

BRITISH COUNCIL OF ORGANISATIONS OF DISABLED PEOPLE

Yeoman House, 76 St James's Lane, London N10 3DF

Schemes for Independent Living

Paper presented to the Medical Disability Society

Vic Finkelstein - December 1984

1. A voice of our own

During the late 1960s and early 1970s there was a rapid growth in new types of organisation controlled by disabled people. These organisations developed all over the world and were more directly concerned with addressing the social problems faced by disabled people. Behind this development was a spontaneous recognition that once a physical impairment or injury had been treated and stabilised there remained a fundamental social problem. There is increasing recognition that this problem arises, not because of the individual's impaired body, but because society is organised for able-bodied living. The establishment of able-bodied 'normality' as a criterion for participation in society, of course, actively excludes people whose bodies are different. Disability, in this context then, is the permanent social status of those with a socially significant bodily impairment. Disability is a particular form of social discrimination.

Human beings are, by nature, agents of change and the new organisations not only express the collective voice of disabled people against their discrimination, but are themselves increasingly the agents of social change. It is this involvement of disabled people in their own affairs that has paved the way for a transformation of the group, from passive recipients of care and treatments to active directors of change in society. Attempts by others, however well-meaning, to solve social problems on behalf of disabled people, in the end, serve only to keep disabled people passive and dehumanised. The new voice of disabled people speaks confidently of the right to be involved in our own affairs and to control our own destiny within the community.

2. The professionalisation of disability

The history of disability is inseparable from the progressive division of the physically impaired person's life into a collection of problem areas, each of which has become the focus of specialist intervention. The irony of this development is that the more the disabled individual is divided into a collection of problems, each for expert intervention, the less there is a role for that individual in his or her own life! Increased professional intervention, therefore, can easily increase the passivity of the disabled person **under care**.

Tearing a patient apart for a series of interventions is, of course, widely recognised as not the most helpful way of assisting disabled people. It is appreciated that behind the bits there is a whole person who, somehow, has to be stitched together again into a functioning being. To the mind of the interventionist what better way to stitch the person together than to stitch the interventions together! Hence there arose the idea of the professional team. But, of course, this does not lead to any greater control by disabled people over their own lives. On the contrary, the more effective the team the more effective are their interventions on **behalf of** the individual. The individual becomes even more passive (or rebellious against the professionals)!

In time the inevitable limitations of such interventions are recognised and there is a logical move to relate the problems to the **whole** individual within that person's own social setting. Moving the context of intervention, beyond the confines of the hospital and rehabilitation

centre into the community and home, however, does not necessarily mean that the disabled person will be given a greater chance of directing his or her own life. It may well mean that there is never a need for disabled people to be active agents of social change because there are **always** experts who can more effectively solve their problems! This approach could well turn out to be a deeper stage in the professionalisation of disability and the reinforcement of passivity amongst disabled people.

3. Self-control through Centres for Independent/Integrated Living

The increasing recognition that there is a limit to **appropriate professional intervention** within the social setting, does not deny that there is a continuing and important role for hospital-based medical and para-medical interventions in helping disabled people enter the social world. The growing number of severely physically impaired people living within the community attests, in part, to the success of this medical intervention. However, the increasing numbers of severely impaired people living in the community has not been matched by the development of appropriate community support systems. The call for more professional intervention in the community does not solve this problem but regenerates the **vicious circle**. It increases the dehumanising passivity of disabled people and so creates a new round of problems! Social problems, therefore, cannot be solved by simply escalating the involvement of professional intervention in the community.

The lack of appropriate services, and increasing experience of enforced passivity in the community, has led disabled people to attempt to break out of this **vicious circle** by promoting and setting up centres for the provision of services in which they have a more direct role. These centres are known in the USA as Centres for Independent Living and in the UK are sometimes called Centres for Integrated Living (CILs). The fundamental objectives of CILs are that they will:

- (a) enable disabled people to exercise much greater control over the services that they receive in the community;
- (b) facilitate more direct involvement in all relevant decision-making;
- (c) provide a base for disabled people to become more active in service provision and in effecting social change;
- (d) become a communications channel for expressing the democratic voice of disabled people to central and local government, professional and voluntary workers and the general public.

The increasingly strident promotion of the independent views of disabled people seems to provoke some curious misgivings. Suddenly the right of articulate disabled people to speak on behalf of non-articulate and less confident disabled people is raised! This question is nearly always posed by articulate able-bodied people, usually medical or para-medical professionals, who for centuries have not questioned, nor lacked confidence, in **their** right to speak on behalf of less articulate and self-confident disabled people. How is one to interpret this sudden concern about the legitimacy of **advocacy** or **leadership**?

4. CILs in the USA

The dynamics behind the creation of CILs can only be fully identified when they are analysed as part of a world-wide movement of disabled people for emancipation. In this paper, however, we are concerned with the concrete expression of the movement in the form of CILs. The development of these centres in the USA is said to have been influenced by the

disabled students programme at the University of Illinois at Champaign-Urbana where in 1962 four severely disabled students were provided with assistance to move into a modified home close to the campus. This programme was one of the first to assist disabled people live in the community. A similar programme in Berkeley, California, culminated in the establishment of a Centre for Independent Living in 1972.

It was the Berkeley CIL that eventually gained world-wide recognition and gave a tremendous boost to the further struggles of disabled people for integration into their communities. This CIL, essentially a centre for self-help managed by disabled people, provides a wide range of related services such as peer counselling, advocacy, transport, training in independence skills, attendant care referral, health maintenance, housing referral, wheelchair repair, etc. It is the inadequate provision and inappropriate design and control of these community-based services that have been considered, particularly by **severely** impaired people, to be an important barrier to integration into the community. The need to have a major say in the control and decision-making concerned with these services, as well as to participate in their provision, therefore, was a major impetus to the creation of CILs. This impetus was given a framework by the university disabled students programmes. The creation of services designed to assist severely disabled people live in the community, who were otherwise not considered eligible for vocational rehabilitation because of inability to work, represented a significant new development in the provision of services in the USA. What is, however, of world significance is the key position disabled people hold in developing and running these services.

Pressure on government to provide financial support for CILs and their community services (there are now about 150 CILs in USA) led to new legislation which recognised the two support systems provided by vocational rehabilitation and independent living services. There remains, however, confusion about the purpose of these parallel vocational and community services for severely disabled people and this is perhaps remarkably illustrated by the experiences of Ed Roberts. Mr Roberts was ineligible for rehabilitation services because the severity of his disability was said to make him unemployable. His activities as one of the founders of the Berkeley CIL, however, resulted in his employment there. Subsequently, when his innovative contribution to community services for disabled people was appreciated, his employability was recognised and he eventually became director of rehabilitation services in California'.

For us in the UK it is worth noting that, on the whole, professionals in the USA have tended to see **independent living rehabilitation** as an alternative to **vocational rehabilitation** for those who cannot work (a kind of British 'significant living without work' programme) and physically impaired people in the USA have tended to see the **independent living movement** as part of a struggle for integration.

5. The UK way forward: resource-based rehabilitation?

The struggle of disabled people for integration into the community in the UK has, of course, been different to that in the USA. The same need to become active and have a greater say in the control and delivery of community support services has, however, encouraged disabled people in this country to look carefully at the successes achieved in the USA through the development of their CIL movement and CILs are being proposed in Hampshire, Norwich and Derbyshire. Groups in Devon and Islington are also promoting CIL development and interest is growing in Strathclyde and Manchester as well as in many other areas where disabled people are active.

Conditions in the UK where there are some, although inadequate, community support services has raised the possibility of developing joint control between disabled people and the statutory services. Areas where joint control might be appropriate could include information, counselling, housing, technical aids, personal assistance, transport, access and service planning. At this time it is, of course, unclear what final form joint control might take but there is a growing and exciting debate amongst disabled people about the **pros** and **cons** of formalising such a collaborative approach. What is clear, however, is that there are certain pre-requisites for the development of collaboration between organisations of disabled people and the statutory services.

Firstly, there is a need for national, regional and local organisations of disabled people to unite in a comprehensive network, to discuss the issues, to encourage and support a more active role for disabled people in service planning and delivery and to present a coherent policy on CILs to government and the professions. The British Council of Organisations of Disabled People (BCODP) was set up in 1981 to meet just such a need and its standing committee on CILs was agreed as the forum for the development of a UK CIL policy. Interest in the BCODP is growing and with seventeen member organisations, all controlled by disabled people, the creation of a UK voice of disabled people is rapidly approaching fruition. This network now extends into the international arena, through the BCODP membership of the Disabled Peoples International (DPI), where there is a useful and growing exchange of information and support between organisations of disabled people in different countries.

Secondly, there is an urgent need for a change in prevailing professional attitudes towards service delivery in the community. Approaches which encourage professional and voluntary workers to believe that they can solve problems for their disabled client groups are no longer viable and represent a major barrier to the further integration of disabled people. These approaches need to be replaced by ones which support collaborative and joint work with disabled people. In this respect the BCODP and its constituent regional and local groups could well become an important source for collaboration in reformulating the education and training of future professional workers. Such new approaches might perhaps follow the lines encouraged in the Open University pack of learning materials - **Rehabilitation: a collaborative approach to working with disabled people**.

Thirdly, there is a need for enabling legislation which will facilitate a new distribution and control of financial and other resources so that collaborative ways of working can materialise. In this respect it will be a major advance for professional and representative bodies of disabled people, such as the BCODP, to establish formal working relations so that jointly agreed proposals for legislation can be put forward.

CILs which incorporate a collaborative or joint approach between disabled people and service providers, such as is being formulated by the Derbyshire Coalition, have been called Centres for Integrated Living. This formulation takes cognisance of the British social services system and emphasises the importance of community involvement in supporting the integration of disabled people. In this approach professional and voluntary service providers have to learn how to place their expertise at the service of disabled people who, in turn, have to learn how to take an **active** role in making effective use of the support available to them. In this formulation those providing help and support become a resource, to be drawn upon by disabled people according to need. A new theoretical framework for professional work in this way will most likely focus around ideas about '**resource-based rehabilitation**'.

Periods of growth, the expansion of ideas and the creation of new relationships are times of great interest and personal development. Certainly the disabled people actively involved in these new developments are beginning to sense that they have grasped a new and significant

historical initiative in their hands. The tragedy is that far too many professional workers are isolated from the new ideas emanating from the modern movement of disabled people. The result is moribund interpretations of disability, such as the **WHO International Classification of Impairments, Disabilities and Handicaps**, which could only have been prepared by workers isolated from the movement of disabled people.

If prevailing professional attitudes are not to become a barrier to the advancement of disabled people into the community, and if they are to play a constructive role in the development and planning of future services which serve the needs of disabled people in a modern electronic world, then they must learn how to work **with** disabled people rather than for them. The planning, construction and maintenance of '**Centres for Integrated Living**' will be a testing time for the future of both the helpers (professional and voluntary) and the helped (disabled people) in Britain.

REFERENCES

DAVIS, Ken (1983) *Consumer participation in service design, delivery and control*, paper presented to the 'Centres for Independent Living' Conference, Kensington Town Hall, London, 28th November 1983. Derbyshire Coalition of Disabled People.

DAVIS, Ken (1983) *Personal assistance as an example of the Independent Living Movement's ideology and praxis*, paper presented to the 'Seminar on Independent Living', Stockholm, Sweden, 9th/10th December 1983. Derbyshire Coalition of Disabled People.

DE JONG, Gerben (n.d.) *The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research*, reprinted in BRECHIN, Ann, LIDDIARD, Penny and SWAIN, John (Eds.) (1981) *Handicap in a Social World*, Hodder and Stoughton.

FINKELSTEIN, Vic (1981) *Disability and Professional Attitudes*, Conference Proceedings: Naidex '81, 21-24 October 1981, Royal Association for Disability and Rehabilitation.

KAY, Susan (1983) *Issues for statutory bodies in the transition to integrated living services*, paper presented to the Centres for Independent Living conference, Kensington Town Hall, London, 28th November 1983.