Autistic spectrum disorders: a challenge and a model for inclusion in education

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Rita Jordan, Professor in Autism Studies at the School of Education, University of Birmingham, gave last year’s Gulliford Lecture at the University of Birmingham on 4 October 2007. This article is based upon that lecture. In it, Professor Jordan discusses the role of education in the lives of people with autistic spectrum disorders. She traces the growth in our knowledge about autistic spectrum disorders and the development of a variety of ways of responding to autism, from the highly specialised, and frequently strictly segregated, to the explicitly inclusive. She uses her analysis to draw distinctions between ‘therapeutic’ models of education and education as ‘entitlement’ – and identifies problems with either paradigm. Professor Jordan closes her article by setting out her vision for a future in which there is greater flexibility and diversity in which specialisation has a key role to play in making inclusion a working reality. The challenge of teaching pupils with autistic spectrum disorders will, argues Professor Jordan, help us all to imagine a truly inclusive model for education in which equity is achieved by treating all learners differently.

Key words: autism, therapy, education, specialisation, inclusion.

What is so special about autistic spectrum disorders?

Education can be, and perhaps should be, an effective ‘treatment’ for autistic spectrum disorders (ASD) in the sense that, since there is so much that individuals with ASD have to learn that is just intuitively grasped by the non-autistic, learning may best be enhanced through high-quality teaching. This is true whether we are thinking of individuals whose autism is a daily burden, interfering with development and causing distress and disablement, or whether it is an interesting difference in personal development that only becomes a problem for a person with autism when he/she encounters people and institutions lacking understanding and with an unwillingness to adjust (Jordan, 2005a, 2007). But education is more than just another ‘treatment’. It is the way that citizens are taught the values, understanding, knowledge and skills that will enable their full participation in their community; it is the gateway to full social inclusion. That is why every civilised society gives all its citizens the entitlement to education.

I first encountered autism in my attempt to do something for the children who were then excluded from education in the UK and who, without education (and without even health provision until they were seven years old), were ending up in the back wards of what were then called ‘subnormality hospitals’. Anyone who has read Oswin’s (1971) account of the ‘empty hours’ characteristic of the lives spent in such hospitals will have some idea of what that was like, although I think one needed to see it to fully comprehend its barbarity. Jack Tizard (personal communication) once said that it was not the encouraging statistics showing improvements in social and adaptive functioning that brought about change, following the famous Brookland’s Experiment (whereby children in such hospitals were introduced to ‘family-style’ care). Rather, it was the film of the experiment that made the difference, by enabling people to ‘just see’ what was humane and what was right; sometimes we do not need research as much as humanity.

So the first battles for those with ASD were fought for the same purpose as the battles for those with severe learning difficulties (SLD): the right to be included at all. This was at a time when most individuals with ASD were thought to have additional SLD, and long before the work of Asperger (1944, translated Frith, 1991) became known, and before the subsequent change in diagnostic categories to include a much broader range of what became designated a spectrum of autistic conditions (Wing, 1996). However, even among those with SLD, it was apparent that children with ASD presented particular educational challenges, and it was left to the voluntary sector to make the first provision, as a kind of demonstration that these children were able to benefit from education. As ever, the first specialist, and thus segregated, provision came about through the work of parents, dissatisfied with existing provision, or in response to the lack of it.

The decades since these events have seen an exponential growth in knowledge of ASD. There was the recognition of a biological aetiology and a gradual, and as yet incomplete, unravelling of the many biological factors involved. There was a recognition also that intelligence varied independently from degree of autism and that autism could occur across the full ability range. Specific techniques were developed for working with those with ASD, based on research into a particular ‘autistic style’ of learning and making sense of the world (Mesibov, 1997; Mesibov & Howley, 2003). The problems in not attending to social stimuli were documented in
numerous research studies (for example, Klin, 1991) but, with a few exceptions (Chandler, Christie, Newson & Prevezer, 2002; Nind & Hewett, 1994), it has only been in very recent years that these characteristic socio-communicative features of ASD have been targeted in interventions (Charman & Stone, 2006), beyond attempts to modify their behavioural consequences.

In the meantime, interventions that started with those with SLD, such as operant conditioning, began to be fashioned (and marketed) as specialist techniques for autism, leading to influential, if uncorroborated, claims that early intensive behavioural intervention (EIBI) could lead to virtual ‘recovery’ in almost half of the specially selected young children undergoing the therapy for two years (Lovaas, 1987). As Dawson (2004) has pointed out, the parent-led pressure for interventions to ‘cure’ autism has been a force against inclusion, and represents a view that is not always shared by those with ASD themselves, who may wish to be accepted as they are.

The Lovaas (1987) study, however, led not only to parental pressure for such interventions during the early years of children with ASD, but also – as the hoped-for ‘recovery’ failed to materialise by school age – to pressure for such behavioural interventions to be the teaching choice in the school years. Such parental pressure has even led to the establishment of separate segregated special ‘schools’ (often run by clinical psychologists rather than teachers) based on this repetitive ‘drilling’ of basic skills. With proponents of the method claiming it as the only scientifically validated technique, there was little room for the incorporation of other approaches and, in any case, an ‘eclectic’ curriculum had been much derided by the proponents of behavioural interventions. Nevertheless, the less extreme forms of applied behaviour analysis (ABA) often do incorporate other approaches, although their roots are seldom acknowledged and they are referred to as ‘tactics’ of ABA.

This is all somewhat ironic, in that the original Lovaas study could be interpreted not as a vindication of ABA discrete trial drills, but as the first systematic attempt to involve inclusion in the treatment of ASD in the early years. After all, Lovaas had been using discrete trial training for many years prior to the Young Autism Project, with very little sustained effect – most beneficial changes in the people with ASD involved disappeared unless the ‘treatment’ continued. It may have been the intensity of the treatment (40 hours a week for two years) or the young age or selection of the children that made the difference with the Young Autism Project, but there is no solid evidence that age and intensity are the crucial variables. Only IQ and language ability are established as important variables affecting outcome. A good case could be made for the crucial variable in the Young Autism Project being the fact that Lovaas targeted children who had access to receptive nursery schools. An important (but seldom talked about) aspect of the programme was the early inclusion of the children in the mainstream nurseries, as soon as they had been trained to develop necessary ‘entry’ skills for interaction and any disruptive behaviour had been minimised.

**Inclusion: conception, policy and practice**

It can be seen, nevertheless, that most specialist techniques were rooted in segregated provision. These techniques were also based on a therapeutic model of education; that is, its power to help the individuals overcome the developmental difficulties arising from their autism. However, with the broadening of the diagnostic category, it became clear that the majority of children with ASD were in mainstream schools; often because they had not been identified, but also because they were part of the social and political movement towards inclusion. This was based on the entitlement view of education as the only way of becoming a full member of society. Inclusion came to be seen as a right and a matter of social justice (UNESCO, 1994) and the only question then became how children, like those with ASD, were to access their entitlement, as if the conceptualisation of those values was not in itself often discriminatory, being based on a model of typical development.

The bases of most programmes for inclusion, in fact, were not inclusion at all, but forms of integration (Jordan & Powell, 1994). The content and the teaching approaches of the National Curriculum in mainstream schools were not changed to accommodate children with ASD, as it was assumed that the content was of equal relevance to all children, albeit requiring modification and ‘breaking down’ to make it accessible in some cases; approaches were geared to a mythical ‘norm’ of how children think and learn. In fact, the model of ‘breaking down’ curriculum content into smaller steps (which is often effective for individuals with learning difficulties) is not appropriate for children with ASD, where the developmental and learning patterns are different; these children need to learn about the goal and intentional behaviour.

There is even a problem with the main purpose of mainstream education, which, in terms of inclusion, is surely to gain from co-operation and collaboration with typical peers. Yet many of the ‘supports’ to enable inclusion of children with ASD serve to make the child more isolated from peers, and support assistants are seldom given training (or a role) in enabling such children to have positive contact with their peers. If a child is different, or has ‘special needs’, extra resources are provided to enable the child to have access to other children, even though the success of those resources in bringing that about has never been tested. The mainstream system, until recently, remained oblivious to the diversity of children, even those as extreme in their difference as those with ASD. Some departments in local authorities (and in higher education) that had been responsible for special needs education now renamed themselves as ‘inclusion’ departments, emphasising how inclusion itself was seen as an issue for special needs and nothing to do with mainstream colleagues. If ‘inclusion’ failed, it was usually the child who was blamed and then given specialist, probably segregated, support. The kind of help that might have prepared them to benefit from
mainstream schooling was often denied until that failure had occurred. By then, the route back to the mainstream was almost impossible for them to manage.

Just as the implications of a lack of social intuition became apparent in an educational system based on social and verbal mediation (Jordan & Powell, 1990, 1995), so medical models of disability also became unacceptable and teachers were told they must respond to individual needs and differentiate the curriculum to make it accessible to all (Jordan, in press). Originally, these changes were driven by research showing that segregated schooling led to segregated (and, by implication, less valued) lives (UNESCO, 1994), although this research has not been replicated for children with ASD. As Jordan (2005b) has argued, one has to have some understanding of ASD to provide a lens through which one sees behaviour, in order to accurately identify individual needs in ASD. It is not enough for an educator to note a child’s behaviour without some understanding of what it might mean in a particular case; a child who hits another child may be attempting to play chase, rather than displaying an act of aggression; similarly, a child who interprets language literally is unlikely to be attempting to act as the ‘class clown’ but is displaying signs of a distressing confusion, and an inability to compute context.

The evidence from research (Barnard, Prior & Potter, 2000; Batten, Corbett, Rosenblatt, Withers & Yuille, 2006; Jones, Jordan, Gulberg, MacLeod & Plimley, 2006; Simpson, Boer-Ott & Smith-Myles, 2003), the views of those with ASD (Gerland, 1997; Jackson, 2002; Sainsbury, 2000), parental experience (as evidenced in cases brought to tribunal) and a European survey (Jordan, in preparation) is that the reaction to ‘forced integration’ without understanding or adaptation of the system has been a regression to forms of segregation that owe more to the isolation of the past rather than the ‘cutting edge specialism’ that many promote. Yet there are good principles for practice developed in the UK (DfES, 2002) and growing pockets of identified good practice (Plevin & Jones, 2000). We have to learn from that good practice and apply it more widely. We cannot persist in a system that is neither meeting the special needs of people with ASD nor achieving the goal of an inclusive society. The situation faced by children with ASD is just an extreme example of the failure of the system, and getting it right for them might serve as a model of how to get it right for everyone.

An inclusive model for education
So, what would an effective inclusive educational system look like? Primarily, it would need to be flexible. It cannot rely on centrally-determined curricula and teaching methodologies, although there could, of course, be guidance. Who could manage such a system? Surely it could only be done by properly trained, and professional, teachers. I do not mean that all mainstream teachers must be ‘experts’ on ASD, but they must know about learning and teaching (and not just ‘delivery’ of packages) and about the diversity that exists in humankind in the way we learn and understand the world. If educators teach in a way that attains diversity (and modern Information Technology (IT) techniques will make this so much easier), then more children with different minds will be able to manage in mainstream settings, without needing to have special (and certainly not segregated) support. This will also benefit those disruptive boys currently disaffected by our female- and language-dominated educational system, and those with attention deficit hyperactivity disorder (ADHD), dyslexia and so on.

There will be some individuals with ASD whose autism is so severe that they will need specialist support, but that does not need to be in a segregated setting. Resource bases are the best model (Hesmondhalgh & Breakey, 2001), where the child with ASD belongs to his peer group teacher but has the support of staff with expertise and a ‘haven’ in which to recover when needed. I still think there is a role for specialist schools, but they must have a better reason for their existence than that they pick up those who ‘fail’ in mainstream schooling, or that they fit the Government’s entrepreneurial vision of education. Specialist schools should really be centres of excellence (not just so claimed), pioneering new ways of working with ASD and dealing with the most extreme cases. They should be centres of research as well as teaching (perhaps in collaboration with universities) and have a role in working alongside mainstream schools to bring about more effective inclusion. However, this too is a role for which training is needed and special schools must be seen more as supports for an inclusive system rather than an alternative to it.

Teaching students with ASD is hard. It is hard for just the same reasons that students with ASD find it difficult to learn in our current school system. Just as these students have no natural intuitive ways to understand their teachers, teachers, in turn, have no natural intuitive ways of understanding students with ASD. That means we, as educators, have to work out what to do cognitively when working with these students, just as they do with us; we cannot just rely on our natural social instincts in relating to students with ASD. That means our interactions are going to be more laborious, and we are going to be exhausted from this conscious effort to understand and to do what does not come naturally. Yet through that understanding we develop skills and knowledge that can enrich our teaching of all children, and the more our teaching recognises and respects diversity, the easier this will be.

We, as teachers, need to develop the capacity to imagine things differently. Imagine a Government that trusted teachers as professionals and allowed them to act as such, rather than as technicians. Imagine an educational system that recognised that to treat people equally we have to treat them differently, not the same. Imagine teachers who displayed informed empathy for those who are different (including those with ASD) just as much as they tried to teach children ‘emotional literacy’. Imagine if we allowed people to develop their talents rather than concentrating on their difficulties (will social skills lessons ever end?). Imagine if we were able to exclude fear from school, rather than excluding children.
Imagine that we really valued difference and cared about enabling people to be the best they could become and did not place such a high value on conformity. Imagine creating situations where learning was fun or, if there were difficult parts, nevertheless the purpose was clear. Fun, after all, is ‘money in the bank’; if the child does not learn, at least he/she has fun. In any case, we all learn more when we care; it is almost impossible to learn things you do not care about.

Wouldn’t such a system be one in which all could flourish? Understanding and getting it right for children with ASD can be a way of getting it right for everyone.

References


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