

Draft version of: Rix, J (2007) Labels of opportunity - A Response to Carson and Rowley, Ethical Space, 4, 3, 25 – 27

Labels of opportunity - A Response to Carson and Rowley

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The debate in *Does it matter what we call them? Labelling people on the basis of notions of intellect* is, as Rowley points out, centuries old. The paper suggests that its inevitable re-emergence is as a consequence of individuals' struggles with changing practices and expectations. Hardly surprisingly, therefore, as Carson rightly says, the debate explores issues that for specialists are 'old news'; yet what it contains still strikes many lay people as new. At the start of the paper, I explained how this divide is part of the problem when thinking about issues of impairment. The arguments presented by the disability movement have not become part of the mainstream. They are nuanced, academic and unaccessed by the majority of lay people.

Consider the term 'disabled'. This word has two entirely contradictory meanings that can only be understood if a person has engaged with the social model discourse. To the majority of the population 'a disabled person' means a person who is disabled by their impairment; far fewer people are also aware that from a Social Model perspective 'a disabled person' means a person who is disabled by social barriers. It is this latter definition, of course, that disability activists would like more people to engage with.

At the heart of my paper is the point that very few lay people are encouraged by the language they use to re-evaluate their practices and ways of thinking. This is why, as Rowley points out, I was 'careful' to explain the nuances behind the labels I used, such as 'disabled person' and 'people with learning difficulties'. I did not explain them to justify myself. I explained them because lay people have rarely been exposed to the arguments, and don't understand why one label is deemed better or worse. This does not mean, as Carson suggests, that the paper is saying that 'Words cannot say it all and therefore they must inevitably fail to truly say who the disabled are' (p30). Words can say a great deal. They can capture the essence of people in many ways. The paper clearly sets out at the end that our language can be a key factor in changing thinking and practices. I am saying that labels specifically - the automated phrases we use - can generalise the individual, triggering assumptions and ways of thinking about them.

I agree, as my paper suggests, with Carson's view that 'Our labelling helps to change our attitudes in ways that then feed back into our labels' (2006: 30), and that labels are not something that we can get away from. But I find it hard to accept his suggestion that 'Something that we cannot avoid cannot be a "barrier".' (2006: 30). Is he seriously suggesting, for example, that throughout history people have not suffered deprivations because of the label they have been given? How about the caste system in India, or the frequent legalised attacks on Jewish people down the centuries, or being an ex-prisoner trying to get a job? In certain contexts, merely having a label applied to them can totally change an individual's life experience. The label in these instances carries with it disdain

for individuals. The disdain exists in many ways, but the label is a central vehicle for expressing and reifying that disdain. Thus it acts as a barrier. This is not to say that labels only act as barriers. Labels can serve some individuals well. Consider a child who suddenly achieves the dyslexia label after years of struggle in the education system. This can open up all kinds of new opportunities for them.

Similarly I cannot accept Carson's assertion that 'Labelling is not a barrier to our helping people who suffer from disabling conditions any more than it's a barrier to our having relationships with anyone.' (2006: 30) As Rowley concurs, the label can dominate how a person is seen. People change their behaviours on the basis of the label they encounter and their perceptions of its meaning. This is why, as a number of studies in the 1990s showed (eg Simons, 1992; Hastings and Remington, 1993; Riddell et al, 1994; Norwich, 1999) people often have strong preferences towards one label as opposed to another. A label is not just a spoken thing. It is so often a trigger for a whole range of assumptions. As a brother growing up with a sister with Down syndrome I saw the impact that the label alone had on people and their ways of responding to me. As a parent of a child with Down syndrome I have seen the ways in which people seek out labels to contain him and thereby facilitate their ways of dealing with him. It is, of course, this very power of the label to contain individuals that leads me to question the form of those labels.

Carson's commentary focuses on tensions and contradictions that I have highlighted as being created by the process of labeling, and suggests that these are contradictions in my argument. For example, he reframes my analysis as if I think it is a simple matter of one thing being good and another being bad, in other words as if I am simply saying there are good and bad labelling practices. This is a pity. It misses the subtlety of the process. Similarly he suggests that I am simplifying diversity. He suggests that I am characterising 'us' as the normalising society, who create labels en masse and are an 'aggregate of bad intentions'. Nowhere do I make this suggestion. However, neither do I refute it, so perhaps I left space for the misconception. I believe that the vast majority of individuals who work with people with learning difficulties are doing so for the very best of intentions. That 'we' (or is it 'they' to you) get it wrong is an essential part of the process, but it does not make us deliberate and malevolent. My use of 'we' and 'them' is not intended to position the 'normalising society' in conflict with the 'the disabled' as Carson describes. It is intended to express a fundamental effect of labels. I am saying that by our use of labels we divide ourselves into 'them' and 'us'. This is not exactly controversial. This is the nature of labels. They are, as Carson seems to agree, a key process in how we structure society and our own thinking. If I use a label to describe another individual's difference then that individual and those to whom I would also apply that label become 'them'. Society is made up of multiple versions of 'we' and 'them'; they overlap, dissipate and congregate. People with a learning difficulty are part of the 'we' or the 'them', depending on the context. It is unlikely, of course, that they are part of the 'we' involved in this academic discussion in *Ethical Space*, but such issues are discussed, for example, in self-advocacy groups around the country. It would be a mistake, as Carson suggests, to simplify this diversity, so that 'we' become this mass of humanity and 'them' becomes 'the disabled'. This however is a risk encouraged when using current labeling, which places the deficit within the individual and does not contextualise that individual

and their experience.

Both Carson and Rowley point to a very real gap in my original paper, namely that I fail to suggest the sort of language that might achieve the goals I set out in my paper, in other words, ‘...labels that clearly position the barriers faced by individuals within the social structures around them, not within the individuals themselves’ (2007:28). The intention of the paper, of course, was to unpack the ethics of the current situation for an audience unfamiliar with the debate, rather than to examine the possible solutions. There is just so much that can be fitted into one paper and to present, explain and analyse solutions will require considerably more space. The following, however, should give a taste of what I envision.

My son’s label is Down syndrome. As a label it tells you nothing. For it to have meaning you have to know about the statistically defined characteristics linked to it. Knowing these characteristics will, however, still be of little use when you meet my son. Because they are statistically defined characteristics you will either have to go through the list ticking them off, or you will have to deal with the characteristics he presents just as you would with anyone else. However, if we were to seek a label that might ‘encourage those who hear them to engage with possibilities’ (Rix, 2007:28), we might choose to describe him as a ‘person supported by signing and visual communication’. This of course does not cover everything, but it would be a start. It would help both of you.

I do not believe that labels such as these would be, as Carson suggests ‘taking us away from who we really are’ (p30), but would instead help users of the phrase re-consider the label and the people to whom it refers and their relationship to them. I feel sure, too, that that if such terms were adopted Rowley would be proved right and ‘over time the core ideas that underpinned their adoption [would] become diluted or distorted as they are passed on from generation to generation’. My original paper was not calling for terms that provide absolute answers. It was encouraging the next step forward. It was part of an on-going process. It was attempting to stimulate new ways of thinking and engaging with people who have... Well, which label would you use?

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