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Independent Living, Politics and Implications

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Independent Living, Politics and Implications

Abstract
[Excerpt] The idea of 'independent' living as used by the disabled people's movement around the world is a radical concept firmly rooted in the ideological, cultural and pragmatic traditions of western society. It is a radical concept because it poses a direct challenge to conventional thinking on disability and combines both an ideological and practical solution to the everyday environmental and cultural problems encountered by disabled people and their families. Furthermore, the notion of '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.

In order to explain these claims this paper is divided into two main sections. The first part will examine orthodox thinking on disability and an alternative perspective developed by disabled people themselves. The second will focus on the concept of independent living and its impact on policy development. The conclusion will address the ideological, cultural and practical implications of these developments.

Keywords
disability, discrimination, independent living, policy development, public policy

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Independent Living, Politics and Implications

by Colin Barnes, 2003

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Colin Barnes is Professor of Disability Studies and Director of the Centre for Disability Studies in the Department of Sociology and Social Policy at the University of Leeds, England. **In this chapter of the book he gives a concise explanation of orthodox thinking on disability and an a different perspective developed by disabled people themselves. He then examines the concept of independent living and its impact on policy development.**

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Introduction

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

Conventional Thinking on Disability and the Challenge from Disabled People and their Organisations

There is substantial anthropological and scientific 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 quite evident that societal responses to impairment and disability are historically, culturally and geographically variable (Ingstaad and Reynolds-Whyte, 1995).

However, there is a general consensus that within western culture there is a discernable cultural bias against people with any form of perceived biological 'abnormality' or 'flaw' that can be traced back to the ancient world of the Greeks and Romans (Garland, 1995). Whilst there has been some variation, 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 (Stiker, 1998).

This transformation is attributable to the ideological, cultural and material changes accompanying capitalist development. During the eighteenth century Enlightenment thinkers developed 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 (Oliver, 1990).

Such people were scrutinised and categorised in various ways by the burgeoning medical profession and segregated from the community into various residential institutions and long stay hospitals. 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, R. 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, nurses 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).

During the eighteenth, nineteenth and twentieth centuries civil, political and social rights were gradually, and often grudgingly, extended to various sections of the population throughout Europe and North America. Also, as a result of the economic regeneration in the post 1945 years, many people were able to secure a higher standard of living than previous periods. But equal rights and affluence were not distributed equally or fairly in most countries of the western world. This generated a period of growing political unrest in many nations, and the emergence of various trans-national civil rights movements composed of structurally disadvantaged groups. These included women, minority ethnic and racial communities, lesbian and gay groups and disabled people.

Underpinning the political demands of the international disabled people’s movement 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 a modern 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 Rethinking Care from Disabled People’s Perspectives, 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 impairments are disabled by society’s failure to accommodate their individual and collective needs within the mainstream of economic and cultural life.

The social model of disability does not ignore questions of impairment and/or the importance of medical and therapeutic treatments. Advocates adapt a holistic approach to impairment in recognition that all impairments have both psychological and physiological implications, and acknowledge that appropriate medical interventions are necessary and often beneficial, but maintain that these should never overshadow the need for radical social change to facilitate disabled people's meaningful inclusion into the mainstream of community life (Barnes and Mercer, 2003).

It is this train of thought that has influenced the concept of 'independent living' as it is understood in the new millennium.

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 organisations 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.

As we shall see throughout the rest of this book, 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 international and national levels. Additionally, there are CILs or similar user controlled organisations providing services and support for disabled people and their families in many countries across the globe (Charlton, 1998).

Part of the reason for this apparent and unprecedented success is the almost universal appeal of the concept of 'independent living' within the context of 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. 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.

But 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 peoples 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: first, that all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth; second, 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; third, 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, fourth, 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).

Conclusion

Clearly then the concept of ‘independent living’ is a broad one that encompasses the full range of human experience and rights. It follows therefore that regardless of the nature and complexity of impairment disabled people should have the right to be born and have access to appropriate medical treatments as and when they are needed. Other rights include the right to be educated alongside ‘non-disabled peers, equal access to work, leisure activities, political institutions and processes, the right to personal and sexual relationships and parenthood, and to participate fully in community life. Further, although the disabled people’s movement is commonly associated with disabled people with ‘physical’ or ‘sensory’ conditions in the younger or middle age groups, advocates of the ‘independent living’ philosophy are quite clear that it applies to all sections of the disabled population in all countries across the world. 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 point 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, hetrosexism, racism, ageism and other forms of structural oppression and prejudice. Consequently, to enable all disabled people to achieve a meaningful autonomous lifestyle necessitates the eradication of all forms of structural and cultural disadvantage. This has obvious and wide-ranging economic, political and cultural implications for all nation states particularly within the context of the ever increasingly interdependent global society of the 21st century.

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