

## **Independent Living for Disabled People: A Policy Initiative That Can No Longer Be ignored.**

*(Draft of an article prepared for the magazine 'Community Care' in November 1992. The article was never published).*

Sue is a disabled woman with muscular dystrophy. An electric wheelchair user in her mid thirties, she lives alone in her West Yorkshire home by employing personal assistants (PAs) - 'carers' - using a combination of her own money and state funding. David is eighteen years old and has a similar condition. He lives with his parents in Dundee and is reliant on them for essential services. Currently at college, David hopes to employ his own PA and leave home as soon as he finishes his studies.

Sue and David both attended Britain's first national seminar on Independent Living and Personal Assistance Use staged by the British Council of Organisations of Disabled People (BCODP) at Herewood College Coventry on 7, 8, and 9 August. The event brought together eighty five disabled people and their PAs from all over England, Scotland and Wales to discuss and develop further principles for independent living with particular reference to self operated personal assistance schemes.

This truly memorable event was organised solely by disabled people for disabled people. Accommodation was provided free of charge and the BCODP supplied PAs for participants who were unable to bring their own. The agenda included talks and workshops on independent living, equal opportunities, financing personal assistance schemes, employing a PA, the user/PA relationship, and the role of Centres for independent/integrated living (CILs) in the development of PA services. Only two of the nine speakers were non-disabled people: a representative from the Independent Living Fund (ILF) gave a talk on funding, and one of the PAs ran a workshop on PA agencies. The BCODP will publish a report later this year.

Of the many important issues raised at the seminar, major concern was expressed by all participants - both users and PAs - over the apparent lack of support for independent living for disabled people from service providers in both the public and the private sectors.

It was felt that this is largely because most professionals still explain the difficulties encountered by disabled people in terms of the traditional individualistic medical view of disability and, as a result, have little understanding of what independent living actually means.

A product of the nineteenth century, the medical approach to disability suggests either explicitly or implicitly that the physical and psychological effects of impairment are so traumatic for the disabled individual that they are unable to achieve a reasonable standard of living by their own efforts. Not surprisingly, this view is rejected by an increasing number of disabled people and their organisations as an adequate basis for understanding the problems associated with impairment.

They rightly argue that it is not impairment which prevents people from achieving a reasonable lifestyle, but restrictive environments and disabling barriers. Thus, 'disability' represents a complex system of social constraints imposed on people with impairments by a highly discriminatory society; to be a disabled person means to be discriminated against. The problem is worse for disabled members of the gay and lesbian communities, disabled black people, and women with impairments. At the core of this discrimination lies the erroneous assumption that disabled people are incapable of running their own affairs.

'Independent living', on the other hand, is a direct challenge to that assumption. Here the term 'independent' does not refer to someone who can do everything themselves, a feat no human being can achieve, whether they have an impairment or not, but refers to a philosophy which allows disabled people to control and choose their own lifestyle in the same way that non-disabled people do.

The concept evolved out of the groundswell of initiative from within the disabled community during the 1960s and 1970s; the impetus for which stemmed from a widespread disillusionment with existing provision and its tendency to focus on people's impairments rather than on the factors which disable them. Much of the inspiration for this development came from abroad - particularly the United States.

Severely critical of existing services and the way they were managed disabled Americans established a more appropriate alternative controlled and run by disabled people themselves. 'Independent living', therefore, is not simply a philosophy but a practical solution to the problems faced by disabled people. It is a metaphor for a range of services designed to give disabled people the same rights and opportunities as non-disabled peers.

Inevitably, the American 'Independent Living Movement' (ILM) had a profound influence on disabled people worldwide. Subsequently, organisations controlled and run by disabled people providing similar

services proliferated in both developed and undeveloped countries. They came together in 1981, the International Year of Disabled People, to form Disabled People's International (DPI).

In Britain, the spread of self organisation during the 1970s resulted in the formation of the BCODP - also in 1981. A member of DPI from the outset, the BCODP now represents over 82 organisations with over 250.000 disabled members. Since its inception, and with little financial support from Government or from traditional disability organisations, the BCODP and its member organisations have spearheaded the campaign for disabled people's rights, and produced a wealth of policy initiatives which make independent living for disabled people a meaningful reality.

These include policies on the provision of appropriate and accessible information, counselling services, accessible housing, accessible transport, technical aids and equipment, physical access and, of course, self operated personal assistance schemes.

They are initiatives which enable disabled individuals free themselves from unnecessary and costly bureaucratic regulation and control; to earn a living rather than live off the state; to expand their role as consumers; and to achieve a degree of personal autonomy comparable to that of non-disabled people. Their implementation is no longer simply a moral imperative but an economic one also.

Britain, in common with several other western democracies, faces an unprecedented 'care' crisis due to our rapidly ageing population. It is essential, therefore, that service providers in both the public and private sectors take appropriate steps to make independent living possible for all those who seek it. Clearly, a failure to do so will not only have dire implications for disabled people like Sue and David but for society as a whole.

**Dr Colin Barnes**  
**British Council of Organisations**  
**of Disabled People**  
**Department of Social Policy and**  
**Sociology**  
**University of Leeds**