

NOTES ON THE DEVELOPMENT OF THE DERBYSHIRE CENTRE FOR INTEGRATED LIVING (DCIL)

1 INTRODUCTION

- 1.1. During 1981 - the International Year of Disabled People -the newly formed Derbyshire Coalition of Disabled People suggested the establishment of a Centre for Independent Living in the County. In a significant step, the Coalition sought and obtained the in principle support of the County Council for the proposal. This set the scene for a collaborative approach to the development of practical services and facilities which are needed if the IYDP Aim. of "full participation and equality" is to be achieved for all disabled people.
- 1.2. In taking this step the Coalition was conscious of a number of issues which seemed to be involved. These included the need to review the philosophy and practices of the independent living movement as it had-developed throughout the Seventies in the USA; the need to relate the development to the work of the disabled peoples' movement in Britain over the same period; and the need to make a positive contribution to the growth of the movement internationally. The purpose of this paper is to briefly discuss aspects of these and other issues which the Coalition has encountered over the early stages of establishing its main practical project - now known as the Derbyshire Centre for Integrated Living.

2. BACKGROUND

- 2.1. Centres for Independent Living have been the response of disabled people in the United States to their exclusion from full social participation. The first CIL was set up by severely disabled students in Berkeley, California in 1972 and has since been emulated across the States in the 150 or so Centres either forming or in existence today. Although there are local variations in how they are organised, generally they are based on the ideas originating in Berkeley. Disabled people themselves run services relevant to their self-determined needs; people with all kinds of impairment are involved; services and facilities help disabled individuals achieve their own life-choices.
- 2.2. In Britain the groundwork of activity laid down in the Sixties led to growth of a number of groups controlled by disabled people in subsequent years. Within our Welfare State the responses of disabled people took a different form to that of their counterparts in the States. The call was not for control of their own services through .. "independent living centres" or their equivalent, but rather for the State to provide better benefits or other services. The assumption was that more money or better organisation of existing resources would solve the problem of our exclusion from mainstream social activity. Some disabled people, however argued strongly that such an administrative approach would be quite wrong and as the movement developed the issue of control over our own lives became paramount.
- 2.3. The proclamation of 1981 as the International Year of Disabled People, with its slogan "full participation and equality", made plain and public just how little had been achieved in either Country, and how much more remained to be tackled worldwide. Reaganomic policies were teaching disabled Americans how vulnerable their independent living centres were in the face of free market forces. At home, disabled people were already disillusioned by the failure of the State to fulfil expectations raised by the CSDP Act. In other countries, disabled people were waking up to the need to become a politically active movement. The Eighties had dawned to the development of the embryo Disabled Peoples' International in Winnipeg and the first half of the decade has witnessed its necessarily slow, but nevertheless steady growth. The Derbyshire Coalition, and its proposal for a Centre for Independent Living, were conceived against this immediate background.

3. HISTORICAL CONTEXT

- 3.1 This movement among disabled people to gain control over their own lives is the most recent phase in an historical progression which remains to be traced in detail. Some work on this has been started by Vic Finkelstein (1) who has argued that the relative independence and autonomy of cripples in pre- industrial Britain was systematically eroded by a number of interlinked developments throughout the industrial revolution. The most significant point emerging from this analysis is that disability is a socially constructed phenomenon which can be measured objectively in terms of our exclusion from participation in mainstream social activity and loss of control over our lives.
- 3.2 This social model of disability has been adopted by the independent living movement in the States and applied tellingly as a corrective to the medical model. However, although the Derbyshire Coalition also defines disability in social terms, it has in addition made progress towards accommodating some other implications of the historical development of disability. Among these are included a recognition that the same social forces which, in the last Century, segregated physically impaired people from the ranks of the unemployed and turned us into objects of charity, also produced the wealth and technical means for our congenial, socially productive re- integration into present day society.
- 3.3 Also included in the Coalition's response is an awareness that the segregative processes inherent in the industrialisation of Britain provided the basis for the proliferation of professionals and other "experts" which occurred mainly after World War 2. It is objectively true that these people, whose practices were built on the established fact of our social exclusion, still largely reproduce the barriers to our integration. Nevertheless, the Coalition fully accepts firstly that disabled people need help to overcome disability and second, that appropriate aspects of professional practice can be potent and productive elements in this process.
- 3.4 In this, the Coalition has seen the potential to make a significant contribution to the development political force to remove barriers to integration in the USA. In as much as it has accomplished this, it of the disabled peoples' movement. The independent living movement has operated as a positive has been as inspiration beyond its own boundaries. But the removal of barriers, per se, is not particularly progressive and may even generate oppressive, practices in the process. The ILM will become a genuinely radical current within the wider movement when it inquires more searchingly into the causes of the barriers it seeks to remove. This requires Me-development of an historical perspective and a more searching analysis of the social relations between disabled and non- disabled people.

4. NOTES ON TERMINOLOGY

- 4.1 Use of the term "independent living" causes problems of understanding. People not directly concerned with disability issues usually interpret the term in an ordinary, commonsense way, i.e. that disabled people want to be self-reliant without help; or that we did not wish to be dependent or to rely on other people; or that we wanted to think and do things for ourselves. In many ways these interpretations differ greatly from definitions put out by those who identify with the ILM. Yet it is held that the raison d'etre of the movement crystallises around the issue of "independence". As a result, the ILM has had no option but to choose its own definitions since the world in which the ILM seeks to participate is often confused as to the purpose of the movement.
- 4.2 It is perhaps no accident that the term originated in a country (founded on a Declaration of Independence) which still promotes rugged individualism and untrammled personal freedom as the epitome of human development. In this context, the choice of terminology is not as naive as it at first seems, since as Gareth H. Williams notes, it entails "a basic commitment to the American capitalist system with its free market, pluralist ideology"(2). For the Americans however the term was apparently their considered choice and, within the status quo, it was nevertheless a radical position for them. For disabled people here in Britain however, we too have

had to make a conscious choice, and in Derbyshire the term "integrated living" has come to be chosen as representing a less confusing as well as more progressive description of what we are about in establishing DCIL.

- 4.3 Although clear words are important to project the message of groups working for social change, both terms inevitably carry deeper, symbolic messages. "Integrated Living" implies a commitment to society: "Independent Living" implies a commitment to self. It may be argued that the latter is a vital corrective for disabled people whose personal development has become subject to the control of others. It may be argued that it is a potent motivator to hold up the idea of independence before those who are denied it. However, the more one attempts to explain what "independent living" is, paradoxically, the closer one comes to discussing the concept in terms of integration. For example, "independent living" is at once described as a process of "identifying choices and creating personal solutions", and as the "quality of life attained with help" (3). In other words, personal choices for disabled people can be sterile in the absence of the help necessary to make them a reality. Introducing help is to introduce the realities of dependence and interdependence which are the very building blocks of integration.
- 4.4 However, despite the obvious fact that all human beings are in some sense dependent both on each other and on the physical environment which sustains all life, the idea of "independent living" is not totally unreal. To seek the ability to decide and choose what one personally wants, to seek to assume and establish self control and self-determination are potent mental constructs which can have devastating effects in the real world. For example, it can lead disabled people into using human and other resources simply as the means to achieve personal ends, to be discarded or changed as the process of identifying personal choices and creating personal solutions also changes. In turn, it can lead non-disabled people to allow their able-bodiedness to be used as mere mechanical extensions of our own physical inability to translate thought into action.
- 4.5 threading through the ideas of "independent living" are these potentially destructive connotations. If symbolically, the focus is indeed on "self", then implicit also is the possibility of a lack of true commitment to all things outside oneself, except those which serve immediate ends. The psychological, social and ecological consequences of this mode of thought are all too obvious in today's world. If however, it is claimed that the true focus is on "equality of opportunity and the full participation of disabled people in everyday life in the mainstream of society" (4) (another description of what "independent living" means) then it is really about integrated living. Implicit in the latter idea can be a commitment to notions of unity, mutuality and wholeness. The focus here is quite different, and it is easy to see how misunderstandings occur when these contraposing views are attempted to be contained within the one "philosophy" of independent living.

5. ENDS AND MEANS

- 5.1 The use of the term "integrated living" is an attempt to make clear and get in context both the end and the means of the DCIL. It aims for the full social integration of disabled people and it seeks to achieve it by disabled and non-disabled people working together. Its constitution builds this mutuality into the various components of control - into its General Council, Management Committee and Sub Committees, and its policy is to duplicate this same process on the "shop-floor". The DCIL is also integrated into a strategy for the development of Social Services which also has as its Aims the integration of disabled people into the social, economic and political life of the County. In turn, this strategy is being jointly developed with the Health Authorities, and DCIL is seeking also to integrate representation from other statutory and voluntary bodies into its management structure. The commitment to integration is being pursued both in theory and practice.
- 5.2 This appears to be a far cry from the original principles of Berkeley CIL and yet, the organisational frameworks are not dissimilar. But, because the focus of DCIL is on "integration" rather than "independence", in other respects its development has been significantly different. One reason is that the Coalition has recognised that a mixture of "consumer advocacy" and service provision within one organisation can be counter-productive. DCDP and DCIL are thus legally separate,

autonomous bodies and each can pursue separate roles with the same overarching aim. DCIL will not have to worry about "biting the hand that feeds" its service provision role. This has in turn cleared the way for putting into practice the principle of prefiguring the aim of full social integration in the means of achieving it.

6. ACCOUNTABILITY

- 6.1 It is perhaps worth reiterating that, in the process of establishing DCIL, the Coalition was developed first. This was to make sure that there was an organisation of disabled people in existence whose members were involved in - and ultimately controlled - its activities. Whilst this ensured accountability to disabled people within the Coalition - a whole range of activities which directly concern disabled people outside the Coalition were provided in the traditional way (by non-disabled people usually without consultation). These activities include those provided by various statutory agencies such as housing, health, planning, and transport.
- 6.2 Had the Coalition sought only to try to bring about greater accountability to disabled people, say, by the use of typical pressure group activity, its strategy would have developed in a different way. It would perhaps have sought *inter alia* representation on the bodies identified in Section 15 of the CSDP Act, coupled with more lobbying of Councillors and efforts to make sure elected members of District, County and City Councils could not ignore the voting power of the disabled section of the electorate. Whilst such activities have not been overlooked by the Coalition, work on them has proceeded slowly for two main reasons. First, putting greater pressure on the present system may do nothing per se to alter the structures which have traditionally been unaccountable to disabled people. Second, the Coalition had chosen to get involved in establishing practical services and facilities - principally through DCIL - on the premise that direct action on this area would produce greater advances for disabled people than concentrating on campaigning alone.
- 6.3 Choosing to develop these practical services and facilities according to a collaborative rather than a separatist model, was consistent with a basic principle of "integrated living" - which recognises that our full social integration requires that services themselves must be integrated in the method of their design, delivery and control. But it also offered an opportunity to introduce a level of accountability into service provision which did not hitherto exist: both General Council and Management Committee of DCIL must consist of at least 50% disabled people (80% of whom are directly appointed by the Coalition). Given that DCIL is built into strategies which affect Health as well as Social Services, opportunities for introducing further layers of collaboration with and accountability to disabled people remain to be explored within the wider framework of public accountability which at present exists.
- 6.4 The work done by the ILM in the States greatly assisted in the development of DCIL. We were able to build on their experience in a way appropriate to our own social organisation and cultural background. Taking out the "consumer advocacy" role allowed a collaborative, more truly integrative development to follow. This in turn prevented the marginalisation of DCIL, and avoided placing the funding of services on an adversarial basis - competing with other disability service providers for the same scarce resources. The "independent living" programmes at Berkeley take this competition on board, as a concomitant of the free-market, pluralist tradition out of which the CIL emerged. However, the consequences for disabled people of this approach such as the financial shortfall which decimated staff at Berkeley CIL from 200 to 45 during 1980, can only be imagined. The Coalition's view is that severely disabled people are too vulnerable to be subject to such vagaries of funding and, while ever resources remain scarce, the duplication of services inherent in the "independent living" approach is unacceptable. Whilst accountability to disabled people certainly needs to be built into the methods of service provision, disabled people, in turn need to be accountable both to funding agencies and to other vulnerable groups in society.

7. RESTRUCTURING RELATIONSHIPS

- 7.1 In her opening address to an "IYDP Conference" in February, 1981, jointly arranged by DIAL Derbyshire and the Social Services Department, -Dr. Mary Croxson said that the task before disabled people was one of taking the lead in restructuring a world which able-bodied people had structured to serve and perpetuate their own interests. These remarks touch another aspect of the development of the concept of "integrated living". It links with the definition of disability first proposed by the Union of the Physically Impaired against Segregation in 1976: disability is "the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. Physical disability is therefore a particular form of social oppression"(5). In adopting such a social definition to guide its future development the Coalition identified disability as a phenomenon which can be overcome.
- 7.2 DCIL is obviously concerned with providing or encouraging the means of overcoming disability but the concept of "integrated living" requires that the task is approached in a particular way. It requires us to become ever more aware of the historical process which has produced the phenomenon we are seeking to overcome. It requires us to recognise that disability is the product of a particular social relationship between disabled and non-disabled people which cannot be cured by isolationism or separatism. It demands that we enquire into the causes of disability and that we reject all the varied devices which deny the participation of disabled people in contemporary social life. It particularly demands of DCIL that those people who seek service from it become active participants in the process of overcoming their disability.
- 7.3 Paulo Friere identified a number of concepts related to "integrated living" in his work with the oppressed Brazilian peasantry in the 1960s. One of these concepts - "assistencialism" – he describes as ".... an especially pernicious method of trying to vitiate popular participation in the historical process. In the first place, it contradicts Man's natural vocation as subject in that it treats the recipient (of help) as a passive object, incapable of participating in the process of his own recuperation; in the second place, it contradicts the process of "fundamental democratisation". The greatest danger of assistencialism is the violence of anti-dialogue which, by imposing silence and passivity, denies men conditions likely to develop or 'open' their consciousness. For without a critical consciousness, men (sic) are not able to integrate themselves into a transitional society" (6). The debate between the Disability Alliance and the Union of the Physically Impaired, described in "Fundamental Principles of Disability" revealed the administrative (assistencialist) approach of the Alliance of seeking to anaesthetise the symptoms of disability though its pressure for a National Disability Income, without actively participating with disabled people in the process of making conscious the causes of the problems they wished to alleviate.
- 7.4 Historically, disabled people have been denied active participation in mainstream social life in general, and in the means of providing for participation in particular. This denial is the root cause of disability and the very antithesis of integrated living. DCIL is a small contribution to the much wider process of creating the means for disabled people to become involved in transforming our own lives and the society we have inherited.

KEN DAVIS
D.C.D.P.
DECEMBER 1984

REFERENCES

- (1) FINKELSTEIN V., Disability and the Helper/Helped relationship: an historical view. Pub. in Handicap in a Social World - Ann Brechin, Penny Liddiard, John Swain. London, 1980, pp 58 - 63.
- (2) WILLIAMS G.H., The Movement for Independent Living: an Evaluation and Critique, Soc. Sci. Med., Vol 17, No 15, p 1004.
- (3) EVANS J., Philosophy and Basic Principles of Independent Living, Seminar Report, CEH, London, 1984. p. 8.
- (4) Ibid, p. 9
- (5) UPIAS, Fundamental Principles of Disability, London, 1976, p.14.
- (6) FRIERE P., Education as the practice of Freedom, London, 1973.