

**DISABILITY: AN ADMINISTRATIVE CHALLENGE?  
(The Health and Welfare Heritage)**

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Published in

Oliver, M (ed) (1991) *Social Work – Disabling People and Disabling Environments*.  
Jessica Kingsley Publishers, London.

**From action to words: segregation**

Incarceration in residential homes has been practised long enough for it to be accepted as a perfectly legitimate way of ‘caring’ for ‘the disabled’. Indeed the founders and supporters of such institutions have been showered with numerous awards from civic and voluntary authorities. Names of individuals<sup>1</sup> have become household words for helping the ‘unfortunate disabled’ and they are acclaimed in public by every sector of the media. There is a singular lack of awareness that there may be something profoundly undemocratic about able-bodied people supporting the systematic removal of disabled people from their communities, that it is only able-bodied people who write glowingly about each other for having done this to disabled people and that it is able-bodied people who give themselves awards for this contribution to the isolation of disabled people from the mainstream of life.

On the other side there is ample evidence in the writings of disabled people<sup>2</sup> that they have always regarded institutionalisation as a means of dealing with the problems that they face in the community with considerable misgivings; as a last resort to be resisted for as long as possible. When they have found themselves in a residential home they have not only complained about being there but have felt acutely aggrieved by the lack of control over their own lives in the day to day running of the institution. Residential homes, therefore, have been an active site for disabled people to struggle for basic citizenship rights. This has meant, firstly, a struggle for the right to control their own personal lifestyles and, secondly, the demand for the democratic right to have a say in the running of the community in which they live (the ‘home’).

In the event it was in the Le Court Cheshire Home that this struggle set in motion circumstances which were eventually to transform radically deeply-rooted views about disability – that is, to be disabled means to be unable to function socially as an independent citizen having the same rights and expectations as ‘normal’ people and that the management of disability demands life-long care and professional expertise.

It has been a characteristic of institutional care that this management was placed in the hands of respected able-bodied public figures who have substantial experience in the management and control of others in a variety of work and social situations. Since the social and physical environment has enabled the successful achievements of these individuals there has been little reason for them to think that the inability of disabled people to cope in the same environment is due to anything other than personal limitations. Removing those disabled people who are having difficulty coping with the able-bodied world is, therefore, seen as an act of kindness. In these circumstances pleas from residents for a greater say in the running of the homes was usually met with blank incomprehension. The idea of residents controlling the management of an institution in which they lived seemed to conflict with the very essence of why they were there in the first place – i.e. placed in ‘care’ because they cannot control their own lives and function independently in the community.

When residents in the Cheshire Le Court institution persisted in pointing out that they wanted

'to extend the range of control over (their) lives . . . to choose our own bedtimes, drink alcohol if we chose, freedom for the sexes to relate without interference, freedom to leave the building without having to notify the authorities, etc.'<sup>3</sup>

their wishes were stubbornly resisted by members of the able-bodied management. It was not only argued that management committee members had been given the responsibility by the charity to administer its funds in running the home but that residents were not qualified to do this. In the circumstances, the isolated and often poorly educated (as a result of interrupted education or attendance at special schools) residents found it difficult to sustain their arguments in the face of the experienced able-bodied public figures. To meet this challenge Paul Hunt, a resident in the Le Court Cheshire Home, and other disabled residents began a search for more factual evidence to back up the moral and logical case that they had been making for more power in the hands of a residents' committee.

Conflict between Le Court residents and the management committee following the appointment of a warden for the home encouraged the disabled residents to support an investigation into the nature and running of the home. Miller and Gwynne,<sup>4</sup> two social scientists from the Centre for Applied Social Research, Tavistock Institute, were invited to carry out a research project on the running of the homes. They made a series of visits to a number of residential homes and suggested that

'by the very fact of committing people to institutions of this type, society is defining them as, in effect, *socially dead*, then the essential task to be carried out is to help the inmates make their transition from social death to physical death'<sup>5</sup> (my emphasis).

In their words, once a disabled person had entered an institution 'society' has effectively washed its hands of the inmates as significant social beings.' Miller and Gwynne concluded that the function of the home was to manage the process from social death to actual death as effectively as possible. They identified two types of institutional residence, one operating a harsh and the other a more humane regime, looking after disabled people until death. Their recommendation was to encourage greater staff training and support so that care (social death) could be more efficiently managed in the homes.

As can be expected Le Court residents were appalled by the outcome of Miller and Gwynne's research.<sup>6</sup> They already knew from individual experiences, such as segregated education, unemployment, inability to use public transport, restricted access to sources of information and their placement in the home, that they were regarded as non-functioning beings. However, they could not accept this as an irreversible state, caused by a medical condition (being 'disabled', or what Miller and Gwynne refer to as being 'crippled'), to be managed or cared for until death. Their active engagement in struggles for control over the running of the institution provided living proof that they were perfectly capable of functioning independently as responsible citizens.

Miller and Gwynne suggested that the boundary between the institution and wider society was also between the 'dead' and the living. However, in making this distinction they did not question the legitimacy of linking disability with social death but rather with effective ways and means of managing this in the institution. Persistence in encouraging administrators to manage residents as if they were socially dead, in the face of overwhelming and contradictory evidence from their active struggle for democratic rights, underlines the strength of popular assumptions that disability *must* mean intrinsic dysfunction and dependency on care. The only difference between the institution and wider society, then, is not between the living and dead but that breakdown of care in the community enables the link between 'social death' and 'disability' to become an *open* reality in an institution. In entering residential homes for disabled people to conduct their research Miller and Gwynne brought with them prevailing

attitudes and allowed their prior ignorance of disability issues (freely acknowledged by them in their book) to colour their interpretation of what they were seeing.

In their research Miller and Gwynne's adoption of the widespread assumption that disability means inability to function independently, crystallised in what amounts to a social interpretation of the meaning of disability. From this point of view the social death of a disabled person can be interpreted as originating in the community, entry into an institution only marking a change in the practical arrangements of its management. What Miller and Gwynne had done was to make explicit an unspoken, but primary, 'social model of disability'. In this model disabled people are seen as socially dead, dependent upon others for a 'cure' or to provide permanent 'care'. Inadvertently, the struggles of residents in Le Court, and other institutional homes, for basic citizenship rights provided the springboard for the clearest presentation of the outstanding social characterisation of disability. This construction or model can be called the 'social death model of disability'.

With Paul Hunt in a leading role the residents concluded that able-bodied social science could not be relied upon to carry out unbiased research – i.e. research which is not prejudiced by able-bodied presumptions about the social effects of medical conditions. Publication of Miller and Gwynne's conclusions did not encourage Paul Hunt and other disabled residents to welcome the better management of their social death! On the contrary, it added more clarity to the reasons behind public attitudes and focussed attention on the need for alternative strategies in interpreting disability and promoting non-segregated solutions.

An early fruitful source of information for discussion about integrated approaches to educational and residential needs was obtained from Sweden. The Fokus<sup>7</sup> scheme provided a useful example of supported residential accommodation for disabled people and Paul Hunt became an expert in writing and disseminating information about this and other non-segregated approaches which enable disabled people to participate in their own communities.

Providing examples of alternatives to residential homes from other countries and criticising the interpretation of disability as an inability to function without able-bodied care and professional interventions in the education, health and welfare services, however, did not meet with much success in the UK. Disabled advocates of alternatives to residential homes found it increasingly necessary to support their case with more detailed criticisms of the British approach to disability. This meant looking more closely at what was wrong with current interpretations. Rejecting and then arguing *against* the dominant social construction of disability (as identified in Miller and Gwynne's model) provided a more rigorous theoretical challenge which, in the long run, prepared the ground for greater sensitivity amongst disabled people that 'disability' is indeed *created* by the existing structural organisation of our society.

### **The experience of disability: a reflexive pause**

By the time Paul Hunt, Peter Wade and other residents managed to move into their own homes in the community they had become thoroughly convinced that the establishment and maintenance of residential homes was a powerful symptom of the predominant public attitude that disability means social death. They saw, therefore, the campaign to provide secure community based alternatives to residential homes as an essential component of regaining the citizenship rights of disabled people. To this end they became active participants in joining and creating organisations of disabled people which they felt could in some way further the integration of disabled people into the community.

An organisation which attracted much attention was the Disablement Income Group (DIG).<sup>8</sup> The stimulation for the creation of DIG came from two disabled women in 1965 and although it expressed wide concerns for social rights it maintained a central and dominant focus on the campaign for a disability allowance. It was argued that since disabled housewives did not contribute to national insurance they were not adequately provided for in the national benefits system. Male members and academics, however, very soon influenced the organisation and broadened its focus onto the campaign for a national disability income for *all* disabled people. The group attracted wide attention, spontaneously drawing in members who felt that a disability allowance would be a major contribution towards their integration into society. Perhaps, too, underneath this was an implicit faith in the ability of a money allowance (received 'as of right') to minimise the experience of social death.

The campaigning needs of DIG provided a base for disabled people to come together and discuss activities in support of the organisation. This created a very good forum for discussion at the grass roots level and there followed a period of vigorous debates about the potential of a disability allowance to facilitate integration. This was set against the established practice of providing segregated facilities. Concern about who was to receive any national disability income contributed to the debate by raising questions about the definition and meaning of disability.

At the narrow level, this discussion was anxious to avoid linking the provision of a statutory disability income with criteria concerned with 'the cause of disability'. DIG wanted to widen provision of an allowance beyond existing arrangements, such as compensation for disability following industrial injury. Here, the cause of disability was confused with site or origins of physical impairment and, as such, was considered irrelevant to the campaign.<sup>9</sup> On the other hand, it firmly maintained its focus on the 'single issue'<sup>10</sup> campaign for financial benefits as the route to integration. Paul Hunt, representing views arising out of residents' struggles against institutional segregation, felt that this approach was unlikely to succeed because it did not address the central issues of disability.

The demand for a disability allowance was presented by DIG as arising out of the need to 'compensate' for disability (meaning, the possession of a physical or mental impairment). But this demand, far from challenging the view that disability results in an inability to function socially, tends to reinforce this assumption (i.e. the social death model). This in turn encourages the dependency of disabled people on special provisions and the goodwill of able-bodied people for financial resources to facilitate their inclusion in society; and this dependency was precisely the situation that Paul Hunt and the residents had tried to change in Le Court.

Those who wanted DIG to promote less dependency amongst disabled people saw it as an organisation which opened up opportunities to engage in active work with its membership at the grass roots level. They therefore pressed DIG for more work within local groups. Those in DIG who were mainly concerned with putting pressure on government for a disability income felt that the paramount function of the organisation was to prepare careful and well-researched presentations to the authorities in the seats of power.

Paul Hunt saw this tension within DIG as repeating the same conflicts that had agitated the residents at Le Court. In the discussions that followed the publication of DIG's various incomes proposals he began to suggest that the time had come to work out a new, comprehensive strategy towards disability issues. He felt that the true condition of disability was consistently being misunderstood as a result of pressure on disabled people to develop single issue campaigns in response to separate statutory provisions in the areas of personal benefits, specialised vehicles, residential accommodation and special education, etc. He

wanted an approach which could unite all these strands within a single philosophy (or theory) of disability which, in turn, could direct the development of a comprehensive support system in the community under the control of disabled people. He decided to pursue this idea by publishing a letter in a national newspaper inviting like-minded disabled people to contact him for discussions to see if a new organisation might be set up.<sup>11</sup>

There was an immediate and vigorous response from a wide range of active disabled people, many of whom had been members of DIG but who felt that its approach was inadequate for the changing situation. There followed a year of intense discussion through an internal circular. This resulted in the formation of a new organisation called the 'Union of the Physically Impaired Against Segregation' (UPIAS). In my view, publication of the UPIAS policy document marked a turning point in thinking about the meaning of disability in the UK because for the first time in this country a group of disabled people interpreted segregated facilities as a symptom of their oppression. In saying 'since the means for integration now undoubtedly exists, our confinement to segregated facilities is increasingly oppressive and dehumanising' the document recognised that social death was imposed upon them and that regaining citizenship rights involved resisting this oppression.<sup>12</sup> Clearly, UPIAS guidelines for action were based upon a 'social oppression theory of disability' and the model of disability inherent in their philosophy could be called a 'social barriers model of disability'.

### **The disabling experience: the administrative model**

As members of UPIAS began presenting their alternative, new social approach to the integration of disabled people, they not only held their own in discussions with the experts but increasingly found themselves at the centre of innovative ideas about the future of community based services. Supporters of existing service approaches aimed at compensating for disability (and based on the 'social death model of disability'), however, have never managed to offer any alternative to their traditional demand for ever more money to be put into services, which they orchestrate, and which provide them with the main benefits in terms of careers and financial income.

At first, ideas from UPIAS attracted only the most active, but the view that disability is socially created steadily percolated into the disabled community. In this arena individuals from the Liberation Network of People with Disabilities (LNPD) (also set up in the early 1970s) asserted their own interpretation that disabled people were an oppressed social group and added momentum to the increasing drift away from DIG. On the other side of the internal DIG argument the advocates of more effective pressure on government for a disability income felt that a broader base than DIG was needed in order to make a more plausible case and they went on to set up the Disability Alliance. The formation of this organisation also significantly contributed to the weakening of DIG. DIG's failure to maintain the centre stage in presenting the basic concerns of disability, and differences between UPIAS and the Disability Alliance about appropriate ways to move forward, focused attention on the need for a clear presentation of the new concepts of disability and an indication of how these ideas could be more relevant to modern society.

In publishing their policy documents both UPIAS and the Disability Alliance recognised their differences as well as the importance of a unified approach to disability-related services and benefits. It was agreed, therefore, that a meeting should be held between the two associations in order to reach a common understanding about the fundamental meaning of disability and the appropriate way forward. No agreement was reached at the meeting but a report<sup>13</sup> was published highlighting the essential differences between the two groups.

In this document UPIAS expanded its policy statement by presenting for the first time a clearly articulated social definition of disability.<sup>14</sup> On this understanding it also argued that the problems faced by disabled people could only be effectively addressed when they were directly involved in decision-making to remove the barriers created by the way society organised exclusively for able-bodied living. The Disability Alliance, agreeing that disability should be defined in social terms, continued to maintain that poverty had to be tackled first, with a state disability allowance, before disabled people could take on the active role of participation in changing society for their integration. Their approach, therefore, maintains the popular assumption that reduction in social functioning is a result of individual possession of a disabling medical condition.

By accepting that disability is associated with poverty, and failing to question the origins of this connection, the Disability Alliance's solutions, like Miller and Gwynne's, were coloured by the simplistic assumption that to be permanently disabled means that the individual is *intrinsically* non-equal to their peers (i.e. without help, a non-being). While all those active in disability issues seem to agree that disabled people are, as a group, relatively impoverished, poorly housed, educated and serviced by public utilities compared to their peers (i.e. non beings),<sup>15</sup> they do not agree about how this originates. On the one side this social deprivation is seen to be the result of personal inadequacy and on the other that it is due to social and environmental barriers. The former encourages campaigns for state handouts (or relief) and extra (or special) services to compensate for the alleged permanent inadequacy (disability). The latter view leads to searches for new ways to engage disabled people more actively in their own affairs to change or eliminate the barriers (which are seen as disabling).

From the point of view developed by UPIAS there is a mechanism in the way that society is organised for able-bodied living which brings about the social death of disabled people. There are then two intervention choices for those who do not question this process but who wish to help – either 'cure' the individual condition allegedly resulting in the deprivation, or provide an elaborate system of 'care'. Both forms of intervention assume that the problems of individual disabled people originate in their deprivation from essential standards of 'normality'. Both approaches, too, involve the imposition of able-bodied standards when defining appropriate actions on behalf of disabled people. As can be seen, the common elements in the cure or care approaches are derived from the same basic model of disability – that disability means social death necessitating interventions by able-bodied professional and lay workers who then 'administer' the cure or care solutions.

In my view the administrative model of service provision dominates all services in the UK, whether these are provided by statutory agencies or voluntary charities, or demanded by pressure group organisations. Facilities for disabled people constructed on the foundation of the administrative model assume services can be delivered in the separate, but tightly linked, cure and care areas of intervention. Each of these forms of service provision are, of course, guided by their own sub-set of the administrative model. For disabled people these are the rehabilitation and personal care service models. Rehabilitation services are prescribed on the well-known medical model and personal care services on the imperfectly identified welfare model of disability. Both these models of disability should be regarded as sub-sets of the dominant social death model of disability.

What is often not recognised, however, is that as long as the administrative model for services used by disabled people remains dominant any reduction in the relative importance of one of its sub-sets in directing services will only strengthen the influence of its linked complementary approach. The relationship between the prevailing disability models and their counterparts in service provision can be illustrated as shown in Figure 1.

The medical interpretation of disability, of course, is widely experienced as dominating service provision models for disabled people. A consequence of this is that in day-to-day interactions the medical model appears to lend the only meaning to the experience of 'disability'. The spontaneous way of reducing this power, therefore, seems to require replacing it with a social model. In my view, however, the medical interpretation of disability does not provide the outstanding principles which govern the dominant understanding and servicing of disability. It is, rather, one of the sub-sets of the over-arching 'social death' model of disability. Reducing the power of medicine in controlling the lives of disabled people while leaving the administrative approach to services intact, therefore, can only lead to the growing power of personal *care* approaches. In recent times we have already seen evidence of this in the growing concern about the needs of *carers* and the call for trained and professional service providers to administer more care in the community, while at the same time assumptions about the intrinsic dependency of disabled people remain unchallenged, if not actually reinforced.<sup>16</sup>

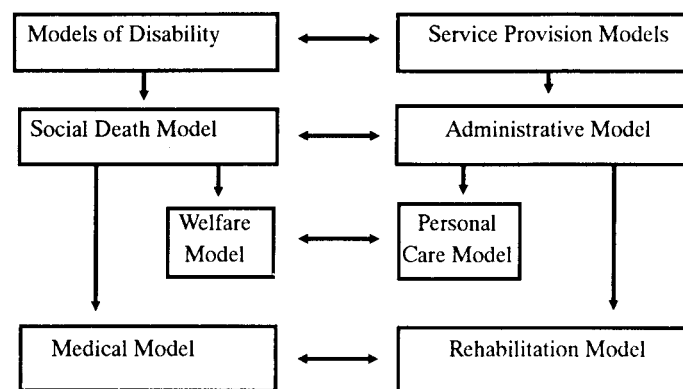


Figure 1

Interventions based on the medical model focus on the individual, and criticising this aspect of prevalent services, as Oliver<sup>17,18</sup> and Borsay<sup>19</sup> do, of course, also challenges one of the important links between the medical model and the various service models. As such polarising models of disability between the social and the individualised medical models undermines confidence in existing practice and opens the door to new approaches based upon different definitions of disability. However, in my view, space for the emergence of new support systems, enabling disabled people to develop their distinctive lifestyles in the community, will best be served by linking criticism of the individualised interpretation of disability with criticism of the dominant social model identifying disability with social death.

This is not the place to present a detailed account of how the social death of disabled people might have evolved within our social system. I have provided an outline<sup>20</sup> of such a possible process where further research might be fruitful, and Oliver<sup>21,22</sup> and Borsay<sup>23</sup> have criticised and taken this suggestion further. For the purposes of this paper, however, the meaning of disability is regarded as a socio-economic construct originating in the way in which the industrial revolution set in motion processes which were to have a profound influence on the social status of disabled people.

In my view the introduction of machinery for factory production on a large scale meant employment, as a source of livelihood, became restricted to those of *normal* functional ability. The ability to integrate into an industrialised society not only required intact bodily functions in order to operate the machinery (i.e. varying degrees of finger dexterity, ambulation, sight and hearing, etc), but also the absence of various impairments to ensure access to public transport (designed to move *physically normal* workers between home and

work), and an ability to read, write and listen so that the complicated skills for modern production could be acquired. Having a normal body was not only required in the area of production but also presumed for employment in the processes involving transportation of commodities from place of manufacture to site of sale and in the transactions across the counter with customers.

Since disabled people deviate from this 'norm' they are susceptible to progressive exclusion from an independent source of income with consequent isolation from mainstream life and their communities. The spread of industrialisation and the drive to increasingly efficient production seems to have operated progressively on disabled people by making them, as a social group, unemployable. Disabled people, therefore, suffered the more serious endless problem of unemployability rather than unemployment.

Disability itself has come to mean 'unable to work' and as non-earners disabled people are now fundamentally identified as incapable home makers and unsuitable love partners. In the formative years following the industrial revolution the modern concept of disability became associated with expectations for a life of dependency upon charity and beggary. When this became a major social problem disabled beggars were removed from the streets and placed in care. Ultimately, this led to the systematic isolation of disabled people from their peers and a thorough form of apartheid evolved which included special residential accommodation, sheltered employment, special transport, and special education geared for leisure rather than for careers in employment.

By the mid-twentieth century this process had succeeded to the point of making disabled people almost totally invisible in mainstream society. This social death of disabled people, however, as suggested by Miller and Gwynne's research, only gains its final material expression on entry into a residential home where all aspects of life are administered by able-bodied carers. Disabled people, of course, have always struggled for the right to life and as the modern meaning of disability evolved they spontaneously sought ways of countering this by defending their human dignity. In the early 1970s the struggle for greater power over their own lives provided the experience for challenging the prevailing understanding of disability and the development of their own interpretation of their situation. Not only was there agreement on the need to cultivate a new social theory of disability as a counter-balance to the prevailing models but it was argued that this should guide the development of future support services which they would control.

However the new model is defined<sup>24</sup> consensus is emerging that this should involve interpreting disability as a result of social and attitudinal barriers constructed by a world built for able-bodied living. This, I believe, can be called a 'social barriers' model of disability. Logically, this view leads to service approaches which focus on barrier removal.

The relationship between a barrier model of disability and related service provision approaches would also need to provide more acceptable boundaries between impairment and disability and their appropriate interventions, perhaps as follows:

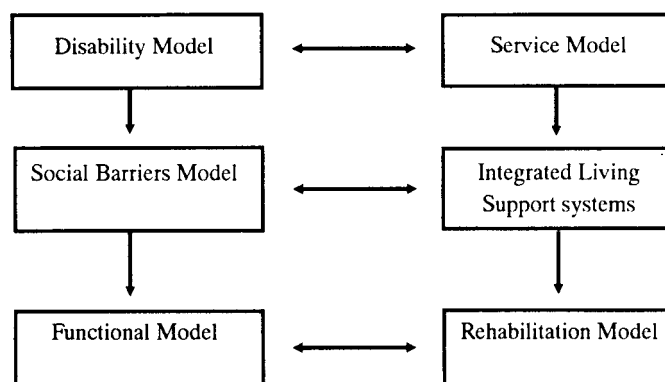


Figure 2

In this scheme the paramount control of disabled people over the support systems that they may use is ensured by structuring the medical 'Functional Model'<sup>25</sup> and its associated 'Rehabilitation Model' for services in the context and under the guidance of developing the higher order 'Social Barriers' and 'Integrated Living Models' respectively.

### From words back to action: integration

It is clear that clarification of new ways of interpreting disability arose directly out of the experience of trying to influence attitudes of service providers about the appropriate control and delivery of support systems. Many disabled people involved in this debate were also engaged in expanding their experience by finding out and initiating practical alternatives for community based services. Ideas from internal discussions amongst disabled people in the UK, therefore, were seasoned with practical examples from other countries.

Paul Hunt, in particular, disseminated information about the FOKUS project in Sweden. This was seen as of particular relevance to residents who wanted to return to their own homes from their isolated institutions. FOKUS was seen as an approach which could enable disabled people to regain control over their lives and bring to an end their 'social death'. The project involved building a proportion of accessible flats within local housing schemes. These are evenly dispersed in an estate, to avoid ghettos, and linked to a central point where home help support staff can provide scheduled assistance and be on call for emergencies. Important elements of the scheme include the control exercised by disabled people over staff management and personal arrangements for home help and efforts to improve access to shops, employment and public transport.

Starting a FOKUS project in the UK, however, required convincing voluntary agencies already committed to residential homes and social services departments who were setting up Chronic Sick Units (later renamed the Younger Disabled Units). It was no surprise, therefore, that pleas to local, and central, government, for changes in residential arrangements for disabled people made no progress. Perhaps, too, the training of service providers has ingrained the social death model of disabled people to such an extent, reinforced by experiences of resigned and passive disabled people in the 'homes', that schemes for independent living in the community seem like far fetched experiments in risk taking.

Individual disabled people were driven to search for personal solutions which could establish the viability of living in their own homes under their own control. Amongst the most significant of the early projects started by disabled people was the Grove Road scheme set up by Ken Davis and Maggie Hines.<sup>26</sup> This was a modified version of the FOKUS approach. Both had experienced living in a residential hostel and they were determined to set up their own home despite consistent advice from professional workers that this was not a possibility.

They began by negotiating a site to build accommodation consisting of a number of accessible ground floor flats with apartments for helpers on the first floor. The scheme involved subsidised rents for the able-bodied helpers and full management in the hands of all the residents in the building. This meant sharing decision-making between helpers and disabled people.

An important aspect of the scheme was the careful planning needed to organise the allocation of help that had to be built into the project. Based upon professional advice and their experience of 'care' in the hostel Ken Davis and Maggie Hines estimated the amount of paid time needed to facilitate security in their own home. This turned out to be a gross over-estimate and, in their view, illustrated both the limitations of professional expertise and the passivity generated by residence in institutions where all care and management is provided by able-bodied staff. The project was a tremendous confidence booster and a practical challenge to informed opinion about what services were appropriate for disabled people.

These messages spread rapidly through the disability grapevine, feeding the growing consensus that disability is manufactured by attitudinal and environmental barriers rather than functional limitations in the individual. Ideas about practical ways of enhancing the control of disabled people over their own lives were shared between individuals and organisations working in many areas, such as the Association of Disabled Professionals (ADP) and Association of Blind and Partially Sighted Teachers and Students (ABAPSTAS) who were promoting integrated education and the Spinal Injuries Association (SIA) encouraging greater self-management in daily life. This led to a more robust public profile and expansion of the self-help component of their aims. Local associations created with traditional charitable goals of providing leisure activities and putting pressure on local government for more able-bodied services came under increasing criticism for lack of 'consumer' representation and some were radically transformed. Many of the older organisations, such as the British Deaf Association (BDA) and National Federation of the Blind (NFB) became even more active in challenging the dependency assumed in the meaning of disability.

The growth in power and influence of these organisations highlighted the lack of knowledge amongst disabled people about achievements that were possible in the community. It became increasingly clear that limited information was itself an important barrier<sup>27</sup> hindering the development of new services planned, developed, set up and run by disabled people. The jealous control of knowledge exercised by able-bodied professional workers was attributed to their exclusive position in service delivery. As the sole administrators of services, only they required possession of the information and skills necessary for effecting the services. Paul Hunt, Ken Davis, Mike Oliver, Paddy Ladd, Anne Rae and the many others who agreed on the central role that disabled people should play in their own affairs made a point of stressing the importance of information networks and the need for self-education about new approaches to disability.

Ken Davis took the initiative and helped create a service run by disabled people to pass on information and advice. Disability Information and Advice Line (DIAL) local groups grew rapidly throughout the country and were very frequently managed and staffed by disabled people. DIAL not only contributed to the break-down in the knowledge monopoly held by professional disability experts but also gave disabled people a deeper sense of the increased choices possible for those wanting to live independently in their own homes in the community.

When this spread of knowledge was combined with the confidence and skills acquired in the new disability organisations, success in schemes like the Grove Road project and well rehearsed arguments that disability defined as functional inability could no longer be

sustained, very many more disabled people added their voice for a controlling role in all aspects of their own lives. What can be called the social barriers model of disability intuitively appealed to active disabled people struggling for changes to the way they were being defined and they increasingly turned their attention to problems in removing barriers preventing their right to full citizenship.

A new round of organisations were created to bring different disability groups together. Most of these 'coalitions of disabled people' not only presented themselves as the democratic voice of disabled people at the local level but also as a vehicle for setting up new integrated (or independent) living services under the control of disabled people. The coalitions have also been joined by a rapid growth in arts groups. These have shifted their attention from the traditional focus of providing leisure activities for isolated disabled people and promoting access to able-bodied arts to the development and celebration of a disability culture.<sup>28</sup> The positive self-image emerging from these organisations directly contradicts the presentation of disabled people as inherently dependent on charity and functionally passive in the social death model which guides current services. The British Council of Organisations of Disabled People (BCODP) was founded in 1981 as the national body uniting all organisations controlled by disabled people. A common feature of these groups is that disability is not seen as a personal problem but as the social consequence of a disabling society. The focus is on removing the barriers which prevent the equal opportunities of disabled citizens.

The past five years have consolidated the ideas developed during the earlier period of struggles against segregation, mainly against residential institutions but also in opposition to special schools and sheltered employment. This has taken the form of struggles to implement practical projects in which disabled people could be directly involved. The organisations controlled by disabled people provided space for confidence building and the development of new skills. These experiences in turn paved the way for testing managerial and professional abilities in setting up and running community based services – the 'Centres for Integrated Living' (CILs). These are also often called Centres for Independent Living but not to be confused with independent living centres run by able-bodied professionals.

### **Integrated living: support systems**

As is clear from the developments outlined above, a great deal of energy has been expended in this country to shift professional (local authority social services) and voluntary charities away from their acceptance of guiding principles based upon the assumed incapacity of disabled people to function independently of care in the community. This has not been successful despite recent marginal gains and consequently disabled people have established organisations, based upon a social barriers model of disability, to set up their own CIL services. CILs originated in the USA as a means of involving disabled people directly in community based services and were first adapted to the UK situation by Ken Davis in Derbyshire.<sup>29</sup>

CILs function in a number of ways, challenging disability stereotypes, providing examples of more relevant services concerned with advice, housing adaptations and ways of managing independence in the home. The CILs are also a focal point for disabled people to marshal their citizenship rights in campaigning for an accessible public environment, suitable housing, mass transport system, educational facilities, leisure opportunities and employment prospects. The fact that the centres and services they provide have been devised and delivered by disabled people also presents a positive and vigorous public image contradicting the general depiction of disabled people as a burden on the state and an appropriate focus for the attention of charity.

The emphasis is on changing the real world, removing real barriers to equality of opportunity, and not just modifying attitudes and changing the practice of service providers while maintaining dependency upon able-bodied people to 'administer' the solutions. From this point of view disabled people increasingly see themselves as oppressed, denied citizenship rights and disempowered. An important component of the changes wanted, therefore, is a 'Charter of Rights' and civil rights legislation which will facilitate more power in their own hands. Barrier removal is not only seen as involving the provision of ramps, information in Braille and tape, signing on television, etc, to enable access to able-bodied facilities but also the right to develop a unique disabled peoples' perspective of the world and the opportunity to contribute to its future shape.

The administrative 'cure and care' approach to disability set service providers apart from those they wished to serve under the illusion that they were being 'objective'. We now see this 'professionalism' as having legitimised the imposition of able-bodied assumptions that to have a disability is to experience a form of social death. In this respect the promoters and defenders of existing services can themselves often be experienced as disabling barriers inhibiting the control of disabled people over their own lives.

The modern challenge is to provide alternatives to current practice so that workers and disabled people can share expertise in barrier identification and removal, both at the personal level (for the individual setting their own goals) and at the social level where public facilities need to be made truly public (and not just for able-bodied citizens). No doubt collaborating in this active way, agreeing to shift the focus from the disabled person as possessing the problem, will open up new experiences from which new and non-confrontational ideas can emerge. It was, after all, the actions of disabled people in just such a manner for the removal of barriers which prevented control over their own lives in the Cheshire Home that provided the springboard for a radical criticism of the administrative approach to service provision and the development of an exciting new interpretation of disability.

Shifting attention from the individual to the disabling barriers involves seeing disability as a consequence of the totality of the individual's relationships and provides an opportunity for sharing an objective discussion about the perspectives between the helper and disabled person. I feel sure that there is no more effective way of identifying and assessing this form of disability than with and through disabled people. This approach too, should help identify boundaries between appropriate models of disability and service approaches. Where an individual, for example, has recently sustained a permanent impairment, medical interventions involving rehabilitation to establish new skills in body management may well be appropriate.

However, as I suggested in the figure illustrating a social barriers model of disability, the medical model and its rehabilitation service approach should always be determined in the context of the social (barriers) model and not vice versa.<sup>30</sup> In effect, this means that the extent, duration and nature of medical interventions should be guided by an understanding and analysis of the barriers to be overcome, rather than on the functional limitations of the individual. Such an analysis, of course, cannot be provided wholly by the professional helper without falling into the administrative model trap. The shift from a functional assessment is, in my view, not only a radical transformation of accepted practice but a firm step in the direction of establishing a resource-based rehabilitation service. By this I mean workers in rehabilitation services should see themselves as a resource, to be tapped by disabled clients, rather than as professionals trained to make highly specialised assessments of what is appropriate for individual disabled people.

The 'social barriers model' of disability and its associated 'integrated living support systems' approach places disability related services logically in the same section of government concerned with barriers for able-bodied people – i.e. the Department of the Environment (rather than Health and Welfare) - and, of course, there would be a need for important new discipline developments in engineering and architecture. From this point of view, it seems perfectly appropriate for housing and adaptations officers working in local authorities to be disabled people and to be trained in the schools of architecture (or perhaps engineering).

Social workers are experienced in working with vulnerable and oppressed sectors of the community and would clearly have a major role in assisting disabled people attain and maintain their citizenship rights. Assistance with skills in managing personal support staff and liaising with CILs are other areas where the expertise of social workers could be very relevant. However, I believe that their main contribution could be as advocates in support and working with disabled people in identifying and helping to remove social and physical barriers in the local environment.

To summarise: a social barriers model of disability suggests at least the following fundamental changes:

- (a) shifting the base for disability related service from 'health and welfare' to 'environment' based services,
- (b) reformulated disability related services so that they are no longer service led but provided as a resource with clear access rights for disabled people,
- (c) restructuring disability related services so that the integrated living support systems (CILs) provide the necessary central focus and guidance for all services used by disabled people including medical, educational, housing and transport services,
- (d) redirecting the education and training of all service providers so that there are more fitting criteria for determining appropriate intervention (service) models, especially in relation to medical rehabilitation approaches, and improving the education and training of community based service providers so that their analytical and organisational skills are better focussed on barrier identification and removal with less emphasis on functional assessment, and
- (e) enacting civil rights legislation as a framework for guiding the development of community based support systems for disabled people living in their own homes and ensuring equal opportunities in employment and equal access to education and medical services, housing, transport, leisure, the environment and information.

The adoption of a programme promoting aims along these lines will, I am sure, win the approval of disabled people who have pioneered a totally new perception of themselves and the services that they need. It will also bring to an end the long process triggered by the industrial revolution which led to the construction of disability as a form of permanent social death.

## Notes

1. See for example Russell, W. *New Lives for Old: the Story of Cheshire Homes*. Victor Gollancz Ltd, London, 1980.
2. See especially copies of *Cheshire Smile* published in the late 1960s and early 1970s for a sample of critical writing from disabled residents.
3. Hunt, P. 'Settling Accounts with the Parasite People: a Critique of *A Life Apart* by E. J. Miller and O. V. Gwynne' *Disability Challenge*. 1, May 1981, 38. UPIAS.

4. Miller, E. J. and Gwynne, G. V. *A Life Apart*. Tavistock Publications, London, 1972.
5. Miller and Gwynne, 1972, p. 89.
6. See Hunt, P., 1981, in particular, for a scathing critique of Miller and Gwynne.
7. Brattgard, S. O. 'Social and Psychological Aspects of the Situation of the Disabled.' Twelfth World Congress of Rehabilitation International, Sydney, Australia (Aug./Sept. 1972). Vol. 1, 1972. A number of pamphlets on the FOKUS scheme became available in the UK during the early 1970s Which attracted a great deal of attention; articles by Dr. Brattgard were read and discussed by many activists.
8. See the editorial in *Disability Challenge* 1, May 1981, UPIAS, for a criticism of DIG; also Oliver, M. *The Politics of Disablement*. Macmillan Education Ltd, Basingstoke, Hampshire, 1990; also Pagel, M. *On Our Own Behalf*. Greater Manchester Coalition of Disabled People Publications, 1988.
9. Mary Greaves, an active member of DIG, made clear her views that 'we all want integration, whatever the cause of disability', DIG Progress.
10. This was a point made both in Union of the Physically Impaired Against Segregation *Fundamental Principles of Disability*. UPIAS, 1976; and the editorial in *Disability Challenge*. 1, May 1981, UPIAS.
11. The letter was published in *The Guardian* on 20 September 1972 and subsequently in many of 'disability' journals.
12. Union of the Physically Impaired Against Segregation. *Policy Statement*. UPIAS, 1976
13. Union of the Physically Impaired Against Segregation. *Fundamental Principles of Disability*. UPIAS, 1976.
14. For example, 'impairment [is defined] as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; disability [is defined as the disadvantage or restriction activity caused by a 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. Physical disability is therefore a particular form of social oppression.' Union of Physically Impaired Against Segregation. *Fundamental Principles of Disability*. UPIAS, 1976.
15. See for example, the latest Office of Population Census and Statistics (OPCS) survey findings.
16. For example, *Care in the Community*. HMSO, 1989.
17. Oliver, M. *Social Work with Disabled People*. Macmillan, Basingstoke, 1983.
18. For example, '. . . functional definitions . . . focus on the problems of the disabled individual and do not attempt to develop research tools for measuring the disabling effects of the economic, social and physical environments.' Oliver, M. 'Social Policy and Disability: Some Theoretical issues' *Disability, Handicap and Society*. 1, 1, 1986, 9.
19. '. . . the individualistic approach has a number of flaws . . . impairment is assumed automatically trigger off a single reaction which restricts functioning in all spheres . . . Most telling, however, the omission of societal factors because without the socio-economic and political content provided by the 'public issue' or social perspective, we are ill-equipped to comprehend both the causes of disability and the social policies which it has provoked.' Borsay, A. 'Personal Trouble or Public Issue? Towards a Model of Policy for People with Physical and Mental Disabilities' *Disability, Handicap & Society*. 1, 2, 1986, 180.
20. Finkelstein, V. *Attitudes and Disabled People: Issues for Discussion*. World Rehabilitation Fund, New York, 1980.
21. In referring to my 1980 publication for the World Rehabilitation Fund, Oliver suggests that this publication offers '. . . the possibility of beginning to construct a social theory of disability . . .' He goes on to suggest that the model proposed '. . . over-simplifies, or over-romanticises . . . aspects of the historical process.' Oliver, M. *Social Policy and Disability: Some Theoretical Issues* *Disability, Handicap & Society*. 1, 1, 1986, 14.
22. In referring to the 'role and potential of new technology' to provide directions for the future, Oliver suggests that the significance I attribute to developments in technology in triggering social transformations in the status of disabled people is too optimistic. He says, 'not all commentators see the issue as one of outdated attitudes, moulding technology in particular directions, but point to the fact that technology itself will not necessarily produce or equally distribute its benefits.' Oliver, M. *The Politics of Disablement*. Macmillan, Basingstoke, 1990, 125.

23. Borsay, A. 'Personal Trouble or Public Issue? Towards a Model of Policy for People with Physical and Mental Disabilities' *Disability, Handicap & Society*. 1, 2, 1986, 183.
24. The Disabled People's International (DPI) definitions, for example, refer to 'disability' and 'handicap' (in British terms 'impairment' and 'disability' respectively) as follows: 'Whereas disability has too long been viewed as a problem of the individual and not the relationship between an individual and his/her environment, it is necessary to distinguish between: (a) disability is the functional limitation within the individual caused by a physical, mental or sensory impairment and (b) handicap is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.' DPI Constitution.
25. Functional models not only service medical interventions with rehabilitation goals but also all approaches which assume that poverty amongst disabled people directly results from individual disability. The Disablement Income Group, the Disability Alliance and the Office for Population Census and Statistics have assumed just such an individualistic functional (or medical) model. Their concern is to clarify eligibility for the allocation of financial benefits to compensate for disability and determine the administration of resources.
26. Davis, K. 'Grove Road' *Disability Challenge*. UPIAS, 1, May 1981.
27. Davis, K. and Woodward, J. 'DIAL UK: Development of the National Association of Disablement and Advice Services'. In Brechin, A. , Liddiard, P. and Swain, J. *Handicap in a Social World*. Hodder and Stoughton, London, 1981.
28. Finkelstein, V. 'Disabled People and Our Cultural Development.' Paper presented to London Disability Arts Forum Conference, April 1987.
29. Davis, K. 'Consumer Participation in Service Design, Delivery and Control.' Derbyshire Coalition of Disabled People, Derbyshire, 1983.
30. The Disabled People's International (DPI) does not go this far, but is concerned with drawing boundaries between rehabilitation and community based services: 'Whereas rehabilitation is a process aimed at enabling a person to reach optimum physical, mental and/or social functioning level in order to provide that person with the tools to direct his/her own life, independent living and community services are not, and should not be, part of that process.' DPI Constitution.