won't need to. You'll feel ok and it won't be a problem.
R	I do feel ok in Mr P's lessons.
MW	Good. He's probably able to create a calm environment (pointing to post-it note). Then we've got 'understanding' (pointing to another post-it note), so when your teachers understand you that's ok isn't it. Some sort of escape route, possibly especially for you E is really important isn't it? (E agreeing) So VU is kind of reassuring. It must be reassuring to know it's there (E agreeing). Mmm. Um, what does that say (trying to read post-it note upside down). 'Helpful resources and strategies', we've talked about those before. Then we've got (reading sub heading on paper) 'when things go wrong'. So there's quite a few times that you remembered when things go wrong. The girl who was in the special school, had real problems in her primary school because she'd had to fight for things - to be allowed to do things or not to do things, and she'd had to beg - that's really sad. And then we've got here, this is very much going back to what you said E, 'actions of teachers create your actions, and your actions create teachers' reactions'. So I need to pull that out, and it can go this way (indicating upward spiral) getting better, of this way (indicating downward spiral) getting worse. Umm, I don't know if you've had this situation, but again this girl in her primary school, she had loads of detentions, so her primary school would just give her a detention every time she did something wrong, and so she'd have detention after detention after detention. Very sad.
R	I've never had a detention.
MW	Well, she - I can't remember which school she went to - but she had loads. She also ran out of classrooms. Have any of you done that?
E	I've done that.
R	What does that?
MW	Well, because you just find that the stress and the anxiety gets so bad that you just have to go. Is that what happened then with you E? (E nodding) Mmm, can you remember what it was that made you get to that stage?
E	Um it was - the fact that, all the Year 4s were coming in - this was in my primary school - all the Year 4s were coming into our classroom to read our work and look at our work, and everything just got too much so I just ran out.
MW	Mmm, and that does help doesn't it, to be able to run away. And I can see why you you did it, and I can see why she did it (R's hand goes up). Yes R.
R	__ (names second primary school) was really really good at that type of stuff. I mean I felt calm in that school. There's this one lesson where we were split up into different classrooms and I was in the classroom that was Year R, and Miss gave us a choice where we could either do our work or play with the Year Rs. I chose to play with the Year Rs and I was just having a good old time.

MW	(Laughing) One of the things that this other girl mentioned was that she would do something that would get misunderstood (pointing to post-it note) she'd have a sanction, so for her that was a detention, she'd think that was very unfair, and then she'd want *payback*! Can you understand that?
R	Oh yeah!
MW	Have you felt that sometimes things have been very unfair (asking others generally - nods given)? And why were they unfair?
E	Because, I felt that it was in my right to run out of the classroom, or like do that even if it wasn't what everyone else did. So yeah.
MW (23:52)	A, you've got loads of experiences that I know you felt things were unfair. Can you remember one in particular?
A	Um, I got more shouted at - I didn't even do anything wrong. I was just sat - sitting there doing my work and then I'd get shouted at for someone else doing something.
MW	And then did that make you want to get payback? Even though you probably didn't. Did it make you cross?
A	Yeah.
MW	So it didn't help the relationship you probably had with the teacher (A shaking head). What about you R?
R	This is funny and devastating at the same time (laughing).
MW	Oh no - go on (laughing).
R	There was this one lesson that I had - it was in my old - it was in my old old school in __ (names first primary school). There was this one teacher that I really liked, her name was Miss R, and um, we had a cover teacher, cos something was happening with Miss R. And one day, the cover teacher got so mad with the class because he wanted to get their attention - (MW interrupting).
MW	This isn't the breaking the ruler one is it?
R	Yeah.
MW	Oh my goodness, you told us that one.
R	Yeah, but I got payback for it because I told Miss R that he broke one of the rulers and um, and um, so Miss R said that um, she would have a word with him.
MW	Oh my goodness - and did you have him again?
R	I don't remember. I don't think so.
MW	(Showing final sheet of paper divided into two sections) What I've got here are - the interesting thing is that when you've got friends you can choose, you can choose whether to sit with them, usually, play with them, have them round to your house, have them for sleep overs (A shaking head). Are you saying no? Go on A.
A (25:33)	In primary school, someone forced me to play with them.
MW	Really - how did they do that?
A	Um two people, cos I just did what they did.
MW	They must have really wanted you to play with them then. Were they nice or not?
A	No, they'd hit me and stuff like that.
MW	Oh no - that's not playing is it then?

A	They just wanted to tell me to do what they'd want, otherwise they'd tell a dinner lady.
MW	So how did you manage to get out of that?
A	They left the school.
MW	(Laughing quietly) Oh, ok, they're not friends are they - I don't think you should call those sorts of people friends, if they behave like that, that's not what a friend should do.
A	Yes because there was - um - I had a friend I met in Year R, and she left in Year 1 then she came back in Year 5 cos it was like - (Unintelligible) ur no it was Year 3, and she brought another friend. And then she was really nice and that person left, and then she just started bossing me around, half way through Year 4
MW	That's really difficult isn't it?
A	And then she left at the beginning of Year 6.
MW	Thank goodness for that.
R	Can I tell you about that horrible friend?
MW	Yes.
R (27:21)	Um, I think it was Saturday that we found a baby bird that couldn't even fly. Its wings were injured from running over of tyres. And what happened is we went to the park, because we were taking care of the bird. And then after that, he wanted to kill the bird - after we had tooken care of it. I was like "No!" I was getting so mad. In the end, he let the bird go, but after that when I was going to get my bike, he called me over and he wanted me to go into a prickle bush because he wanted, like a fishing rod reel - but I said no, I put my foot down.
MW	It sounds weird. I'm glad you put your foot down. Right, let's look at these (Indicating paper on the table). So we've got these situations generally, with friends or peers, so that's where you said your 'friend or foe' (pointing to post-it note with R's words written on it). You can have physical responses to people.
E	Yup.
MW	One of the things B said was 'just be yourself', and we kind of thought about that but it's kind of tricky at times isn't it. Ideally you would want that. 'Be cautious' (reading from another post-it), 'characteristics of a good friend', right - what are they?
E	You feel safe around them.
MW	Safe around them (writing on post-it), yup.
A	They understand you.
MW	Yup. (Long pause) Anything else?
R	They're just the right person for you.
MW	But how do you know?
R	Beca - Because they understand just how you're feeling.
MW	Ok, what about 'a foe' - somebody who you'd need to avoid?
E	They start off as a friend.
R	They tell your secrets and that sort of stuff.
MW	Ok, (writing) tell your secrets, start off as a friend - interesting.

R	That's that's probably why they say 'keep your friends close but your enemies closer'.
MW	Yes maybe, but you wouldn't want to tell secrets to someone who was going to behave like that would you. Right are there any other characteristics of somebody who was not a friend?
E	They're mean.
MW (29:15)	Yeah, ok. So one of the things that you could do is choose just to not play with those people, if you can, A obviously. You can choose to be silent - not communicate at all.
R	So sort of the silent treatment.
MW	Umm, is it - yeah the silent treatment - totally, yeah. Is it better then for your friends to know about autism?
A	I would say yeah because little ones just don't understand it and they think you're just mean and horrible.
MW	Yeah, but if they knew, they would understand why - would they? (A nodding) But the trouble is, I don't think children understand very much about autism do they?
A	No, because my cousin, when she found out I had autism she just went "oh so you're mean and horrible".
MW	So that didn't work. That went against you then! How do you think schools can work with that? How can they make it better for children to know more about autism?
A	Teach them, in a lesson.
MW	Do you think then?
A	Or do an assembly.
MW	Yeah, and do you think that would have helped you?
E	Yeah.
MW	You do as well A? (A nodding) Ok, well then we've got this other situation about relationships in school, with the teacher, and that's so difficult isn't it because you've got to stay with your teacher, and it's not something you can choose (E agreeing). So we've got (reading from post-it) 'a long term impact on self-confidence' either it's going to make your self-confidence better or it's going to make it worse depending on how that teacher is with you - is that right?
E	Yeah.
MW	Mutual benefit' - so if your teachers spend time trying to understand you, it's usually better isn't it (E agreeing). And then I think presumably you are able to be better understood, you are better to understand your teachers, it's kind of a two-way thing. They understand you more and maybe you understand them more. Is that possible? (All agreeing) I know that E with your one-to-one, you said there were certain things that you shared, in common, and that was really important wasn't it? (E agreeing) How long did you have your one-to-one for?
E	About two years.
MW	Was that the same time as you had your assistance dog? (E agreeing) So that was the last two years in the school.
E	The last two years in the primary - yeah.

MW	(R's hand has gone up) What were you going to say R?
R	I don't know if I've already told you this or not, but I had a really good relationship with one of my teachers in __ (names second primary school), and she was just so nice to me.
MW	In what way was it particularly good?
R (31:54)	Well, she understood how I felt because she was the one that - she, well, when she was the SENCo teacher, she thought that I had - (trailing off)
MW	I remember, ASD, err no, ADHD wasn't it or ADD, or something that you said - yeah.
R	Yeah, she thought that I might have ADHD from the way that I acted, so she suggested that I get a diagnosis from CAMHS.
MW	Yeah, I do remember that.
R	And it turned out that I had autism.
MW	But it was the thing that you liked the most about her was that she understood you? (R agreeing) And that's so important. 'Anxiety' (reading from post-it), this is about you here A, 'anxiety needs to be recognised, even when it's masked' (A smiling). So you're very good at hiding aren't you, and not showing when you feel anxious, but some people are able to see beyond it - and you need them to don't you? (Agreeing). What does that say (reading post-it note upside down) can you read that? 'Knowledge of individuals' oh yes, because that's what you said E and I think you might have said it as well R, that it's much better when people understand how you learn because then they can teach you in a better way (E agreeing).
R	Yeah, um (thinking).
MW	Let me just finish this R - just a second - 'time given for exchange of information to build knowledge of individuals' - so it's not just that knowledge of autism - it's the knowledge of you as an individual. (All agreeing). 'Opportunity to alter the environment' - so if your teachers had known - so you were saying A about that corridor - so you knew that you could go along the stairs at the top didn't you or something and come down a different corridor - was that you?
A	Yeah - this school has two stairs and when it's busy I go to the other one.
MW	Mmm, yeah - so you've worked that out, you've managed to alter that sort of stress trigger.
A	Cos I hate busy corridors, especially stairs.
MW	Mmm, I wonder why that is - I mean I don't like it?
A	And if I go upstairs and there's too many people, I have to go next to the banister.
MW	Is it because you think you might fall? (A agreeing) Yeah.
A	Because I have once, because somebody pushed me down.
MW	Really?
A	There's this girl and every time she'd see me down the corridor she'd just push me into the wall.
E	Yeah (and nodding).
MW	What, you had something like that as well E?
A	(Interrupting) She'd push both of us.
E	Yeah, she'd push both of us.

A	Because every time she saw me, she'd push me. And then I told my tutor and she sorted it out, and I haven't - (MW interrupting).
MW	(Interrupting) Oh that was here - of course that was here.
A	Cos on my first day she kicked my lunch box across the room.
MW	Mmm, ok - but that's all stopped now. Thank goodness for that.
R	I've had multiple people push me into a wall, I don't know why (long pause) And I don't even know them - (trailing off).
MW	No I can't answer that, I can't understand either.
R	Neither do I.
MW	But you must always tell somebody if something like that happens. You would wouldn't you?
R	Probably.
MW	Well you should. Because people can't think that it's ok to behave like that - because it's not. They would be in serious trouble if they were an adult and they did that wouldn't they. What were you going to say A?
A	Normally when people are mean to me, I just don't tell the teachers.
MW	You don't?
A	And then it - I don't know I just don't. I don't want to keep telling too - If it keeps happening I will tell my parents, once. If I don't do anything about it, they'll tell the teacher and I just won't tell them - until it gets to a serious stage.
MW	Do you think that's why you choose to 'act normal' then so that it's less likely to happen? Or is that not connected?
A	Umm yeah.
MW	It is connected. (R's hand has gone up) Go on R.
R (35:35)	There's this thing that people say - that if people know that they're bothering you, they'll keep on doing it, but if they think that they're not bothering you, they'll stop.
MW	That's certainly true. They do it for a reaction, and when you don't react, quite often there's no point, and they'll find somebody else who will. 'Awareness of black and white thinking' (reading from post-it note). So you - it's helpful to know that isn't it, so like your - you feel very strongly about rules don't you (turning to E who nods) And I think a lot of other people do as well, and it's useful for teachers to know that as well. So is there anything else? Are you happy with these? Do you think I've missed anything important?
R	I don't think so.
MW	Right.
R	Ah there's this one thing that I wanted to say (pointing to post-it note) what does this one say?
MW	This one says, 'knowledge of individual's preferred learning style'. So if you prefer to learn somewhere quiet rather than in a group, then if your teacher knew that they might be able to organise it better. Because this was something from you E - can you explain it to R a bit better?
E	So, (reading from post-it note) 'knowledge of individuals' - so like having a quieter environment, um (reading from note) 'preferred learning' - so like giving the right level of work, even though they might not be able to you know - handle it.

R	I - I was just thinking about that, I - I can only - I struggle when I get two different types of work. What I mean by that, like, like my teachers used to give me work when I hadn't finished the other work, and I couldn't concentrate on the other work if I hadn't done the first one.
MW	Well that would also be in here (indicating part on large paper) - that sort of thing is teachers needing to know that, because that's quite a common thing - it can be overload can't it. Ok, so let me just see about anything else. Ooo, one thing that I just wanted to find out. If you had to give one piece of advice, to you when you were at primary school, what would you say? (Long pause). So, you're talking to the little you. What would you say R?
R	Don't look back - keep on moving forwards. In other - in other words, don't give up.
MW	Mmm, ok.
R	Don't give up on life; there always can be something in life that you'll like.
MW	Mmm, A, what about you?
A	(Long pause) Ummm. Don't let people boss you around?
MW	Don't let people boss you around. Yeah, ok, yeah thank you. E have you got one?
E	Umm, the world wasn't built for you so, it's not your fault that you're like this.
MW	Mmm. It's not - it's not easy is it when you are one in - I mean they say one in a hundred, but I think that's wrong. I think there are many many more people who have autism, and I think also there are more females with autism. So I think that in the next twenty years, you will find that you won't be one in a hundred, you'll be one in about sixty-five. In America, they say, that everyone with autism, is one in sixty-eight, and here we are a bit behind, so I think, I think it will change. It could even be more than that, so you could be less unusual than you think you are - which is kind of nice, because people just need to accept it don't they. Ok?
R	Is it rare for a boy to have autism?
MW	No, it's not rare, it's about one in a hundred, but as I said it will be less than that. But interestingly, they used to say that if you put everyone with autism together, there would be four times more boys than girls with autism, and that's going to change - that's definitely going to change - it will be equal.
A	Isn't it harder to work out if a girl has autism?
MW	At the moment, yeah, but that's also changing. So there's lots of documents that are going into schools, and into um places like CAMHS and into um GPs so they begin to understand that actually, the characteristics of females with autism are different. And they've only been looking at the male ones, which is why they didn't spot the female ones. It's really interesting isn't it? I find it fascinating.
R	Can't they use a machine to tell - to look at your brain waves and how they work?
MW	They kind of wish that they could, and one day, in the future they might be able to, but they're not there yet. But they're finding out all sorts of things. There all those things - you know you can see people with those funny things attached onto their heads where they are measuring brain waves, so they are doing lots and lots of trials. What about - do you think autism is a disability, a difference, or something else? How would you describe it?
E	A difference.

MW	A difference - why?
E	Um because, it's not a disability if you're in the right environment, but it is a difference as you need to be in the right environment.
MW	Mmm, nicely explained E. Um, what would you call it (turning to A)?
A	A disability in that you wouldn't be able to do things in certain ways, like you were to work in certain environments.
MW	Ok. What about you R - what would you call it?
R (41:52)	I think it's a - I think it's kind of a gift. Because people - what I think cos this is what I've heard - um that people only think, people only think - people only bully you because they wish that they stood out from the crowd.
MW	It's certainly possible. If you think about those people I mentioned to you with autism who are incredible because they are different thinkers - and in fact actually that's so powerful and so important but sometimes it's a bit hard to hang onto isn't it?
R	I mean, I'm a good artist.
MW	I know you're very creative.
R	I think it was either last week or the week before that I - that we did an assessment in art, and my work was so good that it was almost identical to the teacher's.
MW	That's brilliant - well done you. Right hang on - let me just check now. Errr I think that's probably just about all. Do you want to have a biscuit? Go on A.
A	(Unintelligible).
MW	Is this people with autism do you think or people without?
A	With. It's like people with.
MW	People with. So explain again, they try to figure out stuff.
A	Well they like just sit there - I don't know how to explain it.
MW	Is it like a way of coping, to sort of shut out the world. Because this is what you used to do (turning to E) and maybe still do to some extent. Is that what you mean A?
A	Sometimes, I don't run I just stayed there.
MW	Yeah, so you probably shut down, shut your ears and stop letting your eyes think about things, is that what happens? (A nodding) Yeah. Go on R.
R	Did I - did I say that they wished they stood out the crowd or they wished you stood out the crowd?
MW	I don't know. A, there you go (passing cookies to A).
R	Because, I was supposed to say that they wished they stood out the crowd.
MW	Ok, I understand that. And how do you think, this is the final question, how does your autism affect you?
R	This is a tough one.
MW	(Laughing) Good I like to finish on a good one.
E	It stops me from doing certain things - it shouldn't but it does.
B	Same thing here.
E	Also it stops me from having the experiences I, like - other kids my age would have.
MW	So those are the things it does negatively. Does it do any things do you think yet - positively, that you are able to because of it?
E	I have A L which is a lovely place, I got a dog - my artistic skills are better.

MW	So that, they're like yours then R, that for you is a positive - yes?
R	That's a positive, cos I really like art.
MW	Mmm, ok. A, what about you? (Long pause). I mean we've covered all this already haven't we - so I don't think we need to do it all again. Are you going to have another biscuit R?
R	I don't know.
MW	I think you should.
R	You should see my Pokemon that I drew for my teacher.
MW	Oh my goodness - is it a good one?
R	Err, no, I mean I drew loads of them.
MW	You drew loads of them? Oh, because there are lots of different ones aren't there?
R	Yeah, I drew loads of Pokemon.
	[End of recording 45:50]

Appendix 15 M Interview 1

M 1	
Name	**Comment**
MW	All it's gonna do is be just there. Now - (M interrupting).
M	So it can hear what we're saying.
MW	Yeah, it means that I don't have to be - (M interrupting).
M	So you can watch at home.
MW	Yeah but not watch. It's nothing I can see, but I can listen to it again. Because otherwise I'd be thinking "Stop M, I can't write fast enough!" If I was having to write down everything you were saying. So just tell me a few things. Do you remember when we did, we filled in those post-it notes didn't we, do you remember?
M	Umm, no.
MW	Did you do any of those or not? I can't remember whether you did. Do you remember doing any of these when I was in last time?
M	I err, no I don't think so.
MW	No, ok. So, let's just do a few things in here then. What can you remember, just tell me? We can have a page for a memory (showing M the book to put ideas in). What can you remember about school?
M	Umm that I had a one-to-one?
MW	(Writing in book) One-to-one. Ok, what else do you remember?
M	Umm, I remember the playground and that lot.
MW	Ok, so these are things that - what we'll do is we'll come back and talk about. Yeah, what else do you remember?
M	Um, I got angry? (Questioning tone).
MW	Yup, and can you remember the sorts of things that made you angry?
M	Yeah, kind of. I can't remember it every time, but I remember it was just something to do in class (trailing off).
MW	In class?
M	Silly things like not letting me have my blu-tac so I would teach, like (trailing off).
MW	It is silly isn't it, because I mean it doesn't hurt anyone does it?
M	No.
MW	Ok, did any other things make you angry?
M	Umm yeah, they used to give me a lot of detentions.
MW	Ok.
M	And I got a report one day.
MW	And did you think that wasn't fair?
M	No.
MW	Mmm. Ok, what else do you remember? We'll come back to these so we can talk about them more.
M	Umm, that's about it what you'll be interested of.
MW	Oh I don't know. Just tell me anything. What about your friends?
M	Umm, I have four?
MW	Yeah? And are any of them here?
M	No.

MW	All of them went to a different school?
M	Well, four of my main friends. But I got other people what I do know like Maisie and George.
MW	And they're here aren't they now?
M	Yeah. They're in my classroom.
MW	Oh, that's nice. So there are some that you are still with. Do you still see the other four?
M	Yeah.
MW	So they live near you?
M	Yeah.
MW	What about your favourite subject?
M	Umm, I don't know, but I liked PE in my old school, but I don't really like PE in this school.
MW	That's interesting. Why?
M	I don't know. Just - I'm not really sure of the other subjects, just that they're a bit different to what it was.
MW	Yeah, I mean primary school and secondary school are really different aren't they. Cos you just - everything here is bigger isn't it?
M	Um, no, actually I've found out I think my last school is bigger than this school. I find this school really really really small.
MW	Really, I've never been to __ (names school). Your last school was bigger! Didn't you get lost?
M	No because I been there for a long time, so I knew everything. But yeah, there might be upstairs, but it's just like really small. I could show you round, it would probably be an hour. If we were quick.
MW	In here, honestly, I would get so lost. I couldn't even tell you how to get back to your classroom. It would be very confusing.
M	But it's easy.
MW	Is it? Well you, when we go back - (M interrupting)
M	Just go down the green stairs.
MW	Yeah. Ok, I'll get nervous. The more time I spend - (M interrupting)
M	There's, there's there's about four stairs in this school, it's just like I don't know, your house. There's an upstairs and a downstairs, so - (MW interrupting)
MW	Oh yeah, so are we upstairs now?
M	Yeah we're upstairs, and my classroom is downstairs.
MW	Ok. Oh yes, of course, I remember I remember! Ok, so what about, let me think, what else? Lunchtime?
M	Lunchtime.
MW	In your last school.
M	Umm, quite fun.
MW	Oh good.
M	But a bit boring I would say. Because there weren't really nothing to do. And nothing fun. There was just a plain playground. Whereas here I would say there's a bit more. You've got the gym at lunch time, and - (trailing off).
MW	A gym? Inside gym?

M	Yeah, and also an outside gym too, like a play area too.
MW	Ok.
M	So it's a bit more.
MW	So, what did you do at lunchtime when you were bored?
M	Played.
MW	With your four friends?
M	Yeah.
MW	Ok, and what about your teachers?
M	Umm, they were ok.
MW	Yup
M	Just normal teachers.
MW	So who was your favourite teacher?
M (5:25)	My one-to-one.
MW	But what about the teachers that had responsibility for everybody in the class? Was there one that you liked better than the others?
M	Mmm, no not really.
MW	Were there some things that any teachers did that you thought "oh that's really good, I like that?"
M	Mmm no.
MW	Mmm were there things they did that you didn't like?
M	Umm I don't like all the detentions that was it.
MW	Mmm, ok (writing in book)
M	But at this school I haven't had any really, in detentions. Only like two minutes.
MW	That's interesting, so why do you think that's - (M interrupting)
M	I had half an hour in the old school.
MW	Half an hour. So what - why - why was that different?
M	Because, cos it's such different time. Like, - I don't know - probably be more worse than this school like I don't have any detentions.
MW	That's really interesting isn't it? Did you - if you had to kind of say, say, say if we drew a line like this look (drawing straight horizontal line with marker pen on A3 sheet of plain paper), and that's really really happy (drawing happy face at one end of the line), really really happy, and that one, is really really, I mean very, very unhappy. Let's do some tears (drawing sad face at other end of line). So this one is middling yeah? (Pointing to the middle of the line).
M	Mmm
MW	On an average day, where would you put yourself? Put a piece of your putty stuff or - (M interrupting).
M	What, umm - (trailing off).
MW	So, on an average day in your last school, where would you say you were? Really really unhappy? (Pointing to the unhappy face on the line) Up to the middle? (Pointing midway on the line). Kind of ok?
M (7:13)	Probably up to the middle because some things were good and I miss it, but other things were really bad and I don't and it's different.
MW	Yeah, ok.
M	And the same with this school - just put it in the middle. I don't really know.

MW	Yeah, I mean you haven't spent as long here have you because you've only been here since September, is that right?
M	Cos, I feel like this school is probably the same. They are giving me a bit of detentions, and yeah, and there's every strict. So I'd say they're about the same. Up to middle, I weren't really really sad and I weren't really really really 'appy.
MW	Ok, so if, if there was a way of - What I do is I work with, um, grown ups, do you remember that thing I showed you where I showed you all the pictures? And I work with ones that are going to be teachers, so if there were some things I could say to them - M says, "if you did this it would - move you more in that way" (pointing to the line). So what are more of the things that the teachers could do?
M	Do you mean like, giving me a one-to-one? Cos that would help me a bit more. But this school don't - so, also I feel like that's quite good because, cos sometimes they can get quite annoying cos they follow you way around and you can't get up to any mischief
MW	(Laughing) Do you get up to mischief then? Would you do that if you could?
M	Yeah, but I couldn't do any sneaky stuff because they're always there, only at break and lunchtime do they leave me alone.
MW	Ok, so - (M interrupting).
M	They're always working with me because they're *my* one-to-one.
MW	Oh ok that's interesting. So you'd like to have one, but not all of the time, yeah?
M	Yeah, I would like to have one, and all the time, but then, then I don't really mind.
MW	Mmm (writing).
M	I do miss it but also I don't, so I don't really mind, so I don't really need a one-to-one.
MW	In this school? Did you think you did need it in the last school?
M	Yeah. But, this school won't co-operate that and it's a small class and everything anyway, so it's like a little one-to-one anyway cos there's only like ten children in my class, and someone's ill so it's only - so I've left eight children in my classroom only.
MW	What, today?
M	And then when I come back it will be nine.
MW	So, you've got one teacher, and have you got any LSAs with you as well in that class?
M	I got one TA and one teacher, but it did come with two TAs but one - one got chucked out of the job and 'ad to go somewhere else, well not really chucked out of the job, just somewhere else in the school.
MW	Oh, ok I understand yeah.
M	So she's not working with us any more, so, so we're kind of swapping with other people, like taking next door's TAs and all that lot.
MW	Ok, I used to work in a school and I know sometimes that it's difficult with TAs, trying to make them in the right place at the right time. Right, so hang on, if we're going to move you from there (indicating the middle of the line) to here (indicating the happy side of the line), one of the things you said - was (bell rings). What's that mean?

M	Um, assembly time?
MW	Ok.
M	I don't really know. So that means, that means we need to go.
MW	No, because Mr E (head teacher) said that you don't, that you just need to be back at playtime, so that's five to, so we've got five minutes. Right, so - (M interrupting).
M	Oh good 'cos I don't go to assembly today.
MW	Oh fabulous, there you go. So one of the things that we could think about, is that one-to-one - (M interrupting)
M	But I think I've got - but I do have the class assembly. But don't really matter to miss it today, assembly's boring.
MW	Ok. Are they - they're always boring aren't they. In every school, I don't think any pupil likes assemblies. That's funny isn't it? Ok what else would have made your life better, in your __ school. So you said a one-to-one - (M interrupting).
M	Ummm, it was a problem school too, kind of?
MW	What do you mean?
M	Cos I felt like all those kids all had a bit of problems, and all needed a bit of help. So they should have just changed it into a problem school, but a primary one. That would have been better, but it would take a lot of building and that, and changing the rooms and changing the name, but still - (trailing off)
MW	Ok, what about, what - (M interrupting)
M	And that school needs to get a bit better because it's one of the worst schools, in the country.
MW	How do you know?
M	Feel like it is. And it does say it on line I think.
MW	Ok, I'll have a look - see what they say. Ok, what about umm, what could they do to make it better to - (M interrupting)
M	Well, probably not in the country, probably like __ (names local authority), something little like that, but but one of them, because, cos that school could get shut down maybe one day.
MW	Oh dear, though you wouldn't say that would be a bad thing would you? You would say that would be quite good wouldn't you?
M	Yeah, cos I left people behind, struggling.
MW	Yeah, that's sad isn't it?
M	They need to go to a problem school.
MW	But then when you left, you left in Year Six did you, at the end of Year Six and came here at Year Seven? And where did the rest of the people go then who didn't come to this school?
M	To __ (names two schools) because they don't have problems, it was a normal secondary school so you had to go to normal secondary school stuff, so it was __ or __ whatever.
MW	Yeah, I don't know the schools around here very well. Alright, what about um.
M	(Interrupting) I don't live round here.
MW	Where do you live?
M	__ (Names town).

MW	I get very lost, it's very confusing - (trailing off).
M	Yeah, most people don't live around here.
MW	They come in, so they get dropped off in the morning?
M	They, they – yeah there's taxi and minibuses and they take all the children back home, because none of the children really live here. They're all - a couple of them went to __ (names school), the same school as me.
MW	Yeah ok. And then do you come in the same taxi with other people then?
M	Ah, I come in - some taxis are different to others. My taxi is quite a small one, it's got, it's got a boy called Jake in it and it's got Alice and then two kids in the back called Ben and Ollie. And, they all try and get a house like me, so they all live __ (names location), those five kids. And there's also others - loads of taxis in the morning.
MW	So, what time do you have to leave home then, what time do you get picked up, do you know?
M	Mmm, don't really know, probably about half eight, or eight probably.
MW	Oh, ok. So when you went to __ (names primary school), did you go in a taxi?
M	No, I just walked cos it was only down the road, this school is more than down the road. I has to catch a taxi by rented by the school.
MW	Yeah.
M (15:00)	That's what most kids all take - there's a big line of taxis at the end of the day
MW	So the people who have gone to __ and __ (names two secondary schools), so would they walk then?
M	Yeah, or drive or, I don't know.
MW	Right, very different isn't it. As soon as you change to Year Seven it does get different doesn't it. Whichever school you go to, it's going to be different. But thinking about __ (M's primary school) what about when you said that, um, teachers - would no teacher allow you to have blu-tac?
M	Um sometimes, maybe. Some, but they wouldn't - they didn't really like it.
MW	And what about then, you said that some playtimes were a bit boring, so what would have made - would you put yourself in the middle (indicated line) for playtime?
M	Umm, a bit sad because of they could have made it better, like one day they said draw your own playground, this was years ago, and I drawed like a pool and slides and that, that was how I wanted it to be. But literally it was just (taking paper and pen and drawing out ideas as she talked) umm, one square, a bit of a basketball hoop, a bit of a basketball hoop, and a little tiny football bit. Um, a sitting area, another sitting area - done (pen down hard on table to make the point).
MW	Yeah. That's not very exciting. So where you said you'd put yourself - so what colour do you want to be for you?
M	Umm you used that blue so I'll do the yellow.
MW	Ok, so you'd put yourself here in general, so do you want to just put your face or something that is you - so this is general isn't it, but for playtime, you said more over this side (pointing to the wrong side by mistake as paper upside down).
M	Playtime would be more over this end (indicating sad side of line).

MW	Oh sorry, I'm looking at it upside down now. Ok, can you put where you would be for playtime?
M	(Drawing just to the side of the middle) Just a bit because I did make it my own fun way.
MW (17:11)	Good for you, well done. And you must have really liked your friends; they must have helped make it more fun.
M	It was kind of like fun, but I would say this school is not really any better. It has a bit more stuff in the playground, but not really any slides or any pools out there, not really anything interesting either.
MW	It's a shame isn't it, because I think playtime - and then it's lunchtime too isn't it - (interrupted by M).
M	But, but, but they go walk somewhere, so like I walk to the shop and go past the nursery and they got this big slide and this big playground area and it's like __ (names play park).
MW	(Affirming) Yeah, that's what you'd like for playtime.
M	And that's what they kind of need. In schools don't they.
MW	I agree, I agree. And I've been in quite a few different schools because one of the things I did some research on before was I went round to four different primary schools and I looked at what they did at playtime and lunchtime and I worked with four children in particular, one in each different school. And one of the schools was amazing, it was like that one that you were talking about, like the nursery stuff, but the pupils could get out boxes of games, (M listening intently and interjecting "Yeah" every now and then) they had this big Jenga stuff, and they had Lego and they had all sorts of things, it was amazing. And I think I completely agree - (M interrupting)
M	Yeah, well my school, __ (names primary school) did kind of have boxes of things, they did have skipping ropes and that lot, now and again, but then people kept on losing them. But then I found that a bit boring too. So, then they tried to do this four different group thing, one with weird colouring in and then that went all bonkers too.
MW	(Laughing) So, they had some ideas and they were trying things out but it didn't work long term by the sounds of things?
M	Anyway, I left, so I don't know what's going on now.
MW	I mean, all I'm interested in is what you felt about it - (M interrupting)
M	But all I remember is that it's pretty much just a plain playground; they should have put a slide or something, that would have made the kids happy. A slide. That slide would have been there when I left.
MW	Yeah. You know why one of the reasons that I'm doing this research, and you're going to be fantastic, you're going to be a big part of this – I won't be able to use your name. Because, it's got to be - have you heard of the term 'anonymous'? (M shakes head). It means that umm, you, that I can use another name for you, so nobody would know who you are.
M	Why?
MW	So, you've got to think of another name that I could use instead of your real name.
M	Why?

MW	Well, I can't say M, it's got to be anonymous. It's got to be something that you know it was you, but nobody else would know it was you. And I can't use the name of the school either (names school) because they might get very cross with me if I sort of said things. So, I won't be able to use their name, but what I'm doing is finding out what you have thought about your time in primary school. So when I come back - (M interrupting).
M	(Sounding subdued) So, why do I has to change my name?
MW	Well it's just because, I could probably use the name M (alternative name suggested) maybe, do you ever get called M?
M	(Shaking head) Rarely.
MW	Ok, we could do that. And then I wouldn't say your first name and your second name because then it could be that you were identified and it might be that somebody might read this report or if it goes into a book - (M interrupting).
M	And they might recognise __ (names primary school)
MW	Yeah, and they thought she was at __, she's been talking about __ and then it wouldn't be very good for you or me.
M	Can I not put it into a book? Can I just keep this as you and me?
MW	Yeah well, we can keep this as you and me and then what happens is that I need to write - I will have to write some things down, but it won't go any bigger than that, so it won't be something that anyone else can read.
M	I only want it just to be me so I can keep my name then.
MW	Yeah, ok. So let's do it that way then. So, what I'll do when I come back is - (M interrupting).
M	So, it's only going to go be me into my school, innit? It won't come in this school or in __ (names primary school) that this has been up there.
MW	Nobody at __ (names primary school) will know that you're talking about your time - that will never happen, they won't find that out. So, you don't need to worry about it at all. I want to find out more about these sorts of things that we were already talking about (M interrupting).
M	No, because, why would that school be upset anyway? Like I probably would tell.
MW	Exactly.
M	Stuff. Like say, let's say I reported it. Because my one-to-one followed me here and I could tell her a bit about the school today, if I wanted to, but I probably won't, it's not really that interesting. It'll just be sent to me like in a little book, then that will be it.
MW	So, what I'll do, I'll type up some of the things that we talk about over the next few weeks when I come in and see you, and then, what I'll do is I'm gonna - then check it with you. So everything I type up, you'll have a copy of, and you can make sure that you think it's right. Because I don't want to write something that's not right but I'll write it from this (indicating recorder), but I won't write everything, because I won't have time to write everything, but I'll write down the bits that I think are important, does that sound ok?
M	Yeah.
MW	And then what we can do is we can look at those bits and maybe get some ideas.

M	Yeah. But I don't really want it written in any book or anything that's not what I really meant. I just wanted to talk about it because I think that school was every bad. That's all. So to have it written in a book to have proof maybe one day if I have problems with that school. Cos time changes.
MW	Exactly. There'll always be - no person I speak to is going to have had, in any school a completely lovely time or a completely awful time, and that will be the same for absolutely everybody. And that's the same for me at work as well. Some days I have really good days and some days I really don't want to go to work at all. So, it's just the way that it works. Everybody has good days and bad days don't they? (M nodding). Yeah. So, when I come back, we'll chat some more.
M	Yeah.
MW	So if you remember, if suddenly you think "Oooh, umm, I remember I did this and it was really good", or "oh I remember this and it made me really cross", then can you just write it down on a post-it note? If I leave you with this packet of post-it notes?
M	Umm I probably won't do it, because I'll just save it for next time.
MW	Will you remember it though?
M	What?
MW	Will you remember? So, so what might happen is that you might think of some ideas and then you'll forget them, and by the time we meet next time, they might not - (M interrupting)
M	No, cos I'll probably think about next time - cos I'll not really gonna worry about them and just carry on with my life until I see you next time.
MW	Yeah, all right. Ok, that sounds absolutely fabulous.
M	Yeah, cos I completely forgot you were coming today, so it was unexpected. I didn't know that you were coming today.
MW	I hope you didn't mind. I hope I didn't take you away from something you really wanted to do did I?
M	Well, I was actually being quite impressive in school because they said, they said do these rhyming words and then they gave me this sheet and the next thing it's done.
MW	Well, it's just as well that I came, or you would have been bored.
M	And then you came, so I couldn't do the next one to impress her.
MW	Was that ok, you didn't mind did you?
M	Well - (scraping of chairs)
	[End of recording 25:00]

Appendix 16 M Interview 2

M 2	
Name	**Comment**
MW	Glasses at school, brown hair, autistic, carry on - (trailing off).
M	My friends are called Harry, Minnie, Macey and Rick and everyone else in the class what you just seen.
MW	Yeah, they're great aren't they?
M	R was the girl you saw that sat there.
MW	Oh right yes, I know she said "Oooooh she's back - the lady's back" isn't she. Ok, what about family?
M	Ummm, I got a Mum and a Dad and a little sister.
MW	How old is your little sister?
M	In Year 4.
MW	And is she at __ (names school)?
M	Yeah.
MW	Ok. What sort of things do you like, apart from bouncing the ball?
M	Ummmm I like playing with slime, bouncing my ball, catering around corridors.
MW	Why?
M	Cos it's just fun.
MW	Ok. Maybe one time, maybe next time I come back we could wander around the corridors here. Because do you know, I managed to find my way here - even, I know it probably doesn't seem very difficult to you, but it does to me. Wandering around corridors, yup?
M	I'm not really allowed to do that; I'm just saying that.
MW	You're not, oh ok.
M	Cos, cos, cos people will be working in lessons.
MW	Oh yeah, of course. So what else do you do? (M interrupting)
M	Cos if I was the only one in this school we're in then there'd be plenty, plenty of help you could do that.
MW	And what else do you like?
M	Uhhhhhhh - (thinking).
MW	Just generally, it doesn't have to be at school, just what do you like?
M	Playing around?
MW	Playing? Yeah. Outside or inside?
M	Any.
MW	And those are the things that you like. What would be the things that you don't like then? (M's teacher entered class).
M	Working.
MW	Any type of work?
M (2:20)	Ummm English, reading.
MW	So do you have to do that here sometimes? Even though you don't like it.
M	Yeah (sounding incredulous).
MW	(Laughing) So did you have to do that in your last school as well?
M	Yeah.

MW	And is it easier here?
M	I don't know.
MW	Ok. So working generally, English and reading are the worse things are they?
M	Yeah.
MW	Ok, so what about when things are making you happy?
M	What do you mean?
MW	Well, I know that I like - if I'm feeling miserable and I listen to music sometimes that makes me happy. Or if I play the piano or I, umm - (trailing off).
M	I don't really have something for that. I don't really know yet. What could be my thing, cos people can have it when they're angry and they do something and it makes them happy, but I haven't figured mine out yet, I don't think. I would probably like to bounce my ball, or do something like that. But I haven't properly figured that out.
MW	Do you remember umm, last time I was here and we did that line, didn't we? And we said about being, things that made you feel maybe a little unhappy in the last school, that was playtime wasn't it? But maybe if they'd allowed you to bounce your ball, do you think you would you have moved up into that side a bit?
M	Yeah (Sounding as though the answer was obvious).
MW	Yeah.
M	Well they did let me bring bouncy balls in but they don't let me bring basketballs in. When this school - when it starts getting more hot, I'll start bringing in a basket ball instead of this. Cos this is corridor like and because it's cold that's also what makes me want to do the corridors, but as soon as it's hot then I probably will spend more time outside than inside.
MW	So, do you think you prefer being outside than inside?
M	Yeah - outside is a bit more funner.
MW	So if I put 'likes being outside' (writes on paper while M bounces ball). It's interesting isn't it? When you think about things that might make you happy and you said you hadn't worked yours out yet, do you think you will work it out sometime?
M	Dunno.
MW	Do you think people do work them out?
M	Yeah.
MW	They might do, mightn't they? And then what sort of things make you sad?
M	(Bouncing ball and dropping it). Nothing.
MW	Nothing? Well maybe that's why you don't ever need to be made happy because you always are happy.
M	Yeah (contemplating idea).
MW	It would be nice wouldn't it? So you know when we talked - (M interrupting)
M	When am I allowed to leave?
MW	Well, do you want to go to music? (A nod from M) Ok, so if I spend just another few minutes going through some of this stuff with you - (M interrupting).
M	Yeah.

MW	And I'll make sure you go to music. Yeah? Twenty past is when she said music stops so I'll definitely, definitely get you there before that, ok?
M	Ok then. Well I could miss music.
MW	Let's just see how it goes with this shall we? Because I don't want you to stay here if you really don't want to. That wouldn't make me feel happy, that would make me feel bad. But I really really could just do with finding out a few things. Do you remember that we talked about some of the things that were good in your last school, and you said that your one-to-one was good?
M	Yeah.
MW	What was good about your one-to-one?
M	It was because - nothing really.
MW	Did everyone have one?
M	No - umm no.
MW	Ok, so how did you manage to have one? Especially that you liked them, I know sometimes you didn't - (M interrupting).
M	Cos I've got problems and I fighted for it.
MW	So did that person help you?
M	Yeah.
MW	How did they help you?
M	I don't know (sounding tired of the questions), they just helped me, but I don't need a one-to-one in this school.
MW	I know, and that's good is it?
M	Yeah, cos some things I can't do with one-to-ones. There's difference. Like, as I said, I couldn't get up into any mischief having a one-to-one, they're always a ghost - (trailing off).
MW	(Laughing) That's a funny way of thinking about it - I like that. Yeah?
M	And yeah, and they could get quite buggy because if you just run you could get into trouble cos there's always someone there - to watch you and you would get in trouble. But it's also good because they can help you learn. So, I think I'm going to play; I had a one-to-one in my old school but not one in this school because I'm old enough now.
MW	Yeah, I agree.
M	(Not seeming to want to stop on this subject) And this school don't put up with it, and they help me anyway when I'm, when I do have problems. And they pretty much are on my back because it's only a little classroom.
MW	So this school helps you because the class is smaller yes?
M	Yes - you don't need a one-to-one because there's only ten people in my class.
MW	So if your one-to-one was taken away, in your last school, were there any other things that maybe could have helped you?
M	No (decisively) not really. Cos, cos they done that before, moving up to Year 4, and then I had a terrible life and then in Year 5 they had to put a like different one-to-one back, cos, cos, cos that was one of the worst years what I've had cos of that situation.
MW	Right. Ok, so your one-to-one really was important in that last school?
M	Yeah (decisively).
MW	Mmm, and even though sometimes you said they were a bit annoying, they were like a ghost, overall you preferred to have one than not to have one?

M	Yeah, in that school. And in this one, I'd just prefer to not have one.
MW	So it's actually working quite well then isn't it? Cos you've now had a whole term without a one-to-one - (M interrupting).
M	More than a whole term.
MW	Yeah, a whole term and what, two weeks now?
M	I'd say more, I would say two whole terms, two whole terms now, being already past Christmas, cos I started in September.
MW	Yeah, so quite a long time. That's brilliant isn't it? So, so, when your one-to-one was taken away in Year 4 - (trailing off).
M	Yeah (questioningly)?
MW	Did they do anything else instead, in school?
M	No, I can't really remember that back.
MW	It probably wasn't a very easy time, was it?
M	No.
MW	No, ok. And what about you said about the playground in your last school. What were the things - (M interrupting)
M	I did like it but it was just like, a piece of like boring. Like, like, if you go back to that drawing, it's just a couple of seats weren't it?
MW	Yup.
M	You remember?
MW	(Finding drawing) Yup, I do remember.
M	Oh.
MW	Look (showing previous drawing), there we are.
M (9.50)	And this one has got a bit more fun into it, but I would say it's still not properly great; I would still like a slide or something.
MW	And was there, was there anything that you were allowed to do maybe because of your autism, that some of the other pupils who didn't have autism would not be allowed to do?
M	(Bouncing ball). Loads of things.
MW	Really? Like what?
M	Probably like I - like normal people in school weren't even allowed to take their bouncy ball in, into school, but I was allowed to, and also I was allowed to bring a squishy into lessons. Only because I begged, because I got a bit bored in the lessons because they talked so on and so on. But now they let me have blu-tac, which is what I really wanted in the first place at my old school. Cos blu-tac I quite like to play with - it's just like slime.
MW	I don't think I've ever played with slime. Is that the stuff that's kind of green?
M	It never has to be green; it's all sorts of colours. It's the colours that all kids like.
MW	And sometimes does it have like sparkly things in it?
M	Yeah, it can have sparkly things, gold slime, there's all different kind of slimes. Some can be like water stuff; others can be like putty slime. Some can have polystyrene in. You get all kinds of slime.
MW	What, and you just buy it like that do you?
M	Yeah (incredulously). And when they dry out you just add soap into them.
MW	Soap?
M	Yeah.

MW	Oh, what like hand soap or washing up liquid?
M	Yeah, hand soap or washing up liquid.
MW	Can you make it then?
M	Yeah, you can make your slime but - but usually you buy it from the shop
MW	Ok, so yeah, if it goes wrong you can put it back to rights? Yeah?
M	Yeah. Because some slime gets a bit like tough like play dough after - (trailing off).
MW	So in the classroom what was your favourite time of the day, in your last school, can you remember?
M	Why?
MW	Just wondering.
M	Playtime?
MW	But if you were in the classroom, apart from playtime - oh you said before PE didn't you?
M	I did like PE. But - (trailing off).
MW	So what was good about PE? (Long pause while ball was dropped). So what was good about PE? (Long pause). Is it because you like being physical, moving around do you think?
M	Yeah (bouncing ball).
MW	And it's better than having to sit down - (long pause to see if she would carry on with this conversation). Have you got any pets M?
M	Why?
MW	I was just wondering. Because we could put that on that - cos I could add that on about you couldn't I. What pets have you got?
M	A dog and a cat (throw away type of answer – different to the others given previously).
MW	Really, a dog and a cat? Ok, what's the dog called?
M	Why? (subdued and wary)
MW	(Laughing) Just wondering.
M	Neville.
MW	Really. And what was the cat called?
M	Tilly (names cat).
MW	That's nice. And have you had them for a long time?
M	Mmm, not really (quite quiet and withdrawn).
MW	Do you know, I had a cat, but she was very very old and she had to be put down. That's very sad. It's nice having animals though isn't it?
M	Yeah.
MW	But you can't have animals in school can you?
M	Now can I go to music?
MW	Yes, can I just ask you one more question then you can go to music?
M	Yeah.
MW	So, what about the teachers? Can you remember things that you really liked that they did? So, one of them allowed you to have blu-tac?
M	No.
MW	Never in that last school?
M	No.
MW	So that was something that you really didn't like. What else did you *like*?

M	What?
MW	What did you like that they did?
M	They done nothing really kind (long pause).
MW	Really? (Long pause) So did you not feel that they made any changes for you?
M	Maybe a little, but - but it's not really their fault, it's the school equipment fault. Like, like I guess the teachers get told to do that.
MW	Maybe. What do you think they could have done that would have been better though?
M	Let me have blu-tac.
MW	Yes, what else?
M	Just made it a bit more funner. And they should have changed it into a problem school.
MW	Yes, I remember you said that last time, didn't you. But if they had changed it into a problem school, what would have been different?
M	It would have been just like this. So it would have made a difference.
MW	Yeah, so the classes would have been smaller yeah? So apart from the classes being smaller, what's different about this then?
M	It's got soft play, in here. It's a tiny room, but still it's got soft play, and loads of fun stuff. They understand when you're angry. You got the sensory room even though I never really go in there. Loads of stuff.
MW	And is there anything in this classroom that you think, if that was in my other classroom it would have been better?
M	Smaller people? And also I find it quite good over here because I never knew I was going to make good friends, cos the only old friends what I knew were Molly and Hetty and now I've got a friend called Macey and Rick and all the rest of my class are all friends.
MW	So why do you think you've got more friends here?
M	Well, I did have different friends in my other school, but - but these friends are more like me - a little bit more.
MW	Yeah, so do you think the people in this class understand you better?
M	About the same?
MW	You said you thought they understood you better. Do you mean the teachers then?
M	I think the teachers understand a bit better than the old teachers. The kids are like the same. Cos there some of the kids in my old school did have their own problems. They used to get angry all the time too. Loads of kids.
MW	So do you think it is because the teachers here have a better understanding about the pupils who they are working with than they did in the last one?
M	Yeah.
MW	Alright M. Can you think of anything else you want to tell me?
M	No.
MW	Well thank you, you've been absolutely brilliant. I suppose you had better put that ball away hadn't you before you go off to music. What are you going to do in music, do you know?
M	Dunno.
MW	Well, I hope you have loads of fun.
	[End of recording 17:51]

Appendix 17 M Interview 3

M 3	
Name	**Comment**
MW	Right look at these (showing pictures to create a timeline). I thought it might help us just to check - so that you can understand exactly what we are doing. So, at some point - I don't know if they are in any order, let's just … put them out like that (putting pictures on table), so this is, this is kind of in - well - what I'm wanting to do over time. So I started off with an idea (finding picture of idea), are you ok with that one at the beginning?
M	Yeah.
MW	So, if I shove that right up here because I think it might fall off the table if I don't start it quite far back. So, if I start that right there. Then, from an idea, I had to come and talk to you, and lots of other people. Do you remember when I came and talked to your class?
M	Yup.
MW	Do you reckon it might be that one? (Indicating particular picture)
M	Yup.
MW	We might change these - let's put that one there (placing this picture next to first picture to create a line). And then I worked with you and while I was working with you, we were kind of working together weren't we (agreement from M) because I can't do this without you, and so that was you and me (indicating another picture for the timeline). Then while you and me were together we recorded - I think that thing there is the recorder (indicating picture). It doesn't look quite the same as that (indicating own recorder on table) does it?
M	No.
MW	I think we're still going to go off the table, let's shove them up here. So I've recorded it and also we did stuff in a book didn't we which is here (picking up note book with page written in from previous visits), and then I have been doing lots of reading, since I've seen you, I've also been doing lots of typing (picking up several pictures as talking to indicate these steps, passing to M who puts on timeline). I've also been having lots more ideas, and then hopefully all of this is going to become a book. Now (indicating final picture on table of a frog lying down with arms clasped across a large stomach) what can we do with him?
M	What's that supposed to be?
MW	A frog - just having a rest. (Pause to see if M would choose where to place it, but she didn't). Shall we - I suppose, I suppose what the nice thing would be if you felt relaxed while we were talking together, because certainly when I'm doing the typing bit I don't feel like that (indicating frog) because I'm busy. Maybe I could put it down the end - when I've finished it I could relax. (M agreeing and placing it there) It would be nice to think it wouldn't it. Let's shove all of these up - (M interrupting).
M (2:53)	Maybe it's saying like relax while the book's is done.

MW	*When* it's done? You mean when it's finished? (M agreeing) Ok, let's shove that at the very end then. (M places frog at end of line of pictures) Wow, the table's just long enough isn't it? That's good. Ok, so this is the plan. And are you still happy to take part in here? (Indicating M's section of the line)
M	Yup.
MW	Yup, ok, and then we'll just kind of see how it all works. Shall we see if we can leave it like that for the moment, and I'll see if I can find out some of these things I need to check out with you (finding paper with a few questions on in file of other material). Look at this; I thought you'd be interested in this (indicating transcripts of two previous interviews to see if she showed any interest in looking at them). This is all the pages of stuff that I typed up from what we said. Look, can you see how many there are. These are all pages of things we said. Pages and pages and pages. That was the first one, then we had another one (indicating another transcript). Do you remember doing this (showing M the hand drawing and things written about her from previous session)? 'Cos I'd like to add a little bit more to this. This is all about you, and actually you might have changed. (M putting her hand back into the hand drawing). Has your hand changed shape? It's pretty much the same. Um, so I've written down here you've got Mum and Dad and little sister in Year 4, you with your friends, Harry, Minnie, Macey and Rick, yeah? (M agreeing) This is what you said 'you wear glasses at school' - I wear glasses too sometimes, you've got brown hair, you're autistic, you don't like working, but particularly you don't like English and reading - is that still the same? (M agreeing) You've got a dog called Neville and a cat called - what's that say, is it Tilly?
M	Tilly.
MW	It is Tilly. And then you like bouncing your ball, is that still the same? (M agreeing) Playing with slime, wandering around corridors, playing outside and inside, playing just generally, but you particularly like being outside. And then did I write down where you were at school? No I haven't. What colour shall we use? (M chooses colour) So, shall we write in where you were at school - before, that was __ (names school) wasn't it? (M agreeing) I don't know how to spell __ (names school) do you? (M shaking head) Shall I write it down or do you want to write it?
M	You write it.
MW	Cos I'm not quite sure. I'm gonna write it the way I think it might be, because it might be that but I don't know. And were you there all the time? When you were at your last school?
M	Yup.
MW	(Writing). All the time?
M	Well, from Year 2.
MW	Ok, so where were you in Year 1 then? Do you remember?
M	In __ school, not really.
MW	(Writing name of school)
M	But it don't really matter.
MW	No - Ok.
M	Cos the story is about this.
MW	I'm just interested - yeah, it's about how you were in your primary school, but you were also here in Year 1 were you? I'm just interested to find out.

M	Yeah, but it's not really my primary school. I don't really - really really the main primary school is that because I spent most of my time there.
MW	Ok, right ok, so we might add a few more things, let's leave that over there for the moment (moving hand print paper away to the side), and let's put the lid on the pen so they don't run out. Now, I have a few questions. You know you mentioned things that you like and things that you don't like, can we just check I've got these right as well because I don't want to do this wrong. Your memory about school - one of the first things that you said you liked was that you had a one-to-one, yeah?
M	Yeah.
MW	And you had friends in your last school - of which most of them have gone somewhere else haven't they? (M agreeing) But now you've got new friends here. You liked PE, in your last school?
M	Yeah, but not in this school because I don't like the PE teacher.
MW	Yeah, ok - teachers are important aren't they, as to whether you like things or not? (M agreeing). And you liked, well - sometimes you liked the playground and sometimes you didn't like the playground - in your last school. Do you remember that?
M	Yeah, I don't like it because it was boring and I just had to make up my own games.
MW	Yup and you did that with your friends didn't you?
M	Yup.
MW	Ok, and lunchtime was sometimes ok and sometimes not ok.
M	Yeah - normal.
MW	I'll put it in the middle yeah? (M agreeing). So, what I'm interested in is I kind of wanted to check up about some of these things. The teachers in your last school, did they allow you to use that blu-tac (indicating the bit that M is manipulating) or not?
M	No.
MW	Never?
M	Hmm, well I think they did not - so they made me bring in a squishy instead.
MW	Ok. And did the squishy work in the same way, was that alright?
M	Mmm, not really, I'd have rather had the blu-tac.
MW	Why, what's different then about that?
M	I dunno.
MW	You just find it better to use do you?
M	Yeah, probly because I can make shapes and that - I don't know - (trailing off).
MW	Oh, so a squishy is just something you can squish.
M	Yeah. (Unintelligible) squish like a foam thing - or you can get water ones too.
MW	But this one you can actually make something with it?
M	Yeah, and it's a bit like slime. I probably prefer slime more than squishy.
MW	Uhh I remember you telling me about slime (laughing). So, some - but they didn't - do you wanted that (indicating blu-tac) but they preferred you to have the squishy in your lessons at school.
M	Yeah 'cos they were mean.
MW	Yeah, you mentioned that before, what was it that was 'mean' about them?

M	Cos, they didn't let me use the blu-tac.
MW	Mmm.
M	And I always kept on getting angry.
MW	Yeah, and you mentioned that as well before. Hmm what did you say about getting angry - was it because of the teachers that you got angry do you think?
M	I think everything. Maybe a student, maybe a teacher, maybe they're not letting me have somethink that day, maybe I've got a detention from like a couple of days and that's wound me up all over again.
MW	Yeah, so, is this school - do you think they underst - well one of the things you said last time was that they understand you better here - the teachers understand you better here.
M (9:24)	Yeah, I think, because I don't get as angry as in that school. In that school I was really naughty, in this school I don't ever, hardly ever get angry really.
MW	And when you're angry, does it make you naughty? Are the two things linked do you think?
M	Yeah, because, because obviously when I'm angry I used to disappear in my old school and run away, not out - out of the school, but in the school. But if I'd stayed there for longer then I probably would have figured out how to escape the school.
MW	Yeah, 'cos you would have been that much bigger as well. And so do you think that was *naughty* what you were doing?
M	Yeah.
MW	It was naughty.
M	Yeah, most probably.
MW	But you don't feel the need to do that here?
M	No because really all it was was that I didn't really like it. Because I've never ever ran away out of my class - never.
MW	That's really interesting. So, what's better - (M interrupting).
M	But I have got angry though.
MW	Yeah, everyone gets angry sometimes don't they.
M	Got angry and then kicked doors maybe a couple, and then, then they've calmed me down. In that school, they didn't know how to calm me down, they'd just say I'd got a detention.
MW	Mmm, ok. So this school understands you better because they know what to do when you get angry?
M	Yeah, I think.
MW	But you also get angry less?
M	Yeah (thoughtful).
MW	That's really good isn't it?
M	Well - maybe not get angry less. I do get angry but what I mean is I copes more and it's gone, where in my old school that would ruin the whole day. Not, not just that I would disappear *and* get a detention that day.
MW	Mmm, so did you think your teachers in the last school were not fair?
M	Hmm, no not really - I don't know. But they didn't really understand did they?

MW	No, no they didn't understand. And these teachers seem to understand more don't they? (M agreeing) Another thing that you said, you said that your last school should have been 'turned into a problem school'. What's a 'problem school' do you think?
M	Like, like this school.
MW	So what - what does that mean?
M	Help and support and that. Because I noticed there's a lot of kids like me who have problems, and because they ain't got a primary school with problems, then they has to go to a normal school. There's lots of kids in the world now who've got - got problems so they need to make a primary school, so that's why I was just saying that they should turn that school maybe into a problem school.
MW	Yeah, so, so if you have a problem - what sort of children have problems? Do you think everyone has a problem?
M	No, what I mean is like - needing help and support because they got like, I don't know, they can't learn or they're autistic, or they're too hyper or something. Most kids are like that these days now. They need to go to schools like this.
MW	Or do you think, in your last school, if the teachers had understood more, and maybe allowed you to have blu-tac, or worked with you when you were feeling angry, would, would that have made it better?
M	Don't know.
MW	Mmm, it's difficult to tell isn't it, because it wasn't that way and that's just how you remember it?
M	Yeah, I can't remember it all, cos I can't remember all the angries - cos I got angry so much. There's so much chapters of each angriness, I only remember like a couple because, I don't know, 'cos I got loads of detentions. Or something will make me remember it. Like I remember climbing all over the tables and then coming back on Monday to a half an hour detention. And then the day after they gave another half an hour detention.
MW	Yeah, ok. Well you said - one of the things you said was that 'your teachers hadn't done anything really kind'. So you just felt - a bit sad there did you?
M (13:20)	They probably did do some stuff kind, I don't know.
MW	But that's not what you remember at the moment? I'm sure they did - I'm sure you must have had some nice times, and some good teachers, but the thing that you remember the most is the detentions and being angry, yeah? (M nodding) But you also said, it's not really their fault - the teachers' fault and the school's fault. Why was that?
M	Because they didn't understand.
MW	Mmm, and what's different then? Why do these teachers understand - do you think?

M	Because they've got teached - how to- how to understand. 'Cos, cos say if you've had a child then you need to learn, and they have the problem 'cos there's all different problems. What you need to learn for all different cases, like when they get angry, I've noticed more problem childs get angry than normal childs. So they'll be the type of people you see kicking off down the road, and kicking doors and all that lot. They might have something wrong with them, because - or her, because - and - yeah, you need to learn how to cope and that when they get there.
MW	(Pause) Yeah. Maybe you could be a teacher M, when you grow older.
M	Yeah, and you also need to cope that they can't do that normal mainstream work what probably made me angry too. Because work today in a normal mainstream school is counting, where they're doing a thousand times tables to about a hundred and two, really really really hard work. In my old school they were teaching Year 1 how to do five times tables. Yeah?
MW	Yeah, I think I'd struggle with some of that.
M	Yeah (affirming response). But in this school we're count - learning how to um, we just moved off from money and all that lot, which is better.
MW	Yeah, ok. And you said in your last school - you mentioned twice actually that you needed to *fight* for your LSA to stay with you. Your one-to-one, do you remember? You said they were taken away in year 4 and that was a horrible year wasn't it?
M	Oh, yeah, and then I got it back in - in - because they were like, um awkward like that. You'd like fight for stuff and they'd take it away from you and then you'd have to fight again, so it was lots of fighting. All the time. Which also affected me getting angry. So I might be angry just because of something because I just know there's been fighting going on to get something.
MW	And did you think that your parents were cross and annoyed as well?
M	Yeah.
MW	Yeah, ok. And also, you said you had to beg for - what was it, using a ball, or blu-tac or something? So you said, it was interesting (M interrupting).
M	I had to beg for using a ball - I wasn't allowed to take a basketball to school or a football. That's how mean they were. I don't know why, I was not allowed to - it was a bouncy ball or nothing. Which don't make sense - they've got a playground. That, that was also a loss. I never never brung basketballs to that school.
MW	You never did?
M	No. That happened in this school when I started to bring basketballs.
MW	Yeah - And then you mentioned a really funny phrase about your TA, or your one-to-one - she was a bit like a ghost. Sometimes you liked her being nearby but other times you couldn't get up to mischief, and so you didn't like it quite so much. Do you remember that?
M	Yeah. I didn't like it when they got angry 'cos I was annoyed at all the teachers.
MW	Mmm, but now - here - you don't have a one-to-one do you? (M affirming) And that's better yeah?
M	Hmm, I don't feel like I need it.
MW	So, why, why do you not feel like you need it? So what's what's different

	then?
M	Because, cos I, get small work - I don't know - it's smaller classrooms.
MW	Yeah, so the work's different, the classes are smaller and the teachers understand more?
M	Yeah.
MW	And so you don't need your one-to-one.
M	And and that sometimes they'd get buggy and I'd get up to more mischief. I don't know, I just felt like I wanted a one-to-one in that school, but in this school I don't. And that's just how I'm going to cope with it.
MW	Yeah, and were you the only one in your last class who had a one-to-one?
M	Yeah.
MW	Yeah. And did you like that or not like that because you were different?
M	I liked having a one-to-one because I wasn't in the class half the time. Which is better. I got to do more jobs, more fun - and more better stuff, and more help with the work. Like someone's constantly watching you so if you do something wrong, they'll always mind you, and quick in a flash, or something. Whereas in this school, you have to constantly put your hand up if you want, if you want help or something.
MW	Mmm, ok. So, you don't need a one-to-one here, and you don't really want a one-to-one here do you?
M	No because I'm not allowed it and I don't really want one anyway. I don't need it.
MW	Cos you're, you're the same as everybody in this school. Do you feel, did you feel more different in your last school than in this school?
M	No - not really.
MW	Because - you - tell me, tell me about your autism. What happens - what happens with that? What do you know about autism?
M	Not really much - it's all a bit confusing for me. I just know that I'm autistic (slightly questioning tone).
MW	Did you know - do you know how many, if other people are autistic in this school?
M	Yeah.
MW	You know they are?
M	Yeah. Loads of people in my class and everything. Pretty much - that's one of the reasons how to get in.
MW	So actually that's kind of worked well hasn't it, because it's given you an opportunity to come to a school that you think understands you better.
M	Yeah. Friends are like that. People in my class are like that.
MW	People in this school?
M	They they, they - you least have to have a word problem or or or need help with the work to get in this school, like like to get put on the list, but it takes a long time to get into there.
MW (20:00)	And then, do you think you make better - is it - are you - this is hard - do you think you make better friends here than you did in your last school or not?

M	(Pause) Bout the same, I don't really have trouble with friends in my old school. Whereas most kids do - but I don't really. I, I, I thought it was hard to make friends in the beginning when I first moved to the school, but I made friends at the end - like loads.
MW	Do you think your friends here, because they have autism as well, might understand you better? Or does that not make a difference?
M	No it don't make its different, because my friends are kinder in my old school, which also gives me a clue they might have problems too which is why I think they should have changed that school into a problem school.
MW	That's why you know I said - when you have a new load of pupils here, when you move up to Year 8, I think you'd be a really good person to help look after some of them. You're very caring and I really picked that out from the last times that we were together. Some of the things you said, you really care for some of the people who were at that school, or who are at different schools - (M interrupting).
M	Yeah, because I got really angry and I, and - and - and I used to fight. And it was mainly no fair really because I used to get loads of detentions. Loads. I never ever hanged out outside at all, which also made me feel angry cos I feel like I missed my break.
MW	Oh so was a detention at break time then - was that how it worked?
M	Break time or lunchtime, and they even do after school, but luckily I didn't get an after school.
MW	So, when you had a detention, it would be for the next day's break or lunch - yeah?
M	Well, if it was in the afternoon, it's - it - but, but the thing is if I feel like I missed a minute I feel like I missed my break. Kind of do in this school too. Any time I - because I've had so much detentions I get really kind of like annoyed that I've missed a minute or even a half an hour or, be ten minutes in the whole lunch, but I'll still feel like I've missed.
MW	And what do you have to do in the detentions? Is that where you sit in a classroom?
M	We just sit - something different - I remember one time I had to write, and that was about ages ago, but in Year 6 when I got in detention it was just sit in a room and I had to bring my lunch in there too and eat my lunch and then sit down and be quiet.
MW	And not do anything, just be there?
M	Yeah.
MW	Yeah - For somebody like you, who likes being outside that must have been really hard.
M	Naaah - I had to do it.
MW	Yeah.
M	But then I would fight after - that's what I mean. It wouldn't be over after that, I would get angry still. It's not over until I get my, until I get pay back.
MW	And what was your pay back?
M	That's what - that's what was naughty of me, cos then I'd do pay back because I would either forget about it, or carry it on and then get really angry and then run and then end up having another detention.

MW	Oh, I can see how - it was difficult.
M	(Sounding subdued) Yeah.
MW	Yeah, so, I think I've got another (looking for notes in book which we created together in the first interview) - where is my other list - I've got down here - oh no I have got down here - look - detention. So I'm just going to write down here they tended to be lunchtime, playtime, and they could have been after school but they weren't were they?
M	No, but it was lunchtime and break time. Mostly lunchtime. I don't know why but they chose lunchtime - it gets half an hour. Cos lunchtime is a whole hour in it, so if I needed half an hour then that was lunchtime.
MW	Mmm, ok.
M	Cos break time is only about ten minutes. I don't really get ten minutes it was half an hour or something, so they - loads of half an hours.
MW (24:04)	Mmm, and so in a week, would you miss maybe one or two lunchtimes do you think - or not that many?
M	Probably about two or three a week.
MW	So, more than half sometimes then. Ok, it just gives me an idea about kind of - (M interrupting).
M	Or - probably once a - probably always up on once a week. But it went up into every day every day every day, it wouldn't be that bad - but I would probably get one of these once a week - or - get tooken out of the classroom somewhere.
MW	So you know you said that here, you think the teachers have been taught better about how to understand people like you, yeah? What would you say to a teacher in your last school that would help them to understand more?
M	I don't know (sudden change in tone and now sounding bored).
MW	No - I mean, maybe it would have helped if they had spent more time talking with you. What about, do you think it's good if people know you've got autism? Like your teachers. Did they know you had autism?
M	Yeah.
MW	Your last teachers in your last school?
M	Yeah, of course.
MW	But it didn't make a difference?
M	I blubbed it out pretty much - I want people to know pretty much. I don't know.
MW	Yeah. Why, why do you want people to know?
M	Well, so they - aware are they now.
MW	Mmm, but but your last teachers in your last school, did they - (M interrupting).
M	Because of course they had to so I got the help too.
MW	Here?
M	No in the old school. And also they has to know here so I can get in and get the help still.
MW	So, what help did you get in your last school? Was it just the one-to-one?
M	One-to-one, I got the squishy - Can't really remember.
MW	Mmm, and you got those because you have autism.

M	Uhh, and probably because of other problems I don't really know about.
MW	So is there good stuff about being autistic?
M	Don't really know.
MW	Cos I read, there's um - there's some books written about people who are famous who have autism.
M	Yeah I know.
MW	So, so their brains work in a slightly different way, which helps them to do things in a different way. You're probably really good at concentrating on one thing for quite a long time. I'm not. I'm really bad at that.
M	Yeah, because they're different. But obviously, it affects other stuff.
MW	Yeah, so some things it might make better, some things it might make more complicated. Do you think that's the case?
M	Yeah, maybe.
MW	Does your sister have autism?
M	Mmm, no, but she's having trouble in that school at the moment. Which is why they should turn it into a problem school because it's not just us two, it's loads of children who struggle.
MW	Mmm, and and - (trailing off).
M	(M picking up on conversation again) That's why I feel a little bit sorry because - I don't know, that I protected myself so I could protect other people. Because that was the gang up trying to make the school better too. In a way trying to make it better for myself.
MW	(Long pause) Yeah. Maybe you have M, maybe people now understand better but maybe not quite enough.
M	(Interjecting) No they don't.
MW	No - ok.
M	They don't really.
MW	What about - where's your favourite place? Anywhere. Not just in school. Where would be your favourite place, the place you felt you could just be you, however you wanted to be? (Long pause) Do you think you're yourself at school, or do you have to be somebody else?
M	No, I'm myself at school.
MW	Yeah, so do you feel comfortable at school - here?
M	Yeah.
MW	Did you feel comfortable in your old school?
M	Yeah, I was still myself. Why would I has to put an act on, it wouldn't really work, can't get rid of it. Can't get rid of it for a few seconds, cos if I could, then what's the point? I don't have it then, if I could get rid of it, then I'm just acting.
MW	Yeah.
M	If I could act like someone else, completely different, without it, then that means I don't have it really don't it. I'd just be putting an act on the whole time.
MW	But some people do that you know. It's not a good thing to do but they do do it.
M	What (sounding amazed)?

MW	They put an act on - lots of people. People who've got problems, people who pretend that they haven't got problems. A lot of people, because they think they need to behave in a certain way - grown ups as well - to fit in.
M	Mmm.
MW	It's a bit silly sometimes isn't it? So, you don't think you act differently - in a different place? Would you act differently at home?
M	Mmm, a bit more childish? I'm a bit more grown up here - I don't know. Pretty much the same.
MW	Yeah. So you don't ever feel you have to 'act normal'? Which is what somebody said - um, because I have worked with some other pupils in Year 7, not in this school, who um have autism. And one of them said to me, that sometimes - a lot of the time, she tries to 'act normal', and I just thought that was a really interesting thing to say.
M	(Long pause). (Quiet tone). Where does she go? That girl?
MW	So, she's in a - a, um, a big you know, mainstream secondary school, but in that school, they've got a special sort of base. So sometimes they're out in the lessons and sometimes they work in the base, which is - it's a bigger room than this - it's probably about the same size as your classroom actually.
M (30:00)	Mmm.
MW	But I think sometimes because they're in a school where they're working with loads - in much bigger classrooms, they - (M interrupting).
M	I don't think it still puts the same, even like, all all all schools have got their own little base now where problems kids can go in mainstream schools and all that. But I don't think it really works.
MW	Why?
M	Because there's loads of children and also they don't really understand still. They pretend they do.
MW	The teachers?
M	But they don't. They have been trained, got to get trained to work in this school. They have been trained so they're be still mean to you.
MW	so, the teachers in this school are better because they've had more training, is that what you're saying?
M	Yeah.
MW	And it means that they understand you more, and so they do different things - and those different things are what?
M	When's it almost lunch (suddenly distracted)?
MW	Well, I don't know, what time is lunch?
M	I don't know.
MW	That clock - (M interrupting)
M	Can I go back to class now?
MW	Yes, just a second, I've nearly finished.
M	That clock, it says nearly half past eleven. Do you know what the time is really?
MW	No.

M	It's nearly half past twelve (laughing). So that clock is an hour out isn't it? Yeah.
MW	So is there anything you want to tell me that you want to add that you think maybe we haven't covered already?
M	Mmm, (long pause). Naah.
MW	Because it's really useful for me to find out - because you're older, and you're here, and you can think about your last school, and see differences, it's just really really helpful. Because it will help me to help other teachers in the future be better at understanding people like you, and ther people as well. (Interruption while someone picked something up from office). Yes, so I'm very grateful M, that's what I'm saying, I'm really grateful because without finding out from people like you, I wouldn't know how to help other teachers, so what you're doing is really so important. So, I am grateful. So, I'm hoping that at some point I'm going to be able to relax (indicating frog picture) and do that lying down, but before I can do that, I've got to think about writing a book that can then help these other teachers.
M	Hmm.
MW	Is there anything on here that you want to add on here - anything about you that you think we haven't got? Things you like, things you don't like? Have we got them all? What's your favourite subject? Because you said you don't like - well it was PE in your last school, what is it here?
M	Well science, I like going on school trips.
MW	Have you got one coming up?
M	No, I've had two this term.
MW	This term? Where have you been?
M	I, I - science museum, I've been to the theatre.
MW	Oooh, you lucky thing.
M	I go to loads of school trips in this school, which is also better.
MW	That's really nice isn't it? You're very lucky. And I'm sure you will do some next term but you've only got I think a week left at school until the Easter holidays haven't you? (M nodding) Yeah, well I hope you have a lovely lovely Easter holiday. I might see you again, I might not, who knows (M interrupting).
M	This is our last day until we break up.
MW	(Sounding amazed) Today?
M	Yeah.
MW	Really?
M	Yeah. We're breaking up today. This is my last day; we've got two weeks off, and an inset day so we've got an extra day than normal schools.
MW	You are very lucky. So, when I'm busy typing and writing, think of me while you're having a lovely time playing. You know those pictures up there (indicating pictures on wall in office)? I've just realised that - can you see on the desk over there, where the calendar is, it's the same - it's not quite the same, but it must be the same artist. They're lovely - I do like them.
	[End of recording 34:14]

Appendix 18 M Interview 4

M 4	
Name	**Comment**
MW	So, these are all that we worked on together with you and with the other school. I wrote it all up and I - looked at everything that you said, and I think it goes into three themes (getting out pieces of paper to share). So one of those themes is all about the importance of relationships. So if you have a good relationship with your friends it's nice isn't it. If your friends are against you it's not nice. If you have a good relationship with your teacher it works well (M agreeing), and if it doesn't - (trailing off).
M	Well it - doesn't work well.
MW	Its, its - I know you had some really difficult times didn't you in your primary school because they didn't really work with your relationship. So that was one, and then we've got all of this (indicating post-it notes stuck on) which I'm just going to put on the floor, but these are all little bits (pointing to sub-headings and post-its). That one there is about your friends and your relationships, and this one here is about your relationship with the teacher and the school and another one is this (getting out the next piece of paper with a new theme). These all kind of fit together. So these are 'actions and reactions to concepts of normality and difference'. What this means is for example, you know when you did something, which the school didn't like and then they gave you a detention, and then you wanted payback - do you remember that?
M	Yeah.
MW	That's what this means - this is actions and reactions. And do you remember me saying that some of the other pupils felt they had to act normal, so not be who they really were, but pretend to be somebody else, do you remember that? (M agreeing), and you said you didn't do that did you (M agreeing). So that's the other one, and then the last one is this one here - understanding. So, understanding yourself, understanding other people, and other people understanding you (M agreeing). So, those are the three main themes, and then all of this kind of (indicating post-it notes) - I have to write about as well. So, are you happy with those?
M	(Long pause) Yeah.
MW	Do you - do you think I've missed anything really important - in everything that we've said that is maybe not a theme?
M	No.
MW	Ok. Let me just check (looking at page of questions to follow up). Do you know how old you were when you had your diagnosis?
M	No.
MW	No - ok. And you know you talked about your one-to-one in your last school, I know you don't have one now, you don't need one here, can you tell me what they did with you?
M	Helped me?
MW	In what way?
M	Like they were - nice to me, like they were always with me with work. It's a bit like easier and life, and all that lot.

MW	But they weren't with you at playtime and lunchtime though were they?
M	(Considering) Well they were outside on the playground. But - they weren't like keeping an eye on me, they were just outside looking after kids like - sometimes, so sometimes you'd be out - although - like say because you was my one-to-one, if I wanted any help, it's just my choice and I chose that. I wouldn't normally go to another teacher, but if I needed help and she was out there at the time, I would probably choose her to go and talk to about the problems.
MW (3:59)	Oh ok so there were other adults outside, but you chose her because she knew you better?
M	Yeah.
MW	That's a really good idea isn't it - I hadn't thought of that. And then in class, she stayed with you in the class did she? (M agreeing) All of the time, or just in the morning?
M	No - all of the time.
MW	All of the time. Ok. And she helped you with your work. Yup?
M	Yeah.
MW	Umm, and if you had to talk to yourself - if you could see yourself in your primary school now, what would you tell yourself?
M	(Looking confused) So, like - I don't know.
MW	What advice would you give to maybe other children who have autism?
M	Umm, don't be naughty maybe. Like what I did, and just - I think they should make a primary school just like this really because it's sometimes easier.
MW	What makes it easier here then?
M	Well because I wouldn't know what I would say to them what advice; because I would say 'don't be naughty, don't kick off', but then you can't help yourself. It does make life easier really. Instead of them let - letting you go in the trash or whatever, like - (trailing off).
MW	Yeah, so - so you felt you were naughty, but did you feel like it was ok being naughty because they weren't fair to you?
M	Yeah.
MW	Yeah, but then it made - (M interrupting)
M	It's a little bit hard to not to be naughty because - that's just - (trailing off). I don't know.
MW	And then that made your life difficult didn't it because you had lots of detentions?
M	Yeah.
MW	And then you wanted to be more naughty because you were probably cross weren't you?
M (6.00)	Yeah, I wanted to be more naughty because as I said to you - pay back time for doing that - to me. So then they'd be angry about the payback time and then the end of the day, it just goes on and on.
MW	I wonder why this doesn't happen here - what's the difference then?

M	I don't know, it just - it's just more - like the first ever thing to start detention and me getting angries was not letting stuff really get in my way when it actually helps me, like blu-tac. That would help me in lessons, but they didn't listen, whereas this school - I've got it right now (indicating what she was rolling out on the table as talking). So, it's really easy and I'm not kicking off over it.
MW	Yeah, so do you think if your - you know you said this school is better and if your primary school could be like this school it would be better, is that because people listen to you?
M	What?
MW	Is it because people listen to you? Is that what makes it better?
M	Well yeah - make life better. And I know there's more like kids that are like me and also they all understand, all the - all the adults - all there aware. But in my old school they don't - they don't really understand what I'm like and why this has happened. They would, like if they just noticed a girl being really naughty you'd probably think 'she's being really naughty - that's an un-nice girl - being really naughty over there'. And even if you tell them, they don't understand - what that girl is actually got, and in this school they do. I don't even has to tell them - I got problems. They all know - I've got something wrong with me.
MW	And do you think you have got something wrong with you or do you think you're just different?
M	Yeah - I'm just different.
MW	You're different. Because have you heard the word 'disability'?
M	Yeah (slightly hesitant).
MW	So sometimes you might say that is you or I broke our legs or something we would have to be in a wheelchair, we would be disabled wouldn't we because we wouldn't be able to walk. It wouldn't be forever but for a bit of a time. Do you think you are disabled by your autism or not?
M	Umm, if my autism was worser - I could be disabled, and my autism is pretty good, so I'm not in a wheelchair or anything am I?
MW	No. And do you think there are things that you can't do because of your autism?
M	No not really. No, I'm pretty much just like a normal kid.
MW	Yeah, so when you say you've got problems, do you think everybody has problems?
M	Most people in this school probably.
MW	Yeah, but even people in your other school, in your primary school - do you think they've got problems as well?
M	I think the whole world has got problems. I feel like - I feel there are so many kids now with problems - different problems.
MW	Yeah, so I think, I think everyone probably has problems don't they? (M agreeing) So is there anything else that you want me to write about, to add that you think I might not have put in? I won't go through all of these bits of paper, unless you want me to - do you?
M	No.
MW	There's quite a lot of writing isn't there. It's a lot about anxiety and I expect you probably feel less anxious here don't you?

M	Yeah
MW	Ok - so I think that's probably it then M.
M	So shall I go back to class?
MW	You can do - just press stop.
	[End of recording 9:31]