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Difference versus Disability: implications of characterisation of autism for education & support (UK)

By Dr. Damian E M Milton

Introduction

A note on terminology

There is much current debate regarding the terminology related to autism. This chapter will resist people-first phrasing, in accordance with other autistic authors (Sinclair, 1993; Sainsbury, 2000):

“We are not people who “just happen to have autism”; it is not an appendage that can be separated from who we are as people, nor is it something shameful that has to be reduced to a sub-clause.” (Sainsbury, 2000: 12).

For most of the twentieth century autism was considered to be an extremely rare disorder, affecting a tiny proportion of the population, however in recent decades the numbers of those diagnosed or self-identifying as autistic has risen exponentially, with estimated figures of more than 1 in 100 (Brugha, 2012). Autism has been variously described as everything from an evil spirit that robs parents of their children, to a differing cognitive style, or even a fundamental asset to human evolution. The spectrum of ways in which autistic people can present to educational and clinical practitioners is so myriad, that it may be little wonder that the ‘enigma’ (Frith, 1989) still evades simplistic descriptions, as scientists search in vain for what exactly autism is. Although various attempts have been made to categorise differing subgroups of the autism spectrum, e.g. ‘Asperger Syndrome’, ‘low-functioning autism’, ‘atypical autism’; it is highly questionable as to how accurately such distinctions can be made and how useful they are in practice.

When looking at educational theory and practice, as Scrimshaw (1983) suggests, there is hardly any agreement either. What educational supports one decides to put in place will be highly dependent on how one conceives of education and the learning process in the first place, and therefore the nature of human beings. Consequently, how one sees autism will have a fundamental impact on how one seeks to address the educational needs of autistic people.

There is often an assumption that children and young people on the autism spectrum need to live and act like those who are not autistic. Many autistic adults take exception to this assumption and the fact that much literature on autism uses medical terms such as ‘deficit’ and ‘disorder’. Within this chapter, both medical and social models of disability, and even post-social models of disability, will be considered in relation to autism, and how deficit models have become dominant in narratives regarding autism. Further, it will explore alternatives to these approaches. How we think about autism relates to the language and terminology we use to describe it. There are also links between how we define autism, the educational approaches we use, and finally, how we can build understanding across dispositional and ideological divides.

Models of disability and how they apply to autism

The origins of the social model of disability can be traced back to a publication made by the *Union of the Physically Impaired Against Segregation* (UPIAS) in 1976, entitled: *The Fundamental Principles of Disability*, in which it was stated:

“In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.” (UPIAS 1976:14).

The social model of disability was proposed by Oliver (1990) and conceived in opposition to the traditional medical model of disability, which framed disability in terms of the remediation of individual biological impairments (Safilios-Rothschild, 1970). As Oliver (2004) states, the main intention at this time was to shift the focus of practical intervention away from targeting remediation and towards the changing of professional practice. According to a social model of disability, individual biological impairment is not seen as the root cause of disability, but rather that within a society designed to accommodate the needs of those with more typical ways of moving, communicating and thinking, those who are atypical are discriminated against. Thus, society has a responsibility to seek to include the needs of all, rather than excluding and disabling people who have varying impairments.

Within the field of critical disability studies however, the social model of disability has also come under criticism. Shakespeare and Watson (2002) argued that there was a need to move beyond a social model of disability due to three main criticisms: the issue of impairment, the impairment/disability dualism, and the issue of identity. Shakespeare and Watson (ibid) conclude by suggesting that we need to consider disability in the ecological context in which the term has developed (what they refer to as ‘an embodied ontology of disability’ which should be central to a theoretical account of disability. They argue that the social model creates a binary division, between the biological ‘impairment’ and the social ‘disability’, analogous to that made by feminists over sex and gender (Oakley, 1972), a conceptual split that has since been largely abandoned (e.g. Butler, 1990). Impairment, by the same token, cannot be theorised as something pre-social (Thomas, 1999). Whilst acknowledging how useful the social model had been as a political tool, Shakespeare and Watson (2002) found it inadequate as a basis for a social theory of disability.

However, Oliver (2004) defended the social model and its practical/political ethos. He discussed five criticisms, from the disability movement and disability studies, often levied at the social model of disability. The first criticism was that the social model ignored, or failed to adequately account for, the realities of living with an impairment (Shakespeare and Watson, 2002). Oliver countered this by saying that the social model was about the collective experience of disability. By making such claims, Oliver (1996) frames disability as a public/social issue rather than a personal trouble (Mills, 1956), yet he does not give a theoretical account of impairments or their potential effects. As Oliver (1996) suggests, support for the social model of disability, does not mean that interventions based on remediation of specific impairments are of no use, or always counter-productive, but just means a shift in attention away from the individual in terms of one’s perception of disability.

A second criticism is that subjective experiences of impairment and disability are ignored by the social model (Crow, 1996). This is countered by the social model having arisen from disability activism. A third criticism is that the social model is not able to adequately account for intersections with other social divisions, such as gender or ageing. Oliver (2004) responds by suggesting, that if this has not been the case, then it would be better for theorists to put their efforts into solving such perceived failures rather than by apportioning this failure to the social model or disability activists alone.

A fourth critique comes from postmodern theory, which regards disability as residing primarily in cultural representations viewing disabled people as 'other'. Whilst this represents a common tension between postmodern and more materialist theories of society, Oliver (2004) suggests correctly that materialist social model theories do not discount cultural factors, but may not afford them the same primacy. The final criticism is whether the social model is an adequate theory of disablement. Oliver (2004) counters this by suggesting that these debates should not be seen just as academic disputes, because of the political and practical ethos of those who originated the social model. Implementing a social model may be difficult, however, if people disagree as to what that entails, or how to implement it practically. Theoretical debates are not without practical import. Whilst the social model of disability can be an empowering tool for autistic people one still needs to try to build upon any working theory of disability.

Cadman (2010) examined the ethical issues involved in applying models of disability to the field of autism. He discusses how contrasting theoretical and ethical concerns imply differing practicalities, e.g. the acceptability of behavioural interventions and the allocation of resources. For Cadman (2010), according to a traditional medical model, autism would be viewed as inherently limited to social functioning – a 'harmed condition' (Harris, 2000, cited Cadman 2010). This is countered by autistic activists and scholars as a categorical error of normative thinking. Such a view of autism and humanity reifies normalcy as the ideal, with any deviation from normalcy seen as a pathology to be remediated. Those following a view akin to a 'neurodiversity paradigm' (Walker, 2014), would view what we call autism as part of a wider diversity of neurological development and a discriminated against minority, with many activists taking on a social model (or post-social model) of disability and autism. From such a viewpoint, one could critique the notion of autism being a medical condition in need of remediation, but view it instead as an aspect of human life that is being ill-catered for socially. For Cadman (2010), neither a traditional medical or social model is satisfactory. Cadman (2010) suggests certain things can be considered either good or bad for a person, regardless of their own attitudes towards those things (even if such a view can be considered paternalistic). The amount one can and should impose one's standards on others is certainly an issue any parent of a child (autistic or otherwise) or professional working with autistic people needs to reflect upon.

For autistic scholar and activist Steve Graby (2012), autism can be said to fall between the established categories of 'impairment' and 'disability', with activists reclaiming what is also a medical categorisation as a cultural identity. Graby (2012) suggests that where impairment-specific organisations exist, they usually follow an individual/medical model approach and thus are often frowned upon by those following a social model of disability, where differences between impairments are viewed as less important than an analysis of social disablement. Autistic activists however, commonly draw upon a social model of disability (Milton, 2016), whilst also referring to

autism-specific issues. For Graby (2012), there are a number of considerations when looking at autism and autistic people: firstly, autism is defined medically as a 'social impairment' and therefore might be seen as in need of sociological analysis; secondly, there is the creation of autistic culture, communities and political movements, and finally, the significant reclaiming of what autism pertains to, and the cultural acceptance within autistic communities of peer recognition and self-diagnosis. Importantly, Graby (2012) also points out that not all autistic people personally identify as being 'disabled', with autism often being presented as a cognitive and cultural minority rather than being seen as a set of impairments. Graby (2012) illustrates a linguistic difference, in that when one refers to 'disabled people' one is frequently illustrating things 'done to' a person, rather than a positive affirmation of identity, as is the case with the use of 'autistic person'. Such a view of autism is more akin to the 'affirmation model of disability' as proposed by Swain and French (2000), and developed by Cameron (2008). In this sense, autism is seen as a natural aspect of human diversity.

Deficit models of autism and alternative explanations

One of the most important developments in the history of autism was the work of Wing and Gould (1979) and the subsequent widening of the autism spectrum to include Asperger syndrome. This work largely created the discourse of a triad of impairments in autism: social communication, social interaction, and social imagination (repetitive interests/activities).

"Autistic children do have imagination, but it is not social." (Wing, cited in Feinstein, 2010: 152).

Autism has since become defined as primarily a social 'disorder', with other important aspects of autistic experience having received relatively less attention, such as sensory processing, being absent in diagnostic criteria until fairly recently (DSM-V: APA, 2013). A diagnosis of autism is dependent on a clinician perceiving a client to be both dysfunctional in terms of normative communication and interaction, and in terms of perceived repetitive behaviours and interests being observed.

Models of autism that attempt to explain what autism 'is', have been dominated by theories originating in cognitive-psychological theorising. These models include: theory of mind deficit, executive dysfunction, weak coherence theory, and empathising-systemising theory. All of these theories have been previously criticised by autistic scholars (Lawson, 2010; Milton, 2012a, 2012b) for their lack of universality, specificity, and explanatory power in describing autism. According to autistic scholars and activists drawing upon social and/or post-social models of disability (Lawson, 2010; Arnold, 2012; Milton, 2012a, 2012b; Graby, 2012), autism can be seen both as a social construction and as a description of an embodied and culturally filtered experience. Therefore, presenting autism as purely a set of behavioural and cognitive deficits, does not take into account the disabling affects that any given society or context holds for autistic people.

"Although there is a biological aspect to this condition named autism, the social factors involved in its identification, representation, interpretation, remediation, and performance are the most important factors in the determination of what it means to be autistic, for individuals, for families and for society." (Nadesan, 2005: 2).

According to Nadesan (2005), the emerging dominance of cognitive psychology in the late 20th century narrowed the frame of what was considered normal and pathologised behaviours that had hitherto escaped the medical/scientific gaze. She also questioned Wing's (1997) assertion that a shift to a cognitive understanding of autism had been an advance in knowledge, but instead represented socially and historically situated ways of knowing.

Nadesan (2005) argues that constructing an ontological divergence between autistic and neuro-typical people, creates the impression of two separate and ontologically homogenous groups, reducing individual differences expressed at the level of mind (open to social influence) to the level of the brain (where they are fixed), and that despite celebrations of 'autistic genius', people with autism know that their difference is ultimately devalued in relation to neuro-typical cultural normality. In widening the spectrum of what can be considered autistic however, Wing and Gould (1979) also opened up the possibility for autistic self-advocacy at an individual and group level, in terms of the numbers of people diagnosed and their potential capacity to communicate with one another. By opening up a public discourse about neurological diversity, it has enabled a cultural space for people on the autism spectrum to interact with one another, resist medical model descriptions of themselves, and to begin to build an autistic culture.

Timimi et al. (2011) charge the autistic rights movement with not considering the implications of supporting the label as a 'diff-ability', and the associated self-fulfilling prophecy of seeing oneself as genetically different in terms of empathy. They warn of the dangers of the autistic rights movement staying loyal to the pseudoscience supporting the concept, unaware that many in the movement challenge the concept of the medical model of autism (Lawson, 2008; Arnold, 2010; Milton, 2012a; 2012b). Timimi et al. (2011) argue that the autism label is likely to produce a distraction from a full appreciation of an individual's situation. However, this view is equally subject to the diagnostic procedures that it is discrediting. What Timimi et al. (2011) fail to acknowledge, is that a lack of a universal positive consequence from receiving the label for all autistic people, is not a good enough reason to abolish its use, at least without replacing it with something more beneficial.

Autistic scholars and activists (Graby, 2012; Milton, 2015) have argued that impairment is a culturally constructed and normative category, yet do not deny the significance of embodied experiences and diversity, seeing impairment as relative and not absolute, and are thus more akin to a post-social model of autism and disability. Views regarding autism held by autistic people are of course hugely varied, yet there is evidence that a critical / social model of disability is a strongly and widely held viewpoint (Milton, 2016). Both historically and more recently, a number of theories have arisen from autistic scholars themselves to try and explain autistic ways of thinking, perceiving and being in the world. Many of these theories have received less attention than the dominant cognitive theories of autism, despite some of them having much to offer:

Monotropism

Originating in the work of Dinah Murray (Murray, 1992; Murray et al., 2005) and influencing the work of Wenn Lawson (2010), the theory of monotropism contends that the amount of 'interest' or perceptual attention available to a person at any one time is a limited resource, and that within the differing cognitive neurodivergent profile associated with autism, one often finds a tendency toward

a 'monotropic' rather than a 'polytropic' attention style. Such a 'monotropic' style of attention use is likened to an intense 'torch beam' as opposed to a 'diffused light'. Murray et al. (2005) suggest that social interaction, the use of language, and the shifting of object attention (implicated by the dominant psychological explanations of autism) are all tasks that require broader attention, and are inhibited by a highly focused or 'canalised' use of attention (or indeed, of a way of managing sensory input).

The theory of monotropism can perhaps help to shed light on a number of experiences often relayed in autistic accounts but not attended to by other theories. For instance, it helps explain the tendency autistic people have to passionately follow their interests, or to completely lack motivation in a given task, or how a sudden and unexpected change 'within the attentional tunnel' could lead to a highly stressful disconnection from a previously 'safe' state of mind.

"We suggest that the uneven skills profile in autism depends on which interests have been fired into monotropic superdrive and which have been left unstimulated by any felt experience." (Murray et al. 2005: 143).

According to the theory of monotropism, important differences occur with regard to development and experiences pursuant to which particular interests are followed at certain points in the life course, and which are suffocated by negative experiences when attempting to engage in them. It is also suggested that if an autistic person is employing a monotropic interest system, the ability to use information gained in the past is compromised, as information is gained only in relation to a narrow set of interests. Thus 'top-down' or 'whole picture' processing is not 'dispreferred' as such, but will tend to be idiosyncratic and resistant to change or criticism.

Filling in the Gaps

Utilising social psychological theory, Milton (2013) suggested that autistic people may have a tendency to use information perceived in the present, rather than mental schema built up from previous experiences and 'whole picture' processing. Such a theorising of autistic perceptual differences was also postulated by Pellicano and Burr (2012). When theorists and academics from differing disciplines and using differing methods come to similar conclusions, perhaps this indicates a need for further exploration?

The Double Empathy Problem

Due to the cognitive and dispositional diversity attested to in theories ranging from executive functioning theory to monotropism (Milton, 2012a), coupled with the numerous accounts of autistic authors (such as Sinclair, 1992) – Milton (2012b) proposed that rather than the 'theory of mind' or 'empathy' problems associated with autism being solely locatable in the autistic brain/mind, that such difficulties were reciprocal in nature; a 'double empathy problem' exists between the two parties. This theory suggests that it is both the autistic and non-autistic person who can struggle to understand and relate to the experiences and perceptions of the other. This theory has been reflected and expanded upon by other autistic theorists (Chown, 2014) and is also beginning to be reflected in empirical evidence (Sheppard et al. 2015).

How one defines autism and educational priorities

“Grant me the dignity of meeting me on my own terms...Recognise that we are equally alien to each other, that my ways of being are not merely damaged versions of yours.” (Sinclair, 1993).

From the early days of autistic self-advocacy movements a case has been made to use identity-first rather than person-first language, i.e. autistic person (Sinclair, 1999). Such a language preference usually indicates a rejection of medical model assertions of what it means to be ‘autistic’ in favour of a ‘neurodiversity paradigm’ of some sort. Of course, not all people with a diagnosis of autism choose to use this language and indeed some are likely to use a medical model narrative. Kenny et al. (2015) conducted a survey of UK stakeholders in the field of autism to enquire about preferences in the use of language. Whilst language regarding ‘functioning labels’ was largely denounced by all, differences between stakeholder groups were apparent. Amongst autistic adults, the term ‘autistic person/people’ was the most commonly preferred term. The most preferred term amongst all stakeholders on average was ‘people on the autism spectrum’. Kenny et al. (2015) concluded that it was important for people to use the language that was comfortable for them.

How a person talks about autism often reflects their experience of autism, the materials and resources they have had access to, and so on; the language we use can reflect how we think about autism. There are many controversies and differences of view with regard to what autism is, and therefore how best to help autistic people. In the production of the National Standards for Schools stakeholder groups were surveyed for their views regarding educational priorities for autistic children and young people (Milton and Giannadou, 2012). These consultations found that there were similarities in priorities reported: a curriculum tailored to individual need, good communication between staff and parents, and staff training. Yet there were also significant differences found. Parents of autistic children often highlighted communication with staff as fundamentally important. Autistic children and young people however mentioned the experience of being bullied above any other factor. This group also reported more frequently issues regarding the school environment, such as navigating crowds and having sufficient personal space. Whilst parents and practitioners highlighted the importance of teaching ‘social skills’, such a phrase was missing from the accounts of the autistic children and young people, who were more likely to discuss issues with particular subject areas, or elements of them, such as literacy or the use of words in mathematics questions. The autistic young people consulted for this work ranged in age and educational setting. Participation for some autistic young people in such exercises can be difficult, and although efforts were made in this regard to widen access (through methods such as talking mats and ‘smiley face’ choices), the reliability of data produced in such ways can be questioned. When examining educational ideology and practice with autistic children and young people with severe learning disabilities, the fault lines can become even more divisive and fraught (e.g. Milton, 2014; Keenan et al., 2014). Milton (2016) conducted a study looking into the educational priorities of stakeholders in the field of autism using a Q-sort ranking exercise of forty-two statements. In this sample a wide spread of views were found. However, amongst autistic adults there was a tendency towards either a critical or radical pedagogy, or at least a progressive interactionist practice involving pupil or interest-led activities. Within this group the most favoured statement of educational priority was to ‘celebrate learners and not attempt to normalise them’. Amongst non-autistic parents within this sample there

was a tendency toward an educational approach akin to Positive Behaviour Support (PBS) with common issues raised being the teaching of 'functional communication' and 'social skills'. Academics and practitioners sampled for this study were found to have a less coherent and more eclectic range of views that drew upon these two dominant narratives. Consensus within this sample (of just sixty people) was rare. Again, issues relating to navigating unfriendly school environments were more regularly discussed by autistic participants. All who were sampled were against notions of making autistic children 'indistinguishable from their peers'. The most commonly agreed upon statement by all groups was 'good communication between staff, pupils and parents'.

Although ideology and narrative are likely to affect practice, we cannot take this for granted. Jordan and Powell (1996) suggest that whatever the ideology of a practitioner, there is a tendency toward what they term 'therapist drift'. Therapist drift occurs where practitioners, particularly those utilising forms of interaction less natural to those receiving an educational intervention, drift toward a more natural form of interaction, and conversely, those using a child-centred approach may find themselves taking on the role of a professional teacher within certain interactions. Due to 'therapist drift' as outlined by Jordan and Powell (1996), it may be the case that in practice there is more similarity between those espousing differing intervention models than practitioners claim.

Building understanding

Wenger (1998) introduced the idea of 'communities of practice'. Such communities are formed whenever a collection of people engage in a process of learning through their activities. Communities of practice can have a range of participation available to members, from core participants to those on the periphery, but all involved in the community share a level of mutual engagement and common activity or interest through which they learn common practices. Through the membership of such groups, participants learn social competencies from interacting with one another that distinguish them from other groups, and in doing so, develop a repertoire of resources that represent their experiences and practices, and ways of addressing common social issues... This means that members of communities need to engage in relationships with one another over a sustained period of time. As a consequence of being organised around common principles and activity, communities of practice can also create a shared sense of identity. They generate a shared repertoire of ideas that become translated into materials, documents, and language.

Like Collins and Evans (2007), Wenger (1998) argues that the acquisition of knowledge can be seen as socially situated and contextual. As members of communities become more competent, they become 'contributory experts' (according to the schema of Collins and Evans, 2007), or 'core members' (according to the schema of Wenger, 1998). Thus, learning is seen as accomplished through a process of social participation. Of course, not all communities of practice are equally advantageous to all of their members, and some are distorted by unequal power relationships and the tight patrolling of membership and participation.

When applied to the field of autism, one can see that a number of communities of practice have evolved in relative isolation to one another. From autistic self-advocacy groups, through communities of practice that have developed through a particular academic discipline or paradigm, to parent support groups and forums, and professional conferences, one can see that many

communities of practice exist. Each of these communities produces their own language, their own culture, and their own sets of resources and materials. The extent that there have been shared practices between these communities however has been traditionally at their respective fringes. Such a separation of related communities is a significant issue within the field of autism, characterised by Arnold (2010) as the 'silo mentality'. One of the downsides of communities of practice, is that they develop in ways in which their shared competencies, experiences and practices, distinguish them from other groups. This provides a sense of identity and pride for their members, but may also ferment a disparaging view of 'outsiders', especially if they hold opposing views and perform practices that are seen as abhorrent to those within one's own group. Such disparities can easily lead to apathy, dyspathy (Cameron, 2012), and antipathy and/or stigma toward others. Therefore, to limit the effects of the 'silo mentality' the barriers separating these communities need to be reduced and collaborative communities of practice need to be established in order that stakeholders do not feel alienated and disenfranchised.

By including members of teams that occupy differing dispositions and outlooks, one is able to weigh-up the arguments presented by differing interpretations of the same phenomena or data, and these can be openly debated. Of course, not all stakeholder groups can be said to be content with their current level of involvement (ABA4All, 2014; Dillenberger et al., 2015), and perhaps what is needed is some kind of 'summit' or 'peace workshop' in order to initiate contact and build a common acceptance, or even an understanding, if not a consensus, of opinion. Initial attempts at creating such discursive spaces can be said to have originated within the autistic community, with examples such as the Theorising Autism Project (Greenstein, 2014) that sought to bring together people from all stakeholder groups so that they can work interactively. This project, as well as the Participatory Autism Research Collective (PARC) based at London South Bank University have organised seminar days with this purpose in mind and been led by autistic people and their concerns, which at this stage may well be required to redress the traditional power imbalance between stakeholders in the field.

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