What's in a name? Disability terminology for writers and editors

Tom Shakespeare

Anxieties about disabled people often coalesce around the appeal 'But what do we call you?' Nobody wants to give offence, and there is a fear that disabled people are very sensitive.

Traditional disability words – like 'spastic' or 'Mongol' or 'retarded' or 'deaf and dumb' – are now rightly regarded as offensive. There's also a hint of a suggestion that concerns about the status and treatment of disabled people are really just another aspect of 'political correctness'. I've never heard anyone use terms like 'vertically challenged' except in jest. When people talk about 'differently abled', it feels like a slightly misguided liberal attempt to say that everyone has things they are more or less good at, whereas disabled people would rather shift the emphasis to the ways that society treats us.

Generally, the terms 'disabled people' and 'people with disabilities' are preferred, depending on whether you are in Britain (disabled people) or the United States and other English-speaking countries. The query about terminology is a useful one, because it gets to the heart of the complexity of disability.

The history of disability terminology

The idea that everyone with some sort of physical or mental impairment can be categorised together is rather new in human history. Prior to the early 1900s, it would have been unusual to have thought of all these people with so many different experiences as having anything in common. A variety of words were used: 'feeble-minded', 'cripple', 'blind', 'insane'. It's interesting to see that most of these terms would be considered insults today. The underlying point is that disability is very diverse. The body or mind can be affected in many different ways. Some conditions are usually obvious at birth – for example cerebral palsy or Down syndrome. Some issues become evident when a child does not develop like other children – for example, autistic spectrum conditions. Then there are traumatic injuries such as head injury or spinal cord injury that strike out of the blue, often affecting active young men. Some adult illnesses are episodic or degenerative – like depression or multiple sclerosis. Finally, there are conditions associated with ageing, such as stroke or dementia. As well as these differences of onset, it's also obvious that some disability is visible – such as restricted growth – and other forms are invisible – like epilepsy.

About the author

Tom Shakespeare FBA is a social scientist and bioethicist who has been writing about disability for nearly 30 years. He is currently Professor of Disability Research at London School of Hygiene and Tropical Medicine. Most recently, he worked at Norwich Medical School and before that for the World Health Organization. He has written or edited a dozen books and over a hundred papers.

This diversity of disability explains why it took centuries for 'disabled people' to be considered as having something in common, regardless of our differences. It's probably true to say that it took even longer for us to think of ourselves as one community. Why would someone with paraplegia think they had anything in common with someone who experiences mental illness? She might say to herself 'I may not be able to walk, but at least my mind is working just fine'. When my team conducted research with people with restricted growth, many of them insisted: 'I am different, not disabled.' A government research project in 2003 found that more than half of those who could be defined as disabled do not think of themselves as disabled.[1] This is because disability is a stigmatised identity. Many do not want to be categorised in a way which seems limiting or negative.

In 1915, the word 'handicap' started to be used, mainly of children, and in Britain and America it was more and more commonly employed to connote people with a range of impairments. Around the same time, 'disability', which had previously been used to mean legal restrictions, was transferred for use as a collective noun. In the 1970s, my father, a disabled doctor, had the honour of being appointed a vice-president of PHAB (Physically Handicapped and Able Bodied), a club which brought together young people with and without disabilities to socialise. But as the disability rights movement became stronger, so the term 'handicap' became associated with outdated approaches. A false etymology associated the word with begging, and by extension charity, to which the new activists were vigorously opposed. Increasingly, like 'homosexual' as a term for gay people, 'handicap' became an inappropriate term for referring to an individual or a group.

Outdated terms	Preferred terms
Handicapped/Crippled	Disabled person/Person with disabilities
Invalid	Person with chronic illness
Retarded	Person with learning difficulties
Spastic	Person with cerebral palsy
Deaf and dumb	Deaf or hard of hearing person
Mute	Deaf person or person who has no speech
Mad/Crazy/Psycho	Person with a mental health condition/Service user/ Person with schizophrenia

'**Disabled people would rather shift the emphasis to the ways that society treats us.**'

Models of disability

Back to the split I noted in the outset. Why does most of the world prefer 'people with disabilities' while in Britain 'disabled people' is preferred? The reason comes down to the social model of disability, which was developed in Britain in the late 1970s by a radical group called the Union of the Physically Impaired Against Segregation.[2] This posits that people are disabled by society, not their bodies. It shifts attention to barriers – physical, cultural, political – which make it harder to have a different body or mind. Language itself is one of those barriers, particularly mocking or insulting language. Globally, people prefer to adopt 'people first' language. If you shift from a British to a global frame you have to change your language in order to signal that you are progressive. I work in international development, and I have had to relearn 'Organisations of people with disabilities', reduced to the acronym OPD, whereas for the last 30 years I have been referring to 'Disabled people's organisations', or DPOs.

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Disability identity

Through activism, a strong disability identity has coalesced. Disabled people are in a position to insist on being called what they want to be called. When I write 'Deaf people', I follow best practice stemming from people who cannot hear and use sign language, and who self-identify as a linguistic minority. For example, I learned recently that it has become preferable to say 'Autistic people' not 'people with autism'. This is because people with that lived experience feel that it is a major part of who they are, not just a condition they have. While 'neurodiversity' as a concept about humanity has been around for about 25 years, I notice that people now increasingly proudly refer to themselves as 'Neurodivergent'.

Finally, many people now talk about 'ableism', by which they mean discrimination against disabled people, particularly through language and culture. It seems to have taken over from 'disableism', which meant very much the same thing. In this lexicon of disability identity, the people I have always thought of as 'non-disabled people' are now dismissingly referred to as 'ableds'. I have written about the dangers I see in a disability identity politics. I consider disability is the combination of the individual and the structural: we are disabled by our society and by our bodies. In fact, this is what most people think.

I believe most disabled people want to be known as people first, and to connect to other people, disabled or not. They do not want to join a ghetto. But, it has to be admitted, I am 55 next birthday, and language changes.

Notes

1   Disabled for Life? Department for Work and Pensions, 2003.

2   en.wikipedia.org/wiki/Union_of_the_Physically_Impaired_Against_Segregation

Resources and links

CIEP Dignity Policy. ciep.uk/standards/dignity-policy

Scope. End the Awkward. scope.org.uk/campaigns/end-the-awkward and Social model of disability. scope.org.uk/about-us/social-model-of-disability

Equality and Human Rights Commission. Disability reading list. equalityhumanrights.com/en/our-research/reading-lists/disability-reading-list

GOV.UK. Inclusive language: words to use and avoid when writing about disability. gov.uk/government/publications/inclusive-communication/inclusive-language-words-to-use-and-avoid-when-writing-about-disability

British Council. Promoting inclusion. britishcouncil.org/sites/default/files/guide-disability-equality.pdf

Conscious Style Guide: consciousstyleguide.com

Written by Tom Shakespeare

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