Record

103

File Number

10077

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Title: Who has the learning difficulty?

Original source: Community Living Volume 2 Number 1

Resource type: Written

Publisher Info: Hexagon Press

Publication Date: 01/07/88

Abstract

Mark Burton, a psychologist and service manager with a community support team in Victoria, discusses such terms as "learning difficulties", the problems associated with them, and the use of collective terms for people who have disabilities. In a separate article attached, Len Spriggs responds to Burton's article and argues that it has no mattered what people are called - it has had very little impact on the status and opportunities for people - each change of label is still a label by which WE can describe THEM. **Keyword: Attitudes**

WHO HAS THE LEARNING DIFFICULTY?

Why terminology is still damaging and inaccurate.

Mark Burton argues that the trend towards using the term "learning difficulties" does not solve the problem of labelling clients. He explains why and offers his own alternative.

People can suffer damage through the language and images surrounding them. The way people with serious disabilities are represented can influence the way others understand their requirements for support, thereby opening or closing whole avenues of opportunity. The way people and their disabilities are described is often also a description of action that needs taking. It may also define whom that action is intended to benefit.

If we define someone (as we might have done as recently as 15 years ago) as a 'subnormal patient', we not only suggest that the person has less (sub) worth than others, but we also imply the appropriateness of hospitalisation and of medical intervention. By describing someone as 'mentally retarded' we suggest slowness, and perhaps the implausibility of their aspiring to adult experiences and roles.

Careful

Accurate and respectful descriptions are likely to reflect a person's proper place in the world and the steps the rest of us will have to take to make that participation a reality. Being careful about our language will not by itself significantly affect people with major disabilities but it represents one element in the complex set of changes that will have to occur. It also costs very little.

Many of us thought we 'had it cracked' in 1979-1980 when the term

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"The term 'learning difficulties' is inaccurate - many users have little difficulty in learning."

'subnormality', was dropped and 'mental handicap' took hold. Later I discovered groups of service users who strongly objected to the term, so I shelved any ideas for introducing them to a body like CMH. As one man explained: "It's that 'mental' I can't stand". Besides the insult felt by people who have to wear this label, the term causes dangerous confusion with people who have severe emotional/psychological disorders. Even some health service workers seem to get confused. An academic friend with research interests in social policy invariably introduces me as "Mark, who works in mental health".

Alternative

What is an acceptable alternative? More and more sensitive service providers refer to clients as 'people with learning difficulties': alternatively 'people with learning disabilities'. Neither will do because:

- *The terms are psychologically inaccurate,* defining the problem facing these people as one of learning. Yet many users of mental handicap services have little difficulty in learning. For those who do find learning difficult, the primary problem is often not ability as such, but another function, such as maintaining attention, co-ordinating two sensory modalities, sequencing acts, or something we probably haven't even guessed at yet. Defining someone as learning disabled may write off their learning ability, or may mean we have failed to discern the real difficulties.

- *They are over inclusive,* embracing those who do have specific learning disabilities but without the more generalised skill impairments that

characterise people with mental handicaps.

- *They define the action* services should take in terms of learning - indeed it comes out of the 1981 Education Act. In other words the terms *fail to recognise the social nature of handicap*. Defining the problem in terms of a person-centred difficulty focuses efforts towards an agenda of skills acquisition and technological inputs to aid learning. Effective teaching and skills acquisition is important, but only as a means to an end - an end that involves participation in the everyday life of the real world. Only when we have worked with a person to open up social opportunities does it make sense to start teaching skills. Failing to realise this will mean we waste time, both our own and our clients'.

Any such collective term defining this group of people would have to be respectful, would have to encompass the diversity of disabling conditions, and would have to suggest appropriate action.

"It might be no bad thing if there were recognition of the continuity between ordinary and severe intellectual disadvantage."

Most of the time a collective term isn't necessary - only when discussing whom the services are meant for, or in explaining whose oppression we need to reverse. There is something to be said for refusing to simplify or abbreviate and for using the clumsiest term possible: starting with 'people' and incorporating references to the nature of the disability and the social handicap.

I have yet to find a wholly adequate way of referring to the people I work with. Since visiting Australia last year, I have tended to use a term almost universally used there (even among taxi drivers): 'people with intellectual disabilities'. This strikes me as more accurate, and offers less possibility of confusion with mental illness. However, I find it still too individualised, locating the problem in the person rather than in the relationship that person has with the world.

Recognition

A Melbourne-based self-advocacy group calls itself 'REINFORCE': Union of Intellectually Disadvantaged Citizens'. This describes the nature of the oppression, is neatly ambiguous about the relative contributions of disability and discrimination to the disadvantage and it affirms a person's worth. The only problem is that 'intellectual disadvantage' might apply to a large proportion of the general population, denied access to opportunities for intellectual development. But then it might be no bad thing if there were more recognition of the continuity between ordinary and severe intellectual disadvantage, or if the general term were appropriated by those most oppressed by the way our society homogenises human diversity.

Mark Burton is a psychologist and service manager with a community support team.

NEUER MIND THE SERUICE FEEL THE LANGUAGE!

Len Spriggs

"Sticks and stones may break my bones but names will never hurt me."

Mark Burton is right to draw our attention to the fact that, contrary to the proverb, names may indeed hurt. He is also correct in reminding us that the way people with serious disabilities are represented can, or perhaps more correctly may, influence the way others understand "their requirements for support". However, there is one major problem with the argument. It clearly matters not a jot what particular label we attach to people with a mental or intellectual impairment, for it has had very little effect on the status, opportunities or life-style of the people so labelled. Families still bear most of the burden of looking after the majority of people with an intellectual impairment and service provision, in general, is minimal. Indeed we have become so concerned with disablist language that we seem to have forgotten, perhaps conveniently, disablist services.

Since the turn of the century, if not before, we have been preoccupied with inventing appropriate labels by which <u>we</u> can describe <u>them</u>. Each change of label has been accompanied by what is, in effect, an identical argument - change the label and, ipso facto, there should follow a change in the status and opportunities of those we label. But can we say that there has been any real change? The answer can only, in all honesty, be no. Mark Burton is right when he says that, "being careful about our language will not by itself significantly affect people with major disabilities". The only problem is that he overstates the case. Being careful about our language clearly has a negligible effect.

Labels are not totally irrelevant, of course, because they do tell us something about the attitudes and assumptions of those who use them and that is why we have to think very carefully about how we use such language. Let us take some of the terms used by Mark Burton; e.g. "groups of service users" and "users of <u>mental handicap services</u>". I find it difficult, especially as we are asked to think carefully about our use of language, to know what "mental handicap services" means precisely. I know, however, what message it carries. And that is simply that <u>we</u> provide the services for <u>them</u>. <u>They</u> make use of the services <u>we</u> offer. The image is reinforced when Mark Burton talks about "the people I work with". Might it not be more appropriate, if there is a genuine commitment to change the status and opportunities of people with an intellectual impairment to talk about working <u>for</u> and not just <u>with</u>. The Oxford English Dictionary defines 'service' as "being servant, servant status". Maybe service providers should begin to question who plays the role of servant and who is the master/mistress. This isn't easy, of course, and, no doubt, will be experienced as threatening. Professionals are loath to lose <u>their</u> status, and service managers must, of course, <u>manage!</u>

Rachel Hurst, Chair of Greenwich Association of Disabled People, talking about physically impaired people and the development of Centres for Integrated /Independent Living, says, "The contradictions are sharpening up. Disabled people want less and less people doing things for them ...
There really is a revolution going on. Most professionals don't understand it. They have no information about this movement because it is outside their professional experience", and she makes the point that, "We wanted to get rid of that form of welfarism based on the perception of people as passive recipients. That had to be challenged". That challenge is inevitably and

invariably more difficult to mount by people with an intellectual impairment, but simply changing what we call them doesn't even begin to make that challenge. It is a challenge to the power of those who run the services. It is about control. Control of agencies and services by people with an intellectual impairment.

We are told that "most of the time a collective term isn't necessary - only when discussing whom the services are meant for, or in explaining whose oppression we need to reverse". The implication, of course, is that the services offered are not part of that oppression. Such an assumption is, to say the least, questionable. Mark Burton finds the term "intellectual disability" too individualised "locating the problem in the person, rather than in the relationship that person has with the world". What world? Whose world? What relationships? Burton is closer to the truth than he perhaps realises, for it is professionals who shape that world in the way they design and manage services. For people with an intellectual impairment the problem does, indeed, usually lie in their relationship with that world!

There is a final irony here. Rachel Hurst, talking about CILs and the 'disability movement', describes it as the last civil rights movement. Perhaps, then, a leaf needs to be taken out of the black consciousness movement. It is only when they developed the collective term 'black' that the civil rights movement took off. The term 'black' precisely ignores individual differences and highlights the common source of their oppression - the colour of their skin. This is not to say that there are no individual differences in intellectual capacity or degrees of intellectual impairment which can be located, as Mark Burton suggests on a continuum (with us at one end and them at the other?), but such a continuum then conveniently fails to distinguish between the oppressors and the oppressed. One doesn't wish to appear overly critical of Mark Burton's sentiments. It is just that sentiment hasn't helped a great deal, as early civil rights campaigners found out. It is political action that matters and political action means identifying just who the oppressors are! Professionals must facilitate the revolution which Rachel Hurst talks about and the goal must be the 're-labelling' of professionals and not simply the 're-labelling' of their 'clients'.

One could, of course, engage in further intellectual exchanges about the niceties of language. My point is that such intellectual word games are virtually pointless - if we are honest they have achieved very little. However, it is very difficult not to join in such games, especially when the rules are so clearly transparent. Yes, we must recognise the social nature of handicap. However, it is not just that some people are intellectually impaired or intellectually disabled or, indeed, intellectually disadvantaged, but that they are intellectually excluded, just as they are socially excluded. Their intellectual qualities are considered unacceptable and inappropriate. If a clumsy term, as Mark Burton suggests, is needed, what about 'people who are intellectually and socially excluded'. The question then becomes who are the gate keepers and who really are the intellectually impaired?