AUTISM AND EDUCATION

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AUTISM AND EDUCATION

VOLUME I

Key Perspectives and Themes in Autism Education

Edited by

Neil Humphrey

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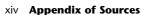   1791–1796.
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Introduction: Key Perspectives and Themes in Autism Education

Neil Humphrey, Caroline Bond, Judith Hebron,
Wendy Symes, and Gareth Morewood

Introduction

Autism is a lifelong developmental disability that influences how affected individuals communicate with and relate to other people (National Autistic Society, 2014). It is a spectrum condition. This means that individuals with autism share difficulties in key areas, but these can affect them in different ways. The first area in the 'triad of impairments'[1] (Wing, Gould, & Gillberg, 2011) is *social interaction*. Here we may see problems in the development of social relationships. Individuals with autism may struggle to understand their own and/or other people's emotions and unwritten social rules. The second area is *social communication*. This may include, for example, difficulties or delays in language development and understanding (e.g. the tendency to interpret things in a very literal manner). Finally, autism is characterised by difficulties in *social imagination*. This can include problems in understanding how and why other people think, feel, and behave in the way they do. It can also lead to a strong preference for routine because of difficulties in imagining a changed, new, or unfamiliar situation. Put simply, individuals with autismcan struggle to make sense of the world around them (National Autistic Society, 2014).

There are a number of terms that have been used to describe individuals with different autism spectrum conditions (ASCs). These include autism, Asperger syndrome, and pervasive developmental disorder, not otherwise specified (PDD-NOS) (Blenner, Reddy, & Augustyn, 2011). However, a recent change to the main diagnostic system used by clinicians (the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* – American Psychiatric Association, 2013) has led to the preferred use of the broad term 'autism spectrum disorder' (Lauritsen, 2013). In this text we adopt the term ASC, in recognition of the more respectful view that autism should be seen as representing difference rather than deficit (O'Neil, 2008). Here we also acknowledge the areas of strength that ASC can bring – often including enhanced memory, persistence, adherence to routine, and attention to detail (Morewood, Humphrey, & Symes, 2011).

ASC manifests in early childhood. However, high-functioning cases (e.g. those described as having Asperger syndrome) may not be recognised until later in life when increased social demands begin to outpace an individual's capabilities. The median prevalence estimate for ASC in a recent international review was 62/10,000 (Elsabbagh et al., 2012), although there is considerable variation from country to country (Taylor, Jick, & Maclaughlin, 2013). This variation, along with the marked increase in reported incidence of ASC in recent years, can be ascribed to changes and differences in diagnostic procedures, availability of services, and growing public and professional awareness (Elsabbagh et al., 2012). Males are disproportionately affected, with a sex difference ratio of around 4.75:1 (Taylor et al., 2013). ASC is often accompanied by other difficulties, which can include learning disabilities, medical, and psychiatric conditions (Gillberg & Billstedt, 2000). It is now commonly accepted that there is no single cause of autism.

Experiences and Outcomes of Education for Learners with ASC

Very few countries across the world collect detailed data about educational provision and outcomes for learners with autism (Bond, Symes, Hebron, Humphrey, & Morewood, 2014). England is an exception and so we use it as the primary exemplar here. Around 70% of children and young people with ASC attend ordinary mainstream schools, with the remainder placed in resourced units in mainstream schools, specialist ASC schools, or other types of specialist provision (e.g. schools for children with social, emotional, and behavioural difficulties) (Keen & Ward, 2004). Policy developments have been very influential. So, for example, in 1997 the New Labour government in England published a powerful manifesto for inclusive education entitled *Excellence for All Children* (Department for Education and Employment, 1997). The following five years saw a 16% increase in the proportion of children with ASC placed in mainstream schools in England (Keen & Ward, 2004). Research has revealed a number of factors that influence these educational placement destinations. White, Scahill, Klin, Koenig, and Volkmar's (2007) study in the United States found that lower cognitive ability and communication skills were most strongly associated with placement in specialist education settings. Their research also demonstrated that most students with ASC stayed in the same placement (e.g. mainstream or specialist) in which they began school.

Developing and implementing effective processes and practices to meet the needs of affected children and young people across the full range of provision continues to be a major and significant challenge in education systems worldwide. An inquiry into the state of special educational provision remarked, 'Children with ASD . . . provide an excellent example of . . .

where significant cracks exist in the system, to the detriment of those who fall between them' (House of Commons Education and Skills Committee, 2006, p. 18). The available evidence supports this, suggesting that the experiences and outcomes of schooling among those with ASC can be markedly worse than for other children. For example, in 2009/10 only around 23% achieved the level of academic attainment expected by the end of their compulsory education in England[2] compared to 54% among all students in the same year (Department for Education, 2010, 2011). Furthermore, such students are more likely to receive both fixed-term and permanent exclusions from school than their typically developing peers (Department for Education, 2013a, 2013b). A range of studies in different countries has also demonstrated that they are amongst the most likely to be bullied in the school population (see Schroeder, Cappadocia, Bebko, Pepler, & Weiss, 2014). Children with ASC are more often on the periphery of social networks, experience poorer quality peer relationships, and have fewer reciprocal friendships (Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011). Teachers – particularly those in mainstream education – report experiencing tensions relating to frustration over the enduring emotional and behavioural manifestations of ASC (Emam & Farrell, 2009). Finally, 70% of parents report experiencing difficulties in getting the educational support their child needs, with 18% having to resort to the tribunal system to achieve this (National Autistic Society, 2011). It will come as no surprise that these experiences and outcomes are reported to be a key driver of greatly increased prevalence rates of anxiety, depression, and anger problems among affected students (Hebron & Humphrey, 2014), with one quarter not happy at school (National Autistic Society, 2011). Furthermore, the rate of suicidal ideation and attempts among children with autism is reported to be 28 times greater than that of their typically developing peers (Mayes, Gorman, Hillwig-Garcia, & Syed, 2013).

Why does education – particularly regular, mainstream schooling – present such a challenge for many children and young people with ASC? Morewood et al. (2011) highlight a number of issues relating to the students themselves, their teachers, and peer group. Affected students may experience difficulties learning in a social setting, particularly in relation to complex language environments with limited visual support. Understanding and communicating with other members of the school community and reading social situations that arise can also be problematic. Change, transitions, and unexpected breaks in routine may cause considerable anxiety, creating a barrier to learning and participation. For school staff, gaining, maintaining, and refocusing attention of students with ASC may be challenging. The need to differentiate language and/or the curriculum to accommodate such learners requires teachers to move beyond 'the usual'. Managing behaviour and accommodating the special interests expressed by those with autism may also be demanding. Finally, the student's peer group may not understand why they behave in the way that they do, resent the extra attention or affordances given to them

(e.g. teaching assistant support), be offended if their social advances are ignored or rejected, and/or exclude, tease or bully them.

As noted by the National Autistic Society, 'Children with autism grow up to be adults with autism, and a good education can equip them with the skills and confidence they need in life' (2011, p. 4). Here the evidence demonstrates just how much we may be failing those with ASC. A recent meta-analysis revealed people with autism experience a much lower quality of life compared to the rest of the population (van Heijst & Geurts, 2014). Only 15% are in full-time employment, despite the majority expressing a desire to be employed (National Autistic Society, 2009). At a societal level, ASC represents a significant economic burden associated with greatly increased health, education, and social care use (Lavelle et al., 2014). In England, the estimated annual cost of supporting affected adults is £25 billion (Knapp, Romeo, & Beecham, 2009). Thus, there is clear and compelling evidence of the need to improve the education of children and young people with ASC. Above and beyond the basic right of every child to experience a high-quality education, better provision will enable those with autism to become more independent and autonomous adults who can make a greater contribution to society than is perhaps currently possible.

Conceptual Frameworks for Autism and Education

Our work is primarily influenced by two theoretical perspectives. First, Lewis and Norwich's (2005) 'general differences' framework for understanding special educational needs and disabilities (SEND) informs the positioning of this edited collection. In considering the educational needs of learners with SEND, Lewis and Norwich begin by posing two questions. First, they ask whether differences between students (by particular SEND 'groupings', such as ASC, dyslexia, and hearing impairment) can be identified and linked with needs for differential approaches to teaching and provision. Second, they query the key criteria for identifying learner groups that are pedagogically useful or informative. That is, if traditional SEND groupings are not valid, there may be other groupings that help us to think about how to support children more effectively in the classroom (e.g. we might consider executive dysfunction and the role it plays in students' learning needs).

Lewis and Norwich's (2005) conceptual framework proposes that we may think about pedagogical needs in terms of whose needs are being served – are they common to all learners, specific to a particular group (e.g. those with ASC), or unique to the individual? A model of pedagogy may make use of any combination of these three, but two are key to the current text. The *unique differences* position draws only from needs that are common to all and unique to the individual, and therefore maps closely to the 'radical' inclusion perspective, in which the idea of needs based on SEND groupings

are an anathema. By contrast, the *general differences* approach posits that while there are pedagogical needs that are common to all learners and others that are unique to individuals, some are specific for certain groups, such as those with ASC. This is the position we adopt in these pages. Indeed, the very rationale for our text, a collection of writings focused on the education of a specific group of learners, reflects such an approach. Note that this is not the same – or even close – to advocating segregated education for students with autism (or any other SEND group for that matter). However, a range of provision – from ordinary mainstream, through resourced mainstream, and finally to specialist schooling – is advocated, in recognition of the fact that the nature of specific group and/or individual pedagogical needs may sometimes mean that specialist education is the most judicious option. This is in line with Ravet's (2011) 'integrative' perspective (included in Volume 1), in which a balance is struck between children's rights and their needs, and the notion of a distinct autism pedagogy is not seen as contradictory to an inclusive approach.

The second theoretical tool at our disposal is the bio-ecosystemic model of human development (Bronfenbrenner, 2005; see Figure 1). Bronfenbrenner

Figure 1: The bio-ecosystemic model of human development (Bronfenbrenner, 2005; image derived from http://www.c4eo.org.uk)

proposed an ecology of nested systems within which the individual interacts through the lifespan, shaping their development. At the broadest level – the *chrono-system*–we may consider the socio-historical context in which development takes place and the patterning of events and transitions through the life course. In terms of the former, knowledge and understanding of ASC has increased dramatically since Leo Kanner and Hans Asperger first described 'early infantile autism' and 'autistic psychopathy in childhood', respectively in the early 1940s (Pearce, 2005). In relation to the latter, the importance of early identification, assessment, and intervention is reinforced, shaping as it does later trajectories and outcomes. The *macro-system*, which includes political philosophies, belief systems, and ideologies at the cultural level, is also proposed to shape the development of the individual. Research highlights how the meaning of autism is constructed and interpreted differentially across cultures, and the influence of this on approaches to assessment and identification (Kim, 2012). National and local developments in policy are presumed play a pivotal role in the experiences and outcomes of education for students with ASC, but much of this remains conjecture. A recent international scoping exercise by Bond et al. (2014) revealed that of 14 different countries (e.g. Sweden, Finland) and jurisdictions (e.g. North Carolina, USA; Queensland, Australia) reviewed, the overwhelming majority had enacted general policies relating to special education needs, but very few defined autism in specific legislation. A natural corollary of this is that data pertaining to educational provision and outcomes for students with ASC was very limited. This means that tracking how such outcomes vary as a function of education policy/legislation can be very difficult. However, we can see more generally how ideology relating to notions of difference and disability plays out in national (Department for Education and Employment, 1997) and international (United Nations Scientific Educational and Cultural Organisation, 1994, 2000) policy directives, and the subsequent influence this has on educational provision 'at the chalkface' for learners with autism (e.g. the aforementioned shift towards mainstream placement of students following *Excellence for All Children*).

The third level – the *exo-system* – of Bronfenbrenner's model highlights the role played the institutions such as the mass media, economy, and local community. In the case of ASC, media coverage of the measles, mumps, and rubella vaccine controversy provides a powerful example whose influence has had, and continues to have, considerable consequences for public health (Lewis & Speers, 2003).

The most proximal level of the ecosystem – the *micro-system* – represents the immediate social context of the individual. This includes the classroom, family, peers, and religious settings. Bronfenbrenner proposed that the individual's endogenous features (e.g. gender) were an important, interactive component of the microsystem (hence the reference to 'bio' ecosystemic theory). The *meso-system* describes the interactions between different microsystem

elements (e.g. between the individual and his/her peers). In this vein, Humphrey and Symes (2011) proposed a reciprocal effects model in which endogenous difficulties in social understanding among students with autism and a lack of awareness and understanding among peers interact to produce peer interaction patterns that are reduced in both quality and frequency, ultimately leading to poor social outcomes such as bullying and social exclusion. On a related note, Robertson, Chamberlain, and Kasari's (2003) study demonstrated the associations between levels of behavioural problems displayed by learners with ASC, their relationship with their class teacher, and the extent to which they were socially included in the classroom.

Bronfenbrenner's (2005) model provides a useful 'organising idea' for our consideration of key issues in autism education. The four volumes of this Sage Major Work have been arranged with this model in mind. Hence, in Volume 1, texts have been selected that explore and illustrate perspectives across the chrono-, macro-, and exo-systems. These are juxtaposed with articles that draw on the lived experience of individuals with ASC and their navigation of the education system. The second and third volumes focus on three key microsystem constituents – the school and classroom (Volume 2), teachers and support staff (Volume 2), and the peer group (Volume 3) – in addition to meso-system interactions within and across them. In Volume 4 we come full circle, and our attention turns to the application of this accumulated body of knowledge to improve experiences and outcomes of education for learners with autism. Consistent with our theoretical position, this includes consideration of a range of texts spanning different ecological systems.

Autism and the Lived Experience of Education

There is perhaps a danger in a collection such as this for the perspectives of those most central to the issue at hand – those with an ASC – to be lost amidst the general cacophony of voices, some of which (e.g. academics) are often given more 'privileged' status. We therefore make an explicit attempt to bring the views and experiences of those with autism to the foreground. Doing so can yield considerable insights (McLaughlin & Rafferty, 2014), and it is therefore pleasing to see that the trend for education research directly utilising the perspectives of the autism community has increased significantly in recent years. This mirrors accompanying shifts towards the use of 'insider accounts' in autism research more generally (Billington, 2006), and in governmental guidance (e.g. Department for Education and Skills, 2001). Examples of such work, including Connor (2000), Carrington and Graham (2001), Humphrey and Lewis (2008), and McLaughlin and Rafferty (2014) are included in Volume 1. These and other studies have contributed to significant developments in our understanding of the lived experience of education among those with ASC. However, just as the needs of those with

autism require teachers and school staff to move beyond their usual practice, researchers also need to adapt and differentiate their methods in order to ensure that the perspectives of a broad range of students can be accessed. Hence, Humphrey and Lewis (2008) utilised interviews, diaries (written, audio-recorded, word-processed), and drawings in an attempt to ensure that each participating student was able to express their views in a mode that suited them.

A useful starting point in exploring the lived experience of education for students with ASC is to consider how their understanding of their autism is constructed. What 'Asperger syndrome', 'autism', or other associated terms mean to a young person, and the extent to which this understanding is part of their developing identity, will likely influence the way in which they make sense of their educational experiences (Humphrey & Lewis, 2008). Here we see parallels with the continuum evident in the academic and professional literatures for autism, which by turns make reference to deficit/disorder, disability or difference. For those young people whose understanding tended towards a 'deficit/disorder' view in which ASC is pathologised (e.g. '*It's like I have a bad brain*' – Humphrey & Lewis, 2008, p. 31), there are obvious sequelae for identity, aspirations, and expectations. In sharp contrast, where a 'difference' view prevails (e.g. '*My brain is different but I'm not bad*' – National Autistic Society, 2011, p. 4) this is accompanied by greater acceptance of autism and integration into the self-concept. In accounting for how children and young people can arrive at such dramatically different understandings, Bronfenbrenner's (2005) model is again useful, highlighting as it does many and varied influences at different ecological levels and the interactions between them. For example, consider the role played by the mass media in shaping public perceptions of autism (e.g. Jones & Harwood, 2009) and the trickle-down effect this may have on meso-system behaviour (such as teachers' expectations of children's capabilities).

How might we characterise the everyday experience of schooling for students with autism? Clearly, it is not possible to generalise to all individuals. Every child with autism is different, as is every school, and the evidence base remains emergent as opposed to comprehensive. Besides which, our theoretical frameworks would not predict uniform experiences. Nonetheless, there are themes in the research literature that appear with consistency and resonate with our professional experiences working in autism education. The 'negotiation of difference' was highlighted as a key issue by Humphrey and Lewis (2008) (see also McLaughlin & Rafferty, 2014). Here we refer to the inherent dilemma faced by those with ASC in relation to the social world of school. Can they 'be themselves' and hope that teachers, peers, and others will accept and adapt to their differences? Or do they adapt themselves, and in doing so potentially compromise their identities (what Carrington & Graham (2001) and Baines (2012) refer to as 'masquerading'

and 'positioning', respectively)? For one informant in Sciutto, Richwine, Mentrikoski, and Niedzwiecki's (2012) study, a teacher provided resolution: '*I did have a teacher that had us do a journaling exercise. In one entry, I was whining about all the things that I tried to be "normal" and he told me that I should think about just not trying for once and being myself. I would feel more successful. It took me a lot of years to figure out what that meant, but I finally figured it out and I live by that. Don't try to do what you think everyone else wants or needs you to do, just be yourself*' (p. 182). This dilemma raises a whole range of issues relating to disclosure (e.g. to what extent should staff and students should be made aware of an individual's autism?), pedagogy (e.g. what adaptations to teaching approaches need to be made to enable the differences associated with autism to be successfully accommodated? This is a key issue highlighted by Lewis and Norwich (2005) above), provision (e.g. are there ways in which specialist provision may inadvertently highlight or accentuate differences in a negative way?), and ethos (e.g. how can one effectively promote and celebrate difference at all levels of a school?).

A corollary of the above is the student–school goodness of fit. In Bronfenbrenner's (2005) terms we may think of this as the meso-system interactions between the individual and his/her school/classroom microsystems. Where there is limited understanding of autism (and its effects on the individual student) and/or minimal attempts to adapt aspects of the school environment to be more ASC friendly, we see this manifested in reduced learning and participation, in addition to emotional and behavioural difficulties: '*It's really hard to go to school. People don't understand how hard it is. They judge me for doing things I can't help*' (National Autistic Society, 2011, p. 7). Consistently reported examples include greatly increased stress and anxiety as a result of sensory overload (e.g. '*The noisier or larger the group, the more difficult it is*' – Connor, 2000, p. 291), lack of predictability, and/or changes to routine (e.g. '*The taxi*[3] *is RUBBISH! I arrived home at 15:30 with [previous taxi driver], now I arrive home at 16:30 with this taxi driver. We MUST change the taxi*' – Humphrey & Lewis, 2008, p. 37), or difficulties with teachers and/or peers (e.g. '*My problems were mostly from my peers who bullied me because (in my view) of a lack on [sic] understanding on their part*' – Sciutto et al., 2012, p. 181).

The interactions between the individual with ASC and his/her peers (see Volume 2) and school staff (see Volume 3) also form key aspects of most first-hand accounts of educational experiences. As a starting point, the meso-system relationship between them is worthy of note. For example, an informant in Sciutto et al.'s (2012) study explains, '*You, the teacher, can make a huge difference – positive or negative – in the way other students view a child with AS. As the leader of the classroom, you set the tone. Be careful not to set a tone that give the others license to bully that child*' (p. 182). This assertion is
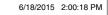
given further credence by theoretical work from Murray and Pianta (2007) and empirical evidence reported by Robertson et al. (2003).

In terms of the peer group, there are compelling narratives of bullying and teasing experienced by many students with ASC at the hands of classmates (e.g. *'Two girls; one hits me when I don't say hello, the other hits me every time I say hello'* – Connor, 2000, p. 291). As noted earlier, the evidence suggests that children and young people with autism are affected disproportionately by bullying and social exclusion in terms of both prevalence and outcomes. The perspectives of such students can be particularly useful here, as they can highlight the factors that influence how they respond to such experiences. For example, whether they seek support from teachers or other peers or 'go it alone' can depend upon the perceived efficacy of this response and the social influence of their advocate(s) (e.g. *'If I have a friend who knows who they are, they might be able to do something about it'* – Humphrey & Symes, 2010, p. 86). Furthermore, they also emphasise just how important social support from friends can be in helping to prevent, reduce or cope with victimisation (e.g. *'I do have friends who very often stick up for me'* – Humphrey & Lewis, 2008, p. 38).

Turning to teachers and other school staff, reports of learners with ASC suggest that knowledge and understanding of autism and the variety of ways in which it may affect individuals are bare minimum pre-requisites for the development of inclusive and effective practices and positive relationships. Where this basic understanding is lacking or misplaced, difficulties can ensue (e.g. *'Because I am well-behaved in school, I get overlooked when I am requiring help'* – National Autistic Society, 2011, p. 27; see also Moore, 2007). However, autism awareness alone is insufficient. Consistent with the general differences position, it is an understanding of the individual student *and* their autism that is required (e.g. 'He is a CHILD first' – Sciutto et al., 2012, p.180). Thus, teacher strategies and practices reported to have a positive impact for such learners typically incorporate both aspects. Consider, for example, the following account from a parent, in which the teacher's awareness of a common characteristic in ASC and knowledge of an individual student are used to adapt pedagogic strategies and create opportunities for learning: *'His teacher realized that my son's "obsessive interest" revolved around sprinklers, fire alarms and fire bells. He asked my son to bring in some of his collection and made it a point to design many of his Algebra classes around these items (Find the circumference of the fire bell . . .). My son not only got an A in that class but for the first time, actually looked forward to going to school in the morning. It was huge for us!'* (Sciutto et al., 2012, p. 183). In Volume 2 we will explore the variety of factors that can influence the nature of the strategies employed by school staff, including (but not limited to) their experience and confidence (Gregor & Campbell, 2001), attitudes (Park & Chitiyo, 2011), and philosophy (Jennett, Harris, & Mesibov, 2003).

Summary

Autism is a lifelong developmental disability associated with difficulties in social communication, interaction, and imagination. Autism education is a rapidly growing field that seeks to advance knowledge and understanding of the range of factors that influence educational experiences and outcomes for affected individuals. The available evidence suggests an impoverished experience for many, with negative consequences that can pervade well into adulthood. Bringing the views of those with ASC to the fore has been a critical advancement in recent years, although there is more to be done in this regard. Two conceptual frameworks – those of Lewis and Norwich (2005) and Bronfenbrenner (2005) – are helpful tools in framing discussion of core issues in autism education and have been adopted throughout the current body of work.

Notes

1. The newly implemented diagnostic criteria for autism in the 5th edition of the *Diagnostic and Statistical Manual*, published in 2013, refers to a dyad of impairments, in social communication and restrictive, repetitive behaviours, respectively (APA, 2013).
2. This is set by the government as achieving 5 or more A* -C grades (including English and Maths) for the general certificate of secondary education (GCSE).
3. The student in this example was taken to school by taxi each day. A new driver had recently taken over, and his route was altered to allow another student to be picked up.

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