

**CHAPTER 3 (In 'Disability Studies: Past Present and Future' edited by Len Barton and Mike Oliver (1997), Leeds, The Disability Press, pp. 45 - 62).**

## **From Normalisation a to Where?**

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### **INTRODUCTION**

This chapter will attempt to do two things. First of all, I want to acknowledge the progress that has been made with reference to challenges to the normalisation principle, as the hitherto predominant model for understanding the experiences of people with learning difficulties. Secondly, I want to take the opportunity to raise some concerns about the theoretical position of people with learning difficulties within the social model of disability. In so doing, I don't claim to have any answers. Rather, the paper is a reflection of continuing concerns about the application of the social model of disability to what has been termed the sociology of disability or disability studies. I write this paper then in the hope that the issues it raises will prompt some useful discussion. Perhaps the answers, if there are any, will come later.

### **THE RISE AND FALL OF NORMALISATION**

My interest in disability issues was stimulated by what appeared to be, some 10 years ago, the progressive potential of the normalisation principle and its promise to improve the lives of people with learning difficulties. For those who are unfamiliar with normalisation, a simple summary is:

‘The use of means which are valued in our society in order to develop and support personal behaviour experiences and characteristics which are likewise valued’ (Campaign for People with a Mental Handicap, 1981, p 1)

The normalisation principle argues that people with learning difficulties are devalued by society and have stigmatised identities. A vicious circle of devalued identities reinforced by poor quality services is created. Putting into practice the normalisation principle will transform the vicious circle into a virtuous circle of high quality services which will create high quality lifestyles and enable people with learning difficulties to mix with those who have socially valued identities.

The research in which I was engaged at that time intended to use normalisation as its theoretical framework. As the research progressed, however, interviews

and conversations with people with learning difficulties began to highlight a conflict between the experiences and priorities of my respondents and the goals of normalisation which claimed to articulate these experiences and priorities. At the same time, the social model of disability was emerging in the academic literature (Abberley 1987, Oliver 1990). The analysis of disability presented by the social model provided a much better fit with the experiences of the people whom I was interviewing. From here developed an attempt to critique normalisation.

At that time, it felt very difficult to raise public concerns about normalisation. There are two main reasons why this was so. The first concerns the history of normalisation. In the early 1970s, the British Government set targets for the closure of long-stay mental handicap hospitals (DHSS 1971). This marked the first clear Government commitment to community care for people with learning difficulties. It coincided with the dissemination of the North American version of normalisation within the UK. Advocates of normalisation saw this policy commitment to community care as a move in the right direction, but wanted to go much further.

In their attempts to spread the word of normalisation to service planners and providers, its advocates argued that community care was for all people with learning difficulties, regardless of the degree of impairment. Such a radical assertion went far beyond the terms of Government policy on community care. It provoked a significant degree of scepticism, if not hostility, among some service planners and providers, who feared for their jobs in the long-stay hospitals or who believed that, while people with mild learning difficulties might cope in the community, those with severe impairments always would require hospital care.

Alan Tyne, writing as long-standing supporter of normalisation has described the derision and abuse that was heaped on those who advocated hospital closure and community-based services (1987, p 80). Standing firm against this sort of hostility did not create the kind of open environment where it was permissible to question normalisation without providing ammunition for those who were opposed to community care. As Ward has noted, to question normalisation in public was to risk association with the 'forces of reaction' (1992, foreword).

The second reason concerns the content of normalisation. It is based on a powerful vision of what services should be like for devalued people. This emphasis on explicit values creates a moral blueprint for service design. Holding on to "the dream", this vision of high quality services creating a high quality life-style, has been a cornerstone of normalisation. "The dream" is

conveyed to services planners and providers via intensive training programmes which can last several days. The techniques used are intended to pull on the emotions and are based on strong moral convictions, if not zeal, in some cases. Again, this doesn't create an open, questioning environment. In addition, the emphasis placed in normalisation of the power of the subconscious (drawn from Goffman's notion of the manifest and latent functions of the long-stay institution), makes it possible to claim that those who are sceptical about normalisation have failed to acknowledge their own subconscious fears and negative values about people with learning difficulties.

Normalisation is riddled with argon: the conservatism corollary, social role valorisation, symbolic marking, Program: Analysis of Service Systems implementation of Normalisation's Goals (PASSING). Being party to this exclusive language created a sense of belonging to a select and enlightened group.

During the 1980s, normalisation came to dominate the agenda for debates about services for people with learning difficulties. It epitomised the way forward for the design of services: anything progressive could be achieved only by adopting the normalisation principle. It had moved from being ridiculous and naive to become the accepted wisdom. To criticise it was tantamount to heresy.

For these reasons, public criticism of normalisation was muted. The cracks in this apparent consensus began to appear at the very end of the 1980s. In the UK, these concerns came from different perspectives. The first I would term the "whole person" approach. Bayley (1991), for example, argued that the concept of culturally valued roles, so central to normalisation, was in danger of failing to support the valuable characteristics of people with learning difficulties. The emphasis was on making them conform rather than on unconditional acceptance.

Other work, for example Brown and Smith (1989) and Baxter et al (1990), pointed to the dangers inherent within normalisation of the unquestioning value attached to cultural norms and the determination that devalued people should aspire to them. Such an approach merely reproduces other discriminatory social norms, such as sexism and racism. These were very important arguments as they highlighted that social norms are not neutral, but are products of the society which constructs them. However, some of this work - in particular that of Brown and Smith - has advocated a rehabilitation of normalisation through debate and review. They argue that normalisation:

'is the best we have got to date, and should therefore be used as a starting point' (1992, pp 691-2).

My concern was to re-examine normalisation in the light of the social model of disability. I argued that normalisation was increasingly accepted by many services planners and academics who attempted to use it to improve services for people with learning difficulties. Normalisation enabled professionals, therefore, to maintain a key role in community care and adapt to new services by developing new models of practice. It continued to legitimate the authority of professionals in the move from hospital-based to community-based services. However, it is interesting to note, as Whitehead (1992) and Oliver (1994) have indicated, normalisation may have influenced many professionals, but it has not been adopted as a model for change by disabled people themselves or any organisations which are accountable to disabled people.

The functionalism of normalisation means that the power relationship between professionals and users remains intact. As normalisation reflects the concerns of professionals, it is services and not their economic and social context which are the priority. This begs the question for people with learning difficulties: what if I don't want to be in the day centre/residential home at all (however well decorated it might be), but want to live in my own flat or with friends, have a job and make my own decisions without having staff around. Community care and normalisation have generated a language about services and the people who use them but, as Oliver comments:

'the material fact remains, it is still professionals doing it, whatever "it" is called, to disabled people' (1994, p 7)

Normalisation's preoccupation with deviance, labelling and stigma means that people should be taught the skills to enable them to associate with those who have been ascribed a high social value. Associating with those who are likewise devalued merely creates a vicious circle of deviance, by reinforcing the stigmatised identity of the individual. Such an argument has serious implications for the nature of social relations between people with learning difficulties.

First, it demonstrates an unquestioning acceptance of the concept of stigmatised identities. There is no recognition of stigma itself as a social construct: a mark imposed by an economically, socially and politically powerful group on one which is economically, socially and politically disempowered. Secondly, normalisation concentrates on the social behaviour of the devalued person with the intention of modifying it by teaching social skills in order to facilitate relationships with socially valued (i.e. non-disabled) people. The social and material constraints on the ability of people with learning difficulties to develop friendships (notably, low income, lack of access to one's money, the way that services are organised which undermines privacy and subjects individuals to

public humiliation and disciplining, the authority of staff) tend not to figure as reasons which may explain some of the problems which they face.

Normalisation encourages people with learning difficulties to mix with socially valued people, while distancing themselves from those who have stigmatised identities. Such an argument misunderstands fundamentally the nature of friendship as a voluntary relationship based on mutual respect and affection, which has at its centre shared experiences and interests. People tend to select as their friends others who are like themselves. This is not to suggest that friendships between people with learning difficulties and non-disabled people shouldn't happen; only that by discouraging people with learning difficulties from associating with other disabled people, they will be isolated from an important potential source of friendship and support. Furthermore, identifying other people with learning difficulties as the problem to be avoided (literally), undermines the possibility of collective political action, based on commonality of experience.

The first part of this chapter has recounted the history of the spread of normalisation and the development of concerns and critiques about it over the last few years. I want to look now at ways to move on from normalisation and examine the possibilities of the social model of disability for people with learning difficulties.

## MOVING FORWARD FROM NORMALISATION

The critical scrutiny of normalisation and challenges to its dominance over community care debates should be regarded as positive steps. There now exists the possibility of another theoretical tool (the social model of disability) which could assist people with learning difficulties, not just in a struggle for better services (the primary concern of normalisation), but for full economic, social and political inclusion in society.

However, it is necessary to examine the implications of the social model of disability for people with learning difficulties. This section of the paper intends to raise a number of questions. Part of the impetus for wanting to address these questions comes from attending two seminars on disability. The first was in June 1992 and was intended as a forum to discuss approaches to researching disability. The second was in October 1995 and aimed to take forward some of the debates within the sociology of disability. Both these seminars were very stimulating. Yet I was struck in each by the neglect of learning difficulty within the general discussion of disability, even when in some of the discussions, it seemed to me at least, learning difficulty was of central relevance to the analyses that participants were trying to establish.

For the purposes of this chapter I will concentrate on the relationship between the social model of disability and people with learning difficulties on a theoretical level, in particular the continued marginality of learning difficulty within the sociology of disability. The disability movement comprises people with physical/sensory impairments, people with mental illness and people with learning difficulties. Clearly, this includes people with a very wide range of impairments who, traditionally, have been classified by the medical model of disability and, therefore, have defined as having little in common.

Furthermore, there is great diversity among disabled people on the basis of age, gender, ethnicity, class or sexuality. The concerns about marginality within the social model do not apply solely to people with learning difficulties, but also to disabled women or older disabled people and so on. As Morris argues in the context of the experiences of disabled women:

'within the disabled people's movement, (it) has tended to be tacked on as a "special interest".' (1996, p 1)

My worry about the position of learning difficulty within the social model, however, is that it is almost entirely ignored - it hasn't yet ever attained the status of a "special interest". The danger is then, that some of the analyses which emerge from the sociology of disability are theoretically flawed and their explanatory power is weakened.

In the early 1990s, it seemed hopeful that learning difficulty could come to figure more prominently on the agenda of the social model of disability. The analysis of disability presented by the social model is that disability is a social construct created by a range of historically and culturally specific factors. It is the social and economic structures of a particular society which create disability through processes of prejudice, exclusion and discrimination. This explication of disability can apply equally to the experiences of people with learning difficulties or physical/sensory impairments. For example, a brief look at the history of disabled people in Britain points to certain key events which led to the emergence of the long-stay institution:

- the rise of capitalism in Western Europe
- the expansion of state activity into new areas of economic and social life and the emergence of professionals
- the growing influence of eugenicist ideas about the quality of the population

These factors all combined in the late 19th and early 20th centuries to identify disabled people as a social problem. This was the impetus to develop a system

of lifetime segregation for disabled people, regardless of the nature of impairment.

As I have indicated, the social model attempts to encompass the experiences of all disabled people. In so doing, it challenges the traditional separation of disabled people from each other. To apply the social model to physical/sensory impairment, but not learning difficulty, seems to me to be akin to suggesting that the analyses of society offered by feminism are applicable only to white women, and that the neglect of the experiences of black women within much feminist writing is because patriarchy has no explanatory power for them.

Having said this, nevertheless, the question remains as to why learning difficulty is neglected within the analyses of the social model. What appeared to be the promise of the sociology of disability does not seem to have materialised. The experiences of people with learning difficulties remain as marginal as ever.

My reasons for this worrying conclusion are two-fold. First, an examination of the literature produced by writers and academics associated with the disability movement reveal that there is little usage of literature produced by writers concerned with learning difficulty to develop their arguments. The debates about disability appear to be continuing on two parallel tracks with comparatively little cross-fertilisation of ideas. There are some exceptions to this general rule. For example, in 1994, Mike Oliver presented a conference paper which used the social model to apply a materialist critique of normalisation although, to my knowledge, this paper has not been published and is not widely available. Jenny Morris's book *Encounters with Strangers: Feminism and Disability* (1996) includes a chapter about The Powerhouse, a refuge for women with learning difficulties who have experienced physical or sexual abuse. Yet these tend to be the exceptions and much literature is produced which utilises the social model, but says nothing about learning difficulty. Thus, Oliver's sketch of some of the key literature associated with the social model (Oliver, 1996) mentions no writers or debates which are specific to learning difficulty. It appears the best that people with learning difficulties can expect is an implicit inclusion in any writing about disability.

Secondly, the experiences of people with learning difficulties are generally omitted from much of the disability literature, even when those experiences are, I would argue, relevant to the arguments presented by the author. The implicit inclusion of learning difficulty mentioned above means that some of the arguments emanating from within the social model are assumed to refer to all disabled people, when in reality they do not. Such arguments clearly are very partial.

Important aspects of a debate may not be developed because they are more relevant to people with learning difficulties than those with physical/sensory impairments. For example, in 1994, I wrote that the campaign for civil rights for disabled people appeared to have little to say about the relationship between disabled people, the police and the Criminal Justice System even though equal treatment under the law is a crucial element of civil rights - a point fully recognised by feminist and anti-racist campaigners and writers (Chappell, 1994). Of specific concern to the civil rights campaign should be the powers of the 1991 Criminal Procedure (Insanity and Unfitness to Plead) Act to incarcerate defendants in special hospitals by identifying them as unfit to plead, and the many cases where people with learning difficulties have been wrongly convicted of crimes. While writers associated with the disability movement are producing important work which examines what happens to disabled people who are victims of crime (see Kennedy, 1996, Shakespeare, 1996), there is little on the discrimination against disabled people who are accused of committing crimes.

If we accept the premise that the social model of disability can and should include learning difficulty, there is a need to examine why learning difficulty remains so marginal to debates within the disability movement. There are, I think, a number of possible explanations.

## FOCUSING ON THE BODY

Much of the disability literature tends to define impairment in terms of the body. There is nothing intrinsic to the word impairment which suggests physical rather than intellectual imperfection. However, the usage of the term often suggests that this is so. For example, a perusal of debates about disability and culture illustrates this, because it is images of disabled people which being examined.

Furthermore, there are occasions in the literature where "able-bodied" is used as the opposite of "disabled" (for example, French, 1993). Barnes (1996, p 43), for example, writes of the material and cultural forces 'which created the myth of "bodily perfection" or the "able-bodied" ideal'. This would be fair enough if the chapter clearly was about physical/sensory impairment, but it is entitled *Theories of disability and the origins of the oppression of disabled people in western society* (my bold italics). The use of the term "disabled people" should include people with learning difficulties, but often it does not and their experiences remain hidden.

Hevey (1993) also focuses on physical/sensory impairment in his discussion of the cultural representation of disabled people. He argues that the



representation of impairment is based on gazing on the body and portraying this in cultural terms. Bodily imperfection (Oedipus and Richard III are oft quoted examples) becomes a metaphor character defect, which entails his (usually his) eventual downfall. Thus, as Hevey argues:

'The history of the portrayal of disabled people is that disabled people are portrayed as flawed able-bodied people' (1993, p 118)

Such an analysis may well be applicable to people with physical/sensory impairments. However, for people with learning difficulties, it is more problematic. Here, the body is not the site of the impairment, the impairment may not be immediately apparent and nor may it be associated with any physical imperfection. Indeed, I can think of many people with learning difficulties whom I have met over the years who are, in conventional terms, extremely physically attractive. For them, impairment does not equal a failure to meet the conventional ideals of the body.

A similar problem emerges concerning the question of the sexuality of disabled people. The literature here tends to use as its starting point the conventional assumption that disabled people are asexual. This stereotype is assumed to refer to all disabled people. Yet, for people with learning difficulties, there is more than one stereotype of their sexuality. There certainly exists a view that people with learning difficulties are eternal children who never develop an adult sexuality. However, there also is a strong historical association between learning difficulty and powerful images of a very threatening and promiscuous sexuality which must be restrained.

Thus, a key factor in the segregation of people with learning difficulties in the early 20th century was their supposedly threatening sexuality. As Williams (1989) points out, not only did people with learning difficulties fail as workers, they failed as parents. Eugenicist concerns of this period were underpinned by fears of trade competition, the struggle for imperial expansion and the immigration of Jews from Eastern Europe. The labelling of people with Down's syndrome as "mongols" underscores the link that was made between racial and intellectual inferiority (Booth 1987).

Such concerns focused attention on people with learning difficulties and the way that their supposedly uncontrollable sexuality, promiscuity and high fertility threatened the moral fibre of society. In particular, it was people with mild or borderline learning difficulty who were seen as being especially dangerous. Their impairments were unrecognisable to the untrained person and, if unchecked, they would be able to merge into wider society and spread their pernicious immoral influence. (Discrimination against people with

learning difficulties under the Criminal Justice System, which I mentioned earlier, echoes this long-standing connection between moral and mental degeneracy.)

It was for this reason, Gelb argues (1987), the American psychologist Goddard adapted the European Binet test, which attempted to classify different degrees of learning difficulty, so that it was deliberately harsh at the upper end of the scale. The express purpose of doing this was so that the test would pin-point those with a presumed mental age of 12 years who were defined as having a mild learning difficulty and retarded moral development. At the same time, pseudo-scientific studies were made of the genealogy of so-called deviant families in order to demonstrate that idiocy, moral degeneracy and criminality were all hereditary. (Interestingly, this technique of tracing the histories of deviant families has been rejuvenated in the USA in an attempt to establish the existence of the "criminal gene.") The sexuality of people with learning difficulties, therefore, appeared as socially dangerous and this was part of the impetus behind their segregation from society under the terms of the 1913 Mental Deficiency Act.

This connection between moral and mental degeneracy also operated the other way around. Contravening sexual codes of behaviour, for example, having an illegitimate child while claiming poor relief or even fraternising too closely with American soldiers during the last war (which was the reason for the incarceration in a long-stay hospital of one woman I have met) was sufficient to be classified as having a learning difficulty.

This is not to suggest that all writing on disability and sexuality excludes learning difficulty. Shakespeare (1996), for example, notes the vulnerability of people with learning difficulties to sexual abuse. Obviously, this is a very serious matter which must be discussed. Nonetheless, it accords with the more general view expressed in the disability literature that disabled people are stereotyped as sexually passive and powerless and it is this which makes them vulnerable to abuse. It does not explore the possibility that some people with learning difficulties may be stereotyped as sexually predatory and dangerous (that is, stereotyped as abusers) and experience discrimination on those grounds.

## THE MEANING OF IMPAIRMENT

A new area of debate which has been emerging in the disability literature seeks to examine the "reality" of the experience of impairment. Some writers and academics associated with the disability movement have indicated a concern that the definitions presented by the social model deny that

impairment has any relevance. That is, there are no limitations imposed by impairment which cannot be removed by, what French refers to as, 'social and environmental manipulation' (French, 1993, p 22). This debate is sensitive because of the danger that it will be used to reassert individualistic models of disability in which impairment and disability are synonymous (Oliver 1996, Crow 1996).

My concern about this debate is its assumption that impairment is located in the body. As Crow argues, 'impairment means the experience of our bodies can be unpleasant or difficult' (1996, p 209). It is the bodily pain of impairment that is referred to and the body which must be theorised. If the view is accepted that the meaning of impairment must not be denied and that it warrants examination, then this is an important issue for people with learning difficulties too. Yet what happens to the analysis if impairment is located in the intellect? Without the inclusion of the experiences of people with learning difficulties, any analysis of the meaning of impairment will be incomplete. Moreover, the question of impairment raises issues which relate to the limitations faced by people with learning difficulties to ensure that their experiences form a central part of the agenda of the social model. Are these limitations socially-driven or impairment-driven or both? I will return to this point a little later.

## THE PERSONAL IS POLITICAL

One of the most important features of the emergence of the social model has been the relevance of personal history and experience to the writing that has been produced. Writers such as Mike Oliver, Jenny Morris, Sally French, Lois Keith and Paul Abberley to name a few, have theorised their personal experiences as disabled people to develop political insights into the meaning of disability. In taking such an approach, writing about disability reflects the feminist principle that one's personal experiences do not take place in isolation from wider social, economic and political structures. The personal also must be theorised.

However, the experiences of writers and academics who have written about disability in this way is physical/sensory impairment. It is this that has tended to shape the analysis which has developed. For people with learning difficulties, the issues are more problematic. While it is possible to call to mind a number of people with physical/sensory impairments who research, write and publish (whether based inside or outside academia), I can think of none who have learning difficulties.

Why should this be? Is it simply another of the discrimination that is meted out to disabled people? Does it mean that the intellectual and academic environment should be manipulated (to use French's phrase) so that people with intellectual/developmental impairments can participate? Should we be seeking to undo the emphasis on presenting material in a theoretical way, if it precludes people with learning difficulties? What would this mean for the development of disability theory?

Or is the nature of intellectual/developmental impairment more likely to create restrictions on the ability of people with learning difficulties to gain positions (for example, as researchers) where they can present their own theorised accounts of the world in the way that people with physical/sensory impairments have been able to do? How does this fit into calls to re-examine the meaning of impairment? To paraphrase Liz Crow (1996), external disabling barriers may create social and economic disadvantage, but the subjective experience of the intellectual/developmental impairments of people with learning difficulties is part of their everyday reality.

I am not suggesting that people with learning difficulties are not capable of articulating their experiences or do not recognise prejudice and discrimination when they encounter them. It is clear that many do. However, these views and experiences have not been conveyed in the disability literature to the same extent as those of people with physical/sensory impairments. Neither have they been conveyed without the involvement of non-disabled people as "allies", "supporters" or "facilitators" (and I would identify myself as someone who has taken this approach).

The obvious danger here is that non-disabled sympathisers will assume a dominant role. For example, in some self advocacy groups attached to day centres, staff may begin as facilitators with the intention of supporting the self-advocates. Yet they end up dominating proceedings so that meetings become an opportunity for staff to justify the operation of the service and pay lip service to the principle of self-advocacy. If people with learning difficulties do require allies to enable them convey their experiences in a way which is acceptable to researchers, examiners, editors, publishers and other gatekeepers, how should the integrity of their accounts be safeguarded?

## DISABILITY THEORY: AVOIDING THE ERRORS OF THE PAST

Presenting the arguments along the lines of this chapter should create a sense of *deja vu*. Any reading of the history of second-wave feminism makes it clear

that the first feminist literature which emerged in the early 1960s, with its idealist emphasis, claimed to articulate the experiences of all women. With hindsight, we can recognise that this was not the case.

The experiences of white women (vis-a-vis their place within the family and their relationships to the workplace and the Welfare State, for example) are quite different from the experiences of ethnic minority women. Similarly, disabled feminists (Morris 1991 and Keith 1992) and non-disabled feminists (Walmsley, 1993) have exposed the partiality of the conventional feminist wisdom on informal care, by highlighting the way that feminism has ignored the experiences of disabled women and relegated them to the status of "the other".

Is this the destiny of people with learning difficulties within the social model? Is it inevitable that their views and experiences will be ignored, marginalised and rendered largely invisible? How much more literature will be produced that begins by using the term "disabled people", but gradually lapses into the term "able-bodied people"? How much more theory will develop that fails to include and explain the experiences of people of learning difficulties?

## CONCLUSION

The sociology of disability (underpinned by the social model of disability), has been one of the most significant intellectual and political developments of the last 10 years. It has transformed the meaning of disability, at a personal, intellectual and political level, for many people. As Oliver (1996) points out, this transformation is a continuing process.

So, while it is important to celebrate achievements, it is necessary also to raise concerns about the direction of some of the debates in the sociology of disability and point to new pathways for debate. Much of the content of this paper has been shaped by a sense of frustration at the continued exclusion of people with learning difficulties from the analyses of the sociology of disability. Striving to include analysis of learning difficulty in the continuing transformation of disability indeed would be an achievement worthy of celebration.

The problem of marginality requires a shared response. Part of this responsibility rests clearly with people who are committed to the social model and interested in learning difficulty. However, to strive to embrace all disabled people within the social model also is a wider collective responsibility. I end with a plea that writers in the disability movement keep the question of learning difficulty in their minds and ask themselves whether the empirical or

theoretical work in which they are engaged is solely about physical/sensory impairment (if it is, this must be made clear) or is it about disability. If the latter, the analysis must address the question of learning difficulty.

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