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Disability and stigma: an unequal life

Sarah Earle

Read this if you want to understand more about

- **disability theories**

- **barriers in society**

- **enabling clients**

Half as likely to go to university, half as likely to get qualifications, half as likely to get a job -

the Disability Rights Commission campaign asks, is a disabled person only half a person? Sarah Earle suggests a 'cure and care' approach can inadvertently contribute to the process of disablement so in this, the third of four sociological perspectives on inequality, she explores how we can break down barriers and at the same time play an important role in treatment and rehabilitation.

Definitions and understandings of disability have changed radically over time. Traditionally, disability was perceived as the tragic problem of unfortunate individuals whereas now disability is often seen as a form of social oppression and social exclusion (Oliver & Barnes, 1998). But what exactly do we mean when we use the term, 'disability'?

In 1980 the World Health Organisation published the International Classification of Impairment, Disability and Handicap. This classification adopts a three-fold typology, outlined in figure 1.

Figure 1 International Classification of Impairments, Disabilities and Handicaps (World Health Organisation)

Impairment

any loss or abnormality of psychological, physiological or anatomical structure of function;

Disability

any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being;

Handicap

a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.

Source: Wood (1980, p.29)

Although the international classification is commonly regarded as comprehensive and is widely used across the world, it is not unproblematic. Firstly, the typology assumes the existence of psychological and physical 'normality' as well as the ability to measure and define it. However sociologists are critical of this, arguing that normality is, in fact, very difficult to define and is often dependent on a range of situational, temporal and cultural factors; that is, what might be regarded as 'normal' in one time and place may be regarded as 'abnormal' in another. Secondly, implicit within the typology is a *causal* relationship between 'impairment' and 'handicap'. Thus, people with impairments become objects of intervention, therapy and rehabilitation in the quest for 'normalcy'. However, as Oliver & Barnes have contended, although intervention and rehabilitation are sometimes appropriate, 'it is increasingly argued by a growing number of disabled people that it is quite inappropriate to treat disability' (1998, p.15). Figure 2 highlights some points to consider with respect to definitions of disability.

Figure 2 Definitions of disability: thinking points

- to what extent is the World Health Organisation definition of disability helpful to speech and language therapists?

- are speech and language therapy clients 'disabled'?

- do you, and your clients, find the label of 'disability' a helpful one?

Disability theorists have been critical of the World Health Organisation classification which has been described as extremely 'individualistic', and a new definition, a social model of disability, has emerged (Oliver, 1983). A social model of disability rejects the causal relationship between impairment and handicap, arguing that it is not impairment *per se* which is disabling, but the environment in which an individual finds him or herself. A social model also seeks to move away from a medical model of disability which focuses on the 'cure and care' (Finkelstein, 1993) of people with impairments. The Union of the Physically Impaired Against Segregation thus describes disability as, 'the disadvantage or restriction caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities' (1976, p.14). More recently, the 1995 Disability Discrimination Act has defined a disabled person as somebody who, 'has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'.

It is difficult to establish a precise demography of disability and inequality in Britain, particularly given the difficulties with defining 'disability' and the fact that definitions have changed over time. Thus, any attempt to quantify the numbers of disabled people must be treated with caution. However, in 1999, the Disability Rights Task Force suggested that approximately 8.5 million people in Britain came under the definition of

disability provided by the Disability Discrimination Act (1995). Recent figures indicate that one in five of all people of working age are disabled and that 3.7 million of these are men and 3.4 million are women (Smith & Tworney, 2002).

Social oppression

Theorists argue that disability is a form of social oppression and that disabled people experience considerable inequality in all areas of social life, including: education, health care, employment, housing, and transport (Barnes et al, 1999). For example, whilst 81 per cent of non-disabled people of working age are in employment, this applies to only 48 per cent of disabled people (Smith & Tworney, 2002). Furthermore, 50 per cent of disabled people who are not in work would like to be but are unable to find suitable employment. Research also shows that disabled people in work are more likely to be in manual occupations and have lower than average earnings. Indeed, 50 per cent of all disabled people are living in poverty, affecting a substantial number of children either directly or indirectly (Burchardt, 2000). Evidence also suggests that there is inequality in education at all levels and that disabled people are more likely to have no qualifications than non-disabled people (Disability Rights Task Force, 1999). They are also more likely to live in poorer housing and have less than adequate access to transport and leisure facilities (Bagilhole, 1997).

For disability theorists, inequalities are produced by the 'disabling barriers' within contemporary societies which prevent or hinder disabled people from full participation within society. Bowe (1978) has suggested six principal barriers: architectural, attitudinal, educational, occupational, legal and personal. Sociologists would argue that these barriers are both structural and material, as well as cultural.

Sociologists also argue that disabled people experience 'stigma', which is a powerful discrediting label that can change and 'spoil' the way in which the individual is perceived. This idea was proposed by the sociologist Erving Goffman (1963), who argued that there are two types of stigmatising condition. Firstly, *discrediting* conditions which are readily obvious to others, for example; eczema, psoriasis, and stammering. Secondly, *discreditable* conditions, those that are usually not visible to others, or can be easily concealed, for example epilepsy, HIV or depression. Goffman also argued that a person's condition can become their 'master-status'; that is, whatever else he or she might be or accomplish, the condition is the first thing that other people see. For example, interviews with disabled women have revealed that general practitioners often (wrongly) attribute health problems to the individual's impairment (Begum, 1996).

It is also worth considering here the concept of 'courtesy stigma', which has been defined as a 'tendency for stigma to spread from the stigmatised

individual to his close connections...' (Goffman, 1963, p.30). There is evidence, for example, that the family and carers of those with Alzheimer's disease often experience considerable embarrassment and shame (MacRae, 1999). Hence, it is not just disabled people themselves who experience inequality - evidence suggests that it can affect the life chances of an entire family (Barnes et al, 1999). Figure 3 has thinking points on disability and inequality.

Figure 3 Disability and inequality: thinking points

- in what ways might the inequalities experienced by disabled people influence the relationship between client and therapist?
- how might stigma affect your clients?
- how relevant is courtesy stigma to the role of the therapist?

Accessible information

What then are the implications of disability politics for speech and language therapists? It is clear that the organisation of contemporary society plays an important role in creating and sustaining barriers which prevent disabled people from participating fully within the social and economic life of their communities. The Disability Discrimination Act (1995) goes some way towards the eradication of disabling environments, but it has been criticised for drawing more on an individualistic, rather than a social, model of disability (Fawcett, 2000). Speech and language therapists are often involved in working with clients and their families to

ameliorate the consequences of this; examples of good practice might include the provision of accessible information for disabled clients, parents and relevant others, and the involvement of disabled people as advisors at all stages of policy development and review within clinical practice

Some disability theorists, however, have argued that the therapies themselves contribute to the process of disablement. For example:

> Rehabilitation can be seen as a major instrument of bodily rationalisation. Disguised as 'scientific' and operating under the banner of biomedicine, rehabilitation is a powerful agent in the ratification of particular types of bodies...Common to most rehabilitation work, however, is a set of moral ideas about what bodies should be like.
>
> (Seymour, 1998, p.20)

Others argue that, whilst it is important to recognise that disability is a form of social oppression, it is also important to 'bring back impairment', and recognise the significance of this for individuals:

> The experience of impairment is not always irrelevant, neutral or positive... How can it be when pain, fatigue, depression and chronic illness are constant facts of life for so many of us? ... for

many disabled people personal struggle related to impairment
will remain even when disabling barriers no longer exist.

Crow (1996, p.58)

This implies that although a 'cure and care' approach can be disabling, there is a role for treatment and rehabilitation in which speech and language therapists can play an important part (figure 4).

Figure 4 Implications for speech and language therapists

- how can therapists avoid contributing to the process of disablement?
- do you make moral judgements about your clients based on their impairment?
- is it always appropriate to treat disability?
- how far can therapists contribute to the removal of disabling barriers within society?

Reflections

- **Do I recognise that the word 'normal' can mean different things to different people at different times?**
- **Do I structure therapy to facilitate inclusion in the mainstream of social activities?**
- **Do I involve clients as advisors when developing departmental policy?**

References

Bagilhole, B. (1997) Equal Opportunities and Social Policy. London: Longman.

Barnes, C., Mercer, G. & Shakespeare T. (1999) Exploring Disability: A Sociological Introduction. Cambridge: Polity.

Begum, N. (1996) General Practitioner's Role in Shaping Disabled Women's Lives. In: C. Barnes & G. Mercer (eds) Exploring the Divide: Illness and Disability. Leeds: The Disability Press.

Bowe, F. (1978) Handicapping America. New York: Harper & Rowe.

Burchardt, T. (2000) Enduring economic exclusion: disabled people, income and work. London: YPS.

Crow, L. (1996) Including All of Our Lives: renewing the social model of disability. In: C. Barnes & G. Mercer (eds) Exploring the Divide: Illness and Disability. Leeds: The Disability Press.

Disability Rights Task Force (1999) From Exclusion to Inclusion: Final Report of the Disability Rights Task Force. [available from: http://www.disability.gov.uk].

Fawcett, B. (2000) Feminist Perspectives on Disability. Harlow: Pearson Education.

Finkelstein, V. (1993) Disability: An Administrative Challenge?. In: M. Oliver (ed.) Social Work: Disabled People and Disabling Environments, Research Highlights in Social Work 2. London: Jessica Kingsley.

Goffman, E. (1963) Stigma: Notes on the management of a spoiled identity. Englewood Cliffs, NJ: Prentice Hall.

MacRae, H. (1999) Managing courtesy stigma: The case of Alzheimer's Disease. *Sociology of Health & Illness* 21 (1) 54-70.

Oliver, M. (1983) Social Work with Disabled People. Basingstoke: Macmillan.

Oliver, M. & Barnes, C. (1998) Disabled People and Social Policy: From Exclusion to Inclusion. London: Longman.

Seymour, W. (1998) Remaking the Body: Rehabilitation and Change. London: Routledge.

Smith, A. & Tworney, B. (2002) Labour market experiences of people with disabilities. *Labour Market Trends* 110 (8) London: ONS.

UPIAS (1976) Fundamental Principles of Disability. London: Union of the Physically Impaired Against Segregation.

Wood, P. (1980) International Classification of Impairments, Disabilities and Handicaps. Geneva, WHO.