The Disability Movement and the Professions

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The rise of the disability movement and the ideas that have emerged from it are raising key issues that the professions need to take on board. It is imperative that the professions respond positively to the social model of disability, independent living and civil rights and seek to open up a constructive dialogue with disabled people and their organisations.

Throughout the 20th century there have been two dominant perspectives that have shaped our perceptions of disability. The first of these was disability as a tragedy which has required the assistance of charity. The second has been disability as illness which has required treatment by medicine and its professional handmaidens. However, in the past 30 years and largely led by disabled people ourselves, these dominant perspectives have increasingly been challenged. Disabled people have argued that our problems are not caused by tragedy but by the failure of society to take account of our needs and therefore we need social change not charity. Additionally we have argued that illness and disability are not the same thing and most of our difficulties require changes to the environment and not individual medical interventions designed to cure or change us (Barnes and Mercer, 1996).

What we must recognize, however, is that disabled people have not only been critical of these dominant perspectives, but have also developed their own perspective to replace them. Central to this new perspective have been three big ideas which have emerged entirely from disabled people ourselves and the organizations we have created: these are the social model of disability, independent living and civil rights. These ideas have already had a big impact on, for example, those charities who have turned themselves into voluntary organizations and now speak in our name but without any legitimate authority so to do. The medical perspective on disability is also severely challenged by these ideas too, and it is the significance of this for professional practice which will form the basis for this article (Oliver, 1996).

THE SOCIAL MODEL OF DISABILITY

The social model emerged from the publication of a document called The Fundamental Principles of Disability published by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976. The document stated:

> ‘In our view it is society which disables physically impaired people. Disability is something imposed on top our impairments by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS,1976)’

The social model developed as an attempt to apply this insight in practice first to the training of social workers and second as the main mechanism for delivering disability equality training.

The main argument about the social model, and the one being presented here is that too much is invested in individually based interventions with ever-diminishing returns. As a consequence, modifications to environments tend to be neglected or under resourced when the potential benefits of such investments are much greater. To put it simply, providing a barrier free environment is likely to benefit everyone with mobility impairments as well as other groups (e.g. mothers with prams and pushchairs, porters with trolleys) whereas physical rehabilitation will only benefit those privileged enough to be able to access it. This is not an argument against rehabilitation per se, but about the efficient use of scare resources.

Clearly the adoption of the social model has profound implications for those professions whose practice is based upon one-to-one interventions because the social model is not about individual adaption or personal change. Indeed, it raises the question of whether there is a role for professionals at all? This question has to be placed in the context of the restructuring of the welfare state where it is becoming increasingly obvious that society, whether we can afford it or not is no longer willing to pay the full price for such expensive and often unproductive approaches to professional practice.

It is not my argument here that there is no role for such professions, but rather that their role must change and that professionals must work with disabled people to develop appropriate practice based upon the social model of disability. Indeed some 16 years ago I wrote a book (Oliver, 1983) designed to reconstruct social work practice on the basis of the social model but in it I warned that if social work failed so to do, it was liable to do itself out of business. When rewriting the book recently (Oliver and Sapey, 1999), it became obvious that social work had not heeded this warning and as a consequence, it is in severe danger of disappearing altogether. The social model poses the same threat and offers the same opportunities for other individually based professions such as occupational therapy, speech therapy and physiotherapy: do they want to adapt to a more relevant, productive and cost-effective form of practice or suffer the slow lingering demise that social work appears to be going through?

INDEPENDENT LIVING

At first glance it would seem that the big idea of independent living is one that both disabled people, professionals and even Governments would agree on. However, this is appearance rather than reality, as any analysis of policy and practice over the past 50 years will show (Oliver and Barnes, 1998). Governments, when promoting the idea of independent living, see independence as self-reliance and not being a burden on the state. The professions see independence as the ability to undertake the full range of self-care activities. Disabled people see independence in terms of personal autonomy and the ability to take control of all aspects of our own lives.

The differences between professional definitions and those advanced by disabled people often give rise to conflicts at the levels of both practice and policy. At the level of practice, in rehabilitation disabled people are exhorted to function with assistance of equipment; to push their own wheelchairs, to dress themselves, to toilet themselves, to shop and cook for themselves and so on. Disabled people, however, are much more concerned with being in control of the processes by which their personal mobility is ensured, to decide who will dress them, when and what clothes they will wear, what food will be bought, when and how it will be cooked and eaten and so on. Hence professional practice aims to give disabled people the skills to do these things unaided, while disabled people are increasingly setting up their own personal assistance schemes to employ others to do these things on our behalf and under our control (Barnes, 1993).

This conflict can also be seen at the level of services and policy. Professionals often set up or work out of independent living (CILs). To the uninitiated this might seem to be nothing more than a matter of terminology, but the reality of services offered is very different. ILCs are staffed by professionals and provide aids and equipment and professional assessments. CILs are staffed by disabled people and provide advice and support in respect of personal assistance schemes as well as peer advice and counselling. Furthermore CILs have become an integral part of what has come to be called the Independent Living Movement (ILM) which is now worldwide with CILs in Britain, across Europe, in the United States and Canada as well as Japan and Australasia.

This struggle between competing definitions of disability has also to be placed in the context of recent developments in social policy, notably the Direct Payments Act 1996. This legislation enables local authorities to give disabled people cash to provide their own services rather than rely on professionally dominated ones provided by the authorities themselves. When given this cash disabled people are using it almost exclusively to purchase their own personal assistance schemes rather than to buy professional services, seeing personal assistance as the key to ensuring autonomy and control in our lives (Hasler et al, 1999).

This is the vanguard of a policy trend which will gradually see the transfer of resources from expensive statutory services towards cheaper personal assistance schemes (Zarb and Nadash, 1995). It should not, however, be assumed from my argument in this section, that there is no role for professionals in these developments. But it remains a fact, unpalatable as it may be, that cash is the best way to give disabled people autonomy and control in their lives. It is a challenge to the professions and all professional to see whether they can adapt their practice to help disabled people to achieve the autonomy and control that disabled people want in our lives rather than to achieve independence in self-care activities. Failure to take up this challenge will, in my view, guarantee to many other professions a similar fate to that of social work.

CIVIL RIGHTS

The third big idea born out of the disability movement is that of civil rights. It evolved during the 1970s, despite the fact that many of the traditional disability organizations who now support the idea were denying that rights legislation was necessary at the time. It evolved because many of the rights that disabled people thought we had under existing welfare legislation, notably the Chronically Sick and Disabled Persons Act 1970, were being denied to us (Oliver, 1990; Barnes, 1991).

It might be thought from this that this has nothing to do with professional practice; that the issue of civil rights is a wholly political issue. However, it is an inescapable fact that professionals have acted as gatekeepers to the services provided by the welfare state through their assessment procedures, their management of budgets and the decisions they make about who will and who will not get services. It is often argued that, while this may be true, professionals are no more in control of all this than are disabled people. It is service managers and ultimately politicians who determine how much will be spent on which services and therefore ultimately responsibility lies with them.

While this is true to some extent, when confronted with decisions about scarce recourses, professional have usually sided with their management rather than with disabled people and our organizations in mounting political challenges to the unacceptability of such rationing. To put it bluntly, when professionals have addressed the question as to whose side they are on, they have sided with their employers rather than their clients and they have often put their own careers ahead of assessments of real need.

This will not carry on unchanged, particularly as successive governments have come to accept civil rights as a legitimate demand of the disability movement. So far their responses have been somewhat lukewarm, the DDA being only a pale imitation of what fully comprehensive civil rights legislation will look like. In addition, the new Disability Rights Commission is as yet an emasculated enforcement agency with little worthwhile to enforce. However, fully comprehensive fully enforceable civil rights legislation is the demand of the disability movement and there is no doubt that this will be achieved (Barnes et al, 1999).

When it is, it will include welfare legislation and those who gatekeep the services of the welfare state under its rubric. This will inevitably mean that professionals and disabled people will meet in the courts and will fully test the claims of the professions to be caring vocations rather than merely occupations. It is not too late to avoid this situation, and it is still possible for the professions and the disability movement to build meaningful alliances, but given the recent history of the relationship between the two groups, it is an urgent task to open up the necessary dialogues. If the professions are to re-establish themselves as caring vocations, it is imperative that they attempt to address the political dimensions of their work rather than merely continue as Government agents and administrators.

CONCLUSIONS

In this article I have argued that the existence of the disability movement and the ideas emerging from it are posing profound challenges to the existence of the professions and have radical implications for their professional practice. I have not written it from an antiprofessional position because I believe that disabled people should be entitled to the very best and most appropriate professional intervention in our lives and that disabled people and professionals exist in a state of mutual dependency.

What I have attempted to show, however, is that over the past 30 years disabled people have attempted to transform our own lives but that professional practice has been, by and large, untouched by this and thereby virtually unchanged. Given the current renegotiation of the role and position of the welfare state in society, most notably how and by whom professional services will be paid for, it is incumbent on the professions to adapt and change to these pressures from both above and below. Failure to do so might not quite be professional suicide but it will see the professions suffer a slow and lingering demise.

Barnes C (1991) Disabled People and Discrimination in Great Britain. Hurst and Co, London

Barnes C, ed. (1993) Making Our Own Choices: Independent Living, Personal Assistance, and Disabled People. British Council of Disabled People, Belper

Barnes C, Mercer G, eds.(1996) Exploring the Divide: Illness and Disability. The Disability Press, Leeds

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

Hasler F, Zarb G, Campbell C (1999) Direct Routes to Independence, Policy Studies Institute and National Centre for Independent Living, London

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

Oliver M (1990) The Politics of Disablement MacMillan, Basingstoke

Oliver M (1996) Understanding Disability: From Theory to Practice. MacMillan, Basingstoke

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

Oliver M, Sapey B (1999) Social Work with Disabled People. 2nd edn. MacMillan, Basingstoke

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

Zarb G, Nadash P (1995) Cashing in on Independence: Comparing the Costs and Benefits of Cash or Services. Policy Studies Institute, London

KEY POINTS

- Disabled people ad the organizations we have created have been extremely critical of existing services and the practices upon which they are based
- The disability movement has developed three big ideas of its own; the social model, independent living and civil rights
- The social model of disability poses important questions for one-to-one professional practice