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Abstract

This article is written in the form of a letter, and slightly tongue-in-cheek, about the jargon and labelling used when referring to people who have disabilities.
Keyword: Attitudes

What's in a word?

Dear Sir,

This is written tongue in cheek. Or rather tongue in tooth. Something's been niggling for a while, but it became particularly inflamed after reading the description of normalization — what it is and what it isn't — in the first issue of *Community Living*.

What's niggling is the way we use language in the field of mental handicap. The normalization piece was a classic case in point. It was very clear

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and succinct within its own terms of reference—but it reminded me of the religious debates I used to have in my youth, about what was, and what wasn't, the 'true' scripture, the 'right' religion. All too often the argument seemed to be about the *definition* as an end in itself—it seemed to have little effect on the *action*, the way people behaved. You were either true believers or your weren't, and justification was by faith alone.
Yet the people are actually more elusive, 'messier' then any concept, however well intentioned. This applies to people who have mental handicap as much as any other group. The very concept of mental handicap itself is a relative one, as well as being an inherent oversimplification. We justify it as a necessary shorthand, a common currency that we need to have to deliver services to people who have special needs. But we all know that in the money market the currency system can become the master, not the servant. The same danger applies in mental handicap—the definitions are not neutral, they have causal effects. The label carries with it certain expectations—particularly about what people can't do. People are treated accordingly, and respond accordingly—thus 'confirming' the expectations—a classic self-fulfilling prophecy.

Language tests
So what to do about it? My proposal is that we adopt a variety of tests which we should stringently apply to our own language, and the language of our fellow professionals. The first test I have already mentioned—the **true believer** test. Evangelical blindness is as dangerous in the field of mental handicap as anywhere else. Also, challenging it within the field might heighten our awareness of the need to challenge it everywhere.

Another test would be the **perishable food test**. Every concept, every report, every conference, should have a sell by date, together with storage and cooking instructions. All words should carry a declaration that they were free of artificial preservatives, additives and sugar junk—and if not, a health warning that they were likely to silt up in your mind. A frequent intervals, all ideas that outlive their usefulness should be destroyed, and replaced. No idea should be immune from this process.

Discomfort
To some extent this is already happening in the field. The very term 'mental handicap' sits uneasily with others such as 'severe learning difficulty' (the education jargon), or 'challenging behaviour', the latest American import. Such discomfort is all to the good, as long as it is permanent, as long as no particular label gains the upper hand.
Then we should apply the **precision test**. Slack phrases are a sign of corroded

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minds. Too often we assume we all know what we mean by terms like 'core and cluster' and 'community care'. Yet I have heard core and cluster applied to a 25-bedded hostel (the cluster) in the grounds of a large hospital (the core) and community care applied to describe a situation where community nurses 'occasionally pop in' to talk with unvetted and unsupported landladies. Phrases need persistent challenge, so that the degree, the precision, the context, the accountability and the purpose of each term is made clearer and clearer. The reductive challenge leads in the right direction—to the individual for whom, to whom, and with whom the ideas apply. Finally, we should apply the

"The final question on any service has to be, does it apply a speedy, sensitive and appropriate service to the people who need it most?"

bureaucracy test. There is a bureaucrat in all of us, someone who lurks in our psyche for whom a sense of order is the most important virtue of all. Challenge and change are inherently confusing and unsettling. I am wary of people who enthusiastically espouse their virtues—they often are people who have won a power struggle, and want to assert their ideas , their faith. It is only the orthodoxy that is new. They don't want *that* challenged.

If they adopted new ideas, it is with a sense of relief that a new order can be imposed. It is imposed with speed and thoroughness, and quickly becomes an end in itself. Those things that can be easily measured take precedence over others, and everything is anyway turned into figures. These can then be produced to say how often it is happening , and how many people have been involved. They can be trumpeted and paraded, yet the Emperor may not have any clothes at all, or at best be still clad only in vest and underpants.

Paper exercise
This is my fear, about for instance the independent program plan (IPP) system—a jargon for a careful plan produced with the person—that it becomes a paper exercise, divorced from the reality it was meant to change. I have an image of a person attending an ATC. Knocking on the door of the manager's office in distress and being told to go away because the manager was busy—writing up his IPP. Of course, it couldn't happen, could it? Yet, for IPPs or any other service, the final question has to be, does it actually provide in a real way, day to day, a speedy sensitive and appropriate service to the people who need it most? So here's hoping that in five years time, normalization, IPPs, core and cluster, center of excellence, behaviour modification and all the other vogue terms will have taken their place alongside Mongol, low grade and idiot in Longman's revised edition of obsolete words. It is the task of language to be chasing the future, and to be constantly dissatisfied with itself. That way lies the freedom for the people we care about.

Yours sincerely,

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