

Research Articles

Independent Living, Politics and Policy in the United Kingdom: A Social Model Account

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Abstract: This paper provides a social model of disability inspired analysis of the philosophy of independent living and its implications for policy developments for disabled people in the United Kingdom. It is argued that the policy changes needed for disabled people's meaningful emancipation pose a direct challenge to current thinking on disability policy in particular and capitalist development in general.

Key Words: capitalism, independent living, politics

Introduction

Firmly rooted in the ideological and cultural traditions of western society, the notion of independent living, as used by the international disabled people's movement, represents a radical challenge to conventional thinking on disability. It encompasses both an ideological and practical solution to the everyday economic and social deprivations encountered by the overwhelming majority of disabled people and their families across the world. Also independent living has the potential not only to enhance the quality of life of people directly affected by disability, but also that of other structurally disadvantaged groups such as women, minority ethnic groups, lesbians and gay men, and older people.

To explain these claims further this paper will first examine orthodox thinking on disability and an alternative view emanating from disabled people and their organisations. Attention will then turn to the idea of independent living

and its impact on policy development. The final part will address the ideological, cultural and practical implications of these developments.

Orthodox Views of Disability and the Challenge from Disabled People and Their Organisations

There is a wealth of anthropological evidence that throughout history people with accredited impairments, who would today be considered disabled, have existed in relatively large numbers in all societies across the world. It is also evident that social responses to impairment and disability are historically, culturally and situationally variable (Hanks & Hanks, 1948; Scheer & Groce, 1988; Ingstad & Whyte, 1995).

Notwithstanding variations within Western culture, there is a discernable cultural bias against people with any perceived biological abnormality or flaw that can be traced back to the ancient world of the Greeks and Romans (Garland, 1995). Although variable both in form and degree at different times and in different locations across Europe during the dark ages and the feudal period, perceptions of impairment and disability have been fairly consistent since the Enlightenment and the industrial revolution of the nineteenth century (Finkelstein, 1980; Oliver, 1990; Stiker, 1998; Gleeson, 1999).

This bias is due to the ideological, cultural and material changes that accompanied capitalist development. During the eighteenth century, Enlightenment thinkers produced a range of progressive ideas including a critique of established religions, an emphasis on the value of rational science, a commitment to social progress, and the generation of philosophies of secular, rational self-interest such as Liberal Utilitarianism. Later, these ideas were compounded by the evolutionary theories of Charles Darwin and their use by Social Darwinists and the Eugenics Movement.

In the nineteenth century, industrialisation, urbanisation and the spread of wage labour further enhanced the problems faced by anyone either unable or unwilling to compete for employment in the newly formed factory-based work systems (Ryan & Thomas, 1980; Oliver, 1990; Barnes, 1991; Gleeson, 1999). Such people were scrutinised and categorised in various ways by doctors and related professionals and segregated from the community into long stay hospitals and various institutions. These policies proliferated throughout much of the Western world during the first half of the twentieth century. The eugenic legacy was particularly influential in many developed countries including the USA and Sweden. The eugenic impulse came to its logical conclusion in the death camps of Nazi Germany in the 1930s and 40s, with the systematic murder of thousands of disabled people considered a burden to the state and, therefore, unworthy of life. A more so-called humanitarian response to the problem of the growing problem of disability did not emerge until the post 1945 period (Drake, 1999).

Before the eighteenth century, impairment and any subsequent disablement was usually explained with reference to religious teachings and/or traditional superstitions, myths and legends from earlier times. Notwithstanding that these miss-interpretations are still evident in some circles, today the prevalent view is that impairment causes disability and that disability is an individual medical problem or personal tragedy with overtly negative economic and social consequences for the individuals concerned, their families and society as a whole.

Moreover, since impairments are the cause of the problem logic dictates that they must be eradicated, minimised or cured. But where cures are ineffective, which is more often than not the case, people with impairments who are labelled disabled are viewed as not quite whole, not normal, and incapable of participating in and contributing to the everyday life of the community. They are, therefore, in need of care. In many

countries this has resulted in the generation of a thriving and costly disability industry comprised of state institutions, private businesses, charities and voluntary organisations staffed by vast armies of professional helpers including doctors, nurses, therapists and social workers. The end result is that disabled people's assumed inadequacy and dependence is assured and reinforced. These perceptions were not seriously challenged until the 1960s and the emergence of the disabled people's movement (Campbell & Oliver, 1995).

Underpinning the political demands of disabled people and their organisations is a socio/political re-interpretation of disability widely referred to as the social model of disability. Originally devised by disabled activists in Britain, this approach derives from disabled people's direct experiences of living with impairment in Western society (UPIAS, 1976). Since its development in the 1970s, the social model has been increasingly accepted and adapted by disability groups throughout the world, and now underpins, either implicitly or explicitly, their thinking (WHO, 2001). It is also evident in disability related policies and initiatives in countries as diverse as Britain, the European Union and China (Stone, 1999; European Commission, 2003; Prime Minister's Strategy Unit, 2005) and the World Health Organization's recently devised "International Classification of Functioning Disability and Health" (WHO, 1999).

The social model of disability is nothing more complicated than an emphasis on the economic, environmental and cultural barriers encountered by people viewed by others as having some form of impairment. These barriers include (a) inaccessible education, information and communication systems, and working environments, (b) inadequate disability benefits, (c) discriminatory health and social support services, (d) inaccessible transport, housing and public buildings and amenities, and (e) the devaluing of people labelled as disabled by negative imagery and representation in the media – films, television and

newspapers. From this perspective, people with designated impairments are disabled by society's failure to accommodate their individual and collective needs within the mainstream of economic and cultural life (Barnes, 1991).

Although the social model has been linked to various theoretical approaches (Priestley, 1998) it is not, nor never was, conceptualised as a social theory of disability. The social model has provided the conceptual foundation for the development of a fully comprehensive materialist account of the social creation of disability, rooted in the work of Karl Marx and Antonio Gramsci and evidenced in the work of Vic Finkelstein (1980), Mike Oliver (1990), and Brendan Gleeson (1999). However, and in view of recent misrepresentations by some writers (Shakespeare & Watson, 2001; Watson, 2002), there are three main points that need to be reiterated about the social model of disability:

- 1) In contrast to the conventional individual medical/deficit model of disability, the social model is a deliberate attempt to switch the focus away from the functional limitations of impaired individuals onto the problems caused by disabling environments, barriers and cultures.
- 2) The social model is a holistic approach that explains specific problems experienced by disabled people in terms of the totality of disabling environments and cultures.
- 3) A social model perspective does not deny the importance or value of appropriate individually based interventions in the lives of disabled people, whether they be medically, re/habilitative, educational or employment based, but draws attention to their limitations in terms of furthering their empowerment and inclusion in a society constructed by non-disabled people for non-disabled people.

In short, the social model of disability is a tool with which to gain an insight into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication (Oliver, 2004). It is this train of thought that has influenced the concept of independent living as it is understood in the new millennium in the United Kingdom (UK) (Barnes, 2003).

Independent Living in the 21st Century

The phrase "independent living" first entered the English language in the 1970s, following its adoption by disability activists in the USA. What became known as the American Independent Living Movement (ILM) emerged partly from within the campus culture of American universities and partly from repeated efforts by American disability activists to influence US disability legislation. During the 1960s, some American universities had introduced various self-help programmes to enable students with "severe" physical impairments to attend mainstream courses. But these schemes were rarely available outside university campuses. This unacceptable situation prompted some disabled students to develop their own services under the banner of "Centres for Independent Living" (CILs).

Unlike other services *for* disabled people controlled by mainly non-disabled professionals, these new CILs were self-help organisations exclusively run and controlled by disabled people. Further, in contrast to other professionally dominated provisions that focused almost exclusively on medical treatments and therapies within institutional settings, effectively removing disabled people from everyday life, CILs provided a new and innovative range of services and support systems designed to enable people with impairments to adopt a lifestyle of their own choosing within rather than apart from the local community.

Subsequently, the phrase “independent living” has had a considerable impact on disability policy throughout the world. Disabled people and representative organisations are increasingly involved in the development of disability policy at both the national and international level. Also, there are now CILs or similar user controlled organisations providing services and support for disabled people and their families throughout Britain (Barnes, Mercer & Morgan, 2000) and many countries across the globe (Charlton, 1998; Alonso, 2003).

Part of the reason for this apparent and unprecedented success is the almost universal appeal of the concept of independent living within Western culture. The term is apolitical in the sense that it appeals directly to advocates of the politics of the right and of the left, and it is political in that the environmental and cultural changes needed to facilitate meaningful independent living for disabled people will benefit everyone regardless of impairment or status.

Early exponents of independent living allied themselves with the radical consumerism of the 1960s and 70s. Consequently, the independent living movement has a particular appeal to proponents of the ideological cornerstones of capitalist development such as economic and political freedom, consumer sovereignty, and self-reliance. This realization prompted some critics to suggest that the philosophy and policies of the ILM favoured only a relatively small section of the disabled population; notably, young, intellectually-able, middle-class white males (Williams, 1984).

This is, however, a misrepresentation of what the term independent living has come to represent. Indeed, though they are often characterised as providing services for people with physical impairments only, historically, CILs have struggled to provide services for all sections of the disabled community. Where they have not, this is usually due to limited resources, material and human, and/or entrenched opposition from

vested interests within traditional disability service providers.

Furthermore, in view of the dangers of misinterpretation, some disability activists, particularly in the UK where social model thinking is especially influential, have adopted the terms “integrated” or “inclusive” living rather than the original “independent” living to characterise the philosophy on which their activities are based. Such terms have a far greater appeal to the left of centre elements within Britain’s disabled people’s movement. They recognise that humans are by definition “social” beings, and that *all* humans, regardless of the degree and nature of impairment, are interdependent and, therefore, that a truly independent lifestyle is inconceivable (Barnes, 2003).

From this perspective, the ideologies and practices that justify the systematic oppression of people with impairments within capitalist society are similar to those that legitimise the oppression of other disadvantaged sections of the population such as women, minority ethnic groups, lesbians and gay men, and older people. Taken together, they represent an increasingly costly and complex barrier to the development of a truly meaningful inclusive and representative democracy.

Due largely to the intensifying politicisation of disability by disabled people and their organisations during the 1980s and 90s, both in the UK and elsewhere, the phrase “independent living” has been increasingly evident in policy documents produced by health and social service professionals in the context of “community care” services for disabled people. Usually focusing on professionally-led assessments of functional ability and inability, these initiatives bear little resemblance to the principles and practices of the international disabled people’s movement. It is therefore important in the context of political and policy analysis to establish clearly the fundamental principles of independent living according to the writings of disabled activ-

ists, their organisations and supporters around the world.

Despite terminological differences there is general agreement amongst disabled activists and their allies that the philosophy of independent living is founded on four basic assumptions. These include:

- 1) That all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth;
- 2) That anyone, whatever the nature, complexity and/or severity of their impairment, has the capacity to make choices and should be enabled to make those choices;
- 3) That people who are disabled by societal responses to any form of accredited impairment – physical, sensory or cognitive – have the right to exercise control over their lives, and
- 4) That people with perceived impairments who are labeled “disabled” have the right to participate fully in all areas, economic, political and cultural, of mainstream community living on a par with non-disabled peers (Bracking, 1993; Morris, 1993; Charlton, 1998; Barnes, 2003).

Discussion: A Way Forward?

Clearly the concept of independent living is a broad one that encompasses the full range of human experience and rights, including the right to be born with access to appropriate medical treatments as and when they are needed. Moreover, although independent living is commonly associated with disabled people with physical or sensory conditions in the younger or middle age groups, it applies to all sections of the disabled population. This includes people with complex and high support needs, people with cognitive conditions who are labelled in various ways (“learning difficulties”, “behavioural difficulties”, “mental illness”, etc.). Equally impor-

tant, disabled activists have long since pointed out that disabled women, disabled lesbians and disabled gay men, disabled people from minority ethnic groups, disabled children and older disabled people are particularly disadvantaged due to sexism, heterosexism, racism, ageism and other forms of structural oppression and prejudice.

Furthermore, people with designated impairments, however defined, will always experience varying degrees of economic, political and social disadvantage in societies organised around the core capitalist values of individual self help, economic rationality, and the profit motive. In the current socio/political context, in order for disabled people to secure an independent lifestyle, they are required to make a considerable effort. Hence, we need to re-configure the meaning of work for disabled people with complex and comprehensive support needs (Oliver & Barnes, 1998; Abberley, 2002; Barnes, 2003).

To pursue the goal of a “society in which all disabled people are able to participate as equal citizens” (DRC, 2004), we must generate a cultural environment that places the needs of the many on a par with those of the few, and rejects the market led policies of the past. We must also celebrate rather than denigrate the meaning of social welfare, and the state’s role in its provision (Oliver & Barnes, 1998). This is not to suggest that we need more of the traditional top-down approach to state welfare; quite the reverse. There is mounting evidence, from a variety of sources, that conventional professionally-led services are counter productive both in terms of the effective use of resources, financial and human, and the elimination of dependence.

What is needed is a significant shift away from Government support for services controlled and run by professionals and non-disabled people, whether they be state-run or in the voluntary sector, and far greater investment in user-led initiatives at both the national and local levels.

Two notable examples in the U.K. include direct payments to disabled individuals, and the network of user controlled service providers and advocacy groups known variously as Centres for Independent, Integrated, or more recently, Inclusive Living: namely, CILs. The former allows the disabled individual to devise, pay for and, therefore, control their own support systems including the employment of personal assistance according to their own requirements. As in many countries across the world, Britain's CILs provide a range of services for disabled people, their families and related professionals. Examples include user-controlled information, advice and peer support systems, self-operated personal assistance schemes, personal assistant users' support groups, and advocacy and campaign groups. The general ethos of these organisations is to enable people with impairment/s, regardless of cause, to achieve an independent lifestyle of their own choosing and commensurate with that of non-disabled peers (Barnes, Mercer & Morgan, 2000).

Moreover, given that thousands of disabled people across the UK are denied the chance to achieve independent living due to the reluctance of many local authorities to implement a direct payment policy (Glasby & Littlechild, 2002; CSCI, 2004) (legalised under the 1996 "Community Care [Direct Payments] Act", following years of lobbying by disabled people's organisations [Hasler, Campbell & Zarb, 1999]), the distribution of direct payments should be centralised. This could be achieved by setting up a new national body accountable directly to the National Centre for Independent Living (NCIL), an organisation controlled and run by disabled people that emerged from within and is accountable to Britain's CIL movement.

Besides the distribution of direct payments, this new national body could have two further roles; first, to produce an appropriate and standardised assessment procedure for accessing direct payments and, second, to develop and support the nationwide network of locally-based

user-controlled agencies and groups providing services for local direct payment users. To fulfil these roles, NCIL would naturally draw on the wealth of experience that already exists amongst its member organisations, many of whom have been providing these and similar services for more than twenty years (Barnes, 2004).

To achieve a lifestyle comparable to non-disabled peers, disabled people need far more than simply user-controlled services. To attain Independent living disabled people need equal access to mainstream schools, jobs, transport, houses, public buildings, leisure etc. or all the things that non-disabled people take for granted (Bracking, 1993, 14). It is a goal that is far from being achieved despite the introduction of the U.K.'s 1995 Disability Discrimination Act and subsequent amendments. It will be necessary to strengthen and enforce the law and ensure that people with an awareness of disability and "independent living" issues are integrated fully into *all* Government Departments at *all* levels, nationally, regionally and locally. The aim is to initiate and develop effective policies with which to eradicate the various barriers to inclusion in *all* areas of economic and social activity and, in so doing, usher in a further stage in the on-going struggle for a truly equitable and inclusive society.

It is inevitable that this strategy will have significant implications for those charged with the responsibility for managing the economy, as effective barrier-removal will prove costly. But these short-term costs must be offset against the long-term gains of a barrier-free environment in which socially created dependence is considerably reduced if not eliminated altogether. Moreover, whilst such a policy may fly in the face of recent economic and political trends in Britain and elsewhere, it is important to remember that any notion of an inclusive and equitable capitalism is unrealistic and unachievable. And that over recent decades the gulf between the rich and poor has increased rather than decreased within and across nation states, environmental instabil-

ity remains unchecked, and political and social uncertainty has intensified at both the national and international levels. If these tendencies are not to intensify further it is high time that politicians and policy makers, both in Britain and throughout the world, acknowledge this fact and take appropriate steps to develop a meaningful and just alternative.

For disabled people this alternative must be a society in which all human beings regardless of impairment, age, gender, sexual orientation, social class, minority ethnic status can coexist as equal members of the community, secure in the knowledge that their needs will be accommodated in full and that their views will be recognised, respected and valued. It will be a very different society from the one in which we now live. It will be a society that is truly democratic, characterised by genuine and meaningful equal opportunities and outcomes with far greater equity in terms of income and wealth, with enhanced choice and freedom, and with a proper regard for environmental and social interdependence and continuity.

The creation of such a world will be a difficult arduous process and progress toward its construction will be inhibited by cynics who will argue that such a world is unachievable, and little more than a utopian dream. However, as Oscar Wilde so cogently pointed out over a century ago in *The Soul of Man Under Socialism* (first published in 1990):

“A map of the world that does not include Utopia is not even worth glancing at, for it leaves out the one country that Humanity is always landing. And when Humanity lands there, it looks out, and seeing a better country sets sail. Progress is the realisation of Utopias”
(Wilde, 1966, 1090).

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(Other relevant literature can be downloaded free from the Disability Archive UK at: <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>)

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Leprosy in South India: The Paradox of Disablement as Enablement*

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Abstract: Rooted in ethnographic fieldwork with people affected by leprosy in India, this article argues that certain impairments, in certain social contexts, are simultaneously disabling *and* enabling. This paradox poses difficult challenges, not only for those working with individuals affected with leprosy, but for disability activists and policy-makers.

Key Words: social anthropology, leprosy, South India

Introduction

A clawed hand, with missing or deformed digits, and a face distorted by a sunken nose speaks unambiguously, in most parts of the world, of leprosy. It is the presence of these corporeal signifiers of untreated leprosy that, in the Indian context at least, stigmatises the person affected with leprosy as “a leper” and sees him, or her, barred from many social spaces. Prevent bodily difference, runs much contemporary thinking within leprosy aid agencies, and the person with leprosy will be able to continue with life as usual, rehabilitated within the community, rather than rejected from it. What such a perspective misses, however, is that the same clawed hand and distorted face that provokes social ostracism might also serve as a vital resource for collecting alms and for accessing other benefits. It is this paradox, and its ramifications, that this article sets out to address. It will argue that, in certain contexts, commonly accepted meanings attributed to disability, including those defined by the social model (Oliver, 1990), do not fit with the lived experiences of disabled people. This has important implications both for disability theory and activism.