

POINT OF VIEW Dumping Old Terms

G. McDONALD,¹⁾ J. GOLLOGLY¹⁾ and D. N. MACKAY²⁾

INTRODUCTION

A month ago, we went rummaging in the mental health cellar. In a basket, beneath linsey-woolsey petticoats, leg-iron, leather muffs, emetics and a blistering cup, we found a pile of labels: madhouse, lunacy, mindless, fatuous, idiocy, furious and many more. Further along, beside a bowl for stirabout and a bottle of chloral hydrate, there were more: amentia, asylum, imbecile, low grade, feebleminded, amongst others. Over by the far door, on top of an old Stanford-Binet, were a few more: mental subnormality, severe subnormality, defective, retardation – less dusty, certainly, but with all the appearance of having been discarded for good. As we left in the dankness and the smell of the gloomy cellar, a glass syringe rolled off a pharmacopoeia and splintered on the floor. There was no doubt about it: the obsolete, often iniquitous and cruel "scientific contrivances", the crude medicines and outdated labels had been justifiably dumped.

Back in the office, we looked at the current labels, words and phrases stacked beside the computer terminal. Developmentally delayed, intellectually disadvantaged and Down's Syndrome caught our eye. We hope they'll have a longer shelf life than some of their ephemeral predecessors, a quite minor reason being that, if we continue to discard, we'll run out of vocabulary. Workers in the U.S.A. seem to be enthusiastic about dumping: hostel has become community residential facility; hostel staff have become care-givers; nurses, a rare species, may still be lurking in beleaguered, fortress-like institutions; disobedience has become non-compliance; bad has become maladaptive; superintendents have become directors; good or desirable has become adaptive.

Will the constant, perhaps compulsive, search for synonyms, euphemisms and new labels continue? Whatever the answer, we are intrigued as to why, in mental handicap more than anywhere else in mental health in general, we have become so quickly dissatisfied with words or terms. Of course, some of us are dead set against labels of any kind: hang DSM classifications round people's necks and they are no longer people, or so the argument goes. Three main reasons spring to mind for our chronic dissatisfaction: certain words or labels offend sensibilities; they do not quite capture the scientific nuances and niceties we have clearly in mind; they arouse misleading "perceptions" of the mentally handicapped.

OFFENDED SENSIBILITIES

For years, we were content to say, without thinking very much about it, that, since odium accrues to certain labels they have to be changed in order to restore dignity and worth to affected individuals and their families, and to alter others' "perceptions". If the parents of handicapped children find the label "mental subnormality" unpleasant, then we shall certainly not use it. Unfortunately, we have to put something in its place. Why should a fresh word, label or term eventually

1) Tower Hill Hospital, Armagh, N. Ireland 2) Muckamore Abbey Hospital, Antrim, N. Ireland

become undesirable at best, repulsive at worst? For a start, mental deficiency, amentia, mental subnormality and the like are not diagnoses and therefore carry no information or implications about aetiology. They simply serve to denote a mixed bag of individuals whose characteristic is that they are not as bright as most others. However, from that pot-pourri we can extract labels which endure because they are diagnoses which bear information/implications about both aetiology and treatment (e.g. phenylketonuria) or information/implications about aetiology but not treatment (e.g. epiloia).

We shall not pursue this particular line since others (e.g. Eysenck, 1960) have done so much more competently than we can. What we do want to suggest, however, is that in addition to the lack of satisfactory information in labels, criticisms of one profession by another have perhaps contributed more than we would expect to the odium-making process. In the sentence, "John, who is mentally defective and mongoloid, has been a long-stay patient in this hospital for 30 years" (taken verbatim from an old file), the total effect is much greater than the sum of its parts (four, possibly five, unpleasant, undesirable, inappropriate labels) in that nearly all psychologists would renounce the explicit but dated acceptance of the medical model. Thus it may be easier to offend the sensibilities of professionals than those of parents and relatives of the mentally handicapped. If so, it may be that we, as professionals, start to make the odium and so influence others against a particular label, word or phrase. An extreme and perhaps misleading example of this occurred when Doman (1974), in a sweeping revision of our admittedly dodgy aetiological classification systems, suggested that nearly all mentally handicapped children, including Down's Syndrome were, in fact, brain damaged.

But hang about a bit. If phenylketonuria and epiloia are going to stay, why has the 'mongol' label been thrown in the cellar? (Actually, it still survives in a few places such as modern medical encyclopaedias, e.g. Wingate, 1985). Immediately associated with the term are, for example, the following: trisomy, translocation, mosaic, amniocentesis, behaviour modification effects, increased longevity, plastic surgery etc. It seems to us a bit curious that, with all these exciting advances in aetiology, health and management, the label should have been discarded in favour of Down's Syndrome with its explicit disease connotation. The establishment of Down's Syndrome Associations throughout the country by concerned parents may have had something to do with it: quite understandably, these parents may have felt that the word 'mongol' was all too easily interchangeable with other less desirable labels, that it was dated, that it was redolent of a bygone age.

Much more curious, in view of the haste with which we dispose of words, labels and phrases, is the stubborn survival of "institution" in our vocabulary. Psychologists and others have argued for some time that an institution is a bad thing that does bad things to its residents. Well, it could be that it's there to be knocked down. By adding a prefix and lengthening the word to deinstitutionalisation, we show that we mean business in a fairly radical way. Add 'normalisation' and the picture of massive reform fills out. Add the concept of the developmental model and the picture is all but complete. However, as we've tried to suggest in a rather tentative way, the institution may not, after all, disappear (McDonald et al 1987 a,b; Gollogly et al, 1987). If it doesn't will the label go instead?

At present, we gather some professionals are toying with terms such as "exceptional" and "children with special needs", surely quite neutral, if not attractive, labels. Since 'exceptional' means anything that deviates from a real or imagined norm on any dimension whatever, it tells us nothing. Since teachers could

justifiably argue that all children have special needs, that label is also pretty empty unless we add something more specific. To say that "exceptional children are children with special needs" hardly makes the category any more precise. What sort of shelf life would these terms have?

INADEQUATE LABELS

There is an unwelcome air of permanence about a term like "mentally sub-normal": once defective, always defective. When work such as that of Fisher and Zeaman (1970) is reported (to the effect that mental ages of many handicapped people continue to rise well after the age of 20 and 30) we realise at once that that was probably one main reason why psychologists became dissatisfied with labels and terms. The defective plods along behind, falling further and further away. The developmentally delayed individual, on the other hand, plods along behind but could eventually begin to close the gap. This is a very important conceptual difference.

We (the writers) are in a somewhat different sense plodders as well. We are certainly not theorists or scientists. And we must admit there are times, especially when we're physically guiding a profoundly handicapped person's hands through self-feeding motions with a spoon, or teaching a severely handicapped child to imitate clapping movements, when we find it difficult to become animated about the deficit/lag controversy. But we do agree, of course, that once a term fails to reflect current theory it ought to be replaced by something more appropriate. Almost as an after-thought, what happened to "slow learner"? Is it still around or is it below?

"PERCEPTIONS" OF OTHERS

The main reasons why we can identify mentally handicapped or developmentally delayed individuals is because they are not as bright as most others. Tautologous, of course, but worth saying for a number of reasons. If we believe it is worth identifying the mentally handicapped (prevalence surveys etc.) for whatever reason, we have to use some measure of intelligence, however rough and ready the instrument and however controversial the concept. Using a happiness-unhappiness dimension will not do since intelligence and happiness are not renowned for a high correlation.

It seems perfectly reasonable to us to seek a new way of defining that group we currently call the mentally handicapped or developmentally delayed, particularly since, in the vitally important attempt to reintegrate formerly institutionalised residents into society, and in other community experiments for that matter, the IQ is a useless predictor. The relatively recent switch in emphasis from intelligence to social competence is welcome but, perhaps because there is a high correlation between the two, we seem to revert to the former in questions of definition and identification.

As to perceptions of the mentally handicapped and the mentally ill, there must be very few other minorities that have so often been cast in an unfavourable light. In literature, from classical to light, in drama from old to new. The "mad" person not infrequently makes an appearance as someone to be feared, sneered at, or ridiculed. In pot-boiler suspense films, the "mad" person was as much a cliché as the isolated, gaunt house, weak moonlight, creaking floorboards, unexplained slivers of light under doors, distant muffled screams and the rest. The trouble with clichés is that they endure.

Professionals know better. But they have, in the not too distant past, made big mistakes. For example, the eugenics movement, which promised so much, was based on misperceptions as absurd as those we have just discussed. And if we can do it once, we can do it again. Leaving to one side these gross misperceptions (and admitting that at least some will persist, whatever we do), we are left with quite a few that can still be damaging. Psychiatric texts used to define profoundly handicapped children (idiots) in a series of negatives (cannot . . . is unable . . .) so exhaustive that it was a wonder the children could live at all. Not only were they "useless" there was no point in trying to teach or train them to do anything. (However, there were honourable exceptions: elsewhere, we have argued that Mitchell - 1864 - anticipated many of the principles of normalisation and de-institutionalisation, McDonald et al., 1987). Such misperceptions may encourage inertia, so that various negatives become self-fulfilling prophesies. Again, there is no need to elaborate, since these views have been widely discussed by others.

DISCUSSION

We sent a very early draft of this paper to a colleague in another discipline. His comments are summarised as follows. Some labels (e.g. encephalitis lethargica) can be safely consigned to the cellar because what they denote no longer exists, or is rare. However, many of last century's lunatics are today's mentally ill and mentally handicapped, the main difference being that nosology is now more advanced. Certainly, odious labels and words should be dumped, but the replacements will themselves become unpopular, primarily because the combined efforts of all professionals have so far failed to make progress in "doing away" with various forms of mental handicap and mental illness. "Expert" implies that we should not only know a good deal about what causes mental handicap but also about making it good. Statistically significant achievements in, for example, self-help skills may fall far short of the expectations aroused in parents and others by the very language, labels and phrases we use. Thus, also, the term "developmentally delayed" may hold for many people the sort of promise that will never be fulfilled. Punctilious avoidance of taboo words such as "defective" may be due more to superstition than heightened sensibility in that we believe, or make ourselves believe, that the use of "new" labels will bring about the sort of improvements unachieved with the old (Sweeney, personal communication, 1986).

Predicting that the labels "clinical psychologist" and "psychiatrist" will join the others in the cellar within the next fifty years, Sweeney drew our attention to Tukes's bellicose questions in 1859 (Cunynham Brown, 1908).

In this paper (entitled 'Lunatics as patients not prisoners') Sir John Bally Tuke asked whether, commensurately with the increasing expenditure on the care and treatment of lunatics, even at that time enormous, there had been achieved an understanding of the hidden processes which underlie the insanities, and some means of arresting their occurrence, such as the rate-paying citizen might reasonably expect . . . These questions Sir John Tuke answered by a decided negative . . . (Pages 532-533).

Sweeney makes a rather poor devil's advocate. For a start, he doesn't know the basic differences between criterion references. More important, he is clearly ignorant of the advances clinical psychologists and others have made, advances that have been well documented (e.g. Eysenck, 1979; Clarke and Clarke, 1974). Finally, he does not offer a plausible explanation for our perennial dissatisfaction with words to do with mental handicap.

If we glance at allied fields, the picture becomes curiouser and curiouser. "Autism" remains as a label. So does "schizophrenia". The interminable wrangle about differences between reactive and endogenous depression drags on. These labels have survived for a long time. Will they, too, become obsolete?

We have no regrets about throwing old, misleading or "bad" words, labels and phrases into the mental health cellar. But we are puzzled at the rate at which we discard them. It seems to us, for example, that the International Classification grades (profound, severe, moderate etc.) won't be around for too long. What will the word smiths offer in their place? If the cut-off points remain tied to standard deviations of the most frequently used tests, what explanation will be given for the changes in terminology? Simply to say that they're dated may have intuitive appeal, but is that enough?

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