

To be or not to be disabled: autism, disablement and identity politics

**Presented at the 3rd international 'Theorising Normalcy and the Mundane' conference (27th June 2012, University of Chester) by Steve Graby, University of Leeds
Contact: sgraby@googlemail.com**

In Rebecca Mallett's keynote presentation at Normalcy 2011 she mentioned the fact that autism is far more referenced in academic contexts (such as Disability Studies conferences) than any other specific impairment label. Mallett's suggestion is that autism is a particularly commodified impairment label; however, this leaves open the question of *why* autism is more commodified than other impairment labels. I suggest that autism is more frequently referenced than any other specific impairment because it is more than *just* an impairment label, but in fact falls between established categories of "impairment" and "disability", resulting in its treatment as *sui generis* because of difficulty in placing and processing it neatly within pre-existing categories.

The term "autism" was originated by the Swiss psychiatrist Eugen Bleuler as a description of symptoms of psychiatric conditions such as schizophrenia (Crespi 2010), but evolved into its current medical usage to denote something that could be more accurately referred to as a syndrome, or even a spectrum of related syndromes. However, since autism has gained more cultural recognition and become established as a phenomenon of political and economic significance, it has - unlike most other comparable medical categories, although perhaps comparably to other formerly-medicalised categories such as homosexuality or transgender/transsexual identities - been reclaimed by the people coercively labelled with it. This has resulted in a specific pattern of convergences and divergences with more general theorising of disability and impairment.

Most other impairment categories are treated much more generally within Disability Studies and the Disabled People's Movement - there is no particular movement of, for example, people with cerebral palsy or multiple sclerosis, or where such impairment-specific organisations do exist, they tend to be focused on individual and medical models of impairment and disability, whereas the social model perspective has generally frowned upon impairment-specific organisation, sometimes even dismissing the idea that differences in impairment have any relevance to a social analysis of disability. Thus it is no surprise that such particular categories of physical impairment do not commonly appear in titles of presentations at Disability Studies conferences. However, autism is arguably a different kind of category.

Some of the reasons I think autism is different are:

- Autism is conceptualised as a "social impairment". This makes consideration of autism "sociological", or even "social model", in a way that consideration of (e.g.) paraplegia is not.
- Autistic people have developed their own "movement", arguably separately from the wider "disabled people's movement".
- Unlike many other impairment labels, autism has been significantly reclaimed from its medical authority to define it by the population it is affixed to - thus autistic people analyse autism and come to different conclusions about what it "is" than professional psychologists and neurologists do, and a criterion of "self-diagnosis and peer-confirmation" has been established to define the boundaries of "who is/is not autistic", in conflict or competition with strictly-medically-diagnosed hegemonic criteria (see for example the editorial "Who Can Call Themselves Autistic?" on the autistics.org website (Baggs et al 2006), written in response to a demand that that people claiming to be autistic and speaking at conferences should be asked for proof that they are autistic, and signed by a list of many of the most prominent members of the autistic self-advocacy community).
- Thus, "autism" has been reappropriated by those labelled with it from a label into an identity, and can be compared to a different set of categories, such as sexual, gender and ethnic identities, all of which can also be coercively assigned to people, but can also be willingly chosen and politically

defended. **(For reasons of time I am not fully exploring this comparison here.)**

This focus on the right to determine for oneself whether one is or is not "autistic", rather than deferring to the definitional authority of medicine or psychology, brings to mind the use of phrases such as "self-defining disabled people" in the disability identity literature. The concept of self-defining as a disabled person is typified by Susan Gabel (1999), who states: "If... I experience my body as a disabled body, regardless of what others think of me, then I am disabled. In contrast, if I do not view my body or my self as disabled, then I am not disabled, even though others may disagree." (p.42)

Thus to Gabel "being disabled" appears to be wholly subjective, yet at the same time constitutes a material reality determined exclusively by the self-defining person; it is also defined as being an "ontological claim" (p.42) about the individual body (presumably including the brain within the definition of the body). She goes on to categorise the claim of an individual to be disabled not as an empirical fact but as a "statement of resistance" against nonconsensual labelling by the medical establishment (p.46) - apparently leaving no room for anything other than individual self-definition as a valid delimitation of the category "disabled people".

While such an absolute statement is perhaps rare, this is echoed by the common usage of phrases such as "self-identifying disabled people" in organisations of the Disabled People's Movement: for example, we see the question "Do you consider yourself a disabled person?" asked on Southampton Centre for Independent Living's membership form (Southampton CIL n.d.), and the Disabled Students Campaign at Cambridge University Students' Union says on their website that "Any student who self defines as disabled is able to stand for executive positions" (CUSU Disabled Students Campaign 2011).

However, there is a tension between the idea of self-identification defining the category of disabled people and the core idea of the social model of disability: that "disability" is not a possession or attribute of an individual, but an oppressive social relationship, and thus "to be disabled" is to experience a particular type of material oppression. This definition of disability was pioneered by British disabled activists in groups such as the Union of the Physically Impaired Against Segregation (UPIAS) in the 1970s and 1980s, and has been extended in more recent years by writers such as Carol Thomas (1999) to include psycho-emotional dimensions of oppression. Thomas defines "disability" as "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being." (1999, p.60). Using this definition of "disability", it follows that it is not disabled people themselves who define who is and is not a disabled person, but the society which disables them. It is not exclusively British writers and activists who take this position: in a US context, Carol Gill (1994) argues (in the context of arguing against the claim that there is a continuum between disabled and non-disabled people, i.e. that "disabled people" is a distinct and valid category): "I tend to think you're disabled when society says you're disabled... You know you have a 'real' disability when you know society will label and marginalise you once your difference shows." (pp.46; 49)

Due to the fact that both these definitions of "disabled" are in use in activist movements, confusion and ambiguities can occur. In an attempt to address these, the US-based disabled feminist activist Mia Mingus (2011) makes a distinction between being "descriptively" and "politically" disabled:

"When I say "descriptively disabled", I mean someone who has the lived experience of being disabled. They may not talk about ableism, discrimination or even call them selves "disabled," but they know what it feels like to use a wheelchair, experience chronic pain, have people stare at you, be institutionalized, walk with a brace, be isolated, etc. There are many people who are

descriptively disabled who never become or identify as “politically disabled.” When I say “politically disabled,” I mean someone who is descriptively disabled and has a political understanding about that lived experience. I mean someone who has an analysis about ableism, power, privilege, who feels connected to and is in solidarity with other disabled people (regardless of whatever language you use). I mean someone who thinks of disability as a political identity/experience, grounded in their descriptive lived experience.” (Mingus 2011, unpagged)

Mingus's definition of "descriptively disabled" corresponds roughly to the social model definition(s) used by authors such as Gill and Thomas. Her definition of "politically disabled" approximates to "self-defining disabled", but does not exactly correspond to Gabel's absolutist framing thereof, as Mingus makes it clear that "in order to politically identify as... disabled... one needs to have a descriptive lived experience to ground it in"; thus, while for Gabel self-identification is the only necessary and sufficient condition for "being disabled", for Mingus being "descriptively disabled" is a necessary, if not sufficient, condition for being "politically disabled".

Is there a parallel here with the autistic self-advocacy movement's reclamation of the label "autistic"? The assertion of the validity of self-diagnosis seems to parallel Gabel's assertion of a self-definition criterion for "being disabled", while one could apply Mingus's schema to autism by defining those labelled as autistic by medical/psychological authorities as "descriptively autistic" and proudly self-identifying autistic people as "politically autistic". However, self-diagnosis seems to break with Mingus's assertion that descriptive identity is a necessary condition for political identity, as self-diagnosed autistic people are "politically autistic" *without* being "descriptively autistic", if medical labelling is regarded as the criterion for the latter. This suggested to me that the relationship between "being autistic" and "being disabled" needed further examination, leading me to identify several conceptual differences, which suggest that identifying as autistic is *not* necessarily equivalent to, and does not constitute a subset of, identifying as "disabled":

Firstly, not every person who identifies as autistic also identifies as "disabled". This arguably represents a cleavage within the autistic movement, to at least some extent reflecting whether or not people within it identify with a wider "disability" movement, and also reflects different understandings that people have of the terms "disabled" and "disability"; for example, the common claim that "autism is not a disability" can be made in a social model context, identifying autism as impairment rather than disability, but is more likely to be made without a social model understanding of the impairment/disability distinction, and thus is better understood as a claim that autism is not (or can be seen as something other than) an impairment - instead, for example, autism may be framed as a "cognitive minority" (Seidel 2004) or as a form of difference which has positive components and is overall neutral or even advantageous rather than "impairing" (see for example O'Neill 1997; Baggs 2003). In some contexts this claim can also represent an attempt by autistic people to dissociate themselves from people with other impairments who they see (unlike themselves, and in a medical/individual model context) as "really disabled"; this parallels, and is sometimes possibly inspired by, the efforts by "capital-D Deaf" activists to reconceptualise deafness as a "linguistic minority" rather than an impairment or "disability" (Dekker 2004).

Another difference is the way language is used to define identity. The objections of autistic activists such as Jim Sinclair (1999) to "person-first" language suggest a kinship with the deliberate use of the phrase "disabled people" by (particularly British) exponents of the social model (see for example Clark & Marsh 2002). However, on examination these linguistic preferences, while parallel, are for significantly different reasons: Sinclair prefers to be considered an "autistic person" rather than a "person with autism" because the latter phrase suggests that autism can be separated from the person, that it is a devalued or inessential part of a person, and that it is an inherently negative attribute that it is desirable to separate from the person, whereas the phrase "disabled people" is preferred over "people with disabilities" because it places "disabled" as something that

has been (nonconsensually) *done to* a person, rather than "a disability" as something that is inherent to, or is the property or responsibility of, that person. Thus "autistic person" is preferred because "autistic" is an adjective describing an essential quality of a person, whereas "disabled person" is preferred because "disabled" is *not* an adjective but a (past-tense, transitive) verb (expressed in the passive voice), describing something that is *not* an essential quality of a person, but an oppression experienced by them.

For autistic activists such as Sinclair, autism is clearly not merely an impairment but an identity, and one which can be viewed positively in defiance of its negative valuation in dominant medical and psychological discourses. In this respect the autistic self-advocacy movement can be said to take a stance similar to the "affirmation model of disability" proposed by Swain and French (2000), but in a form incorporating the constructive critique of it by Colin Cameron (2008), who argues that, if an affirmative model of "disabled" identity is to be consistent with and complementary to the social model, it ought to "affirm" not disability but (the differences generally categorised as) impairment. Autism, as such a "difference to be expected and respected on its own terms in a diverse society" (Cameron 2008, p.24) is, however, placed unambiguously as an essential (bio/neurological) characteristic of an individual.

However, the categorisation of autism as, at least in part, a "social impairment" complicates this, as that which is social by definition involves relationships between people, rather than merely characteristics of individuals. Autistic activists and writers have also, as part of their reclamation of autism from diagnosis to identity, questioned the individualistic framing of autism as involving deficits residing solely in the "socially impaired" autistic person (without denying that autistic people experience difficulties with social interaction) - for example Damian Milton's (2011) argument that, rather than autistic people having a one-sided deficit of "empathy", there is a "double-empathy problem" in interactions between autistic and neurotypical people (in which autistic people, due to their minority and marginalised status, are likely to experience the greater difficulty and to be the person categorised as "having a problem").

This brings to mind Carol Thomas's (1999) description of impairment as "profoundly bio-social, that is, shaped by the interaction of biological and social factors, and... bound up with processes of socio-cultural naming" (p.43). As Thomas states that it is possible, without contradiction, to "make a conceptual distinction between impairment and disability, reconceptualise the latter as a form of social oppression, understand that bodily variations classed as impairments are materially shaped by the interaction of social and biological factors and processes, and appreciate that impairment is a culturally constructed category which exists in particular times and places" (p.141), so there may be no contradiction in regarding autism as both a real neurological difference and a social construction.

The interrogation and reclamation of the label "autism" by the autistic community can be seen as an 'organic' (meant here in a sense analogous to Gramsci's use of 'organic intellectuals' (Burke 2005)) example of the kind of "sociology of impairment" called for by Tom Campbell (2008) - one whose focus is not so much on human biological difference *per se* as on the ways in which society categorises and problematises particular types of biological difference as "impairments", thus being a branch of the sociology of knowledge. Campbell describes impairment categories as "technologies of government concerned with differentiating people with impairments from the rest of the population" (p.37); the redefinition of criteria for identifying autism (such as the assertion of the validity of self-diagnosis) by the autistic community can be seen as an act of subversive *reappropriation* of such technologies.

How, then, is it possible to reconcile a social model approach to disability with the community of identity developed by autistic people and arrive at a coherent standpoint on autism that acknowledges both the arbitrary and nonconsensual social construction of the category of "autistic

people", and its reappropriation as a category of diversity to be affirmed and defended by those positioned within it? I would make the following assertions, from a position more or less aligned with Carol Thomas's "non-reductionist materialist feminism" (1999, p.143):

- There is a spectrum of real neurological difference - this I see as uncontested.
- A section of that spectrum has been, perhaps somewhat arbitrarily, defined as "autistic people".
- Arguments have been advanced both for the essential unity of that category and for it actually being an arbitrary lumping together of conditions with quite different etiologies. In general, autistic activists have tended to take the former position and proponents of normalisation or 'cure' the latter, in both cases for reasons that are arguably more tactical than evidence-based, and having much to do with the politics of identity and representation. Davidson & Henderson (2010) suggest that the emphasis on similarity across the autistic spectrum by autistic authors is due to a "focus on solidarity rather than specificity" (p.163), and a response to the claims by 'pro-cure' activists that supposedly 'high-functioning' or 'mildly autistic' self-advocates do not experience the same impairments as, and thus cannot rightfully represent, supposedly 'low-functioning' or 'severely autistic' people (who *they* then represent as desiring normalisation or 'cure').

However, I would argue that it is possible to defend neurodiversity and take a social model position that strongly opposes efforts to 'cure' autism (and believes that society must be changed, not individuals) while accepting that autism is not necessarily "one thing"; as the autonomist Marxist John Holloway (2002, p.63) says of social class, "Classes in this sense are always more or less arbitrary: any collection of identities can be thrown into a sack together, sub-divided into smaller bags, put together into larger containers, and so on." This does not mean that social class is not a real phenomenon, but that it can be divided up into many different combinations of categories without changing the real experiences of the people around whom those boundaries are drawn.

(It is worth mentioning that the definition of another section of this spectrum as "neurotypical people" is equally arbitrary, and that the boundaries of the "normal" or "unimpaired" are as variable and socially determined as those of particular impairment categories.)

- The definition of the section called "autistic" has changed, been expanded, etc., and is contested - while it was initially defined as a pathology within a normalising medical paradigm, an anti-normalising paradigm has risen to challenge this through the reclamation of "autism" by those labelled autistic, in which it is a difference that should be regarded as real but not pathological. This is not necessarily inconsistent with aspects of neurological difference (such as executive function difficulties or sensory processing difficulties) being (seen as) impairment by those who have them.
- However, "impairment" must be conceived of as relative rather than absolute, as there is no "absolutely normal" person against which to define it; as the autistic blogger Amanda Baggs (2003) points out, autistic people are considered 'impaired' for the cognitive skills they lack in comparison to neurotypical people, but neurotypical people are not considered 'impaired' for the cognitive skills they lack in comparison to autistics. Thus impairment is simultaneously a biological reality *and* a social construction. This recalls the claim by Shelley Tremain (2002, p.42) that "impairment has been disability all along", but in my analysis the key difference is that impairment is simultaneously a biological fact and a social relationship (which can be unequal but arguably does not have to be), whereas disability is a social relationship which is by definition unequal and oppressive.

This analysis leaves open the question of whether "autism" is, on a neurological level, one "thing" or several, and of whether it is more useful to use the term "autism" for a neurological phenotype, a self-defined identity, or a social location; however, it has been shown that the term has been, is, and

will continue to be, used for all of these (and without necessary contradiction). While autism may not be unique among impairment categories in the challenges it presents to definitions of impairment, disability and 'disabled' identity (other neuropsychiatric labels as well as d/Deafness and 'learning difficulties' come to mind), an analysis of it certainly suggests possible resolutions of dichotomies between materialist and 'self-defined' or 'identity' models of disability.

References

- Baggs, A. (2003) "The Validity of Autistic Opinions", available online at <http://archive.autistics.org/library/autopin.html>
- Baggs, A. et al (2006) "Who Can Call Themselves Autistic?" (autistics.org editorial), available online at <http://archive.autistics.org/library/whoisautistic.html>
- Burke, B. (2005) 'Antonio Gramsci, schooling and education', Encyclopedia of Informal Education, available online at <http://www.infed.org/thinkers/et-gram.htm>
- Cambridge University Students' Union Disabled Students Campaign (2011) 'The Executive', available online at <http://www.disabled.cusu.cam.ac.uk/exec/>
- Cameron, C. (2008) "Further Towards an Affirmation Model" in Campbell, T. et al (eds) *Disability Studies: Emerging Insights and Perspectives*, Leeds, The Disability Press, pp. 14-30
- Campbell, T. (2008) "A Case for the Sociology of Impairment" in Campbell, T. et al (eds) *Disability Studies: Emerging Insights and Perspectives*, Leeds, The Disability Press, pp. 31-47
- Clark, L. and Marsh, S. (2002) "Patriarchy in the UK: The Language of Disability " (available online at <http://www.disability-archive.leeds.ac.uk/>)
- Crespi, B. (2010) 'Revisiting Bleuler: relationship between autism and schizophrenia ', *British Journal of Psychiatry* 196, pp. 495-497
- Davidson, J. and Henderson, V. (2010) "'Coming out" on the spectrum: autism, identity and disclosure', *Social & Cultural Geography*, 11: 2, pp. 155-170
- Dekker, M. (2004) 'On Our Own Terms: Emerging Autistic Culture', available online at <http://web.archive.org/web/20040216032556/http://trainland.tripod.com/martijn.htm>
- Gabel, S. (1999) "Depressed and disabled: some discursive problems with mental illness" in Corker, M. and French, S. (eds) *Disability Discourse*, Buckingham, Open University Press, pp. 38-46
- Gill, C. (1994) "Questioning Continuum" in Shaw, B. (ed) *The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag*, Louisville, The Advocado Press
- Holloway, J. (2002) *Change the World Without Taking Power: The Meaning of Revolution Today*, London, Pluto Press
- Mallett, R. (2011) "Buying New Normals: When Impairment Labels Become Commodities" (presentation at "Theorising Normalcy and the Mundane" conference, Manchester Metropolitan University, 2011)
- Milton, D. (2011) "An insider's critique of the dominant psychological models of autism" (presentation at Autscape 2011; slides available from <http://www.autscape.org/programme/presentations>)
- Mingus, M. (2011) "Moving Toward the Ugly: A Politic Beyond Desirability" (Femmes Of Color Symposium Keynote Speech, Oakland, CA (8/21/11), available online at <http://leavingevidence.wordpress.com/2011/08/22/moving-toward-the-ugly-a-politic-beyond-desirability>)
- O'Neil, Sara(2008) 'The meaning of autism: beyond disorder', *Disability & Society*, 23: 7, pp. 787-799
- Seidel, K. (2004) "The Autistic Distinction", available online at http://www.neurodiversity.com/autistic_distinction.html
- Sinclair, J. (1999) "Why I dislike 'person first' language", available online at http://web.archive.org/web/20090210190652/http://web.syr.edu/~jisincla/person_first.htm
- Southampton Centre for Independent Living (n.d.) 'Membership', available online at

<http://www.southamptoncil.co.uk/getting-involved/membershipmc/>

Swain, J. and French, S. (2000) 'Towards an Affirmation Model of Disability', *Disability & Society*, 15: 4, pp. 569-582

Thomas, C. (1999) *Female Forms: Experiencing and Understanding Disability*, Buckingham, Open University Press

Tremain, S. (2002) 'On the Subject of Impairment', in Corker, M. and Shakespeare, T. (ed.) *Disability/Postmodernity: Embodying Disability Theory*, London, Continuum, pp. 32-47