

Patriarchy in the UK: The Language of Disability

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1 Introduction

Over the years a large amount of terminology concerning disability has evolved which denies the social construction of disability and is now considered offensive by many people in the British disabled people's civil rights movement. These terms have originated and been perpetuated by the likes of the medical, religious and welfare professions. Many are patriarchal in nature, evoking the notion that disabled people need looking after. Others are based on false premises that have since been disproved.

The language that people use reflects what they think and can influence how they deal with situations. If they behave as if the problem is with the individual, they will take a different approach than if they regard the problem as being with the attitudes, systems and practices that create disabling barriers. Therefore it is important to re-examine their origins and evaluate their meanings and connotations today.

The "Shorter Oxford English Dictionary of Historical Principles" (Little et al, 1969) is used to look-up dates when words were first used and whether they were derived from Greek or Latin words. In addition a number of key texts are referenced in order to how strongly some of these terms have been embedded in the English language. These include the 1611 King James Bible, which was used as the standard for hundreds of years and had a great influence on our language. Also the 1914 Oxford Edition of the Complete Works of Shakespeare was searched for occurrences.

The aim of this paper is not to dictate which terms should and should not be used, but to highlight the hidden connotations that may be implied. It is entirely up to the reader to decide whether they want to still use these terms or not in light of their true meanings.

2 The social construction of disability

2.1 Disabled People

Traditionally it is thought that a disabled person's medical condition was the root cause of their exclusion from society, an approach now referred to as the medical or

individual model of disability. Social exclusion led to inadequate policies and legislation, inappropriate attitudes, a poor stereotyped media image and inaccessible buildings and information.

In the mid-seventies a new way of thinking about disability emerged from the disabled people's civil rights movement called the social model of disability or barriers approach (Union of Physically Impaired Against Segregation, 1976; Oliver, 1983). This stated that disabled people are those people with impairments who experience barriers within society. It redefined disability as pertaining to the disabling effect of society, rather than the functioning of people's minds, bodies and senses, by making the following definitions (Barnes, 1991, page 2):

- a) Impairment is a physical, mental or sensory functional limitation within the individual.
- b) Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.

Therefore the term 'disabled people' was redefined by the movement to mean "people with impairments who are disabled by socially constructed barriers."

2.2 'People with Disabilities'

The British civil rights movement has rejected the term 'people with disabilities', as it implies that the disabling effect rests within the individual person rather than from society. 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 (Barnes, 1992, page 43; Oliver and Barnes, 1998, page 18). Indeed some are now going further and writing Disabled with a capital 'D', in order to emphasise the word's political connotations. The Deaf people's movement largely does not identify with the term 'disabled people', instead adopting a cultural model and defining themselves as a linguistic minority. Corker (2002) defines Deaf people as "that group of people with hearing impairments who are excluded from the dominant areas of social and cultural reproduction by the perpetuation of a phonocentric world-view." Deaf people too have adopted a capital 'D' in order to politicise the word.

None of the rest of the terms discussed here come from disabled people themselves and portray the social construction of disability.

3 Historical implications

The origins and implications of some terms, which are still in use to certain degrees, have been forgotten. However although the actual meaning may not be apparent to the user, that does not necessarily mean that others will not be aware of it.

3.1 'Mongoloid'

A physician named John Langdon Down, a superintendent of an asylum for children in Surrey U.K., was the first to make the separation between people with mental health issues and people with learning difficulties (Ward, 1998, p. 129). In a paper entitled "Observations on an Ethnic Classification of Idiots" (Down, 1866) he described distinct sets of children with learning difficulties who had common features. He defines "a classification of the feeble-minded, by arranging them around various ethnic standards": namely Ethiopian, Malayan, Native American and Mongolian people. The latter became the accepted name for people with Down syndrome for nearly 100 years, and gave rise to the derogatory terms 'mong', 'mongol', 'mongolism' and 'mongoloid'. Down based his theory on the mistaken notion that racial characteristics represented degeneracy within humans - people from Mongolia were thought at the time to have arrested development (Leshin, 1997). For example: "the boy's aspect is such that it is difficult to realize he is the child of Europeans, but so frequently are these characters presented, that there can be no doubt that these ethnic features are the result of degeneration" (Down, 1866).

In the end he abandoned his ethnic concept, but not before he had sown the seed that was to become a basis for the division of children with learning difficulty into different scientific categories (Ward, 1998, p. 179). Eventually in 1961 a consortium of "experts in the field of disability" (Ward, 1998, p. 200), all of whom were medics, sent a letter to the Lancet suggesting that the term 'Mongolism' be dropped in favour of "Down's syndrome" (Allan et al, 1961). They wrote: "the occurrence of this anomaly among Europeans and their descendents is not related to the segregation of genes derived from Asians..." and that "the increasing participation of Chinese and Japanese investigators in the study of the condition imposes on them the use of an embarrassing term." Based on the argument that the term was an insult to Asian people (but not disabled people) and despite objections from several doctors, the editor of the Lancet accepted the new designation (Spalding et al, 1961). Nowadays the word 'monged' is used to describe somebody 'coming down' after taking an illegal substance.

3.2 'Moron'

'Moron' comes from Greek word 'moros' meaning: "foolish, stupid." It was coined as a scientific term by Dr. Henry H. Goddard and proposed to the American Association for the Study of the Feebleminded by him in 1910. It was accepted by the Association and described a person with a mental age between eight and twelve years and who possessed an I.Q. below 75." It was the highest rating, the two lower ratings being

'imbecile' and 'idiot'. 'Moron' was quickly adopted in common English to mean: "fool", and it is no longer in scientific use (Crowley and Crowley, 2001).

3.3 'Idiot'

Of the two lower ratings, 'idiot' derives from the Greek word 'idiotus', meaning: "a person who does not take part in public life." Its usage can be traced back at least to the thirteenth century (Payne and Patton, 1981, page 31), although it does not appear in the 1611 King James Bible. However Shakespeare often uses it: "What's here? the portrait of a blinking idiot, presenting me a schedule!" (The Merchant of Venice, act II, scene 9).

3.4 'Feeble-minded'

'Feeble' derives from the Latin word 'flebilis' meaning doleful, sad and melancholy (Little et al, 1969). It was used as early as 1611 in the bible: "Now we exhort you, brethren, warn them that are unruly, comfort the feeble-minded, support the weak, be patient toward all" (Thessalonians 5:14). Until recently it was still used widely, for example the National Association for the Care and Control of the Feeble-minded set up in 1896 (Oliver and Barnes, 1998, page 33), and as previously mentioned, the American Association for the Study of the Feeble-minded from the last century.

3.5 'Cretin'

This word was borrowed from the French word 'crétin' in 1779. It comes from an earlier word, cretin, which meant 'Christian' in the French dialects of Valais and Savoie, although the word 'Christian' was not being used in its present-day sense. This is because, from the parochial perspective of the medieval inhabitants of remote Alpine valleys, everyone in the world was Christian. Therefore the word became synonymous with "human being". Due to the lack of iodine in the medieval Alpine diet, certain regions of Switzerland were prone to severe thyroid problems, which led to more people being born with learning difficulties. Moved by compassion, the local priests encouraged the populace to treat them kindly. They argued that they deserved pity because they were, at least, Christians (i.e. "human beings"). Hence the word came to be used to refer to people with learning difficulties (Crowley and Crowley, 1999a).

3.6 'Cripple'

Reiser (2001) credits the derivation of the word 'cripple' to the Middle German word 'Kripple' meaning: "to be without power". Whilst this may be currently true in the political sense, the inference is a lack of physical or intellectual power. On the other hand, Crowley and Crowley (2000) date its usage back to before 950 AD, the earliest form being the Old English 'crypel' which is a form of 'creep'. Therefore a 'cripple' would be one who can only creep. The word is only used once in the King James bible: "and there sat a certain man at Lystra, impotent in his feet, being a cripple from

his mother's womb, who never had walked" (Acts 14:8). However it is used a number of times by Shakespeare:

“And chide the cripple tardy-gaited night
Who, like a foul and ugly witch, doth limp
So tediously away.” (Henry V, act IV chorus)

The word is still commonly used as an adjective: e.g. “crippling pain”, “crippling debts” and “the health service is crippled”; or as an undesirable fate: “to end up a cripple”. More recently the abbreviated form ‘crip’ has been reclaimed and used by disabled people in the United Kingdom in the same positive way that ‘queer’ was adopted by lesbians and gay men, however it could not be used in that same way by non-disabled people.

3.7 ‘Lame’

A 17th century word used to describe a person with a physical impairment (Little et al, 1969), which became associated with various negative connotations. For example, the term “lame duck” is often used to describe a competitor who does not stand a good chance of winning. Similarly a “lame excuse” is one which is not very convincing.

3.8 ‘Dwarf’ and ‘Midget’

These words have been commonly used to refer to people with restricted growth. Midget was formed from the word midge, meaning: "small fly", and '-et', so that a midget is etymologically a "very small, small fly". It was first used 1848 in Canada with the meaning "sand fly". By 1865, midget was being used to describe a “very small person”, and by 1884 it referred to small people who were exhibited in freak shows and circuses. Dwarf is of Germanic ancestry, coming ultimately from the proto-Germanic root ‘dhwergwhos’ meaning "tiny". In Old English it was ‘dweorg’ and meant "person of abnormally small stature". That remained the only meaning until the late 18th century, when, with the influence of German mythology, dwarf came also to mean "small, manlike creature that lives underground and works metal" (Crowley and Crowley, 2001). It is often used in fairytales such as “Snow White and the Seven Dwarves” and fantasy novels such as “The Lord of the Rings”, often to further the stereotype that disabled people are sinister or evil (Barnes, 1992, page 22) and implying that small people are from a different race. In America people self-identify with the word ‘Dwarf’, however in the U.K. the alternative terms ‘short person’ or ‘person with restricted growth’ are generally used.

3.9 ‘Siamese Twins’

This term originated in the nineteenth century freak-shows. It was used to describe Chang and Eng, conjoined twins who were born in Siam in 1811 (Drimmer, 1991). It was first used to describe conjoined twins in 1829 (Little et al, 1969).

3.10 'Mad'

It is thought that this comes from the Latin term 'mutare' meaning "to change", and was first used to refer to a person with mental health issues around the end of the 16th century (Little et al, 1969). Other possible influences are the Sanskrit word for "thought", 'mata'; and the Greek word 'matos' denoting "acting for itself".

3.11 'Lunatic'

In the fourteenth century the word was spelt 'lunatyke' and it was borrowed from the Old French word for 'insane.' It came from the Latin 'lunaticus' meaning: "moon-struck"; which in turn comes from the Latin word for moon, 'luna'. This term arose because it was thought that recurring periods of "madness" were caused by phases of the moon's cycle (Crowley and Crowley, 2002).

3.12 Names of Institutions

The names of institutions for disabled people can sometimes find their way into everyday conversation. For example, the playground insult 'Botleyhead' is still used in Surrey, despite it deriving from the Botley Park institution, which has been closed for over 10 years. More famously the term 'bedlam' is derived from the Hospital of St. Mary of Bethlehem, established in London in 1247, which became famous as an asylum by 1402. By 1547 it was incorporated as a royal foundation "for the reception of lunatics." As the hospital became more famous, the name was shortened in popular speech to 'Bethleem', 'Bedlem', and finally 'Bedlam'. Simultaneously, 'bedlam' became a popular synonym for any asylum, and by the 17th century it was being used to mean any scene of great confusion or uproar (Morris, 2001).

4 Misleading Terms

4.1 Emotive Terms

Emotive terms relating to disabled people, such as 'afflicted', 'restricted', 'stricken', 'sufferer', 'unfortunate' and 'victim' tend to reflect a person's negative reactions to a disabled person. Similarly terms like 'housebound', 'wheelchair bound' and "confined to a wheelchair" are emotive and inaccurate, since wheelchairs are pieces of equipment that empower rather than restrict (Corcoran, 1977). In addition, many wheelchair users can walk short distances, often using mobility aids other than their wheelchairs, and are not therefore attached to them.

4.2 Denial of Individuality

Phrases that dehumanise and objectify disabled people, denying individuality, are also regarded as oppressive by the movement (Barnes, 1992, page 43). Examples include: 'the disabled', 'the blind', 'the deaf' and 'the deaf and dumb'. Various acts such as the Poor Law (1601) use such terminology: "And also competent Sums of Money for and towards the necessary Relief of the Lame, Impotent, Old, Blind..." There are also numerous examples of this from the bible: "But when thou makest a feast, call the poor, the maimed, the lame, the blind..." (Luke 14:13). The acceptable alternatives are, of course, disabled people, blind people, Deaf people, etc.

4.3 'Able-bodied'

This term is also often incorrectly used, in this case to refer to people who are not disabled. This ignores the fact some disabled people, for example people with learning difficulties may also be 'able-bodied'. Morris (1993, page x) explains: "the term non-disabled people is used rather than able-bodied people because the point is that people who do not experience physical, sensory or intellectual impairments are not disabled by the prejudice and discrimination which denies opportunities to people who do experience such impairments." Similarly the British movement rejected American terms that revolve around ability, such as 'differently-abled' and 'temporarily able-bodied' (Rae, 1989).

4.4 'Disabled' versus 'Accessible'

The word 'disabled' is also often incorrectly used in place of 'accessible', for example 'disabled toilet' instead of accessible toilet, 'disabled parking space' instead of accessible parking space, etc. Similarly 'deaf aid' is typically used to incorrectly refer to a hearing aid.

4.5 'Deaf and Dumb'

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 (Carver, 1995). 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, the word 'dumb' is misleading since it automatically implies that all Deaf people also have a learning difficulty (Gannon, 1981). The two words are associated with each other a couple of times in the bible: "And were beyond measure astonished, saying, He hath

done all things well: he maketh both the deaf to hear, and the dumb to speak” (Mark 7:37).

4.6 '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.

4.7 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. 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 (Gregory, 1996). Ideally a visual symbol is required depicting disability as a social construct.

5 Life as a Competition

A popular misconception is that the whole of life is a competition, and therefore disabled people are hampered and will not do well.

5.1 'Handicapped' / 'Mentally Handicapped'

This word was traditionally thought of as having allusions to begging and going 'cap in hand' (Barnes, 1992, page 43). However recent work has rejected notion of the word originating from begging, instead tracing its derivation from a 17th century method for setting odds. Crowley and Crowley (1999b) say that the game of 'handicap' was first mentioned by that name in 1653, though it was known centuries earlier by the name of 'Newe Faire'. Basically, one person would challenge another for an article that he owned, and offer something of his own in exchange. If the challenge was accepted, an umpire was chosen to decide the difference of value between the two articles, and all three parties (including the umpire) deposited forfeit-money in a cap or hat. The two contending parties each placed a hand in the cap (hence the name hand i' cap). The umpire then announced how much money was to make up the difference in value between the two items. Both parties then withdrew their hands from the cap at the same time. If either person thought the deal unfair then they would withdraw an open hand, otherwise they would pull out a closed fist. If both parties were in agreement the

umpire took all the cash. However if they disagreed then the money went to whoever had been willing for the deal to occur.

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. However these issues have still not dissuaded the non-user led organisation Mencap from using and perpetuating the term (People First, 1992).

5.2 '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).

6 Impairment-related terms

6.1 Referring to people solely by their impairment

It is offensive to refer to groups of people by either their impairment or aspects related to their impairment: for example 'epileptic', 'dyslexic' and 'arthritic', and 'haemophiliac'. Equally offensive and grammatically incorrect is the tendency to refer to a person by the name of their impairment, e.g. "he's cerebral palsy" or "the one with muscular dystrophy". Where it is absolutely necessary to refer to an individual's impairment it is better to state 'person who has dyslexia' or 'people with arthritis' (Barnes, 1992, page 43).

6.2 '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 it 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).

7 Confusion of disability with illness

Another myth propagated by both religion and 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." There are also numerous references to disabled people as "the sick" in the bible: "When Jesus saw their faith, he said unto the sick of the palsy, Son, thy sins be forgiven thee" (Mark 2:5).

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 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).

8 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',

‘defective’ and ‘deviant’, which quite clearly segregate people into either the ‘normal’ group or the ‘not normal’ group.

8.1 ‘Partially Sighted’ / ‘Hard of Hearing’

Although still used by the Royal National Institute for the Blind, the term ‘partially sighted’ is based on a concept of deviation from the ‘normality’ of being ‘sighted’. The phrase that people within the movement tend to self-identify with is ‘visual-impaired person’. The same could also be said of ‘hard of hearing’, however in contrast this is the term that people tend to identify with than ‘hearing-impaired’. This is because in many sign languages including British Sign Language, the sign for impairment is the same as the sign for ‘handicap’, and makes allusions to being broken. For these reasons, the World Federation of the Deaf voted in 1991 to use ‘Deaf’ and ‘hard of hearing’ as their official designations.

8.2 ‘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, 355 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 is still a welfare benefit payment in the UK called “Invalid Care Allowance”.

8.3 ‘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), particularly in America.

9 Professional Terms

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

9.1 ‘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, page 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’.

‘Special needs’ is now being used as a term of insult, for example British comedian Harry Enfield used it to describe a boy character in order to instil some level of fear of what the boy might do. This is also an indication that whatever term is used to describe a group who are unwanted, not accepted and derided can become derogatory and used as a term of abuse over time. For example the word ‘gay’ is now used as a way of saying something is dire.

9.2 ‘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).

9.3 ‘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). However this has not stopped state services, and organisations like Mencap who are not user led, from perpetuating its use.

9.4 ‘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 appear 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).

9.5 ‘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”.

10 Conclusion

When assessing whether a new term will be acceptable, the following criteria should be used:

- a) Is it based on the social model of disability, locating the root of disablement with society?
- b) Has it arisen from self-definition and does not affect perceptions of other groups (as in the case of 'carers')?

All of the negative terms discussed here could be substituted for either 'disabled person', meaning "a person who is disabled by society", or 'Deaf person' as appropriate. Where it is absolutely necessary to indicate someone's specific impairment, this should be prefixed with "a person with..." Correct terms for indicating a general type of impairment are 'physical impairment', 'restricted growth', 'visual impairment', 'learning difficulty', 'Mental Health System Survivor' and 'Deaf / hard of hearing'.

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