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An investigation into making mainstream sex and relationship education 'autism-friendly'

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An investigation into making mainstream sex and relationship education 'autism-friendly'

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Abstract:

Considerable attention has been given to deciphering the unique social impairments associated with autism. However, little is known about how these social deficits affect the individual's ability to understand sex and relationship education (SRE) in school, and whether a lack of understanding of this kind of education is a contributory factor in their social difficulties beyond their childhood years. This article examines what may be missing from current SRE, and considers how this kind of education could be improved. It also discusses various common practice autism interventions into which SRE could be embedded (social skill training, social stories, and Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)), as well as a number of key factors in ensuring successful learning on the part of students with autism (teacher and peer training, and early tuition in social skills). From my emancipatory perspective on autism I believe in teaching young persons with autism to understand non-autistic social behaviours, including relationship behaviours, not in pressuring them to adopt such behaviours.

Keywords: Asperger's syndrome; autism; sex and relationship education; social skills training

Introduction

Considerable attention has been given to deciphering the unique social impairments associated with autism (Travis and Sigman, 1998; Volkmar et al., 1997). However, little is known about how these social deficits affect the individual’s ability to understand sex and relationship education (SRE) in school, and whether a lack of understanding of this kind of education is a contributory factor in their social difficulties beyond their childhood years. This paper examines what may be missing from current SRE, and considers how this kind of education could be improved.

It is likely that many children with autism will not innately develop the social skills necessary to function successfully in society (Myles and Simpson, 2001). Social skill deficits associated with autism can affect the ability of an individual to initiate and maintain social relationships, and individuals with autism often struggle to create meaningful relationships throughout their lives (Attwood,2000; Seltzer et al., 2003). Understanding issues related to social interaction, relationships and sexuality may be difficult for individuals with autism without some intervention. Many individuals with autism are not cognitively impaired and are able to attend mainstream education (Emam and Farrell, 2009), yet mainstream schools may lack components that are able to guide these individuals throughout their social development. Attwood (2000) contends that schools do not pay enough attention to the development of social skills, which is necessary for the autistic population that attend mainstream education. Many schools incorporate relationship guidance into statutory sex education within the curriculum of science in secondary schools (Monk, 2001), and by this time it is likely that neurotypical (NT) children will have developed the social knowledge relevant to process this information. Individuals with autism may need some support to develop the same level of social knowledge as their NT peers (Schopler, 1997), and may not have the relevant understanding to process information about sex and relationships at this time.

Specific programmes have been designed in order to help individuals with autism develop social skills and their understanding of social rules (e.g. Beaumont and Sofronoff, 2008; Charlop-Christy and Daneshvar, 2003; Gray, 1998; Sofronoff et al., 2011). However, these practices are often carried out in specialised settings. This paper intends to investigate whether it is possible to improve mainstream education so that it addresses the needs of people with autism by including components that are recognised in the literature as being beneficial for these individuals, and currently incorporated into specialised programmes.

In order to understand what may benefit the autistic population in mainstream education, it is important to discuss the social skill deficits often associated with autism.

An overview of the social skill deficits associated with autism

Individuals with autism frequently show impairments in reciprocal social interactions and demonstrate a repertoire of limited behaviours and interests (APA, 2000). Bauminger (2002) suggests that individuals with autism have difficulties with reciprocal peer interaction and impairments in social cognition. This affects various social mechanisms such as the understanding of the perspectives of others, the interpretation of verbal and non-verbal communication, and the ability to predict the behaviours of others (Crick and Dodge, 1994).

Theorists have suggested that individuals with autism lack socio-emotional understanding (Bacon et al., 1998; Sigman and Ruskin, 1999), and social intelligence (Greenspan and Love, 1997). However, it can be argued that deficits in these areas may be affected by a lack of social experience (Bauminger and Kasari, 2000; Hobson, 1993; Wing, 1992).

Impairments associated with autism may be impediments to the development of satisfactory, age appropriate peer relationships. If an individual exhibits fewer social impairments, they are more likely to achieve friendships with their peers (Orsmond, Wyngaarden Krauss and Seltzer, 2004). Studies have shown that individuals with less verbal ability are likely to have fewer interactions with peers (Sigman and Ruskin, 1999; Stone and Caro-Martinez, 1990), and individuals with fewer stereotypical behaviours associated with autism will have more engagement in social activities and more acceptance from peers (Attwood, Frith and Hermelin, 1988; Lord and Hopkins, 1986).

Research indicates that children and adolescents with autism initiate fewer social interactions than their NT peers (Attwood, Frith and Hermelin, 1988; Hauck et al., 1995; Lord and Magill-Evans, 1995; Sigman and Ruskin, 1999) and spend less time in proximity with their peers (McGee, Feldman and Morrier, 1997). Peer interaction is low in frequency and poor in quality (Lord and Magill-Evans, 1995; Sigman and Ruskin, 1999). Children and adolescents with autism tend to have fewer friends and more experiences of bullying than their typically developing peers (Koning and Magill-Evans, 2001). These individuals will experience less potential for friendship and will be at a significant disadvantage in mainstream school environments.

Social difficulties often persist across the lifespan and many individuals with autism continue to have social difficulties in adulthood (Church, Alisanski and Amunallah, 2000; DeMyer, Hingtgen and Jackson, 1981; Seltzer et al., 2003). Adults with autism tend to have fewer friendships and are less likely to move away from home or get married (Howlin, 2000; Rumsey, Rapoport and Sceery, 1985; Szatmari et al., 1989). In a study in 2000, Howlin, Mawhood and Rutter discovered that around half of adults with autism were reported to have no particular friends with whom they had a reciprocal social relationship. These findings indicate a need for further consideration of what may have been missing from these individuals' education in childhood and adolescence, which may have affected their ability to create positive social relationships.

To date, there has been relatively little research that considers the autistic perspective when developing social skills in mainstream school environments. In order to facilitate research in this area, it is important to investigate the prevalence of students with autism within mainstream schools.

Prevalence of autism in mainstream schools

It will be difficult to accurately confirm prevalence figures regarding autism within mainstream schools, as estimates often include varying data which may be the result of different methodologies such as case finding, sampling, and the use of different diagnostic definitions (Baron Cohen et al., 2009). However, recent studies suggest that approximately 1% of the population have autism (Baird et al., 2006; Baron Cohen et al., 2009). Over the past 10 years, there has been a considerable increase in the number of students with autism who are included in mainstream environments (Emam and Farrell, 2009) and recent figures suggest that around 70% of children with autism are educated in mainstream schools (DfE, 2012).

It is likely that current prevalence figures only account for those diagnosed with autism. Many of the children with autism in mainstream schools are likely to be on a register that confirms that they have special educational needs (SEN), and some studies that have attempted to calculate prevalence figures have screen only children in schools who require additional support in education and a formal diagnosis of autism (Baird et al., 2006). It is possible that in these instances, cases of autism were missed because the children were not recognised as requiring additional support. Also, there are likely to be many individuals with autism who do not have a formal diagnosis. Girls are less likely to be given a formal diagnosis than their male counterparts (Russell, Steer and Golding, 2010). Lower-functioning autism is more likely to be detected during school years (Baron-Cohen et al., 2009). Higher cognitive ability may disguise the pervasive nature of social impairments (Shery, 2000; Willey, 1999) and some children may go through school without being identified as having additional needs. The process of appointing relevant additional support is often dependent on psychologists (Glashan, MacKay and Grieve, 2004), so children without a formal diagnosis my not have access to the same support as those who are recognised as requiring additional support.

The National Autistic Society (NAS, 2003) recommended that interventions for autistic children should commence no later than six weeks after diagnosis. This suggests that individuals with autism who remain undiagnosed are at a disadvantage. Warnock (2010) argued that the needs of this population are more likely to be met in specialised institutions. She expressed concern that autistic individuals may experience inclusion in mainstream education as “a painful kind of exclusion” (p.35), and they are especially at risk of poor outcomes due to negative experiences in school.

There is relatively little research that investigates the impact of educational settings for individuals with autism (Jones, 2006). The assessment of outcomes for children with autism who are included in mainstream education significantly influence policy initiatives (DfES, 2003) yet despite this guidance, assessments seem to be poorly maintained (OFSTED, 2004) and follow-up studies are scarce (Barnard et al., 2000). Parents and professionals are in need of clear evidence on which to base decisions regarding educational placements (Dyson, Howes and Roberts, 2002).

Educational policies in the UK advocate the inclusion of students with SEN in mainstream schools, providing that they have access to additional support, and schools are required to make adjustments to enable students with SEN to be included in every area of school life (DfEE, 2001). If individuals with autism are included in mainstream education, it is intended that they will benefit from positive interactions with NT peers (Robertson, Chamberlain and Kasari, 2003). However, children with autism may require more than just inclusion to facilitate these interactions.

Continuing difficulty in adulthood within the autistic population identifies that there may be flaws in mainstream education, and highlights a need for a better understanding and insight into the unique social needs of this population, and for professionals to continue to learn how to use this insight to improve social skills training and relationship guidance. If education for children with autism includes significantly different approaches in specialised settings, and some (possibly many) children with autism require more than just inclusion in the mainstream to facilitate the interactions with their NT peers that may lead to improved peer learning, it is important to question whether these children are benefiting from inclusion in mainstream schools.

This paper aims to examine whether current SRE practices in the UK can be developed in order to be better understood by the autistic population in mainstream schools, and how current guidelines may be improved. The next section summarises current government guidelines on SRE in mainstream schools.

Current guidelines relating to sex and relationship education

Guidance with regards to social relationships has been incorporated into mainstream sex education since the Government issued new guidelines on SRE in 2000. Currently, there is a responsibility of all educational authorities and managements within each school to include relationship guidance alongside sex education (DfEE, 2000). However, since the release of these guidelines, there has been argument over whether there are inconsistencies in sex education within the UK, as methods of delivering these guidelines differ between schools (Blake, 2008; Buston and Wight, 2001: McLaughlin et al., 2007: Monk, 2001). Although the Education Act 1993 made sex education compulsory in secondary schools in England and Wales, the provision is determined by the management within the schools (DfEE, 2000). Minimal government guidance has led to a lack of consensus on how much SRE to deliver in British schools, what to include in it's content, and the best way to deliver the material (McLaughlin et al., 2007). Inconsistency in the content and delivery of SRE is likely to make the quality of the delivery of these guidelines variable and subject to the personal views of the teaching and governing staff.

Due to rising rates of teenage pregnancies and sexually transmitted infections, guidelines dictate that secondary schools should provide more information and guidance regarding contraception (DfEE, 2000). However, there does not seem to be much recognition that these figures could be improved with more education regarding relationships. Although relationship guidance is included in the guidelines, this is often taught alongside sex education, and therefore included within the curriculum of science within secondary education (Monk, 2001). Relationship guidance seems to have a lower priority than learning about biological aspects such as anatomy, reproduction, contraception and risk of contracting diseases (DfEE, 2000). Guidelines suggest that individuals should be advised on how to navigate relationships, but there does not seem to be written support for how to improve social understanding in order for individuals to create healthy bases for the development of successful relationships.

There does not appear to be any government guidance that indicates that the specific needs of autistic children should be considered in the development of mainstream SRE programmes. The guidelines suggest incorporating the importance of “stable and loving relationships” (DfEE, 2000, Introduction, paragraph 9), but for individuals with autism, there is little direction for schools to help students achieve the social skills necessary to develop these relationships. Some children, especially those with autism, may be learning about the biological aspects of sex before they are able to understand these issues in a social context. It is important that they are given social guidance to support this information before it is introduced. With a greater number of individuals with autism being taught alongside NT students exploring their sexuality during adolescence, it is becoming increasingly important that children with autism develop adequate social understanding at an early stage.

There are many different interventions that have been recognised as being beneficial for children with autism that aid the development of their social skills. The next section discusses the importance of social skill training, and includes some examples of what may help these children through their social development.

Social skill training

It is important that all individuals, regardless of disability, receive the appropriate guidance in order to acquire the skills involved in developing a sexual identity, creating healthy social relationships, and ensuring a positive quality of life (Whitehouse and McCabe, 1997). In order to ensure that people have the best possible support through learning these skills, it is necessary that this support is offered at the appropriate time and at a level that they can understand (Gordon, 1971).

Myles and Simpson (2001) describe the development of social skills as being part of a “hidden curriculum”, which children with autism find difficult to access, but significantly influences their ability to make friends. Often, individuals with autism find social rules much more difficult to understand than those that can be written of generalised in other contexts, which often hinders the development of peer relationships (Emam and Farrell, 2009). Although individuals with autism may have more difficulty developing their social skills than their NT peers, Nichols, Moravcik and Tetenbaum (2008) contend that individuals with autism, regardless of their level of social impairment, are able to achieve the same social skills as NT people if they are offered the appropriate guidance at the right time.

Social skills training has been considered a priority in special education, as a result of many years of concern regarding the risk of individuals with autism exhibiting inappropriate behaviours in public (Tarnai 2006), and research in social skills training for the autistic population continues to address minimising risk of these behaviours (e.g. Charlop-Christy and Haymes, 1996; Griffiths, Quinsey and Hingsburger, 1989; Haracopos and Pederson, 1992; Ruble and Dalrymple, 1993; Tarnai 2006). Within specialised settings, education for individuals with autism has maintained a strong focus on developing social skills (HMIE, 2006). This suggests that people with autism in mainstream education are expected to develop the same skills without the same intervention. However, there may be many students in mainstream environments who could benefit from autism-specific social skills training but do not have access to the same support that is specifically designed for this population.

Most NT people become aware of the social rules regarding developing relationships, but people with autism may have difficulty learning how to interpret social cues, understand responses from others, and follow other rules that govern social interactions that NT people learn as they grow up, through the indirect learning from frequent peer interaction. (Attwood, 1998; Jones, 2006). Myles and Simpson (2001) contend that social skills training and interpretation of social situations should be an integral part of the education of children with autism. With guidance that improves social skills, it is possible that individuals with autism will be able to benefit from an increase in the quality and quantity of social interactions and these children will then have more access to the same indirect learning as their NT peers.

Certain methods have proven useful in social skills training for the autistic population. Although longitudinal research in this area seems to be scarce, and the long-term success of these interventions may be difficult to measure with any accuracy, it is possible that they are able to improve the skills necessary for children to develop social networks in school that provide positive influences for a considerable period throughout their transition into adulthood. As a result, children with autism may have a more positive experience of school, and have greater access to the peer interactions that provide an important source of indirect learning of social skills (Bandura, 1977).

Various strategies have been developed that concentrate on teaching adolescents with autism the social skills necessary to achieve healthy relationships and positive social integration in preparation for adulthood. With certain interventions designed to teach social skills to the autistic population, it is possible to increase their social confidence and knowledge about all aspects relating to relationships and sexuality (Attwood, 2008). Data from social skill interventions designed for individuals with autism may provide important information that could improve mainstream SRE programmes. The next section discusses some of the main approaches of social skill training for this population, and considers other aspects that may improve the individual experiences of people with autism in mainstream environments.

Social Stories

Gray (1998) developed the use of Social Stories to teach children with autism to interact with their peers. Social Stories originated from collaborating with children with autism, and have been successful in teaching social cues and adaptive behaviours to this population (Barry and Burlew, 2004; Reynhout and Carter, 2006; Swaggart et al., 1995), and this strategy has often been used within various teaching programmes (Gray, 1998).

Social Stories describe social situations in a format that has been shown to be easily understood by individuals with autism (Reynhout and Carter, 2006). It is the general understanding that many individuals with autism have strengths in visual processing (Dettmer et al., 2000). Visual supports used in Social Story techniques have been able to enhance understanding of different social situations, and increase social understanding in children with autism (Gray, 1998).

Social Stories can be used to explain various social situations that are often experienced by children with autism, by considering the perspective of each child in the social situations (Gray, 1995). The perspective of the child for whom the story was created is adopted and maintained throughout the duration of the narrative. Stories can be easily individualised for different perspectives according to the specific needs and abilities of each student (Gray and Garand, 1993).

This strategy is derived from the concept that individuals with autism perceive their environment differently to NT people. If this is the case, then it will be important to consider different perspectives in the education of this population, especially when teaching the rules that govern social interactions. For individuals with autism, Social Stories may be helpful in their understanding of social rules, as they are able to provide more explanation for the reasons behind societal expectations (Ivey, Heflin and Alberto, 2004). Throughout the programme, the student’s comprehension of different social contexts is monitored during these sessions, and this has been useful in discovering how each individual perceives a social situation and assessing whether the student has adequate understanding of target behaviours before they are practised in a real-life setting (Gray, 1998). Potential areas of concern are identified and these can be addressed by adapting the Social Story and the approach of this intervention (Gray and Garland, 1993).

Social Stories have been effective in improving appropriate play and increasing positive social behaviours (Barry and Burlew, 2004; Ivey, Heflin and Alberto, 2004), increasing frequency of positive communication between peers (Theimann and Goldstein, 2001), improving the quality of interactions (Swaggart et al., 1995), and reducing inappropriate or aggressive behaviours (Adams et al., 2004; Lorimer et al., 2002).

Myles and Simpson (2001) describe Social Stories as a technique that may be able to provide access to a curriculum of social understanding that the individual with autism may not yet have been able to access. This has been able to provide guidance in how to respond in social situations, and has helped individuals develop self-awareness. Tarnai and Wolfe (2008) suggest the use of

Social Stories when teaching children with autism about issues relating to sex and sexuality, as it may offer help to students regarding potential problematic situations or help them prepare for future stages of sexual development.

Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH)

TEACCH was developed as a programme for children with autism, which included all areas of education, including social skills. This was intended to address the need for an educational tool that could be helpful for individuals with autism of all ages and levels of functioning (Olley, 1986). TEACCH incorporates structured teaching techniques, which regulate the material the child uses, how long the child uses this material, and how the child interacts with this material (Schopler et al., 1971). The structured teaching techniques involved in this programme help children with autism throughout their development by organising their environment, and providing meaningful visual information to support learning (Mesibov, 1997; Schopler, Mesibov and Hearsey, 1995).

TEACCH is based on the concept that individuals with autism share a pattern of neuropsychological deficits and strengths (Mesibov and Shea, 2010). The structured teaching techniques incorporated into TEACCH interventions can be individualised for each student, taking into account the deficits and strengths that are specific to them.

One of the main principles of TEACCH is that parents have active involvement in the educational process, from the initial assessments of individual needs to the subsequent practices that are influenced by these assessments (Olley, 1986). Marcus et al. (1978) were able to show that structured teaching techniques similar to those implemented in TEACCH programmes could be easily transferred into the child's home environment so parents were able to continue promoting positive behaviours at home. Although the level of involvement of the parents differ between each family (Schopler and Olley, 1982), it is likely that the child will benefit more from TEACCH the more actively the parents are involved (Schopler et al., 1984). Comparisons of observations in school and at home will inform practices regarding the specific needs of each individual (Olley, 1986).

Implementation of the TEACCH programme has been able to assist children with autism with non-verbal communication skills (Ozonoff and Cathcart, 1998), and has been shown to have a positive impact on social behaviour (Clements and Zarkowska, 2000; Jordan and Jones, 1999; Jordan and Powell, 1998; Powell and Jordan, 1997). Coupled with a high level of parental contribution, structured teaching techniques have been shown to increase frequency of social interaction, and incidences of appropriate behaviours in play and communication (Short, 1984). In addition, Ozonoff and Cathcart (1998) argue that implementation of TEACCH services in the education of children with autism may help them function more independently as adults.

Mesibov (1982) used the TEACCH programme to outline a developmental approach to teaching sex education, by matching the programme to the child by taking account of the child’s existing social skills. The notion of this programme being used in SRE was developed under the assumption that all individuals with autism require assistance with this kind of education at some point in their lives, but the amount of assistance will vary between individuals and needs to be specified for each person. Once the individual has reached optimum understanding of the social skills necessary to understand the concepts involved in sex education, they are able to move onto the next level, and they are introduced to more advanced concepts in this area. Schopler (1997) created a sex education programme with different levels that can apply to autistic students based on their cognitive functioning. This programme aims to focus on the person with autism and their individual needs, and requires making appropriate adaptations between the tuition of each child in order to meet these needs, and building on their existing skills.

Many theorists have argued that, contrary to the original beliefs that TEACCH is a programme intended to be used in autism-specific contexts, it is possible that the techniques implemented in this programme can supplement current mainstream education and benefit all students, including those with autism who are included in these environments (Mesibov and Howley, 2003). TEACCH may also benefit NT peers by promoting recognition of autism, which may help facilitate healthier partnerships between these populations (Ijichi and Ijichi, 2006).

Teacher and peer training

Difficulties relating to certain characteristics associated with autism have been found to affect the student’s relationship with their peers and teachers (Barnard et al., 2000; Emam and Farrell, 2009). Successful inclusion for individuals with autism, where they can experience positive social interactions, can be achieved if there is a better understanding of autism among professionals and peers (Dugan, Kamps and Leonard, 1995; Kamps et al., 1994).

There is currently no requirement for teachers to undertake any training in autism (Batten et al., 2006). However, Jordan (2005) argues that the role of the teacher is a significant driver in the transformation of mainstream schools into ‘autism-friendly’ environments. A child’s relationship with their teacher can significantly influence their educational experiences and can affect the child's progress through school (Birch and Ladd, 1998; Pianta, 2006). If teachers do not have adequate support and training, this is likely to affect their relationship with the children (Batten, 2005; Glashan, Mackay and Grieve, 2004). In one study, only 22% of teachers had received specific autism training (Barnard et al., 2002), and some studies found that teaching assistants (TAs) had little or no understanding of autism (Glashan, MacKay and Grieve, 2004).

Children with autism may exhibit challenging behaviours in the classroom (Howlin, 1998), and teachers tend to have more successful relationships with children with fewer behavioural difficulties (Birch and Ladd, 1998; Pianta, 2006; Pianta and Steinberg, 1992). Evidence suggests that the personal beliefs of the teacher affect their attitude within the classroom, which can influence the student's self-esteem and achievements (Ashton and Webb, 1986; Tschannen-Moran, Woolfolk Hoy, and Hoy, 1998).

Not all students with autism in mainstream schools will have a statement of SEN, or require additional staffing (Jones, 2006). However, when students with SEN have additional help from a TA, it is possible that these TAs may adopt primary responsibility for the included student, thus reducing interaction between the child and their general teacher (Marks, Schrader and Levine, 1999) and therefore interfere with the development of the student-teacher relationship. The relationship a student has with their teacher can affect their social status (Robertson, Chamberlain and Kasari, 2003), and this can affect their relationship with their peers (Pianta, Steinberg and Rollins, 1995).

Research has shown that many of the successful interventions for individuals with autism in mainstream environments involve actively teaching NT peers about autism and encouraging them to interact with children who seem to exhibit social difficulties (Chan et al., 2009; McConnell, 2002; Rogers, 2000). Peer training techniques are able to help children with autism integrate into mainstream settings (Kalyva and Avramidis, 2005) and increase duration and frequency of peer interactions (Gonzalez-Lopez and Kamps, 1997; Morrison et al., 2001).

Early tuition of social skills

Individuals who are able to successfully navigate social interactions in primary school are able to use this social knowledge as they grow up and are more likely to profit from continued development of social understanding (Hamre and Pianta, 2001; Rogers, 1996). Children who develop greater social understanding at a young age are less likely to have behavioural problems. Such children are also more likely to achieve a higher academic performance in secondary school (Entwisle and Hayduk, 1988; Lynch and Cicchetti, 1997; Pianta, Steinberg and Rollins, 1995).

Incorporated into the Children Act 2004, was an initiative called Every Child Matters: a new approach to help the well-being of children up to the age of 19, regardless of their background or circumstances (Hallam, 2009). An idea that arose from the Every Child Matters initiative was one that described five social and emotional aspects of learning (SEAL): self-awareness, managing feelings, motivation, empathy, and social skills. SEAL promotes the social and emotional skills that are thought to be the basis of positive behaviours and emotional well-being (DfES, 2005) and is incorporated into the tuition of children during various stages and levels of learning. It is currently utilised in over 80% of primary schools (Humphrey et al., 2008).

There are three elements to the delivery of SEAL (Humphrey et al., 2008): the first centres on the development of the school, and intends to create a climate in which the social-emotional skills can be effectively encouraged; the second involves the interventions for children who are thought to require additional support to develop social skills; and the third involves one-to-one interventions with those who are believed to not be benefiting from the first two elements of SEAL.

The SEAL programme focuses on developing social skills and promoting positive social behaviour. Implementation of this programme in a NT context has been able to increase children's communication skills, social and emotional understanding, and confidence in peer interaction (Humphrey et al., 2008), and has had a positive impact on student-teacher relationships (Hallam, 2009). In addition, reports show that SEAL can help children achieve positive outcomes in mental health and educational success (Weare and Gray, 2003).

Although this programme has been shown to have a positive effect on social skill development, there appears to be relatively little research that determines its influence in the social development of children with autism.

As previously mentioned, studies have shown that a relatively small number of teachers and TAs in mainstream environments are appropriately trained to work with children with autism. Evidence has shown that children learn better when their teachers and TAs have a good understanding of the needs of each individual and are appropriately trained to meet those needs (Downs, Downs and Rau, 2008). Also, effectiveness of interventions has been shown to be affected by the level of training of the professionals involved in implementing them (McGee and Morrier, 2005). This is likely to be the same for teaching social skills using the SEAL programme. If teachers are not appropriately trained to work with children with autism within their class, this may affect the success of the SEAL programme.

Discussion

Understanding issues related to social interaction, relationships and sexuality may be difficult for children with autism without some intervention over and above the statutory requirement for SRE. These children have the same rights as NT people to accurate information and comprehensive education that guides them into fulfilling social lives and healthy sexual relationships in adulthood.

Jones and Frederickson (2010) argue that treating all school children equally may not be the best approach in mainstream education. It can be argued that curricular structure in mainstream schools is designed for typically developing children and may not be appropriate for everyone (MacKay, 2002). This paper suggests that current guidelines should take into account that individuals with autism in mainstream education may benefit from social skill training *before* SRE. The fact that people with autism still encounter social difficulties in adulthood suggests that there is still a great deal of work to do through research studies and observations in education in order to determine how to improve the social integration of children. If children experience more and better interactions, they will have more opportunities to develop the social skills and social confidence in interacting with their peers that can create positive social relationships in adulthood. If there is social skills training within primary curricula, this may help ensure that the autistic population receive adequate guidance in the complexities of social interaction at the optimum time to assist them to achieve positive social networks through school and fulfilling social lives in adulthood. However, it is important to ensure that generic primary level social skills training is designed and delivered appropriately for the autistic population.

When SRE is introduced, it is important that all individuals are able to understand and process this information successfully. SRE in mainstream schools is based on typically developing levels of understanding and social maturity. SRE for the autistic population needs to be related to their level of understanding and social maturity (Schopler, 1997). It is possible that current sex and relationship education guidelines can be improved by examining the approaches undertaken by autism-specific educational strategies relating to SRE.

Due to the increase in the inclusion of students with autism in mainstream education, professionals feel a sense of urgency to ensure that children with autism have access to the most effective intervention (Jones, 2006). Teachers are under considerable pressure to ensure that the inclusion of these children brings maximum benefit to the children themselves, and their NT peers (Emam and Farrell, 2009). It is important that teachers understand that children with autism may need additional support through school, and this may involve allowing extra time to process new information (Happé, 1999; Lawson, 2001), or teaching skills that they would not normally teach (Jones, 2006).

Schools can benefit from raising awareness of autism. The provision of support and the views of the teachers are significant predictors on whether the inclusion of a pupil with SEN is likely to be successful (Balshaw and Farrell, 2002). Many children with autism with a statement of SEN due to behavioural problems, but no formal diagnosis of autism, will have distinct needs that are different from NT children with behavioural problems (Happé, 1999). With appropriate training for educational staff, the children with autism within mainstream environments will benefit from the fact that professionals involved in their care have a sufficient understanding of their perspective. Teachers with a thorough understanding of autism are more likely to successfully guide their students' integration and encourage their interaction with NT peers.

With interventions in place that educate NT peers about autism, it is possible to encourage more frequent and better quality interactions during school time and beyond the class environment. Peer-mediated strategies have been shown to be successful in increasing social interactions, and with a better understanding of the perspectives of children with autism, their NT peers may have a greater willingness to discount the social impairments often associated with autism (Jones and Frederickson, 2010).

Parents should be aware of their influence in the education of their children. As previously mentioned, the more the parents are involved, the more likely the child will benefit from continued social skill development at home. Also, with healthy partnerships between the parents and the professionals involved in the child's education it will be easier to assess individual developmental levels, which may be able to guide further educational approaches.

Often, people with autism lack the opportunities to practise social skills. With recognition of this lack of experience, it is not necessarily complicated to address. With interventions throughout primary and secondary education that concentrate on increasing the frequency and quality of social interactions, partnered with social skills training to increase social understanding, these individuals are able to learn important skills necessary to have positive social experiences throughout their life. Social skills training strengthens the resources of individuals with autism, and provides the kind of support needed for the individual to integrate into social worlds. This integration will not only increase the quality of life of individuals with autism, but it will also benefit society if there is a greater understanding and acceptance of autism in the community and a greater opportunity for individuals with autism to achieve their full potential as citizens.

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Does the different presentation of Asperger syndrome in girls affect their problem areas and chances of diagnosis and support?

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Does the different presentation of Asperger syndrome in girls affect their problem areas and chances of diagnosis and support?

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Abstract:

I do not suggest that it is only girls with Asperger's syndrome (AS) who go undiagnosed and unsupported. But it was becoming involved with a family friend, and others driven to distraction trying to get their daughters' needs recognised, that motivated me to reconsider the purported ratio of between eight and ten boys with AS to every girl and to examine whether the professionals' perceptions of what AS "looks like" are too narrow, and the diagnostic tools too male-centric. To achieve this I have reviewed autism theory, considered how and why girls present differently, discussed the specific problem areas faced by girls with AS, and issues around diagnosis of girls. In addition, I undertook a survey of women with autism to ascertain their experiences of seeking diagnosis and support. I conclude with a list of 30 alternative diagnoses given to females subsequently diagnosed with autism, and various quotations that highlight the difficulties these women faced.

Keywords: Asperger syndrome; autism; diagnosis; support

Introduction

> Sophie used to be physically sick in the mornings because she didn't want to go to school. Then one day she walked home while [her mother]Nic was at work and texted her to say "Please don't ever make me go back". Sophie was a target for bullies because she too constantly found herself on the edge of things, unable to interpret social cues... however, she would not retaliate – terrified of breaking any school rules – and instead

> soaked up the abuse until she got home to safety, when the tears and meltdowns would start.
>
> She would say “Why am I like this? Why am I so stupid? I wish I was dead!” But the head just said they needed to toughen up.(Walker, 2012, p. 49)

Sophie, who was originally diagnosed with Sensory Processing Disorder (SPD), eventually received a diagnosis of Asperger’s Syndrome (AS) and went to a different primary school for year six, where she was treated with much greater understanding and intelligence. However she suffered long term psychological consequences lasting into secondary school, sometimes causing much alarm to her parents, who attended the “ASD parents' support” drop-in, run by our local Child and Adolescent Mental Health Services(CAMHS). Sophie and my daughter Libby now rank among each other's best friends - not that either has many friends – and Nicky and I find ourselves constantly on the lookout for things pertaining to giraffes and dolphins, being respectively Sophie and Libby’s “special interests”. We understand these things about our daughters, and appreciate that they have found each other, as most other children we know diagnosed with AS are boys.

Our family's experience was very different to Sophie’s. Although Libby is far from conforming to the “norm” compared to other girls in her class, she is also quite far from the “norm” for girls on the autism spectrum. At times excruciatingly shy, she is at other times to the same degree compelled to announce her opinions or dissatisfactions. At the inception day for the reception class at her primary school, she had within minutes found a board rubber, and replaced the welcome message with a drawing of a dolphin. Subsequent outbursts in class, such as when a teaching assistant (TA) cropped a picture of her guinea pigs to make a collage, meant that her reception teacher identified her at age four as apparently requiring a diagnosis. Within a short time, Libby had an AS diagnosis and a Statement of Special Educational needs (SEN) in place, as well as a wonderfully knowledgeable and kind TA. We have good support from an excellent Speech and Language Therapist (SALT), and also the team at CAMHS. Although we still have a lot of difficulties, stresses, frustrations and sometimes heartbreak due to Libby having AS, I came to realise that relatively, we were very much the lucky ones.

I do not suggest that it is only girls with AS who go undiagnosed and unsupported – I know several boys who were only diagnosed in Key Stage 2 or even later. But it was becoming involved with Sophie's family, and others who were driven to distraction trying to get their daughters' needs recognised, that motivated me to reconsider the purported ratio of between eight and ten boys with AS to every girl (Brugha, 2009; Roth, 2010; WHO, 2010) and to examine whether the professionals' perceptions of what AS “looks like” are too narrow, and the diagnostic tools too male-centric.

Overview of theories relating to Asperger Syndrome

The term Asperger Syndrome was initially coined by Wing in 1981, after her husband translated Austrian paediatrician Asperger’s paper, from 1944. Written in German, Asperger’s paper described what he termed “autistic psychopathy", a particular pattern of behaviour observed in a group of children who were his patients. By this he meant that these children seemed to have little social interest in other children or adults, and were more focused on objects, as well as demonstrating repetitive behaviours. Additionally, diminished eye contact, motor clumsiness, unusual speech, impulsiveness and sensitivity to sensory stimuli and to unexpected events were noted.

Coincidentally, in 1943 another Austrian, psychiatrist Kanner, published a paper entitled “Autistic disturbances of affective contact”, about a similarly presenting group of children. The key differences were that Kanner’s group of children also had learning difficulties, and that as he had emigrated to America twenty years previously, his work, in English, became widely circulated, whereas Asperger’s did not. Consequently, for about four decades the belief prevailed that autism was intrinsically linked with a low Intelligence Quotient (IQ).

During the 1980s, Wing, and her colleague Gould, introduced the concept of an autistic spectrum. The spectrum encapsulated the full range of intellect, from those with severe learning difficulties, to the very intellectually able – much like the general population. Additionally, the spectrum concept acknowledged the great variance in the way that other markers of autism might present in an individual. For example some might cope better with unexpected change, or have more ritualistic behaviour, better emotional regulation or greater sensitivity to sensory input.

In 1979, Wing and Gould developed the theory of the Triad of Impairments in autism, as a result of the “Camberwell Study” of a group of children at London’s Mawdsley Hospital. This “triad” consisted of differences in social interaction, social communication, and flexibility of thought. These areas of difference are still very widely used by practitioners when considering a diagnosis of autism or AS, although under the recently compiled Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5) the two social differences have become merged. DSM-5 has also ceased to use the term Asperger Syndrome, so people who had a diagnosis of AS now have autism.

Removal of the AS diagnosis can be confusing or upsetting for some people; as will be discussed below, identification with a particular group can be empowering for many people. However, it seems that in the UK for now at least, where the World Health Organisation's diagnostic manual (currently the International Classification of Diseases, version 10) is in general usage, practitioners are tending to ignore the DSM and continue to give diagnoses of AS where appropriate. The main differences, and possible reasons why people may wish to maintain a separate classification, are that those with AS are recognised as having at least an average IQ, often higher, also no significant speech delay. However there are many with "high functioning autism" (HFA), who may be just as intelligent, but did have delayed speech. Various writers, notably Ros Blackburn, argue that unlike people with AS, those with HFA have no social interest whatsoever. (Blackburn, 2011).

The theory that if someone is unable to imagine or work out what somebody else is thinking or feeling, they would struggle with social interaction and social communication is referred to as a lack of "Theory of Mind" (ToM). In 1978 the philosopher Dennet suggested that a good test of whether or not someone had a ToM would be see if they were able to understand the concept of false belief. In 1985, Baron-Cohen and Frith applied this theory to a selected group of children, using the "Sally – Ann False Belief Test". Some of the children were known to be autistic, some had Down Syndrome, and some neither. They were matched for mental age. In the test a doll named Sally put a marble into a basket and then went out of the room. While she was away another doll named Ann transferred the marble to a box. The children were then asked where Sally would look for the marble on returning to the room. The prediction was that most children with autism would expect Sally to look in the box because they would fail to understand the information *they* had, from having seen Ann's action, was not shared by Sally.

This test allegedly demonstrated that children with autism lacked ToM as they did not realise Sally lacked the knowledge of events that they had. This conclusion has, however, been criticised for several reasons. Firstly, the experiment involved only twenty children who had autism – a small sample population. Additionally, the test

> …relies upon verbal interaction and language processing, areas in which autistic people are understood to have serious difficulties. In fact, in a 2005 paper, Morton Ann Gernsbacher and Jennifer L. Frymiare point out that the syntactic form of the questions posed by the test is one of the most complex in the English language (Cohen-Rottenberg, 2011)

Linked to Baron-Cohen’s theory of impaired ToM, was the theory that people on the autism spectrum therefore also lack empathy. But many examples can be given of situations where people on the spectrum demonstrate more empathy than those who are not on the spectrum. In our own case, I vividly remember Libby becoming extremely distressed in year three from learning about the Second World War, and subsequently in year four from learning about the lives of Victorian children working in the cotton mills of north west England. Both topics involved school trips, firstly to the Manchester War Museum, and Stockport Air Raid Shelter, and subsequently to Quarry Bank Mill in Cheshire. The trips did an excellent job of bringing the topics to life for the children – too much so for Libby, who had huge difficulty getting to sleep afterwards, because she felt so anxious and sad about the plight of children who were either in danger of being bombed, or of becoming trapped in the mill machinery, and generally mistreated. She was eventually re-referred to CAMHS with anxiety and depression. Nobody else in her class seemed to be so affected – they just learned about it, and moved on.

According to Henry and Camilla Markram’s Intense World Syndrome theory (2007):

> The intense world that the autistic person faces could easily become aversive if the amygdala and related emotional areas are affected with hyper-reactivity and hyper-plasticity. The lack of social interaction in autism may therefore not be because of deficits in the ability to process social and emotional cues as previously thought, but because a subset of cues are overly intense, compulsively attended to, excessively processed, and remembered with frightening clarity and intensity. Autistic people may therefore neither be mind-blind at all nor lack empathy for others, but be hyper-aware of selected fragments of the mind, which may be so intense that they avoid eye contact, withdraw from social interactions and stop communicating.

Additionally, it is worth considering how many crimes are committed, showing total lack of empathy, by people who are of the predominant neurotype (PNT)![1]

Another area where people with autism and AS are perceived to have a weakness is in the area of Executive Function, that is, the ability to plan, self-monitor, and organise time and resources (Sainsbury, 2008, in Roth, 2010).

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[1] The predominant neurotype refers to those people who do not have an autistic neurological profile i.e. the majority of the population.

Tests such as the “Tower of Hanoi” and the “Winsconsin Card Sorting Test”[2] are claimed to demonstrate “perseveration” over the ability to see and respond to the bigger picture. (Klin, 2000).In some ways, I see this every morning, where Libby becomes so engrossed in cuddling the cat, or trying out hairstyles / faces in the bathroom mirror, that we frequently have a nearly-late-for-school trauma. But no children are great at this sort of discipline, and with hope, she will grow to join the large number of adults with AS who are very capable of planning and understanding the need to avoid becoming “stuck” in one activity. Yes, she forgot to take her flute to school, but if *her mother* had not also forgotten, it would not have presented a problem!

According to the original theory of Weak Central Coherence (Frith, 1989), people with AS and autism tended to be so focused on the detail of input from the environment, whether it be a picture, or a story, that they missed the wider context, and the overall significance of what they were seeing, or hearing. Donna Williams describes this aspect of differing sensory perception in a way that I think gives particular insight to those not on the spectrum: ‘The three hour trip was in slow motion. Everything was back in bits. Everything was a captivation pattern of colours – green triangles, gold squares, blue into which I looked up and felt myself swimming’ (Williams, 1992, p. 58).

However, as with all of the theories mentioned above, the huge diversity within autism means that the extent to which individuals are affected can vary greatly, and attention to detail can be seen as a strength. Happé and Frith have, more recently, pointed out that ‘The person with strong coherence may be a terrible proof reader’ (Happé and Frith, 2006, p. 11.), and conclude:

> There is a strong and growing body of evidence that people with ASD [autism spectrum disorders] are characterised by superior performance on tasks requiring detail-focused processing. Whether this superiority is achieved at the cost of normal global processing is less clear… It has also become clear that people with ASD can process globally for meaning when explicitly required to do so, leading to the notion of a processing bias for local over global levels of information [+REF]

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[2] The Tower of Hanoi is a mathematical puzzle involving the movement of a stack of discs, much like a toddler’s “stacking rings” toy, from one vertical pole to another, using certain rules. It is used in psychology to test the ability to form a strategy, i.e. executive functioning. The Wisconsin Card Sorting Test uses different cards with colours, shapes and numbers of symbols designed to test ability to switch tactics, i.e. mental flexibility.

Of particular interest to me is the perceived link between this processing style, and prosopagnosia, or “face-blindness” (Happé and Frith, 2008).Many times, a TA or a playground assistant has said “Hello Libby” at the local supermarket, but she just stares blankly at them, even though she sees them every day at school, and thinks that they are nice. Yet she can describe in detail the cot and the carpet in the crèche, from nine years ago.

How and why Girls present differently

Probably the most obvious areas in which the presentation of girls with AS differs from that of boys are that girls tend to be more sociable and are less likely to be disruptive, aggressive, to have attention deficit hyperactivity disorder (ADHD) or extremely arcane “special interests”(Attwood, 2006).Again, there is great variance, and there are overlaps of behaviour between genders. For example, when our daughter was first referred, I thought that the teachers suspected ADHD, as she was so impulsive and hyperactive. At that time she was also far more interested in bikes and “Bob the Builder” toys than she was in dolls and toy kitchens, like most little girls of three or four.

Generally, however, girlswith AS demonstrate better concentration, and their behaviour and play will centre more on obtaining attention from another person. As young children, they are more likely than boys to engage in “joint attention”; sharing a gaze and an interest with another person. They are usually more interested in social interaction, though often are frustrated by their lack of success in this area. Boys’ play is typically more about obtaining objects, and less about being socially interactive (Ashton-Smith, 2013). Girls are more likely to be able to speak about their feelings, and their “special interest” is more likely to be dolls, horses, cats, or literature, which on the surface seem age appropriate whereas an exhaustive knowledge of 17thcentury French mathematicians or different kinds of pylons or manhole covers would generally be regarded as odd or eccentric at any age. However, it is the *intensity* of these girls' interests that are unusual, but often overlooked by teachers and parents.

Autism is known to be of polygenic epidemiology, that is, there are many different genes involved in the genetic inheritance of a person who has autism, and therefore the manifestation of autism can vary greatly between individuals. [+REF]It is also widely believed that “environmental factors” play a role, but currently, those factors remain largely elusive. However, some studies (Schellenberg, 2006) have suggested that the genes that code for autism in girls are not the same as those for boys. Seemingly just as red-green colour blindness is mainly transmitted through male genes, or a tortoiseshell cat is always female, the different facets that make up autism seem more likely to be exhibited in one gender or the other. This often results in more acquiescent behaviour in girls, and more aggression or disruptive behaviour in boys, who are consequently more likely to be referred for diagnosis.

Girls’ language typically develops in sophistication and abstraction earlier than that of their male classmates. This, combined with different physiological and emotional development, and transition to secondary school, frequently causes the time of puberty to distinguish girls on the spectrum, who had previously seemed to blend in through their use of echopraxic behaviours. That is, girls with AS will very often carefully watch other girls, to learn how they are expected to behave, and therefore can for several years seem to be fitting in socially. For example, an autistic autobiographer has written that: ‘I watched people like a scientist watches an experiment’ (Holliday Willey, 1999, p.42).

Whereas for most of the boys their differences in social interaction and communication will have been more obvious at an earlier age:

> Often the drawbacks for an AS girl only become painfully obvious when she hits adolescence or puberty when her childhood friends, if she had any, may begin to distance themselves from her quirks and align themselves with other, less awkward, more popular girls.
> (Simone, in Clark, 2010,p. X)

Specific Problems of Girls with Asperger Syndrome

At first glance it may appear that girls with AS are relatively at an advantage compared to boys. After all, they quite often develop the social skills to make at least one friend, whereas boys are less likely to do so. Girls are more likely to be taken into the protective oversight of older girls with mothering instincts (Ashton-Smith, 2013). Boys are more at risk of being physically bullied, and/or of being suspended or expelled from school because of retaliation to such bullying, or because of aggressive or disruptive behaviour in response to other triggers. But the apparent advantages of being a girl with AS can be very much a double-edged sword because below the surface can be many issues some of which I shall now discuss.

Although girls with AS may be able to make a friend, they are often quite possessive, and tend to struggle if that friend wants to widen their social circle. The life of a friendship can be limited if a girl becomes too ‘clingy’ and suffocating. Holliday Willey writes that: 'I simply could not see the point in having more than one friend and I could never imagine Maureen might feel differently...I never understood group dynamics' (HolidayWilley, 1999, p. 20).As Iland says, 'Girls travel in packs and have a group mentality' (Iland, in

Attwood, 2006, p. 30) which poses significant problems for girls who can only cope with mutually exclusive[3] friendships.

Even if a girl has been “taken under the wing” of older girls in primary school, their difficulties are not all resolved as there will come a time when the older girls move on to secondary school, leaving the AS girl without the buffer that had previously existed between her and other less nurturing personalities in the playground. This has happened to my daughter recently as two girls from year six who spontaneously and unofficially mentored her, have now finished primary school. It is an unsettling time, and her parents are at least as apprehensive as she is about what year six will be like for her. We are trying to reassure her that there will still be some friendly faces in her class and we invited the two former mentors to join her sailing on a local lake in the holidays. They all had a fun and exciting time, and hopefully it will help to maintain that friendship into the future.

For many girls on the spectrum it is transition to high school that really puts their issues into stark relief (Reynolds, 2013). Although they share with boys the difficulties associated with having lessons with different teachers, in different classrooms, and needing to find their way there on time, with the right equipment, they have additional problems. At this age, the conversation of most girls increases rapidly in abstraction and sophistication, discussing relationships, and using intimation and the latest vernacular. Often girls with AS are left behind.(Fahertry, in Attwood, 2006). They usually do not pick up on social trends, or learn lessons by inference or indirect learning, needing to be told things explicitly, so are commonly left behind in both areas. They will not instinctively tell a “white lie” to promote social harmony; '...life is full of double standards. Don't lie, but tell me my haircut looks good….' (Clark, 2010, p. 153) Poor social skills limit opportunities to improve social skills. Girls with AS often struggle to distinguish between the gentle, friendly teasing and sarcasm that can strengthen affectionate ties between friends, and the malicious sarcasm that is associated with bullying, especially by girls. Several times I have witnessed Libby almost kill off a friendship by responding angrily to what I *know* was genuinely friendly banter. It is confusing for her, and also bewildering for the other children.

Holiday Willey graphically explains the difficulty she experienced trying to “keep up” with her peers' conversations:

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[3] By ‘mutually exclusive friendships’ I mean that both girls are only friends with each other, to the exclusion of other friendships, not the more usual meaning of the phrase whereby two things cannot occur simultaneously, such as summer and winter.

> I understood their language, knew if they had made grammatical errors in speech, and I was able to make replies to anything that was spoken to me; but I never came to hear what they were really saying. I never understood their vernacular...I was unable to read between the lines... Subtext and innuendo may as well have been birds flying by my window. It was frustrating being unable to break into the thought processes of my peers but I was even more upset when I came to learn that I never learned from one experience to the next.
> (Holiday Willey, 1999, pp. 56-57)

By the teenage years, most PNT girls will reflect on their own thoughts (metacognition). As this level of abstraction tends not to come so easily to girls with AS, it increases the divide between them and their peers (Nichols et al., 2009).Left out of groups and cliques, they may stand out, and become vulnerable to bullying. Although less likely to be physically attacked than boys, many people would argue that the effects of the more subtle “bitchiness” of girl-style bullying can actually have more profound consequences on the emotional health of a girl, especially if the bullying is fairly cryptic so that it takes time for them to realise they have been bullied, then feel additionally stupid and low(Ashton-Smith, 2013). Simone writes that: “Sometimes we don't realise we are being bullied until it gets really bad” (Simone, 2011).

Physical bullying is obviously very traumatic, but as it is usually more obvious than whispers, giggles and knowing looks, it may be more likely that schools will intervene, where as it is much harder for them to notice and stop sly, hurtful comments. Simone explains:

> Bullying happens when someone is different and is seen as a threat in some ways, yet seen as weak in others. Aspergirls fit the bill perfectly...For a spectrum child it can be the beginning of lifelong post-traumatic stress disorder (PTSD)
> (Simone, 2010, p. 28).

There is no sharp divide between the behaviour of males and females in this respect; girls do sometimes physically attack, and boys make derogatory jibes, but ‘In a 1994 paper, Lainhart and Folstein pointed out that despite the 4-to-1 male-female ratio for autism, females made up half the autistic patients with mood disorders described in the medical literature’ (Bazelon, 2007).

Simone says 'When the perpetrators see what an effect they're having they redouble their efforts’ (Simone, 2010, p. 31).Libby had experience of this towards the end of year five. One lunch time she was followed around the playground by three slightly younger girls who kept saying “You're weird” and giggling. Libby, who was on her own at that time, had the acumen to say “How would you feel if it was you?” to which one replied “We don't care ha ha-ha!” and another said “Yeah! Keep on laughing!” As I had taughtLibby not to retaliate physically in this sort of situation, she approached the adult supervising that playground, who said “Oh just ignore them”. I subsequently asked the school how a ten year old girl with AS can be expected to “ignore” three girls who are going out of their way to taunt her for forty minutes. The school did intervene swiftly and effectively after I complained, but sadly many parents report that schools commonly fail to take such action.

Despite the dawn of the “new man” in recent decades in some areas of society, the fact remains that women generally face greater expectations to conform to the perceived requirement to dress attractively, to be sociable, supportive, and to be able to multi-task, for example juggling childcare, work, providing food and keeping the house clean. This places girls and women with AS under greater strain than either their more typically developing female peers, or males with AS. They truly are in the position of being “a subculture within a subculture” (Simone, 2010, p.13).

As Ashton-Smith (2013, n.p.) points out:

> Bright but eccentric” is a description that seems acceptable when applied to males, but somehow not so much when referring to a female. A professor of nuclear physics may have a “social navigator” wife to guide and smooth over social hiccups, but as women are supposed to be the most social beings, the reverse situation is unlikely.

Lawson conveys the situation eloquently in her poem 'Build Your Own Life. A Self-help Guide for individuals with Asperger's Syndrome':

> I cannot account for these feelings
> Emotions intense and extreme
> But my issues with everyday dealings
> Can cause me to rant, shout and scream
>
> I don't desire the “make up”,
> Fashion and high heels don't appeal
> I don't like perfume or my hair cut,
> But my need for understanding is real...

> Your children and men depend on you
> You must be strong, independent and sure
> What if these things I cannot do?
> What if my timing is poor?
> (Lawson, 2003, p.81)

Sadly, females with AS are more vulnerable than their peers to unwanted sexual attention, whether it is relatively milder forms of harassment, or serious criminality. As many of them are less socially mature, or aware of appearances, than their classmates or workmates, they are more likely stand out, and more likely to be alone. Because of difficulty in “reading between the lines”, girls can struggle to work out the intentions of approaches from the opposite sex, or to find the confidence to effectively rebuff unwelcome advances. For example, Williams writes that: 'I was easily led and easily conned and I was easy pickings for egocentric bullying types... As I was completely unable to say, let alone acknowledge what I did or didn't want, boys found that they could mentally corner me' (Williams, 1992, p.74)

If they stand out as being awkward, and not very “streetwise”, girls with AS can become targets for opportunistic offenders. (There are indications that several of the girls involved in the recent high profile cases of grooming by paedophile gangs are on the autistic spectrum.) Girls with AS usually have a stronger desire than boys to have friends (Holtman et al., 2007, in Reynolds, 2013) and as such can be particularly susceptible to grooming. According to Newport and Newport (2002, p. 34) 'The relative naiveté of autistic girls or their possible wish to trade sex for 'popularity' may initiate them far earlier [into sexual activity] but rarely in a healthy way’. Mary Newport writes:

> Puberty helped me in some respects because I became sexy. I did everything to cultivate my looks. My peers’ reactions began to change in ninth grade. I was not ridiculed as much. However, puberty was hard because adults were having sex with me, offering me marijuana etc. I only had relationships with adults. None of my friends were my age.

As a parent, I become increasingly preoccupied by the difficult balancing act of teaching awareness of matters concerning relationships to my daughter, without stirring up so much suspicion that she might execute a martial arts defence move on the first boy who tries to hold her hand or put an arm around her! But the unsettling fact remains that there are plenty of men willing to use and abuse females, and those on the spectrum are less likely to instinctively realise when they are in a manipulative or dangerous situation. It is well documented that boys can be subjected to abuse as well, but, statistically, it happens far more to girls and women, especially if they are vulnerable to begin with.

In the context of relationships and sexual maturity, the time of puberty can be particularly distressing for girls on the spectrum. They are often bewildered and unsettled by changes to their bodies. One girl I know of was so unhappy about starting to develop breasts that she handed a pair of scissors to her mother, and asked her to cut them off. *She was totally serious.* A girl who began menstruation had to miss school on the first few occasions as she found it so overwhelming. The anxiety about managing sanitary items, and the hormonal onslaught on her already delicate emotional balance, was all too much. I know that Libby is relatively lucky that I am reasonably “ahead of the game” in this respect; I have tried to inform myself well, and learn from the experiences of families with girls on the spectrum. (But there are times when the false reassurance of being blissfully unaware would be more conducive to being able to sleep.) Girls with AS may also be more prone to precocious puberty than their peers and may experience more severe pre-menstrual (PMS) symptoms than non-autistic girls. (Sicile-Keira, 2006,in Nicols et al., 2009).These symptoms can involve:

> Type A: Tension, irritability mood swings angry outbursts
> Type B: Breast tenderness, swelling, upset stomach, weight gain, swollen hands and feet
> Type C: Appetite changes, cravings, feeling tired, overeating
> Type D: Moodiness, memory loss, sadness, crying spell
>
> Not fun for anyone but imagine how it must feel for a young woman with an ASD who thrives on stability
> (Nicols et al., 2000, p. 119).

Fortunately, being a syndrome, not every woman experiences all of these PMS symptoms, but mood swings can be particularly extreme for girls with AS, and that can be very frightening for them. The physical pain of menstruation may also be overwhelming, especially for someone with sensory hypersensitivity, and can have implications in terms of functioning at school and work.

In connection with the issue of weight gain during puberty, it is not uncommon for girls and young women on the spectrum to be anorexic, as this offers an opportunity to gain some control over their immediate environment (i.e. their own bodies), and to slow or even reverse the otherwise unstoppable progress of puberty. Anorexia predominantly affects girls, and it is believed that twenty percent of anorexia patients are on the autism spectrum(Treasure, 2010). Treasure explained that the effect of starvation on the brain can reduce the set-shifting ability of girls who are already attracted to the rules and systems involved in being anorexic, so the cycle becomes ever harder to break (Laurence,2010, n.p.)

Some people view anorexia as simply “a diet gone too far” or a desire to resemble a celebrity, rather than a serious mental health issue. I personally know two women who are or have been anorexic; one is my sister's best friend, and one is a very close friend's niece. Both are intelligent women, neither has been diagnosed with AS, but both became anorexic in response to emotional trauma; childhood abuse in one case, and her parents' divorce in the other.

My sister's friend managed to break the anorexic cycle when she became a mother, but after her marriage failed, her teenage daughter began self-harming, and displaying quite a lot of signs that she may have AS. She is under her local CAMHS; I hope that they will pursue this. My friend's niece has been in and out of “The Priory” for years, and has been very close to death several times; the effect of anorexia on her and on her family is devastating. She is also tall. Apparently tall girls are more at risk of anorexia, depression and teasing (Nichols et al., 2009). Libby is on the 98th percentile for height(i.e. out of every 100 girls her age, two are taller, and 97 are shorter.)(Sometimes I wish I had not learned so much; it could be counter-productive if I worry myself into ill health. I have already cracked two teeth and developed temporo-mandibular joint disorder (TMJ) from stress-related grinding of my teeth at night.) Another disadvantage of Libby being so tall is that people assume she is about thirteen, and therefore expect her to be far more mature and socially able than she is. And it is another way in which she stands out among her peers.

Self- harming is another area where girls with AS seem to be disproportionately represented (Ashton-Smith, 2013). It can seem like a form of control over one's emotions, as the physical pain temporarily replaces the emotional pain of being bullied, ostracised, lonely and anxious. The publicity surrounding the recent suicide attempt and apparent self-harming of Michael Jackson's teenage daughter Paris has drawn attention to the alarming rise in the number of girls who self-harm. Many elude the attention of medical or mental health services, and many have issues that are not as a result of being on the spectrum. As widely reported in the media, many children in the Western world are unhappy mainly due to lack of input from time-poor, or disinterested parents, focus on material possessions, and pressure to live up to the image and lifestyles of celebrities, in their own environment, and on social networking sites. But girls on the spectrum are additionally likely to feel excluded and the stresses are often compounded by the emotional exhaustion of using social echolalia to try to fit in. They are less likely to have friends to turn to for emotional support. Ashton-Smith (2013, n.p.) describes the potential effects of AS girls' usage of social echolalia as follows:

> Girls tend to be more tuned into watching social skills, and using social echolalia to give the superficial appearance of social understanding. If we want to relate with someone, we tend to act more like them...But to lose themselves in the emulation of the identity of another person, however talented, popular, kind or clever that person may be, is to lose touch with oneself, and this can be very damaging, and lead to profound psychological problems, and also to self-harm. Girls on the spectrum are very prone to depression.

Yaul-Smith (2008) in Nichols et al. (2009) writes of the "social exhaustion" experienced by females on the spectrum, as a result of the strain of pretending to fit in, using intellect and effort, rather than instinct and inclination. Simone describes the debilitating effect of the expectation to engage in social chit-chat which to many AS girls has no obvious function. Social discomfort can cause adrenaline overload, which in turn can lead to stomach problems, or sometimes to selective mutism. In this respect, Simone writes that: '...our challenges are very real, but not always obvious to others. Therefore our behaviour is not understood.' (Simone, 2010, p.13)

Diagnosis

Before a child is referred for an AS assessment, they need to have been identified as possibly having AS by a teacher, SALT, general practitioner or paediatrician. Setting aside influences such as funding, politics, or the ethos of an individual school, which can affect the chances of this happening, a child needs to stand out in a way that will alert the teacher or practitioner to the possibility that they may have autism. As girls are often so good at masking their traits, and are usually less disruptive, teachers are less likely to refer them than boys. Girls are often regarded as "too affectionate" to be on the spectrum (Nichols et al., 2009, p. 21), lack of eye contact is often dismissed as being demure, and girls tend not to be so inflexible in their behaviour as boys.

Parents too can be reluctant to press for assessment and intervention if the child seems to be managing at school (Attwood, 2006). Nobody particularly wishes for their child to be labelled as "SEN", as despite better understanding these days, there are still those who will stigmatise. In our case, a referral to CAMHS was made by a SALT, partly because Libby was so impulsive at ages three and four. However, a paediatrician we saw in regard to her allergies told me "Look at her – she's fine! If anyone is going to refer her it will be us and we're not going to!”At the time, I felt relieved, as I perceived him to be a superior authority to the SALT. But his proclamation was based on his having watched her playing *alone* with some toys in his room for about five minutes, and I had a lot to learn (as did he).

Of those girls who are referred, the next hurdle to receiving an appropriate diagnosis is what I see as an unfortunate historical bias of the diagnostic tools, and the consequent tendency of many practitioners to diagnose what they are used to diagnosing i.e., mainly autism in boys. In my view, this is because,dating back to the time of Kanner and Asperger, it was predominantly boys who were identified for diagnosis, and this has shaped the diagnostic tools in a way that does not allow for the often more subtle presentation of girls. I consider that the inherent underlying gender differences are overlooked by the Autism Diagnostic Observation Schedule (ADOS), the Autism Diagnostic Interview (ADI) and the Diagnostic Interview for Social and Communication Disorders (DISCO). Girls are usually naturally more sociable and affectionate, with less rigid behaviour. The same is true of the DSM and ICD.In regard to the, so-called, “Gold Standard” ADOS, Nichols et al.(2009, pp. 21-22) found that:

> …girls who presented with more subtle ASDs were eventually able to answer questions about social situations, social communication and friendships, that similarly high-functioning boys would be less able to answer. However, the answers tend not to come naturally or quickly; it often takes these girls longer than normal to process information and then respond. You can imagine the difficulty they would have keeping up in a conversation with a group of chatty teenagers at school! The answers themselves that the girls provide also seem to reflect a more surface-level understanding rather than the depth of social comprehension, cognition and awareness observed in typically developing girls.

Gould says that many professionals are not “up to speed” in understanding how girls present. (Hill,2009, n.p) As a result, girls can be subjected “to lives of such misery that many resort to extreme self-harm and anorexia” (Hill, 2009, n.p.). Bazelon quotes Skuseas saying “There is no doubt in my mind that the way we have defined autism currently biases our assessments strongly in the direction of identifying a male stereotype,” and that girls of higher intellect are less likely to be diagnosed because of their greater ability to hide their difficulties in the context of a fairly short observation process. (Bazelon,2007, n.p.)

In April 2013 I ran an online survey asking for information from people with AS, or who had children with AS (Appendix A) I wanted to investigate the experiences of females relative to males in terms of how hard they found it to obtain a diagnosis, whether they had been misdiagnosed, and to what extent they thought having a correct diagnosis of AS made a difference to their self-awareness, and the support that they received.. From this survey, as well as from the literature, I have compiled the following quite shocking list of spurious diagnoses that females commonly received prior to a diagnosis of AS:

Psychosis
Schizophrenia
Pathological Demand Avoidance
Neurosis
Obsessive-Compulsive Disorder
Personality Disorder
Anxiety Disorder
Social Phobia
Sensory Integration Disorder
Sensory Processing Disorder
Eating Disorders
Behavioural problems
Attention Deficit Disorder
Attention Deficit Hyperactivity Disorder
Anxiety
Depression
Language Disorder
Mood Disorder
Generalised Anxiety Disorder
Oppositional Defiant Disorder
Post Traumatic Stress Disorder
Nervous Breakdown
Learning Disability
Bipolar Disorder
Tourette’s Syndrome
Nervous Stomach
Multiple Personality Disorder
Dysgraphia
Behavioural Problems
“Sophomoritis”! (Only in the USA)

The following are some of the responses to the survey:

> I was always told that men had Asperger's not women. Even though I could not make eye contact, and had all the other symptoms, the fact that I was a woman and laughed and talked a lot denied me the diagnosis.
>
> There is very little understanding of how autism presents differently in adults, who've had a lifetime to learn coping strategies and learn to 'pass'. Also NO understanding of how autism presents differently in females.
>
> It was nearly impossible to find anyone who would diagnosis me. Once I found someone I learned of many resources. But until then it was like the best kept secret. I don't think especially woman (sic) know where to go.
>
> It was a long uphill battle. People said that I COULDN'T be on the spectrum because I was "too high functioning", "a girl", or "too social" or "too intelligent". I am so glad I finally understand myself now, though.

Logically, there must be many other misdiagnosed (and possibly also wrongly medicated) women who have yet to be correctly diagnosed. Gould believes that up to 42% of females are misdiagnosed (Gould, 2011), and Simone explains why it is so important to have a correct diagnosis:

> …the naming of something will give it more power. Naming *is* a powerful thing - “Asperger's Syndrome” aligns us with a group, it gives us a backdrop and a catalogue of information. So many females don't have the name; Asperger's manifests itself differently in girls, often resulting in multiple misdiagnoses
> (Simone in Clark, 2010, p. X)

Attwood (2000), Ehlers and Gillberg (1993) and Wing (1981) all acknowledge that many girls and women with AS are never referred for assessment and diagnosis for AS, or are misdiagnosed, and are therefore missed from statistics and research. Many girls and women do not meet diagnostic criteria as the criteria are based on the behavioural phenotype of boys so there exists a critical need for diagnostic criteria to reflect the female phenotype(Marshall, 2013). It is profoundly unsettling that: So many women tell us that trying to get a diagnosis feels like an insurmountable hurdle and they have to fight tremendous battles to get the help support and services they desperately need. (Lever, 2010, in The Independent, Feb 2010)

Lai, who has worked on a recent study of gender differences in autism at the The University of Cambridge Autism Research Centre, recently stated:

> …we should not blindly assume that everything found for males or from male-predominant mixed samples will apply to females… there really needs to be more research and clinical attention toward females 'on the spectrum' (BBC News, August 2013)

Additionally, the mental health and life chances of women on the spectrum are further hampered by what Gomez de la Cuesta & Mason (2002) refer to as the "double-glazed glass ceiling", i.e. women on the spectrum face the challenges and prejudices that women still face in the world of employment, and are additionally hampered by the difficulties faced by many people on the spectrum in terms of being able to deal with the social demands of the workplace.

Support solutions

Holiday Willey entreats that those on the spectrum should seek 'People who share the same interests, beliefs, morals and general lifestyles**…** join special interest clubs… pets can bring out the best in all kinds of people and because they can bring strangers together" (HolidayWilley,1999, p. 57). Libby currently regularly takes part in martial arts classes, trampoline, and Irish dancing. In each of these activities she has built up a small group of friends, both girls, and boys, and they are mainly mutually supportive. Each of these activities builds her self-esteem, as she moves through the ranks; particularly in Irish dancing she has absolutely amazed us by "dancing out" on St Patrick's night and other occasions in local venues, to deafening applause. We hope that the knowledge of martial arts will help her protect herself when she is of an age to be out of the range of my current "helicopter parenting".

Wagner writes that:

> ...teachers and parents should investigate and implement peer programming[4] in order to build socially appropriate behaviours, improve chances of acceptance, better the possibility of inclusion, increase self-esteem, and lessen the chances of depression.'

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[4] The idea behind peer programming is to engage a small, select group of suitably motivated, emotionally mature and reliable peers to support the child with AS, both in and out of class, protect them from bullying, model appropriate social interaction, and provide a potential relationship link to the wider peer group.

(Wagner in Attwood, 2006, p. 23).

To minimise the amount of bullying to which they are likely to be subjected, Iland advocates that females with AS need to learn whom to avoid. She also warns that 'Disclosing can lead to many different outcomes …... A girl with Aspergers should be very sure she can trust a person before disclosing to him/her.' (Attwood, 2006, p.48) This is something that I have very mixed feelings about. Walker quoted her friend Sam: 'Aspergers is difficult. You don't really fit in the "normal" world and you don't really fit in the disabled world. You sort of fall through the middle' (Walker, 2012, p. 56). So for me, there is the dilemma of whether Libby's life might be made easier or harder by disclosure to the wider community. As this is not a process that can be reversed, I think it is extremely important to be very sure first.

Some children we know have prepared PowerPoint presentations to explain to their classmates about AS, and how it specifically affects them. This has been done with the help of staff from the local authority Additional Needs Services. As we actually live in a neighbouring borough, I used my contacts to access their material, and staff from school and the LEA have helped Libby formulate a PowerPoint presentation of her own. She did enjoy doing this, and I am adamant that I do not want her to grow up thinking that AS is an embarrassing secret that she should have to hide. However, by the end of year five, she still has not presented her PowerPoint to the class as planned, partly due to Libby understandably having "cold feet" about it. It is a huge thing for her to do, and it could backfire, so I am not really sure about it anymore.Maybe we should continue with more selective disclosure to trusted people, until she is old enough to really understand the possible ramifications. Either way, I think that it has been a very positive and self-affirming process for her thus far.

Libby's current mantra is "I am half tomboy" so she scorns butterfly hair accessories, but likes doing fancy hairstyles, likes (and is very good at) Irish dancing, but also plays more tom-boyish games in the school playground. I remember my childhood being similar, but there was no pressure on young girls to be the next Taylor Swift or Rihanna (or even Lulu!) in those days. Simone's advice is 'Try to find friends who will accept you as you are, rather than trying to hang with the cool kids' (Simone, 2010, p. 32), and I would totally agree with that. Simone also says that 'most if not *all* Aspergirls have similar perceptions about gender...Mostly it manifests as frustration, and disinterest in society's expectations of what being female means. As usual, we march to our own drum'(Simone, 2010, p. 62).

I will be encouraging Libby's current primary school, and her intended secondary school to implement girl-friendly social skills classes, as advocated by Gould and Ashton-Smith (2011) and to make sure that she knows what to do at break time, and how to report when she feels intimidated. They also recommend the use of role play, drama and video to convey socially appropriate behaviour. Simone observes 'Scripts are helpful. The little niceties that Aspies don't like, because they seem shallow and insincere, are actually very helpful — like saying, 'Hi, how are you?' (Simone,2011, n.p.)

As Libby grows older, she will be able to access various AS forums, such as "Wrong Planet", "Aspergers Support Network", and the "Aspergers Awareness Community". Although there are currently more males represented by and contributing to these sites, the balance is changing with time, so hopefully she will feel more connected with other youngsters who can relate to her. But that will also require careful supervision through her teens as there are a lot of internet "trolls" out there who bully females, and people with autism (BBC News, 2013, n.p.).

Conclusion

As previously stated, I do not imply that all the difficulties relating to having AS are apportioned to females. I know boys whose experiences have been more like the story of Sophie, in terms of not being recognised at school, diagnosed or helped, until too much precious time has been wasted. However, my survey received 150 responses from most of the English-speaking world, and it did starkly highlight the problems which seem to particularly affect females.

Nichols et al. (2009) point out that consideration of gender differences in autism are about two decades behind the recognition that has been afforded to the understanding of ADHD. Possibly that is partly because ADHD tends by definition to be disruptive, and therefore prompts more attention to both sexes from teachers, parents and health professionals.

Below are further quotations from some of the responses that I feel speak most emphatically about the situation of females with AS, and articulately encapsulate many of the issues discussed above.

> If I had been diagnosed when I had the breakdown in 2003, at the very latest, it might have saved my marriage, my children and my home. My husband and I always tried to get help/counselling but were just pushed from pillar to post with no one realising what the root cause of my problems were. After my breakdown my husband could not take any more stress caused by me and our marriage broke down irretrievably…. There is also still a very big problem with the

stereotyping of autism/Aspergers with diagnosticians still not recognising that women and girls on the spectrum present differently from males

As a result of the diagnosis being missed, Kenda spent almost 2 years in foster care for supposed abuse springing from unexplained bruises. Kenda often ran into things without telling me because of certain insensitivity to pain… Most professionals here are only educated about severe autism and have more trouble recognizing the high functioning type that my daughter has.

I suffered with an eating disorder as a teenager which I hid very well as it wasn't a need to be thin as much as a need to control myself and feel more accepted by my peers. I had selective mutism and was also agoraphobic to a degree - I went to school and came home following a stupid remark by a local girl that I took literally and was afraid for my safety outside alone, aged 13-16yrs. I've had a knife to my throat - been hauled into a car and given a date rape drug during my early 20's after misunderstanding others intent.. If I had a diagnosis I know that I would feel worthy in the human race again and my family would hopefully no longer judge me so harshly. I am 38 and only this year after realizing my 7 year old is on the spectrum did I find out about Aspergirls and it was more of an explosion than a light bulb moment for me! I have no idea of the help I would receive but to be understood would be a dream come true.

She is now in year 3 at school and is the typical unassuming quiet shy anxious girl at school. Her school thinks she is just a little bit asd because she does not display at school like the boys on the spectrum do. They have no concerns for her at all yet on the inside she is not coping. So in our case we have an early diagnosis against trend but now find ourselves in the position of her acting like all the missed girls and nobody in the school system having any understanding of this

I was diagnosed with Social Anxiety Disorder in 2000 as an explanation for severe depression and suicide attempt…I sought autism-specific testing in 2013 and was immediately diagnosed with Aspergers…I have spent a great deal of my life not understanding why I felt different and had a difficult time dealing with people. Had I been properly diagnosed while in school, I may have developed the skills necessary to help me cope with life outside of academia...I think I went undiagnosed during school because I did well grade-wise and

> was not a discipline problem, but I struggled a great deal socially and was labelled "shy," so no one thought anything more about it.
>
> I took my daughter to CAMHS for assessments and various stages form (sic) age 5, we were told by a psychiatrist when she was 14 that she couldn’t have Aspergers because she can make eye contact. My daughter went through hell growing up and it makes me so angry that help was not there when it should have been for us
>
> No diagnosis meant school were reluctant to listen to our concerns. Therefore she struggled with homework and the social aspect of school which resulted in bullying from peers and ended with a move to a different school in year 6 as we got her diagnosis.
>
> I did not receive much help at all, I was introduced to a few other (sic) teens with a diagnosis, none of which wee(sic) female, which made my diagnosis feel even stranger to me…After diagnosis many people egteahers(sic) tried to get my diagnosis retracted due to the fact I was a girl and this (sic) misconceptions that girls don't get Asperger’s
>
> LISTENING is supposed to be what NTs (neurotypicals i.e. non autistic people) are good at. But when they become doctors, they stop doing it

These comments are from women, or parents of girls, mostly in the UK and USA. These are some of the countries in which most of the research into autism has taken place over the last few decades, but none the less it is obvious from these comments that there is still an appalling lack of understanding and knowledge. Although we have had difficulties and stresses, and I often feel a lot of apprehension about the prospect of Libby moving into her teenage years, I do realise that we have things a lot better than many others. Resources are dwindling due to the recession, and many males with AS do not receive as much support as they need, but for females, the situation is often even more bleak, but less recognised. While awareness is growing in some areas, I do not believe that it generally is in most schools. And even the best clinical psychologists cannot diagnose children who have not been referred to them.

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Does the Equality Act 2010 ensure equality for individuals with Asperger syndrome in the legal arena?: A survey of recent UK case law

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Does the Equality Act 2010 ensure equality for individuals with Asperger syndrome in the legal arena?: A survey of recent UK case law

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Abstract:

The recent history of AS has been perhaps the most controversial since the first publication relating to the syndrome in 1944, especially regarding its nosology. For example, the latest (5th) version of the Diagnostic and Statistical Manual (DSM-V) published in May, 2013 does not include Asperger syndrome (AS) and instead refers to AS as an 'autistic spectrum disorder'. This change is controversial, and indeed, supports the suggestion that the research presented in this article is timely, given the potential for AS (as defined prior to DSM-V) to disappear from current clinical practice and cease to be recognised in law. In this article I investigate whether the Equality Act 2010 ensures equality for individuals with AS in the legal arena. My investigation involved identifying individual cases using two commonly used legal search engines, Westlaw and LexisNexis. Following the identification of specific cases, these were then analysed for relevance using any available case analyses and official transcripts. The findings presented in this article suggest that the Law may well still be potentially discriminating and not ensuring equality for individuals with AS, despite the introduction of the Equality Act 2010.

Keywords: Asperger syndrome; autism; Equality Act 2010

Introduction

Until there is a change in the laws themselves to adapt to the neurological processes of those with AS (Asperger Syndrome) to ensure that the conceptual legal framework is inclusive, there appears to be a need for alternative *strategies to be in place for those with AS who break the law, but who do not appear to be covered by the current legal framework.* [1]

These words, written by Beardon in 2008, relate to his seminal research regarding the complex association between individuals with AS and the criminal justice system (CJS). He further proposed, for example, that, in some cases AS may account in part or in whole for the behaviour of an individual – and, as such, should be taken into account when decision making processes take place". [2]

While this has been echoed in recent reviews showing that the needs of individuals with AS and autistic spectrum disorders (ASD) are not always appreciated or met in the CJS, [3] a recently introduced UK statute may well provide the boost for Beardon's desire for inclusivity in the conceptual legal framework. For, on 8 April 2010, the Equality Act 2010 ("The Act") received Royal Assent and subsequently came into force on 1 October 2010 [4] with additional provisions coming into force in April and September, 2011. [5] This Act replaced some nine previous pieces of legislation, [6] and set out a number of key provisions, including protection against discrimination, harassment and victimisation, introducing the concept of "discrimination arising from disability", provisions relating to work (including new powers for employment tribunals and "positive action" duties for public authorities), banning age discrimination, defining a duty of equality for public bodies and more. That the Act is substantial and wide-ranging is clear: not only does it comprise some

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[1] Luke Beardon, Asperger Syndrome and Perceived Offending Conduct: A Qualitative Study' (PhD Thesis, Sheffield Hallam University 2008) 178 <http://shura.shu.ac.uk/7155/1/Beardon_aspergers_-_full.pdf> Accessed 4 January 2014; it should be noted that as the current work will quote from a variety of legal and judicial sources, the OSCOLA ('Oxford Standard for the Citation of Legal Authorities') referencing system will be utilised. Further details may be found at <http://www.law.ox.ac.uk/published/OSCOLA_4th_edn.pdf>

[2] Beardon (n2) 204

[3] See, for example, Russell Foster, 'What Theories of Asperger Syndrome Support or Undermine the Suggestion that Individuals with Asperger Syndrome are Likely to Break the Law?' Unpublished Coursework, PostGraduate Certificate in Autism and Asperger Syndrome, Sheffield Hallam University (31 August 2013) and Nigel Archer and Elisabeth Ann Hurley, 'A Justice System Failing the Autistic Community' (2013) 4(12) Journal of Intellectual Disabilities and Offending Behaviour 53

[4] Equality Act 2010

[5] Department of Culture, Media and Sport and Government Equality Office, 'Equality Act 2010: Guidance' (*Gov.uk* 27 February 2013) <https://www.gov.uk/equality-act-2010-guidance> accessed 5 January 2014

[6] Bob Hepple, 'The New Single Equality Act in Britain' (2010) 5 The Equal Rights Review 11. These nine statutes or statutory instruments are: 1) The Equal Pay Act 1970; 2) The Sex Discrimination Act 1975; 3) The Race Relations Act 1976; 4) The disability Discrimination Act 1995; 5) The Employment Equality (Religion or Belief) Regulations 2003; 6) Employment Equality (Sexual Orientation) Regulations 2003; 7) Employment Equality (Age) Regulations 2006; 8) Equality Act 2006; 9) Equality Act (Sexual Orientation) Regulations 2007

sixteen parts, with 218 sections, but it also includes 28 schedules. [7]

The Act is notable due to its inclusion of a number of key definitions. For example, under the Act, AS and ASD are classified as disabilities according to the following definition: "A person (P) has a disability if—(a) P has a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities". [8] The Act should thus ensure that individuals with any form of disability will be afforded appropriate protection, although, discussed later, the influence of this Act in relation to individuals with AS and ASD - at least in UK case law - appears to be somewhat limited.

Given that the Act has now been in force for over two years, it is instructive to consider its impact thus far in relation to AS and ASD. To do this, available published legal cases will be analysed. It should be noted that this is but one of myriad ways of measuring the potential impact of a law, statute or policy, [9] and the results reported here should be considered as a limited pilot project. A search of the current literature suggests that this approach has not been previously attempted, although a short article has been published on the legal impact of the Act on mental health disability claims. [10] This publication does not refer specifically to AS or ASD, although it raises some interesting legal points, which will be considered later.

While the published literature is sparse in relation to AS and case law, a recent Australian publication has stated that,
a review of superior court decisions suggests that persons diagnosed in the pre-DSM-V era with AD [Asperger's Disorder] were significantly and increasingly frequently appearing in court judgments especially the family law and criminal law areas – in the latter as both offenders and victims. [11]

This 'review' is not a systemic analysis of cases, and its findings are not specifically referenced anywhere in the paper. It does consider of a number of legal cases, however, which may be a useful comparator for future UK-based

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[7] A summary of the contents of the Act may be found in appendix one.
[8] Equality Act 2010 s6(1)
[9] See, for example, United Nations Rule of Law, 'Measuring Effectiveness' (2013) <http://www.unrol.org/article.aspx?article_id=32> (United Nations 2013) accessed 16 January 2014; Charles Tremper and others, 'Measuring Law for Evaluation Research' (2010) 34(3) Evaluation Research 242
[10] Chris Phillips, 'The Equality Act 2010: Impact on mental health-related disability claims' (2012) 109 Employment Law Bulletin 2
[11] Ian Freckleton, 'Autism Spectrum Disorder: Forensic Issues and Challenges for Mental Health Professionals and Courts' (2013) 26(5) Journal of Applied Research in Intellectual Disabilities 420, 420

research. While other authors have looked at the relationship between the Equality Act 2010 and mental health, [12] this has not been undertaken specifically in relation to AS and ASD.

To address this apparent lacuna, the current work will attempt to answer the key question of whether the Equality Act 2010 has had an impact on how courts deal with individuals with AS and ASD. A secondary question will also be considered, namely whether the published legal cases support or refute the epidemiological data relating to offending and AS. It is hoped that the answers to these two questions these will then allow for a more considered evaluation of Beardon's statement at the start of this article. It should be noted that a full consideration of all the potential legal aspects of AS is beyond the scope of the current work, and space limitations will necessarily curtail the extent of both the legal analysis as well as the resulting discussion. This work will only examine the Equality Act 2010 as it applies in English and Wales, with the Law considered as at 8 January 2014. It will thus necessarily have a number of limitations, which will be discussed later.

Asperger Syndrome and the Criminal Justice System

The recent history of AS has been perhaps the most controversial since the first publication relating to the syndrome in 1944, [13] especially regarding its nosology. For example, the latest (5th) version of the Diagnostic and Statistical Manual (DSM-V) published in May, 2013 does not include AS and instead refers to AS as an 'autistic spectrum disorder'. [14] This change is controversial, and indeed, supports the suggestion that the research presented in this article is timely, given the potential for AS (as defined prior to DSM-V) to disappear from current clinical practice and cease to be recognised in law. Of note, in the UK, the ICD-10 (International Classification of Diseases) system of nosology is utilised for physical and mental health conditions, and the impact of DSM-V in the UK has been suggested likely to be minimal, at least in the short-term. [15] While one UK author has clearly stated that, "…these changes in DSM-5 in relation to autism are radical and will lead to patients losing their diagnosis and

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[12] Graeme Lockwood and others, 'The Equality Act 2010 and mental health' (2012) 200 British Journal of Psychiatry 182

[13] Hans Asperger, 'Die Autistischen Pychopathen im Kindesalder' (1944) 177 Archiv für Psychkiatrie und Nervenkrankheiten 76

[14] Alison Knopf, 'Asperger's diagnosis disappears, will treatment disappear too?' [2013] Behavioral Healthcare <http://www.behavioral.net/article/asperger-s-diagnosis-disappears-will-treatment-disappear-too> accessed 5 January 2014

[15] NHS Choices, 'Asperger's not in DSM-5 mental health manual' (NHS Choices 1 December 2012) <http://www.nhs.uk/news/2012/12December/Pages/Aspergers-dropped-from-mental-health-manual-DSM-5.aspx> accessed 7 January 2014

services”, [16] the impact of this remains to be confirmed. It should be noted that AS is not the first condition to be removed from diagnostic manuals, and conditions such as hysteria, [17] neurasthenia [18] and others have ‘disappeared’. [19] This confirms that psychiatric nosology remains somewhat unscientific and in a state of continual flux.[20]

For the purposes of this article, the ICD-10 definition of AS will be utilised: [21]

> A disorder of uncertain nosological validity, characterised by the same type of quantitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autism primarily in the fact that there is no general delay or retardation in language or in cognitive development.

This definition is not without its limitations, with a review from 2011 of the diagnostic criteria for AS in children utilised in 69 studies finding a high degree of variation and inconsistency in diagnosis, with great overlaps between AS and autism. [22] This finding clearly supports Beardon’s view that, “the similarities between those with a diagnosis of autism and those with a diagnosis of AS outweigh any significant difference”. [23]

The currently available epidemiological data regarding the relationship between AS and the CJS suggest that there is as yet no definitive evidence that individuals with AS are more (or less) prone to committing offences or coming into contact with the CJS. [24] Indeed, the relationship between AS and the CJS has been referred to as a “square peg in a round hole”. [25] To complicate matters, current research findings are contradictory, with no definitive studies yet

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[16] Michael Fitzgerald, ‘Loss of autism in DSM-V’ (2012) 201 British Journal of Psychiatry 74

[17] Mark S. Micale, ‘On the “Disappearance” of Hysteria: A Study in the Clinical Deconstruction of a Diagnosis’ (1993) 84(3) Isis 496

[18] Ruth E. Taylor, ‘Death of neurasthenia and its psychological reincarnation A study of neurasthenia at the National Hospital for the Relief and Cure of the Paralysed and Epileptic, Queen Square, London, 1870-1932’ (2001) 179(6) The British Journal of Psychiatry 550

[19] See, for example, Edward Shorter and John C. Marshall, *A History of Psychiatry* (Wiley 1997) and Joel Paris, *Fads and Fallacies in Psychiatry* (RCPsych Publications 2013)

[20] See, for example, Kenneth Kendler, ‘An historic framework for psychiatric nosology’ (2009) 39(12) Psychological Medicine 1935

[21] John E. Cooper, *Pocket Guide to the ICD-10 Classification of Mental and Behavioural Disorders with Glossary and Diagnostic Criteria for Research* (Churchill Livingstone 1999) 286

[22] Shilpi Sharma and others, ‘Confusion and inconsistency in diagnosis of Asperger syndrome: a review of studies from 1981 to 2010’ (2011) 16(5) Autism 465

[23] Beardon (n1) 10

[24] Eddie Chaplin and others ‘Autism Spectrum Conditions and Offending: An Introduction to the special edition’ (2013) 4(1/2) Journal of Intellectual Disabilities and Offending Behaviour 1

[25] Kenneth J Weiss, ‘Autism Spectrum Disorder and Criminal Justice: Square Peg in a Round Hole’ (2011) 32(3) American Journal of Forensic Psychiatry 3

proving a link between AS and offending behaviour. [26] For example, studies have found higher rates of AS in secure settings than in general populations, [27] although these have been criticised due to methodological flaws. [28] Conversely, studies have found lower rates of offending. [29] Additionally, there is one published study which found no association between AS and offending behaviour. [30]

But what of the more contemporary links between the law and AS? That AS remains of topical interest is clear from the attention paid in the media and elsewhere to the recent scandal regarding autism and vaccination. [31] Additionally, the case of Gary McKinnon remains topical; this individual is a Scottish man who was accused of hacking into US military computers between 2001 and 2002. He was subsequently indicted by an American jury (in his absence) on a number of charges, [32] and was later diagnosed with AS. Whilst he was due to be extradited to the US, this was eventually overturned after a long legal battle involving arguments concerning his human rights. [33] While his case, and those of others [34] may well suggest an association between computer hacking and AS, the very limited research in this area does not support this. [35] Examination of the published literature suggests that individuals with AS (especially in the US) have been associated with a range of number of crimes,

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[26] Ann Browning and Laura Caulfield, 'The prevalence and treatment of people with Asperger's Syndrome in the criminal justice system' (2011) 11(2) Criminology and Criminal Justice 165

[27] See, for example, Paul Scragg and Amitta Shah, 'Prevalence of Asperger's Syndrome in a secure hospital' (1994) 165 British Journal of Psychiatry 679; Dougal J Hare and others, *A Preliminary Study of Individuals with Autistic Spectrum Disorders in Three Special Hospitals in England* (National Autistic Society 1999); Leila Siponmaa and others, 'Juvenile and young adult mentally disordered offenders: The role of child neuropsychiatric disorders' (2001) 29 Journal of the American Academy of Psychiatry and the Law 420

[28] Browning and Calufield (n22)

[29] See, for example, Mark Woodbury-Smith and others, 'High functioning autistic spectrum disorders, offending and other law-breaking from a community sample' (2006) 17(1) Journal of Forensic Psychiatry and Psychology 108; and, Svend Erik Mouridson and others, 'Pervasive developmental disorders and criminal behaviour: A case control study' (2008) 52(2) International Journal of Offender Therapy and Comparative Criminology 196

[30] David Allen and others, 'Offending behaviour in adults with Asperger Syndrome' (2008) 38 Journal of Autism and Developmental Disorders 748

[31] See, for example, Fiona Godlee and others, 'Wakefield's article linking MMR vaccine and autism was fraudulent' (2011) British Medical Journal 342 1678; and Gregory A Poland, 'MMR vaccine and autism: vaccine nihilism and postmodern science' (2011) 86(9) Mayo Clinic Proceedings 869

[32] Paul Arnell and Alan Reid, 'Hackers beware: the cautionary story of Gary McKinnon' (2009) 18(1) Information and Communications Technology Law 1

[33] Graham Arnold, 'UK-US extradition: the case of Gary McKinnon' (2012) 67 Student Law Review 14

[34] Freckelton (n8)

[35] Bernadette H Schell, and June Melnychuk. 'Female and Male Hacker Conferences Attendees: Their Autism-Spectrum Quotient (AQ) Scores and Self-Reported Adulthood Experiences' *Corporate hacking and technology driven crime: Social dynamics and implications* (Information Science reference 2010) 144

including manslaughter and murder, [36] although these latter cases are rare and do not in themselves support any clear link between AS and offending.

As an aside, it is noteworthy that in Asperger's original description of the syndrome, the cases of four children were presented, two of whom were reported to be violent, with one of these also reported to be sexually disinhibited. [37] While this perhaps could suggest a link between violence or offending behaviour and AS, later research conducted into Asperger's original cohort of 177 former patients over a period of 22 years failed to find any differences in the rates of conviction as compared to a general male population. [38]

Recent Policy and Legislation relating to Autistic Spectrum Disorders

The last five years has seen a number of specific policy and legal changes in the UK specifically regarding AS and ASD, in addition to what has been described as, "a policy waterfall, both within and beyond the arena of mental health services" [39]. Here, specific policies and one statute are worthy of brief mention. In 2001, the UK government published a white paper, 'Valuing People',[40] which aimed to increase social inclusion of individuals with learning difficulties, including AS and ASD, and a subsequent government publication, "Valuing People Now", reiterated these principles, and included the need for awareness training for prison staff. [41]

On 12 November 2009, the Autism Act 2009, came into force, [42] partly as a result of a concerted campaign by the National Autistic Society.[43] The Act contains six parts, including the requirement for the Secretary of State to

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[36] Weiss (n16)

[37] Asperger (n10)

[38] Kathrin Hippler and others, 'Brief report: No increase in Criminal Convictions in Hans Asperger's Original Cohort' (2010) 40 Journal of Autism and Developmental Disorders 774

[39] Steve Onyett and Helen Lester, 'Managing in Mental Health' in Kieran Walshe and Judith Smith (eds), *Healthcare Management* (Open University Press 2006)

[40] Department of Health, 'Health Service Circular 2001/016. Valuing People: A New Strategy for Learning Difficulty for the 21st Century: Implementation Guidance' (Department of Health, 31 August 2001) <http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4012281.pdf> accessed 16 January 2014

[41] Department of Health, 'Valuing People Now: a new three year strategy for people with learning difficulties. Making it happen for everyone' (Department of Health, 19 January 2009) <http://www.dwp.gov.uk/docs/dla-reform-andover-and-district-mencap-appendix-3.pdf> accessed 16 January 2014

[42] HM Government, 'Autism Act 2009 Explanatory Notes' <http://www.legislation.gov.uk/ukpga/2009/15/notes> accessed 16 January 2014

[43] National Autistic Society, 'I Exist Campaign in England' (National Autistic Society 9 May 2013) <http://www.autism.org.uk/get-involved/campaign-for-change/learn-more/our-campaigns/past-campaigns/i-exist/i-exist-campaign-in-england.aspx> accessed 16 January 2014

produce and publish an autism strategy to include how bodies such as the NHS and local authorities should implement that strategy. This was indeed published, [44] and sets out a range of recommendations and requirements. These relate to five key areas, namely appropriate community assessment in for adults with a diagnosis of autism, compulsory training for individuals working in health and social care, the need for a senior manager or joint commissioner with responsibility for commissioning of services for adults with autism, clear access to diagnostic services and local plans for development of services. Despite the comprehensive aims of this strategy, its impact appears unclear, with on-going variations in knowledge of AS and ASD [45] and the Autism Strategy. [46] It is perhaps worthy of debate whether this variability of knowledge among the public and stakeholders would change if the high economic costs of the disorder were fully recognised. [47]

Despite these potential shortcomings, a positive corollary of these various policies and the Autism Act 2009 is the Equality Act 2010, which, "builds upon requirements already in force through the first ever disability-specific law, the Autism Act 2009".[48] It is thus of great interest and utility to consider the impact of this important and wide-ranging statute as it relates to AS and ASD.

Methodology

Individual cases were identified using two commonly used legal search engines, Westlaw [49] and LexisNexis [50]. The searches started with all relevant, cases published in the UK, irrespective of date, in order to determine the total number of cases referring to AS, autism or ASD. Then, further searches were conducted, which were limited to only those cases reported in English and Welsh legal jurisdictions and published after 1 October 2010 (that is, following the introduction of the Act). Initial searches were conducted using six, specific search terms: "Asperger", "Asperger Syndrome", "Autistic", "Autistic Spectrum Disorder", "Autistic Spectrum" and "Autism". Following this, searches adding the phrase "Equality Act 2010" to these six search terms were

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[44] Department of Health, 'Implementing "Fulfilling and rewarding lives". Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy' (Department of Health 17 December 2010) <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216129/dh_122908.pdf> accessed 16 January 2014

[45] Karola Dillenburger, and others, 'Awareness and knowledge of autism and autism interventions: A general population survey' (2013) 7(12) Research in Autism Spectrum Disorders 1558

[46] Nick Walsh and Ian Hall, 'The Autism Strategy: implications for people with autism and for service development' (2012) 6(3) Advances in Mental Health and Intellectual Disabilities 113

[47] Martin Knapp and others, 'Economic cost of autism in the UK' (2009) 13(3) Autism 317

[48] Marios Adamou, 'Hidden impairments, the Equality Act and occupational physicians' 61(7) Occupational Medicine 453

[49] Westlaw UK, <http://legalresearch.Westlaw.co.uk> accessed 8 January 2014

[50] LexisNexis UK, <https://www.lexisnexis.co.uk/en-uk/home.page> accessed 8 January 2014

conducted using the "search within results" tool. The results of these initial searches are summarized in appendices two and three (for Westlaw and LexisNexis searches, respectively). In addition, two "control" searches using the search phrase "Equality Act 2010" were carried out using both search engines to include published cases after 1 October 2010. These results are also included in appendices two and three.

Following the identification of specific cases, these were then analysed for relevance using any available case analyses and official transcripts. The information obtained from these relevant cases is summarised in appendix four.

Results

(1) Total Number of Cases found

Different numbers of cases were identified, depending on which search term, phrase or search engine was utilised. The majority of cases on Westlaw were found using the search term "Autistic" and the least with the search term "Asperger", while the majority of cases on LexisNexis were also found using the search term "Autistic" and the least with "Autistic Spectrum Disorder". Of note, the search with LexisNexis found more cases referring specifically to Asperger than in Westlaw. Total numbers of cases found using LexisNexis were also higher than for Westlaw, with the exception of the search using the phrase, "Autistic Spectrum Disorder".

For searches using both search engines, the number of potentially relevant cases was found to decrease when only considering cases reported after 1 October 2010, and were further noted to decrease dramatically in the final search, with the addition of the search phrase "Equality Act 2010". Here, the number of potentially relevant cases ranged from 2-14, representing less than 1% of the previously identified cases. Only seven cases were ultimately found to be of direct relevance to the current work (see appendix four). The "control" searches utilizing the search phrase "Equality Act 2010" indicated the total numbers of published cases in both search engines from all available dates and after 1 October 2012. Using this latter figure suggests a significant number of these cases were concerned in some measure with individuals with AS or ASD. In the Westlaw cohort, depending on the search phrase under consideration, these figures range from 20.1% of cases to 43.4%, while for the LexisNexis cases the figures range from 11.8% of cases to 34.1%.

(2) Specific Legal Domains

Westlaw and LexisNexis utilise different classifications for each domain, although there is some overlap. In the Westlaw series, the majority of cases were related to ‘legal system’, ‘crime’, ‘health and social security’, ‘family and private life’, ‘local government’ and ‘public services and utilities’, while for LexisNexis similar trends were seen, with the majority of cases referring to ‘criminal law and disposition of offenders’, ‘criminal procedure’, ‘family law’, ‘health law’, ‘education law’ and ‘civil procedure and administration of justice’.

(3) Individual Cases

Westlaw and LexisNexis utilise different legal domain classifications, making direct comparisons difficult. Thus only the domains of “Crime” in Westlaw and “Criminal Law and Disposition of Offenders” and “Criminal Procedure” in LexisNexis will be considered. In the Westlaw case series, the total number of ‘Crime’ cases ranged from 69 (“Autism”) to 139 (“Autistic”) with a significant reduction (in all cases of over 50%) in the number of cases from 1 October 2010 and to a maximum of 2 when reference to the Equality Act 2010 was considered. In the LexisNexis series, similar trends were seen, with a maximum of 1 case identified when the search included the Equality Act 2010. In either search engine the search for criminal cases including either “Asperger” or “Asperger Syndrome” only resulted in 1 case, found using LexisNexis. The small number of cases makes any sort of definitive analysis impossible, and the variations failed to demonstrate any clear trends or associations relating to which court was involved, the defendants’ ages, nature of the offence or offences, the reported diagnosis or diagnoses, the outcomes or the section(s) of the Act referred to. There were, however, more males (six) than females (one) identified in this small case series.

Discussion

The purpose of this work was to consider two key questions: i) does the Equality Act 2010 ensure equality for individuals with AS and ASD in the legal arena?; and ii) do the published legal cases support or refute the epidemiological data relating to offending and AS? The research presented in this article found a relatively small number of relevant cases. Thus, despite the introduction of the Act over three years ago, its impact on case law appears limited. Although the numbers of cases found using the different search terms resulted in a number of potentially relevant cases, further analysis by ensuring specific reference to both individuals with AS or ASD and the Equality Act 2010 resulted in only seven cases. A possible reasons for this is the time it takes to incorporate a new statute into case law, given the fact that statutes are “inevitably incomplete” [51] together with the complexity of statutory interpretation. [52] Thus the relatively short time frame under consideration may well be too short to determine meaningfully the impact of the Act, although – interestingly - other Acts have been rapidly challenged in case law.[53] Why this is the case in relation to the Equality Act 2010 remains to be determined.

Although the current work has concerned itself with the impact of the Equality Act 2010 in relation to AS and ASD, it is useful to consider its impact generally and then specifically in relation to AS and ASD. It is clear from the current work that the majority of published cases do not relate to individuals with AS or ASD, and the variety of legal domains which these cases encompass further suggests a broad influence of the Act. Regarding mental health in general, Veale [54] has suggested that while the NHS Constitution has incorporated the Equality Act, individuals with mental disorders (considered as disabilities under the Equality Act) remain discriminated against in terms of choice and access to secondary services. That there is continued discrimination against individuals with mental health disorders and learning difficulties is clear, [55] with a large body of literature discussing the nature of stigma and mental illness [56] especially in relation to discrimination and mental illness in the elderly, [57] children with disabilities [58] as well as AS. [59] In addition, there are examples from case law involving individuals with AS and alleged harassment or unfair treatment, [60]

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[51] Luca Anderlini and others, ‘Statute Law or Case Law’ (2008) <http://econ.lse.ac.uk/staff/lfelli/papers/Common.pdf> accessed 18 January 2014

[52] Richard A. Posner, ‘Statutory Interpretation—in the Classroom and in the Courtroom’ (1983) 50 Chicago Law Review 800

[53] For example, the Mental Health Act 2007- as shown by the 59 cases found in a Westlaw search conducted on 18 January 2014 using the search phrase “Mental Health Act 2007” between 19 July 2007 (when this Act came into force) and 19 October 2009 – roughly the same period as considered in this article for the Equality Act 2010 (which came into force on 1 November 2010 and including cases as of 8 January 2014).

[54] David Veale, ‘The Department of Health and the Equality Act 2010’ (2012) 201 British Journal of Psychiatry 75

[55] Elizabeth Corker and others, ‘Experiences of discrimination among people using mental health services in England 2008-2011’ (2013) 202(s55) The British Journal of Psychiatry s58

[56] See, for example, Graham Thornicroft, *Shunned: Discrimination against people with mental illness* (Oxford University Press 2006)

[57] See, for example, David Anderson and others, ‘Mental health service discrimination against older people’ (2013) 37(3) The Psychiatrist 98; and Caroline Bernard, ‘Achieving age equality in health and social care’ (2013) 17 (1) Working with Older People 19

[58] See, for example, Jill Porter and others, ‘Recognising the needs of every disabled child: the development of tools for a disability census’ (2011) 38(3) British Journal of Special Education 120; and Janet Read and others, ‘Disabled children and their families: a decade of policy change’ (2012) 26(3) Children & Society 223

[59] Robert C Butler and Jennifer M. Gillis, ‘The impact of labels and behaviors on the stigmatization of adults with Asperger’s disorder’ (2011) 41(6) Journal of Autism and Developmental Disorders 741

[60] See, for example, R. (on the application of W) v Aylesbury Crown Court [2013] EWHC 3228 (Admin)

although relevant cases appear to be few in number. [61] In the case of *R. (on the application of W),* [62] the appellant, who had a diagnosis of AS, had been charged with harassment and appealed this charge on the basis of his AS, which made him vulnerable and contributed to his claim of a lack of a fair trial. This was rejected by the court, which, in its decision, stated,
In our judgment, the judge and his colleagues did ensure that the trial was fair and did accommodate the appellant's vulnerability as a person suffering from Asperger's Syndrome [63]

Various justifications for this included the judge allowing the appellant to cross-examine witnesses, to give his evidence without undue interruption, for interruptions to be appropriate and sympathetic and for the cross-examination to be “brief and [of a] friendly nature”. [64] Interestingly, there is a reference in the official court transcript to the appellant’s oral evidence having to be curtailed after an hour and a quarter lest the case be prolonged “for days”; this may well be a reflection on the nature of the appellant but likely more to do with the many years the case had taken thus far to resolve.

Encouragingly, there was clear reference in this case to the acknowledgement of the Court of the appellant’s AS and how this could be reasonably accommodated. It is noteworthy that these adjustments and efforts to accommodate this individual with AS were referred to specifically and at some length, and it is curious that similar accommodations do not appear to be routinely described in other cases involving individuals with AS. [65] Whether this lacuna will eventually be challenged in future case law remains to be seen.

In an earlier case, that of *Hewett*, [66] it was argued successfully that an individual with AS who had difficulty understanding social interactions could be considered as having limited understanding and thus be considered disabled under the Disability Discrimination Act 1995. This case was based on a previous key case, that of *Goodwin*, [67] which defined the concept of “understanding” as having a broad interpretation. While these two cases date prior to the introduction of the Equality Act 2010, their reference to AS and the legal interpretation of the concept of ‘understanding’ make them seminal cases that are likely to be referred to in future cases involving individuals with AS. At

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[61] As shown in a search conducted on Westlaw on 31 January 2014 using the search phrase “discrimination” and “Asperger”; this search only revealed some 30 results, the majority of which, after analysing the official case transcripts, were not directly relevant to the current discussion
[62] R. (on the application of W) n57
[63] ibid [77]
[64] ibid [79]
[65] As based on analysis of the cases identified in the current work (appendix four)
[66] Hewett v Motorola Ltd [2004] I.R.L.R. 545
[67] Goodwin v Patent Office [1999] I.C.R. 302

the very least they confirm that the difficulties in social interaction found in individuals with AS do constitute a disability and as such have the potential to form a cogent basis for future legal challenges involving the Equality Act.

Returning to the current research, it is important to consider other relevant aspects of AS and its association with the law. Given that the epidemiology of AS varies considerably, [68] and the "misdiagnosis or delayed diagnosis of this disorder is a serious problem", [69] the small number of cases found will necessarily miss individuals with AS or ASD. Indeed, it is "generally agreed that there are likely to be many individuals in prisons who have unrecognised autistic spectrum disorders" [70] and it is thus the CJS as a whole is likely not to be recognising these individuals. In the current case series, the preponderance of males (six males versus one female) was consistent with previous research findings,[71] although the number of females with the disorder may well be under-recognised. There is a suggestion in the published literature that the diagnostic criteria for AS are "tuned to the male manifestation of the syndrome" [72] and, as a result of this, females with AS may not be recognised. [73] Further support for this comes from identification of gender-specific specific biological markers for AS and ASD. [74]

The seven identified cases are noteworthy as they do not address individual differences in ability to communicate, nor are 'reasonable adjustments' referred to. Furthermore, in only one case, *Swan Housing Association*, [75] is 'disability' referred to. In this case, the defendant's claim of AS constituting a disability was felt to be independent of the AS, for which no confirmatory medical evidence had been presented. A similar outcome was found in *Telchadder*, [76] in which anti-social behaviour was also a factor but was not felt to be related to disability arising from autistic traits. In another case, AS was claimed as the cause of unfitness to practice by a consultant psychiatrist but was dismissed, [77]

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[68] Chaplin (n23)

[69] Michael Fitzgerald and Aiden Corvin, 'Diagnosis and differential diagnosis of Asperger syndrome' (2001) 7 Advances in Psychiatric Treatment 310

[70] Lisa Underwood and others, 'Prisoners with neurodevelopmental disorders' (2013) 4 Journal of Intellectual Disabilities and Offending Behaviour 17

[71] Marja-Leena Mattila and others, 'An epidemiological and diagnostic study of Asperger syndrome according to four sets of diagnostic criteria' (2007) 46(5) Journal of the American Academy of Child and Adolescent Psychiatry 636

[72] Stephan Ehlers and Christopher Gillberg, 'The epidemiology of Asperger syndrome' (1993) 34(8) Journal of Child Psychology and Psychiatry 1327

[73] Lee A. Wilkinson, 'The Gender Gap in Asperger Syndrome: Where are the Girls?' (2008) 4(4) Teaching Exceptional Children Plus 3

[74] Emanuel Schwarz and others, 'Sex-specific serum biomarker patterns in adults with Asperger's syndrome' (2010) 16(12) Molecular Psychiatry 1213

[75] Swan Housing Association Ltd v Gill [2013] EWCA Civ 1566

[76] Telchadder v Wickland (Holdings) Ltd [2012] EWCA Civ 635

[77] R (on the application of Islam) v General Medical Council [2013] EWHC 3763

on the basis that the provisions of the Equality Act 2010 did not apply. It is noteworthy, however, that in a different case, that of *Parents of C,* [78] the defendant's vulnerability *was* felt to be an aspect of her disability. This case perhaps best illustrates the application of the Equality Act 2010 to individuals with AS and autistic spectrum disorders, with the case of *P* [79] highlighting the importance of 'reasonable adjustments'.

It is perhaps ironic that the cases considered here do not refer to any specific features of AS in any great detail, nor to how diagnoses were actually determined. While this omission may appear curious, in the majority of these cases diagnosis was not the major focus. In none of the cases was there any consideration of whether the defendants were fit to plead (itself a complex legal entity, especially in relation to AS and ASD [80]), whether they had *mens rea* (intent to commit a crime [81]) or whether they were 'reliable' witnesses. [82] The lack of reference to these may well suggest that fairness under the law was partially lacking, and future cases may consider these and result in different findings and possibly more appeals to higher courts.

As noted in the introduction to the current work, there is a published paper considering the impact of the Equality Act 2010 on mental health-related disability claims. [83] This paper suggests that up to 2005 here was a need in law for mental impairments to be 'clinically well-recognised', and the removal of this requirement was likely an important step in ensuring equality for mentally-disordered individuals (as well as those with AS or ASD) in the legal arena. It has also been suggested that the scope of the Equality Act 2010 may well result in an increased number of discrimination and harassment claims in relation to metal health, [84] although, whether this will include sizeable numbers of individuals with AS and ASD remains unclear.

Finally, do the published legal cases support or refute the epidemiological data relating to offending and AS? While the small number of cases makes the formulation of any definitive conclusions impossible, these cases do not in themselves suggest any clear link between offending and AS. Looking at the crude measure of the total numbers of cases involving individuals with AS or

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[78] Parents of C v Stanbridge Earls School [2013] Eq. L.R. 304

[79] P v Governing Body of A Primary School [2013] UKUT 154 (AAT)

[80] Jill Peay, 'Fitness to Plead and Core Competencies: Problems and Possibilities' (London School of Economics Law, Society and Economy Working Papers 2012) <http://www.lse.ac.uk/collections/law/wps/WPS2012-02_Peay.pdf> accessed 18 January 2014

[81] Nachum Katz and Zvi Zemishlany, 'Criminal Responsibility in Asperger Syndrome' (2006) 43(3) Israeli Journal of Psychiatry Related Science 166

[82] Allen (n30)

[83] Phillips (n7)

[84] ibid.

autism identified compared to the total number of published cases in all legal domains and jurisdictions suggests that these comprise a minimal percentage.[85] If accurate, this very low percentage would confirm that individuals with AS are not at a particularly high risk of offending. It may well be that while courts fail to identify AS and ASD, once in prison the medical and educational services will do so. The variation in court diversion services may also play a role here, [86] as will the level of awareness by legal professionals. [87] But whatever the reason, the likely under-recognition of individuals with AS and ASD "because of clinical unfamiliarity with its adult presentation" [88] in the criminal justice system does suggest that equality in the legal arena remains some way off.

Limitations of the current work

Despite the potential utility of the current work, it does have some important limitations. For example, the use of additional legal databases may well have identified additional cases. As the current work may be considered as a pilot project, future work in this area could utilise additional data sources to overcome this limitation. Another potential limitation is the restriction of cases to English and Welsh jurisdictions; a comparison of other jurisdictions may well yield valuable information, although 'comparative law' is beset with complexities. [89] An additional concern could relate to the lack of attention paid to excluded cases, although the sheer amount of new information discovered in the various searches meant that this was necessarily un-examined. However, an analysis of those cases deemed not to be relevant due to their exclusion of specific reference to the Equality Act 2010 may be useful to determine why there appears to be a lacuna.

This work undertook a qualitative analysis of the various cases identified as relevant. In Law there appears to be a dearth of quantitative research, [90] and the data in the current work could form a basis for prospective quantitative studies. These could, for example, compare the impact of the Equality Act 2010 with

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[85] A crude attempt to determine the total number of cases on Westlaw and LexisNexis was made by undertaking a search on 8 January 2014 for cases using the search term "case". On Westlaw this resulted in some 790,000 cases. For LexisNexis the total number of cases could not be determined using this method

[86] Anthony Kearns, 'Forensic services and people with learning disability: in the shadow of the Reed Report' (2001) 12(1) Journal of Forensic Psychiatry 8

[87] Dennis Debbaudt, *Autism, advocates, and law enforcement professionals. Recognising and reducing risk situations for people with Autism Spectrum Disorders* (Jessica Kingsley 2002)

[88] Barbara G Haskins and J. Arturo Silva, 'Asperger's Disorder and Criminal Behavior: Forensic-Psychiatric Considerations' (2006) 34(3) Journal of the American Academy of Psychiatry and Law 374

[89] Smith (n68)

[90] Gregory Sisk, 'The Quantitative Moment and the Qualitative Opportunity: Legal Studies of Judicial Decision Making (Book Review)' (2008) 93 Cornell Law Review 8

other Acts, such as the Criminal Justice Act 2003 or the Autism Act 2009. While all the cases under discussion referred to a range of Statutes, it was not possible here to consider these here, although further analysis may well have revealed pertinent legal issues. This could be addressed in future research.

Finally, any Law, statute, regulation or other legal instrument, especially a new one, will only be as effective as its safeguards, and whether these are actually recognised, monitored and enforced. While the measurement of the impact of any law is difficult, there are validated ways of doing this,[91] which could be incorporated into future research. The current work has not been able to consider these in any detail, not least because of the vastness of the Equality Act 2010, the complexity of the legal system in general and the difficulties in conducting comparative legal research. [92] That said, a comparison between cases considered in Australia and the UK could be of interest, especially in view of the finding that individuals with AS in Australian jurisdictions have been disproportionately found to have committed certain types of offences such as arson, computer-related crimes, stalking, sexual offences, violence and neglect offences and 'dishonesty' offences. [93] There may well be a number of cogent reasons for these findings, and it would indeed be of value to undertake a meta-analysis of AS and offending to determine the actual association between AS and offending.

Of note, the legal system may, in itself, be considered a form of safeguard, although like any system, it may actually promote social inequality and fail to safeguard vulnerable individuals. [94]. Although the Law itself is an artificial, nebulous and ever-changing construct, it is the interpretation and application of the Law, which is of fundamental importance. An apparent lack of understanding of the Law coupled with a lack of knowledge of AS and ASD may well be considered as a major reason why there appears to be such a large lacuna in the application of the Equality Act 2010.

Possible Solutions

The current work, together with recent UK policy and published research, suggests that more needs to be done to improve the fate of individuals with AS and ASD in the CJS. A key means of doing this is through improved education and training, as enshrined in the Autism Act 2009. Yet the impact of this Act

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[91] Tremper (n8)

[92] Stephen A Smith, 'Comparative legal scholarship as ordinary legal scholarship' (2012) 5(3) Journal of Comparative Law 331

[93] Ian Freckleton, 'Asperger's disorder and the criminal law' (2011) 18 Journal of Law and Medicine 677

[94] Bartłomiej Kacper Przybylski. 'The Legal Framework as a Factor Generating Social Inequality: The Case of the Criminal Justice System' in Dieter Eissel, Ewa Rokicka and Jeremy Leaman (eds), *Welfare State at Risk* (Springer International Publishing 2014)

appears less than that of the Equality Act 2010: searches using the search phrase "Autism Act 2009" failed to find any cases on either Westlaw or LexisNexis. [95] While the significance of this is unclear, this lack of reference to this Act in case law does not appear to support equality in the legal arena for individuals with AS or ASD. While AS and ASD have been referred to as "invisible disorders", [96] the Autism and Equality Acts should ensure that these disorders are more commonly recognised and managed, although to date these Acts do not appear to have had a major impact on the legal arena. It is unfortunate that the Autism Act 2009 does not specifically refer to the CJS and the need for appropriate training, and it is of concern that current legal reforms, such as reducing legal aid, [97] are further likely to reduce equality and access to justice.

Looking at police, court, law and health and social care professionals' understanding of AS and ASD shows large inadequacies; for example, in one recent American study involving a randomized trial of AS awareness training of police, it was reported that, "despite the significant gains in knowledge following training, post-test scores for participants in both groups did not indicate mastery of the training material". [98] Studies in the UK looking at knowledge and understanding of AS and ASD have further supported this finding. [99] As discussed in the current work, references to AS and ASD in UK case law are limited, and various authors have looked at the inadequacies of the justice system and its difficulties when dealing with individuals with AS and ASD.[100] In addition to this, there is a growing body of literature looking at the variations in levels of knowledge of AS and ASD among healthcare workers in general, [101] with specific studies confirming this in, for example, medical

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[95] Searches were carried out on 18 January 2014 and failed to identify a single case in either Westlaw or Lexisnexis

[96] Bethany J Brewin and others, 'Parental perspectives of the quality of life in school environments for children with Asperger Syndrome' (2008) 23 'Focus on Autism and Other Developmental Disabilities' 242

[97] Graham Cookson, 'Unintended Consequences: the cost of the Government's Legal Aid Reforms' (King's College London 2011) <http://www.kcl.ac.uk/campuslife/student/news/stories/UnintendedConsequences-FinalReport.pdf> accessed 18 January 2014

[98] Jill Teagardin and others, 'Randomized trial of law enforcement training on autism spectrum disorders' (2012) 6(3) Research in Autism Spectrum Disorders 1113

[99] See, for example, Nicholas Chown, 'Do you have any difficulties that I may not be aware of?' A study of autism awareness and understanding in the UK police service' (2010) 12(2) International Journal of Police Science & Management 256; and Susan Young and others, 'The effectiveness of police custody assessments in identifying suspects with intellectual disabilities and attention deficit hyperactivity disorder' (2013) 11(1) BMC Medicine 248.

[100] See, for example, Nigel Archer and Elisabeth Ann Hurley, 'A Justice System Failing the Autistic Community' (2013) 4(12) Journal of Intellectual Disabilities and Offending Behaviour 53; Freckleton (n12)

[101] Amanda D Heiderken and others, 'A survey of autism knowledge in a health care setting' (2005) 35(3) Journal of Autism and Developmental Disorders 323

students, [102] general practitioners, [103] social workers [104]and psychiatrists. [105] While there are perhaps complex reasons for these findings, they nonetheless illustrate lacunae in knowledge, training and ability, which can all combine to lead to poor quality services and further promote inequalities in health, social and legal arenas.

Although increased awareness of AS and ASD is clearly desirable, this may have resulted as a consequence of the MMR vaccination and autism scandal. [106] Yet, the varying accuracy of media portrayals of these disorders [107] and the potential for sensationalisation may increase stigma and discrimination, and promulgate negative stereotypes and misinformation. [108] . While this remains to be fully evaluated, the MMR scare has, for example, been reported to have adversely affect vaccination rates [109] and its repercussions remain unresolved. [110]

Apart from specific clinical knowledge regarding AS and ASD, it is also important to understand healthcare policy, given the fundamental importance of this. As mentioned previously, the National Autism Strategy does not appear to have been implemented adequately and there remains a “lack of a coherent national strategy”. [111] Yet there are ways that this may be addressed, with Archer and Hurley suggesting these specific solutions: [112]

1. Having a “simple identification marker for ASD” on all IT systems and personal records across the entire public sector, including health, education and the CJS;

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[102] Kalpna Shah, ‘What do medical students know about autism?’ (2001) 5(2) Autism 127

[103] Wee Bin Lian and others, ‘General practitioners' knowledge on childhood developmental and behavioural disorders’ (2003) 44(8) Singapore Medical Journal 397

[104] Ernst O Vanbergeijk and Oren Shtayermman, ‘Asperger's syndrome: An enigma for social work’ (2005) 12(1) Journal of Human Behavior in the Social Environment 23

[105] Meera Roy and Sivasankaran Balaratnasingam, ‘Missed diagnosis of autism in an Australian Indigenous psychiatric population’ (2010) 18(6) Australasian Psychiatry 534

[106] Mary Langan, ‘Parental voices and controversies in autism’ (2011) 26(2) Disability and Society 193

[107] Jaci C Huws and Robert SP Jones, ‘Missing voices: representations of autism in British newspapers, 1999–2008’ (2011) 39(2) British Journal of Learning Disabilities 98

[108] See, for example, Sandra C Jones and Valerie Harwood, ‘Representations of autism in Australian print media’ (2009) 24(1) Disability And Society 5

[109] Gregory A Poland and Robert M. Jacobson, ‘The age-old struggle against the antivaccinationists’ (2011) 364(2) New England Journal of Medicine 97

[110] Nigel W Crawford and Jim P. Buttery, ‘Adverse events following immunizations: fact and fiction’ (2013) 23(3) Paediatrics and Child Health 121

[111] Nigel Archer and Elisabeth Ann Hurley, ‘A Justice System Failing the Autistic Community’ (2013) 4(12) Journal of Intellectual Disabilities and Offending Behaviour 53, 58

[112] Archer and Hurley (n107) 56

2. Having a tiered autism awareness system for all public sector staff, ranging from basic, generic training for any staff having public contact, to contextualised training for staff in specific roles and finally specialised training for staff in roles requiring the implementation of interventions;
3. Each Commissioning Group (Specialist and Clinical) having a specialist ASD service with a simple referral pathway available to GPs, local authorities and criminal justice agencies;
4. Police custody staff should be provided with a simple "initial screening tool" to identify individuals who may be vulnerable and in need of further intervention, including the services of an "appropriate adult", and diversion to appropriate services rather than prosecution;
5. There should be a series of disposals for "low level offences" such as specialist leisure programmes, mentoring and life coaching, education and vocational training;

A final suggestion [113] as regards the law is the incorporation of a "reasonable adjustments" test for AS and ASD as identified in part in *R. (on the application of W)*. [114] UK Law does contain a great many such tests (such as the 'Pritchard Criteria' for fitness to plead[115] and the test for Mental Capacity[116]) and developing and applying such a legal test may well help to ensure legal equality for individuals with AS and ASD. While this and the other suggested solutions may appear straight-forward and realistic, it is unclear whether there is currently sufficient political, economic or social motivation to implement these, thus potentially perpetuating the status quo in terms of inequality for individuals with AS and ASD.

Conclusions

This article has considered the question of whether the Equality Act 2010 ensures equality for individuals with AS and ASD in the legal arena. It looked at published legal cases and found so few cases as to make definitive conclusions difficult. Of the seven cases that were identified, few were won based on any specific violation of the Equality Act, although it may perhaps be argued that without this Act those that did win may otherwise have lost. While this Act may well be the change in law that, to re-quote Beardon, "ensures the inclusivity of the conceptual legal framework", [117] its application does not yet appear to have made a great impact and further exploration, analysis and understanding of the ever-expanding canon of case law is needed.

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[113] This is a suggestion made by the author of this article
[114] R. (on the application of W) n57
[115] R v Pritchard (1836) 7 C & P 303
[116] Mental Capacity Act 2005 s3
[117] Beardon (n2)

Thus, individuals with AS and ASD may well continue to experience sub-optimal treatment at the hands of the law, for, according to Beardon, [118] Of critical importance is the question raised over the legal framework and whether it is, in fact, unlawful in potentially discriminating against individuals with AS by not taking their AS into account.

The findings presented in this article suggest that the Law may well still be potentially discriminating and not ensuring equality for individuals with AS, despite the introduction of the Equality Act 2010. Other factors are clearly important here, and the lack of definitive implementation of the National Autism Strategy remains a key omission. Perhaps future social and legal and other research will show that this has been remedied, and that the Equality Act 2010 will have exerted - and will continue to exert - its intended impact. This remains to be seen.

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[118] ibid, 204

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		210.The Scottish Ministers
	Amendments, etc.	211.Amendments, repeals and revocations
	Interpretation	212.General interpretation
		213.References to maternity leave, etc.
		214.Index of defined expressions
	Final provisions	215. Money
		216. Commencement
		217. Extent
		218. Short title
SCHEDULES		
1 Disability: supplementary provision		
2 Services and public functions: reasonable adjustments		
3 Services and public functions: exceptions		
4 Premises: reasonable adjustments		
5 Premises: exceptions		
6 Office-holders: excluded offices		
7 Equality of terms: exceptions		
8 Work: reasonable adjustments		
9 Work: exceptions		
10 Accessibility for disabled pupils		
11 Schools: exceptions		
12 Further and higher education exceptions		
13 Education: reasonable adjustments		
14 Educational charities and endowments		
15 Associations: reasonable adjustments		
16 Associations: exceptions		
17 Disabled pupils: enforcement		
18 Public sector equality duty: exceptions		
19 Public authorities		
20 Rail vehicle accessibility: compliance		
21 Reasonable adjustments: supplementary		
22 Statutory provisions		
23 General exceptions		
24 Harmonisation: exceptions		
25 Information society services		
26 Amendments		
27 Repeals and revocations		
28 Index of defined expressions		

Appendix 2: Cases Found on Westlaw

Search Term	“Asperger”			“Asperger Syndrome”			“Autistic”			“Autistic Spectrum Disorder”			“Autistic Spectrum”			“Autism”			“Equality Act 2010”	
Total Number of cases found*	A	B	C	A	B	C	A	B	C	A	B	C	A	B	C	A	B	C	A	B
	210	69	3	202	66	3	558	142	14	298	86	11	328	91	11	338	113	11	395	327
Legal Domain:	Number of case references:																			
Commercial Law	5	0	3	3	0	3	9	2	0	3	0	0	4	0	0	5	1	0	11	11
Contract Law	7	4	0	7	4	0	29	4	1	9	1	0	9	1	0	15	3	0	19	16
Crime	105	44	0	103	43	0	139	48	1	83	34	1	90	2	1	69	30	2	37	30
Environment	8	1	0	3	1	0	12	3	0	4	1	0	7	0	0	7	0	1	24	18
Equity	3	2	0	3	2	0	2	1	0	1	1	0	2	1	0	1	0	0	1	1
Family and Private Life	62	23	3	58	21	3	167	51	15	90	34	12	98	36	11	109	45	12	300	239
Finance	4	2	0	2	2	0	6	1	0	2	0	0	2	0	0	3	2	0	11	11
Health and Social Security	39	19	1	38	18	1	150	59	8	95	41	6	102	42	6	106	49	8	79	70
Human Rights	19	9	0	19	9	0	80	31	4	42	19	3	44	20	2	63	30	3	58	46
Information and Media	2	1	0	2	1	0	11	4	0	6	4	0	7	4	0	5	2	0	5	3
Intellectual Property	0	0	0	0	0	0	7	2	0	2	1	0	2	1	0	2	1	0	1	1
International	11	6	1	11	1	0	23	6	1	17	5	1	17	5	1	8	3	1	24	18
Land	10	4	2	10	4	1	26	8	3	9	4	2	13	5	2	17	6	2	1	25
Legal System	131	46		27	45		252	32	1	130	38	1	144	40	1	159	44	2	129	115
Local Government	34	7	2	31	5	2	148	46	9	90	31	7	95	32	7	105	44	7	92	78
Property (other than land)	3	2	0	3	2	0	6	1	0	4	0	0	4	0	0	2	1	0	3	2
Public Law	17	2	0	16	1	0	60	12	1	34	8	1	38	8	1	34	10	1	83	71
Public Services and Utilities	47	7	1	45	6	1	187	37	5	126	27	5	134	28	4	112	25	5	33	26

Social Regulation	3	5	0	7	4	0	24	15	1	19	14	1	19	14	1	10	8	1	32	28
Tax	4	2	0	3	2	0	9	2	0	0	0	0	1	1	0	5	3	0	2	2
Torts	12	3	0	12	3	0	47	12	1	33	9	1	37	9	1	23	7	1	12	6
Trades, Professions and Industries	9	3	0	9	3	0	8	3	0	6	2	0	1	2	0	2	3	0	14	13
Transport	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	2	1	0	8	8
Unclassified	1	0	0	1	0	0	8	0	0	1	0	0	0	0	0	7	0	0	3	3
Work	30	6	3	20	6	3	91	29	14	45	19	11	46	2	10	39	20	10	330	269

***LEGEND**:
A = All Available Cases; B = Cases from 1 October 2010; C = Cases from 1 October 2010 including the term “Equality Act 2010”

Appendix 3: Cases Found on LexisNexis																			
Search Term	“Asperger”			“Asperger Syndrome”			“Autistic”			“Autistic Spectrum Disorder”			“Autistic Spectrum”			“Autism”			“Equality Act 2010”	
Total Number of cases found*	A	B	C	A	B	C	A	B	C	A	B	C	A	B	C	A	B	C	A	B
	329	124	8	279	114	8	715	176	8	222	61	2	320	94	6	536	167	11	537	515
Legal Domain:	Number of Case References:																			
Accounting	3	1	0	3	1	0	4	61	0	0	0	0	2	1	0	5	1	0	7	7
Administrative Law and Judicial Review	29	12	5	26	10	5	95	21	3	3	7	1	42	11	1	64	27	7	93	90
Agriculture, Animals and Fisheries	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0
Banking and Finance Law	14	3	0	9	3	0	15	2	0	0	0	0	5	1	0	7	0	0	17	15
Charities	1	40	0	1	0	0	2	1	0	0	0	0	0	0	0	6	0	0	9	8
Civil Procedure and Administration of Justice	149	0	6	124	35	6	483	98	7	7	28	1	232	53	2	345	90	10	401	381
Commercial Law	10	1	0	5	1	0	17	6	0	0	1	0	7	4	0	21	5	0	49	45
Company Law and Business Entities	19	5	0	15	5	0	15	7	0	0	3	0	7	4	0	9	4	0	36	32
Competition Law	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	4	1	0	23	21
Conflict of Laws	1	0	0	1	0	0	23	8	0	0	3	0	8	3	0	17	5	0	28	28
Constitutional Law	12	6	2	11	6	2	23	7	1	1	2	0	9	5	0	9	5	1	75	69
Construction Law	7	0	0	2	0	0	11	0	0	0	0	0	2	0	0	4	1	1	31	29
Consumer Law	2	0	0	2	0	0	6	0	0	0	0	0	2	0	0	7	1	0	3	3
Contract Law	11	1	0	4	1	0	52	12	0	0	1	0	26	6	0	32	7	1	117	111
Criminal Law and Disposition of Offenders	149	72	1	135	67	1	159	65	1	7	27	0	72	32	0	116	52	0	41	41

Criminal Procedure	152	78	1	138	73	1	155	59	0	0	28	0	71	35	0	104	43	0	41	37
Ecclesiastical Law	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	9	8
Education Law	68	1	0	59	1	0	217	24	0	0	10	0	123	14	0	177	19	0	37	35
Employment and Labour Law	23	12	3	22	12	3	71	21	1	1	1	0	36	8	0	49	21	5	322	304
Environment Law	0	0	0	0	0	0	2	0	0	0	0	0	1	0	0	0	0	0	3	3
Equity and Trusts	9	6	3	8	6	3	31	8	1	1	3	1	14	6	1	29	12	2	47	45
European Union Law	1	0	0	0	0	0	7	2	0	0	0	0	5	2	0	4	0	0	61	53
Family Law	70	20	0	61	18	0	264	70	1	1	16	0	115	35	0	210	68	1	42	38
Health and Safety	1	1	0	1	1	0	7	3	0	0	1	0	3	2	0	2	1	0	15	15
Health Law	51	22	1	46	20	1	137	26	3	3	12	0	62	14	0	141	46	3	64	63
Human Rights and Civil Liberties	37	6	5	34	6	5	99	20	5	5	1	1	35	2	1	87	22	8	278	259
Immigration and Nationality	1	1	0	1	1	0	10	2	0	0	0	0	4	2	0	12	4	0	19	19
Information technology and telecommunications	11	7	0	10	7	0	12	3	0	0	2	0	3	2	0	15	1	0	19	9
Insolvency Law	1	1	0	1	1	0	7	1	0	0	0	0	3	1	0	6	0	0	9	9
Insurance Law	5	0	0	0	0	0	2	1	0	0	0	0	0	0	0	0	0	0	10	9
Intellectual Property Law	2	0	0	2	0	0	16	2	0	0	1	0	9	2	0	11	1	0	8	8
International Law	10	4	0	8	1	0	21	14	2	2	5	2	9	7	2	24	14	2	48	47
Landlord and Tenant	4	2	1	4	2	1	21	2	1	1	0	0	6	0	0	13	2	1	2	19
Leisure and Licensing	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	2	
Local Government	30	3	1	29	3	1	165	31	0	2	10	1	58	13	1	141	47	3	86	85
Media and Communications	4	0	0	4	0	0	11	1	0	0	0	0	2	1	0	16	3	0	8	8
Military and War	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	4	4	0	1	1
Natural resources,	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	0	0	0	0	0

Energy and Utilities Law																				
Pensions Law	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	4	4	0	19	18
Personal Injury	22	3	1	21	3	1	71	8	1	1	2	0	36	3	0	60	7	1	65	62
Professions and Ethics	29	15	1	25	13	1	62	9	0	0	4	0	29	5	0	57	17	0	31	31
Real Property Law	10	6	0	10	6	0	28	4	1	1	2	0	9	2	0	9	2	0	27	26
Securities	1	1		1	1	0	1	1	0	0	0	0	1	1	0	0	0	0	0	0
Succession Law and Estate Planning	2	2	0	2	2	0	13	3	0	0	2	0	5	2	0	8	2	0	12	10
Tax Law	16	7	0	11	7	0	31	13	0	0	7	0	12	9	0	21	8	0	35	33
Tort and Delict	44	12	1	41	12	1	132	20	4	4	6	0	65	9	0	91	17	4	86	83
Transport Law	7	1	0	3	1	0	3	0	0	0	0	0	0	0	0	12	1	1	16	15
Unclassified	3	1	0	0	0	0	15	1	0	0	0	0	4	0	0	15	5	0	16	15
Welfare, Housing and Social Security Law	10	2	0	9	2	0	47	6	0	0	3	0	15	4	0	36	9	0	26	25

***LEGEND**:
A = All Available Cases; B = Cases from 1 October 2010; C = Cases from 1 October 2010 including the term “Equality Act 2010”

Appendix 4: Summary of Cases Referring to Asperger Syndrome/Autistic Spectrum Disorder and Equality Act 2010

No	Date of Publication	Case Reference(s)	Court	Age of Defendant	Gender of Defendant	Reported Diagnosis/ Diagnoses	Brief Summary of Case	Verdict/ Outcome	Equality Act Section(s) Considered
1	16 May 2012	Telchadder v Wickland (Holdings) Ltd [2012] EWCA Civ 635	Court of Appeal (Civil Division)	Not given	Male	“Mild learning difficulty and autistic traits”	The defendant appealed against the decision to terminate his occupancy of a mobile home due to acts of anti-social behaviour and failure to comply with a notice sent under the Mobile Homes Act 1983	Appeal dismissed; “There were no good grounds for contending that the judge took the wrong approach to the issue of whether it was reasonable to terminate the agreement or that he left out of account factors…having regard to disability discrimination, equality law and human rights”	s15 s15(1) s15(2) s35 s5
2	15	Parents of C v	First-tier	15	Female	“Autistic	“The parents…	Upheld; “…she	s13

	January 2013	Stanbridge Earls School [2013] Eq. L.R. 304	Tribunal			Spectrum Disorder, attention deficit hyperactivity disorder and severe mood swings”	brought a claim alleging that the school has discriminated… contrary to the Equality Act 2010 s85	was excluded by reason of her being abused; the abuse arose in consequence of her vulnerability, and that vulnerability was a clear aspect of her disability”	s15 s85
3	14 February 2013	ZH v Commissioner of Police of the Metropolis [2013] EWCA Civ 69	Court of Appeal (Civil Division)	16	Male	“Severely autistic and epileptic”	The defendant was taken to the local swimming baths by his carers and at the poolside became fixated by the water and did not move. After 30 minutes the pool manager called the police who, after touching gently on the back, had to lift him out of the	Appeal dismissed on the basis of a breach of art 3 of the European Convention of Human Rights 1950	s21B

							pool after he jumped in. He was then restrained and handcuffed, taken to a police van and left alone in a cage for about 25 minutes before the restraints were removed and his carers were allowed to take him home. As a result the defendant suffered PTSD and an exacerbation of his epilepsy. When the case was heard two years later the police were found liable.		
4	25 March 2013	P v Governing Body of A Primary School [2013] UKUT	Upper Tribunal (Administrative Appeals	10	Male	Asperger's syndrome and "likely to be suffering	"In a case where a pupil with disabilities had been permanently	Appeal allowed; "The tribunal had erred by concentrating	Disability Regs 2010, sch 1, sch 4, sch 13,

		154 (AAT)	Chamber)			from attention deficit hyperactivity disorder”	excluded from school after repeatedly kicking a teaching assistant, the First-tier Tribunal …had erred by failing…to identify the reasons for his exclusion”	on the events at the time of exclusion and failing to identify the reason he was excluded. It had also erred by failing to consider the issue of reasonable adjustments”	reg 4 s6 s15 s20 s21 s22 s26 s85
5	3 May 2013	R. (on the application of T) v Secretary of State for Justice [2013] EWHC 1119 Admin	Divisional Court	13	Male	“Autism, attention deficit hyperactivity disorder and a severe impairment of intellectual functioning”	“He had voluntarily attended a police station, knowing that he had breached a bail condition, and was arrested. Whilst detained in custody at the Magistrates’ court he walked form his cell past two adult detainees and experienced a	Upheld, as s 31 of the Children and Young Persons Act 1933 held (duty to prevent association with adult defendants)	s149 – Public Sector Equality Duty

							“cacophony” of sounds in the cell area. [He] submitted that his detention in the cells constituted a breach of the Children and Young Person Act 1993 s31, the European Convention on Human Rights 1950 art 8 and the Equality Act 2010 s149”		
6	5 November 2013	R (on the application of Islam) v General Medical Council [2013] EWHC 3763	High Court of Justice, Queen’s Bench Division, the Administrative Court	Not given	Male	Asperger Syndrome and Childhood Attention Deficit Attention Disorder	The defendant, a consultant psychiatrist, was not performing at the level expected of an individual in his position and so it was decided that the matter should be put	Not upheld; the defendant claimed that his AS was the cause of his unfitness to practice however, “the equality requirements of the 2010 Act cannot apply in	No specific sections referred to

							to an Interim Orders Panel to decide whether any conditions were needed. The panel decided that conditions regarding his practice were needed and he sought to argue that the panel had no jurisdiction.	the same way where this issue, that is to say fitness to practise resulting from illness, is in issue”	
7	9 December 2013	Swan Housing Association Ltd v Gill [2013] EWCA Civ 1566	Court of Appeal (Civil Division)	Not given	Male	Asperger Syndrome, “although there was no medical evidence that he suffered from that condition”	“A judge’s finding that a housing association’s tenant suffered from Asperger’s syndrome and was therefore disabled was not supported by evidence”	Appeal allowed; “Asperger’s was a disorder which manifested itself across a wide spectrum from slight to severe. For it to form any part of the argument for not granting an injunction, proper medical	s6 s15 s18 s35 s135 s149

								evidence of its extent and effect would have been essential. But for the judge’s belief that there had been discrimination and a beach of equal duty, he would have granted the injunction. Once that misconception had been removed, there was no impediment to its grant”	

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The potential impact of the SEN Green Paper '*Support and Aspiration: A new approach to special educational needs and disability*' on the educational inclusion of autistic children in mainstream education

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The potential impact of the SEN Green Paper '*Support and Aspiration: A new approach to special educational needs and disability*' on the educational inclusion of autistic children in mainstream education

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(Final version received 19 August 2014)

Abstract:
Since every child with a diagnosis of autism is assumed to have special educational needs (SEN), any new SEN policy and legislation will impact on their education. I consider why children with autism are more difficult to include in mainstream schools than those with other SEN and what, if anything, is being proposed to address this difficulty in the SEN Green Paper 'Support and aspiration: A new approach to special educational needs and disability'. I position the Green Paper in relation to current good autism practice guidelines and international SEN inclusion policy; and evaluate other recent developments in UK SEN policy and autism-specific teacher training. I highlight why mainstream teachers need a thorough understanding of autism to successfully include autistic children in their classrooms and conclude that, in order to achieve a positive impact, the aspirations of the Green Paper must be enshrined in law[1] and appropriately funded.

Keywords: Asperger's syndrome; autism; good practice; inclusion; special educational needs

Introduction

Since every child with a diagnosis of autism is assumed to have special educational needs (SEN), any new SEN policy and legislation will have an impact on their education. As a parent of four autistic children I am keen to

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[1] The Green Paper has now been enshrined in law following the passing of the Children and Families Act in 2014. I have made some key points in connection with the Act in a letter to the editors of Autism Policy & Practice and am working on a further article in this regard.

understand the context of their mainstream educational provision and any issues and policies likely to affect their futures. According to the House of Commons Education and Skills Committee (2006) children with autism are more difficult to include in mainstream schools than children with other forms of SEN. I would like to know why this is and what, if anything, is being proposed to address this difficulty through the latest government initiative - the SEN Green Paper '*Support and aspiration: A new approach to special educational needs and disability'* (DfE, 2011a).

In order to position the Green Paper within the current educational context I shall identify developments in the understanding of autism and how this has led to the provision of good practice guidelines for the education of autistic children; briefly describe international SEN inclusion policy and how the current UK position fits with this; evaluate recent developments in UK SEN policy and autism-specific education training, in terms of the potential impact on autistic children; and use relevant research literature concerned with autistic pupils' learning style and behaviour to highlight *why* teachers need autism knowledge in order to be able to include autistic children effectively in their mainstream classrooms. My aim is to determine whether the Green Paper includes strategies which are likely to be of benefit to, and increase the effective inclusion of, autistic children in mainstream education.

When discussing educational inclusion it is important to consider how its meaning is construed (Humphrey, 2008). The intended meaning will be context and research specific, depending on the theoretical and ideological position of the author/s and, in some cases, the commissioning organisation. My personal definition of inclusion has been influenced by what I would like my own children to experience in their schools and what I have learned about good (effective) inclusive practice from the autism literature (Jordan, 2008; Humphrey and Lewis, 2008; Wilkinson and Twist, 2010). I agree with Connor (2006) and Dybvik (2003) that, for inclusion to be achieved, the school system must adapt itself to the child's needs, rather than expecting the child to accommodate the demands of the school. For me, inclusion involves a flexibility of procedures and teaching style, in a school with a culture of respect and acceptance of diversity and with a willingness to identify and meet the idiosyncratic needs of the child. In addition, educational inclusion should not only be concerned with where, what and how a child is taught. For inclusion to be considered a success an autistic child's acceptance into a school *must* be more than physical (Jordan, 2005). The child must *feel* included and valued within their school community. The consideration of the emotional aspects of inclusion is not usually written into the definitions of national/international policy documents (EADSNE[2], 2010a; UNESCO[3], 2005) but is frequently discussed in research literature (Humphrey and Lewis, 2008; Jordan, 2005; Whitaker, 2002) and is sometimes included in local policy, such as that provided by individual schools. I will be looking for evidence that emotional aspects of inclusion have been addressed when evaluating the new policy and strategy proposals.

Understanding of autism and development of autism-specific policy

A decade ago there was a real lack of understanding of autism and the best methods for teaching those diagnosed with it (Myles and Simpson, 2001). A study carried out by the National Autistic Society (NAS) found that one fifth of autistic children had been excluded from school at some time - most commonly because their school felt they could not cope with the child's behaviour (Barnard et al., 2000). Professionals involved in the education of pupils with autism were advised to make themselves familiar with the DSM-IV-TR (2000), a psychiatric manual listing the criteria necessary for a diagnosis to be given. Educators were expected to develop and implement appropriate and effective practices, supports and interventions for autistic pupils with little understanding of the characteristics most directly related to and affecting school performance (Myles and Simpson, 2001). This limited understanding of the needs of autistic pupils was linked to academic failure and decreased social inclusion (Humphrey and Lewis, 2008). When traditional forms of SEN research were replaced by methods that sought the voices of disabled people, their families and advocates (Barnard et al., 2000; Batten and Reid, 2006; Whitaker, 2007), researchers began to understand more about what it was actually like to live with autism. These researchers concluded that in order to meet the educational needs of autistic children, and to create autism-friendly environments in which to educate them, autism-specific staff training was essential. In order to include autistic children successfully, teachers must have a working knowledge of autistic children's school-related social, behavioural/emotional, intellectual/cognitive, academic, sensory, and motor characteristics (Barnard et al., 2000; Myles and Simpson, 2001). Without this knowledge it would not be possible to establish even a simple routine of autism-friendliness, which relies on teachers thinking about things such as their use of language when teaching, the structure of their classroom and the removal of pupils' anxiety by avoiding any uncertainty about what is expected (Barnard et al., 2000).

Soon after the publication of the NAS research (Barnard et al., 2000), the government produced specific information to guide service provision for autistic children with the DfES (2001) and DfES and DH (2002) producing

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[2] EADSNE - European Agency for the Development of Special Needs Education

[3] UNESCO - United Nations Educational, Scientific and Cultural Organisation

good practice guidance about autism for local authorities which included information for schools (POSTnote, 2008). Further guidance *'Supporting pupils on the autism spectrum'* was produced by the DCSF (2009) as part of their Inclusion Development Programme and the Autism Education Trust (AET) has recently been commissioned to develop a set of 'National Autism Education Standards' for good practice in the education of children and young people with autism. I shall look at this in more detail later.

Unfortunately, although explicit concerns were raised about how well the earlier guidelines were actually being used by schools (House of Commons Education and Skills Committee, 2006) there is no evidence that the more recent ones are being utilised any better. Many teachers (55%) still feel that they lack the 'specialist knowledge' to enable them to provide effectively for autistic children (Charman et al., 2011) and 76% feel that better autism knowledge would help them to help autistic children have a more positive experience of school (Macbeath et al., 2011). Such lack of professional development in autism is a barrier to teaching autistic children (Humphrey and Lewis, 2008).

International SEN policy and the current UK position

In the UK autism is considered to be a disability under the Disability Discrimination Act (1995). Under the Disability Equality Duty (2006), all public bodies, including schools, must promote the equality of autistic individuals (POSTnote, 2008). The UNESCO (2005) guidelines for inclusion state that education policy and provision should aim to promote child-friendly school cultures and environments, which are conducive to effective learning and inclusive of *all* children and they have recently produced a document titled '*Everyone has the right to education*' (UNESCO, 2011). Within Europe, the EADSNE aims to highlight and promote principles of equal opportunities in terms of genuine access to learning experiences that respect individual differences. It promotes 'Quality Education for All' focusing on personal strengths rather than weaknesses. The ultimate aim of the EADSNE is to improve educational policy and practice for all learners with SEN and it is hoped that the key principle recommendations of the agency will contribute to the work of policy makers across Europe concerned with inclusive education. The current UK position is that schools are required by law to make 'reasonable adjustments' to ensure that autistic pupils are not disadvantaged compared to their peers (Special Educational Needs and Disability Act (SENDA), 2001). Furthermore, teachers *should* understand their responsibilities under the SEN code of practice, differentiate their teaching to meet individual needs and be able to identify and support pupils who experience behavioural, emotional or social difficulties (Pearson, 2007); local education authorities (LEAs) are *encouraged to* provide clear guidelines on their policies and practice and to demonstrate a flexibility and willingness to listen to requests and ideas from parents and professionals; and schools and LEAs are *expected to* develop their cultures, policies and practices towards achieving an inclusive educational environment, ensuring *all* pupils have equal access to the curriculum (Wilkinson and Twist, 2010). The use of these non-compulsory terms (‘should’ ‘encouraged to’ and ‘expected to’) when referring to teachers’ and LEAs’ inclusive practice, highlights the lack of legislation in this area. Despite a general agenda for inclusion and research suggesting teacher education in autism is vital for the successful inclusion of autistic children (Wilkinson and Twist, 2010; Myles and Simpson, 2001; Barnard et al., 2000), there is still no legal requirement for teachers to receive any autism-specific training (Humphrey and Lewis, 2008), nor obligation to make use of the good practice guidance that exists (DfES, 2001; DfES and DH, 2002; DSCF, 2009) and unfortunately the gap between inclusion rhetoric and classroom reality remains very wide (Humphrey and Lewis, 2008; Parsons et al., 2009). Although the current UK position regarding the inclusion of children with SEN *sounds* positive, the reality for autistic children and their parents is often that their experiences do not match up to expectations and successful inclusion is not achieved.

Why are Autistic Children More Difficult to Include?

It has been reported that children with autism are more difficult to include than children with other forms of SEN (House of Commons Education and Skills Committee, 2006) and that children with autism need ‘different’ forms of provision (DfE, 2010a). The very nature of autism as a social and communication difficulty means that many traditional teaching methods, which rely on an understanding of language and social behaviours, leave autistic pupils at a disadvantage and teachers having to find alternative methods of communicating with them (Humphrey and Lewis, 2008). To better understand the many challenges that face teachers when they have an autistic child (usually with a diagnosis of AS) in their mainstream class, I shall highlight some of the particular thinking and learning styles and patterns of behaviour common to these children and suggest how these might impact on teachers’ ability to include them successfully.

Motivation, anxiety and behaviour

Unlike many other disabilities, AS is not immediately apparent to others (Myles and Simpson, 2002). Because of this, some teachers can find it hard to recognise, and in some cases difficult to believe, the extent of the problems which can arise from it. Children with AS understand and respond to the world in a very different way from non-autistic children (Jacobsen, 2004) and it is very easy to attribute meaning to their behaviour that is wholly inaccurate (Jordan, 2008). It may be difficult for mainstream teachers to appreciate the extremes of anxiety that can be produced by everyday situations (Powell and

Jordan, 1991). Daily occurrences that cannot be planned for or anticipated can lead to major distress and challenging behaviour. Autistic children are sometimes labeled as lazy, difficult or defiant when they fail to complete a task (Humphrey and Lewis, 2008) because their teachers fail to understand their autistic perspective (Jones et al., 2009). Often children with AS have obsessive or narrowly defined interests (Myles and Simpson, 2002) and they lack motivation towards ‘other-directed’ or ‘socially-meaningful’ tasks. The teacher cannot use his/her own enthusiasm to motivate (as he/she might with a PNT child) if the autistic child does not care about what the teacher cares about (Jordan and Powell, 1991). Even with the motivation some autistic children have fundamental difficulties which affect their capacity to become independent learners. High levels of anxiety about whether their responses and actions are appropriate can prevent them from carrying out a task and this performance anxiety may bear no relationship to their actual abilities. They may not do anything, physical or intellectual, without continual encouragement or approval, even when they are perfectly able to complete a task. This dependency on their teacher is likely to increase when ‘new’ activities are encountered and the class teacher may simply not have the resources to devote to the autistic child when they need it. To compound this difficulty for teachers, what works to motivate and support an autistic child one week (or in one situation) may not work the next and this will be influenced by many factors including the child’s mood, pre-school stress, or changes in their sensory environment. Smells, sounds and other sensory stimuli may affect the autistic child and their ability to concentrate, stay seated, remain calm etc. but may remain undetectable to the teacher. Such sensory stimulation is likely to have a profound effect on a child with AS and determine which learning environments are most effective and which are counter-productive, leading to withdrawal or distress (Jordan, 2005). The class teacher may not be able to tell that the autistic child is becoming distressed until it is too late, as many children with AS do not reveal stress through voice tone or overt agitation (Myles and Simpson, 2002). As a result they may escalate to the point of crisis before their teacher becomes aware of their excitement, or the discomfort they feel due to their inability to predict, control and manage uncomfortable situations (Myles and Simpson, 2002). Teachers need to become familiar with individual children’s anxiety triggers and telltale signals of stress and remain attentive to the child at all times in order to help them manage difficult situations effectively. This level of attentiveness is likely to be difficult for a class teacher who also has the diverse needs of thirty other children to meet - and even more so because it is not always easy to predict when the autistic child will cope and when they won’t.

The child with AS may not be able to tell what others are thinking and may be very rigid about the way things need to be done. This can cause difficulties between the autistic child and their PNT peers who might want, or have been instructed, to share or co-operate in a play or group-teaching situation. Often the child with AS wants other children to play with them but insists that they follow strict rules which may or may not be articulated, making it extremely difficult for the PNT child to join in. The autistic child might find it difficult to accept the ideas of their non-autistic classmates, understand what they are thinking or why they want to do something in a particular way and neither one is able to communicate their ideas effectively to the other. Such situations can lead all parties involved to feel frustrated. The difference for the child with AS is that they (unlike the PNT child) might react to high levels of anxiety or frustration with verbally aggressive or physically violent behaviour. This type of challenging behaviour must be particularly difficult for a teacher to manage in a mainstream classroom. Even when teachers understand and accept that these behaviours are not deliberately defiant or disruptive (Connor, 2001) they still have the task of containing and calming the child who may be out of control. At the same time they are responsible for protecting the other children present and for keeping their classroom a safe, supportive and accepting place for everyone. Children with AS can be easy targets. They tend to be gullible and naïve and are easy to manipulate into having extreme reactions. Expecting and ensuring that all children respect, support and take responsibility for each other is at the centre of any commitment to embrace diversity (Safran, 2002). PNT children might need help to recognise the positive characteristics of autism (of which there are many) and friendships should be facilitated and encouraged as much as possible. The PNT children need to understand that their autistic classmate is treated differently because he/she *is* different and not because of some form of injustice or favouritism on the part of the teacher. The production of inclusive policies and the creation of inclusive communities and cultures underpin inclusive practice in schools (Humphrey, 2008). The ethos of the school, and in particular the way in which ‘inclusion’ is understood, is crucial in determining the extent to which government policy and guidance are followed (Humphrey and Lewis, 2008). A true (rather than token) commitment to inclusive principles from the leadership team seems to make the difference when it comes to translating policy into practice (Jordan, 2008). I have seen evidence of this first hand. My son has exhibited all of the difficulties and behaviours described above since starting school and many ‘reasonable adjustments’ have been made by his teachers in order to include him. It has taken a year for staff to really get to know and understand him and they have shown a real commitment to trying to meet his needs. He attends a school with a reputation for effective inclusion, where the culture, practice, management and deployment of school resources are designed to ensure *all* children’s needs are met and that *all* children, regardless of ability, are valued equally. Children with SEN are not viewed as a separate entity, but are part of a whole school approach. Different children’s needs are recognised and met through varied and flexible provision throughout the curriculum (extract from his school’s SEN Policy, 2009). The inclusion policy sets out the school's aims to provide equality of educational opportunity; to engender a culture of tolerance and acceptance of all; and to help the children develop self-respect and a sense of responsibility and caring for each other. Inclusion is seen as an ongoing process that celebrates diversity and involves identifying and minimising barriers to learning and participation that may be experienced by any pupils. I believe that my son's inclusion is a success. He 'feels' part of his school community and is respected and accepted by his peers. He is happy to be in school and is beginning to reach the targets which have been set for him. His teachers have had to manage many conflicting and fluctuating demands. For teachers with less knowledge of autism and without such a strong commitment to inclusion and training from the head teacher, his successful inclusion into a mainstream environment would have been much more difficult and perhaps impossible.

Assessment

The accurate assessment of children's capabilities and potentials is one of the key processes involved in all teaching (Jordan, 2005). The development of inclusive policies, such as '*Removing Barriers to Achievement*' (DfES[4], 2004); the 2004 Children Act; and the *'Every Child Matters: Change for Children'* policy (DfE[5], 2004), which requires all schools to consider factors in meeting *all* pupils' needs (Watkins (Ed.), 2007), led to the development of inclusive strategies for assessment, such as '*Assessment for Learning*' (AfL) (DfES, 2004) and more recently the '*Assessment for All*' (AfA) pilot programme (DCSF[6], 2010). The aim of these strategies was/is to enable teachers to adjust their teaching to meet the needs of *all* their pupils and at improving educational achievement for *all* children, by treating them as individuals which is the 'only way to achieve equity in the classroom' (Jordan, 2008). It is suggested that the AfL and AfA methods and tools can be used for all pupils including those with SEN and therefore autism. Teachers are expected to modify and adjust these assessment methods and tools appropriately for use with autistic children although there is still no evidence that these tools *are* effective at evaluating the performance of autistic children (EADSNE, 2010b). With so many teachers reporting that they have not received the training they feel they need to teach autistic children (Charman et al., 2011; Macbeath et al., 2011), getting these assessments right without further autism-specific training might not be possible. Even with appropriate tools and training, the continual fluctuation of autistic children's performance is likely to make accurate assessment a real on-going difficulty for their teachers who need to seek direct evidence of their pupils' understanding. They cannot rely on the child communicating his or her thinking or the reasons for it (Powell and Jordan, 1991). A teacher who does not

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[4] DfES - Department for Education and Skills
[5] DfE - Department for Education
[6] DCSF – Department for Children, Schools and families

understand how a child is affected by their autism might wrongly attribute lack of task performance to lack of ability, when actually the autistic child is confused about what is expected of them or distracted by some external stimuli. Their poor self-management skills (Jordan, 2003), concrete and literal thinking styles, poor organisation, distractibility, and difficulty discerning relevant from irrelevant information might all interfere with the teacher's ability to assess their true capabilities (Myles and Simpson, 2002). Many children with AS have visual-motor coordination difficulties and find it hard to produce work that is legible or fulfill the requirements of a written task in the time they are given. These children need their teacher to recognise their need for more time or an alternative method of completing the task (such as using a keyboard for writing). Children with AS might have visual memory weakness (Myles and Simpson, 2002) or poor working memory. They might not remember what has been learned or, if remembered, not be able to generalise learning from one situation to another, or from one day to the next. They might even be able to do something in one room but not in another depending where they were when they first learnt to do it. All of this poses a challenge for a teacher trying to establish what they *can* do. The autistic child's apparent competence with verbal language might mask a lack of comprehension. They might not realise when they are being spoken to and not consider themselves to be included in instructions that are directed at 'everyone'. Their processing time might be slower than would be expected for a child of their intellectual ability and they could need much longer to respond to even a simple question. They might be exceptionally skilled in some areas but lack basic knowledge in others.

The fluctuating academic profiles and day-to-day behaviours of autistic children means that there is no particular recipe for their teaching in general, or even of an individual child throughout the school year. Teachers need to possess a particular kind of sensitivity to feedback gained from their pupils (Powell and Jordan, 1991). This feedback must be informed by an understanding of the reasons why pupils are learning and behaving in the ways that they are coupled with an understanding of the individual child. This is why high quality autism-specific training for teachers is so important.

The SEN Green Paper

The SEN Green Paper, '*Support and aspiration: A new approach to special educational needs and disability*' (DfE, 2011a) includes many of the recommendations made by the latest international conference concerned with inclusive education (EADSNE, 2010c). The authors of the Green Paper suggest it 'marks an important milestone in the development of the government's approach to supporting children and young people with SEN'. I am interested in the potential impact of this 'approach' on the educational experience of autistic children.

Several organisations have published responses to the Green Paper as part of the government's on-going consultation process. In my analysis of the Green Paper, I shall highlight some of the issues put forward by organisations that have a particular commitment to/interest in educational inclusion, autism or both. I have chosen to concentrate on those issues within the Green Paper that I feel have the greatest potential to influence the educational inclusion of autistic children. These are the introduction of Education Health and Care Plans (EHCPs); the removal of Individual Education Plans (IEPs); the collapsing of the current School Action (SA) and School Action Plus (SA+) levels of SEN into one single school-based level; the commitment to reduce exclusions; the introduction of the Pupil Premium; and the commitment to improve autism-specific teacher training.

The National Autistic Society (NAS), Ambitious about Autism (AaA), The Council for Disabled Children (CDC), National Parent Partnership (NPP) and the Special Education Consortium (SEC) have all welcomed the aspirations and intentions of the government to improve the SEN system to make it work better for families. However, these groups believe that children with autism will continue to be failed by the system unless, amongst other things, a 'legal duty' to assess and provide for all their support needs is introduced.

One criticism of the Green Paper put forward by all these agencies is the notable absence of the voice of children and young people. Children with SEN are experts in the support they need, and are well placed to determine the support and services that will work well for them (SEC, 2011; CDC, 2011) but the importance of their views is not adequately recognised (NPP, 2011). A consultation by the SEC found that many disabled children, including those with autism, are still experiencing barriers to inclusion and indeed the Office for National Statistics (2009) puts that figure at 30% compared to 3% of their non-disabled peers. It is apparent that there are still many failures to make 'reasonable adjustments' (SENDA, 2001; Equality Act, 2006) to school policies and practices, to prevent *bullying*, to celebrate achievements and to take account of the different ways in which children learn (SEC, 2011). The main barrier to inclusion identified is the attitude of others (SEC, 2011). The SEC and the CDC both feel that the Green Paper does not focus adequately on the removal of such barriers or the improvement of quality of education and outcomes for disabled children. For example, there is no reference within the Green Paper to the Equality Act Duties (2006) to make 'reasonable adjustments' for disabled pupils. Many adjustments, both to teaching style and to the educational environment, have to be made by mainstream teachers in order to successfully include autistic children in their classrooms. Lack of focus on (or any dilution of) the existing legislation in this area is likely to have a negative impact on children with autism.

Education Health and Care Plans (EHCPs)

The focus of the Green Paper appears to be on children and young people with high-level multiple disabilities. It is not clear from the new proposals what (if any) statutory protection is going to be available for children with autism or whether autistic children will be eligible for the EHCPs which are due to replace Statements of SEN by 2014 (SENlegal, 2011). Under the current system it can be more difficult for autistic children who are academically able or even gifted to get support through a Statement (NAS, 2011), despite the clear social difficulties these children have and their need to gain other skills and understanding, such as communicative competence; social understanding; physical and emotional well-being; and independence skills. Without these skills they may fail to benefit from their academic successes in terms of their future education, employment or living arrangements (Parsons et al., 2011). I have been told that none of my autistic children would receive Statements of SEN because they are *too* academically able and intelligent. As children with AS have average or above average intelligence by definition (DSM-IV-TR, 2000) they are likely to be academically competent. It shows a complete lack of appreciation of the social, emotional, behavioural and sensory difficulties experienced by these children to deny them a statement of SEN, and therefore guaranteed support, on the grounds of their academic strengths. When left unsupported, social and emotional difficulties can have a profound impact on children’s wellbeing and progress (NAS, 2011) and must not be overlooked. The NAS would like to see a coherent process, which meets the needs of all children with autism, whatever level of official support they are on.

Consultation has shown that parents at SA+ are twice as dissatisfied about most areas of their child’s education as those parents whose child has obtained a Statement of SEN because of the difficulty they have accessing the right support for their child. The NAS (2011) urge the government to make sure that *all* children identified with SEN have clear rights and entitlements in order to give parents confidence that the system will meet their child’s needs and propose that *every* child with autism will need an assessment of their needs regardless of whether they are thought likely to get a Statement or EHCP. Other agencies have gone further and suggested that *all* children who would benefit from an EHCP should get one (CDC, 2011; SEC, 2011). This should include children currently at SA+ and *all* children identified as having a disability (which includes autism) who are therefore considered as being ‘in need’ through the Children Act (2004). There is no suggestion in the Green Paper that this will be the case. If the EHCP is to have a positive impact on children with autism it must be backed by a legal right to assessment and support which is coordinated across agencies and it must be clear about who is accountable for funding and delivering both the assessment and the plan (AaA, 2011). There is no commitment provided by the Green Paper that this will happen either.

Individual Education Plans (IEPs)

The Green Paper proposes to abolish IEPs in order to cut bureaucracy. Currently all children with SEN, and therefore all autistic children, should have an IEP. It should include details of the criteria used by school to measure and evaluate a child's achievements and provide details of the methods and approaches used to ensure the child achieves his/her targets. IEPs can be useful tools for parents to understand what their child is working towards (NAS, 2011). As a parent with autistic children, I find that their regular IEP reviews provide me with a welcome opportunity to go into school to meet their teachers to discuss their progress and attainment. These meetings provide much needed contact and information including what I can do to support my children's learning at home. Autistic children need a consistency of approach and it can be very helpful for school and home to be working on the development of certain skills in the same way at the same time. As well as proposing to abolish IEPs, the Green Paper makes no mention of Annual Reviews. Depriving parents of these opportunities to find out information from the school on a regular basis is neither a parent centred, nor a child centred approach (NPP, 2011). Rather than abolish IEPs, the introduction of SMART targets (specific, measurable, achievable, and realistic) with an agreed date for completion, to be set, monitored and re-set through the IEP has been suggested (SENLegal, 2011). I think this proposal is a good one. I really appreciate the time I am given to discuss my children's IEPs and the information I learn about them through doing so. It will be very disappointing if they are abolished and I am concerned that it is yet another safeguard of autistic children's needs that is going be withdrawn. A close partnership between school and parents is important for the inclusion of autistic children (Jordan, 2008; Humphrey and Lewis, 2008; Wilkinson and Twist, 2010) and any erosion of the pathways of communication parents have with their child's school is likely to be detrimental to that child's educational inclusion.

The single SEN category

The Green Paper proposes to replace the current SEN levels of SA and SA+ with a single school-based SEN category and several organisations have real concerns about this (AaA, 2011; NPP, 2011; NAS, 2011). It is possible that merging the two categories will reduce the access to the support that children need in order to make progress (AaA, 2011) and might lead to children with autism who have less obvious needs being overlooked (NAS, 2011). The NAS (2011) propose that the definition of the new category of SEN *must* continue to take into account wider social aspects of a child's education and not focus purely on his/her academic attainment. Clarification that children currently at either SA or SA+ will still be able to access the support they need, and information about how they will access it, has been asked for (AaA, 2011).

Reducing exclusions

The Green Paper acknowledges that exclusions can often be the result of an unrecognised or unmet SEN, which has led to challenging behaviour. Exclusions have a disproportionate impact on children with autism and can damage children's progress, behaviour, confidence, relationships, mental health and social development (AaA, 2011). The Green Paper proposes that the risk of exclusion should trigger an assessment of additional needs, to ensure children are not excluded because a school fails to meet their needs. If implemented, this proposal has the potential to impact positively on children with autism who are the most excluded group, with 43% being excluded over a 12-month period (AaA, 2011). The proposal to put an end to unfair exclusions by introducing assessments to identify unmet SEN at school is welcomed by agencies concerned with inclusion issues and/or autism (NAS; AaA; CDC; SEC).

The Pupil Premium (PP)

The Green Paper acknowledges the need for better funding of children with additional needs. The PP has been introduced to provide extra money 'directly for those pupils who need it the most' (DfE, 2011b). The government believes the PP, which is additional to main school funding, is the best way to address the current underlying inequalities between children eligible for Free School Meals (FSM) and their wealthier peers, as 'all the evidence and facts make it abundantly clear that poverty is the single most important factor in predicting a child's future life chances' (DfE, 2011c). Whilst I am not arguing this point, I maintain that to *only* target children entitled to FSM is to deny support to other underperforming groups which includes children with SEN. Prior to the introduction of the PP, SEN funding was allocated to individual schools according to the needs of the children they had on role, with additional money provided for children with Statements of SEN. This has now changed as it was thought head teachers might be incentivised to request statutory assessments for Statements in order to procure additional funding for their schools. Schools now receive a set main budget per year. This includes their SEN funding, which is no longer calculated according to the needs of the pupils on role. Each child entitled to FSM is then awarded an additional £600 each year, which *is* provided to the school they attend and must be spent on enhancing their individual attainment in some way. As 30% of pupils with SEN are known to be entitled to FSM, and therefore the PP, and schools already have some money allocated in their budgets for SEN, the government argues that this distribution is still the best way to help the poorest pupils whilst still reaching many with SEN (they make no mention of the 70% of children with SEN who are not entitled to FSM). Unfortunately this system disadvantages schools in affluent areas that still have many children with SEN but few children who qualify for the PP. This is the case at my son’s school where only 8 children on role are entitled to FSM (bringing in an extra £4800/year). The number of children on the SEN register at the school is much greater (47) with 4 identified as autistic and another 4 undergoing assessment and expecting a diagnosis of autism. No additional financial provision is made for these children through the PP. A child with a Statement of SEN is legally entitled to the specific provision set out within that Statement. Under the new system, the funding for this individual provision no longer exists. In schools where the provision for children with Statements of SEN uses up the entire SEN budget, no further funding is available for other children with SEN who do not have a Statement. Without the legal protection of a Statement the provision of support depends on the priorities and ethos of the head teacher, who has to balance the special needs of the exceptional few against the needs of the other children in the school. This situation is likely to have a very negative impact on the inclusion of autistic children in mainstream schools. For children with Asperger Syndrome (like mine) who are ‘too high functioning’ (according to their educational psychologists) to be considered for a statement of SEN (and probably for an EHCP in the future) there is a real danger that the support they need will not be available due to lack of funding. Without a head teacher committed to inclusion for all, parents could find themselves having to fight to obtain the right support for their child. This is exactly the sort of barrier to inclusion that drives parents to seek a place for their child in specialist educational provision where the sort of support they are fighting for is more likely to be given as standard. The head teacher of my son’s infant school is currently sitting on a steering group trying to influence the funding provided for children with a Statement of SEN. The group’s aim is to secure individual funding for those children with exceptional need (a Statement allocating 15 hours/week or more of support) in order to prevent their presence in a school using up the entire SEN budget as it does now.

Improving the Standard of SEN Teaching and Support in Schools

The Green Paper acknowledges that, at present, initial teacher training does not always equip teachers with the tools to identify and meet the broad range of SEN they are likely to encounter in the classroom. Reference is made to the White Paper ‘*The Importance of Teaching*’ (DfE, 2010a) which sets out plans for new standards in qualified teacher status, with a stronger focus on support for children with additional needs. Autism has been identified as ‘a specific category within the wider group of SEN’ (DfE, 2010b) and the difference between the needs of autistic children and those with other forms of SEN is recognised in the Green Paper.

That teachers need better training in SEN and autism is nothing new. It has been over a decade since the publication of the NAS report (Barnard et al., 2000) which concluded that autism-specific teacher training was crucial to the successful inclusion of autistic children in the mainstream and since then many other researchers have said the same (Myles and Simpson, 2001; Batten et al., 2006; Whitaker, 2007). Inclusive schools are understood to be those that make major adjustments to their organisation and processes in response to their diverse populations (Nind and Wearmouth, 2006). A key element of adjustment is the way that teachers teach. To develop inclusive pedagogy teachers need access to good information (Barnard, 2000; Batten et al., 2006; Nind and Wearmouth, 2006; Jordan, 2008). Parents agree that skilled and competent staff make the biggest difference for their children in school (AaA, 2011) and it is certainly my experience that my autistic children have been happiest and most successfully included when they have had knowledgeable teachers who understood their needs.

To address the on-going need for better training for teachers who are already qualified, the Green Paper promises 'free' online training materials about autism to schools and it is intended that these will be nationally recognised and flexible. These will replace the previous Inclusion Development Programme (IDP) teaching resource *'Supporting pupils on the autism spectrum'* (DCSF, 2009), which was withdrawn following the change of government in 2010 and archived because 'it may not reflect current government policy'. The Autism Education Trust were commissioned by the current government to produce a report characterising aspects of good practice in autism education and have since produced an autism-specific resource, *'Tools for Teachers: Practical resources for classroom success'* (AET, 2011). School staff are able to view the PDF guide online at no cost but, contrary to the promise of 'free' training resources, the *'Tools for Teachers'* pack and interactive DVD have to be paid for by schools. This is a real shame when school budgets are already under increased strain. Interested staff might have to persuade school leadership to purchase the resource against other competing priorities. Making the toolkit free to schools, as the IDP (DCSF, 2009) was, would ensure it reached more teachers and therefore had a better chance of benefitting more children.

Tools for teachers

It was suggested (Humphrey, 2008) that what schools need is evidence based on what works, how it works and why, to enable them to provide better education to autistic pupils. In my opinion the *'Tools for teachers'* kit (AET, 2011) has the potential to provide this. The 'toolkit' examines social imagination, communication and understanding; sensory sensitivities; and behaviour management. The effect of each area of difficulty on a child's functioning at school is described and strategies for compensating for these difficulties and their effects are suggested. Specific tried and tested 'tools' such as visual timetables; workstations; prompt cards etc. are demonstrated and available to print, with clear instruction for their use and when and why they might be appropriate. I am particularly impressed by the unit focusing on sensory sensitivities, which gives examples of how a child with autism may be affected by hyper- or hyposensitivity; the impact such sensitivities might have on a child's behaviour; and strategies to address his/her needs as a result. In my experience, the area of the sensory difficulties experienced by children with autism is often the one least understood by school staff. This comprehensive guide provides teachers with a good basic knowledge of sensory issues and insight into why their autistic pupil might be behaving in a particular way. The 'toolkit' concludes with a 'recommended reading' list and links to 'useful websites'.

Teacher training - continuing professional development

It is intended that the DfE supported AET training programme, *'National Autism Education Standards'*, due to begin in 2014, will be delivered through 'Training Hubs' and provided at 3 levels. Professionals who complete all three levels will be able train as trainers, enabling them to deliver levels 1 and 2. It is hoped that this will extend the reach of the programme and enhance its sustainability. Level 1 (whole school) training is free but there is no mention on the AET website (www.autismeducationtrust.org.uk) of how level 2 and 3 are intended to be funded or how schools are going to be encouraged to take advantage of it.

Conclusion

The intentions of the government, to improve the SEN system to make it work better for children and their families, are only likely to have a positive impact on the educational inclusion of autistic children if legislation is passed to ensure the measures needed to achieve the aspirations of the Green Paper are enshrined in law. If 'legal duties' to assess need and provide support are not introduced, it is unlikely that the situation for those autistic children, too 'high functioning' to be considered for statutory assessment at the moment, will become any better in the future. In fact, there is a danger that the implementation of the Green Paper recommendations could actually serve to reduce services currently accessible to autistic children through SA and SA+. It is clear that teachers still lack understanding and knowledge of autism. The government has gone some way to addressing this with proposed improvements to initial teacher training and the commissioning of *'Tools for Teachers: Practical Resources for Classroom Success'* (AET, 2011). This resource provides the sort of information which, if understood and acted upon by teachers, could really improve the educational experience of autistic children in mainstream classrooms academically, socially and emotionally. However, training teachers costs schools money - even if the training itself is free. Schools are already operating on reduced budgets and have to prioritise their spending. Without an appropriate funding package from central government, to enable schools to release teachers for compulsory training, there will always be schools who do not make use of the new resources and autistic children who are left misunderstood and under-supported as a result. I have an ethical objection to the very existence of a SEN Green Paper. If *all* children's needs were met in an appropriately funded education system we would not need a separate SEN category. Governments should not be making value judgments about which of the most 'disadvantaged' groups of children to help and offering them a 'premium' - in this case those entitled to FSM. There should be a large enough investment in schools that the needs of *all* children can be provided for to ensure full-inclusion is achieved and every child is able to reach his/her potential. Unless this happens the successful inclusion of autistic children will still largely depend on the commitment of head teachers to promote inclusive practice and of individual teaching staff to try to understand and empathise with the autistic child's difficulties and to be flexible in their response to his/her needs. My children attend mainstream schools where this is the case. They feel valued and respected within their school communities and are happy and achieving their potentials. I recognise how very lucky they are.

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