What is autism really?

The multiple realities of autism in practice

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Dedication

I dedicate this thesis to my parents; my mother, who inspired me to enter the field of education in the first place and gave me the confidence to speak up, stick to my guns, assert myself when I needed to, demand respect, and stay true to my values; my father, who made me believe that whatever decisions I make or risks I take I will always be supported, protected and loved; my friends, who support me, distract me, laugh and cry with me; and my brother and best friend, who ensures, that no matter what I achieve, I can never take myself too seriously; and finally, to the children who have inspired and enhanced my life. The greatest of those thanks has to go to Alan and his family who first started me on my career in autism and whose family I have the pleasure of continuing to call my friends.

Abstract

This thesis aims to examine how we can involve autistics in research, policy making and as active participants in decisions which impact their lives. It will consider the reality of the condition of autism and how this is presented through a range of facets: medically, academically, and educationally; specifically focusing on the diametric portrayal of autism as beatified gods and a demonised disability. It will also use the teachings of Gert Biesta (2008) to review the role of special education, compared to mainstream education and consider the similarities and differences in the purpose of education between these two settings. The epistemic injustices which are committed against autistics will be reviewed, why this occurs and the impact of this injustice upon the autistics and knowledge itself. In order to combat the looping effect of autism it is argued that a case study approach mitigates the epistemic injustice committed against autistics . These representations of autism are presented to an autistic adult himself who, whilst being autistic, is also the father to two autistic sons and works with young people with autism. In a unique approach, the autistic subject is positioned as an expert of their own condition and use their insights, my own professional observations as an active practitioner and a head teacher of two special needs schools; the impact of the perceptions of autism will be considered and the ways in which knowledge on autism is disseminated and how this impacts on the lives of the autistics themselves.

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Introduction

In recent years, there has been a dramatic increase in the rate of autism diagnosis in the population; in 1967 only 4 to 6 per 10,000 people were diagnosed with autism (Lotter, 1967; Baron-Cohen, Scott, Allison & Williams, 2009) compared to 1 in 110 today (Centers for Disease Control, 2009; Brugha, Cooper, McManus & Purdon 2012; Leonard, Dixon, Whitehouse & Bourke, 2010) which means that autism is considerably more common than Down's Syndrome (Walsh and Hurley, 2013). The escalation in prevalence has meant a surge in public and professional interest in autism as well as an increase in research into the biological basis of this inscrutable condition (Walsh and Hurley, 2013). Due to the highly complex and diverse nature of autism, its exact causes remain elusive (Toth and King, 2008; Chakrabarti, Dudbridge, Kent & Wheelwright, 2009) and professionals struggle to reach definitive agreement on strategies which effectively support autistics (Francis, 2005; McConnell, 2005; Odom, 2003). This situation is particularly acute in educational settings, where there are difficulties in agreements of what interventions are useful in improving the outcomes for young people with special needs (Francis, 2005).

Unlike many special needs practitioners who enter the field due to personal experiences (Sands, 2017), I did not. Until recently, I did not have any personal experience of disability or special needs and initially became a teacher as a stepping stone to becoming an educational psychologist. However, I quickly realised that I loved teaching and the direct contact with the young people, which I would not have as an educational psychologist, and so decided to pursue a career in teaching. In September 2010 I embarked on the journey of my teaching career, a proud student on the Graduate Teacher Programme, at that time, a prestigious teacher training programme where you learnt on the job, but more importantly for me – received a salary whilst training! By chance and fortune I had been placed in an outstanding special needs school for my main placement and thus began a love and interest in special needs. I felt both comfortable and challenged as a special needs teacher, with just the right degree of determination, strength, empathy and challenge that is needed. I struggled in my second placement at a mainstream school and was pleased when due to a bizarre winter of heavy snow my second placement was cut short and I was free to return to the safety net of special needs. I enjoyed the freedom that being a special needs teacher gave me; the norm was for lessons to be creative and led by the children's moods and interests and this matched my own ethos of what teaching should be (as written in a credulous essay for my qualified teacher status).

I first began working solely with young people with autism, at a specialist resource unit (SRP) for young people with autism within a mainstream setting. The SRPs were established in Manchester in 2011 in mainstream high schools for students with autistic spectrum conditions and speech and language disorders. The provisions had 27 places across six primary schools and 28 places across three secondary schools. The students were assessed at a panel, involving teachers, Special Educational Needs Coordinators (SENCOs) and professionals, in order to determine whether they should be placed at special school, SRP or mainstream with support; the parents and students did not attend but their views were taken into account.

The SRP's aims were to improve the quality of education for pupils with social, emotional and/or behavioural difficulties by providing a greater scope for inclusion in mainstream settings. The idea was that this would create an environment where mutual respect and self-esteem was developed and valued in both students and their peer groups. It would be mutually beneficial to all students in school by having the SRPs as a part of the school.

At this point in my career I thought that this approach would benefit the autistics; that integrating with normal-cognitively developed children, they would develop their own skills through osmosis. I also felt that there would be an increased attitude of inclusion and reduced incidents of bullying; to give the scheme some credit, this was the case and the young people with autism were accepted and encouraged to interact with their peers. However, to my surprise, this did not have a positive impact on the autistics themselves; they simply were not interested in interacting with their peers, due to their impairments in social communication. It was this first interaction which caused a disruption to me – why are we adopting this approach, in the best interest of the autistics, when the autistics have no interest in it themselves? Has anyone asked the autistics what kind of education they would like?

However, despite these disruptions beginning to form in my mind, in my arrogance as a practitioner and researcher I felt that I had greater insight than just your average teacher (at this point not considering that I should be considering the autistics insight, not the professionals). I minimally engaged with autistics to gauge their views but ultimately adopted my own agenda as I felt that one of the key ways to support young people with developing their social skills would be to improve their communication skills and therefore made a strong investment into speech and language therapy. At this point in my career I thought that autistics' impairments in social interaction was based on the fact that they did not know how to interact. During this time I observed normal cognitively developed young people attempting to interact with autistics; over time, and through genuine consultation with autistics, my view changed that it is not that they do not *know* how to interact but that they do not *want* to interact.

My next role was as deputy head teacher of an independent residential special needs school; the young people, due to the nature of the school, were far more challenging in a number of ways; most were non-verbal with associated challenging behaviour due to their communication impairments. These young people were what would be described as 'severely autistic' and would never be in a position to live an independent life due to their low cognitive ability and challenging behaviour. Working in this setting further confirmed my view that developing social skills is not a key priority for young people who have such significant impairments which prevent them from living independently; as well as not appearing to concern the autistics themselves.

The main barrier for these young people was environmental. They struggled with transitions, physically moving from classroom to dining room, the shift between lessons – from English to mathematics, changes in temperature, lighting, the weather, staffing. The most successful way I could support the young people with these transitions was by providing them with support for their sensory needs through deep pressure massage, music or visual stimulation.

I still continued to employ speech and language therapists but I enhanced the therapeutic package by also employing an occupational therapist who wrote sensory integration plans which stipulated how to support the young people's sensory needs. The plans would state what type of proprioceptors benefit the young people; for example, for some young people a back and forth swing would stimulate and a spinning motion would calm but for others it would be the opposite.

This had an immediate positive impact on supporting the young people to access the complex world in which they lived; they were able to complete transitions and this meant that they were able to access a wider range of environments and experiences. The impact of occupational therapy was immediate and, although the slow, necessary progress which speech and language therapy bestows, meeting their sensory needs was rapid and instantaneous.

During my time as deputy head teacher my knowledge of autism developed exponentially; as the school was residential, I saw the young people in a range of settings and saw how profoundly different they could be. It was also during this time that I was confronted with some of the political issues surrounding autism. One such issue is the medical model for disabilities being applied to autism; the medical model of disability is a model by which illness or disability is the result of a physical condition, is intrinsic to the individual (it is part of that individual's own body), may reduce the individual's quality of life, and causes clear disadvantages to the individual. As a result, curing or managing illness or disability revolves around identifying the illness or disability, understanding it and learning to control and alter its course (Miller, Vandome & McBrewster 2010). But the medical model doesn’t work very well for diversity issues; such as viewing homosexuality as an illness in the 1950’s where people were ‘treated’ for the condition before homosexuals gathered a voice and the gay rights movement was successful.

An alternative way of viewing disability and autism is through the social model; where disability is what happens when needs are not met by an environment. The idea behind the social model of disability stemmed from the Fundamental Principles of Disability document first published in the mid-1970s, which argued that we were not disabled by our impairments but by the disabling barriers we faced in society (UPIAS, 1976), for example, needing the use of a wheelchair is only disabling when there is no lift and you need to get to reach a second floor. Or in the case of autistics, they have impairments (speech, transitions, and sensory needs) but, in the right environment, they are not disabled by them. If an autistic is in a well-designed environment and their needs are met then they will be able to function far more effectively.

Viewing autism in this way, as opposed to treating the condition with speech and language therapy and social stories (a tool used to help people with autism develop greater social understanding), changed my outlook and put the onus of success upon me, the non-autistic. It was my responsibility to change the environment, not the people; in fact I saw it as my obligation to create a successful environment whilst celebrating the people.

In January 2016 I was approached to set up my own special needs school from scratch; to write the education plan, policies, curriculum, staffing structure all from inception. This would finally provide me with the unique opportunity to build a school which was in line with my philosophies and ideologies of what special education should look like.

My curriculum was personalised to every individual child with them each following a completely bespoke programme of study which met their individual needs. I employed staff who held the same beliefs as I did – that autism in itself is not a barrier to learning, it is the difficulties associated with autism, such as inflexibility of thought, communication impairments etcetera, which are the real barrier. Autism did not hold Steve Jobs back; his autistic attention to detail and love for organisation created the most successful company in the world (Elgan, 2015). I therefore recruited staff whose educational ideologies and ethical orientation were closely in line with my own – that young people with autism will achieve without making excuses for their 'disability'. The school's policies all referenced individuals, the behaviour plans were bespoke, interventions were personalised and pupil-centred. But once again, reflecting back, I had missed a key element; contemplating on why I was still dissatisfied I considered whether the pressures from Ofsted, the Trust whom I worked for, the Governors, parents etcetera, all meant that I adopted policies and practices which best met a compromise of their views and opinions, rather than the vital opinion of the autistics themselves. Whilst I was *considering* the autistic I was not *consulting* the autistic, so ultimately committing *epistemic injustice* against them.

It was during this time, under the increased scrutiny and pressure of opening a brand new school, that I was often finding there was a discrepancy between my ideology for the young people and the school and the Trust's vision. The Trust I worked for predominantly had mainstream schools (mine was the only special school) and it was clear that our objectives were very different. To address this question I explored the work of philosopher of education Gert Biesta, specifically his characterisation of the three dimensions that illustrate a good education – *qualification*, *socialisation* and *subjectification* (Biesta, 2008). I questioned whether these dimensions of a good education were equally important, and whether they all still have a role in special education or whether some facets actually are less important at a special school. A special education is, by the very definition, the education which does not fit the general population, can we therefore apply a general purpose of education, to every young person, in every setting?

I found working within a local authority meant that you were contending with an increased number of stakeholders and so returned back to the independent sector where there is more autonomy for schools to design a bespoke curriculum and provision. I had the opportunity to became the Executive Head Teacher of two residential special needs schools for young people with autism. The company for who I work employs 5,000 staff in 300 services and has a UK turnover of 12.6bn per annum. The lead school is registered for 34 young people, at full capacity the school will be staffed with: the head teacher (myself), a deputy head teacher, three assistant head teachers (with teaching responsibilities), three teachers, 45 teaching assistants, a speech and language therapist, an occupational therapist, an educational psychologist (one day a week), a clinical psychiatrist (one day a week), a play therapist, an art therapist and a music therapist. All of the young people are staffed at least 1:1 with many needing two members of staff at all time to support them due to the level of challenging behaviour.

Approximately a quarter of the school's student population is either pre or non-verbal, with no spoken communication and nearly all of the young people present with significant challenging behaviour requiring physical restraints to support them to manage their behaviour. All of the staff in the school are trained in Team Teach, which promotes de-escalation strategies as well as teaching appropriate restraints to respond to behaviours that challenge.

It was during this time that I saw an autistic speaker at a conference called 'Jamie + Lion'; Jamie is a developer, writer, public speaker and mountain biker who lives in London. He works for the BBC as a senior accessibility making BBC products usable by the whole audience. Lion is a 4 foot long plushie who goes everywhere with Jamie. One of the key concepts which Jamie discusses, and one which hugely resonated with me, is that 'Autism professionals serve autistic people. For the few that I work with, I am not their client, I am their boss.' (Jamie + Lion, 2018). As an autism professional it is my role and my huge responsibility to advocate for the young people who I work for. Finally, I had realised the solution to the disruption which I had been facing all my career – I work for the young people in my school and care. I improve *their* world, not *my* world which I want them to fit into. I work to *their* priorities and *their* needs, not my own; whilst I am inevitably a mediator between alternative visions the objective is to reach a shared way of living. And in order to do this effectively I needed to consult with the autistics to actually understand what their priorities are.

This became an outlook I adopted as a headteacher and practitioner working with young people with autism and, through my direct work with autistics, opens possibilities for action research. Action research in the classroom opens the possibility to accommodating a practitioner perspective where practice based expertise provides alternative analytical opportunities in a series of inter-related areas of knowledge and practice: the ways children learn, how to communicate their understanding to pupils, the relationships to promote better motivation and attainment, the environments which support the young people and the communities which surround them (Baumfield, Hall & Wall, 2008). The professional work of teaching does not have a single unifying theory, nor one dominant form of practice (Simon, 1999), as opposed to researchers and academics it is based on experiences, policy directives and inspection criteria alongside personal beliefs about 'good practice' and the meaning and purpose of teaching as a career (Day et al., 2006).

Through this disturbance, I had turned to research to see whether I could find any answers in academia but autism has a long history of 'bad science' (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004; Chahrour and Zoghbi, 2007; Frazier, Youngstrom, Speer & Embacher 2012, Mandy, Charman & Skuse 2012). For example, autism's initial discovery described it as a psychological condition resulting from poor parenting (Dyches et al., 2004) but since then the discovery that autism has a genetic basis has invalidated this theory. Yet, there are still many misconceptions and pseudoscientific ideas surrounding autism which are sometimes fuelled by poor science communication in the media (Ozonoff, 2012; Frazier et al, 2012; Leonard et al, 2010; Murray, 2006).

The age of the internet has facilitated unprecedented access to a wealth of information about a variety of medical conditions and disabilities. People consequently have the potential to inform themselves on numerous subjects previously accessible only to academics and experts and much of the knowledge about autism is generated and conveyed through popular means, and these significantly determine how people perceive autism (Murray, 2006; Treffert, 2009). Much of the information available is unfiltered and pseudo-scientific, consisting of speculation, anecdotes and conjecture (Singh, Hallmayer & Illes 2007). This is certainly the case in relation to autism. For instance, many websites promote the now scientifically discredited idea that vaccines given to young children are responsible for causing autism (Draaisma, 2009). In the UK and United States this has led to reduced levels of vaccination and an increase in the cases of dangerous childhood diseases such as measles. This trend has been intensified by the mainstream media who have often promoted pseudoscientific ideas about the causes of autism and provided uncritical platforms for the spokespeople of the anti-vaccination movement (Murray, 2006; Treffert, 2009). The media also commonly misrepresent genuine science by exaggerating modest results for the sake of a more gripping news story (Walsh & Hurley, 2013); but equally Walsh and Hurley (2013) could also be overstating the exaggerations in order to create a more sensational article.

Despite the progress in research in autism, there is still a huge gap in the engagement between professionals and researchers and with the autistics themselves (Wakschlag & Leventhal, 1996; Gow, 2019; Chown et al., 2017). Autistics and their families are rarely engaged with or included in research; there is a popular term which states that ‘if you have met one person with autism, you have met one person with autism’ (Duffy, Oppermann, Smith & Shore 2007) but this does not appear to have been extended to research which continues to adopt a more generalised approach to strategies, rather than it be personalised to the individual or specific family circumstances (Ravindran & Myers, 2012).

There is a large amount of autism research focused on the causes of autism (Volkmar, Chawarska & Klin, 2005; Danielsson, Gillberg, Billstedt, Gillberg & Olsson, 2005; Adams, Johansen, Powell, Quig, & Rubin, 2011; Bailey, Palferman, Heavey, & Le Couteur, 1998), the genetics of autism (Folstein and Rutter, 1977; Folstein and Rosen-Sheidley, 2001; Hallmayer, Cleveland, Torres, & Phillips, 2011; Muhle, Trentacoste & Rapin 2004), the neurobiology of autism (Geschwind, 2009; Deen & Pelphrey, 2012; Fombonne, Roge, Claverie, Courty, & Fremolle, 1999) and the environmental factors which impact on autism (Schanen, 2006; Braunschweig, Duncanson, Boyce & Hansen, 2012; Heuer, Braunschweig, Ashwood, Van de Water & Campbell, 2011). There is also research into autism interventions which can help people with autism become better adjusted to their environments (Rogers and Vismara, 2008; Francis, 2005; Odom, 2003), where the general consensus appears to be that early intervention is the key. In a study by Gillespie-Lynch, Kapp, Brooks, Pickens and Schwartzman (2017) they found that autistic participants exhibited more scientifically based knowledge than others and suggested that autistic adults should be considered autism experts and involved as partners in autism research, something which is not currently taking place. There is also very little research into low-functioning young people with autism (Pellicano, Dinsmore & Charman, 2014), like the young people who I work with, due to issues with engaging with non-verbal children with limited cognitive skills. However, recent research (e.g. Gillespie-Lynch et al’s, 2017) suggests that autistics have a clearer view of all types of autism, and should be consulted upon.

My study addresses this gap in research by using action research through my own experiences as a senior leader in autism and by developing a case study methodology which highlights and analyses the views and impressions of someone who is autistic. The subject of my case study is Simon, an autistic himself, as well as a practitioner working in a professional environment supporting young people with autism and the father of two profoundly autistic sons. In positioning Simon in this way I have taken the decision to place Simon in a position of the ‘knowledge giver’ and in turn giving the autistic ‘credibility about themselves’ (Origgi & Ciranna, 2017, p303) and as an expert of his own condition.

I first met Simon when I was working as Deputy Head at an independent special needs school; at interview he came across as articulate and passionate although struggled to make eye contact and stimmed (‘stimming is any behaviour of repetitive actions, such as flapping the hands, wiggling the knees, shining a light into one's eye, and spinning in a chair, typically performed by autistic people’ (Oxford Dictionaries, 2015)) by flicking his fingers, although he placed his hands under the table to hide this for the majority of the time. At interview Simon spoke about his own autism and how he felt that he was in a position where he could understand some of the difficulties which the young people faced and therefore felt he could be an advocate for others. Simon also spoke about his children's autism and how that had impacted upon him. I initially had some reservations about employing Simon due to the fact that he obviously had an emotional connection to autism but very quickly it was apparent that I should not have had any concerns. Simon supported some of the most challenging young people in my class and could read their subtle behaviour cues extremely quickly to divert and distract from any potential issues which would lead to a crisis or behaviour incident. Simon also had extremely high aspirations for the young people and would push and challenge them to achieve, without making any excuses for their autism, which often other staff did. On the rare occasions that there would be a behaviour incident Simon would support the young people with compassion and understanding resulting in the incidents lasting shorter periods of time.

I have conducted a number of interviews with Simon where we discussed his ideas, approaches and strategies in order to get his opinions on that particular approach or theory. Simon and I both had the opportunities to revisit a topic, if necessary and, on some occasions, Simon chose to think about a topic or conduct his own research before commenting on a particular approach or strategy. I have dispersed the interviews throughout the thesis, in chapters based on the topics of our discussions, rather than in a traditional methodology approach which would not necessarily make sense in the order which we discussed things.

I received ethical approval for using Simon in a case study and Simon was happy for me to use his full name throughout the thesis and also talks about his two sons, 'A' and 'M', who both also have autism. Simon said he was happy for me to use his son's names but as they do not have the cognitive ability to consent for themselves I made the decision to refer to them by the first letter of their names. Simon and I also spoke about young people who Simon had worked with and their names have been changed to ensure anonymity and they will be referred to as 'Pupil A', for example.

I will review the current academic research which is available into the causes of autism and the interventions to support those young people with autism and present it to Simon to provide an insider's perspective of what it was like for him to grow up with autism and discuss the strategies which supported him. By adopting a case study approach, I will have in-depth access to what experiences autistic people deal with in their day-to-day life, their challenges and supports. By engaging with an autistic who has the ability to share their views, this could hopefully improve the lives of those young people who are not able, either cognitively or due to communication impairments, to share their opinions and outlooks.

Through this approach I will be positioning Simon as someone who has a valid view of his own condition; including this invaluable source of data means that we, as receivers of information, could potentially benefit from vital knowledge from the autistics as potential knowledge givers. Giving autistics the credibility of the knowledge into their own condition means that we are potentially receiving a more valid testimony and data source which could further enhance the knowledge in the field of autism and strategies which we can use to support autistics more effectively. It is key that we adopt this approach, because otherwise 'the hearer misses out on information, and the speaker misses out on the chance to express that information. In turn, anyone who may have benefitted as a result of the sharing of that knowledge also suffers a loss' (Congdon, 2017, p244).

The thesis will be arranged in the following way; the introduction examines the key challenges which I face as a professional working with young people with autism; for example, the conflict demands of too high or too low expectations. I will explore some of these key disruptions which I was facing and some of the ideas and strategies which I attempted as an effort of trying to understand these disruptions.

In the research methodology chapter I discuss how autism has been positioned within research and how this approach has meant that as researchers we have been committing epistemic injustice through not engaging with the autistics. Epistemic injustice is defined as 'a wrong which is done to someone specifically in their capacity as a knower' (Fricker, 2007, p1). In the case of the autistic they need to be positioned as experts in their own condition so that we are not therefore 'underestimate the (potentially true) testimony of a certain person' (Origgi & Ciranna, 2017, p304). The autistics testimony provides researchers with a vital data source, from the autistics themselves. In this chapter I will explain why a case study approach was chosen and why Simon, as the subject, was uniquely situated to be able to provide a unique insight into the challenges faced by autistics. Simon has experiences of being a professional in an autistic setting, a parent of autistic sons and also an autistic himself; he therefore has a range of understanding to evidence some of the key experiences which are faced in the field of autism. I will discuss with Simon some of the ideological perceptions of autism and Simon's perceptions and understanding of how autism is distorted and the impact of this.

The difficulties which professionals and researchers face when attempting to define and pinpoint exactly what autism is means that the autistics become moving targets and our interactions with the targets themselves change them through this interaction; this is what Ian Hacking (2006) defines as the looping effect of autism; which in turn contributes to the epistemic injustices where autistics are wronged in their capacities as a knower; they suffer from testimonial injustice where their credibility as experts of their own conditions is diminished; and also the hermeneutical injustice of the subsequent gap in collective knowledge, which their testimony would have provided us, which consequently puts autistics at an unfair disadvantage. This thesis addresses these injustices by arguing that adopting a case study approach, where the autistic is viewed as an expert of their own condition and as a co-researcher is key in order to combat some of the dire outcomes faced by autistics. The thesis proposes that autistics should be elevated as specialists and consulted on policy, employers should engage with their employees on how best to support them, and also an increased engagement of autistics on research for changes in policy and practice to drive forward improvements in special needs and autism settings.

The looping effect of autism is discussed in more detail in the first chapter relating to research methodology. In the second chapter I shall review how autism is situated with mainstream and special education and some of the difficulties which there are within autism education. In the third chapter I shall review the difficulties which there are in really capturing the reality of the autistic condition and the looping effect of attempting to define what autism is. In the fourth chapter I discuss the polarising perceptions of autism and present some examples of these depictions to Simon, in order to review the potential impact of these perceptions on autistics. In the penultimate chapter I shall use the work of

Gert Biesta to attempt to unpick what the purpose of autism education is and potentially what the purpose of autism education should be and whether there are similarities and differences between the purpose of mainstream education and the purpose of special education. Finally, I shall conclude by suggesting what the future of autism education should look like and ways in which autistics should be engaged with in the future to minimise the effect of the epistemic injustice committed against autistics.

Research Methodology

Case study

Recently, autism research has been criticised for not being truly representative of autistics and for not driving forward improvements on the autist condition (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013; Pellicano et al., 2014a; Kenny, Hattersley, Molins, Buckley, Povey & Nicolaidis cano, 2016). Some authors suggest that this is often because there is a huge barrier when engaging with autistics in that they often have significant communication impairments (Lord and Bailey, 2002; Wing and Atwood, 1987). However, the traditional expert knowledge of autism deriving from observations by professionals, who lack the lived experience of being autistic, is becoming less popular and there is an emerging school of thought of new researchers who favour a view that understanding and acceptance of autism might increase by listening to autistic people (Nicolaidis, 2012; Gillespie-Lynch et al, 2017). There is also growing evidence that autistic people may often have enhanced understanding of fellow autistic individuals (Komeda, 2015; Kapp et al., 2013).

A key element of this thesis is thus to demonstrate the importance of researchers including autistics within research and also in all aspects of decision making. Through this thesis I explore the experiences of one individual, who is in a unique situation to be positioned in three key ways: the institutional, the parental and the autistic. Simon has worked as a teaching assistant for young people with autism, in my last three schools, and now is a training and development manager for my school, training and supporting staff with autism strategies. Simon also has two sons who are profoundly autistic needing full-time care. Simon himself has autism and, although now an adult, gone through the education system. Through Simon's experiences I will explore some of the phenomenon around autism and how that impacts upon the professionals and thus how autism can be situated; which is in line with Sturman's (1997, p3) definition of a case study as a 'general term for the exploration of an individual, group or phenomenon'. This way, my study will address the need for research on autism that takes into account the concrete voices and life experiences of people with autism (Gillespie-Lynch et al., 2017), by deploying a *case study* methodology.

According to Simons (2009), a case study ‘is an in-depth exploration from multiple perspectives of the complexity and uniqueness of a particular project, policy, institution, program or system in a ‘real life’’ (ibid., p21). She also emphasises that a case study should not be seen as a method in and of itself. Rather, it is a design frame that may incorporate a number of methods. It can be argued, therefore that a case study is a choice about what is to be studied, as opposed to a methodology (Stake, 2005) and we can use a variety of methods to study it but always focusing on the case. This is a view which seems to have become quite prevalent in books about case studies with Merriam (1998) also agreeing, arguing that a case could be ‘a person such as a class, a school, a community, a specific policy; and so on’ (Merriam, 1998, p27). In my case it is Simon and although Simon is one individual he represents three different approaches – the institutional, the parent and the autistic. His insights are therefore shaped by all of his experiences of autism, some his own and some from working and living within the field of autism. Crowe, Cresswell, Robertson, Huby, Avery and Sheikh (2011) recommend adopting a case study approach to attempt an in-depth multi-faceted understanding of a complex issue which is appropriate for my research as there are many complexities both to autism and to Simon, as the subject.

State (1995) characterised three main types of case study: intrinsic, instrumental and collective. An intrinsic case study is typically undertaken to learn about a unique phenomenon, which distinguish it from others. In contrast the instrumental case study uses a particular case to gain a broader understanding of an issue or phenomenon and the collective case study involves studying multiple cases simultaneously or sequentially in an attempt to generate still broader appreciation of a particular issue. My study uses an instrumental case study approach as I will use Simon’s experiences and opinions to further understand autism and investigate some of the phenomena associated with people’s perceptions of autism, particularly concerning their experience within educational settings. Case studies can be used to explain, describe or explore events or phenomena which occur in an everyday context and they can then support you in identifying, understanding and explaining causal links (Yin, 2003). Through using Simon’s experiences I will identify some of the obstacles which mainstream education pose to special education and also understand where some of the misconceptions about autism have stemmed from and compare these myths to the realities of autistic people.

In contrast to experimental designs which seek to test specific hypothesis, through deliberately manipulating an environment, a case study approach means you can capture information on more explanatory ‘how’, ‘what’ and ‘why’ questions (Crowe et al, 2011), such as ‘what are the key non-truths of autism which are being promoted’, ‘how are these continuing to keep traction’ and ‘why are people continuing to believe the myths despite the truth being out there’? The case study approach can offer additional insights into what gaps exist or why one strategy has been chosen over another (Starman, 2013). For example, why are there so many un-truths about autism and why do we adopt one strategy over another.

Case studies may be approached in different ways, depending on the epistemological standpoint of the researcher. The researcher needs to decide whether to take a critical (questioning one’s own and others’ assumptions), interpretivist (trying to understand individual and shared social meanings) or a positivist approach (orientating towards the criteria of natural sciences) (Crowe at al., 2011). For my study I will be adopting a qualitative and interpretative approach where I will attempt to understand the meaning and contexts as perceived from different perspectives – of the autistic and non-autistic – to try and understand the individual and shared social meanings (Stake, 1995). A case study approach means that the actors know a lot about the topic, because they are a part of it, this manifests itself through the consequences of their actions (Giddens, 1984). There is however no perfect guarantee that actors have a perfect understanding of their context because human actions can always have unintended consequences; although it can however be difficult to explain the unintended consequences and historical contexts (Doolin, 2004).

Case study research has also sometimes been criticised for lacking scientific rigour and provides little basis for generalisation (Yin, 1995). Yet I will try and reduce those concerns by comparing and contrasting Simon’s responses to the research which is out there and comparing the findings to evidence from my own experience as a practitioner. I will also offer alternative explanations and be explicit about how my conclusions were reached so that the readers can judge the trustworthiness of the case study themselves.

I conducted four interviews with Simon in late 2015 until mid-2016, where we discussed his ideas, approaches and strategies in order to get his opinions on that particular approach or theory. Simon and I both had the opportunities to revisit a topic, if necessary and, on some occasions, Simon chose to think about a topic or conduct his own research before commenting on a particular approach or strategy or would pause to fact check his personal history with his parents or brother. I have dispersed the interviews throughout the thesis, in chapters based on the topics of our discussions, rather than in a traditional methodology approach which would not necessarily match my argumentative line. Once I had written up the interview I would send the notes to Simon so he had an opportunity to add comments, if he wished to, but he never did.

I also conducted a fifth interview in 2018; through writing the thesis, a strong theme around the polarising perceptions of autism was developing; and although I had discussed this a little with Simon, I had not asked him specifically how he felt the perception of demonised and beatified had impacted upon him as an autistic. This diametric portrayal of autism will be addressed later in the thesis where the depictions of the genius autistic and the profoundly disabled autistic will be explored.

Epistemic injustice in autism

Epistemic injustice is a concept first introduced in 2007 by British philosopher Miranda Fricker (2007). The idea of epistemic injustice wronging someone in their capacity as a knower (Fricker, 2007) involves the power relations between different groups of people, in the case of this thesis – autistics and educational practitioners. According to Fricker, there are two kinds of epistemic injustice: testimonial injustice and hermeneutical injustice which she distinguishes as:

> *'Testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word; hermeneutical injustice occurs at a prior stage, when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences'* (Fricker, 2007, p1).

Autistics are victims of both testimonial and hermeneutical injustice as they have not been included or engaged with in research and policies which directly impact upon them (Pellicano et al., 2014) despite research suggesting that autistics have greater insight into all types of autism, and should be consulted upon (Gillespie-Lynch et al., 2017). In the case of autistics we diminish their credibility by stating that they have communication impairments, so cannot adequately represent themselves; state that they have social interaction impairments, so they cannot adequately identify how their impairments impact upon themselves; but ultimately diminish their credibility and lose the potential knowledge which they hold (Lord and Bailey, 2002; Wing and Atwood, 1987).

However, there is conflicting evidence that autistic people may often have enhanced understanding of fellow autistic individuals (Komeda, 2015; Kapp et al., 2013). Therefore you can consult with a verbal autistic to provide an insight into the experiences of non-verbal autistics, who may struggle to access respond to interview questions. Not engaging with autistics and relying on the testimony of experts, diminishing the first-hand testimony of the lived experiences of the autistic reduces their credibility and is therefore testimonial injustice. The conclusions which are subsequently made, with the gap of knowledge and information from the autistics themselves is hermeneutical injustice and puts autistics at an unfair disadvantaged when it comes to them making sense of their own social experiences, which are described by people who have not lived that experience.

Moreover, it is not just the autistic who is damaged by this epistemic injustice, it is the knowledge receivers who also end up with 'less information than she would have had if she had considered the speaker at her face value instead of applying biased filters to her credibility assessment' (Origgi and Ciranna, 2017, p304). Disregarding autistics testimony does not only damage them but we are also damaging ourselves by losing that potentially valuable knowledge. The gap which is caused through the hermeneutical injustice is the enhanced knowledge of what it is actually like to be autistic and experience the world through their eyes.

It is not as simple as just positioning oneself as an expert of their own condition, so to remove the epistemic knowledge. Receivers of knowledge need to ensure that they have epistemic confidence in the knowledge which they are receiving. For the autistic themselves they probably do not have epistemic confidence in their own virtues, due to a repeated history of being epistemically undermined, as a ‘loss of epistemic confidence is likely to inhibit the development of intellectual courage’ (Fricker, 2008, p49). It is therefore the role of the researcher to instil epistemic confidence in their case study to empower them to share their knowledge.

In order to make Simon feel epistemically confident I would often provide him with the topic which we were going to discuss in advance of the interview; for example, if we were discussing the ‘causes of autism’ I would inform him of this in advance and he could complete background reading or reflect upon his own experiences, thus improving his own intellectual courage. However, it is my role as researcher to ensure that I present Simon’s words to you, the reader, in a way which ensures that *you* have the epistemic confidence in Simon’s testimony as an expert of his own condition and ultimately instil confidence in future researchers that they can and should include the testimony of autistics directly as a valid data source.

As a professional working within the field of autism, we are often positioned as the expert of the child and of the strategies which would therefore support that child. Similarly parents are often also positioned in this way as the ‘knowledge givers’ relating to the other person. Notwithstanding the importance of this knowledge, positioning the people around the autistic – the parents, the educationalists, the medical practitioners, social workers etcetera – as the experts of the condition as opposed to the autistic themselves fundamentally deprives ‘people of their credibility about themselves’ (Origgi and Ciranna, p303). As mentioned by Scrutton (2017, p1):

> *“people diagnosed with mental illnesses are often stereo-typed in such a way as to deflate their credibility, and that the authoritative and even exclusive status accorded to third-person, medical perspectives on experiences of mental illness leads to hermeneutical marginalization and silencing”.*

Autistics themselves are not positioned as experts of their own conditions and therefore we, as receivers of information, potentially end up with less information than we would have had if we engaged with autistics as potential knowledge givers. This undermining of the knowledge which autistics have and diminishing their credibility means that we are removing a potentially more valid testimony and data source which could further enhance the knowledge in the field of autism and strategies which we can use to support autistics more effectively. As mentioned by Congdon (2017), ‘The hearer misses out on information, and the speaker misses out on the chance to express that information. In turn, anyone who may have benefitted as a result of the sharing of that knowledge also suffers a loss.’ (p244).

Autism and testimonial injustice

Testimonial injustice is caused by a ‘prejudice in the economy of credibility’ (Fricker, 2007, p1) and this is seen in the way in which we are currently engaging with autistics, or not engaging as the case may be. This lack of engagement, where we are ‘unjustly downgrading one’s trustworthiness via testimonial injustice’ (Congdon, 2017, p243), is not only damaging our knowledge of autism but also the self-esteem and realisation of the autistic themselves. There are ‘two kinds of knowledge: knowledge of what the experience is like, and knowledge of what is good for the person’ (Scrutton, 2017, p1). It cannot be argued that anyone other than the autistic themselves can know what their experiences are like; we may be able to state that statistically only 32% of people with autism are in paid work (Office for National Statistics, 2018) but we cannot begin to speculate about what that experience is like for the autistic themselves. Although parents, researchers and professionals may be able to effectively argue that they have the knowledge to know best what is good for the autistic person, some research states that ‘in addition to having unique knowledge of what an experience is like, experients can also, in some cases, have insight into what is good for them’ (Scrutton, 2017, p9). Broadly speaking, medical professionals tend to be experts primarily in third-person forms of knowledge, while patients are likely to be experts primarily in first-person forms of knowledge. That said, there is no reason that the expertise of each should not come to be extended to the other form of knowledge (Carel and Kidd, 2014, p535).

One of the reasons why this epistemic injustice may have come about is that ‘virtue epistemology in the past has emphasized the kinds of virtues speakers should adopt (such as accuracy and sincerity)’ (Congdon, 2017, p244) which are often virtues which autistics will struggle to achieve due to their speech and language impairments. However, these are not the only virtues in epistemology which are key, it is also 'virtues applying to hearers (e.g., critical openness, humility)' (Congdon, 2017, p244) which are also critical. I believe it is the 'virtues applying to hearers' which are currently lacking in research. We need to be critically open to receiving information from a wider range of data sources and showing humility and self-effacement when dealing with autistics, who may have limited education, learning disabilities or mental health conditions, but are still viewed as the expert into their own condition.

In some cases we are engaging with autistics in research but still committing 'testimonial injustice, which occurs when a hearer downgrades a speaker's credibility on the basis of an unfair identity prejudice' (Congdon, 2017, p244). In this case the autistic is engaged with but their testimony is not seen as important or valid as the professional. In the case of this thesis, I have had to support Simon's testimony with that of experts or research in order to validate his statements. But is this necessary? Why is Simon's testimony, as an autistic, not seen as expert testimony; positioning him as an expert of his own condition? What is it about our social positioning of autism which undermines their own authentication.

This does not only damage the potential knowledge which we are missing out on by diminishing the testimony of the autistics but we are also adopting:

> '*a morally untoward stance towards the speaker that reflects a morally deficient character. As Fricker stresses, the root of testimonial injustice lies in an unjust bias that has become second nature, such that the hearer is affectively and culpably resistant to counterevidence'* (Congdon, 2017, p246).

As researchers and professionals we are, incorrectly, assuming the position of authority of a condition which, by definition, we cannot truly access the reality of. The only way that we can access the real of the condition is to engage with those people who live and exist within it and experience it. To not engage in this, or see a value in approaching research in this way, is detrimental to the autistics we state we wish to improve the outcomes for.

There are a number of ways which we could engage with autistics, first as an "informant" where they are seen as a competent informant who can provide a convincing testimony to enhance the argument which is being presented. The second way is seeing the testimony as a “source of information” where they can provide ‘an observable feature of others’ experienced environment from whom information may be gleaned through perception and inference’ (Congdon, 2017, p247). In the case of this thesis I will be presenting the argument that adopting a case study approach where, in this case, I will view Simon, as both an “informant” and a “source of information”, mitigates epistemic injustice. Simon is in the unique position of being able to be positioned in both ways as he is autistic himself and can therefore provide a testimony of his own experiences; and can also discuss his experiences of working with, and being a parent of, autistics, providing a unique ‘insider’ perspective. I am not relying on experts but an autistic who has real lived experiences, positioning them as someone able to express a pertinent view of their own condition.

Through this engagement I will ensure that Simon has the intelligent confidence in his own testimony thus improving his epistemic confidence. It is important that active attempts to engage with autistic are made as ‘one’s self- worth is developed and upheld through acts of recognition, understood as expressive acts through which individuals and institutions convey acknowledgment of the worth or normative standing of others’ (Congdon, 2017, p248). Due to the already poor outcomes for autistics, relating to self-esteem and confidence and engagement with the neuro-typical world, it is therefore imperative that research is not further damaging ‘one’s self-worth’ due a lack of engagement from researchers and professionals as there are ‘many harms that unjust forms of silencing, ignorance, and false belief generate’ (Congdon, 2017, p243).

Simon as an expert of his own condition

In the case of my thesis I have positioned Simon as an expert of his own condition, and drawn comparisons from Simon’s individual experiences to highlight some of the key issues which autistics may face. As part of that portrayal , however, there is the danger that I have afforded Simon testimonial injustice as ‘many key cases critically involve thick relations of intimacy between acquaintances, and the maltreatment involves a rupture of, or disloyalty within, those thick relationships’ (Kidd, Medina & Pohlhaus, 2017, p35). In order to eradicate this potential testimonial injustice, both Simon and I reflected upon our relationship and the potential imbalance of that relationship and Simon was given the opportunity to clarify, change or elaborate on any of his testimony. Kidd, Medina and Pohlhaus (2017, p37) stated that ‘in intimate relationships forged by thick relations of trust, parties seek each other’s approval, often including recognition of their opinions on matters arising in the course of their interactions’ and through doing this both parties are afforded the recognition of their opinions, as in the case with Simon’s testimony within this thesis.

In a later chapter of the thesis I will be discussing, in more detail, Ian Hacking’s theory of the ‘Looping Effect’ which argues that ‘our investigations interact with the targets themselves, and change them’ (Hacking, 2006, p. 2). By changing the way that we are interacting with autistics we can actually change the way in which they view themselves. In the case of Simon and affording him the status of a professional with the specialist authority to comment of autistic experiences I have shown him that his opinions are valuable and they have an impact upon policies and other autistics lives. Simon is now responsible for the training of a large number of people and influences the long-term focus and development of my education provisions. The elevation of Simon has meant that his previous negative experiences of education have been minimised and the impact of his traumatic past reduced; ultimately, his true value has been recognised and legitimised.

Why can the reality of autism never be truly captured?

Since the late 1960s there has been a substantial growth in the prevalence of autism research, with a remarkable number of new findings published over the past two decades (Thompson, 2013). For many years after the publication of Kanner's 1943 paper, 'infantile autism' was considered to be a very rare disorder affecting fewer than 5 in 10,000 individuals (Lotter, 1966). There was relatively low interest in autism at this time and Kanner's paper was only referenced 34 times between 1943 and 1954; whereas, it was referenced nearly 140 times in 2009 alone (Amaral, 2011). Recent estimates of the prevalence of autism suggest that nearly one in 100 children have autism (Rice, 2009; Baron-Cohen, 2009) which has increased the pressure for professionals to support young people more effectively and for more intensive research. This call for research has most definitely been heard and acted upon as a survey of PubMed citations using the search terms autism and autistic shows that the single year 1990, there were 213 papers published. In 2000 this grew to 441 and in 2009 this had more than tripled with 1,522 papers published on this topic (Amaral, 2011). There are over 85,000 articles in Manchester Metropolitan University's online library, including over 18,000 dissertations; there are also over 13,000 books written on autism which you can purchase on Amazon. The volume of writing and research into autism therefore means that it is likely that you are able to find at least one article to support any interpretation of autism.

Although autism has existed through history it is usually classed as a contemporary condition (Chauhan, Chauhan & Brown 2010, p114) which has become increasingly popular over the past 20 years or so and this is evidenced in the large amount of research and the increase of autism being portrayed in TV, film and books. We have seen a considerable proliferation of autism stereotypes - so much so that one may pause to think whether it is still useful to talk of stereotypes at all (Draaisma, 2009). Autistic people are not only featured as characters in novels and movies, as the subject of biographies or autobiographies, but they are also being used as exemplars in marital guidance books and attempts being made to diagnose historical figures, including attempts to even diagnose Adolf Hitler (Osteen, 2009, p12).

There does not only appear to be an increase in the number of people being diagnosed but it seems as though the spectrum itself has entered into all aspects of life. Autism appears to have become a fashionable feature that people should aspire towards, as opposed to a condition which impairs an individual. In an editorial, Frances Allen (2011), chair of the DSM-IV Task Force and professor emeritus of psychiatry at Duke University School of Medicine, stated that:

> '*The most likely cause of the autism epidemic is that autism has become fashionable — a popular fad diagnosis. Once rare and unmistakable, the term is now used loosely to describe people who do not really satisfy the narrow criteria intended for it by DSM IV. Autism now casts a wide net, catching much milder problems that previously went undiagnosed altogether or were given other labels. Autism is no longer seen as an extremely disabling condition, and many creative and normally eccentric people have discovered their inner autistic self*.'

This quote provides an interesting insight into the terms which professionals are using when engaging with autism. To refer to autism as 'fashionable' and a 'fad' suggests that it is a condition which exists in the here and now and not a condition which spans time and space. A fad is defined as '*an intense and widely shared enthusiasm for something, especially one that is short-lived*' (Oxford Dictionaries, 2015), which is an interesting definition for a doctor to apply to a medical condition. The reference which Allen made to people discovering 'their inner autistic self' was also revealing as it positions itself as something which should be aspired to, as though people should be able to tap into their inner autistic self, as one would tap into their inner child.

Although advances were made medically in autism it took until the 1960s for autism to be featured in the national media; in 1961 Helen Allison spoke on BBC's Women's Hour about how autism affected her son Joe, and in 1962 there was the first newspaper article about autism in London's The Evening News called 'Children in chains'. The article was written as a charity appeal and stated; 'It is easy to feel pity for the child physically crippled… Can't we feel pity too for the baby whose mind is locked?'(quoted in Waltz, 2013, p13). This is very different to the way autism and disabilities are presented by the media today and many people would be quick to condemn someone with autism being described along with someone who was physically disabled or describing autistic minds as 'locked'. The 2015 NAS campaign states that 'We want a world where all people living with autism get to lead the life they choose', there is no mention of needing pity or describing autism as a disability (The National Autistic Society, 2015).

The purpose of this chapter is to review some of the perceptions of autism, in comparison to the reality of the condition. The first section will discuss how the perception of autism has changed over time and some of the key events which caused a shift in perceptions. The second section will discuss why autism has proved so elusive to define and position. The third section will discuss the ideology of autism and how our reality of autism is being presented; it will also consider what distortions are present, leading into a discussion about how autism is positioned within capitalism.

The changing perception of autism

The definition of autism and the labels associated with the condition have changed considerably over time (Draiisma, 2009). These changes have been seen within the medical profession and the changing diagnostic criteria for autism; in turn impacting upon professionals' perceptions and the presentation of autism in the media. This section aims to explore some of those changing perceptions over time.

Throughout time there have been some changes in the understanding of autism. For example, in 1964 the prevalent opinion was that autistic children were mentally retarded whereas, today a common discourse is that autistics are secretly highly intelligent (Frith, 2008). In 1971 the Journal for Autism and Childhood Schizophrenia was first published and at that time autism was claimed to be extremely rare (Wing and Potter, 2002) but by the early 1990s Asperger's syndrome had become a familiar label and was soon mixed up with the older stereotypes of genius as being attributed to those autistics who have high intelligence (Baron-Cohen et al, 2001). It was also during this time that another idea took off, that men in particular have autistic features, namely that they lack social sensitivity and have obsessive interests (Baron-Cohen et al, 2001). As well as the definitions of autism changing through time there were also differing definitions depending upon country (Kim, 2012), society (Grinker, 2007) and gender (Baron-Cohen et al, 2001). This increase tends to be attributed to adjusted understandings of autism in Western societies (Newschaffer, Croen, Daniels, Giarelli, Grether, Levy & Windham, 2011; Fombonne, 2003) but the different facets of autism reflect its different social implications intertwined with cultural expectations and assumptions within a given society (Kim, 2012), country, county and economical structure (Spitzer et al, 2007).

Autism and epilepsy have been linked since Kanner's first paper in 1943. Around 40% of young people with autism also suffer from epilepsy (Gabis, Pomeroy & Andriola, 2005). Historically the ancient Egyptians called epilepsy 'the sacred disease' believing that it gave people special powers (Nunn, 1996) and the Bible states that epilepsy was a sign of a demonic possession (Gabis, et al., 2005, p652). Egyptians viewed disability from an alternative position compared to today; presenting with a disability was a sign of royal blood as many of the Egyptian royals had disabilities due to inbreeding. For example, King Tutankhamun was profoundly disabled apparently due to his parents being brother and sister (Than, 2010). These early representations of disability being a blessing could be the start of what was to come with autism being presented in two polarising ways, that of demonic or sacred. This dichotomising presentation of autism is a recurring feature of how autism is depicted and is discussed further, later on in the thesis.

In 1988 media focus on autism was heightened with the release of the film 'Rain Man' and the success and popularity of the film has heavily impacted on general perceptions of autism. The fame of the film meant that the general public suddenly had an awareness of what autism was and the discourse which surrounded it. In 1988 autism had only been featured in the DSM for eight years and there was still little medical research and information on autism. The portrayal of autism in 'Rain Man' romanticised autism but for the majority of people it was the only thing they could base their discourses on, as it was the only representation available to them. Despite there being a large number of autistic people now being represented in film, TV and books, Rain Man remains a prolific depiction of autism (Chilton, 2018).

Another major depiction of autism in the arts was seen in 2002 when Mark Haddon released the book 'The curious incident of a dog in the night-time', which presented a far less romantic portrayal of autism. The book was about a 15-year-old boy with Asperger

Syndrome, described as "a mathematician with some behavioural difficulties", and presented some of the related difficulties which are associated with autism. The book was a huge success and the popularity of the book resulted in it being adapted as a stage show in 2012. Interestingly, its title was a quote from the fictional detective Sherlock Holmes in Arthur Conan Doyle's 1892 short story "Silver Blaze". Sherlock Holmes is often cited as another fictional representation of autism although Conan Doyle never confirmed or denied this (Freeman-Loftis, 2014).

Autism seems to be a concept which many understand and recognise. Whenever I tell people that I work with young people with autism they always tell me: ‘My next door neighbour has autism’ or ‘I was in the supermarket last week and there was a little boy there with autism’ to demonstrate that they have a knowledge of autism. Or they tell me about somebody that they think has autism and then proceed to describe their symptoms; for example, my mother will often say to me, ‘You won’t believe what your dad did when we were at our friends for dinner last night, do you think he’s autistic?’

Disabilities, including autism, are a social construct (Grinker, 2007) and culture outlines what people define as abnormal or normal and therefore different cultures view disabilities differently. In the Western world we place great emphasis on socialisation and effective communication skills, with the belief that both are a necessary part of personal and professional lives (Watanabe-Crockett, 2016). Autism is more pronounced in Western Societies; the prevalence in USA is 168 to 10,000 people (Baio, 2014) and in France the prevalence is 67 per 10,000 people (Autisme Grande Cause, 2012) compared to 10.3 per 10,000 in Asia (Xiang, 2010) and 18 per 10,000 people in Saudi Arabia (Senecky, Chodick, Diamond, Lobel, Drachman & Inbar, 2010). Studies have shown that developed countries (such as USA, England, Ireland and France) have the highest rates of autism (Dittmann, 2012); this will be due to superior health care and knowledge around autism but could it also be the case that autism is more prevalent in these countries because there is a higher expectation to communicate and therefore a speech and language disorder will be more pronounced (Martin, 2014).

As well as the increased expectation on communication and socialisation in Western societies there is also a preference towards capitalism. This also impacts upon the way disability is viewed, compared to a more socialist society. This therefore means that within the Western World, where there is such an emphasis placed on production and profitability, disability has often come to mean ‘unable to work’ (Finkelstein, 1991, p29).

However, the discourse of positioning autism as being special is still dominant and young people with autism are often considered as savants or as being ‘awesome’ (Dobson, 2015). It could be argued that this is just a modern version of the Egyptians’ thoughts around a ‘sacred disease’ believing that people have special powers. This same discourse can still be seen today, in 2008 Gary McKinnon hacked into US military computers to search for proof of UFOs, and due to his autism diagnosis he was held in high esteem. The USA government branded him a ‘terrorist’ but the Telegraph described him as having a ‘precocious talent’ (The Telegraph, 2009). In Waltz’s 2013 book she states that at around the end of the seventeenth and start of the eighteenth century, before the ‘Age of Enlightenment’, the symptoms, which are now associated with autism, were mainly linked to folklore and religious beliefs. Following the ‘Age of Enlightenment’ autism was mainly viewed medically but some of the previous thoughts of autism remained.

The looping effect of autism

Ian Hacking provides a unique presentation of the way in which we categorise mental disorders and one of the key theories he presents is the idea of ‘making up’ kinds of people (Hacking, 1999, p121). Autism and many other disorders and disabilities are instances of what he calls interactive kinds (Hacking, 2006, p13). For example, the term relating to attention deficit hyperactivity disorder (ADHD) has become larger than the term itself and has actually become a way to be a person, a way of behaving, a mode of experiencing the self, and a style of living in society (Hacking, 2006, p. 13). He writes:

> ‘*Interactive kinds involve ‘looping effects’: We think of these kinds of people as given, as definite classes defined by definite properties … But … they are moving targets because our investigations interact with the targets themselves, and change them … That is the looping effect. Sometimes our sciences create kinds of people that in a certain sense did not exist before. That is making up people’* (Hacking, 2006, p. 2).

Hacking (1999) mainly applies this theory to psychiatric disorders such as schizophrenias and states that these disorders have both indifferent kind and interactive kind characteristics. For example, being labelled as schizophrenic affects those who receive the diagnosis. They are aware of the perceptions and responses to themselves in society. They are aware of what services they need to access and the impact of not being able to access those services. They interact with teachers and medical professionals; react to the questions put to them about their condition, and may change their self-perceptions as a result. What count as key symptoms of the disease shift over time. The classification is a 'moving target'.

Hacking does not feel that this can be directly applied to autism. He dislikes discussing the 'reality' of the disorders on which he focuses, yet accepts that autism is 'almost certainly some combination of neurological, biological, and genetic abnormality' (Hacking, 2006, p8). However, he does argue that the term 'high functioning autism' is something that has been made up – it has become a way of being a person, a way of experiencing and of being in society.

I am not going to debate whether autism is a 'moving target', the aspect of Hacking's theory which is relevant to this thesis is the 'looping effect'; that 'because our investigations interact with the targets themselves, and change them' (Hacking, 2006, p. 2). For this thesis, the key methodological approach is engaging with autistics, to determine their views on the interventions and issues which impact upon them. It is through our interactions with autistics that we can ensure they are empowered, decision-makers of their own futures, and ultimately change the landscape of outcomes for autistics.

Autism: impossible to define?

As discussed in the previous section, autism has struggled to be positioned medically and therefore the perception of autism to professionals and the media has remained elusive. This section aims to explore some of the reasons why autism remains a condition which is so difficult to attach labels to.

Historically views of autism were defined by researchers and medical professionals; however, it appears today as though the representation of autism is led by one of the most influential 20th century creations – the media; and indeed Snyder and Mitchell (2005) stated that ‘Americans learn perspectives on disability from books and films more than from policies or personal interactions’ (p9). In Murray’s 2008 book he discusses the culture of autism and argues that the depictions of autism in the media and the condition itself are highly artificial (Murray, 2008, p4). The media leading the representation of autism and particularly the portrayal of the autistic savant with special talents or special abilities has contributed to a harmful divergence between the general image of autism and the clinical reality of the autistic condition and the struggles and challenges associated with this (Draaisma, 2009). Murray (2008) goes beyond this to argue that the majority of analysis follows stories, accounts and versions that create an idea of autism rather than reflect one; and these narratives of autism are not to understand autism but is actually a complex desire of a society that wishes to be fascinated with a topic that seems precisely to elude comprehension (Murray, 2008, p4).

There are ever changing definitions of autism; I presented some of these definitions to Simon in our first interview and he found it easier to describe what it looks like, rather than what it is, but even then grappled with the concept and stated that it was ‘wide ranging’ and on a ‘huge scale’ (Greenwood, 2015, Interview 1). He eventually concluded that the ‘most apparent one’s a lack of eye contact. A slightly unusual behaviour from the norm. It’s hard to describe really. A sense that something’s different in a person’ (Greenwood, 2015, Interview 1). This is interesting as here is a person who works every day with autistics, has autistic sons and is himself autistic and, similarly to the difficulties faced by academics he also cannot define definitively what autism is. Simon went on to elaborate that this difficulty in defining autism is because it ‘manifests itself in so many different ways’ (Greenwood, 2015, Interview 1). However, Simon conceded that ‘there’s a definitive and I think eye contact is the first definite but there is many ways it manifests’ (Greenwood, 2015, Interview 1). Many researchers would agree with Simon as atypical eye contact is certainly a common trait in autism (Senju and Johnson, 2009; Mundy and Newell, 2007; Kylliainen, Wallace, Coutanche, Leppanen, Cusack & Bailey, 2012). But once again it is not consistent as some autistics actually have excellent eye contact (Spezio et al, 2007) and this therefore makes me wonder whether there actually are traits which are definitively seen in all autistics or whether we just struggle to work in the abstract and always want to work within a definite answer or definition even though this is not quite applicable with autism. There is no common framework to work within, for example, 30% of individuals with autism have seizures but the remainder do not; many have gastrointestinal problems although others do not; some have any enlargement of the nucleus but a small amygdala whereas others have an enlargement of the amygdala (Buie et al, 2010).

Linguistics has also not helped clear the muddy waters of autism as the word ‘autism’ has meant different things through time and this is described well by Laurence Arnold (2009), an adult with autism who states that:

> ‘*Autism is a word, with a history and connotations. It is a semiotic pointer and what it signifies is governed not by any natural laws, but by the rules of communication theory, whereby the originator of the message may not be completely understood by the receiver because of a variety of cultural, neurological, environmental and simply accidental and incidental interference.*’ (Arnold, 2009, p99-100).

The process of attaching meaning and definitions throughout time has been met with much controversy and debate and there is still no agreement for causation or definitive good strategies that will support those with autism (Jick and Kaye, 2003).

The reality of autism is that it is a complex disorder of impairments but today it has far wider meaning. For example, the term ‘being autistic’ in popular culture now applies to someone who is behaving in a socially awkward manner. In 2006 George Osborne suggested that Gordon Brown could be ‘faintly autistic’ in relation to making a point about Brown needing to develop relationships with his back benchers (BBC News, 2006). In complete contradiction to the diagnostic features of autism an article in 2015 suggested that Jeremy Clarkson may be autistic, stating that ‘the reflection upon his behaviour and perceived reputation may be indicative of something further, perhaps even an autism spectrum disorder’ (Borrows, 2015). The article then goes on to detail why Clarkson may be autistic:

> ‘*his highly advanced communication skills (no one can deny he is an exceptional broadcaster) and obsession with mechanical detail, alongside the inability to adhere to social norms and the impulsive desire to say inappropriate things at inappropriate*

> *times suggests that a case could be made to argue that he suffers from a mild form of Aspergers Syndrome'* (p21).

This contradiction of the reality of autism was published on The Telegraph's webpage and was shared 754 times and the article was commented on 676 times. Only one comment related to the suggestion that Clarkson was autistic, where the reader commented that it was 'an attempt at character assassination' to imply that Clarkson was autistic. There were no comments related to the misrepresentation of autism.

As well as academics, researchers and scientists questioning the distortion of autism, parents are also probing the truth of, what is presented as, science. For example, Paul Offit's, a parent of an autistic child, writes in his book 'Autism False Prophets' (2008), calling for all autism information to be fact checked. His book offers in detail a number of quotations from politicians and celebrities and evidence which is apparently backed up by some physicians to support a link between autism and vaccinations; for example a relatively recent genetic analysis research (Morrow et al, 2008) reports that some genes in children with autism are in the off position, waiting to be reactivated by therapies. This paints a scary outlook where there could be the introduction of potentially dangerous therapies, sold to desperate parents, with no evidence supporting the efficacy.

Offit's book (2008) highlights the frightening manner in which the media appears to have a distinct lack of interest in reporting and promoting the truth, coupled with the public's distrust of science which Offit argues has contributed and created a volatile mix of lies and controversy. There are, still today, many examples where politicians and celebrities continue to fan the flames of sensationalising panic and controversy. A quick google search for 'Autism and Daily Mail' (one of the UK's most widely read newspapers) showed a top hit for an article entitled 'Do NOT rush into a second pregnancy: Study warns autism risk is 50% higher for couples who conceive within two years of giving birth' (De Gaff, 2017).

Autism as a controversial condition is also seen presented in the mass media; in March 2016 the Daily Mail ran an article about a mother who was criticising store staff for not being supportive of her 3-year-old autistic daughter during a 2-hour crisis which involved her daughter screaming and crying. All of the comments criticised the mother for not dealing with her child more effectively and some comments were even written by parents of autistic children who claimed she was giving autism a bad name. One of the most liked comments on the online article stated:

> '*Uh, if your child is having a meltdown scream fest in a store, you need to leave the premises. You need to take the kid to a park or somewhere in nature, confiscate digital devices, and stop hiding behind excuses of 21st century preventable syndromes'* (Linning, 2016).

This commenter makes a link between autism and technology, therefore implying that autism is a 21st century creation which could be prevented. This quote provides an interesting insight into the general perception of autism, a condition which is modern and linked to technology and if someone with autism is finding something challenging then they could be 'cured' by taking a quick trip to the park. This also shows an old view of disability that people with disabilities can exist but not seen or impact upon anyone else as they should 'leave the premises'.

It could also be argued that the comment is judging someone's parenting skills as autism, being a disability, is a social construct (Liachowitz, 2010) and, within the Western world, we would judge someone as being a good parent if they take their child to the park and interacted with them (Banin, 2017), rather than letting them just play on a computer. Therefore, is the commenter saying if parents took their child to the park, and more 'effectively' parented would the child not have autism? A very similar criticism of the psychiatric interpretations which led to the promotion of the 'refrigerator mother' hypothesis which proposed that mothers were essentially to blame for the autism in their children by their failure to nurture them adequately (Jack, 2014).

Dominant representations of autism appear to be led mainly by the media, and due to a lack of agreement into what autism is, are free to present autism in whichever way they wish (Huws and Jones, 2010). However, 'autism is a word, with history and connotations' (Arnold, 2009, p99) and over time the word 'autism' has come to mean so much more, often used as a term to mean someone socially awkward (Borrows, 2015). As well as being misrepresented, autism continues to be plagued by a range of falsities – caused by the MMR vaccine (Burgess et al., 2006), therapy that can reignite 'off genes' (Morrow et al, 2008) or that it is caused by poor parenting (Jack, 2014).

It is these labels which link back to Hacking’s theories of the looping effects of labelling. It can be argued that continuing to label people as “autist” exacerbates the idea of social awkwardness associated with the condition, ensuring that autistics will be awkward and uncomfortable in social situations. Against the background of the potential negative effects of labelling autistics it could be questioned whether the term ‘autism’ has any place in education or medicine any more. There are so many untruths and negative connotations which are muddying the waters of understanding to such an extent that they are having significant negative impacts on the autistics themselves. However, the alternative, of parents not seeking a diagnosis of autism for their child means that the non-diagnosed autistic is refused access to vital services including speech and language therapy, to improve communication; occupational therapy, to limit the impact of sensory processing conditions; play and art therapy, to develop social interaction; and child and adolescent mental health services, to support with co-morbid autism conditions such as, depression, problems with food, self-harm, schizophrenia and anxiety, to name a few. Equally, for schools the lack of a diagnosis would mean no access to funds for teaching assistants and additional support. In many cases, it is a catch-22, the diagnosis of autism can cause social anxiety but without the diagnosis you cannot easily access the support for these negative bi-products of autism.

Conclusion

The ideologies surrounding autism have changed over time; when autism was first discussed by Kanner in 1943 it was positioned as a profound disability, however, this key discourse of disability was reduced over time and was replaced by the discourse of beatification; where autistics are revered and aspired to. This perception was further embedded with the release of Rain Man in 1988 and remains one of the key depictions of autism which people cite (Chilton, 2018), even 30 years later.

Despite the high level of research and promotion around autism it has remained a condition which has been difficult to define. This space, created by a lack of clarity, has meant that much of our understandings around autism are led by the media (Snyder and Mitchell, 2005). The media further embeds the perception of the autistic savant, loving sensationalised stories and examples of amazing acts (Murray, 2008).

The changing definitions have been heavily influenced by developments medically and prolific depictions in the media but defining autism seems to be missing the consultation of one key group – the autistics themselves. As Hacking states that ‘our investigations interact with the targets themselves, and change them’ (Hacking, 2006, p. 2) it is surely even more important that how we are choosing to define groups of people is in a way which is making a change for the better.

Labelling and categorising people means that you are not addressing the individuals but the stereotypes associated with that group. The looping effect (Hacking, 2006) exacerbates the epistemic injustice associated with labelling; however, adopting a case study approach mitigates against the negative effects of this and should be adopted at all levels, whether it is consulting with autistics on policy, employers engaging with their employees on how best to support them, or an increased engagement of autistics on research.

Situating autism and education

The autistic condition and the impasses of research and medicine

Autism is a condition surrounded by controversy and debate, and is still an ever changing condition, with new diagnostic criterions still being developed in new editions of the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013). It can be argued that this ever changing definition of autism causes the looping effect of autism, exacerbating the epistemic injustice against autistics. This section gives a brief overview of autism over time, in order to understand how the autism debate has developed, caused the looping effect of autism, exacerbating the epistemic injustice of autism and how this has impacted upon me as a professional. I have always worked in environments dedicated to supporting young people with autism and, as discussed in the first chapter, often changed my position and understanding of autism within that environment. The research detailed in this chapter demonstrates some of the influences which have allowed me to encapsulate what I understand as autism.

Since the late 1960s the growth of autism research discoveries has been exponential, with a remarkable number of new findings published over the past two decades (Thompson, 2013). Despite the high number of research papers there are still vastly different opinions on what causes of autism and therefore there are shifting definitions of autism which have been included in the Diagnostic and Statistical Manual of Mental Disorders, the taxonomic and diagnostic tool published by the American Psychiatric Association (APA, 2013). For example, there are arguments for autism being caused by environmental factors, such as exposure to drugs (Cha, 2015), particularly the drug thalidomide (Stromland et al, 1994). Moreover, there has been research indicating that exposure to the measles-mumps-rubella vaccine might induce autism (Burgess, Burgess and Leask, 2006). The rubella virus (Chess, 1977), traumatic pregnancy (Jick & Kaye, 2003), or genetics (Wright, 2015), have also been indicated as potential causes for the development of autism. Recently it has even been suggested that obesity in pregnancy could cause autism (Dobson, 2015). Diet became a popular issue following publication of a famous article alleging a link between enterogastric toxins arising from eating foods containing gluten and autism (Wakefield et al., 1998). These reports continue to impact upon me as a professional with parents requesting gluten free diets or a ketogenic diet plan as they believe this will reduce the negative traits of autism.

The biological causes of autism have also been greatly researched and one such finding is that brain growth in children with autism occurs differently than in non-autistic children (Carper and Courchesne, 2005) and that the amygdala reaches an adult size earlier in children with autism than typically developing controls (Munson et al, 2006). Yet when post-mortem studies of brains from older individuals with autism have been carried out it has been found that there are significantly fewer neurons than in the brains of people without autism but it has yet to be concluded whether there are fewer neurons in the amygdala from birth or whether a neurodegenerative process takes place in autism (Schumann and Amaral, 2006).

There is also some evidence that one or both parents of children with autism could also be on the autistic spectrum (Szczaluba, 2014). If this is correct, communication problems in the family may involve members other than the affected child. There is strong evidence to suggest a genetic link as studies looking at identical twins have found that when one twin has the condition, in the vast majority of cases, so does the other (Rosenberg et. al, 2009). However, the question of whether this is to do with their genetics or because they have both been raised by the same parents and therefore subjected to the same external factors is still yet to be answered. Equally the looping effect of autism could also be impacting on young people, who’s parents own experiences shape and change their own children. And whilst there is much research into the genetic factors of autism, and, whilst a specific gene has yet to be identified, studies have shown that younger siblings of children with autism have a 5-20% chance of also developing the condition (Earlstein, 2017). But despite the several decades of twin and family studies and the strong evidence to suggest a link it has still not been definitively proven that there is a link to genetics and autism (Bailey et al, 2005; Ritvo et al, 1985). No single gene or even a section of genome coding has been identified, which suggests that autism may emerge from many different causes. As with the myth that autism was caused by the MMR vaccine, there has recently been re-emergence of the concept that autism may have an immunological component as some individuals with autism have abnormalities or deficits of their immune systems (Ashwood and Van de Water, 2004) and children with autism are more likely to contract regular infections (Stern et al, 2005). The author's suggestion that there are genetic consistencies within autistics would be consistent with my practical experiences; within my schools there would often be autistic siblings and some of the parents who I interact with have autistic traits. For example, parents often have difficulty communicating which further exacerbates the condition as it makes it more challenging to set targets or share progress with the family. In some cases, similar to that of Simon, parents have received their own diagnosis later on in life.

Several different theories have been investigated – including single gene mutations and chromosomal abnormalities – but not one of them alone can explain the large number of autism cases. This proves difficult as you can find evidence for individual cases where autism has been attributed to a link with a bacterial or viral infection but not enough to explain all autism cases. There are also cases where autism has been caused by a folic acid deficiency, gestational diabetes, prenatal stress, low birth rate, hypoxia during childbirth, exposure to air pollution, vaccinations, diets, lead poisoning, and this list is not conclusive (Earlstein, 2017, 470).

It appears that current research suggests that both genetics (Wright, 2015), biological (Carper and Courchesne, 2005) and environmental aspects (Stromland et al, 1994) play a role. The genetic factors predominate and a multiplicity of causes does seem the more plausible explanation therefore causing all the different types and manifestations of autism (Geggel, 2016). Early development has often been cited as being key in the diagnosis of; and Frances Tustin, a post-Freudian psychoanalyst pioneered a developmental approach, conceiving the existence of a preverbal stage in early childhood in which abnormal development would be a key flag for autism (Tustin, 1972) which is similar to Kanner's primitive infantile autism (Kanner, 1943). This also contributes to why early intervention is such a widely accepted strategy for supporting young people with autism (Montesorri, 2006). As discussed previously, I see many similar traits between parents and young people; interestingly, some of the young people who attend my schools have been adopted or long-term fostered; and I would argue that there are still autistic traits in those non-biological parents of the young people, despite there been no genetic links. This would support an argument that environmental aspects contribute to the manifestations of autism.

I first began my teaching career in 2009, when the MMR theory was still instigating debate and controversy despite being disproven nearly five years before (Chen et al., 2004). In 2015, my second year as a deputy head teacher, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders was published (Ozonoff, 2012) removing Asperger's as a condition (I will however, continue to refer to Asperger's throughout the thesis for those individuals who did receive a diagnosis of Asperger's prior to 2015). Consequently, I joined the field of autism when my appreciation of autism existed in a state of flux of understanding; one day working with young people with Asperger's and the next day the condition not being recognised by many. This has hugely impacted upon my practice and has made me quite laissez-faire and apathetic to the popularly understood causes of autism.

There is very little research into the opinions of non-verbal young people and what their experiences are and what their understanding is of autism as most of the research concerns the parents of children with a disability and is usually small-scale and qualitative (Scie, 2008). This under-representation of non-verbal autistics is also seen in the depiction of autistics in narrative fiction. A study by Kelley et al (2017) found that few fictional stories depict the difficulties of social communication and often overplays the restrictive, repetitive behaviors and underplays the social communication deficits which perpetuates misconceptions about autism. Narrative fiction with main characters clearly shows ASD symptoms have large implications for professionals working with students with ASD. I also struggle with this in my work setting. When teaching we use a range of alternative augmentative communication (AAC) which encompasses the communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language. We provide the young people with technology which can talk for them, objects of reference, for example a 'plate' can be given to express hunger; we use picture exchange communication (PECs) where they would give a picture of food to express hunger; we teach the young people signs. Whilst these strategies are appropriate and support teaching and learning and I can provide the young people with the necessary language for topics; an issue is that I, as the teacher, choose what signs I teach or pictures I provide. By doing this I effectively choose what topics a young person can communicate within. However, it is therefore practically impossible to ask an open question as it is unfeasible to provide someone with every potential way in which they could respond.

As previously explored, the investigations and way in which we interact with people impacts and changes the target (Hacking, 2006). Assuming that someone with autism will have communication impairments means that communication could be simplified and ultimately exacerbating the condition. The impact of non-autistics undermining the autistics understanding we are impacting upon their ability to communicate and share their opinions and views and we are ultimately committing hermeneutical injustice by the gap in knowledge which is opening up between the autistic and the non-autistic.

One of the difficulties with defining autism is that it is a developmental disorder but the trajectory of autism has barely been studied due to the fact that it is still a relatively new disorder and is therefore difficult to draw some conclusions without longitudinal studies although it is widely accepted that outcomes for autistic people leave a lot to be desired (The National Audit Office, 2009). The level of investment into genetics and autism has left many people feeling uncomfortable and begs the question of what will happen if, or when, we identify the genetics of autism? Will people be given the option to have chorionic villus sampling to check if the baby has the genetic condition and therefore give pregnant women the opportunity to abort their autistic babies? And if so, it would be safe to assume that abortions would follow a similar number of cases to Down’s syndrome abortion cases where ninety per cent of people in the UK who know their child will be born with Down's syndrome have an abortion (Gee, 2016).

Some steps have been taken to eradicate the false reports and controversy. For example, British doctor Andrew Wakefield was struck off the medical register for unethical behaviour and fraud, after his report, which was published in The Lancet, which purported to show a link between the MMR vaccine and autism in children was found to be fraudulent and was discredited (Boseley, 2010, Paul, 2009). Despite this, discrediting Wakefield had little impact on the perceived validity of his study and in 2015 Italy proposed a law against vaccinations because of links to autism (Forster, 2017). The steps taken to try and eradicate the false science of autism has therefore had little impact on the general view, so much so that the World Health Organisation has warned that major measles outbreaks are spreading across Europe resulting in dozens of hospitalisations and deaths because of a lack of vaccinating.

Situating autism within mainstream education

As discussed in the previous section, autistics have struggled, and still continue to struggle, with being positioned both medically and in research. This is also the case educationally; the majority of autistics are educated in a mainstream setting but many teachers state that they do not believe that they have the skills to educate a young person with autism (The National Autistic Society, 2015). Whilst there is evidence that not including people in research is making them 'distinctively wronged in their capacity as knowers' (Origgi and Ciranna, 2017, p303) this argument could be extended within education; not only to autistics but children generally. In universities student satisfaction surveys are conducted (Llorent-Bedmar and Palma, 2019) but this is not the case in mainstream or special education. Very rarely are students views sought about the quality of education they receive and never about what their curriculum should include. I argue that not only should autistics be consulted in research but they should also be consulted within education also. This could be challenging within a mainstream education setting but where young people are receiving a special education, outside the mainstream, then this approach is key to providing the bespoke curriculum for the individual.

Mainstream education is the education which everyone and anyone can access and in contrast, as the name suggests, special education is the education that is offered to individual students (Slavin, 1986). One of the fundamental purposes of mainstream education programmes is to prepare students for further studies in a major by developing a broad knowledge base (Cuevas, Matveev & Miller 2010) with assessment and proving of educational outcomes becoming more and more important (Yang, 2012). This is, by definition, in contrast for young people with special educational needs as they need to be compared as individuals and cannot be standardised. Mainstream education and special education should therefore be different, by definition. This has been an ongoing issue for me in positioning my school, especially when working within a trust which also had mainstream schools, as they were consistently attempting to standardise my special needs young people in the same way as the mainstream students. For example, expecting them to wear blazers, despite their sensory impairments; and expecting them to call the teachers 'sir' and 'miss' despite their communication impairments. This removal of standardisation leaves special schools, and especially independent special schools, the freedom to bespoke their curriculum and educational offer. How schools do this differs but will always involve an element of consultation with stakeholders; whether that be staff, senior leaders, governors, parents or the local authority, but it is very rarely with the children themselves. Whilst both mainstream and special education are both guilty of not consulting enough with young people (Save the Children Child Participation Working Group, 2003), this lack of consultation is causing epistemic injustice as we are undermining children's own 'capacity as a knower' (Fricker, 2007, p1). This is immediately causing a testimonial injustice which young people have a sense of deflated credibility but then over time we ultimately are causing a hermeneutical injustice where we are marred by the lack of knowledge which their testimony would have been able to provide.

At the root of our British education system is a drive for a 'new public management' (Priestland, 2013). According to this view, the best way to ensure that schools drive forward high standards is for them to copy and learn from a business model. A new school of thought argues that old centralised systems were driven by the 'producer', for example, the teachers, academics, schools and universities, and that there is a need for the power to be held by a management team who will have the 'consumers' interests at heart, for example, the parents, students or taxpayer (Brant and Panjwani, 2015). These reports supposedly allow countries to judge which country has the best education systems in place and therefore inform educational policy reform. Another output of this initiative was the introduction of league tables with all schools and universities being measured and compared, against children's test results or student's satisfaction surveys; all a way to capture the quality of education and quantify it. With the belief that the higher up the table you are, the higher the quality. Those schools who are not performing highly, according to whichever league they are being measured within, are blamed and shamed (Tomlinson 1997; Granger 2008). The extent of the measured difference from normal is arbitrary but is assumed to have an objective reality (Dorn, Fuchs & Fuchs 1996). Similarly, a student's academic aptitude is assumed to be a measurable outcome but some researchers call into question the validity of objectively measuring a young person's aptitude and learning (Hoffman, 1975; Smith, 1998).

The political, educational world in which I work is designed to benefit as many young people as possible and is often focused on standardisation (Biesta, 2009). This recent tendency to focus on measurements and comparisons of outcomes proves difficult with young people with special needs whose outcomes may not be academic. Biesta (2009) argues that the equality of opportunity hardly ever translates into the equality of outcomes because the rate of structural factors is beyond the control of schools and teachers. When making decisions about education we are always and necessarily engaged in value judgements – for example, what is educationally desirable? And who is deciding what is educationally desirable? These judgements which are applied to the masses often exclude those young people who are already excluded from mainstream education, the looping effect exacerbating this, further isolating young people with special needs from mainstream education and that looping effect intensifying the epistemic injustice.

Biesta (2015) argues that many educational practices are based upon ideas about what it means to be human. Education is the teaching of this; how to behave in a desirably human manner and supports the development of such identities as the rational person, the autonomous individual, or the democratic citizen (Biesta, 2015). However, Biesta argues that education could be reformed if, instead of deciding what a desirable human is *before* educating someone, we develop our understanding of a desirable human *during* engagement in education. This would be in line with critical hermeneutics, where education is seen largely as a transformative process, which is mainly concerned with the 'emancipation' of the student from the ideological structures which bind his or her action (Gallagher, 1992). News and the media are reported in a particular way to shape the opinions of the people involved, often not representing minorities and the marginalised (Huws and Jones, 2010). This means that people are stuck in a way of thinking which is not necessarily beneficial to the majority of people involved. This is a further example of the looping effect of autism, impacting upon the autistics themselves and ultimately changing the way in which they see themselves; this in turn aggravating the epistemic injustices.

Paulo Freire believed that education is a political act that could not be divorced from pedagogy. Freire defined this as a main tenet of critical pedagogy. Teachers and students must be made aware of the ‘politics’ that surround education. The way students are taught and what they are taught serves a political agenda. Teachers, themselves, have political notions they bring into the classroom (Kincheloe, 2008). Freire even goes as far as to attack what he called the ‘banking’ concept of education, in which the student was viewed as an empty account to be filled by the teacher. He notes that ‘it transforms students into receiving objects. It attempts to control thinking and action, leads men and women to adjust to the world, and inhibits their creative power’ (Freire, 2004, p77). Biesta (2015, p41) states that instead of viewing students as empty vessels to be filled we should view them as ‘unique individuals through responsible responses to what and who is other and different’. However, to follow this approach is difficult as there is a constant emphasis on output and attainment from the Government which has meant that there is little time to place emphasis on developing a 'love of learning' or the skill of learning for learning’s sake.

Situating autism within special education

Biesta (2015) also identifies a further problem with humanist education insofar as it posits a ‘*norm of humaneness’*, a norm of what it means to be human, and in doing so excludes those who do not live up to or are unable to live up to this norm’ (p6). This can be a difficulty within mainstream education for those young people who cannot meet the targets by which mainstream education is measured. This would certainly be the case for autistics who struggle with social interaction and communication, both widely accepted necessities of humaneness. Einstein was believed to have written that ‘Everybody is a genius but if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid’ (Kelly, 2015). It therefore seems unprincipled and illogical to measure autistics by the same outcomes as normally cognitively developed peers.

In order to understand why special education is measured by the same outcomes as mainstream it is important to understand the development of our special educational needs system in the UK. In 1944 a young person with a special need had no legal rights to an education and it was therefore dependent upon where you lived and whether there was provision for special needs in that area. The Education Act in 1944 was the first time that Local Education Authorities (LEAs) were given the responsibility for ensuring ‘that provision was made for 'pupils who suffer from any disability of mind or body' (Education Act 1944, p3); and that boarding accommodation was offered where appropriate’.

Prior to the 1944 Act, the education of any child with a disability was treated as an entirely separate category of provision. Following the Act special educational provision was to be included in LEAs' development plans for primary and secondary education. It stated that the ‘less seriously handicapped’ might be catered for in ordinary schools, while those with more serious disabilities would, wherever practicable, continue to be educated in special schools. The Act dictated very specifically which schools young people should go to, depending upon their disability. The Handicapped Pupils and School Health Service Regulations 1945 defined eleven categories of pupils: blind, partially sighted, deaf, partially deaf, delicate, diabetic, educationally subnormal, epileptic, maladjusted, physically handicapped and those with speech defects. Blind, deaf, epileptic, physically handicapped and aphasic children were considered seriously disabled and were to be educated in special schools. Children with other disabilities might attend ordinary schools if adequate provision for them was available (Gillard, 2011). As there was no defined category for autism at this time it is likely that young people with autism would have been classified as either epileptic, due to the high number of young people who also suffer from epilepsy (Gabis, Pomeroy & Andriola, 2005) or as aphasic as aphasia is a condition that affects the brain and leads to problems using language correctly, which could also present similarly to autism in some cases. Therefore, it is likely that in 1944 a young person with autism, regardless of their cognitive ability would have been placed in a special school; this is in contrast to today where the majority of young people with autism are educated in a mainstream setting (The National Autistic Society, 2015) and it is estimated that one in every 128 mainstream students is on the autistic spectrum (Barnard, Broach, Potter & Prior, 2002).

There was also a key change in approaches during this time with the importance of early diagnosis, assessment and an early start to education being recognised (Warnock, 1978). Young people with special educational needs were described as ‘educationally sub-normal (ESN) pupils’ and although the numbers of children in special schools had nearly doubled between 1947 and 1955 (from 12,060 to 22,639) there were still 12,000 children out of education, awaiting placements (Warnock, 1978).

The Education Reform Act (1988) was the most important education act since 1944. It is sometimes referred to as 'The Baker Act' after secretary of state Kenneth Baker. The Act was presented as giving power to the schools but in reality it took power away from the LEAs and the schools and gave all the power to the secretary of state (Gillard, 2011). A further big change was that, after ten years of trying, Margaret Thatcher and the

Conservative Government took education from being a public service and turned it into a marketable commodity. There were lots of changes proposed in this Act and made very little reference directly to special needs; however, some of the changes had great impact. For example, The National Curriculum resulted from this Act and was written by the Government, with teachers having virtually no say in its design or construction. This therefore meant that the curriculum which was being delivered in a selective grammar school was, in theory, identical to the curriculum being delivered at a special school (HMI, 1985). There was also the introduction of standardised testing which meant that schools became unwilling to take on pupils with learning difficulties as this would impact upon the school's overall test results (Gillard, 2011).

The 1993 Education Act was the largest piece of legislation in the history of education in the UK. It covered five key parts but importantly its third section focused on young people with special educational needs. It stated a legal definition and a Code of Practice on the Identification and Assessment of Special Educational Needs, which came into force in 1994. This was the first Education Act to directly impact upon special needs since 1981, showing that although there had been lots of changes to education in general, there had been little focus on young people with special needs.

The 2006 Education and Inspections Act stated that schools encouraged schools to 'tailor education around the needs of each individual child, so that no child falls behind and no child is held back from achieving their potential' (Secretary of State for Education and Employment, 2005, p5). This meant that it was no longer acceptable for teachers to say that they could not accommodate a young person in their class but they would have to make the necessary adjustments to ensure that all young people had the opportunity to achieve. This was an important change, as when many adults with disabilities have reflected upon their experiences of schooling they have mainly recalled the low expectations of teachers, which inhibited their achievements and perpetuated negative images of them as individuals (Noble, 2003; Toola, 2003).

In 2008 the profile of autism was dramatically increased when World Autism Awareness Day was unanimously agreed by the United Nations General Assembly. In 2009 the Autism Act was passed and became the first ever disability-specific law in the UK. The Autism Act (2009) stated that:

> *'The Secretary of State must prepare and publish a document setting out a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts'.*

The most recent influential act on special education was the Children and Families Act 2014. This act aimed to identify young people with special needs earlier, ensure that staff who work with young people with special needs have the appropriate knowledge and skills, ensure that parents know what to expect from provisions and raise aspirations for young people with special needs. The act also replaced the 'statements' which had been in effect since 1981 with Education, Health and Care plans, which detailed what education, care and health provision needed to be secured and whose responsibility this would be. Statements previously only applied while a young person was in education, but the new Education, Health and Care plans applied from birth to 25 years old.

Special needs has always had negative connotations; from the assumption that a child with SEN will require a different learning environment (Bailey, 1998), to the view that children with SEN are regarded as a challenge to the management and pedagogical skills of the teacher (Rose, 2001). It could be argued that the negative perception of special needs is seen in the overabundance of acts which are created to try and combat this issue; as well as special education acts and research there are also specific acts and research into specific conditions, such as autism.

The effect of labelling a child with a special need condition is widely documented and although much research and opinion sees labelling a child having a negative impact on self-esteem and teacher perceptions (Marsh, 2007; Lauchlan and Boyle, 2007; Gibbs & Elliott, 2015) it continues to be a necessary evil. Young people have to have a diagnosis of a special needs in order to access a range of services and resources, such as, speech and language therapy, occupational therapy which ultimately then support the young person to be able to cope more effectively with their difficulties. There is undoubtedly a stigma associated with the label of autism, with only 16% of autistics in full-time paid work, 32% are in some kind of paid work (full and part-time combined), compared to 47% of disabled people and 80% of non-disabled people, with over three quarters (77%) who are unemployed say they want to work (Office for National Statistics, 2016). Many parents therefore have the decision about whether to receive the label, with the stigma and the support, or choose to not proceed with a diagnosis, and not have the stigma or the support.

Not all autistic people are able to work, but, with understanding from their employer and colleagues, and reasonable adjustments to the interview process and workplace, many autistic people can be a real asset to businesses. When asked about the single biggest thing that needed to change to help autistic people get into work, over 50% said support, understanding or acceptance. And 60% of employers polled stated that they are worried about getting support wrong and they don’t know where to go to get information about supporting autistic employees (Office for National Statistics, 2018). Whilst the looping effect of autism is exacerbating this negative impact of autism it can be mollified by an increased engagement with autistics, for example, through a case study approach such as this thesis or just by employers having open and honest conversations with their employees.

What is the impact of the polarising perception of autism?

As discussed in the previous chapter, there have been some key shifts in the way autism has been portrayed. Historically views of autism were defined by researchers and medical professionals but it appears today as though the representation of autism is led by one of the most influential 21st century creations, the media; and indeed Snyder and Mitchell stated that ‘Americans learn perspectives on disability from books and films more than from policies or personal interactions’ (Snyder and Mitchell, 2005, p9). I have included some of Simon’s views in the previous chapter and Simon will have a large voice in this chapter of the thesis. As an autistic adult, with autistic children and a working autism practitioner, he is in a key position to discuss the impact of the ways in which he has been engaged with as an autistic and the impact of autism on his life.. By engaging with Simon in this way and exploring a case study methodology where the subject of research is himself an autistic person I hope to improve the ‘looping effect’ of autism and ultimately improve on the epistemic injustices which have been committed in the past against autistics.

Simon’s school experiences were far from successful and often saw him positioned as both beatified and demonised. Simon described himself as anything ‘from the ideal pupil and really focussed to unteachable, depending on which teacher you spoke to’; Simon attributed this to the fact that if he was interested in a subject he would ‘dive in head first and be absolutely obsessed with it’ or he ‘had no interest whatsoever so my school life was sometimes horrendous’. Simon said this would all depend on ‘interest in the subject and the personality of the teacher’ (Greenwood, 2016, Interview 2); through education individuals become looping targets and teachers interactions with students themselves ultimately changes them (Hacking, 2006). The impact which professionals have on young people is huge, and the importance of teachers in facilitating student achievement is widely reported with social and emotional connections being a key factor in success (Jimerson and Haddock, 2015; Jones, Bouffard & Weissbourd, 2013; Tournaki and Podell, 2005).

For Simon, his experience of school was immeasurably shaped by the teachers who he interacted with, resulting in him leaving school, unofficially, two weeks before his 14th birthday:

> '*I became more and more isolated because I was unteachable. I left school unofficially 2 weeks before my 14th birthday because I was wasting my time basically. I believed they were wasting my time. I knew I could learn stuff but they just weren't teaching it in the right manner'* (Greenwood, 2016, Interview 2).

The teachers had labelled Simon 'unteachable' and had no interest in investing in his education. Sadly, this opinion of educating autistic young people is becoming more prevalent as the percentage of young people with autism being permanently excluded at some point in their education has quadrupled in ten years (Dybvik, 2014).

Simon was positioned outside of the mainstream education system, figuratively and literally. It was Simon's responsibility to either understand what was being taught or he just did not access that lesson:

> *'I was physically dragged from the chair, thrown out of the class, marched to the headmaster and told that this child is unteachable. And rather than him saying let's look at a different strategy, I spent the next 2 years in every maths lesson in the library and had to read a book on my own. But that suited me because I didn't like maths anyway*' (Greenwood, 2016, Interview 2).

There was no expectation on the teachers to change their practice and become inclusive or provide Simon with an individualised teaching package and engaging with Simon to ask him how he would like to be supported was not even considered, exacerbating the epistemic injustice against Simon. It is probably worth acknowledging that Simon did not have a diagnosis at school and therefore may have had a different experience if he had been labelled autistic. But I doubt that this would have been the case as 60% of all teachers still do not feel they could teach a child with autism (The National Autistic Society, 2015).

One of Simon's coping mechanisms was to become 'a *good actor because I have had to learn how to act to be in this world'* (Greenwood, 2016, Interview 2). Simon behaves very differently when he is alone, compared to when he is in the neuro-typical (NT) world. This feature is expressed in the following speech:

> '*Once I get in this flat this is my world, I can do what I want. I can be as strange as I want. I can put my fibre-optic light on and stare at it for an hour and nobody can tell*

> *me otherwise. But I have learnt that it was sink or swim. It was tough shit. You either conformed or you went under. So I learnt how to act. I always have considered myself an actor and I am acting in this life and I am acting in the NT world. I got good enough to a level to get a job, get married and have kids. But it has never been me'* (Greenwood, 2016, Interview 2).

This attitude of 'fake it till you make it' is a skill which is commonly used to teach autistics social skills (Yapko, 2010) and throughout Simon's life he was never 'he', he was also just representing something in the different worlds in which he exists. This is a common experience of autistics where the label becomes the totality of the child's social identity (Lauchlan and Boyle, 2007). Where the focus is no longer on the child but on a collection of specific impairment behaviours and characteristics which are associated with that particular label. The practitioners lose the individual's identity traits due to being constrained by the labels which are associated with them, either beatified or demonised (Chappell, Goodley & Lawthom, 2001). The effect of imposing a label on a child is that their freedoms to become who they want to be and to live in ways of their choosing are curtailed (Kelly and Norwich, 2004) as the child is expected to change or be changed in order to become as normal as possible (Thomas, 2004).

This section explores in more detail the two different perceptions of autism – the autistic savants and autism as a profound disability. The section then discusses how this dichotomy of portrayal impacts upon professionals, families and society.

The autistic savants

Autistic savants were first discussed in academic research in 1988 (O'Connor and Hermelin, 1988). This was the first time that autism had been discussed in academia and scientific rigour applied in the discussions about savants. Prior to this the discussion of savants had solely been dominated by mainstream media.

The autistic savant portrayal is heavily driven by the mainstream media who regularly portray 'super-human abilities as 'often' associated with autism' (Huws and Jones, 2010, p102). News stories are often framed to justify a particular way of presenting the world

(Corner, Richardson & Fenton, 1990) and, in the case of autism, what people know about it is hugely influenced by what they see in the media (movies, television, and internet), rather than research and experts, and this is further reaffirmed through conversations with others (Huw and Jones, 2010) and in the case of autism the dominant view is that of the savant (Condit, 1994).

One of the hugely prominent portrayals of autism was that of Raymond Babbitt in 'Rain Man', produced nearly thirty years ago. Simon does believe that a media portrayal of autistic savants is important because when you talk about savants 'everyone sits up and listens' because 'people love stuff they can't explain' (Greenwood, 2018, Interview 5). Arguably, without autistic savants, as rare as they are, the condition would not be as prolific; in 1999 there were only 15 articles on autism in the media which had risen to 98 in May 2008 and the majority of these articles were on autistic savants (Huws, 2010). Without the copious interest in autism there would not be as much investment and research into the condition, which continues to be elusive (Pellicano et al., 2014).

Simon also acknowledges this stating that the proliferation of the savant portrayal was down to 'Rain Man', he was generally positive about the impact of 'Rain Man' as ''Hollywood's' take it did at least get people talking about autism and raise awareness when there had been virtually none' (Greenwood, 2018, Interview 5).

Although Simon himself does not have a savant skill, his son, 'A', arguably does. Simon evidenced this by telling this story as an example:

> *It's awful really because you sort of parade him. I have always thought this, and it might be awful to say, but when your kids are born you sort of have real hopes and aspirations for them like any parent would but when you find out that they have got such problems and such disability you grieve as if you have lost that aspiration. That is not what I ordered when I made plans to have kids and you go through a grieving process. It's hard to explain. Your aspirations change a bit, so when you get a situation where your kid can do something that not many other kids can do you start showing off a bit. And you're like "all right he might not have a sense of danger but can your kid do this?" So it became a fascination for me that it became about that.'* (Greenwood, 2016, Interview 3).

Simon's son's abilities show what some people would describe as an autistic savant skill. The estimated prevalence of savant abilities in autism is 10%, whereas the prevalence in the non-autistic population, is less than 1% (Edelson, 2014; Treffert, 2009). Simon has used his son's savant ability as an inspiration to cope with some of the difficulties which he first faced when 'A' was diagnosed. Simon describes the aftermath as the diagnosis as going through 'grief' and that he mourned the potential son he lost when he received the autism diagnosis and then the excitement when 'A' could do something which other normal cognitively functioning children could not do. Simon had something which not only he could be proud of but that he could show off to others, which is similar to what happens in Rain Man when Raymond Babbitt is taken to Las Vegas to showcase his amazing memory skills. Simon clearly supported 'A's' development in memory skills and encouraged 'A' to display these talents. It is interesting however that 'A' does not appreciate that this is a special skill as Simon states:

> *'He gets bored of it but I suppose it's because at the time I was like do it again and again because I found it amazing. But he gets bored and cross sometimes because he is annoyed with it as he's getting sort of treated like a circus entertainer. He is never wrong though.' (Greenwood, 2016, Interview 3).*

The portrayal of the autistic Raymond Babbitt continues to be a challenging perception for the general population to have though as Ghaziuddin et al (1998) found that 65% of adults with Asperger's syndrome presented with symptoms of psychiatric disorder and 50% of individuals have such severe communication impairments that they cannot communicate their daily needs, such as going to the toilet. This directly contradicts the view of the autistic savant and the thoughts that autism is a 'gift' but, the majority of the time, it is this view which is reported in the media. For example, in July 2015 Katie Hopkins's daughter was reported to be autistic and Hopkins released a statement saying 'It's an awesome thing, to live with a child who can memorise a times-table in two minutes' (Leyfield, 2015).

Despite the facts of living with autism, autistic savants are preserved as the dominant portrayal of autism in the media. Although this has some benefits, for example, increasing public interest in the condition, charitable donations and research investments, there is also the danger that viewing those with autism as special or super human appears to romanticise autism and does not allow the reality of autism to be seen which is so drastically needed to actually improve outcomes for autistics. Also, the capacity for symbolisation makes autism fundable but takes it away from what it really ‘is’.

The disabled autistic

In direct contrast to the savant perception of autism, the polarised view of autism as a profound disability is also a key view which is presented. There is little research into this area of presentation of autism (due to difficulties engaging with and accessing profoundly disabled research participants (Jivraj, Sacrey, Newton, Nicholas, & Zwaigenbaum, 2014)) but news stories about people with mental health conditions have often been criticised for using negative language (Day and Page, 1986) and for reinforcing negative stereotypes (Ward, 1997).

Simon believes that the polarising media representations are because ‘people want to be wowed or to have a cry’ (Greenwood, 2018, Interview 5). It is an issue of either ‘human interest’ (in the case of the savants) or ‘human sympathy’ (in the case of profound disability) (Greenwood, 2018, Interview 5). This discourse of autism in the media, results in it often been presented as an ‘affliction of suffering’ and Huws (2010) provided a number of examples where this was the case:

> ‘…one in 110 of the population **suffers** from ‘autism spectrum disorders’ (Fraser, 2002)
>
> ‘**Victims** have difficulties communication ideas’ (McKie and Gold, 2002)
>
> ‘The big, sprawling classes of the modern comprehensive school are no friends to the **victims** of autism’ (Linklater, 2005)

Research has found that children with disabilities are more at risk for developing negative attitudes towards television due to their incorrect portrayals, where they are often depicted as sick, pitiful, aggressive or dangerous (Sprafkin, Gadow & Grayson, 1984). The impact of this is summarised by Murphy (1987, p140) when he stated that ‘The greatest impediment to a person taking full part in his society is not his physical flaws, but rather the issue of myths, fears and misunderstandings that society attaches to them'. Whilst it can be argued that this is true of everyone the impact appears to be heightened for the autistic.

It is also true that this interaction with people as 'victims' will shape a person and change the way they both view themselves and approach the world (Hall, 2014); it is this looping effect which causes autistics to be damaged by epistemic injustice both on a testimonial level and hermeneutically, where outcomes for autistics are negatively impacted but also for the neuro-typical we are robbed of the potential knowledge which we could learn from autistics, if they were not excluded from society.

Simon's experiences emulated this as he reflected that:

> '*I have come across parents over time who are absolutely desperate for their child to have autism and I think why would you want that because it makes life difficult. It makes life harder and it shouldn't be the case, but it also shouldn't be the case that life is harder if you are gay but it is. If you don't fit into a category life is going to be harder for you but that is the media's fault. We are absolutely governed by the media and it rules our lives*.' (Greenwood, 2016, Interview 4).

However the reality of services which are accessible to disabled people paint a difficult landscape. Without a diagnosis or a statement, young people cannot access additional services, but those young people who do have a statement not only access therapeutic services but also can access education until the age of 25 years old. This is obviously a hugely attractive proposition to parents whose major worry for their children will be what happens in adulthood (Robertson, 2009).

The burden of autism is further exacerbated by the media presentation of people with autism as being both vulnerable and dangerous. For example, reports in the May 2008 newspapers refer to the failed terrorist bombing by Nicky Reilly, who according to the 'The Sun', 'has Asperger's syndrome – a form of autism which makes him vulnerable to indoctrination' (The Daily Mail, 2008); and in December 2019, Jeremy Clarkson stated that Greta Thunberg's autism made her 'mad and dangerous' (Sky News, 2019). Reporting autism in such a way means that the 'autism' label is attached to discourses of dangerous, vulnerability, instability and the potential to be exploited. The perception that individuality may be the cause, rather than the autism, is rarely presented. Such discourses potentially dehumanise and further marginalise autistics and those individuals associated with this label or diagnosis, such as families and professionals. This further contributes to autistics who '… long to be part of the human race but find it hard to bridge the gap between their world and ours.' (Linklater 2005, p11). Simon also feels this pressure and states that he overcame it as 'I learnt how to act. I always have considered myself an actor and I am acting in this life and I am acting in the NT world' (Greenwood, 2016, Interview 2).

Demonising autistics appears to be a widely accepted view and that young people with challenging disabilities should be removed from society which also has an impact on professionals who are already fearful of autistics (The National Autistic Society, 2015). With rising pressures in outcome driven initiatives and huge cuts to special educational needs, schools and teachers are struggling to meet rising expectations. With the autistics portrayed as demonic the blame is easy to lay at the feet of the autistics themselves (Busby, 2018).

Polarising views and professionals

Due to the double way in which people can perceive young people with autism – beatified or demonised, they either have too low expectations where young people are demonised or too high expectations where young people are idolised and believe in the autistic savant. This often means there is an opposition between the expectations and the reality. When the ideology of autism does not match what they are presented with, the young person or the professionals are blamed (Press Association, 2018).

One of the impacts of this lack of how to hermeneutically position autism is that the National Autistic Society, which sought the views of teachers, found that three quarters (72%) of schools stated that they were dissatisfied with the extent of their teachers' training in autism and in schools identified as having pupils with autism spectrum disorders, only 22% of teachers had received some autism-specific training but the majority only for between one and four hours. One in five schools (21%) with pupils with autism or Asperger syndrome have no teachers with autism-specific training at all (Barnard et al., 2002, p7). In such a short time, they are unlikely to have received sufficient training to understand crucial areas such as how children with autism learn and how to manage challenging behaviour associated with autism (Barnard et al., 2002). This means that staff, who are meant to be specialists in supporting young people with autism also do not know what autism is and how to cater for their needs. Often they are shocked to be presented with an autistic child as it does not meet the representations which they have seen in the media.

As professionals struggle to reach definitive agreement on strategies which effectively support autistics (Francis, 2005; McConnell, 2005; Odom, 2003) it is often left to the individual class teachers to make the decisions about what strategies are going to be adopted to support young people and this is compounded by the fact that there are obvious barriers to discuss with young people with communication and learning impairments what strategies they find most useful. Simon, in one of his first interviews, suggested this approach:

> '*Observation with very much a standoff approach initially to see how people interact to see how the autistic person would engage or choose not to engage depending upon the type of person they are.*' (Greenwood, 2015, Interview 1).

The idea would be that an expert using observation would therefore analyse the engagement of the child in a particular approach, rather than just enforcing one approach onto them ensuring that the approach is personalised to that individual's needs.

Whilst this approach would remove the epistemic injustice as each individual would be receive a personalised approach one issue is that staff would need to be highly trained in observational skills and have a sound understanding of what autism is and what strategies and approaches are available to young people with autism. This is a level of knowledge which most staff do not have (Barnard, et al., 2002). This causes a cyclical problem – we cannot define autism, therefore training is lacking, so young people are suffering educationally, and the way to combat this is to train teachers. This training needs to be targeted and specific to autism as researchers have shown that developing multicultural and disability understanding in teacher training has done little to disrupt teachers' negative beliefs and maladaptive classroom practices (Ladson-Billings, 2016; Lipman, 1995).

The polarisation of autism is also aggravating the difficulties in defining autism and has resulted in professionals also being divided in their opinions of autism. Moreover, it, leaves little success for society to have a clear understanding of autism. Simon acknowledges this stating that:

> *'People are influenced by popular opinion even when they believe they're not and absolutely shouldn't be professionally. We all stereotype and we all jump to conclusions depending on what narrative we tell ourselves.'* (Greenwood, 2018, Interview 5).

As Simon states, there is no avoiding drawing stereotypes; but where professionals are negatively stereotyping, for example, the demonisation of autism, this leads to a feeling of stereotype threat (Steele et al., 2002). As Steele (1997, p614) describes it, stereotype threat can cause 'those who identify with the domain to which the stereotype is relevant, this predicament can be self-threatening'. The young people who I support all have a level of challenging behaviour, associated with their communication disorder. But research shows that where there is evidence of stereotyping behaviours there is a higher chance of those stereotypes becoming self-fulfilling consequences (Nguyen and Ryan, 2008); supporting Hacking's research (2006). Not only does this cause a fear in an individual, that they will conform to their negative stereotyping but that it also impact upon motivation and engagement (Kalokerinos, von Hippel & Zacher, 2014) and chronic experiences of stereotype threat can lead to dis-identification or disengagement (Steele, 1997), further marginalising the autistics from a society which is already difficult to access.

Although viewing autism as beatified forges a skewed understanding of the prevalence of autistic savants it does not have the same negative impact as professionals positioning autistics as demonic. This perception results in teachers believing they cannot teach young people with autism (Barnard, et al., 2002) and young people with autism being demotivated, unengaged, with a lack of identity and further marginalised from society (Steele, 1997). Although the impact on professionals is extensive it does not appear to have the disheartening impact on professionals as it appears to have on the families of autistics, as discussed in the next section.

Polarising views and families

Raising a child with autism is undeniably challenging. When I searched the MMU library with the search term 'family views on autism' the top hit was titled 'The long, silent scream (of a parent carer)' (Hardy, 2012). The article details one parent's experiences, from birth, of raising a child with autism. It details a long list of professionals who dismissed them; professionals who promised great things, never to be achieved, many experiences of assessment, and ultimately a shift from an attitude of positivity and dreams to that of restrictions and limitations. A story which echoes that of Simon's experiences:

> *'When your kids are born you sort of have real hopes and aspirations for them like any parent would but when you find out that they have got such problems and such disability you grieve as if you have lost that aspiration'* (Greenwood, 2016, Interview 3).

As discussed in the previous section, the disagreement between professionals does not go unmissed by parents as 'each service takes their own view on how to meet my son's needs.' (Hardy, 2012) or as Simon eloquently puts it: 'They come up with all sorts of bollocks' (Greenwood, 2016, Interview 3).

For Simon there is no preferred perception for people to take; if the child is beatified then 'people think they are capable of incredible task rather than see the strain it has on a family' or if they are demonised then 'people can have the perception that your child is a lost cause'. The impact of this is that either 'expectations are raised to unachievable heights' or that 'there's no hope of living independently and give unwanted and unhelpful sympathy' (Greenwood, 2018, Interview 5). Although one of Simon's sons does have a specific savant memory skill, they both have a profound learning disability, so are usually demonised by others as 'people can have the perception that your child is a lost cause'. Simon also stated that 'If I had a pound for every time I've heard 'oh god bless you' 'that's such a shame', 'poor you'.' (Greenwood, 2018, Interview 5). The issue of putting a label upon someone, rather than agreeing, in consultation how they would like to be viewed, is an issue of epistemic injustice where we reduce their capacity as a knower and ultimately put them at an unfair disadvantage in society.

Research shows that families are requesting practical strategies that help parents to have access to resources and support mechanisms to meet their own needs, the needs of their child with autism and their family and to not adopt a ‘one-size fits all’ approach (Hall and Graff, 2008). Every family’s dynamic, understanding and support network will be different and this will therefore mean that their needs are different. One family may need financial support, another knowledge and another emotional support; it is key that whatever support is offered to families is bespoke. There needs to be a stronger focus on family-focused, open teamwork model that aims to acknowledge the context of the situation and take into consideration the strengths and limitations of the child and the family (Ravindran and Myers, 2012).

As well as a lack of understanding of autism within education professionals, there also is a lack of understanding within the public sector. As mentioned by Hardy (2012) there is an enormous need for training of individuals working in all public services to be more aware and to understand the types of difficulties which autism spectrum conditions generate for people with those conditions and their families who talk of their isolation and judgement from others, of not having the skills as a parent to just be able to ‘sort it out’ (Hardy, 2012, p142).

Simon and I often talked about whether he would change his own autism or his son’s autism. Simon never reached a conclusion as he could not imagine who his sons would be without the autism because ‘if I take the autism away then he isn’t A anymore’ but he ‘would take the learning disability’ (Greenwood, 2016, Interview 3). Removing the disability and therefore repositioning Simon’s children as neither beatified nor demonised would remove them from the field of sublime objects. However, Simon describes those autistics who are neither disabled, nor savants, such as himself, as the ‘invisible autistics’ (Greenwood, 2018, Interview 5).

The polarisation of autism ‘gives a distorted view … whichever end of the scale you wish to analyse. There are thousands of people that don’t tick those boxes that struggle in everyday life and struggle as a result of polarisation’ (Greenwood, 2018, Interview 5). Simon understands why these autistics, such as himself, are not represented in the media as they ‘wouldn’t make watchable TV’ (Greenwood, 2018, Interview 5) but states that ‘a more balanced view is called for’.

Research shows that the majority of parents of children with autism want to be more involved in the research process (Pellicano et al., 2014) and when researchers were quizzed as to why they were not approaching parents they stated that there were challenges associated with of parental involvement, due to the busy nature of their lives as ‘‘it is often difficult to round up [parents] and get them involved’’ (Pellicano et al., 2014). This is a barrier which autistic parents refuted and one which I would also challenge; in my experience where parents are engaged they attend every meeting, every parents; evening and every school show.

If we could find a way to engage with autistics and parents so that they are more involved in the research process and contributed to identifying research foci maybe the ‘more balanced view’, which Simon requests, would be seen and the ‘invisible autistics’ who are not represented in the media or research would be brought into the mainstream, shattering the polarising perception of autism, that you are either a genius or disabled. This would then remove the labels and the looping effect of autistics becoming moving targets where our investigations interact with the targets themselves, change them, and further exacerbate the epistemic injustices.

Society and the ‘invisible autistics’

Simon acknowledges that the media have stories to sell and that the ‘extremes of things sells’ but that ‘there are thousands of people that don’t tick those boxes that struggle in everyday life and struggle as a result of polarisation’ (Greenwood, 2018, Interview 5). In the last year or so there has been an increase in the portrayal of the ‘normal autistic’, those autistics who work and can function in the NT world, albeit with difficulty. For example, the Chris Packham documentary ‘Asperger’s and Me’ details Packham’s diagnosis (which he received in his 40’s, similar to Simon’s experience) and some of the difficulties which he still faces today, despite carving a successful career as a naturalist and wildlife documenter (Hogan, 2017). Another example is Anne Hegerty, who was recently in the ‘I’m A Celebrity

Get Me Out Of Here' jungle in Australia, who has had a successful career appearing on gameshows, most famously as the Governess on 'The Chase'.

Simon states that these portrayals are useful but probably only because they were 'famous already' and states that 'society's view of anything is usually what is given to them on a silver platter. Only a few challenge the media concept of anything' (Greenwood, 2018, Interview 5). The tendency of the media is to amplify certain voices, while silencing others (Condit, 1994) but with the media influencing most people's perceptions of what autism is (Huws, 2010) it is key that, now autism has attracted the public's interest, a balanced view begins to be presented.

Simon states that the impact of the polarisation of autism means that, as he does not sit in either the beatified or demonised ideology, he therefore doesn't fit most people's perceptions of what autism should be and so tends to hide it. Simon describes himself as 'a good actor because I have had to learn how to act to be in this world' but that this proves difficult. Simon learnt that he 'either conformed or you went under' but 'once I get in this flat this is my world, I can do what I want … I can put my fibre-optic light on and stare at it for an hour and nobody can tell me otherwise'. There is little research on the real-life experiences of autistics (Cage, et al., 2017) so it cannot be said if Simon's experience is a typical one. However, there is strong evidence that autistics are struggling; for example, rates of suicide in autistic adults are 3.5 times higher than non-autistics and clinical samples suggest that suicide occurs more frequently in high functioning autistics (Richa, Fahed, Khoury & Michara, 2014).

It is therefore imperative that researchers engage with this community who do not fit into either of the polarising ideologies and who are 'invisible' in research, media representations and society. As Simon states: 'I hide my autism daily. It would be nice not to have to' (Greenwood, 2018, Interview 5). This study is a contribution for this endeavour.

Conclusion

It is impossible for the media to capture, in one character, the full spectrum of what autism is and so it needs to be positioned within a particular frame. As Simon states 'The media have to sell. Extremes of things sells' (Greenwood, 2018, Interview 5) and in the case of autism this is the extreme of genius or the extreme of disability.

However, it is no longer useful to present autism in this way as it has meant progress has been stifled and there have been minimal improvements for autistics, families and professionals (Jivraj, et al., 2014). But why do we continue to strive to categorise and enclose autism within a particular frame of beatified or demonised?

The statistics and facts of autism which are already published are showing the reality of autism but these have not forced people to truly understand the actuality of autism. The increase in our knowledge of autism has had little impact on practice as we still continue to have a very rudimentary educational approach to autism. The knowledge has not translated into practice and therefore outcomes for young people with autism remain depressing (Eaves and Ho, 2008). Thirty years ago 'Rain Man' showcased autism in a way in which had never been portrayed before. But over time this has been repositioned as just another step in the mystification of autism; another romantic portrayal to further open the gap between the reality of autism and the lived experiences of autistics.

With the increase in autism diagnosis and the subsequent strain this has placed on special education funding there is mounting evidence that autistics are the problem (Busby, 2018). We need autistics to be labelled and receive a diagnosis in order to access the vital services which autistics require, such as, speech and language therapy, occupational therapy and child and adolescent mental health services. But in order to achieve this diagnosis practitioners are forced to promote the perception of autism as demonic then that forces the parents and the autistics themselves to further promote the beatification perception so to protect themselves. Historically individuals with disability have been subjected to horrendous treatment and still today there are huge stigmas attached to disability. Can it be argued that the showcasing of savant talents in autism is actually a way of protecting them, of reducing those with disabilities isolation from society because they have an amazing talent? For Simon he could then have his son interacting with others showing off his amazing memory skills and have people comment positively towards his son, instead of having him isolated due to his complex needs which society generally finds difficult to meet. The labelling of autistics confirms their position as a moving target, of the looping effect, where the attempts to label actually change the autistics themselves and they respond to that label which is placed upon them. This looping effect then exacerbates the negative impacts of epistemic injustice, both testimonially, deflating the autistics own credibility in oneself and also the hermeneutical gap in collective knowledge which ultimately puts autistics at an unfair disadvantage in society.

The location of autism in institutional educational provision

As discussed in the previous chapter, the impact of the polarising views of autism are far reaching for autistics, families, society and professionals; our interactions with autistics interact with the autistics themselves and change them and the way in which they view themselves, further exacerbating the epistemic injustices associated with being autistic. With this considered, this chapter aims to state how autism should be positioned, outside of mainstream education, looking at the purpose of autism education and specifically the concept of 'learnification' (Biesta, 2009). I will then review three key approaches which are prolifically adopted to support young people with autism; the behaviour analytic approach, theory of mind and the visual environment.

In 1987 a journal article by Rogers, Lewis and Reis outlined a set of procedures to support young people with autism (Rogers, Lewis & Reis, 1987, p180-188). Since this article there has been very few new ideas identified on how to support young people with autism (Corbier, 2005; Yapko, 2018). One issue which they identified entailed involving staff members in identifying their own training needs and to fit the new information to their own individual needs, the setting in which they work, and the students whom they support (Morpurgo, Asper, & Wolf, 1977). Despite this issue being identified nearly thirty years ago there has been little progress made, as in a survey by The National Autistic Society (2015), which sought the views of teachers, it was found that three quarters (72%) of schools stated that they were dissatisfied with the extent of their teachers' training in autism and in schools identified as having pupils with autism spectrum disorders, only 22% of teachers had received some autism-specific training but the majority only for between one and four hours. One in five schools (21%) with pupils with autism or Asperger syndrome have no teachers with autism-specific training at all (Barnard, et al., 2002, p7).

The 1987 article also highlighted the importance of 'enhancing cohesion in the replication team', giving the example of close workings with speech and language therapists (Rogers, Lewis & Reis, 1987, p181). In 2002:

> *'31% of the schools with pupils on the autism spectrum have no speech and language therapy provision at all. The vast majority of children who receive speech and*

> *language therapy receive less than 30 minutes a week, with only 2% of schools with children with autism spectrum disorders able to offer over 2 hours a week'* (Barnard, et al., 2002, p21).

The lack of speech and language services prompted a review into speech and language therapy services in 2008 (Bercow Review, 2008) but the 'Bercow: Ten Years On' report which was recently published, found there has still been little progress in speech and language services (Bernard, 2018). This is despite mounting evidence of the link between speech and language difficulties and outcomes; 60% of young people in youth offending institutes have a speech and language impairment and between 50-60% of young people with speech and language needs have mental health difficulties (Bernard, 2018).

The next piece of advice which Rogers, Lewis and Reis presented was that 'staff carefully plan and coordinate the structure and routine of the classroom environment with special attention to schedule, transitions, competing sensory stimuli, space, and materials' (Rogers, Lewis & Reis, 1987, p182). Yet in 2002 nearly a third of respondents to the NAS survey mentioned insufficient resources, both human and financial (Barnard, et al., 2002, p7) and this lack of resources has continued with thousands of special needs children out of school with schools citing a lack of resources as the cause (Busby, 2018).

Rogers, Lewis and Reis also advised that 'staff handle unwanted or maladaptive behaviours in a manner which recognizes the developmental or emotional meaning of the behaviour and which emphasizes redirection towards more positive behaviours rather than negative consequences for negative behaviours' (1987, p182) but NAS findings show that the majority of teachers who have received training in autism have only received between one and four hours training (The National Autistic Society, 2015). In such a short time, they are unlikely to have received sufficient training to understand crucial areas such as how children with autism learn and how to manage challenging behaviour associated with autism (Barnard, et al., 2002, p24). Recently, a teacher in Bristol was found guilty of misconduct after hitting a special needs pupil and stated that cuts to staff and resources had made the job 'intolerable' and defended her actions to the Bristol Post saying that she had been verbally abused by the pupil before the incident (Busby, 2018).

Rogers, Lewis and Reis's article stated that the existence of programs to support young people had not had an impact on the quality of early intervention programs. This appears to still be the case today, there are lots of innovative strategies around and programs such as the Autism Accreditation scheme which supports services in the interpretation of the standards which will provide an outstanding provision for young people with autism and also advises them on creating quality action groups to assist the process (The National Autistic Society, 2015) but this is not translating into improved provision.

However, there was an intention to improve the lives of young people with autism as in a Written Ministerial Statement, Michael Gove, the Secretary of State for Education stated that the SEN Green Paper was:

> *'about the children and young people in this country who are disabled, or identified as having a special educational need. It is about their aspirations and their hopes. Their desire to become, like every child and young person, independent and successful in their chosen future, and, to the greatest extent possible, the author of their own life story'* (Gillie, 2011).

Some of the recommendations from the report stated that:

> *'We want teachers to know when children have special educational needs. And we want them to know how to help the child in the best way possible.'*
>
> *'We want teachers to be confident about stopping bullying and bad behaviour. And we want them to know how to help as early as possible when there are problems.'*
>
> *'We want schools to have more say in how they help children and young people with special educational needs or a disability. This will help them provide the right help for each child's needs.'* (Department for Education, 2011).

Despite this being published in 2011 (and there has not been a review commissioned as yet), these aspirations do not seem to have been met as parents, teachers, school governors and councillors of children with special educational needs and disabilities (SEND) have handed in a petition with 34,000 signatures to the education secretary. They accuse the government of failing to provide sufficient investment for schools and local councils to provide children with adequate SEND support. The Department for Education select committee, who were investigating SEND provision and funding, heard damning evidence about the plight of families who faced long delays as they fought to secure statutory support for their children. MPs were told councils spent more than £70m over a three-year period fighting parents in tribunal cases, which local authorities go on to lose in almost nine out of 10 cases (Weale, 2018).

The impact of effective practitioners on the progress made by young people with autism is profound but despite the huge levels of research and interventions, based on reports, the outcomes for autistics appear to be getting worse (Adams, 2018; Barnard, 2018; Busby, 2018; Weale, 2018).

What is the purpose of autism education?

Against this background, one can say that special education and, more specifically, autism education is at a crisis point (Adams, 2018; Barnard, 2018; Busby, 2018; Weale, 2018), and is not meeting the needs of either the young people (Bernard, 2018) or the practitioners; 40% of teachers quit in the first five years of teaching but in special education 75% of teachers quit within the first five years (Marsh, 2015). Within my own experiences through working a range of settings (mainstream special, local authority special and independent special) I have struggled with meeting the needs of the young people who I assist. For this chapter I will contrast the literature with my own experience and confront with Simon's speech and discuss how I have implemented this within my own practice. I acknowledge that solutions are not easily found and that there are difficulties in understanding practice in an environment which arguable does not meet supposed levels of the ideal; but identifying the problems at work means that the next steps of actions which will make things better can begin to identified, which is one of the aims of this thesis.

As a starting point it is clear that we are not meeting the needs of this vulnerable group so it is necessary to pause and reflect around, not only what we need to do to meet the needs, but also what is the purpose of autism education. In an article by Burke (2016) she states that:

> *‘people tend to assume that children who are severely disabled aren't going to make any progress to speak of, so she's nothing but a glorified babysitter, right? ‘They have asked things like 'Why send these children to school?' or 'Why waste government money on educating these kids?''*

So, what is the purpose of autism education? To address this question I will explore the work of philosopher of education Gert Biesta, which focuses on the theory and philosophy of education and what the purpose of education should be. In particular I will discuss his characterisation of the three dimensions that illustrate a good education – *qualification*, *socialisation* and *subjectification* (Biesta, 2008).

The *qualification* function of education, according to Biesta (2008) lies in providing young people with the knowledge, skills and understanding which will allow them to ‘do something’. This is therefore also linked to the economic function of education, for young people to leave education with the ability to contribute economically to society.

For the young people who I support this can be problematic. The young people I teach all have autism and an associated learning disability, most are pre or non-verbal, and the majority will never be able to live independently. The skills which these young people need cannot be standardised as each individual will have to be assessed differently, to identify what they need to equip them to ‘do something’.

This requires you to know the young people to identify what it is they want to ‘do’ and to then put the steps in place to support them to achieve this goal; whether this be an independent life, where they can independently toilet and feed themselves, or a life with employability skills. As Simon says you can ‘*take them shopping and get a Freddo but what’s the point in that? It is not just about literacy and numeracy, we are there to enrich them*’ (Greenwood, 2015, Interview 1). Following a standardised curriculum for these young people clearly is not appropriate; Simon clearly makes this point, when discussing his own children he states he is ’*not naive enough to believe that he can live an independent life so why he has to learn about Henry VIII I don’t know’* (Greenwood, 2015, Interview 1). Using Simon’s example, knowledge of Henry VIII will not provide these young people with the knowledge, skills or understanding to *do something* and if it is not meeting this purpose then we should be challenging this status quo and not teaching it. Simon also acknowledged this drive to ‘do’ without thinking, observing that ‘*sometimes it’s just to be seen to be doing something whether it is the right thing or not as long as they are doing something*’ (Greenwood, 2015, Interview 1). If we engage in the ritual of teaching something which we know to have no purpose, we will believe in the ritual before we are aware we are believing in it (Myers, 2003). It is therefore important to ensure we are confronting those acts which we struggle to see the purpose within.

The second function of education, according to Biesta (2004), is the *socialisation* function, which is the way in which, through education, we become members of, and part of, particular social, cultural and political ‘orders’. Biesta (2004) argues that education is never neutral but always represents something and does so in particular ways. Even if socialisation is not the explicit aim of educational programmes and practices, it will still function in this way as, for example, research has shown that emotions influence relationships and practice and ultimately the career decisions which young people choose (Newberry, Gallant & Riley 2013). Biesta (2004) argues that through its socialising function education inserts individuals into existing ways of doing and being and, through this, plays an important role in the continuation of culture and tradition, both with regard to its desirable and its undesirable aspects.

The socialisation function of education, within a setting of autistic education, provides an interesting discussion as autistics, by definition, have a clinically significant impairment in social functioning (American Psychiatric Association, 2013). This, by definition, will reduce the impact of the socialisation function of education. Research has shown that disruption by other atypical processes impact negatively on the development of skills associated with an implicit acquisition (Brown, Aczel, Jiménez, Kaufman & Grant, 2010) and so this function of education would be greatly reduced due to autistics’ specific impairments.

Biesta’s (2004) final function of education is the *subjectification* function, which Biesta describes as the opposite of the *socialisation* function. In subjectification, it is not about fitting a ‘newcomer’ into the already established systems but about developing independence from that system. The development of a free-thinking individual is in line with my personal vision and ethos of education, and I would argue is one of the most important purposes that we could achieve. However, the issue of developing a free-thinking, independent being is a challenging one when so many autistics rely on the help and support of caregivers to lead an independent life. Only 17% of young people with autism ever live independently (Heasley, 2013) so surely the development of independent subjects who are, by the nature of their condition, not independent, needs to be one of the key purposes of autism education.

In order to answer the question of what constitutes good autism education we should first identify what the potential purposes of autism education are. The *qualification* function is to provide the young people with the knowledge, skills and understanding to 'do something' independently; the *socialisation* function would provide the young people with the skills to function independently within a society; and the *subjectification* function develops independent free-thinkers. For young people with autism, the key is developing their skills which would be required for daily living and integration into their communities (Tabone, 2018). For Simon's sons this is the desire for them to '*not have autism and live an independent life'* (Greenwood, 2016, Interview 3) developing the knowledge, skills and understanding to live independently, not relying on the care and support of another so they can get themselves dressed and fed. Whereas for other young people with autism this could be the skills and knowledge so that they are financially independent, in employment. As Simon stated: '*it is not just about literacy and numeracy, we are there to enrich them'* (Greenwood, 2016, Interview 3).

Biesta (2004, p37) states that '*the absence of explicit attention for the aims and ends of education is the effect of often implicit reliance on a particular 'common sense' view of what education is for.*' The focus on the aims and ends of education needs to be even more prominent in autism education as a mainstream education approach cannot be employed due to the wide-ranging needs of young people with autism (Parsons et al., 2017). As mentioned by Simon:

> *'With mainstream it is easier but you just teach the concept of algorithms and you are all either going to get the concept or you're not but with SEN kids it's a bit ambiguous because you are not going to get the one size fits all.'* (Greenwood, 2016, Interview 3).

It is therefore imperative that the purpose of education for each individual is identified. Autistics have an absence of being able to prioritise tasks based on importance, and will be more interest led (Parsons, et al., 2017). Identifying a young person's interests is therefore imperative so that a curriculum can be built around this so that young people's attention can be held for a longer period of time and there is therefore a greater chance of success. Simon also recognises this, stating:

> '*If you enrich someone's life their capacity for learning increases anywhere. If someone is in a good frame of mind then you are far more likely to get them keyed in to the rest of life*' (Greenwood, 2015, Interview 1).

I have also applied this within my setting and, from September 2017 we created, for all young people, a PATH plan; which shows what their long-term goals are and the pathways which they are taking to achieve those goals. The expectations for this was to encourage aspirational thinking for both staff and young people; with an understanding that we never dismiss a young person's aspirations. If a child wants to be an astronaut we can start them on that pathway, even if they never reach their end destination. Adopting an attitude of learning, as opposed to education, is open and never ending (Biesta, 2008). As educationalists it is our responsibility to take them on that journey, not wondering if they will even make the final destination. The PATH plan details what they would need to achieve in the coming year, on their journey to their end goal, whatever that may be. For example, if they wanted to be an astronaut then their PATH plan might state that they need to learn about the planets and gravity. Not worrying about whether the outcome is attainable, but focusing on the process of learning.

Intervening in autistic education

In Biesta's 2009 paper he discusses the 'learnification' of education, which he describes as 'the transformation of an educational vocabulary into a language of learning'. Biesta (2009) describes an educational system where academic knowledge is seen as more valuable than the development of vocational skills. In this article Biesta discusses a phenomenon which he calls 'middle class anxiety' (Biesta, 2004) where he states that those in disadvantaged positions, such as the young people who I work with, will often tend to support the status quo in the (often mistaken) expectation that they will eventually also acquire the benefits currently available to those in more privileged positions (Biesta, 2009). What we teach in our schools is one of the most important decisions we make as a nation. The knowledge passed on to the next generation, the skills and abilities that we think children will need when they become adults, the attitudes and values we wish to instil in them are all at the core of the curriculum and can shape our society and economy for years (Morris, 2012). However, the young people who I teach will not be able to contribute to society in the way in which the national curriculum would hope and anticipate for. Education is one of our greatest tools which contributes to the reproduction of social inequality, which is why a system of learning is key, as opposed to education.

In my setting I have the freedom, due to my school being an independent school, to choose my own curriculum. We therefore have two different curriculums, dependent upon what skills and abilities the young people need. Whether that is the skills for employment or skills needed to be independent. The independence based curriculum teaches life skills and skills for an independent life, for example, cooking and getting dressed. Whereas the employability curriculum is built around employability skills, for example, writing a CV, managing money and gaining qualifications. Identifying the purpose of what education needs to be for each individual means that their curriculum can be bespoke and targeted to ensure that they can reach their personal goals, whether that is to be able to get themselves dressed or to get a successful job.

The education system has shown to contribute to the reproduction of social inequality but there are studies which have recognised this and have focused on children from very disadvantaged families and provided early intervention which have effectively increased their cognitive and non-cognitive skills and change their long-term outcomes (Barnett, 2015). Those young people who receive these early interventions tend to be more successful in school, have lower rates of unemployment, receive higher earnings, are less dependent on social welfare, have a lower crime rate and live a healthier life (Barnett, 2011).

This is also linked to the recent research into childhood experiences, both positive and negative, which have been proven to have a tremendous impact on future violence, victimization and perpetration, and lifelong health and opportunity. Much of the foundational research in this area has been referred to as Adverse Childhood Experiences (ACEs) (Edwards et al., 2005). Due to the nature of the young people who attend my school, all, by definition of the fact that they live in full-time residential care, have been victim to at least one adverse childhood experience. It is therefore key that we identify their potential risk factors from that experience and develop the skills to combat that risk, rather than developing their academic knowledge. Without developing these skills the young people who I work with are at an increased risk of developing lung cancer (Brown et al., 2010), becoming an alcoholic (Strine, Dube, Edwards, Prehn, Rasmussen, Wagenfeld, Dhingra & Croft, 2012), developing drug abuse (Dube, Felitti, Dong, Chapman, Giles & Anda, 2003), commit suicide (Dube, Anda, Felitti, Chapman, Williamson & Giles, 2001) and a number of other negative outcomes. Simon also acknowledged that the role of a special needs school is far greater than a mainstream school:

> ‘*There’s more to life than learning. If you are working more at that level you need to stretch their lives and make memories. I am an advocate that if you enrich someone’s life their capacity for learning increases anywhere. If someone is in a good frame of mind then you are far more likely to get them keyed in to the rest of life’* (Greenwood, 2015, Interview 1).

This is acknowledged by Biesta (2004) that this, already difficult task, is made even more complicated by the fact that those in disadvantaged positions often tend to support the status quo. I think this phenomenon is seen in my setting through the parents’ frequent lack of aspiration for their children. But as Biesta (2009, p34) points out ‘*accountability is often limited to choice from a set menu and thus lacks a real democratic dimension’*. There are limited opportunities for young people who are disabled (Shah, 2012) and young people with physical or sensory impairments do not have the aspirations of their non-disabled peers for further and higher education, for satisfying and rewarding employment and for independent living (Burchardt, 2005).

We therefore need to consider the perceptions, both of the professionals who work with young people with autism but also the autistics themselves. Through this engagement with autistics, the impact of the looping effect and the epistemic injustices committed against them are diminished. Biesta (2009) urges that we redefine teaching as the facilitation of learning and of education as the provision of learning opportunities or learning experiences. As Simon stated, '*It is not just about literacy and numeracy, we are there to enrich them*' (Greenwood, 2015, Interview 1). We need all of the stakeholders to not view education as an outcome driven system, with an ending and a finite point of learning. But instead a journey, which the young person is on, with no limiting factors as learning is infinite. Once you view learning as infinite, anything is possible.

Effective parenting and nurture makes a proven difference to a young person and can enhance their potential, nurturing a child is therefore the best approach to improving outcomes (Hughes, 2012). Which is in line with Simon's view that:

> '*If you enrich someone's life their capacity for learning increases anywhere. If someone is in a good frame of mind then you are far more likely to get them keyed in to the rest of life… They are going to remember the time you taught them how to ride a bike, not what an acrostic poem is. It is more about enrichment*.' (Greenwood, 2015, Interview 1).

There is a significant amount of research to support this argument and one of the statements on the wall in my staffroom is '*There is no point worrying about the Bloom's if you haven't sorted out the Maslow first*', which references Maslow's hierarchy of need, which states that you need to meet a child's physical and emotional needs before they can develop a sense of accomplishment (Pichère, 2015) and Bloom's taxonomy, a framework to scaffold learning (Anderson et al., 2013). Without ensuring that a child has the safety and health to develop a sense of accomplishment there is no point attempting to teach them about history. As Simon states, '*why he has to learn about Henry VIII I don't know, so just enrich his life*' (Greenwood, 2015, Interview 1).

An important piece of research into educational practices was carried out by Simpson et al. (2005) who conducted a large and systematic review and categorised a range of interventions into scientifically based, promising practices and limited evidence. Following Simpson et al.'s review (2005) there was a strong push to ensure that there was a scientific basis for all interventions and that there was a commitment to the ease of implementation

(Detrich, 1999). The best interventions were those which were easy to implement in a real-life classroom setting, not only in a research lab (Detrich, 1999).

Early interventions require wrap-around support from a large number of professionals, such as speech and language therapist, occupational therapists, educational and clinical psychologists, psychotherapists, who are all working towards a common goal. As young people get older, the access to these services become more and more challenging; a challenge which we have solved by commissioning all of these services privately. But without the funding which being an independent school provides me, this would be extremely difficulty and is regularly reported upon. Once again this seems to be getting worse, rather than better, with 94% of head teachers stating that it is harder to support young people with special needs pupils now than two years ago due to a lack of funding (Adams, 2018).

Behaviour Analytic Approach

One of the key difficulties when intervening with young people with autism is that they all have a social interaction impairment and commonly an attachment disorder (Kent, Carrington, Le Couteur, Gould, Wing & Leekam 2013). Therefore when interacting with autistics a different kind of approach needs to be used. One of these approaches is the behaviour analytic approach which was largely developed by Burrhus F. Skinner and O. Ivar Løvaas. Skinner because he promulgated the basic principles and Løvaas because he applied them specifically to young children with autism. Unlike Piaget and Vygotsky's developmental theories that were philosophically driven, Løvaas's behavioural approach to early intervention was more narrowly based on the assumption that young children could be taught specific skills necessary to communicate their needs, to care for themselves and acquire basic cognitive skills using operant learning principles.

The behaviour analytic approach or applied behaviour analysis (ABA) is not a specific set of techniques; it is a family of underlying principles and procedures, which underlie a great many applications (Baer et al. 1968), one such principle is positive reinforcement; if a positive behaviour is reinforced with a reward then that behaviour is more likely to be repeated. Applied behaviour analysis treatments include Incidental Teaching (Hart and

Risley, 1975; Koegel and Frea, 1993, McGee et al,. 1992), Pivotal Response Therapy (Pierce & Schreibman, 1995), Verbal Behaviour (Stafford, Sundberg & Braam, 1988; Carbone, 2007), Pyramid Picture Exchange Communication System (Bondy and Frost, 1994) and Blended Intervention (Thompson, 2011), all of which are based on the principles of ABA (Thompson, 2013). All of these methods have been incorporated within classrooms and entire schools, as components of positive behaviour support (Horner, 1994; Carr, Horner, Turnbull, Marquis, Magito-McLaughlin, McAtee, Smith, Anderson, Ruef & Doolabh 1999), which is based on ABA.

ABA's foundations rely on manipulating consequences to change the rate at which behaviours occur in the future (Research Autism, 2017). The principles of applied behaviour analysis are incorporated within many specific interventions (such as discrete trial training, incidental teaching and pivotal response training). ABA has received wide criticism, one of which being that defining success as behaving like a non-autistic person is unethical and abusive (Parker, 2015), which Simon also acknowledged:

> '*We are not chimpanzees. You can teach things to a chimp. I don't believe in that at all. It is just conditioning. Like mind control. If I teach you that* a *leads to* b *and that is all that we will do – you are not teaching me, you are just rote learning something.'* (Greenwood, 2016, Interview 2).

Critics also comment that the interventions are systematic and do adequately take into account the individual child's thoughts and feelings and own motivations. A further criticism is that the methods impact could be tested quantitatively but there is little data and evidence focused on the actual impact (Thompson, 2013); a concern which Simon also held:

> *'You could teach me to repeat a behaviour but out of the context of the way I have been shown and taught I am not going to apply it. The teaching needs to be more embedded. They will get it right every time they are in the same conditions but take it anywhere else and they won't. I always would say to any new teacher of 'A', whatever you teach him and however insignificant you might think it is, whichever way you want to do it make sure you do it that way the first time. Autistic kids apply that to themselves. Ok that is how I do it but that does not necessarily mean that I can do it in another room.'* (Greenwood, 2016, Interview 2).

Simon’s response appears to be a quite common reaction to ABA therapy. As well as the criticism which Simon raises ABA causes further controversy as it is not an approach which is readily available and many people choose to receive private treatment which can costs tens of thousands of pounds a year (Carter, 2016).

Simon stated that:

> *It seems to be a big thing though at the moment and quite prolific and seems to be the latest craze. These are tantamount to cruelty with me. Being in a room with one person, doing the same thing and getting rewarded is just conditioning. You can condition a chimpanzee to do that. You can’t apply a theory of dogs to humans. You need something more human. I don’t agree with that*.’ (Greenwood, 2016, Interview 2).

ABA is a difficult approach to advocate as a professional, because it is a completely privatised approach. It is extremely expensive and is not funded by most local authorities. But despite the controversy the outcomes for the young people are remarkable; after two years, 50% of the young people were indistinguishable from their neuro-typical peers (Foxx, 2008; Løvaas, 1993). There has since been some concerns raised about the methodology of those studies (Warren, McPheeters, Sathe, Foss-Feig, Glasser, & Veenstra-VanderWeele, 2011) and also the ethical approaches which Løvaas used, in some cases he used brief bursts of physically painful, but supposedly non-damaging electric shock to reduce challenging behaviour (Løvaas, 1987).

Løvaas also argued that young people with autism did not have attachment disorders and could be taught secure attachments through this approach. Following Løvaas’s approach the autistic children were taught to accept people as reinforcers, rather than objects, by pairing praise with food treats (Chezan and Drasgow).

I asked Simon about whether he thought attachment issues were linked to autism (Greenwood, 2016, Interview 2). Simon disagreed with Løvaas and said that he 100% thought that they were and that he had a lot of attachment issues as a child and still had some issues now. Simon did however concede that he did not know whether he had developed attachment disorders because he was autistic or whether his attachment disorders have exacerbated the autism. Interestingly Simon felt that his attachment issues may have even helped him as a child and he used them as a coping mechanism:

> '*My mum and dad, when I was 7 maybe, didn't know what was going on, they had two kids previously, one who was a bit unruly and one who was teacher's pet and top of the class and then I came along and they were like, "What's going on? What's wrong with him?" To the point where they decided the best thing for me would be to be shipped off to live with my nana. She was the matriarch, if anyone can sort me out, she would be able to sort me out. And she did sort me out. She abused me for the next 7 years. She was mentally abusive and used to beat me and lock me under the stairs and hold my hand over a gas flame. She was an alcoholic, I had a lot of detachment issues because I couldn't trust a soul … She would lock me up; I lived under the stairs like Harry Potter. She would lock me under the stairs for five hours but for me, she thought she was punishing me but for me, I am not sure now as an adult, I fully believe I survived that because of my ASD*.' (Greenwood, 2016, Interview 2).

Løvaas and Skinner's programme was based on the assumption that one response a child with autism might learn was generally like any other response, so if one could teach a child to follow a simple direction 'Come sit down', it would also be possible to teach the child more complex responses using the same method, such as respond to the question, 'Where did your mother go?' or 'What is the best way to do that?' (Thompson, 2013). The issue with this is that if a child learns a negative response to a direction then it can be difficult to undo. Simon learnt that if he antagonises people he will be excluded, which does not bother him due to his autism and attachment issues. Simon doesn't want to spend time with people so being isolated is actually a positive experience for him; for example, when Simon was internally excluded from his maths lessons he states that this 'suited me because I didn't like maths anyway' (Greenwood, 2016, Interview 2).

As educators we need to be very careful that we are not teaching negative responses which will become embedded. For example, if a child tells a teacher to 'fuck off' and they get sent out of the classroom then this is working effectively for them as their end goal is to leave the room; therefore why would they ever change this behaviour? I don't think many educators today would advocate Løvaas's approach of using electric shocks to incite a more desired response and even the reward of food could be viewed as a controversial approach today, where, if current trends continue, one-fifth of boys and one-third of girls will be obese by 2020 (NHS, 2007). Secure attachment is developed through trusting caregivers, knowing they will soothe you (Ainsworth, Blehar, Waters & Wall 1978), caregiver attunement and sensitivity (Tronick, 2006) and safety and security (Newton, 2008) and the curriculum and learning environments which are created should be conducive to developing those secure attachment skills.

Theory of Mind

Applied behaviour analysis applies techniques based upon the principles of learning to change behaviour of social significance. One of my key issues with ABA is that it implies that the young people are behaving in a way which is not socially significant, dismissing the fact that it may be significant to them. ABA teaches approaches which are socially acceptable and is often used to reducing stimming behaviours (Kirkham, 2017). Stimming, or self-stimulatory, behaviours are repetitive movement behaviours which an autistic person would use to regulate their sensory input. Reducing this movement, because it is not socially acceptable to be waving your arms in society, is what society would define as socially significant, not what an autistic would define as socially significant.

One of the difficulties with autism is that often autistics cannot share what they are thinking or why they are behaving in a certain way due to their speech and language impairment (Silver, 1954). It is therefore commonly felt that autistics lack a theory of mind; or the ability to attribute mental states; beliefs, intents, desires, pretending, knowledge, etc. to themselves and others and to understand that others have beliefs, desires, intentions, and perspectives that are different from their own (Doherty, 2009). Following laboratory research with a chimpanzee and children with autism (Premack and Woodruff, 1978; Baron-Cohen et al., 1985) it was argued that an absence of theory of mind is the fundamental deficit in autism and all other deficits flow from it.

Baron-Cohen (1997) suggests that children with autism have what he calls 'mindblindness'. He argues that normally as cognitive developed people, we mind-read all the time, effortlessly, automatically, and mostly unconsciously. It is the natural way in which we interpret, predict, and participate in social behaviour and communication. We ascribe mental states to people: states such as thoughts, desires, knowledge, and intentions. Building on many years of research, Baron-Cohen concludes that children with autism, suffer from 'mindblindness' as a result of a selective impairment in mindreading. For these children, the world is essentially devoid of mental things. Consequently children with autism are unable to make sense of actions, to interpret gazes as meaningful, and to decode 'the language of the eyes.'

Simon and I spent a great deal of time discussing theory of mind and kept revisiting it during our interviews. Simon had some increased interest in theory of mind as he had just started a course to train him as a counsellor and had a long-term goal to work full-time as a counsellor and was spending a lot of time reflecting on himself as part of the course and '*would argue that knowing ourselves would reach our full potential and that applies to all of us'* (Greenwood, 2016, Interview 3).

Simon stated that he did not:

> '*think it is a case that autistic people don't know themselves I think it is a case of our world is better than your world. I have learnt to be in the NT world and not all young people have learnt that and they will get very upset and frustrated as you keep dragging them out of their world.'* (Greenwood, 2016, Interview 3).

Simon had stated this previously when he had used the example of just wanting to be at home with his fibre optic sensory toys but he had to enter the NT world for explicit purposes, for example to make money or get food, and that this was more of an end to a means than a desire to interact in the NT world.

As a part of this Simon also stated that:

> '*They know exactly what they want and what makes them happy. I think the issue is not understanding the motivations of others. What you have to bear in mind about so many of these kids is that they have learning disability as well which goes with the autism and if you take that out of the equation. Like I don't have the learning disability I just have the autism and it is a constant battle for me knowing what*

> *everyone else wants, needs and their desires. I can recognise things but only through rote learning. Like I can know that someone is angry but only because I have learnt that face is angry but I don't have the emotional response to it. I have quite a good handle on who I am but knowing what makes other people tick is the issue but wouldn't that be the same for everyone*.' (Greenwood, 2016, Interview 3).

These statements would support the general premise of theory of mind that, although Simon argues that people with autism know themselves, there is a deficit in autistic people's knowledge of others beliefs, intents, desires, pretending, knowledge, etc. However, later on in the interview Simon began to develop his thoughts on this, stating that he thinks that:

> '*I could figure out what people are thinking but I don't know why this matters to me. For example, someone has a broken arm at work and I would never acknowledge that or ask how they were or what they did. If I did ask that it is only because I have been taught to ask about that. Like I can't feel it and it didn't happen to me and I wasn't there when it happened so why am I bothered? And if you add a communication impairment where communication is effort I am not going to bother communicating just to ask that. It doesn't enter my frame of reference. It's not that I don't understand how someone is feeling I just don't have the empathy to care*.' (Greenwood, 2016, Interview 3).

Simon now thinks that he does have the ability to understand what someone is thinking but the real issue is empathy. Although he knows how someone is feeling and could identify it factually it does not then have an impact upon him emotionally. However he thinks that he is developing this skill and is getting better at it:

> '*I have found it difficult throughout my life to empathise how people feel and now I am doing this counselling course I want that to be my job. I am finding it hard but it is becoming an obsession. If I get a new subject that I like I will read and read and absorb it all. Because it is interested it is becoming bigger and bigger. I am getting away with making eye contact because I have learnt how to do that over years. It's doing me a world of good, it's opening my eyes as a person because it is teaching me to enter other people's frame of reference and forcing me to think about how it would feel if it happened to me and how they feel right now. It is getting easier. It's*

> *learnt, it doesn't come naturally. The only thing that comes naturally to me is when I am in the dark room with a laser light. But that is what people would consider as the weird stuff. Everything else, getting up, going to work, interacting with people and socialising is all worked at. But in the same regard don't we all do that, we are all learning. It's just that I have had to learn the stuff which comes naturally to me but I don't know how much stuff does come naturally to you*.' (Greenwood, 2016, Interview 3).

It is an interesting question which Simon poses – how much empathy and theory of mind comes naturally to normal cognitive functioning adults and how much is learnt, in the same way that someone with autism would need to learn it? I would argue that normally-cognitive developed adults trying to prevent a child from self-stimulating behaviours does not demonstrate a great theory of mind. It could therefore be argued that we are all born with the same ability to develop empathy and theory of mind but that people with autism do not see the value in developing this skill so it does not develop but that does not mean that if it is worked on progress will not be seen, as it has been in Simon's case.

Conclusion

As discussed, the purpose of autism education is unclear and contentious, without there been an agreement in how autism education should be situated outside of mainstream education there will be ranging efficacies in the strategies in place to support them. For example, is the role of autism education to readdress unwanted behaviours, as seen in the behaviour analytical approach, or is it to prepare them for qualifications and employability or is it developing a love of learning. Without knowing the purpose you do not know the design and scope of what the role of the school or of teachers is.

This is probably why there are so many strategies available to support young people with autism, ranging in effectiveness and accessibility (without completing expensive training courses). Without overarching guidance of what the role of autism education it is a failing of the professionals themselves, whether that is the individual teachers or the school leaders, to make the decision about what strategies type of education they are going to provide and therefore what strategies are going to be adopted to support young people. There is incongruity across the macro decisions of government strategy to the micro decision of the individual speech and language therapist choosing which symbols are going to be provided. Obviously it is difficult to discuss with young people with communication and learning impairments what strategies they find most useful. However, we need to attempt to understand what approaches the young people would benefit from the most.

Simon advised that, for every child we need to adopt an approach focused on:

> '*Observation with very much a standoff approach initially to see how people interact to see how the autistic person would engage or choose not to engage depending upon the type of person they are.*' (Greenwood, 2015, Interview 1).

Using observations we would therefore analyse the engagement of the child in a particular approach, rather than just enforcing one approach onto them because it is the ethos of the school or because the staff have completed the training.

> *'I think that we are guilty of taking a concept and thinking that this is a good idea so this must work and we will ram it home. But who do you blame for that? You have to look on the basis on that one size does not fit all. It works with some of them. It works with 'M' and doesn't with 'A'.'* (Greenwood, 2016, Interview 3).

Simon's observation here is key and is supported by Tobias and Duffy's research (2009) who stressed that, in autism teaching, a constructivist model should be adopted, by which children were supposed to construct their own realities based on guided discovery-based experiences with a strong focus on the development of communication and language, as these are crucial parts of our everyday working lives (Thompson, 2003). Evidence shows that environments where communication flows efficiently are less prone to stress and frustration (Catuogno, 2016) and communicative competence is directly linked to success both socially and occupationally (Martin, 2014).

I apply the same argument here; would it not be better to ask young people or their families what they feel the purpose of their education would be. This will probably be reliant on what the planned outcomes for that young person will be; and that will be dependent upon whether that young person will be living in full-time care provision, therefore engaging in adult social care provision; living at home with parents attending a specialist college; able to engage with apprenticeships or supported employment or the ability to go on to university.

Mainstream and special schools' expectations are the same and, rightly so, there are no concessions made for special needs schools or pupils. Young people who require additional training for teachers, adapted equipment or support are going to make meeting these expectations harder as there is no additional funding available to schools to support them with these supplementary costs. The impact of this means that autistics are going to be positioned as being a 'problem'. Schools are going to be less likely to accept placements from autistics and government data shows that as of January 2017, 4,050 youngsters with an EHCP or statement were 'awaiting provision', effectively not in school and awaiting for a place in education. This is up 137% compared with January 2016, when the number stood at 1,710, and up 372% compared with 2013 (858 children) (Press Association, 2018).

Whilst it is important to ensure that young people have the tools to effectively communicate, different strategies need to be used at different stages in people's learning process and allow young people to lead their learning. Approaches cannot be proved as successful for all young people, all the time. In order to achieve this it is imperative that a multidisciplinary approach is adopted, where all professionals meet regularly and work together to reach agreed goals and also therefore provide consistency of care and ensure the approach is person-centred and also involves the families (Estrella, 2013). However, with special needs funding at a crisis point, with the majority of schools having to fund their own support with no additional top up funding (Adams, 2015), it seems an impossible goal for most schools to put everything in place which is needed to support young people effectively.

However, it needs to be acknowledged that the quest for improved practice is just a myth. In order to agree what good autism practice looks like would require governance by a new caricature of autism, one that we have already stated is impossible to define. It is therefore key that you adopt a personalised approach, personalised to the individual, needs and setting, and avoid being dogmatic. As Doctor Stephen Shore was famously quoted as saying: 'If you have met one person with autism, you have met one person with autism' (Duffy, Oppermann, Smith & Shore 2007).

Conclusion

The autistic oppressed

In the case of autism, there is no distinction between the reality of the condition and the perceptions of the disorder. Often, within education our actions and our beliefs deceive us; if we are engaging in a ritual, including those we think are ineffective, we will not know that we are beginning to believe in the validity of the ritual before we believe in it. For example, if we behave as though Ofsted judgements are infallible and consequential we will eventually believe that Ofsted judgements are significant. If we promote a strategy, which we know is ineffective but generally thought by non-professionals to be a good thing, then eventually we will believe in the strategy.

This has become the case with autism; we are aware that some of the strategies which we adopt have limited value (Thompson, 2013) but we continue to engage with them. We know that labelling a child inappropriately can damage their self-esteem and self-image but that diagnosis is necessary to access key services.

Autistics have become what Kant would describe as a 'thing-in-itself' where we just see the autistics mere manifestations. We therefore do not know this thing as it is in itself, but only know its appearances (Kant, 1990); in the case of autism, the demonised and the beatified autistic. Similarly, Marx and Engels (1954) argue that when an object is looked at suspended in the air without any context, for example, ignoring the worker who is oppressed under the power of bourgeois, the commodity fetishization occurs. In the case of autism, this commodity fetishization occurs by positioning autistics as 'either severely compromised in their ability to function in the world as we know it or they're a genius' (Greenwood, 2016, Interview 3). Marx argued that commodity fetishism is where a mystical, magical quality is derived from some commodities not because of what they can do for us (use-value) but, rather, from what they mean to us (exchange-value) (Merskin, 2011). This is the case with autism; the autistics have entered a realm where we no longer see the autism as a thing-in-itself but as a mystical being, either beatified or demonised.

This is resulting in autism proving quite an investment for capitalists and this is a further challenge for parents and professionals who want to provide the best support for their young people but are not financially in a position to do so. It therefore falls to the practitioners to create their own resources and adopt strategies, through training one staff member and then cascading the training to other people through internal training, to save money. It is easier in the independent sector where there is a considerably higher level of funding to pay for highly qualified staff, purchase resources and training but equally the young people who the independent sector cater for tend to be the more complex and challenging, therefore requiring a higher level of intervention.

I see the role of a special needs school as far wider than that of a mainstream school, whose role Biesta argues is to standardise young people through *qualification, socialisation* and *subjectification*. Special schools are responsible for developing young people's learning skills, reducing the impact of their adverse childhood experiences, preparing them for an independent life or employment, so that their outcomes are improved from the depressing outcomes which would be their lives if there was no intervention. However, despite the huge pressures on special schools to achieve this wide range of outcomes, on top of academic attainment, we do not seem truly committed to accomplishing this, preferring to keep them oppressed. Individuals with intellectual disabilities have frequently been marginalized, oppressed, and left out of discussions (Brown-Hall, 2018), therefore fortifying their oppression. The looping effect of autism exacerbates the epistemic injustices committed against autistics and ensures that they remain oppressed and controlled by the mainstream, neuro-typicals.

It is argued that autonomy can only be achieved with the castration of its representational object (Tauchert, 2008). We therefore need to remove the looping effect of autism and the false representations, including those of the beatified and demonised autistics, so that the autistics can be truly free them from their oppression. As well as contributing to the looping effect of autism reaffirming the false portrayals of autism, refusing to develop our thinking of autism as a wide spectrum, and not as two polarising points, means that developments in the field are not immediately being translated into practice. Through reading some of the research and developments in autism, there is huge progress being made medically, in identifying an isolated gene (Krishnan, Stoppel, Nong, Johnson, Nadler, Ozkaynak & Anderson, 2017; Wong & Hoeffer, 2018), educationally in new strategies, for example, new ways to teach writing skills (Rago, 2018; Doneski-Nicol & Bartz, 2018); and therapeutically, for example, using social stories in robot-assisted therapy (Silvera-Tawil, Strnadová & Cumming, 2018). Despite all these innovations there has been little improvement in actual practice and outcomes for the autistics themselves.

The work of researchers and practitioners are poles apart and there is a developing chasm between teacher’s practice and researcher’s knowledge, despite the fact that researchers are not the ones engaging with autistics themselves (Pellicano et al., 2014) resulting in us committing epistemic injustice. However, research activity is not established as a meaningful and sustainable expectation of practice within teachers with many citing a lack of capacity and drive as reasons to not engage with research (O'Sullivan, 2017). However, especially with autism education where there are so many changes and developments, it is key that teachers have a positive attitude towards research and ongoing study within the field.

This responsibility can only come from the practitioners themselves to ensure that they keep up-to-date with advances in their own field, to ensure that schools invest time and focus on continued learning for teachers, as well as young people. It is not enough to enter an ever changing and developing field of work like autism and to have completed a course or a master’s degree which in six months’ time is irrelevant due to developments. There needs to be an expectation on continued learning, to drive forward improvements within individual settings whilst also acknowledging that, in education, we work with successive encapsulations all of which produce effects but it is a different register to decide if they are improvements.

This cannot come from the macro because, as discussed, every autistic is unique, with unique interests and needs. Therefore the government has no knowledge of what an individual’s or families’ needs are or what meets the community or school’s ethos and what the prerequisites are. For example, I am the head teacher of two schools, both very different, one specialises in outdoor learning, the other specialises in creativity. Both will therefore follow different pioneering approaches, it is the leaders of those schools responsibilities to ensure that we, like the students, continue learning, to drive forward innovations and therefore improvements in outcomes for young people with autism.

The autistic signifier

Another issue which exacerbates the looping effect of autism and contributes to the epistemic injustices against autistics is that there continues to be many different views and opinions on what autism is, what causes autism, and how to best support autistics. Throughout this thesis I have reviewed the opinions of academics, medical professionals, educationalists, the view of an autistic himself and my own views, as an expert professional situated within the field. However, it has been impossible to truly capture the reality of the autistic condition.

Despite all attempts it is impossible to pinpoint precisely what autism is, it is a discursive enterprise to even attempt. One of the issues with attempting to define autism is that it means many different things to many different people. The presentation in cinema is that of a savant as it is sensationalised for entertainment, print media positions autism as a sublime object, either as beatified or demonised, parents are rightfully protective of their autistic children and tend to promote the perception of savants and the autistics themselves just want a voice. All of these opinions need an equal voice whilst still recognising that everyone is getting it wrong, no one can truly capture the truth of what autism is and everyone is representing only part of the real condition.

‘Autism’ will mean something different to a politician, doctor, academic, teacher or parent. Their understanding of the word will represent their beliefs and knowledge and will influence their understanding of all other signifiers, for example, ‘education’ or ‘progress’. Autism, as an empty signifier, is deprived of any signifying function. Autism is often used in this way to mean something odd and wrong (Borrows, 2015), and not a disorder which signifies a communication or sensory impairment. It is therefore important to have a certain common ground when discussing autism. For example, within my school I have an agreed understanding of what ‘autism’ is with most of my staff; through training and development new staff adopt our shared meaning of ‘autism’. However, if I refer to autism within another setting or with other professionals there is no agreement and I cannot assume that they have the same understanding of autism as I.

This lack of agreement between professionals, academics, families and autistics, further exacerbates the looping effect and contributes to the shortage of understanding of what autism is and, in turn, how best to support autistics. My priority, as a professional driven to improve the lives of autistics, is to understand ways of how I can best advance their progress and outcomes but this seems an impossible task without an agreement on what autism truly is and means the term 'autism' itself is open to equivocation.

Autistics as experts of their own conditions

In order to reduce oppressive action against autistics it is key that there needs to be united effort between researchers and practitioner in a concerted effort to improve outcomes for autistics. However, it is clear that this dual approach is not going to be enough to improve the disappointing outcomes for many autistics and that there has been a gap in autism research to date due to a distinct lack of engagement with the autistics themselves.

The conclusions which are made, by researchers and practitioners, without the contribution of autistics mean that there is a vital gap in the knowledge and conclusions which are been deduced. This hermeneutical injustice immediately puts autistics at an unfair disadvantage when it comes to making sense of their own social experiences, which are described and categorised by people who have not lived that experience.

Whilst we neuro-typicals are missing the critical knowledge which we could gain from the autistics this is insignificant in comparison to the injustice which the autistic faces. The autistics are facing their world and lives been structured by people who have no real understanding of what autistics lived experiences are. It is fair to conclude therefore that there is a dichotomy between the autistics real experiences and the written testimony of researchers and practitioners; further widening the gap between the neuro-typicals and the autistics perceptions of the world. This experience for autistics must be discombobulating and further contributing to the ominous outcomes which they are already facing.

It is clear that this gap in autism research needs to change but this is not going to be done overnight; researchers do not have the epistemic confidence in autistics own testimony (Lord and Bailey, 2002; Wing and Atwood, 1987) despite research suggesting that autistic participants exhibit more scientifically based knowledge than others (Schwartzman, 2017). This change needs to happen gradually and progressively but can only start when more major research engages with autistics as experts of their own condition. Then, over time the receivers of knowledge confidence will improve to ensure that they have the epistemic confidence in the autistics themselves.

A further issue is that the autistics themselves do not have the epistemic confidence in their own testimony and virtues, due to a repeated history of being epistemically undermined, as a 'loss of epistemic confidence is likely to inhibit the development of intellectual courage' (Fricker, 2008, p49). It is therefore a further role of the researcher to instil epistemic confidence in their case study to empower them to share their knowledge.

As argued throughout this thesis a suggested approach to empower autistics to be epistemically confident is to use a case study approach. Engaging with the autistic in this way, viewing them as a co-researcher emboldens them to develop their own epistemic confidence and we all benefit from the increased knowledge their testimony enhances.

Next steps with the autistic experts

One of the key rationalisations of this thesis was that there is very little engagement in research with autistic and this is contributing to a gap in a knowledge about autism, how to define autism, conceptions of autism and, most importantly, how to effectively support autistics (Gillespie et al., 2017). Traditional expert knowledge of autism has often been derived from observations by professionals who often lack the lived experience of being autistic, and there is an understanding that developing a sense of acceptance of autism might increase by listening to autistic people (Nicolaidis, 2012). Research has also found that autistic adults were more likely than non-autistic people to be aware of neurodiversity and to view autism as an essential aspect of identity that needs no cure (Kapp et al., 2013).

Hacking's work (1999, 2006) on the 'looping effect' of autism states that we can shape the way that autism is formed and presented. The loop of interactions between researcher-autistic and professional-autistic not only impacts on the autistic themselves but the non-autistic also. It is this interaction which is key to position autistics as experts in their own conditions and therefore remove the epistemic injustice which has been plaguing autistics.

Some progress has been seen already in this field as autistics have also engaged in contradicting some highly accepted research. For example, Baron-Cohen et al. (1995) stated that a reduced theory of mind is a core deficit within autistic people but Milton (2012) has challenged this thought, instead positioning it as a mutual difficulty relating to neuro-typical people facing the challenge of understanding the minds of autistic people. This new way of shaping previous research could challenge the ways autistic people are positioned.

Research has shown that a greater knowledge of autism results in a lower stigma toward autism (Nevill and White, 2011; White et al., 2016) but, as previously discussed, teachers have minimal training and the majority feel ineffective to teach a child with autism (The National Autistic Society, 2015).

Research has also shown that the best people to educate others about autism are the autistics themselves, Gillespie-Lynch et al. (2017) have demonstrated that autistic adults exhibit a greater awareness of scientific knowledge about autism and describe autism in a less stigmatising way than non-autistic people and may often have an enhanced understanding of fellow autistic individuals (Komeda, 2015).

There is evidence that autistic people often have unique insights which are from their lived experience of being autistic but there are still a limited amount of autistic people being meaningfully involved in research (Jivraj et al., 2014). Simon therefore delivers all of the autism training at my schools. Every staff member has a full day of autism awareness training before joining the team, which ensures that they have the knowledge needed to support the young people and also improves their perceptions of the young people. This also has the effect of new staff seeing Simon being positioned as the expert in the field, something which autistics have been calling for (Gillespie-Lynch et al., 2017).

Another hugely important reason to position Simon, and autistics, as experts in the field and therefore listened to, is the impact which this has on their mental health. The prevalence of comorbid mental health conditions in autism is strikingly high. For example, Eaves and Ho (2008) found that 77% of young autistic adults in their sample had additional mental health diagnoses, including anxiety, depression and bipolar disorder, and difficulties with mental health are consequently thought to contribute to a poorer quality of life in autism (Robertson, 2009). The social model for disability would claim that factors external to the individual cause, for example, an employer’s attitudes or lack of understanding of autism could prevent autistic individuals from finding employment, rather than difficulties an individual may experience as a result of autism itself (Shakespeare, 2006). When applying the social model to mental health in autism, a key factor which has a positive impact on mental health is an individual’s experiences and perceptions of autism acceptance (Cage et al., 2018).

Autism acceptance can be defined as an individual feeling accepted or appreciated as an autistic person (Cage et al., 2018). Autism should be positively recognised as an integral part of a person; Simon acknowledges this with his own children, as he would ‘*take the learning disability away but if I take the autism away then he isn’t A anymore’* (Greenwood, 2016, Interview 3). Autism acceptance from others is important for autistic individuals’ mental health for a number of reasons. Within the mental health literature, perceived stigma from others is thought to contribute negatively to the mental health of stigmatised groups (Mak et al. 2007). Sasson et al. (2017) found that non-autistic individuals tend to make rapid unfavourable judgements about those on the autism spectrum. Furthermore, unconscious biases towards autism can still be prevailingly negative even in those who work regularly with autistic children (Kelly and Barnes-Holmes 2013).

A sense of belonging for any individual is vital to the development of effective well-being (Baumeister and Leary, 1995). This is also the case with autistic adults, research has shown that a sense of acceptance from closer social networks and having the opportunity to engage with others who are like-minded leads to a development of a sense of belonging and therefore improved well-being (Milton and Sims 2016).

Research has shown that young people benefiting from a disabled role model increases their aspirations (Gray and Jackson, 2002) and this is one of the many reasons why I have employed Simon for so many years. The development of high-quality personal connections with autism coincide with lower stigma toward autism (Nevill and White, 2011; White et al., 2016). As a working autistic man he is both a role model and an advocate for my young people. Simon, working in an environment in which he is accepted, inspires the young people in my school to see that there are opportunities and positive work environments in which that can be supported. Simon has also stated he had ‘found it difficult throughout my life to empathise how people feel' but from working in in my schools and being in a supportive environment he thought 'I want that to be my job' (Greenwood, 2016, Interview 3).

For young people knowing that they can work in a setting, despite their autism, where they can be accepted as an autistic is hugely important. Simon describes his working life as 'hard but it is becoming an obsession' (Greenwood, 2016, Interview 3); Simon has approached his job in a similar way as the other obsessions in his life. Simon studies his role and reads around the work which he has done, in one way he is studying how to work in the NT world. For example, he is 'getting away with making eye contact because I have learnt how to do that over years' and this approach to studying his working life means that it is 'getting easier' although 'it's learnt, it doesn't come naturally … getting up, going to work, interacting with people and socialising is all worked at' (Greenwood, 2016, Interview 3). Simon is positioned in a unique position to be an advocate for the other autistics who we work with.

There has been a criticism in autism research that neuro-typical researchers establish the priorities for autistics as opposed to truly establishing what autistic people's priorities are (Pellicano et al., 2014). Having Simon in his role as training and development manager at my school means that he identifies some of the training priorities for the schools which I manage. The fact that Simon is autistic means that the training needs identified are more likely to actually be in line with what autistics need and further drive forward improvements.

The next steps for this research would be to engage with autistic children who have the verbal and cognitive ability to be able to engage in reflective questioning on their condition. This would provide a further insight into strategies which are truly valuable to autistics themselves, not just those strategies which are well marketed or have just become part of the rituals of autism and unquestionably followed.

Final remarks

Throughout this thesis I have discussed the many ways which autistics are epistemically damaged by the looping effect of autism and the dichotomy between autistics experiences and the positioning of autism by researchers and professionals. However, we are beginning to see a shift, the autistics themselves are beginning to rise up and demand that they be seen as the experts in their own condition (Gillespie-Lynch et al., 2017). They are reclaiming autism as their own and not as a commodity controlled by academics, medical professionals or practitioners.

Autistic advocates who are positioned as experts, such as Simon, or Chris Packham (Hogan, 2017), are important within this. To educate others about autism and also to be an inspiration to other autistics to campaign for themselves and to develop intellectual confidence in their own condition. This is especially important within an education setting where role models are key (Lunenberg et al., 2007) and more so important within autism, where being accepted as autistic has such a profound effect on positive mental health (Cage et al., 2018) for a condition which has such shockingly high suicide rates (Richa, et al., 2014).

It is all our responsibility to promote autistics own intellectual insights into their conditions and challenge research which has not engaged with autistics as a vital data source which, if ignored, should invalidate research. Because, if we don’t work with the autistics on this, I think the researchers and professionals are at risk of being left far behind.

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