

Disability-friendly language: human rights imperative or game of linguistic leapfrog?

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Frome, United Kingdom, August 28, 2010.

'I am not a disability, I'm me. I have dyslexia and I've had polio but I'm not 'a dyslexic' or 'a cripple' I'm me', John Swan, 14 in *What it's like to be me* Exley (1981) quoted in Reiser and Mason (1990)

Introduction

My enthusiasm to write this paper was mainly driven by two things: Firstly, the horrific experiences of disabled people around the world and secondly, of the negative phraseology used by some people to denote disability and those who have direct and personal experiences of it. It would be easy to frown, wince or smile at such terminologies. But consider when you last heard, read or used words such as 'demented' schizo or cripple? The fact that some of these derogatory terms are 'inadvertently' used even within disability organisations globally, and have even entered dictionaries and modern parlance – in the process of becoming colloquialisms used in jest – indicates how language, can, unwittingly embed stigma. Therein, I recognise, sits a huge challenge for me to take a stand to make a case for the preferred, disability-friendly language without the risk of being interpreted by others, including some disabled people, as being politically correct, trident, polarizing, or even Stalinist. It is an enormous and sensitive topic that either requires a certain arrogance to tackle, or a measure of trepidation to attempt. With a combination of both such arrogance and trepidation, this paper breaks the ground for a discussion which has been long overdue in organisations or settings where such discussions are yet to take place. This paper discusses the absolute imperativeness of disability-friendly language as a human rights issue, not a vain pursuit of cheap political correctness, and that the inalienable right to choose how they want to be described is one that disabled people do not share with their oppressors, non-disabled people.

The paper begins with an acknowledgement of the sizzling debate that disability terminology sparks off within and outside of the disability movement as well as a definition of disability, offering a critical analysis of the power of language in shaping thoughts and attitudes. It elaborates, with examples, the interplay between language and social relationships as well as language and politics. An admission of the dynamism of language is offered, with an honest rejoinder that what is most important, though, is attitudes and not words.

This paper will argue that professionals and other disability experts (often with no personal or direct experience of disability) are part of the problem of discriminatory attitudes and unequal treatment. It encourages disabled people to exercise unrelenting vigilance against oppressive tendencies of the dominant culture. It calls upon disabled people to emancipate themselves from false consciousness and dual identities, to identify themselves openly as disabled and to guard against resignation in a world where rights have to be constantly won.

The think-piece concludes that the world we live in needs constant deconstruction and reconstruction, that we can improve the quality of all our lives through being proactive in understanding and getting rid of our own ignorance, but also through better policy and changed practice, and that the recognition of the central role language plays in this improvement is imperative.

The offending disablist words list and a corresponding guide to what disabled people and their true allies consider to be inclusive language are annexed.

UNCRPD and the preferred terminology

I am acutely aware of ongoing debate, both in and outside of the disability movement, concerning the use of appropriate terminology to describe people who have impairments and who are disabled by society. Organisations working with and for disabled people should carefully consider the implications of adopting particular terminology.

I deeply respect the choices that disabled people make in choosing how to best describe their identity and experiences. I recognise that some people prefer to use the term 'people with disabilities' while others prefer to use the term 'disabled people'.

I understand that the use of 'disabled people' within any organisation will be contentious to some. My decision to use this terminology has been informed by the disability people movement in the UK. The term 'disabled people' is preferred to "people with disabilities" in the UK because it is based on the idea that disability stems from the barriers disabled people face on a day-to-day basis - prejudice, negative stereotyping, lack of accessible transport, housing and information and a lack of understanding of the needs and rights of disabled people. The argument is that the term 'disabilities' when used in this context refers to a person's medical condition and thus confuses disability with impairment. In addition it denies the political or 'disability identity' which emerges from the disabled people's civil rights movement in a similar way to the Black and Gay political identities.

Those who prefer to use "people with disabilities" have told me that, placing the noun 'people' before 'disabilities' emphasizes the fact that individuals who are disabled by society are in fact people first - something which historically has been denied.

I understand the terms 'disability' and 'disabilities' to mean the range of oppressive practices and barriers by which an individual with impairment is disabled by our society. This includes attitudinal, physical, environmental, social and economic barriers and encompasses institutional and systemic forms of discrimination.

I have not forgotten either that the decision to use the term 'people with disabilities' has also been shaped by the international context. The United Nations Convention on the Rights of Persons with Disabilities (2006) does not explicitly define the term disability, but states that "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others" (Article 1). So, for those who prefer the use of 'people with disabilities', their preference is to be consistent in promoting what they see as the standardisation of international disability terminology and its harmonization with the principles of human rights. Questions have arisen as to whether an organisation working globally should adopt the language used in the UNCRPD or whether we should use certain expressions only in certain circumstances.

In addition, the General Assembly of the United Nations has recently renamed the 'International Day of Disabled Persons' on 3rd December each year as the

'International Day of Persons with Disabilities' to reflect developments on the international stage. The term 'people with disabilities' is also now widely used and preferred by organisations of and for disabled people across the world, not least, perhaps, by many of those individuals, governments and organisations who were involved in negotiating the terms and conditions of the Convention. In South Africa, for example, the government and the disability movement are quite comfortable with using either "disabled people "or "persons with disabilities".

In choosing to use the term 'disabled people', I do not exclude those who prefer the term 'people with disabilities', but believe that 'disabled people' is most appropriate in the UK, where I am currently based.

Though the paper leans heavily on reference to the UK and US, it must be read within the context of each country so that it is relevant to the politically acceptable terminology of that country and does not further alienate the disability sector.

Disability defined and re-defined

The social model of disability is a conceptualisation which the disability movement has developed over the last four decades or so in contradistinction to the so-called medical model of disability. In order to understand these distinctions fully, it is necessary for the reader to be subjected to a short expedition to the 'disability' terminology, which is used in no less than four different senses:

First of all, it is used non-technically, in the way that it is used in general parlance today, to refer to the global phenomenon, disability, the particular form of disadvantage we are dealing with. But since most people are agreed that global phenomenon is a compound phenomenon, it is also used in a technical sense to refer to just one strand of that global phenomenon. The analysis of the global phenomenon in commonest use today is that of the World Health Organisation (1980) who came up with an International Classification of Impairments, Disabilities and Handicaps (ICIDH).

Turning to the components of the Classification, "impairment" refers to a loss or abnormality of psychological, physiological or anatomical structure or function. "Disability" refers to the consequent inability to perform normal activities. Thus "impairment", at the lowest level of analysis, is concerned with specific functions of the body or mind. "Disability" is concerned with compound functions or activities, such as walking or seeing. "Impairment" refers to the various mechanisms which give you the power to move your legs purposefully in an upright position and the fact that they are not working. "Disability" refers to your inability to walk. "Handicap" refers to the disadvantage resulting from the interaction between a person's impairment or disability and their environment.

The only snag, however, is that "disablement" has never really caught on as a generic descriptor, and the disability movement prefers a twofold classification which distinguishes simply between "impairment", corresponding broadly to the WHO's "impairment" and "disability", and "disability", which corresponds broadly to the WHO's "handicap", except that in the latter case there is a difference of emphasis between the WHO and the disability movement - for the WHO it is the individual who is ill-adapted to fit into the environment, whereas for the disability movement it is the

environment which is ill-adapted to accommodate the individual. On the one hand it is used to refer to the global phenomenon, or disadvantage, with which we are dealing, and on the other to the disadvantaging interaction between an impaired individual and his environment.

The medical model of disability can take a variety of forms depending on whether it emphasises biomedical abnormality per se (ICIDH impairment) or the consequent functional limitation, such as the inability to walk, see, etc (ICIDH disability). Notwithstanding the fact that it is called the medical model of disability, the key organising concept for the medical model is, for the disability movement at any rate, impairment. The dominant consideration in disability is mental or physical defect, giving rise to a very negative stereotype of the person with a 'disability'. Disabled people, especially those with the same impairment, are lumped together; all viewed in terms of their impairment as passive, helpless, tragic victims and not as ordinary human beings at all. Impairment, not humanity, comes to construct the identity of the disabled person, and disabled people come to be seen as pathetic objects of pity and care and not as conscious actors in their own situation. Disability, according to the disability movement, therefore means "The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from the mainstream of social activities."

The disadvantage is often referred to as barriers to full participation in society erected against disabled people by society itself, and can be attitudinal or material - physical, economic, social, cultural or political. "It is the way our society is organised that disables us"; and again: "disability is not something we possess, but something our society creates." As Hurst, R (1999), a leading disability activist has put it: "disability is something that happens to you, not something you have." This is why the UK disability movement insists on referring to "disabled people" rather than "people with disabilities", which is a medical model formulation.

According to Low, C (2001), there are at least four ways in which one could understand statements like these: First, one could think of the conditions of society, for example if they were particularly harsh, as literally causing the medical conditions which give rise to disability. A good example of this was contained in an article by the Anti-apartheid Health Committee (1981), which was headed "Apartheid disables". It stated that it was apartheid policy which was responsible for so much disability in South Africa. "The very diseases which disable" it said, "tuberculosis, polio, malnutrition, trachoma, are rife in the black population because of the poverty and appalling living conditions of apartheid."

Second, disability can be seen as a function of social definition. We can say that disability is "socially constructed" in that just when a person deviates sufficiently from the norm to be regarded as disabled, what constitutes normal activity, and just when an impairment becomes a disability, are all matters of definition presupposing social norms. In this incarnation, the social model of disability has much in common with labelling theory in the sociology of deviance, which famously asserted that "Deviance, according to Becker, H (1963), is not a quality that lies in behaviour itself but in the interaction between a person who commits an act and those who respond

to it"; or again even more famously "Deviant behaviour is behaviour that people so label".

Third, disability can be seen as a product of the way human beings have chosen to construct their environment, arrange their society and conduct their affairs, e.g. by using steps to make changes in level in a way that excludes people in wheelchairs, the spoken word for communication in a way that excludes deaf people, and the written word in forms that exclude blind people.

Fourth, disability can be seen as the result of the way disabled people are treated by non-disabled people - shut up in homes, sent away to special schools, turned down for jobs, and so on.

It is important to understand to recognise that it is non-disabled people who oppress disabled people. It is the society that disables people. The common cause of the creation of the disability of impaired people lies within the organisation of society. The process of uncovering and dealing with the social cause of disability helps everyone, however much or little they are affected at any given point in time.

Disability-friendly language is not a game of linguistic leapfrog

***'The difference between the almost right word and the right word is really a large matter – it's the difference between the lightning bug and the lightning,'
Mark Twain, 1888***

Although often dismissed as 'political correctness', getting the language right when talking about disability is non-negotiable.

Using respectful language shows that you have some understanding of personal dignity; and discriminating language can muddy the message that you are trying to convey.

Sometimes preferred language is ignored for literary reasons; it is awkward, uninteresting, wearisome, and repetitive, and it makes articles and reports pointlessly long. Reading repetitive phrases like "persons who are deaf" or "people who are hearing impaired" becomes irksomely repetitive to anyone after ten to fifteen occurrences. This criticism is certainly on the mark; however, it is the least significant weapon in the arguments against the preferred language crusade.

Preferred language aligns respect to things of consequence in the everyday world. Granted, changing labels from negative to the positive does not invariably or necessarily translate into a more humane treatment for disabled people; just that it increases the possibility. Neither are labels all that is at stake when we discuss the roles and use of language. The use of "preferred" language will not effect a magical transformation in attitudes about disability. But a disabled person would rather speak with someone who calls them "a blind person" and accordingly treats them like a person than with someone who refers to them as "a person who is blind" (or, worse yet, "a person with a sight problem"), and then treats them like they are a pathetic creature. Disabled people need, all in all, attitudinal changes and an end to discrimination, not discrimination and bad attitudes camouflaged with "accepted" language.

Achieving disabled people's rights a protracted liberation struggle

The story we have recorded of the lives of disabled people is a story of life lived on the margins. Disabled people have to overcome many physical, structural and sensory barriers in their everyday lives, among them inaccessible buildings and transport and signs printed in small letters. However, the biggest barriers they face are the pejorative public attitudes and misconceptions that many people have about disability. Even some disabled people often have the same attitudes and misconceptions, as explained later in the document. Our choice of language is influenced by our attitudes as much as by our behavior.

For the last four decades, disabled people have waged a political, policy, legal, academic, and philosophical struggle to claim individual and collective rights and sought to change their circumstances in part by changing the words used to describe them in the changing political and cultural world. It is a difficult and protracted struggle. Rights are won rather than given and have to be constantly secured.

By way of emphasis, Charlton, J. (1984) encourages us to, "think of how profound it has been in the world we inhabit to say the word *Black* in a new way." Racism, an ideology of the capitalist profit system which bundles up prejudices into a package to 'prove' that Black people are inferior equates *black* with lazy, corrupt, unemployed, violent, unintelligent, less valued, obliged to work disproportionately harder to prove themselves in a white world, and more. So, in order to say *Black* in a new way, we have to fight off all that *Black* has meant. Similarly, in order to say *disabled* in a new way, we have to fight off all that *disabled* has meant.

Oliver (1989) tried to draw parallels between the struggles of disabled people to control the language that is used to describe and classify them, with similar struggles by other oppressed groups. "The imposition of colonial languages on the natives, Oxford English on the regions, sexist language on women, racist language on black people, spoken language on deaf people, and so on, are all forms of cultural domination. It is agreeable that pidgin, dialects, slang, anti-sexist and anti-racist, anti-disablist language and sign language "are not, therefore, quaint and archaic forms of language use but forms of cultural resistance". The questions of disability, race, class, and gender are all intertwined and haunting each other.

Language and the power of description

The meaning of disability as deformity has a long history. This history is testimony to the force of language and its power of description. *Invalid* (English), *chirema* (Shona), *puth* (Luo), *langda* (Hindi) etc – all signify less human, innately inferior. According to Charlton, J (1984), "the way we talk about the world and the way we experience it are inextricably linked - the names we give to things shapes our experience of them and our experience of things in the world influences the names we give to them.....they provide an ideological mechanism that subtly but convincingly dehumanises people." Not only language is affected by society and culture, society and culture are affected, reciprocally, by language. The words used to describe disability are loaded with social connotations. Schmidt (1985, p. 53) argues that "language is regarded by many as the 'most social' of all 'social facts.'" Disabled people are significantly

affected by the way in which culture(s) explain the cause of disabilities (God's will, reincarnation, witchcraft); the images disability evokes(the sick/deformed body); and how they are described (cripple, invalid, retard).These interact in a circular way to produce the ways in which society at large is socialised to think about disability.

When a word or an idea is expressed, an image is generated. As the Russian linguist V.N Volosinov (1973, p.85) suggests, "experience is organised.....when a term is used over and over again, it establishes meaning, an image, a reality." An etymology of words about disability helps to trace the culturally based sources for many backward ideas about disability. Some would accuse disabled people of linguistic terrorism or being over-sensitive, but words reveal attitudes - they reflect and influence the way people think. Russians have two entirely different words for light blue and dark blue and so tend to think of them as two totally separate colours. English speakers however see the two as shades of the same thing. Ultimately though, attitude is more important than words.

At the individual level, using terminology that individuals prefer might be a matter of dignity and respect which costs nothing and does not control anybody's mind. Oliver M. (1994) argues that at the policy level, there is a suspicion that calling someone a 'retardate' or 'a schizophrenic' makes it easier for a society to lock them up, drug them into insensibility, electrocute or even kill them, and that it is rather difficult to do these things to a survivor of the mental health system or a person with a learning difficulty."

The interplay between language and social relationships

In the past, and even today, the field of disability policy has been dominated by academics, professionals and other disability 'experts' (often with no personal or direct experience of disability) whose definitions of disability have served to reinforce and entrench discriminatory attitudes and unequal treatment. This has happened because their limited observations of the problems disabled people experience have consistently located the cause within the individual and his or her condition.

The interplay between language and social relationships is such that such groups within the dominant culture are able to propagate their interests in the way in which the world is defined and acted in. Included in such groups are not only the dominant economic classes, but also men patriarchal societies, and white racists who take advantage of their whiteness to prejudice millions of black people, as well as professionals in relation to service users. Hugman (1991, p.37) points out that "through language, power is reproduced and communicated."

Language is also about politics

It is often assumed that the function of language is communication. According to Samuel Johnson (1709 – 1784), it is 'the dress of thought'. While it is undoubtedly true that communication is a function of language, it is not the only one. Language is also about politics, domination and control (Barnes 1993, p. 8). The first and most important thing to remember about discussions of language and disability is that they

arise because disabled people experience discrimination daily and are denied the same rights and opportunities as the rest of the population.

We do not use language just to describe the world and name our own experiences of it. Nor does language merely enable us to deconstruct the world and the practices we engage in. It can enable us to conceptualise a better world and begin the process of reconstructing it.

It is disabled people's own re-definition of their social situation which has brought about a struggle for ideas lying at the heart of disability politics. Those who define the problem have the key to controlling the solution. For over four centuries, solutions based on the so-called '*medical model*' have created a lot of work for non-disabled problem solvers. The aggregation of these jobs into what now amounts to a disability industry has created a large vested interest. Nowadays, medical model definitions, according to Davis, K (1996), are seen by the disabled people's movement as "little more than blunt instruments, the main political purpose of which is to surgically divert attention away from the social causes of disability. In this sense...., he adds, (Medical model definitions).... operate as devices to deflect pressure for social change; to protect the vested interests of those with investments in the steam-rolling disability industry....." Luckily, significant distance now exists between popular representations of disability as an individual problem, and politically informed disability cultures that devalue such views.

(Distorted/Misguided) consciousness and alienation

I often come across a mother or father of a daughter or son who clearly feels it would be an affront to describe their daughter, or their grandson, as *mentally handicapped*. Yet it baffles me when they just cannot see why, any more than they could be offended at someone describing their own daughter as mentally handicapped. They think, even argue, that the description is not inaccurate, nor does it imply any moral fault or lack of common humanity. Nor, so far as they would claim to be aware, has the term ever been used as an insult. Yet, most people with a learning disability now look on the term 'mentally handicapped' with horror and disdain.

Such parents are, of course, not alone in their sensitivity. But I sometimes feel that those who have such feelings are betraying their own suppressed horror about their child's condition, and subconsciously hope that if it is described euphemistically then the handicap will be in some ways alleviated, or might become invisible or respectable altogether. Of course wishing makes their reality worse.

In support of the argument above, Davis, K (1996) thinks that far less politically naive are those "caring professionals", do-gooders and dispensers of pity who deploy this kind of language in order to maintain disabled people's dependence on the medical model. It is no accident that terms such as '*physically challenged or differently-abled*' have been so readily accepted and used in some societies. *Abbreviations such as PWDs* often sound worse, even when used by disabled people themselves, and show the ease with which some disabled people unwittingly weaken the impact of the social model, by suggesting that disability is something possessed by themselves rather than being possessed by society. PWD/s is definitely not acceptable. In South

Africa it stands for Public Works Department and the disability movement there has made it explicitly clear that it is an unacceptable term.

Disabled people who adopt such terms play into the hands of those with a vested interest in keeping disabled people dependent and malleable, by suggesting that they cause their own marginalisation and must learn to 'get on with it'. In other instances of social oppression, such as the struggle of women or Black people, I wonder if users of this sort of terminology would suggest that they should be described as '*people with female gender*', or '*people with black skin!*'

Fortunately, in some places, we can witness a gradual transition of terms describing disability - from 'cripple' to 'handicapped' or 'physically challenged', 'differently-abled' to 'person with a disability'. Of course those who use such descriptions apparently subconsciously obscure the socially oppressive nature of disability from themselves and others by attempting to disguise it as a challenge to individual inventiveness, adaptability, personal endeavour and strength of character. And of course, by so doing, they leave the oppressive social milieu unchallenged and unscathed. Be that as it may, it is important to acknowledge that such terms are important symbolic steps forward.

Dual psychological identities

Disability oppression creates psychological internalizations which in turn create impaired self-awareness, dual psychological identities and alienation dividing people and isolating individuals.

Dual identity is when, on the one hand, a disabled person accepts the negative attitudes as part of the reality of the world, and manage them as something of an alter-ego, or altered state, or altered reality; Yet, on the other hand, they safeguard the good and kind nature, the wisdom to see oneself beyond the discrimination and allow it to exist only when it is safe to do so. Most disabled people actually come to believe they are less normal, less capable than others. Self-pity, self-hate, shame and other manifestations of this process prevent disabled people from knowing their real selves, their real needs, and their real capabilities and from recognizing the options they in fact have. So, they think it is okay to call themselves and allow others to call them *PWDs, the disabled, handicapped, differently-abled, and lame*. False consciousness also obscures the source of their oppression. Such disabled people cannot recognise that their self-pitying lives are simply a perverse mirroring of a shameful world order. Marx called this 'the self-annihilation of the worker' and Frantz Fanon 'the psychic alienation of the colonized'.

This dual ego, a strong and necessary survival tactic, leads to difficult and dangerous mental health obstacles which require fortitude to overcome.

Ignorance cannot be an excuse

The thing about language is that it reveals inner attitudes. That forms a huge chunk of my whole point. Just because a child is brought up using foul language, it doesn't mean that it is ok to use it - everyone at every level needs to understand when language and behaviour is unacceptable, whatever the intention. No one has the right to belittle someone else (well perhaps there are exceptions in heated battle) just

because *they did not intend to*. We all probably know someone in life, say a president of some country, who *did not mean* to master over his people but ended up being a mean master. It is never easy to know what people's real intentions are. What I care about is the fear, ignorance or prejudice we harbour, see or experience (depending on what side of the fence you are) and consequences of, say, the non-disabled children who tease and pelt disabled peers with stones, parents who would not give their disabled teenage son a name other than the name of his disability, a mother who forces sterilisation on her disabled daughter, or an employer who gives disabled employees unequal pay for equal work. Just because someone thinks they are well-intentioned, and are clearly ignorant, does not mean that they should be treated with kid gloves. We need to understand the effect of that ignorance and show it in its ugly, existing form. We can all remember times when we said something really stupid and later regretted it; no matter how aware and sensitive we are, we are all subject to making stupid errors. Such is life. However, when someone is, say, working in a paid-professional capacity, they should understand the rules of engagement.

Language is dynamic

Most disabled people are comfortable with the words used to describe daily living. People who use wheelchairs 'go for walks'. People with visual impairments may be very pleased - or not - 'to see you'. Impairment may just mean that some things are done in a different way. It does not usually mean that the words used to describe the activity must be different. However, some common phrases may associate impairments with negative things and are best avoided: 'deaf to our pleas' or 'blind drunk'.

The guidelines in Appendix 2 draw describe situations where appropriate language is vital. However, this code is not intended as a comprehensive guide to inclusive language. It outlines examples of both discriminatory and inclusive language, but because language is changeable, dynamic and political, we need to be sensitive to changing expressions and meanings. For example, the phrase 'people with disabilities' in the UK was originally seen as positive by groups such as People First who felt that the word order placed the importance on the person rather than the disability. Subsequently of course, this perception has changed. It is important to recognise that some terms are more accepted than others and the language of disability can differ between countries.

In general, there are three main aspects of language which can exclude or discriminate. Firstly, language may be discriminatory by giving unnecessary extra visibility to a factor, such as sex, ethnic origin or disability. Secondly, it may be discriminatory to define people in stereotypical ways, rather than illustrating the range of skills or activities a person may pursue. Finally, the language used to describe an individual or group may be discriminatory if it is imposed on the group rather than selected by them.

It is also important to re-examine their origins and evaluate their meanings and connotations today, according to the "shorter Oxford English dictionary of historical misleading terms" in Appendix 1, just after the conclusion. The attitudes that oppress

disabled people and the history of the bloodless struggle for liberation from the yokes of oppression are just as alive today as they were decades ago!

Conclusion

Language is not universal. Disability is an area where language is subject to debate and change. There is often concern as to whether words used are appropriate. As language is constantly evolving this think-piece can only be a guide to what is preferred. It is merely a scratch on the surface. Any further research should try and cover a wide range of vernacular contexts especially as in the developing country arena.

Selecting appropriate words conveys more than appearing to do or say the right thing. It is accurate and effective communication which neither causes offence nor excludes groups or individuals. Inclusive language not only respects all members of the community but encourages individuals to achieve their maximum potential. Furthermore, disability-friendly language is now widely encouraged as appropriate language throughout the disability international non-governmental organisations community and across all employment sectors.

There are bound to be disagreements about particular terms but there is a consensus about some general guidelines. It is most important to remember that people have the right to object to labels and may choose others – these choices should be respected and followed. The right to choose how they want to be described is a right that disabled people should not be expected to share with their non-disabled counterparts.

For disabled people, regardless of what dictionaries say, the word disabled and disability refer to how society treats them, not their impairment, which is a medical matter. Linguistically the disability movement is trying to separate its personal medical situation from society's responsibility to all disabled people. However understandable the internalisation of negative attitudes, the greater need is for non-disabled people to liberate themselves from ignorance in all its ugly form and prejudice and for those concerned to openly identify themselves as disabled people and squarely face the political task of battling the social causes of their oppression.

The world we inhabit needs constant deconstruction and reconstruction. Everybody-disabled and non-disabled, we can all improve the quality of our lives through being proactive in getting rid of our own ignorance, but also through better policy and changed practice. The recognition of the central role (inclusive) language plays in this improvement is imperative. Some people think disability rights have gone too far to the extent of becoming a sort of disability mafia. I do not agree. Disability mafia is really a strong word!

Appendix 1: Origins of disablist terminology

'Deaf and Dumb'

Carver (1995) observes that for thousands of years, being a Deaf person has been associated with 'dumbness' or lack of intelligence; the use of the term 'deaf and dumb' is commonly used to label Deaf people. The Greek philosopher Aristotle (350 BC) is credited with being one of the first to associate 'deaf' with 'dumb': "accordingly, of persons destitute from birth of either sense, the blind are more intelligent than the deaf and dumb." Over the years the word 'dumb' when used in this context became synonymous with 'silent'. The American National Association of the Deaf point out two reasons why Deaf people consider this offensive. First, Deaf and hard of hearing people are by no means silent since they use sign language and lip-reading to communicate. Second, Gannon (1981) argues that the word 'dumb' is misleading since it automatically implies that all Deaf people also have a learning difficulty.

'Mute'

For similar reasons, the word 'mute' is also considered offensive. This term was first used around 1483, stemming from the Latin word 'mutus' meaning: "to press together the lips" (Little et al, 1969). It is technically inaccurate, since Deaf and hard of hearing people generally have functioning vocal chords. However in order for a person to successfully modulate their voice, they need to be able to hear their own voice. Again, because Deaf and hard of hearing people use various methods of communication other than their voices, they are not mute.

Visual Symbols

Other myths about disabled people exist within society through inappropriate visual information. For example, the symbol depicting a person sitting in a wheelchair is often used to represent disabled people as a whole, for example on car park spaces, toilets and in literature. According to Gregory (1996), this propagates the notion that all disabled people use wheelchairs, when in fact only 4% of disabled people are wheelchair users in the United Kingdom. Ideally a visual symbol is required depicting disability as a social construct.

'Handicapped' / 'Mentally Handicapped'

Barnes (1992, p.43) points out that this word was traditionally thought of as having allusions to begging and going 'cap in hand' The use of the term 'handicapped' to refer to a disabled person did not come about until 1915, when a writer used the

phrase "the handicapped child". The term rapidly caught on and, by 1919, the educational journal "School and Society" was using the term 'mentally handicapped'. Disabled people have long since rejected this term as derogatory. In the UK the national organisation of people with learning difficulties, People First, said that 'mentally handicapped' has become a term of insult.

'Challenged'

When 'handicapped' began to fall out of favour in America, it was replaced by phrases still based on the concept of competition. These phrases portray impairment as an obstacle to be overcome, for example: 'physically / mentally challenged', 'challenging behaviour', and 'physically inconvenienced'. However these phrases again ignore the societal barriers that disable people, placing the emphasis instead on impairments as the 'challenging' factor (Disability Rag, 1985; Rae, 1989).

'Spastic'

The word 'spastic', originally a medical term defining a specific type of cerebral palsy, deserves particular mention here. First used in 1753, it derives from the Latin word 'spasticus'. This in turn comes from the Greek word 'spastikos' meaning "drawing in", presumably referring to muscle contraction (Little et al, 1969). In 1861 English orthopedic surgeon Dr. William John Little published the first paper describing 'spastic diplegia', referring to: "the universal spastic rigidity sometimes produced at later periods of existence" (Little, 1861), and thus associated the word with the impairment (Schleichkorn, 1987). The impairment was originally called 'Little's Disease', and Sir William Osler later coined the term 'cerebral palsy' at the end of the nineteenth century (Osler, 1889). In the UK, the term 'spastic' was adopted in 1952 and used by the organisation then known as 'The Spastic Society' for 42 years (Scope, 2001). During this time they ran many advertising campaigns that focused on the impairment, which in turn perpetuated the medical model of disability and charity perspectives, and were designed to invoke feelings of pity in order to fundraise (Hevey, 1992, pages 38-39). The negative imagery that they perpetuated led to the word becoming a playground insult. After nine years of research, the organisation changed its name to 'Scope' in 1994 (Scope, 2001).

Confusion of disability with illness

Another myth propagated by the medical profession is the confusion between disability and illness / disease. Barnes (1991, page 24) states that: "whilst medical intervention for treating illness and disease may be quite appropriate, from the perspective of the disabled people it is quite inappropriate for treating disability."

The confusion is most blatantly seen in the area of mental health, where the terms 'mentally ill' and 'mental health problems' are still frequently used. However people

tend to self-identify with the terms 'people with mental health issues' and 'Mental Health System Survivor'. In addition, some people with psychological impairments find the word 'mental' oppressive (Beresford and Wallcraft, 1997, cited in Oliver and Barnes, 1998, page 17).

In a fairly recent survey the British Medical Journal asked its readers to identify from a list which 10 items were a "non-disease". They defined this as: "a human process or problem that some have defined as a medical condition but where people may have better outcomes if the problem or process was not defined in that way" (British Medical Journal, 2002). Disability got just 15 out of 570 votes (under 3%), reflecting how the medical profession still sees disabled people as in need of medical intervention and cure. A number of people responded to the article by pointing out that disability is a civil rights issue (Pal, 2002; Carter and Marsh, 2002).

Deviation from an alleged 'normality'

A large number of words used to refer to disabled people involve a concept of 'normality', whatever that might be. These terms tend to describe how far people have strayed from that point. Most obvious in this category are terms like 'abnormal'.

'Invalid'

This quite literally stems from "in-valid", meaning not valid (Barnes, 1992, page 43), invoking notions of Social Darwinism. The idea of disabled people not being a valid part of society has been around for thousands of years, for example Aristotle wrote: "let there be a law that no deformed child shall be reared" (Aristotle, 350 BC). The use of the word in this context dates back to 1752 and refers to soldiers and sailors who were on the sick list and deemed unfit for active service (Little et al, 1969). However it soon became used to refer to any disabled person, for example there used to be a welfare benefit payment in the UK called "Invalid Care Allowance", now called 'Carers Allowance.'

'Retard'

'Retard' is an offensive word, stemming from the Latin verb 'retardo' meaning, "to delay", which in turn was taken from the root word 'tardus', meaning "slow or late". In English the word became 'retard', meaning to keep back, delay, hinder or impede development (Little et al, 1969). The word implies that disabled people are slow, under-developed and lagging behind the allegedly 'normal' people. It is often used as an insult (Reiser and Mason, 1990).

Professional Terms

Recently a number of terms have come from health and 'social care' professionals who work with disabled people.

'Special Needs'

The phrase 'special needs' came about as an attempt to demedicalise the labelling of disabled children to what was hoped to be less negative labelling based on educational need (Reiser and Mason, 1990, p. 88). In 1978 the Warnock Report introduced the concept of "Special Educational Needs" to replace the categories of impairment that were used previously. However the concept still retains the assumption that disabled children were "less than human" and required segregated provision (Barnes, 1991, page 33). Micheline Mason argues: "we consider disability to be a norm within every society, borne out by statistics, and we want our needs to be taken into account as normal needs. It seems questionable that even 20% of young people can have special needs. It seems ridiculous that 45% of young people within inner city areas have special needs" (Reiser and Mason, 1990).

The 'needs' referred to here are typically determined by professional assessment, rather than by disabled people themselves. Often these needs are commonplace, for example disabled children 'need' to receive a decent education, just like any other children. However "the disabling culture transforms ordinary human needs into special needs and corrupts the identity of disabled children into special needs children" (Finklestein and Stuart, 1996). Therefore services based on the social model of disability which address societal barriers would not draw distinctions and segregate people via words such as 'special'.

'User'

This term defines them solely in relation to the state services provided for them. The only instance in which disabled people use this term to describe themselves is to specifically refer to the use of a piece of equipment or service, for example 'wheelchair user' or 'personal assistant user'. The word suggests someone who takes from others and gives nothing in return, and is commonly used in relation to the misuse of drugs and intoxicating chemicals (Thomas, 2002). It is also not that far removed from the notion of 'useless people / eaters' - the term used by Nazi Germany to refer to disabled people (Rogow, 2002; United States Holocaust Memorial Museum, 2002).

'People with Learning Disabilities'

Originating from the health service, this term was rejected by the movement since, as with 'people with disabilities', it denies the social construction of disability. It is widely

used today, despite objections from people with learning difficulties. People First, the largest user-led organisation of people with learning difficulties in the United Kingdom, decided against the use of the term some time ago. They reasoned: “if we talk about disabilities, it makes it sound as though we can’t improve. Everybody with a learning difficulty can improve, even if it is only a little” (People First, 1992).

‘Carer’

This is the term self-identified and adopted by the “carers’ movement” in the United Kingdom. However Morris (1993, page 23) observes that the word also has a detrimental effect on perceptions about disabled people, implying “a sense of a need to be looked after”. As Barnes (2001) explains: “besides ‘have a liking’ or ‘desire for’, to ‘care’ means ‘to be concerned about’ or ‘to look after’. It is also associated with the concepts of ‘protection’ and ‘supervision’ and is used with reference to many sections of the community. We care about family and friends. We care about particularly vulnerable groups such as small children, older ‘frail’ people, and people with serious and life-threatening illnesses.” However, in reference to disabled people ‘care’ usually means ‘to be cared for’, ‘to be looked after’, ‘protected’ or ‘supervised’. From the perspective of disabled people this is an overtly patronizing and unhelpful use of the term because (Barnes, 2001):

1. It implies that disabled people can never achieve any degree of independence within their communities.
2. It conceals the fact that there is overwhelming evidence that many of the problems encountered by disabled people are the result of society's failure to meet their needs.

Rock (1988) notes: “The word ‘carer’ is beginning to be synonymous with acts of courage and bravery that is, battling along in a hostile world against uneven odds, with the enemy often, defined as the disabled person for whom she has to care.” Any words and phrases that characterise disabled people as dependent should be avoided (Barnes, 1992, page 43). So whilst the role of self-definition is an important one, it is important to make sure that the adopted term does not further oppress a different group of people. Some alternatives used by disabled people are ‘personal assistant’ (if the person is employed in that capacity) or ‘supporter’ (if the assistance is informal).

‘Vulnerable’

Recent government legislation talks a lot about ‘vulnerable people’. For example the document ‘Supporting People: a new policy and funding framework for support services’ defines the term as including “people with learning disabilities” and “people with mental health problems” (DSS, 1998). However as with ‘carer’, the term implies that disabled people cannot live independently and require “looking after”.

(Source: Little, W. Fowler, HW. Coulson, J 1969, The shorter Oxford English dictionary on historical principles, ed. Onions, C.T. 3rd edition, The Clarendon Press, Oxford).

Appendix 2: A guide to inclusive language

A

Ability

It's important to remember, when communicating with or about people with a disability, that they may have one disability – but they have many abilities. Try to highlight their abilities.

Able-bodied

The opposite of "disabled" is considered to be "able-bodied". However, talking in terms of disabled vs. able-bodied is divisive and can sometimes be read as a dismissal of non-physical impairments, almost a hierarchy of disability. In other words, it ignores the fact some disabled people, for example people with learning difficulties may also be 'able-bodied'. Use *non-disabled people*.

A haemophiliac, an epileptic,

A paraplegic

This use of 'a' before the noun implies that once you know the condition, you can categorise the person solely based on their disability. Instead use *person with haemophilia; woman with epilepsy; a man who has paraplegia*.

Abnormal / sub-normal

Not acceptable. Use *a disabled person*

Albino

Not acceptable. Use *person with albinism*

B

Blind

Use only to describe a person who really is blind. Otherwise *person with a vision impairment* is preferred.

C

Carer

Should be reserved for the 'family' of a person with a disability who provide unpaid support. Paid workers should be referred to as assistants, attendants or care workers.

Challenged

Euphemisms, such as *intellectually challenged*, are seen as 'overly' politically correct. Don't use them.

Confined to a wheelchair

A wheelchair is not confining, it provides mobility to those who can't walk. A person *uses* a wheelchair.

Cripple

Should only be used as part of a direct quote, never to describe a fellow human being.

D

Deaf

Many people who are unable to hear identify themselves as belonging to a group with its own language and culture. In such cases a capital 'D' is used when referring to this group, e.g. *A Deaf spokesperson said...* Use if a person really is Deaf. In other cases *person with a hearing impairment* is preferred.

Deaf/Blind

People who are deaf/blind prefer 'dual sensory impairment'

Defect

Not acceptable. Use *congenital disability, blind from birth* etc.

Despite

Disabled people are active in their community because of their abilities, not despite their disability.

Disabled

Emphasizes the disability not the person. Use *disabled person/people*.

Disabled toilet / disabled parking space

We all know what is meant, but the toilet or car park is not disabled – it is an inaccurate description, use *accessible toilet/ accessible parking space*.

Disadvantaged

Don't use to describe a person just because they have a disability – a disability in itself needn't be a disadvantage (although often society's response to a person's disability can be a disadvantage).

E

Euphemisms

'Nice' terms such as *intellectually challenged, differently abled, physically challenged* are a denial of reality.

F

Fits

The preferred term is seizures.

H

Handicap

Don't use to describe a disability, however this term can be used to describe the obstacles that restrict an individual's participation, e.g. *Handicapped by lack of accessible transport*.

I

Intellectual disability

Terms such as *Mongol*, *retard* or *mentally retarded* are frowned upon. Use *people with an intellectual disability*.

Invalid

An outdated term with negative connotations. 'Invalid' equates disability with illness and can be construed as 'not valid' or 'worthless'. Use *disabled person*.

M

Mental illness

Preferred over mentally disabled. Alternatively use the appropriate clinical name, e.g. Person with schizophrenia. Do not use *insane*, *lunatic*, *mad*, *crazy*.

Mongolism

Use *person with Down syndrome*.

N

Normal

This is a statistical term. In order to distinguish from people with a disability it is acceptable to use double negatives such as *non-disabled* or *person without a disability* or descriptive terms such as *sighted*, *hearing*, *ambulant*.

P

Paranoid schizophrenia

This is a specific condition and these terms should not be used to make a person sound more colourful or dramatic.

Patient

Should only be used when a person is actually receiving medical care or treatment, or in hospital. At other times use the same adjective as you would for a person without a disability, e.g. *client*, *consumer*, *customer*, *commuter*, *visitor*, *patron*.

Patronising language

Don't describe people as *brave*, *special* or *suffering* just because they have a disability.

Politically correct

If in doubt make sure you are politically correct by using *disabled people* or *people with disabilities*. Don't use euphemisms like *physically challenged* or *differently abled*.

Psychiatric disability

An acceptable term to describe a mental illness. Alternatively use the appropriate clinical name e.g. *Person with schizophrenia*. Do not use *insane*, *lunatic*, *mad*, *crazy*.

PWD(s)

This could be an abbreviation for a wide range of nouns from Palm Wine Drinker, Philadelphia Water Department, Pregnant Workers Directive, Pig Welfare Disposal

Scheme to Post-weaning diarrhoea syndrome. Use *disabled people or people with disabilities*.

R

Retarded

Derogatory, outdated and unacceptable – instead use *people with an intellectual disability*.

S

Spastic

Derogatory, outdated and unacceptable. In most cases *person with cerebral palsy* is the acceptable alternative.

Special

Here is what a disabled person had to say about the term ‘Special’ – ‘It gives a false sense, lower expectations and the bigoted baggage that comes with it. I wouldn’t be special if things around me were sorted out.’

Sufferer

Avoid using to indiscriminately describe a person with a disability – individuals don’t suffer just because they have a disability. Phrases like ‘suffers from’ cause discomfort or pity and suggest constant pain and a sense of hopelessness. While this may be a reality for some people, an impairment does not necessarily cause pain or require constant medical attention. People who experience chronic pain and other difficulties can nevertheless experience pleasure and do not necessarily regard themselves as tragic. Alternatives include *survivor or disabled person*.

T

The blind, the deaf

Avoid using ‘the’ in this manner as it unconsciously eliminates the person and creates a generalisation based purely on disability.

U

Uses a wheelchair

Do not say confined to a wheelchair – a wheelchair provides mobility and is liberating, not confining. Say *uses a wheelchair*.

V

Vegetables

Vegetables are what you cook and eat – not to be confused with *people who are comatose, unconscious or in a coma*.

Victim

Some people are victims of war, crime, or exploitative wages. It is inappropriate to describe people as victims of a particular disability.

Visual impairment

Implies a person who is unattractive to look at! Use *vision impairment or sight impairment*.

(Source: NSW Department of Ageing, Disability and Home Care, DADHC “Don’t dis me with that language —the disability language A – Z guide”, London, UK, with adaptations by the writer)

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