**The Politics of Independent Living: Keeping the Movement Radical**

by Ken Davis

A forthcoming seminar[[1]](#footnote-1) on the philosophy and politics of independent living at the Centre on Environment for the Handicapped, could well open up a productive debate on a subject which has considerable emotive content for both disabled people and professionals in Britain. The seminar has to some extent been simulated by a recently published paper by Gareth Williams which attempts to criticise Gerben De Jong’s analyses of the Independent Living Movement (ILM) in the United States. He attempts to do this whilst at the same time avoiding being seen as an apologist for the oppressive status quo which denies disabled people the **full participation and equality** which was the banner of the International Year of Disabled People, and which relegates them to second-class social status along with blacks, women, homosexuals and other minorities.

The seminar raises important political issues for the disabled people’s movement in this country. A growing number of elements of this movement are working actively to set up Centres for Independent Living (CILs) and others are actively forming coalitions at the local level, notably in Greater Manchester, Nottinghamshire and Derbyshire. The British Council of Organisations of Disabled People (BCODP) is bringing together national organisations run by (rather than for) disabled people in an increasingly supportive relationship to this ‘consumer’ groundswell.

It is a point of particular political significance for our movements that we exert greater influence upon debates of this nature. By this I do not mean that we should attempt to stifle debate. But it is vital that those people who do get involved - particularly non disabled people – recognise that their contribution will ultimately be counter-productive unless it builds on the self-help and capacity of disabled people themselves. The key question for them is this: do their efforts promote control by disabled people over their own lives? No matter how well meaning; no matter how ‘expert’; no matter how well informed the contributors may be: it will in the final analysis work against the interests of disabled people if this key question is not properly addressed.

The reason for this lies in the reality of the relationship between disabled people as a group and non-disabled society. An objective examination of this relationship reveals that disabled people are, at almost every turn, restricted or excluded from full social participation. There have course been changes in this relationship over recent years. Nevertheless, it is still overwhelmingly the case that we are starved of access to basic information; have difficulty obtaining well-designed housing; are often denied appropriate aids and equipment; are extremely lucky if we have flexible and comprehensive sources of secure personal assistance; are largely excluded from public transport; and still hold a dream of a barrier free built environment. Over three years on from the International Year, we are still as a group denied full participation and equality in our own society.

The decisions which have led to this state of segregation have historically been made for us by non-disabled people, as they still are. Traditionally they have come to control our lives. The disabled people’s movement worldwide represents our struggle against this form of oppression. Our aim of full participation under quality for all disabled people is of course also shared by our non-disabled supporters. But - no matter how well intentioned this support - no one can participate **for us**; no one can be equal on our behalf. Disabled people themselves are the **only** people who can translate this aim into a reality. That is why the struggle has to be led by disabled people. There is no other way.

Increasingly therefore, the nature of the relationship between disabled people and bodies like CEH, or individuals such as De Jong and Williams, will be measured by the degree of control consciously transferred to disabled people by their activities. They do not operate in a political vacuum, put in the context of a society which demands from disabled people are leading participative role. Now the disabled people’s movement in Britain is becoming increasingly organised, the opportunities for transferring control are becoming more and more available. Derbyshire County Council are one example of the practical ways in which this can be done, in relation to the Derbyshire Coalition of Disabled People. Such support clearly does not lead to an instant change of heart for everyone. In the same way that revolutions always breed counter-revolutions, all progressive actions stir up forms of reaction. This activity helps to clarify issues, which can in turn help to ensure that our movement can become radical rather than merely cosmetic.

# **Recognising reaction**

In Derbyshire, it has always been the intention of the Coalition to encourage debate about the ILM, as a means of clarifying some of the issues it raises for disabled people here in Britain. We recognise that the ILM is the American counterpart of an aspect of the work of the movement in Britain over the last two decades. We share with our American colleagues the same imperative to gain control over our own lives. When Gerben De Jong singles out this imperative as a feature of independent living viewed as an analytic paradigm, we are able to identify with it. After all, this is what we are about. While ever we are deprived of the opportunity to control decisions which directly affect us, we will remain deprived of the full participation and equality which is rightfully ours.

William’s critique of De Jong certainly helps to clarify some fundamental issues facing our movement here in Britain. It has two main prongs: first that the free market, pluralist ideology De Jong appears to accept is myopic inasmuch as it leaves social and economic inequity fundamentally undisturbed and second that his research methodology is unsound. Both charges are sufficiently substantial to raise the temperature of the CEH debate, all part of the ethos surrounding the Seminar. Bringing the issues down to earth and sharing them with the widest audience of disabled people, does not however appear to be a major consideration, either for the principal participants or the organisers. Whilst apparently little can be done about numbers who can attend (limited to thirty), we can hope that the debate is couched in language a little less obscure than that employed by Williams in his critique. However, it is to this critique which disabled people must turn, if we are to discover whether, in political terms, his perspective on the Independent Living Movement is progressive or reactionary.

When Williams advises De Jong that he needs “a sociological perspective” in order to understand disablement as something more than an individual problem and that we need to “define our handicap in sociological terms” to improve our political understanding, disabled people have got to be very careful. We need to remember that the history of other people’s definitions of our situation has been the province of medicine and, more recently, sociology. Both have chosen to locate the cause of our problems with us, as individuals. And both have done so in full knowledge that the world in which physically impaired people live is in the same world that non-impaired people have structured to serve and perpetuate their own interests. Clearly, the kind of political advice offered here by Williams needs to be examined in more detail.

We need to ask why in particular he seeks a **sociological** definition of a disadvantage as the basis for effective action. Why not definitions derived from direct experience such as that, as one example offered by the Union of the Physically Impaired Against Segregation in the Seventies? The Union, paraphrasing the sociologically based definitions of Amelia Harris defined disability as “the disadvantage or restriction of ability caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities”, adding “Physical disability is therefore a particular form of social oppression”. What better way for “government and effective pressure group action” than such an unambiguous political statement which places the source of our disadvantage in its true location in society itself! Surely this places the problem precisely “in the context of the power relationships from which they come” as Williams himself urges. Yet he has apparently chosen to overlook the Union’s contribution to his own arguments.

This is particularly interesting in view of the fact that the social location of the cause of disability is accepted in many quarters of the disabled people’s movement, both at home and abroad, and is becoming increasingly embedded in the literature. Not that Williams is totally out of touch with these issues however, since he cannot but note De Jong’s recognition that the “locus of the problem is not the individual but the environment”. It is fascinating however to see how Williams subsequently undermines the position of the disabled people’s movement on the cause of their own problems. First, he attributes the position to De Jong, thus removing disabled people from the picture. Then he relegates the practical work that disabled people are doing to hypothetical solutions; then suggests the social theory of causation may be merely a belief; then, after apparently conceding that rehabilitation professionals overlook the way the environment and the rehabilitation process itself can increase our dependence, points out “in fairness” that they “are becoming more aware of the ambiguities in their role”. Williams thus systematically reinforces professional dominance at the expense of disabled people, using a critique of De Jong as a convenient vehicle.

All this could be constructed as normal enough, if it was possible to accept that Williams was merely playing the academic game. But his true position becomes clearer still when he attempts to give credence to World Health Organisation definitions at a time when disabled people were themselves challenging them at the recent Rehabilitation International conference in Lisbon.[[2]](#footnote-2) Disabled People need to be clear that the WHO definition referred to by Williams does not, as he puts it, pose handicap as social disadvantage, distinct from the individual. Quite the reserve, it defines handicap as “a disadvantage for a given individual**, resulting from an impairment or disability**; that limits or prevents the fulfilment of a role, that is normal depending on age, sex, social and cultural factors for that individual.”, (my emphasis). In other words, the problem resides ultimately with the individual and his or her impairment, despite any specious WHO riders quoted by Williams to the contrary. The fact that he worked on his critique with Phillip Wood (architect of the reactionary WHO definitions) may be of interest here, but the political meaning for disabled people of such definitions is quite clear; at the end of the day, we take the responsibility of our condition.

# **Hatchet Job**

A clue to understanding more about Williams’ behaviour perhaps lies in his interest in providing a “more comprehensive picture of the problems for policy makers” Nowadays picture painting for policy makers has come increasingly into the province of sociology and social administration, whose influence reaches beyond central government into local authority structures and professional bodies dealing with workers in the disability industry. In other words, the overweening academic influence of a section of social science represented by people like Williams feeds the power of the disability establishment other than supporting control by disabled people over their own lives. Sociology and establishment vested interested are locked together in a mutually agreeable symbiosis, forming policy, administrating and controlling the direction of our lives. Given Williams predisposition to sociology, his concern not to replicate the current weaknesses of research in rehabilitation, and his interest in feeding comprehensive information to policy makers, it is consistent that he resists De Jong’s assertion that independent living presents a new ‘paradigm’. As Williams says “De Jong’s assumptions are an unsound basis for policy.”

At this point, disabled people might be forgiven for feeling that Williams could hardly say anything else. Given the way the disability establishment and sociology work together, it would hardly be to the advantage of that cluster of vested interests to give credence to an ‘analytic paradigm’ which defines the problem as dependence on the establishment; which rejects the establishment view that the source of the problem lies with us as individuals; which vests disabled people with control over the outcome of their lives. Rather would we expect him to do a good hatchet job for the establishment and in this he cannot be faulted.

Williams asserts that De Jong’s research mythology rests on some highly shaky judgements, and that the idea of a new independent living paradigm is little more than the product of terminological laxity. Whether all this is true, it is hard for a non-academic mind to find out, so obscure is Williams own terminology. But the political implications are clear enough. When Williams says that the apparent anomaly of severely disabled people achieving independence without the benefit, or in spite of professional rehabilitation, ‘does not necessarily lead to the demise of a paradigm, it may simply mean that existing theories within the paradigm need to be refined’ we can recognise what he is about. In political terms, all this merely amounts to an attempt to incorporate the struggles of disabled people into the existing disability establishment.

To make it even more plain, he goes on to say that those of us who do battle each day to live independently represent only a small part of the overall field encompassed by rehabilitation professionals. In other words, there is nothing so significant about our efforts that cannot be accommodated within the same sphere of interest which has relegated us in our thousands to a passive existence in institutions or which makes careers out of “rehabilitating” us for a life in a hostile and unaccommodating society.

The ILM and the disabled people’s movement in Britain have already rejected the reactionary, establishment ideas epitomised by William’s critique. To hand such ideas on to the conveniently typical vehicle of independent living gives them neither validity nor credibility: they are redundant. Disabled people here are now developing and extending the experience of the ILM, building a practice of integrated living on its foundations and out of our own direct experiences. We do not exist in Williams’ world of abstract relational models where we are kept a safe academic distance for easy manipulation by administrators and policy makers. Our reality is of a different order.

# **References**

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2. De Jong, G. The movement for Independent Living Origins, Ideology and Implications for Disability Research. University Centre for International Rehabilitation. USA/Michigan State University, 1979
1. The Philosophy and Politics of Independent Living, CEH, 16 July 1984 [↑](#footnote-ref-1)
2. 15th World Congress of Rehabilitation International, 3-8th June 1984, Lisbon, Portugal. [↑](#footnote-ref-2)