

BOOK REVIEW

Independent Futures. Creating User-led Disability Services in a Disabling Society

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The social model of disability has been a great inspiration for people with disabilities and has had a positive impact on both disability policy and research into disability. An important result of the politicization of people with disabilities has been an increase in self-help groups and organizations controlled by people with disabilities. Opposition to the established services controlled by professionals and based on a culture of care is a main target for activism. Instead of care and dependency, people with disabilities claim independence and control over their services and their everyday life. Centres for Independent Living (CILs) are established, with a dual role as both service providers and political advocates for the rights of people with disabilities.

This book is based on the research project *Creating Independent Futures*, organized from the Centre of Disability Studies at the University of Leeds. The intention of the project was to assess the development of CILs and similar user-directed service organizations in the UK. The results of the project are based on case studies of nine organizations including interviews with a range of staff, and in-depth interviews with service users of the organizations.

Besides describing the project, the first four chapters give an historical account of disability policy in the UK (chapter 2), the history of disability activism and struggle for independent living (chapter 3) and a discussion of research on disability issues seen from a social versus a conventional research model perspective (chapter 4). Much of the information presented here has also been presented in former publications, both by the authors of the book and by other researchers representing the social model. Nevertheless, these chapters give useful background information and set up an informative frame for the project. It is interesting to note that the account of the social model, both in general and when the principles of research are discussed, shows a more varied view than the somewhat simplistic political proclamations that

have characterized some of the publications from the Disability Unit from the early 1990s.

The results from the project show, not surprisingly, a widespread consensus among service users that user-led services are preferable to professionally-led ones. In comparing the services they highlighted two main themes in particular: choice and control. User-led organizations were seen as far more responsive to their needs, both in terms of what was on offer and how it was offered. A significant reason underlying this pattern was that the majority of the research participants were involved with direct payments programmes (personal assistance). Running support schemes to enable people with disabilities to use direct payments is an increasing activity for the CILs. However, the fact that people with disabilities were also in control in running the organizations was widely described as a source of considerable satisfaction for the participants. User-controlled agencies were regarded as much more aware of, and consequently more responsive to, their individual needs. In addition, the formal and informal peer support individual service users received from other people with disabilities active in the organizations, was seen as a key factor in combating the social isolation that many people with disabilities encounter.

A dilemma, which I often find is dealt with superficially in literature with its basis in the social model, is the special problems that user-control raises for persons with impairments such as learning disabilities. This is also the case for this book. The authors are well aware of the problem, as they describe how disability politics from the very start had their basis in the organizations of people with physical impairments and have not sufficiently managed to include the interests of people with mental health problems and learning disabilities. However, the special problems and dilemmas such impairments raise for realizing user control are not discussed. For instance, nothing is mentioned about how the slogan of user-control in a market-based economy can easily blur the special needs for services that these persons have. The lack of inclusion is illustrated by the way the great majority of participants in the project have physical impairments, while very few report that they have mental health problems or learning difficulties.

A main theme of the book, and one of great interest, is the discussion about how user-led services have managed in the period of neo-liberal welfare policy, which has dominated the UK since the late 1970s, and, later, what dilemmas New Labour policy has created for user-led organizations. The social model is a radical theory with a strong anti-capitalist profile. At the same time, there is no doubt that neo-liberal policy created an agreeable climate for claims from the Disability Movement and the realization of user-led service organizations. On the surface, the goals of neo-liberal policy overlap with the goals of the Disability Movement with its importance attached to individual choice and an enhanced role for the consumer or service user. They are both concerned with efforts to improve services by enhancing responsiveness to expressed needs or preferences and to enhance users' control over the design, management and delivery of services.

In former books with their basis in the social model, this conflict or dilemma has, in my view, often been under-communicated or not been identified in a sufficient way. In this book, however, the authors make praiseworthy efforts to clarify the fundamental differences between the approaches and are eager to show the consequences of following the consumerist approach. A main difference is the individualistic approach, which is the basis of the neo-liberal model, while the Disability Movement states a distinct preference for the collectivistic position founded on the vigour of organized user groups. And the authors point out that, while the consumerist approach will contribute to make services more responsive, they will still be under the control of service providers and professionals. Removing disabling barriers in society is not on the agenda in the consumerist approach. The right to user-based services must therefore be reinforced by greater emphasis on human rights and equal citizenship. A clear distinction is drawn here between the New Right's view of citizenship, which stresses the restriction of state action as a way of advancing individual freedom and responsibility, and the Disability Movement's advocacy for a more interventionist state. Accordingly, the aim for disabled organizations should be to dismantle disabling barriers and generate a higher profile for the public sector in facilitating independent living support of needs.

However, in practice the dilemmas remain, as the proponents of the market-based model and the radical right-based approach meet in applauding the same models of services. Therefore, to mark out the distinctions clearly as indicated by the authors, represents an important challenge for the Disability Movement.

Another challenge is represented by the New Labour ideology of "mixed welfare", whereby private and voluntary organizations are encouraged to take on a much greater role in delivering services. A major role is intended for the organizations representing people with disabilities, the independent living type support services and user-controlled services. User-control, individual choice and partnership have all been important catchwords in official policy. This readiness of the Government to address disability issues and to incorporate the user-led services into the mainstream of local services has therefore opened up new possibilities. However, it has also raised political dilemmas for the user-led organizations. It allows increased autonomy to user-led organizations, but at the same time this is contained by central regulations, surveillance and funding control. A fear is that the user-led services could be taken over or "colonized" by traditional service providers and professionals. A couple of non-user-led organizations have gradually adopted the terminology of independent living to secure funding. At the same time the user-led organizations are small, recruit few people and are fragile. Funding is scarce, and the main source of funding is the local authorities. Many of the organizations experience a conflict between reconciling user-controlled principles with the harsh reality of securing finances.

The situation raises strong dilemmas for user-led organizations as to how strong their political profile should be. One consequence of political campaigning could be loss of funding and increased resistance from local

officials and professionals. Another problem could be that spending resources on campaigning could undermine the ability of the organizations to provide effective services. The authors here draw interesting comparisons with the development of the Independent Living Movement in the USA. By the 1990s commentators argue that while the CILs there have been in the vanguard of disability politics, most of them now do not hire politically active people and have no strategic views of how to effect social change. Many disability rights groups are apolitical, except for in narrowly disability related issues. They avoid demonstrations because they are considered outdated or because they would alienate funding resources.

As pointed out earlier, the social model and activities such as user-led services have inspired people with disabilities in many parts of the world and have had a great impact on disability policy. The experiences from the UK must be judged within the British welfare state model. Nevertheless, the development illustrates above all the general dilemmas that the Disability Movement face within different contexts. It clearly shows the dilemmas and compromises that easily arise when trying to implement a user-led philosophy and apply a social barriers approach to disability within a policy context dominated by an individualistic model and amidst other local and national political and economic constraints. More generally, it illustrates the dilemmas that social movements will meet to maintain their radical profile when their ideas and policies are incorporated into the mainstream political agenda.

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