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Does it matter what we call them? Labelling people on the basis of notions of intellect

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A Poor Introduction?

In this paper I will use the terms ‘people with learning difficulties’, ‘Down syndrome’ and ‘disabled person’. Some people will recognize the use of these terms as a political statement; for others, including most of the general public - my statement will be in a secret code.

In using the terms that I choose to use, I am drawing upon a discourse of disability whose meanings are not widely understood, let alone agreed upon. For example, in using the term ‘people with learning difficulties’ I am adopting the language advocated by self advocates such as Simons (1992) and self advocacy groups such a People First (People First 1992, 2006). They request that we recognize them as people before anything else, and that we use the term ‘learning difficulties’ to remind others that they can learn for the whole of their lives like everyone else (Goodley 2001). By using the term ‘Down Syndrome’ and not using an apostrophe ‘s’ (as in Down’s Syndrome) I avoid the implication that the syndrome belongs to a long dead scientist (Langdon Down) rather than the people themselves. Finally, by using the term ‘disabled people’, I am demonstrating my support for the Social Model of Disability (Oliver, 1983, 1990), which sees disability as a consequence of social barriers. By placing the ‘person’ second and ‘disabled’ first, I am emphasising my belief in the view that the disability is not part of the person but is a consequence of their socially-constructed surroundings.

It is hardly surprising that my reasoning is not immediately obvious to most people. To understand the language you cannot rely upon the language it uses. Its meanings and their significance hang upon grammatical niceties that are not readily obvious. They require knowledge of a debate that largely takes place within specific groups defined by their impairment labels, and in Journals and upon University Courses. It requires thinking about and a desire to engage. This is ironic, of course, since by using this language I am trying to encourage understanding!

Probably the worst thing about this paper, however, is that I am going to obsess on words that generalize individuals and diminish the richness of their lives. In it I explore issues

around the labelling of individuals who during recent years may have been described as having a:

- Learning Difficulty (or Learning Difficulties)
- Learning Disability (or Learning Disabilities)
- Cognitive Disability
- Intellectual Disability
- Intellectual Impairment
- Cognitive Impairment
- Mental Handicap
- Mental Deficiency
- Mental Retardation

...to name but a few.

These individuals are also commonly sorted into a whole raft of label subgroups which themselves change across the years. What they have in common is that they experience barriers in relation to thinking, remembering and communicating. They face a broad range of social assumptions and biases. In this paper I am going to consider the role that labels play in relation to those assumptions and biases and whether changing labels is an effective tool in overcoming them.

An Everyday Conversation?

Debates around the language used to label people according to a notion of their intellect are surprisingly common. Between January and May of 2006, I came across four such debates - without searching. One, in the letter pages of the *Independent* (24th January to February 3rd 2006), arose in response to an article by a journalist who refers to his child as mentally handicapped. Another appeared on a website in response to the Apple vs Apple court case, during which the defence stated that ‘even a moron in a hurry could not be mistaken’ about the difference between the two companies (Techdirt 2006). The other debates were on a Down syndrome internet discussion forum (DSLitserv) in response to personal experiences of parents and their children.

Certain comments cropped up regularly within these four debates:

- People with learning difficulties don't care and/or can't care about this debate.
- People with learning difficulties can and do care about this debate.
- We need to listen to the views of people with learning difficulties.
- We can't rely on the views of people with learning difficulties.
- The terms used in relation to this identified group of people are offensive.
- The terms 'x', or 'y', are politically correct
- The terms 'x' and 'y' correctly describe a person or their condition.
- The terms 'x' and 'y' incorrectly describe a person or people and their condition.
- The terms used in relation to this identified group of people are important for gaining access to facilities.
- People should not be so sensitive.
- People should think more about the language they use.
- Changing language changes people.
- Changing language doesn't change people.
- Changing Language reflects changing values.
- What really matters is how people think about and treat people with learning difficulties.
- This is a meaningless debate for academics/philosophers/bored professionals

During the course of this paper I will directly and indirectly revisit all these viewpoints in an attempt to clarify and explain my own perspective.

The Label's Role?

The starting point for this problem is the nature of a label. A label is a generalized term which creates a specific identity. It defines an aspect of something to focus upon, not the whole of that thing. So, an 'apple' seems just fine for everyday use for most of us, but it

is a vague description to an apple farmer. Similarly, impairment labels never fully describe individuals, but will often be bandied around as if they do.

All labels are a social construct. Researchers and funders choose which aspects of humanity to research, dependent upon a wide variety of socio-cultural and economic factors. Based on this research they define statistical norms. These norms mask the variability of all people's rates and processes of development, but are used both to define the label and to select which label to apply to an individual.

This acknowledgement of the social construction of labels does not deny the existence of tangible patterns of difference in those with labels such as learning difficulties, but it does require that we acknowledge that the label is a tool for communication, organisation and contemplation rather than an accurate representation of the individual.

All of us group and label others. As Foucault (1978) makes clear, we have to position ourselves within the dominant structure of the normalising society and we do so by assuming identities and meanings constituted in the context of social relationships and structures. A key factor in defining ourselves and others is positioning ourselves within social categories. We respond to others and their behaviours on the basis of whether we perceive them to be insiders or outsiders of the category in which we place ourselves (Waterhouse 2004). Subsequently, labels can provide an explanation for outsider behaviours and can legitimize our responses to them (Gillman, Heyman & Swain 2000).

Labels also carry with them expectations of behaviour. They are never value free. They affect perception, expectation and response. In using them we call up a range of stereotypes that commonly define an individual with that label. In explaining them we make links to a variety of other labels. Whatever label we apply to people according to a notion of their intellect, we are unifying hundreds of sub-groups within a broad title, when the sub-group labels themselves are already a generalisation. Which label each individual engages with depends too upon whether they see a benefit in engaging with it and/or whether engagement is forced upon them. For many, accepting a label is the only

means of gaining access to social resources, limited according to policy and funding decisions. For others, it can be a route to self-determination.

Placing a limitation upon the individual?

The assumptions that people bring to a label are not just a consequence of the label, of course. For many years it has been understood that people have different personal visions of what learning difficulties means (Latimer 1970). St Claire (1986), for example, shows how lay people who are acquainted with people with a learning difficulty have more positive views on people with a learning difficulty than unacquainted lay people, who in turn are more positive than psychologists. But this does not mean there is just one uniform expectation. This could be to do with not having understanding about the nature of a group or clear feelings towards that group (Soder 1990), perhaps because of the lack of encounters (Vehmas 1999) or perhaps because:

We resist the thought, above all, that in the imperfect bodies and minds of those already so categorized, we are seeing a mirror image of our own. We put away the thought and we put away the people. (Shearer, 1981:10).

Perhaps it is as a consequence of this ambivalenceⁱ that we more readily define people with learning difficulties by this label, rather than by the many other identities they may have access to, such as 'football fan' or 'computer user' or 'music lover'. It encourages us to limit our expectations, to define them by what they can't do, by their difficulties. In some instances the label becomes a reason for excusing poor behaviour, in other instances it is used to explain an individual's personal achievements (thereby diminishing them). It can also, as Wilson (2000) points out, limit any moral responsibility that an individual may be held to have for the difficulties they face. By over-simplifying the complexity of using different, fluid, identities in interactions we limit the possibility of our recognising the multiple identities of the individual with the label.

A Knowledge Hierarchy?

People with learning difficulties are surrounded by a constant barrage of terms that reflect a social view of their impairment, and which undermine their relationship with that impairment. Current social norms place great store in intelligence. Status is commonly defined by an ability to demonstrate specific knowledge in specific contexts. We reify knowledge and create the expert. Gradations of this mindset exist all the way down society's knowledge hierarchy. As a consequence if we want to make someone feel lesser we suggest they are without socially-valued knowledge. This is made possible by numerous pejorative terms, which are used constantly. Spanish politicians use the term 'imbecile' to describe a British Prime Minister they disagree with, Lawyers from Lord Denning (Wikipedia) to those representing Apple Computers happily use the phrase 'even a moron in a hurry'; there is a wide range of books with titles such *The Complete Idiot's Guide* (Alpha Books), and numerous websites that have a *Cretin of the Week*, or a name such as www.googleityoumoron.com.

Such terms are not just used to offend or as humour, but also in post-modern, ironical ways. In the world of hip hop for example the term 'retarded' (as in the Black Eyed Peas' song, 'Let's Get Retarded') means to lose control when dancing, while there are many bands who have used these terms of offence in their title (such as the Punk band the Cretin Family). People often use these words having given consideration to their impact or meaning too. Consider this comment from a US chat-room (NeoProductions), where they were discussing:

What is lower, a moron, an idiot, or an imbecile?

You guys are forgetting the ever popular retard and since retard is an actual dissability [sic] to be retarded is a bigger insult than any of the others because even an ignoramous...is something that can be recovered from.

Shifting Definitions?

Many of the terms that people use as insults originate or have had a specific role within a scientific or medical discourse. Over time these labels become laden with a pejorative

meaning because of their association with learning difficulties (Hastings & Remington 1993, Foreman 2005). Such terms are not simply relics of the medical discourse however. For example, Rao identified the use of terms such as ‘imbecile’ and ‘feeble minded’ in Indian official documentation in 2001, while ‘idiot’ was not abolished from British Common Law related to the capacity to vote until 2006. (DCA, 2006)

As Goodley (2001) makes clear, it has been long understood that the whole notion of learning difficulties should also be viewed as a social construct. It too changes across time. The unreliable nature of IQ parameters, for example - and their continued use in many countries - is just one reason that the classification of learning difficulties has long been seen as somewhat arbitrary (Clarke 1958). St Claire (1986) draws on a wide range of literature to demonstrate that there are numerous social, psychological and historical reasons why certain characteristics and behaviours became categorized as learning difficulties. As a result different cultures can be seen to respond in different ways to people who face barriers in relation to thinking, remembering and communicating (Manion & Bersani, 1987; Rao 2001).

Different Rules?

I would suggest that it is because of its normative nature that people are confused by the notion of learning difficulties. Many people assume that it is as an empirical actuality which can be responded to on the basis of proven methodology. Consider the views of Rosa Monckton Monckton) when writing and talking about her daughter who has all or part of an extra chromosome 21 in some of her cells.

Domenica is mentally handicapped. Mentally handicapped accurately describes her mental state.... The word handicapped ...is factually accurate.

In a recent interview for ITV (This Morning April 4 2006) Monckton also explained how her daughter needs support doing things that would come naturally to most children. Here is another normative assumption common to many people when thinking about learning difficulties and issues of impairment. Many people do not consider (or consider it to be

relevant) that everything that a child learns is as a consequence of some level of social support. The nature of all human experience is that it exists through the actions of others. The power to achieve things is not unidirectional; it exists within relationships (Foucault, 1980, 1982), in the give and take between individuals. We choose to downplay this social collaboration, however, when we consider the import of our own lives, but we foreground it in relation to people with learning difficulties. As a society we make much of an individual's independence, and in so doing we fail to recognize that we are fundamentally interdependent (Wendell 1996, Mason, 2000). We assume that some levels of support in specified areas make a person normal and other levels make them worthy of a label. This in turn feeds back into the assumptions we carry about that label and about the individual to whom it is given. In so doing, the individual becomes the problem and not the level of support.

Feeding into Oppression?

The aspect of an individual that is labelled can be seen as part of what Goffman (1963) called the stigma. It is the devalued characteristic that is reacted to negatively by others, causing a tension between the identity an individual's is assumed to have and their 'real' identity. This negative response is a learned response, however, and just as a stereotype must be repeated to be maintained (Bhabha 1994) so too must the negative assumptions about a group or a label. This repetition manifests itself not only in our language but also within our practical responses to individuals who face barriers in relation to thinking, remembering and communicating.

The stigma of intellectual impairment has been consistently greeted by a three pronged social response that Wolfsenburger (1975) called Early 20th Century attitudes, namely:

- 1) Curing the defective
- 2) Sheltering the defective
- 3) Protecting society from the defective.

Sadly, these attitudes are still prevalent in the 21st century. In many countries the child with learning difficulties is still taken away from parents or given away willingly by parents to spend their lives in institutions. In the UK and the rest of the minority world, parents are encouraged to consider killing their foetus on the basis of a statistical probability that the child may be born a person with a learning difficulty. If these 'protective' approaches fail, however, and an individual is born or finds themselves living outside of an institution, then many of them are still 'cured' and 'sheltered' in 'Special' Schools, life-skills courses and day centres. The experience of people with learning difficulties is often one of oppression (Goble, 1998). They are disabled by the social structures and social values that surround them, and they experience this oppression as an ongoing part of their lives.

It is important, too, not to dismiss the constant and extensive support that some people need as a consequence of living with their impairment within their current social context. Particularly, as those around them can be taking regular responsibility for a wide range of decisions and interpretations of feelings on their behalf. If an individual is given this label they will commonly find themselves being assessed and defined within a range of professional discourses, such as medicine, law and social services (Clapton, 2003). From the moment they are identified, within our culture, there will be numerous people who can regularly claim to have an ongoing right of input into decisions about their lives. The list expands and continues throughout the individual's lifetime. And at the point at which any of them make a decision to speak on behalf of the individual they risk denying them. As in issues of bioethics they position themselves as arbiters of others' possibilities.

At the heart of any ethical consideration of issues surrounding learning difficulties is the degree to which individuals with learning difficulties are allowed to engage in the debate. When they do, many people dismiss them as not having enough learning difficulties to qualify for the label. As is clear by the common use of terms other than learning difficulties, the ability of people with learning difficulties to gain respect for their arguments and views is undermined by the fundamental premise that underpins their oppression, namely that they have been positioned at the bottom of the social-knowledge

hierarchy. **We** know more than **them**. And in trying to talk about this issue and mediate its impact, whatever terms **we** use when talking about **them**, this assumed relationship reminds us of this socially-prioritized knowledge imbalance.

Are Labels a vehicle for change?

So, given these concerns about the nature of labels, their impact on users, their reflection of social attitudes and the positioning of people with learning difficulties within our personal and social constructs, is changing a label the ethical thing to do?

There is a history of confrontation over labels. Foreman (2005), for example, outlines the longstanding and ongoing disagreements about the use of ‘mental retardation’ within the US. Much of the drive for change in these battles can come from people with learning difficulties and other service users. Such an alliance was central to the removal of the term ‘mental handicap’ in the UK (Eayrs et al, 1993; Finlay & Lyons, 1998), with the term ‘mental’ being particularly unpopular with parents, doctors and the labelled people themselves (Eayrs et al, 1993). Many people do not give up these labels easily, though. This can be evidenced in the refusal to change the name of the American Association on Mental Retardation (AAMR), and in the finding in the late 1990’s that UK service providers had often stopped using the phrase ‘mental handicap’ while many parents had not (Davies & Jenkins 1997). The media too are often slow to respond. In the US, for example, Haller, Dorries & Rahn (2006) showed that newspapers have only marginally decreased their use of the term ‘handicapped’ despite over 20 years of campaigning against this term by the Disability Rights Movement.

Different terms draw responses from people that are more or less positive (Norwich 1999). For example, in the early 1990s a number of studies, such as that by Hastings and Remington (1993), showed that ‘learning difficulties’, ‘learning disability’ and ‘special educational needs’ were the terms that produced the most positive response in people, yet it is now commonplace for all three terms to be regularly challenged, such as in the four debates mentioned earlier. This change is partly due to an inevitable dissatisfaction with the precision of the label in describing something that cannot be simply described. It

partly results, too, from dissatisfaction with the provision of support services and the attitudes of policy makers, practitioners, the media, and the wider public. It is also a reflection of the changing values of those who create and use the terms. People with learning difficulties are gradually gaining a greater say over their lives. Within the UK, for example, legislation has given them a voice in the decision making process and some control over their own finances; research and self-advocacy has brought individual's life stories to the fore; organisations that operate in their name now assume a need to have people with learning difficulties as trustees; some groups of people with learning difficulties (such as those with the label 'Down syndrome') are regularly included in mainstream schools, and a smaller number have regular paid employment. This however is just the start of what must be an ongoing process. Just as examples can be found to demonstrate progress towards appropriate social support to reduce barriers to thinking, remembering and communicating, there are still far too many examples of where the barriers are being maintained and extended.

As Corker (2000) notes, it is commonplace to find comments about the problems with terms, but changing them creates equal furore. Bolt (2005) suggests that in making the switch many people will see the change as irrelevant and/or confusing and/or ineffectual and/or just political correctness. There is a strong body of opinion that supports the argument that changing terms merely gives into the misguided values that are being confronted. Corbett (1996), for example, argues that the old terms ought to be contested. However, language in use has been shown to have both positive and negative impacts on people's lives (Corker 2000). It is clear that the dominant discourse of the day comes to be seen by the majority as the natural way of things (Gillman et al 2000). As part of the process of creating change in this dominant discourse, language must be persuasive, it must also 'significantly reduce extraneous and erroneous meanings' (Bolt 2005), and reflect the views of those it is applied to (Haller et al 2006).

The words we use cannot be disassociated from the context in which we use them and experience them, and the expectations we bring with us when we do so (Derrida 1976, Bowers, 1984). If we are to have an influence upon the language we use however it is

only through that language that we can expose the thinking and beliefs that underpin our usage. ‘Discourse is not simply that which translates struggles or systems of domination, but is the thing for which and by which there is struggle, discourse is the power which is to be seized.’ (Foucault 1984, p110)

Each time we change a label we re-engage people in this debate about the purpose, form and function of labels. It is not dissimilar to the common business practice of changing the name of a company or a product so that the organisation or product is repositioned in the minds of the consumer, and can therefore re-engage with them in a new way. By debating people’s understanding of the label’s purpose, form and function we encourage them to look at the assumptions that underpin their values. Individuals need to question their assumptions about themselves and the label of learning difficulties if they are to recognize their own role in creating and overcoming barriers in thinking, remembering and communicating. People need to be encouraged to reflect and to be given the opportunity to do so. Many may choose not to do so, of course. They will not see the relevance of the issue to their lives or the need to change. This rump of non-reflexive people can be changed by the ongoing movement of others around them, however. If the dominant discourse moves, so too does the majority’s presumption about what is the natural way of things.

A Conclusion (but not the end...)

Language on its own cannot be enough, but it is the linchpin around which and through which action is formulated and evaluated. It needs to keep moving forward as part of a process interwoven with the actions and values that surround it, reshape it, and are reformed by it. ‘People with learning difficulties’ as my chosen term, is fundamentally flawed, and should be temporary. It needs to change, just as was the case with its ancestors and will be the case with its progeny. Holding onto terms that do not reflect the movement is both counterproductive and a missed opportunity. This is not to say that discussion of the old terms and reclaiming of such terms is not valid, but the priority should be the confrontation of the values and assumptions that underpin our current thinking and actions.

The current aim should be movement towards labels that clearly position the barriers faced by individuals within the social structures around them, not within the individuals themselves. This cannot be achieved through subtle changes to our current terminology. The labels need to move from being a tool of oppression to become a tool of facilitation. They should encourage those who hear them to engage with possibilities. They need to stop encouraging thoughts about **them**, and should instead shift the focus onto **us**.

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ⁱ Note: I have removed a reference to Abberley, P. (1987) The concept of oppression and the development of a social theory of disability, *Disability, Handicap & Society*, Vol 2, No. 1 pp 5-19 from this version of the text. I revisited this paper by Paul Abberley at the end of 2009 and realised that I had used an idea of his within the published version of this paper but not as he had intended.

In his paper Abberley (1987) states:

"What is required is essentially an attitude of ambivalence towards impairment, that is "co-existence in one person of love and hate towards the same object" Concise Oxford Dictionary (1964). Impairment must be identified as a bad thing, insofar as it is an undesirable consequence of a distorted social development, at the same time as it is held to be a positive attribute of the individual who is impaired."(Abberley, 1987, p9)

As a result of misinterpreting my own notes I said:

"Abberley (1987) talks about an ambivalence towards impairment, of 'love and hate towards the same object'. This ambivalence could be to do with not having understanding about the nature of a group or clear feelings towards that group (Soder 1990), perhaps because of the lack of encounters (Vehmas 1999) or perhaps because:

We resist the thought, above all, that in the imperfect bodies and minds of those already so categorized, we are seeing a mirror image of our own. We put away the thought and we put away the people. (Shearer, 1981:10).

Perhaps it is as a consequence of this ambivalence that we more readily define people with learning difficulties by this label, rather than by the many other identities they may have access to, such as 'football fan' or 'computer user' or 'music lover'."(Rix, 1996, p24)

I regret this error not only because I have done Abberley a disservice but also because I failed to explore the subtle tensions between his call for ambivalence and my consideration of the influence of ignorance and fear.