Neglected Voices in Disability Studies: The case of older visually impaired people.

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In 2002 we were asked to review 15 research articles on visual impairment to be included on a large web site for social workers (see www.be-evidencebased.com). We were instructed that the articles must either be large experimental studies or large surveys of relevance to social workers. The research did not necessarily have to undertaken in Britain. We were also asked to write a short introductory paper to put the reviews in context (French and Swain 2002).

It was our inclination to review articles with a strong social model orientation but we quickly realised that very few articles of this type, specific to visual impairment, existed and virtually none involved large numbers of research participants. We only found one suitable article, for example, in *Disability and Society* which involved the opinions of visually impaired people on research into visual impairment.

As the Disability Studies literature provided us with few suitable studies for this task we made use of the RNIB reference library in London which purports to have the most comprehensive range of literature on visual impairment in Europe. Here we found sufficient material to satisfy our brief but it were largely medical and psychological in orientation and espoused an individual model of disability. Six of the studies were large surveys undertaken by the *Royal National Institute for the Blind* and seven were from the *Journal of Visual Impairment and Blindness* and covered such subjects as health, stress and psychosocial adaptation. Although we would not normally be drawn to surveys or experiments of this type we did learn a lot by reading them and realised, in particular, how older visually impaired people are neglected by society and are absent in the Disability Studies literature. Although the research could be criticised in many ways, not least for its individualistic orientation and its emphasis on personal adaptation, the findings had a definite affect on us (mainly in terms of anger) and left us feeling that findings such as these should not be ignored even though they do not sit comfortably within Disability Studies either in terms of their theoretical under-pinnings or in terms of who conducted the research, for instance a large and powerful charity.

We learned from the research we reviewed that, although 90% of visually impaired people are over the age of 60, and one in six people over the age of 75 are visually impaired, only 5% of the social service resources earmarked for visually impaired people are spent on people over 60. We were also struck by the poverty of older visually impaired people, particularly women. Over 70% of older visually impaired people are women (as they tend to live longer than men) and, as is well known, older women are more likely to live in poverty than older men. Older visually impaired people are also likely to have additional impairments. Visual impairment has always been poorly resourced in social services and the research we reviewed showed that older visually impaired people are particularly marginalised. Blindness is rarely total and, among older people, it tends to be viewed as inevitable and non-urgent. Only 12% of people who are registered blind are given any assistance in mobility or 'daily living' and these are mostly younger people. Visually impaired people are not usually thought of as 'mobility impaired' although 60% never go out alone and their housing needs are rarely given any attention. Thus poverty, lack of mobility, age discrimination, marginalisation and lack of support and assistance in, for example, mobility training, leads many older visually impaired people to become socially and emotionally isolated.

Implications for Disability Studies

Looking at disability studies and our own work within disability studies, one view of the position of older visually disabled people is that they are a neglected voice. Yet, the controversies in this arena are complex and encompass some seemingly intractable tensions. For the purposes of debate we shall attempt to characterise contrasting views, setting four interrelated questions.

Is disability studies inclusive of all disabled people?

On the one hand the social model applies to all disabled people. All people with impairments are disabled by the barriers they face in a disablist social world.

Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psychoemotional well-being. (Thomas 1999: 60)

On the other hand structural, environmental and attitudinal barriers are experienced differently by

different individuals and groups. The significant factors include age, age at onset of impairment and type of impairment. This is an interactive social model of disability – and from this viewpoint groups like older visually disabled people have not been included.

For some, the social model focuses too heavily, or exclusively, on socio-structural barriers (determining access to life's material necessities) and downplays or ignores the cultural and experiential dimensions of disablism (Thomas 1999: 24)

 How should we deal with knowledge which is underpinned by an individual model and funded by charities?

On the one hand the individual and charity models are inherently disablist. They have played a fundamental role in the oppression of disabled people.

The concept of charity, as defined by the courts, has an underlying social philosophy which has remained intact and has influenced the whole of our society's view of social welfare provision. Running consistent through the decisions is the idea of "bounty". "Bounty" in the legal context means more than just liberty. Preserved within it, like a fly in amber, is a concept of social relations in which some people are active agents and others just passive recipients. (Williams 1989: 42)

On the other hand information such as the numbers of older people who are visually impaired can be useful not only for influencing policy and service provision – but also for disabled activists. And when researchers talk with disabled people the social model can emerge (disabled people talk about the barriers they face). Furthermore the need to draw on the work of charities may be a direct reflection of the neglect of the voices of older visually disabled people within disability studies – social model research has not focused much on issues around old age.

How well does disability studies deal with excluded voices?

On the one hand there are dominant voices within the literature – male voices, voices of physically disabled people – and some voices are marginalised – people with learning difficulties, mental health survivors.

The academic literature of disability studies consistently privileges minority world accounts (especially those from Western Europe and North America) . . . Majority world perspectives do exist . . . However such contributions are rarely cited within the academic literature of disability studies. (Priestley 2001:3, 4)

On the other hand disability studies has been about the inclusion of excluded voices. As an academic discipline it has opened possibilities for excluded voices.

What was needed to open the door to the radically new approach of 'disability studies' was the infusion of ideas directly from the experiences of disabled people. (Finkelstein 1998: 32,35)

How well does disability studies deal with multiple oppression?

On the one hand postmodernists challenge the bipolarisation of categories of people. Points to fragmentation – recognition of diversity of oppression – including the notion that there are not two categories of people – those who oppress and those who are oppressed. People who are oppressed also oppress. The oppression experienced by older visually disabled people cannot be understood either simply in terms of age or in terms of visual impairment.

No meaningful analysis of multiple oppression can take place without an acknowledgement that Black disabled people are subject to simultaneous oppression and as a consequence of this we cannot simply prioritise one aspect of our oppression to the exclusion of others. (Begum 1994: 35)

On the other hand disability studies is borne out of the collective – the disabled people's movement and its 'big idea', the social model. It is the disablist society that is challenged within disability studies to make a better more inclusive social world for all – irrespective of age, gender, specific impairment, ethnic minority etc.

Disabled people have no choice but to attempt to build a better world because it is impossible to have a vision of inclusionary capitalism: we all need a world where impairment is valued and celebrated and all disabling barriers are eradicated. Such a world would be inclusionary for all. (Oliver and Barnes 1998: 62) References

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