

Terminology to benefit children

Terminology means 'a set of words used in a specially understood or defined sense'. From the standpoint of an international journal welcoming English language material from all over the world, it is apparent that widespread differences in meaning and uses of terminology exist in the field of developmental medicine. Differences in terminology matter, as Bax and Mac Keith¹ commented, 'First, foremost, surely, is how careful we must be in our language. If words are used... (that) confuse us they may in fact harm the patient'.

There are three main areas where terminology has a powerful effect on the lives of children with disabilities. Firstly, when a label which is used to describe characteristics of a health condition is used in a derogatory way, the child may experience distress and an increased feeling of exclusion. Unfortunately, when diagnostic labels are attached to a condition associated with disadvantage, stigmatism readily occurs. This even happens when a term is beneficial to the individual as in the word 'idiot', which seems appalling now, but originally described prisoners with learning disabilities bestowing on them the advantage of being offered care rather than punishment. Likewise, 'spastic', the clinically useful term meaning hypertonic, has developed an alternative unpleasant usage.

Language is a sensitive issue and poses delicate questions for authors and editors. For example, a frequent difficulty arises when a term such as 'mental retardation' enjoys common usage in some countries but is considered negative and inappropriate elsewhere. In the UK the alternative phrase 'learning disability' is favoured by paediatricians, children, parents and the Department of Health. However, the World Health Organization uses 'mental retardation' in its ICD-10 classification (WHO 1993)². Many authors are therefore reluctant to relinquish a term which is widely used in international scientific language. This journal encourages the use of 'learning disability' together with a footnote explaining its equivalence in meaning to 'mental retardation'.

Secondly, confusion about certain terms may frustrate scientific research into childhood disability as criteria for defining study samples may lack consistency. For example, specific learning disorders in the UK (failure in an area of academic achievement such as reading or arithmetic) are termed 'learning disabilities or disorders' in North America – the very term used in the UK to denote generalized cognitive impairment. Such international difficulties are illustrated in a recent note from a paediatrician from the southern hemisphere concerning the use of 'mental retardation'. She was happy for it to be replaced with 'intellectual disability' but not with 'learning disability' because she felt that it meant such things as dyslexia and did not include what people in her region refer to as 'intellectual retardation'.

Even the UK-preferred term 'specific learning disorders' has shortcomings. As Whitmore and Bax³ discuss, the term

'learning' implies acquisition of academic skills and traditionally excludes other 'learned' behaviours such as attention and moderation of activity level. Furthermore, ironically, the concept that disorders are 'specific' is at odds with the clinical picture of comorbidity. It is well recognized that children with one specific learning problem often have another; for example, dysgraphia as well as dyslexia. Whitmore and Bax suggest that an aetiological approach might be more helpful clinically, perhaps using the term 'neurodevelopmental dysfunction' which signals the role of the nervous system and of development in the evolution of the problems. Whatever terminology is chosen, authors should define their population.

A third area in which terminology impinges on the welfare of children lies in the allocation of resources. In some circumstances, a health condition defined in a certain way confers specific entitlement to benefits and services. In North America, largely because of dislike of the term 'mental retardation', the Association for Retarded Citizens (Arc), a parent-based organization, is considering whether to change to an organization representing people with developmental disability. However, according to federal policy, individuals with mental retardation qualify for special education whereas those classified as having developmental disabilities may not. Clearly, decisions to alter terminology should not be taken lightly.

Although terminology may be refined and rationalized, disablement will continue to exist – irrespective of labels. The problem is not only an issue of language but also, and mainly, an issue of the attitudes of other individuals, society, and health care professionals towards disablement. Disablement is in the eye of the beholder and takes no account of the person's inner world or the concepts an individual may have of him/herself. Many persons who have a physical or psychological impairment and appear to be at grave disadvantage in performing everyday tasks do not regard themselves as disabled. What is needed to benefit children, in addition to a change of attitude, is courteous language together with correct content and usage.

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References

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