Social Models as a Basis for Commissioning:
the social model, user involvement and services?

A summary of a 25 minute presentation given by Dr Colin Barnes at the 'Executive Seminar on User Involvement' , Midlands Hotel, Derby, 23 July 1996

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Over recent years a great many policy makers and health professionals have begun to talk about the significance of user involvement in the commissioning and delivery of services. This is due to a variety of factors; one of which is undoubtedly the fact that politicians from both the left and the right are no longer prepared to support the continued expansion of the welfare state in its present form (George and Wilding, 1994). In this presentation I want to address some of the key issues and implications of this development with particular reference to the social model of disability , disabled people's organisations' involvement in the commissioning process, and possible outcomes in terms of service delivery .

A Social Model of Disability?

Firstly, what we now refer to as the' social model of disability , emerged from within the disabled people's movement over two decades ago (UPIAS, 1976). And, although it has had a considerable influence on some policy makers and politicians, there remains a degree of confusion over what it actually entails. The 1995 Disability Discrimination Act, for example, with all its faults and, indeed, there are many (Barnes, 1996; NOG , 1996; Rights Now, 1996) is testament to the growing significance of this perspective.

Much of the confusion stems from recent debates about the supposed limitations of the social model. Probably the most important controversy concerns the relationship between the experience of impairment and the experience of disability .Briefly, several critics -some of whom are disabled
people themselves -have argued that the social model is desperately in need of overhaul. This is because, the critics claim, it undermines or denies altogether the significance of impairment in terms of 'pain, illness, depression and fatigue' and so on (Bury, 1996; Crow, 1992; Morris, 1991, 1996; Shakespeare, 1993; Williams, 1996).

Now it is 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 people with 'perceived' impairments.

Impairments in this context include the whole range of congenital and acquired conditions, illnesses, and abnormalities which supposedly mark disabled people out from the rest of the population. It is ironic, of course, that the latest Government research suggest that this includes one quarter of the general population, and the figures are almost the same for men and women (CSO , 1996) .

Disability , therefore, is about the systematic exclusion of disabled people from everyday life, Examples include the inability of schools and colleges to accommodate the needs of disabled children, discrimination against disabled workers in employment, a disability benefit system which does not cover the cost of living with impairment, housing, transport, public buildings and information systems which take no or little account of the needs of disabled people, and a culture which, in a variety of ways, denies the very existence of impairment and, of course, the experience of disability (Barnes, 1991; Oliver , 1990; Zarb, 1995).

Consequently, the social model of disability is a concerted attempt to focus attention 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.

Furthermore, the disabled people's movement has, since its inception, 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 disabled people's impairment specific needs. The SIA (Spinal Injuries Association) is an obvious example. Moreover, one of the most important functions of Centres for Independent/Integrated Living (CILs) is to provide peer support and counselling services for disabled individuals and their families (DCODP , 1986; de long, 1979).

It is also ironic that now when we think of user led initiatives we tend to forget this particular aspect of the movement's development. Evidence suggests that most service providers seem to prefer to opt for vast armies of professionally trained' experts' rather than disabled people or disabled people's organisations for this particular service (Finkelstein and French, 1993).

The Role of Disabled People's Organisations

Clearly then disabled people's organisations have a significant role to play in clarifying what is meant by the social model of disability , as well as providing peer support services for both the experience of impairment and the experience of disability .It should be remembered too that the importance of consulting disabled people and their organisations on disability issues has been recognised and, indeed, sanctioned ill a variety of Government publications since the Disabled Persons (Services, Consultation and Representation) Act of 1986.

But the first thing that needs to be clarified is what type of organisations are we talking about? This is important because, hitherto, many service providers have tended to consult traditional organisations *for* disabled people rather than the more representative organisations *of* disabled people (Warburton, 1990; Glendinning and Bewley, 1993).

However, it is sometimes difficult to decide which are and which are not representative organisations. Disability is big business and like everything else in our society people can make substantial profits out of providing services.

As a result, there is a growing number of so called 'disability' organisations, both at the national and at the local levels , which at first glance appear to be user led. Many are commonly known by acronyms rather than by their full title; thus, concealing their organisational structure. RADAR the Royal Associatio*n* *for* Disablement and Rehabilitation is a good example.

So we need to be sure, as best we can, what type of organisations we are dealing with. Organisations in which the ruling body is made up of predominantly disabled people who are fully accountable to their membership is probably the best guide. Well known examples include the Derbyshire Coalition *of* Disabled People (DCODP) and the Greater Manchester Coalition *of* Disabled People (GMCDP). There are many of these organisation operating in various parts of the country .The British Council *of* Organisations *of* Disabled People (BCODP) is Britain's national umbrella for these organisations. Its membership currently stands at 113 organisations representing over 400.000 disabled people (BCODP, 1996) – Information about these organisations can be obtained from the BCODP offices in Derby.

However, it may also be the case that service providers are sometimes reluctant to consult with disabled people's organisations because they often appear badly organised, amateurish, and unprofessional. Service professionals are generally professionally trained and, usually, the higher up the service provider hierarchy you go, the higher the level of training. Moreover , professionals like to talk to

other professionals; as a rule they don't like talking to people who don't know how to work the system: how to prepare reports, business plans, case conferences and the like.

But all too often disabled people's organisations, in common with most other user led organisations, appear badly organised because the overwhelming majority suffer from chronic and persistent underfunding. At the same time many disabled people, because of widespread discrimination in education and employment, do not have the skills, experience or inclination to organise themselves according to professionally determined criteria.

Furthermore, when disabled people's organisations are well organised and articulate about their needs they are accused of being unrepresentative of the disabled population as a whole (see for example Bury, 1996; Williams, 1996). But this is precisely the type of organisation that service providers should look to for identifying and commissioning services. After all it is these organisations that are responsible for putting the social model of disability, or the barriers approach, on to the public agenda, and it is these organisations that are best. placed to advise on how to deal with disability in terms of commissioning services .

Indeed, over the last couple of decades the most important and exciting initiatives in service provision have come directly from these organisations frequently working in close collaboration with forward thinking local authorities. Obvious examples include the 'seven needs' approach to service provision identified by DCODP in the early 1980s, integrated housing schemes, self operated personal assistance schemes, direct and third party payments schemes, and centres for independent/integrated living (CILs) (Campbell and Oliver, 1996; Davis and Mullender, 1993; Zarb and Nadash, 1995) .

It is fundamental, therefore, that disabled people's organisations are involved in the commissioning process, and where there are no such organisations local authorities can and should make appropriate resources available to encourage their development. Established disabled people's organisations can provide the right kind of support here too. The Derbyshire Centre for Integrated Living (DCIL), for example, has eleven years experience of this particular activity . And there are a growing number of 'guides' available such as 'Facilitating and Supporting Independent Living' (1996) by Jane Campbell and Fidelity Simpson.

It is important to remember too that setting up local organisations is not an easy task. In general, we are not a nation of 'joiners' ; we do not live in a participatory democracy and many disabled people. like their non-disabled peers, do not have the skills, confidence, nor the motivation to join and take an active part in

forming and running organisations - especially those which, in many ways, are confronting the political and professional establishment.

What Type of Services?

When discussing services for disabled people it is important to remember the crucial distinction between impairment related and disability related services. The former deal directly with medical concerns and the latter with economic, environmental, and social considerations. Historically, the two have frequently been bundled together. As a consequence health ' care' professionals have been charged, often willingly, with the sole responsibility for almost every aspect of disabled people's lives. The futility of .this approach is increasingly and depressingly clear. Professionals are expected to deal directly with issues over which they have little or no control, and disabled people become locked into a dependency creating cycle which is more often than not impossible to break.

All too frequently this results in severe depression and low self esteem among both groups but especially among the latter. Indeed, the limitations of the traditional individualistic medical approach to services for disabled people have been well documented by both disabled and non disabled writers since the 1960s (see for example Hunt, 1966).

So what type of services are needed? .It is important to point out here that many of the problems faced by disabled people require a political solution and are not and should not be the responsibility of the National Health Service (NHS) or, indeed, local authority social services departments (SSDs) .We need fully comprehensive and enforceable anti-discrimination legislation with which to tackle the numerous economic, environmental and social barriers which confront disabled people daily. In the absence of such a policy, however, services must be geared to the specific needs of disabled individuals and their immediate families.

In many ways the key to providing these services is the assessment process. As this is frequently an onerous task for everyone concerned, I will conclude this presentation with reference to a number of recommendations devised jointly by representatives of disabled people's organisations and local service providers at a conference staged by the Coventry Independent Living Group (CILG) and Coventry Social Services Department in May 1995. The purpose of the recommendations is to make the assessment process a more user friendly experience for all those involved, and to reflect more accurately the disabled individual's service needs. They are as follows:

'All service providers, care managers and social services departmental staff must have clear and concise Information and training about the meaning and. significance of independent living and the social model assessment process .

As many people involved in the assessment process will need appropriate training and support. This should be provided by user led organisations -particularly those with experience in this particular field.

The assessment process must be preceded by the provision of comprehensive and accessible information about maximising user options and choice on independent living.

Assessments must be user led but where appropriate support may be needed to enable people to do self-assessments. Here partnerships between local authorities and appropriate peer support/advocacy services are vital.

Assessments should be needs led rather than simply a narrow focus on personal care tasks. The goal of assessment must tie to empower disabled people to control their own lives and pursue their own lifestyle.

Assessment reviews should be subject to negotiation and should not take place without the consent of all concerned' .

(Barnes, McCarthy and Comerford, 1996, p.22).

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