

Independent Living, Politics and Implications

October 2004

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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 this presentation 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 and Hanks 1948; Scheer and Groce 1988; Ingstaad and 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 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 and 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 '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 mis-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 and 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 and 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 and policies in countries as diverse as Britain, Japan, South Africa and the USA (see for example, WHO 2001).

This is mainly because 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 inaccessible education, information and communication systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, housing and public buildings and amenities, and the devaluing of people labelled '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).

In view of recent misrepresentations by some writers (Shakespeare and 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, it 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) It is an holistic approach that explains specific problems experienced by disabled people in terms of the totality of disabling environments and cultures. This includes inaccessible education, information and communication systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media – films, television and newspapers.
- 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 (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 themselves. Further, in contrast to other professionally dominated provision that focused almost exclusively on medical treatments and therapies within institutional settings that effectively removed 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 and 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. It 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, it 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.

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 mis-interpretation 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 peoples movement who 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 populations 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 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 activists, 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 and labelled '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 and labelled in various ways; examples include with 'learning difficulties', 'behavioural' difficulties', or 'mental illness'.

Equally important 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 therefore for disabled people to secure an independent lifestyle requires considerable effort and work on their part. Hence, we need to re-configure the meaning and organisation of 'work' for disabled people with complex and comprehensive support needs (Oliver and Barnes 1998; Abberley 2002; Barnes 2003).

Consequentially 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. It must

also celebrate rather than denigrate the meaning of social welfare, and the state's role in its provision (Oliver and 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; in particular, direct payments, and the nation wide network of user controlled service providers and advocacy groups commonly referred to as CILs.

Moreover, given that thousands of disabled people across the UK are denied the chance to achieve independent living due to many local authorities reluctance to implement direct payment policy (Glasby and Littlechild 2002; CSCI 2004), 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).

Besides the distribution of direct payments, this new organisation 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).

Notwithstanding that 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 1995 Disability Discrimination Act and subsequent amendments.

Consequently, to resolve this unacceptable situation 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.

Whilst such a policy may fly in the face of recent economic and political trends, it is important to remember that any notion of an inclusive and equitable capitalism is unrealistic and unachievable. Over recent decades the gulf between

the rich and poor has increased rather than decreased, and the consequences of unchecked capitalist development, in terms of environmental instability and political and social uncertainty has intensified at both the national and international levels.

If these tendencies are not to intensify further then it is high time that politicians and policy makers, both in Britain and throughout the world, acknowledge this fact and take steps to develop a meaningful and just alternative.

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