The Social Model of Disability: Myths and Misconceptions.

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The recent article by Vic Finkelstein raised a number of important issues which I think everyone involved in the disabled people's movement must consider very carefully. I also believe that the movement is facing major challenges both from without and from within, but, for me, the latter is potentially the most damaging.

At a time when the movement's very existence is seriously under threat a growing number of disabled writers and researchers, both women and men, seem intent on undermining what has already been achieved by generating and perpetuating a number of misguided myths and misconceptions which in my estimation are largely unfounded. The combination of the NHS Community Care reforms, local government reorganisation, new charity funding regulations, and the Disability Discrimination Act threaten the very existence of what, for me, ***is*** the movement - the nationwide network of grass roots organisations of disabled people.

Much of the mythmaking stems from the often repeated claim that, like other political movements, the movement has been dominated by men. This has led to a number of misconceived and damaging assertions: that disabled women's experience has been ignored: that discussions of impairment need to be included in the social model of disability, and that only disabled people can do disability research.

Now I'm not suggesting that the movement is perfect, far from it. We live in a society centred around patriarchy, inequality and elitism, and it is inevitable that these traits should be present in our own organisations. But in my experience the British disabled peoples' movement has done far more than most to address these issues, yet this is rarely acknowledged by the movement's disabled critics.

Indeed, since I first became involved with BCODP (British Council of Organisations of Disabled People) in 1989 the movement has, in fact, been dominated by women. Currently, four of the five principal BCODP elected officers are women, and this has been the case throughout my involvement. In my experience women have also held, and continue to hold, key posts in most of the organisations up and down the country. Take GMCDP, for example, its salaried managerial staff have always been predominantly female.

Each of the BCODP projects I've been associated with: the institutional discrimination project, 1990-1, the media images project, 1991-2, the independent living seminars, 1992, and the direct payments project, 1994/5, have all been directed by research groups which have been chaired by a disabled woman, and whose members included an equal number of women and men. BCODP's 1993 Annual General Meeting was devoted entirely to equal opportunities issues.

It is also the case that disabled women's organisations and disabled women have played a crucial role in shaping the movement of the 1990s. In an anthology of disabled women's writings published by Virago in 1988 entitled 'With Wings' there are eleven national and local organisations specifically for disabled women listed - one of which was the UPIAS)Union of the Physically Impaired Against Segregation) Women's Group. Gemma, the national organisation of disabled lesbians, was one of the eleven founding organisations of the BCODP in 1981.

Throughout the 1980s disabled women played a crucial role in setting the movement's agenda. Well known examples include Rachel Hurst, Brenda Robbins, and Maggie Davis. Besides playing a key role in BCODP and DPI (Disabled Peoples' International) Rachel was a driving force within VOADL (Voluntary Organisations for Anti-Discrimination Legislation) formed in 1985 and now known as Rights Now. Brenda Robbins was the Central Coordinator for DPAA (Disabled People Against Apartheid) and Maggie Davis was a founder member of one of the first and most influential integrated living schemes in the UK - The Grove Road Scheme in Sutton on Ashfield. DPAA was set up in 1981, negotiations for the Grove Road project began in 1972 and the first tenants moved in in 1976.

To suggest that the disabled peoples' movement has been dominated by men is not only inaccurate but also denies the significant contribution that these and countless other disabled women have made to our understanding of disability. As might be expected, given the above, it is also not true to suggest that the experience of disabled women is absent from the literature on disability.

Take for example Paul Hunt's innovative 'Stigma: The Experience of Disability' a book of essays published thirty years ago and which, undoubtedly, contained the fertile seeds of what later became the social model of disability. Six of the twelve chapters were produced by disabled women. Similarly, eight of the contributors to Alan Sutherland's ground breaking 'Disabled We Stand', written in 1981, were women.

It is also the case that, in addition to the book cited earlier, several others have been published in the UK which deal specifically with the experiences of disabled women. Well known examples include Jo Campling's 'Better Lives for Disabled Women', 1978, 'Images of Ourselves', 1981, and Sue Lonsdale's 'Women and Disability', 1990. In addition there are several books from America and Canada dealing directly with this subject, as well as a wealth of material available in other formats such as chapters in books and articles in journals.

Jo Campling's work is particularly relevant for it focuses specifically on many of the issues which contemporary critics claim have been excluded from writings on disability. These include personal relationships, sexuality, motherhood and impairment. For example, in 'Images of Ourselves' a woman called Sue begins her contribution with the following statement: 'When I woke up on the morning of 1 June 1976 I did not know it was to be the beginning of the end. The end of freedom, spontaneity, social anonymity; the beginning of fear, pain, existential isolation..... the beginning of the descent into the world of the "social minority" '.

Now some might argue that this and other work is of less importance because it has not been produced by disabled people, or because it is not couched within a social model perspective. These are important points but it should be remembered that deciding who is and who is not disabled is a highly contentious issue.

Not all impairments are visible, and many seemingly non-disabled people who have written about disability have done so from a perspective of personal experience. For instance, although Jo Campling considered herself 'able bodied' in 1981 she grew up in a 'disabled family' - her mother contracted Polio at the age of three. It is likely, therefore, that she has as much insight, if not more, into the true meaning of disability than many of those writing about it today. Moreover, until very recently, many of the social model's disabled critics have not located their arguments within a social model framework and, as a result, have failed to make the crucial distinction between the experience of impairment and the experience of disability.

This brings me to the thorny question of the relationship between the experience of impairment and the social model of disability. It is frequently stated that there is no place in the social model for discussions of the experience of impairment in terms of 'pain, illness, depression and fatigue'.

Now it's important to point out that the social model of disability is, first and foremost, a focus on the environmental and social barriers which exclude disabled people from mainstream society. It makes a clear distinction between impairment and disability; the former refers to ***biological*** characteristics of the body and the mind, and the latter to society's failure to address the needs of disabled people. The social model, therefore, is a concerted attempt to focus on those aspects of disabled people's lives which ***can*** and ***should*** be changed

This is not a denial of the importance of impairment, appropriate medical intervention or, indeed, discussions of these experiences. Nor is it an assertion that once the barriers have been removed the problems associated with certain types of impairment will disappear - they won't. Indeed, I have never met anyone or read anything that suggested otherwise.

It's worth remembering too that impairment related experiences are unique to the individual; often people with very similar conditions experience them in very different ways. What is 'painful' or depressing for one person may be less so for another. People can only talk of their ***own*** experiences of impairment. This makes any notion of a 'social' model of impairment extremely difficult, if not impossible, to conceive.

What's more, there is, and always has been, literally thousands of books dealing precisely with the experience of impairments or, as some people prefer. 'chronic illness'. And many are written by people with the condition themselves - see for example 'Living With Chronic Illness' edited by Robert Anderson and Mike Bury, 1988.

But most of this writing is either 'sentimental autobiography or else preoccupied with the medical and practical details of a particular condition'. Hitherto, it has only served to endorse negative cultural stereotypes and, in so doing, detract attention away from the material and cultural forces which compound disabled people's disadvantage. Moreover, this work and the implications that flow from it are rarely mentioned by those who call for the inclusion of impairment within the social model of disability,

It has also been suggested that mentioning impairment in Disability Equality Training sessions is taboo. This again seems difficult to believe. According to 'Disability Equality Training: Trainers Guide', written in 1991 by two disabled women, Jane Campbell and Kath Gillespie Sells, experiential exercises are often used to illustrate the significance of the social model of disability following an initial training session.

A fictional case study designed to expose discrimination in the workplace, for example, begins with the following: 'James is a 29 year old British born man of Afro-Caribean descent. He has sickle cell anaemia, a painful intermittent recurring condition..'. Following this particular exercise the Guide gives the following warning to trainers: 'Within this case study there is evidence of heterosexism, racism, prejudice and ignorance about HIV and AIDS, in addition to disablism, and should only be used in the context of tackling ***all*** of these issues' - so much for the accusation that exponents of the social model ignore other forms of oppression.

It is generally forgotten too, that the disabled people's movement has, since its inception, always recognised and made provision for disabled people to talk about their experiences whether impairment or disability related. Several of the movement's core organisations were set up initially in response to impairment specific needs. The SIA (Spinal Injuries Association) is an obvious example. Indeed, one of the most important functions of CILs (Centres for Independent/Integrated Living) is to provide peer support and 'counselling' services for disabled people.

What is evident from all this is the fact that disabled writers and researchers are just as guilty as their non-disabled equivalents of misrepresenting the social model of disability and the impairment/disability equation. Contrary to the views of some of the new generation of disabled writers, acquiring an impairment does not automatically give someone an insight into the process of disablement or what the social model of disability is all about.

I believe that clarity about disability issues is especially important at this point in time because, unlike Vic Finkelstein, I do *not* believe that the battle to establish the social model of disability has been won. The NHS Community Care reforms and the Disability Discrimination Act, for instance, both of which have enormous implications for disabled people, approach disability from a decidedly traditional individualistic perspective.

In my view, disabled people and the disabled peoples' movement face an uncertain future and there is much to learn from the past. What we need, therefore, is more clarity not further muddying of the water by disabled writers and researchers who are driven by either ignorance or their own personal agenda.

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