Debates rage over terminology in relation to autism. Words such as ‘disorder’ (Kenny et al. 2016), ‘condition’ (Broderick and Ne’eman 2008) and person-first language e.g. adult with autism (Gernsbacher 2017) are considered stigmatising, although there is by no means a consensus on this. Meanwhile, rather quietly in the background, the word ‘difference’ has been carrying out some heavy lifting, thought to be a more constructive way of conceptualising autism than the term ‘disorder’. For example, Lawson (2011, 41) posits that autism should be thought of ‘as a cognitive difference or style’ and Baron-Cohen (2002, 181) deliberates whether Asperger Syndrome ‘should necessarily be viewed as a disability or, from a difference perspective, as a difference’. This apparently more positive framing has been adopted within education practitioner training contexts: according to the Autism Education Trust (2019), autism consists of ‘four areas of difference’ which school staff need to understand in order to support autistic pupils.

Yet for such a commonplace and anodyne word, subject to multiple meanings and inferences, its polysemic nature is often underestimated. What you and I understand by ‘different’, when referring to certain individuals, groups of people, or even ourselves, will almost certainly not be the same, and naturally will depend on our own situations and dispositions. If you’re a funky, alternative sort of person, perhaps it’s a positive descriptor. But if you prefer to blend in with the crowd, then ‘difference’ might have unwelcome connotations of being ‘weird’, ‘strange’, ‘not like us’. Indeed, the metaphors of difference abound in the autism context (Broderick and Ne’eman 2008): Does your child swim in the opposite direction of the shoal of fish? I remember reading in a leaflet I was given, shortly after my son was diagnosed with autism, aged three.

So it’s worth thinking about how being ‘different’, as well as autistic, operates in our schools, where for most settings in the UK, uniformity is highly prized. After all, most pupils literally wear ‘a uniform’, and punishments can be meted out for the wrong kind of shoe or length of trouser. Children and young people are expected to line up, to sit down in rows, and chant in
unison in the assembly hall. And so for anyone who won’t, or can’t conform to this requirement for sameness, their difference is viewed as problematic (Wood 2018). After all, ‘persistent disruptive behaviour’ is one of the main reasons autistic pupils are excluded from schools in England (Department for Education 2019).

When I asked the school staff (n = 36), parents of autistic children (n = 10) and autistic adults (n = 10) in my PhD study into the educational inclusion of autistic children to describe autism, their responses, positive, negative, or something in between, were often entangled with notions of difference. For example, some parents, who described their children as “different”, were concerned that others would find them “odd” or “weird”, especially as they got older, citing hand-flapping, making noises and limited speech as being characteristics that might mark their children out as strange, leading them to be shunned socially by their peers. Moreover, the view that children become less tolerant the older they are was reflected by a number of the adults in my study. One autistic adult asserted that even between infants and junior school, children start to “notice your difference” and so become “meaner”, a circumstance which gradually worsens in secondary school and beyond as “people’s tolerance of difference gets smaller”. As a result, she said, for most of her life she had been made to feel like she “didn’t fit”.

Meanwhile, another autistic adult felt that at primary school, she was made to feel “like an alien” to such an extent that she was almost convinced that she was “not human”. This sense of alienation and estrangement also applied to some parents, as one complained that she was stared at as if she was “an alien or something, like weird” for helping her daughter, who had motor planning difficulties, down some steps at the local cinema. Moreover, having read books about autism in a drive to understand their children better, some parents found little help in these sources of information, as the descriptions of autism, especially when framed negatively, did not match their own offspring. This led one parent to conclude that not only was her child ‘different’ by dint of being autistic, but that he was “different to every other child”.

For some school staff, autistic children, by their very nature, are somehow psychologically elsewhere. According to a SENCo (Special Educational Needs Co-ordinator), autistic children “are prone to drift off”, and a teaching assistant commented that they “live within their own world far more than they do in the world that we do”. Moreover, this apparent disconnectedness was associated with ‘severity’ of autism, whether a child was ‘high’ or ‘low functioning’ on the ‘spectrum’, terms I did not initiate in interviews. A SENCo said that autism “sits on a spectrum”, and “at the top end there is Asperger’s” while “at the extreme end, they’re in a complete bubble”. One teacher said that she could not understand how a highly able autistic
boy in her class who “functions perfectly well without support” even received a diagnosis of autism, while by contrast, according to one parent, “a low functioning child” would “really freak, like, roll around the floor and scream”. In other words, unless autism manifests itself as a highly problematic form of difference, it doesn’t really exist. Nevertheless, according to one teaching assistant, all autistic children have difficulties, regardless of where they sit on the “scale”:

*There are so many different types. You have the ones at the lower end of the scale, they’ve got no life skills, no retention. You’ve got the ones at the higher end of the scale, they are very bright, but not able to get on with their peers. They all don’t get on with their peers, they have trouble with that.*

Therefore, in these accounts, ideas about difference are enmeshed with negative conceptualisations of autism and the sense that autistic children are somehow ‘other’. However, none of the autistic adults used the term ‘spectrum’, only one employed functioning labels and none of the parents who used the descriptor ‘low functioning’ felt their own children fell into this category.

Furthermore, not all participants problematised the apparent disconnectedness and ‘otherness’ of autistic people and indeed associated difference with positive attributes. One parent, who thought that her son was in “a little world of his own”, rather admired this about him, and wished she could “get into his head for an hour or so, or even a day”, because in her view, he was “completely awesome”. Another parent felt that her autistic son had taught her to “look at the world differently” and that this was “very positive”. Moreover, half of the autistic adults considered autistic people have certain specific abilities deriving directly from being autistic, particularly in relation to attention to detail. Indeed, two of the autistic adults thought that autistic traits, such as not wasting time on small talk, have contributed to the evolution of the human race. One autistic adult said that autism enables her “to see the world differently” in a revelatory, enlightening way, “rather like a pair of glasses which give someone the ability to see”, and a SENCo asserted that some autistic people have “amazing skills” which can be associated with genius. Therefore, in these instances, difference was very much seen as a positive attribute.

Moreover, some school staff asserted that the presence of autistic children teaches others to “not be afraid of children with differences” and another teacher stated that autistic children help pupils to “understand everybody is different (...) understand different behaviour” and
“respect it”. Even so, one teacher was of the view that autistic children don’t especially benefit from this scenario:

*You know this whole idea about it helps the other children be more understanding and maybe that works, but I don’t know if the autistic child always gets a lot out of it.*

The problem, according to one parent, was that schools simply weren’t doing enough to teach pupils about differences and present them with disabled role models:

*“There’s no heroes as in a disabled person. You know, you’ve got your Winston Churchills, but (...) it’s always about typical people (...). Like about the Paralympics and things like that, the Paralympics was on BBC2 and the Olympics was on B...do you know what I mean? You just think to yourself well hold on a minute...this is society.”*

According to three of the autistic adults, meanwhile, autism is a “*neurological difference*” which impacts on how people think, process information and respond to the environment, a view which was shared by some school staff and parents. One autistic adult stated that even though autistic people are different from each other, she felt “*connected*” to all autistic people nonetheless, as it is non-autistic people who are “*odd*” in certain respects. Indeed, for another autistic adult, the problematisation of autism results from the fact that they are a minority, different from the norm, and so subject to prejudice and exclusion. And perhaps surprisingly, given that this interview took place relatively recently at the end of 2015, only one participant – an autistic adult – used the term ‘neurodiversity’, which was introduced rather hesitantly: *“I was wondering if I should mention neurodiversity.”*

So where does all of this leave us? It would seem, in the context of autism and education at least, that notions of difference become inevitably enmeshed with ideas about ability – or the lack of it – the problems that autistic children seemingly create and their apparent failure to engage with the real world, which is assumed to be distinct and knowable. Even when autistic traits are admired, attitudes stray uneasily close to notions of othering (Devlin and Pothier 2006; Hughes 2009) exoticism (Arnold 2013) and ‘fishbowling’ (Moon 2014). Indeed, too often the notion of ‘difference’ as manifested in schools equates to individual deficit models (Liasidou 2012), creating ‘a problem and a spectacle of difference, to be managed and tolerated’ (Allan 2008, 21) by teachers. Describing certain individuals or groups as ‘different’ also creates the problem of norm referencing, the issue of ‘different to what?’ (Allan 2008; Ravet 2011), as such representations can be ‘constructed through binaries, with one being the norm, and also superior’ (Williams and Mavin, 2012, 161). Moreover, when complex attitudes
towards difference cause pupils to ‘mask’ in school in order to ‘fit in’, this can be at a significant emotional cost to them (Cook, Ogden and Winstone 2017).

And so in education and no doubt other contexts, the word ‘different’ appears to be crumbling under the sheer weight of the contradictions and complexities it is expected to carry. Perhaps, therefore, we need a better, more fluid terminology. The autistic adults in my study provided insights into the value of the intra-autistic communication, of challenging our concept of normality and understanding ‘diversity and difference as part of everyday normal’ (Lawson 2011, 26), rather than as somehow separate to it. Here, the diversity of the autistic population is something to be celebrated and embraced, so that we can be alive to ‘the positive characteristics of autism that contribute to human diversity and creativity’ and so understand how autism can contribute to the creation of ‘new social identities’ (Grinker 2015, 345). Taking this a step further, the concept of neurodiversity, even while its meaning is still contested, could help us to understand that autism, whether accompanied by impairments or not, is a manifestation of human diversity (Kapp et al. 2013), a view echoed by some of the autistic adults in my study. Within education contexts, such a conceptualisation drives a shift of focus onto the diversity of learner needs (Liasidou 2012) and the right to varied representation. Therefore, instead of marking some children out as ‘different’ or ‘special’, our attention is on how to support all learners and their diverse dispositions in school, whether or not they follow the crowd. After all, if the shoal of fish was swimming into the mouth of a shark, you wouldn’t want to just tag along, would you?

References


