

A SOCIAL BARRIERS MODEL OF DISABILITY: THEORY INTO PRACTICE

The Emergence of the "Seven Needs"

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1. Introduction

1.1. This paper sets out to explore the origins of a practice, or method of working, which has come to be labelled 'the seven needs'. The phrase is a shortened version of something which started out in life as "*seven areas for practical action if the phenomenon of disability is to be overcome*" (1). This intriguing statement first emerged out of the work of the Derbyshire Coalition of Disabled People (DCDP) in establishing the Derbyshire Centre for Integrated Living (DCIL).

1.2. DCDP's work on this project began in 1981, when it sought and obtained the in principle support of Derbyshire County Council (DCC) for the idea of a CIL. In February, 1982 a Joint Working Party between DCDP and DCC engaged in a mutual exploration of how such a Centre might work, and how it could relate to statutory forms of service provision. The Working Party was informed by a series of papers (2), which can be seen as a running record of DCIL's early development.

1.3. The officers of DCC and the members of DCDP on the Joint Working Party were coming from very different backgrounds. On the one hand, the awareness of the DCC representatives was for the most part limited by their able-bodied, observational perspective on disability; by their training based on the 'medical model' and by the constraints of local authority forms of service provision. On the other hand, DCDP members' knowledge of disability was drawn from an experiential perspective, and focussed on the 'social model': they saw the source of the problems they faced as lying in society not in themselves. They also knew that they were negotiating with local authority workers whose jobs were based on a discriminatory foundation. The disability legislation which conferred powers upon local authorities to provide disability services had been framed in the absence of disabled people's active participation in the democratic process.

1.4. Given these differences, it is small wonder that many obstacles and difficulties beset the various phases of developing DCIL. These have been explored in some detail elsewhere (3), but here the focus will be on the practical problem facing DCDP of translating the social definition of disability into a framework for practical action. The 'seven needs' approach turned out to be the Coalition's solution. It is derived from its members' direct experience of disability, and is designed to draw

the main facets of this direct experience together in a rational scheme for practical action. It required them to develop their awareness of the material basis of their oppression; of its historical dimensions; and of the political forces which formed and maintained it.

2. Background notes - the political significance of definitions of disability

2.1. Traditionally, the 'problem' of disabled people has been defined by non-disabled people. The act of defining the problem has *ipso facto* given them control over the solution. The solutions have created a lot of work for non-disabled 'problem solvers'. The aggregation of these jobs into what now amounts to a disability industry, has created a large vested interest. The grip of this vested interest on disability definitions is very far reaching.

2.2. The prime political purpose of able-bodied disability definitions is to protect the status quo, and control the pace and direction of social change. Disability definitions are thus a powerful preservative tool in the service of the dominant able-bodied culture. The main agents of this culture are the so-called 'caring professionals' along with their political and academic supporters. One important political task facing the disabled people's movement - as for any other oppressed social group - is to gain control over the way their situation is described and defined.

2.3. In Britain, the controllers of disability policy, building on the work of generations of their able-bodied predecessors, have defined disability in terms of the 'medical model'. Such definitions locate the cause of the problems we face in us and our individual impairments. For as long as these people are able to maintain the idea that it is our bodies that are at fault, the social structure they have created can be protected. By the simple device of focussing on our bodies, these definitions draw attention away from their discriminatory society. Such definitions underpin the dominant hegemony of ideas these people have constructed to support their vested interests.

2.4. Typical of definitions according to the medical model, are those put forward by the World Health Organisation (WHO) (4):-

- *Impairment*: any loss or abnormality of psychological, physiological or anatomical structure or function.
- *Disability*: any restriction or lack, resulting from an impairment, of ability to perform any activity in the manner or within the range considered normal for a human being.
- *Handicap*: a disadvantage for a given individual, resulting from an impairment or disability, that prevents the fulfillment of a role that is normal depending on age, sex, social and cultural factors for that individual.

2.5. The process of re-defining disability and challenging the dominant climate of ideas appears to have reached a decisive stage in Britain, with the emergence of fresh thinking and new organisations controlled by disabled people themselves during the Seventies. An important example of this is the work pursued by the Union of the Physically Impaired against Segregation (UPIAS), which resulted in a careful re-working of the set of definitions - similar to those of the WHO - used by Amelia Harris in the 1971 OPCS Surveys (5).

2.6. The significance of this development can only be clearly understood when it is set against the apparatus of social control used by the dominant able-bodied culture to keep disabled people subservient. The OPCS surveys are very much part of this apparatus. They raise no searching questions about the purpose, implications or adequacy of the medical model upon which they are based. When, for instance, the latest Survey, published in 1989, was being planned, the OPCS made no secret of the fact that they were asked by the DHSS to base their work on the medical model that was being touted by the 'expert' able-bodied dominated definers of disability who were working under the aegis of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (6). But the iron grip of able-bodied control over disability affairs received its first direct challenge from disabled people with the UPIAS definitions (7).

- impairment: lacking all or part of a limb, or having a defective limb, organ or mechanism of the body.
- disability: the disadvantage or restriction of activity caused by contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

2.6. The political significance of these definitions lies in the fact that they are a statement coming out of the direct experience of disability; that they place the cause of disability fairly and squarely with society; that they separate and sharpen the distinction between the individual and the environment with which he or she interacts; that they are a tool for measuring the role and relevance of existing service systems; that they pose disability positively as a phenomenon which can be overcome; and that they lift the veil which obscures the ugly face of discrimination against disabled people in contemporary British society.

2.7. These definitions singled out the pivotal word used by the disability industry in Britain - disability - for our political attention. In turning the construction placed upon it by able-bodied people on its head, by challenging and contradicting it, a basis was established for the disabled people's movement in this country to isolate those with a vested interest in maintaining our oppression. This 'social model' of disability is now broadly adopted by the disabled peoples' movement world-wide. It is enshrined, for example, in the Constitution of the Disabled Peoples' Internationals - although in that document the terms 'disability' and 'handicap' replace 'impairment' and 'disability' in the UPIAS example quoted above.

2.8. Consistency within the movement lies, however, in the concept rather than the terms. The social model helps disabled people world-wide to focus attention on the

same source of the problems we face - on the way societies are organised to restrict or exclude us. This consistency is very important, since it promotes our unity of purpose and gives cohesion to our movement. However, it is obviously of equal importance that, within this unifying concept, the different member nations of DPI adopt terminology that is most appropriate to the local conditions existing in each individual country. A BCODP discussion paper produced in 1986, set out to stimulate discussion among its member organisations in Britain to this end⁹, but the Council has since adopted a scheme of definitions similar to those employed by DPI (10).

3. Adopting appropriate terminology in Derbyshire

3.1. Some of the founder members of the Coalition - through their involvement in developing a local Disablement Information and Advice Line (DIAL Derbyshire) - were, by 1981, in touch with broader national and international trends in disability, including the development of Centres for Independent Living (CILs) in the USA. This had given rise, as indicated at 1.2. above, to the taxing question of how CILs might relate to Britain's long established welfare apparatus and its vested interests in disability services.

3.2. Finkelstein's work (11) in particular, impinged on the resolution of this difficult problem. Having adopted the broad sweep of Finkelstein's ideas, DCDP members recognised the historical possibility that disabled people had been squeezed out of mainstream economic activity in the course of the Industrial Revolution. This involved the social creation of disabled people's dependence, making them ripe for capture by successive waves of service providers. Aware that the empire of services that these people had built up over the years were little more than devices which used disabled people as the raw material for careers in the 'caring professions' - they realised that this situation had to be changed. They could see that re-structuring these service systems was an enormous task, the success of which would depend as much upon the theoretical soundness of their work, as upon political awareness and application in seeing, it through.

3.3. They were also aware that, as noted at 1.3. above, having been built out of society, disabled people were gravely disadvantaged in organising a strong voice of their own. Disabled people had been politically emasculated in a society which had been structured to serve and perpetuate able-bodied interests. As a consequence, in the absence of an effective disability lobby campaigning for appropriate legislation, able-bodied people in the voluntary and statutory sectors were securing legislation designed to serve their own vested interests.

3.4. Various Acts of Parliament impinged as substantially, on the lives of local disabled people as it did on their fellows elsewhere in Britain. In reviewing and assessing this legislation, it was plain to the Coalition that, particularly since World War 11, much of it was enhancing the career prospects of able-bodied service providers without yielding improvements which matched disabled people's changing expectations. It was doing little or nothing to enable disabled people to gain control over their own lives. It was often tokenistic and toothless in terms of creating the

means of equal citizenship. It was almost entirely based on the medical model of disability.

3.5. DCDP members were aware that most of the major pieces of legislation used the word 'disabled' in the title and, in sections setting out the interpretation of terms, defined the meaning - not of 'impairment' or 'handicapped' - but of 'disability' or 'disabled person'. Disability was the key word to be captured and re-defined. In any strategy for gaining control over the definitions which circumscribed our lives, disability had to be the term that was singled out for political attention. Thus, in the process of turning policy into practice, DCDP adopted the following definition (12):

- *Disability*: "the restriction on activity resulting from social and physical barriers erected by people who have failed to take into account the needs of individuals with physical, sensory or mental impairments."

3.6. In so doing, DCDP aligned itself with the social concept of disability which underpinned the aims of the wider disabled peoples' movement. In terms of their ideas for establishing a CIL in the County, this concept set the agenda for the way the CIL was to be put into practice.

4. Drawing on the direct experience of disability

4.1. It is the case that a number of Coalition members had, in the years leading up to the formation of DCDP, made the difficult transition from segregated residential institutions into the community. Others had made what, in some cases, was an equally difficult transition from the confines of their family into a home of their own. Significant among these experiences, was the development of the Grove Road Scheme in Sutton in Ashfield (13).

4.2. The Grove Road Housing Scheme was set up at the instigation of disabled people between 1972 - 76. It was built by a Housing Association using Local Authority finance and the disabled people concerned worked closely with the architects on the design of the scheme from inception to completion. Built before there had been any significant advances in the availability of local domiciliary services, the Scheme aimed to provide out of its own resources for those needs which could not be satisfied from statutory or other bodies.

4.3. This Scheme offered three flats for disabled families linked to three for non-disabled 'supporting families', the whole operating in some respects as a tenants collective. The disabled tenants chose that their first line of support would be their own self-sufficiency - which had been facilitated and enhanced by good basic design features coupled with the provision of appropriate aids to independence. They took what limited help was available from Health and Social Services, and this was supplemented by personal assistance from the 'supporting families' who were close at hand to deal with immediate or emergency needs on an agreed rota basis. The disabled tenants did their own background research, provided for their own information needs and operated an ad hoc peer counselling arrangement for mutual support,

4.4. The success at Grove Road was later extended to a variation on this collective arrangement at 22 Main Street, Newton (14) and successively to a number of individual arrangements throughout Derbyshire. It produced a wealth of knowledge drawn from direct experience of independent and integrated living, which was invaluable to the development of the Coalition's ideas about the operation of DCIL.

5. The emergence of the "seven needs"

5.1. From the beginning of its thinking about a CIL in Derbyshire in March 1981 (15) suggestions were being made about the kind of practical services or facilities such a Centre could offer. These suggestions included: maintenance of the County's Disabled Persons Register; a Care Attendant Register; Housing Services - designing to direct labour; a Transport Service; Mixed physical ability Workshops; an Information, Communications and Publicity Service; an Aids and Equipment Showroom and Store; a 'Halfway House' rehabilitation service; and a Peer Counselling Service.

5.2. All of these early suggestions were based on the problems disabled people had themselves experienced in their struggles for independent living. Some of them were expressed in forms that were already operational in CILs in the USA. In many cases they reflected the absence of, or shortcomings in, services offered by the so-called 'professionals' in the disability industry. But it was not until 1984, that these practical services and facilities had been drawn together within a coherent philosophical and organisational framework.

5.3. It was to some extent the notion of 'independent living' that provided the stimulus for thinking about DCIL's eventual services in a rational rather than a reactive or ad hoc way. Independent living has been described as being about the process of improving the quality of life, by having access to the help necessary for disabled people to identify and pursue their own life choices (16). The process of comparing local experiences of de-institutionalisation with the independent living philosophy forced a careful analysis of the elements involved.

5.4. Local expression of personal life choices had, in the run up to the formation of DCDP, been focussed mainly on the task of finding or creating alternative accommodation and personal assistance to that provided in institutions. From the Grove Road experience, it had emerged very clearly that -in order to maximise personal independent functioning in the most economical way - the three key elements of housing of good basic design, appropriate technical aids, and a flexible system of personal assistance, were tightly inter-related. But it was also clear that they had been thought about in that sequence. No move was possible without first thinking of housing; it was housing design which facilitated the efficient use of certain technical aids; and those two elements in combination had a dramatic effect on the amount of personal assistance needed to make the whole scheme work.

5.5. The logic of this process was then extended to other key elements. It was realised that the identification of any life choice - such as moving out of an institution or away from a family home - depended on information. The research which preceded the development of the Grove Road Scheme had yielded a lot of information on a wide variety of topics, e.g. about housing providers; state benefits

and allowances; local statutory duties, powers and provisions; aids and equipment; and a range of other matters. What also became clear was the fact that simply having access to information was not in itself enough. There were problems, not just in interpreting information, but also in gaining the knowledge, confidence and skills required to use it effectively. There was an element of advice and counselling involved in translating and turning information into practical use. Again, these two elements had come up in that order, and they preceded the three elements identified at 5.4. above.

5.6. Because the dominant local concern of disabled people had been to get themselves established in a home of their own, for the most part, what might follow from such a change was left for later consideration. There were enough problems involved in the process of achieving physical and functional integration, without getting too concerned about the practicalities of social integration. But of course this question did come up, and it led to the identification of two further basic elements involved in the process of pursuing independent living choices. First there was the element of accessible transport - some way of making journeys outside the home - and then that of environmental access. The benefit of having accessible transport could not be fully experienced, if disabled people were confronted with insurmountable physical barriers when they reached the destination of their choice.

5.7. It was out of this kind of analysis that the step-by-step schema, later to be dubbed the 'seven needs', emerged. From the point of view of disabled people who were setting out to achieve full social integration from the extremity of social deprivation in segregated residential institutions, these seven elements were encountered in the following logical order:

- information
- counselling
- housing
- technical aids
- personal assistance
- transport
- access

The identification of these areas for practical action at once underpinned the operational framework for DCIL and put flesh on the social model of disability.

6. Infrastructural discrimination

6.1. It was observed that these seven elements - often so familiar, everyday and taken-for-granted - were needs shared in common by everyone in contemporary society. But, variously in the case of disabled people, these ordinary needs had been turned into special needs by the propensity of our able-bodied culture to reproduce the organisation of social activities in their own interests.

6.2. These 'special' needs were thus indicators of just how deeply discriminatory able-bodied practices had penetrated the social structure. The presentation and communication of information favoured sighted and hearing people; the built

environment of streets, buildings and houses were designed without regard for the needs of people with mobility impairments; public transport systems were designed and organised to suit the able-bodied; and if the range of implements, tools and devices produced for everyday use, also served disabled people's needs - it was certainly more by accident than design.

6.3. These artificial, socially created areas of need thus present a comprehensive barrier to our participation in mainstream social activities. At a series of workshops with disabled people held throughout the County in 1984, Derbyshire County Council's Social Services Department confirmed the social deprivation resulting from this barrier, and the importance of these areas of need with groups of their 'clients'. They also point out the difference between these seven primary need and other needs which individuals may identify – e.g. the need for education, employment and leisure. Such needs they rightly point out to be secondary needs which could be met through mainstream facilities, once primary needs had been met (17).

6.4. This observation indicates the depth of institutional discrimination facing disabled people in contemporary British Society. Inequality of access to information, housing, technical aids, personal assistance, transport and the built environment prevents disabled people sharing on the same terms as their non-disabled fellows almost all of the important activities of life which go on in mainstream society. For some disabled people, tackling the primary areas of need - housing, for example - can become ends in themselves rather than means to an end, as is the case for the majority of able-bodied people. The struggle to obtain and survive in a home of one's own, to secure the basis of physical integration, can be hard enough without then going on to engage in the further struggle to get into education or to find and hold down a job. Beneath the statistics dealing with disabled people's participation in schools and colleges, or in training and employment, lies an infrastructure of discrimination which separates disabled people from everyday life in society.

6.5. Thus the 'seven needs' can operate as one signpost to the identification of those aspects of our social organisation which need attention if "full participation and equality" (the slogan of the International Year of Disabled People, 1981) is to be achieved for all disabled people. They reveal the material elements in a self-perpetuating social process in which people's attitudes are both formed by, and reinforce the many aspects of discrimination experienced by disabled people in today's society. They offer a practical way forward to verify the prediction made by Vic Finkelstein in 1980:

"once social barriers to the re-integration of people with physical impairments are removed, the disability itself is eliminated. The requirements are for changes to society, material changes to the environment, changes in environmental control systems, changes in social roles, and changes in attitudes by people i» the community as a whole. The focus is decisively shifted on to the source of the problem - the society in which disability is created. (18)

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