Chapter 6 (In 'Disabled People in Britain and Discrimination : A case for anti-discrimination legislation', Colin Barnes (1991)

The Health and Social Support Services

Earlier chapters have shown that since the 1939-45 war Government policies on health and support systems for disabled people have been increasingly geared toward provision within the community. This has led to both an expansion of services at the local level and a proliferation of professional helpers who exercise considerable power over those they profess to be helping. It has also been demonstrated that disabled people's ability to participate in the economic and social life of the community is frequently adversely affected by this provision. This chapter looks in detail at health and social support systems and raises a number of major issues which must be addressed if institutional discrimination against disabled people is to be eliminated.

The Organisation and Funding of Health and Social Support Services for Disabled People Organisation. Throughout the post-1945 period the expansion of the health and social support services for disabled people has been constructed upon the erroneous belief that disabled people are not competent to make basic decisions about their own individual service needs (Wood, 1990). This has far-reaching negative implications for disabled people, since logic dictates that if they cannot assume responsibility for organising their own lives then they cannot assume the responsibilities of citizenship. Recent developments within these services will do little to change this perception.

Since the rhetoric of 'community care' has intensified markedly throughout the 1980s (Barclay Report, 1982; Audit Commission, 1986; Griffiths, 1988; HMSO, 1989b), it is important to remember the discriminatory implications of the phrase itself. The concept 'community' is a hazy one, but within the context of community care it suggests life outside an institution within a bounded locality characterised by close social networks between neighbours. Broadly, the verb 'to care' means to look after and protect, with a definite implication of dependence in the person cared for (Rae, 1990). Consequently, what is really meant by the term 'community care' is community dependence or, to be more precise, dependence upon the community.

During the 1970s and 1980s community-based services for disabled people remained confused and extremely variable with no clear national guide-lines (Griffiths, 1988; HMSO, 1989b). For example, the Audit Commission in 1986 pointed out that there was an urgent need for wide-ranging organisational changes and new approaches from service providers if effective community-based

provision was to become a reality (Audit Commission, 1986). In 1988 a report by Sir Roy Griffiths, then Vice Chairman of the National Health Service (NHS) management board, recommended that there should be sufficient 'ring-fenced' funding made available for the expansion and development of a wide range of community-based services by both statutory and private agencies, and that the responsibility for coordinating this provision should rest with local authorities (Griffiths, 1988).

One year later the White Paper Caring For People announced Government plans for the development of community-based services. Briefly, its stated aim was to end the confusion and fragmentation of responsibilities for the provision of services between social security, health, local authorities, private and voluntary agencies; to extend consumer choice; to encourage private and voluntary pro-vision; and to make services more accountable. From April 1991 primary responsibility for planning, coordinating and paying for support services was to be assigned to local authority social services departments, along with instructions to look to the private sector to achieve cost-effectiveness (HMSO, 1989b).

Although the White Paper proposed widespread changes to the administration and funding of community-based services, it did not propose the ring-fencing of funding or recommend any overall increase in resources as Griffiths had recommended. Moreover, recent ministerial concern over the cost of implementation has meant that it has been postponed. Latest estimates suggest that the Government plans will not be implemented until well into 1993 (Langan, 1990).

Viewed in conjunction with the recent changes to the benefit system (discussed in the last chapter), these proposals are unlikely to lead to an increase in choice, control, accountability and autonomy for the overwhelming majority of disabled people. On the whole, disabled people do not have the financial resources to purchase services on the open market, and the only ones available under the new system will be those which have contracts with local authorities (Glendinning, 1990). Most important, the traditional view that disabled people are not able to take control of their own lives has been reiterated and indeed strengthened with the assertion that local authorities should appoint 'case' managers to organise and manage 'care packages' for individual disabled people (HMSO, 1989b). This clearly ignores the views of disabled people and their organisations, who have consistently called for a more holistic and realistic view of disabled people's needs. Commenting on the new proposals, Richard Wood, Director of the British Council of Organizations of Disabled People (BCODP), has stated that they ignored the call from disabled people for self management and concentrated instead on the rehashing of existing inappropriate services and devising new roles for yet another

new breed of professionals who will have more control over our lives than we have (Wood, 199CI, unpaged).

By ignoring the views of disabled people in this way and by emphasising and expanding the role of professionals, the new proposals add significant weight to the growing belief among disabled people that the British welfare system is organised around the needs of service providers rather than those of the users of those services.

Funding. Notwithstanding that Government spending on community-based provision increased steadily in the 1980s (in 1979/80 it stood at £1,169 million, rising to £3.444 million in 1987/8 [HMSO, 1989b]), it has always been accorded a low priority within the health and social support services. In the NHS it has taken second place to hospital-based facilities for acute patients and in local authorities to child care and the elderly (Beardshaw, 1988).

Recent evidence suggests that this situation is unlikely to change within the foreseeable future. At a time when demand for services will almost certainly increase due to an ageing population, Government spending on the health and social support services is expected to fall (Langan, 1990). Additionally, a Department of Health report recently noted that service developments for disabled people are often 'given a lower priority then service developments for other groups of service users and other local authority service committees' (Warburton" 1990, p.2).

It should be remembered here that the lion's share of any money allocated to services for disabled people will go to service providers. The biggest consumers of welfare services are the producers of those services (Oliver, 1990a, Wolfensberger, 1980). By far the largest proportion of the health and social services budget, for example, up to 70 per cent in some cases, is spent on staff wages (Oliver, 1990a).

Present arrangements allow state officials considerable discretion as to how funds allocated for services for disabled people are spent at the local level. Information concerning funding for community services is difficult to obtain, and there is little data on expenditure on disabled people. However, a recent report by the Health Economics Consortium at the University of York, commissioned to provide evidence for the Griffiths review, provides some comparative data in this area.

The report examines health and local authority spending on a variety of health and support services for elderly and disabled people. The data are taken from six district health authorities in England and their associate local authorities. The areas were chosen for their diversity. They are not a representative sample and the

numbers are too small for the information to be indicative of the national picture, but the report does demonstrate the extreme variation in funding and gives some insight into local priorities.

The report shows that funding for community services comes from a variety of sources, including district health authorities (DHAs), local authorities, social security payments and voluntary agencies. As the focus of the report was public expenditure, no attempt was made to quantify the finances independently raised through fund-raising activities and bequests (Gray et al, 1988).

Table 6.1. Percentage of Total Expenditure on Community-Based Services for Disabled and Elderly People

Source of funding	%
District health authorities	52
Local authorities	34
Benefits (board and lodging payments)	11
Private/voluntary sector	3

Source: Adapted from Fig. 1 in Gray et al., 1988

There were important differences between localities in who provided what services and the amounts provided. For example, in two of the districts over 70 per cent of funding came from the health authority while in two others the local authority spent more. In general, however, district health authorities were the largest providers, giving 52 per cent; local authorities provided 34 per cent, 11 per cent came from welfare benefits in board and lodging payments, and the private/voluntary sector funded 3 per cent (see Table 6.1).

Table 6.2 Per Capita Expenditure from all Sources on all Types of Provision for Disabled and Elderly People in Six District Health Authorities, 1985-6

Area	Elderly people	People + mental illness	People + learning difficulties	People + physical impairments	All
1	72	14	10	5	100
2	71	41	21	7	140
3	72	10	17	6	106
4	49	61	54	8	172
5	63	30	64	4	162
6	60	25	23	5	112
Average	66	24	27	5	123

Source: Adapted from Table 3.4 in Gray et al., 1988

There was also some variation in the allocation of resources to the different user-groups. The average expenditure per head of the total local population was £123, but two areas spent over £160 while two others spent less than £110. In addition, spending on disabled people was divided three ways, namely for people with mental illness, people with learning difficulties and people with physical impairments (see Table 6.2).

Overall, spending was weighted heavily toward institutional provision of one form or another. Seventy-three per cent of all finance went on residential or hospital-based services, with only 18 per cent toward community provision; 7 per cent went on day care and 1 per cent each on respite care and group homes (see Table 6.3). This is particularly alarming considering that the debilitating psychological effects of institutional life are now well known.

Table 6.3. Allocation of Expenditure on Community- Based Services for Disabled and Elderly People Service

Service	% of expenditure
Residential and hospital based care	73
Community Service	18
Day centres	7
Group homes	1
Respite care	1

Source: Adapted from Fig. 5 in Gray et al., 1988,

Clearly, spending on services for disabled people is accorded a low priority within official circles. While this might be construed as evidence of institutional discrimination against disabled people, it is important to remember that underfunding is unfortunately a common feature of the British welfare system as a whole. It is not peculiar to provision for this particular user-group. Institutional discrimination is evident, however, in the way in which most of the money allocated to services for disabled people is currently being spent, namely on professionals' salaries and on outdated and out-moded forms of service provision. Hitherto, professional interventions and traditional facilities have achieved little in terms of giving disabled people the same level of autonomy and independence as their able-bodied peers. Indeed, they have tended to achieve the reverse.

Residential Care

It is evident that despite the rhetoric of community care there remains a strong emphasis upon segregated residential care for disabled people. Traditional prejudices maintain that disabled people are dependent and unable to look after themselves (Wood, 1990). In many cases they are confined to a residential institution and kept from making the most basic of decisions and deprived of the opportunities which able-bodied people take for granted (Brisenden, 1985). Disabled people in such places 'suffer loss of social skills and self-confidence'. The Independent Living Movement (ILM) has repeatedly demonstrated that nobody, regardless of type and extent of impairment, 'need waste her or his life in an institution if provided with appropriate services within the community' (Ratzka, 1988, p. 5).

Here, the term 'independent' does not refer to someone who can do everything themselves, a feat that no human being can achieve, whether they have an

impairment or not, but indicates someone who is able to take control of their own life and to choose how that life should be led. It is a thought process not contingent upon physical abilities:

> It cannot be applied to someone living in an institutional setting ..., because the routine of their life will be predetermined, to a greater or lesser extent, by the needs of the professionals in charge of the institution (Brisenden, 1985, p.2).

Life in an institution, therefore, is central to the discriminatory process because it denies inmates the right to control their lives as those do who live outside it. Independent living, on the other hand, is primarily about giving disabled people access to and control of a range of community-based services which enable them to identify and pursue their own lifestyles (Evans, 1984).

It is apparent that for many those services are not available within the community. The OPCS surveys showed that 422,000 disabled people, 20 per cent of whom are below retirement age, still live in 'communal establishments' or institutions (Martin, Meltzer and Elliot, 1988). Moreover, it is sometimes suggested that a substantial number of these people are well over retirement age and 'choose' residential living because of the security it brings (Canter and Barnitt, 1982; Harrison, 1987). It is highly questionable, however, whether this would be their choice if adequate community-based support were available, and since it is not (see below) such arguments cannot be seen as a justification for the disproportionate level of funding that residential institutions continue to receive from official sources.

It is ironic that as the criticisms of residential care during the post-1945 period intensified (see Chapter 2) there was something of an expansion of segregated residential facilities for disabled people (Harrison, 1987). At its inception in 1948 the National Health Service (NHS) had some 55,000 beds for the 'chronic sick' in England and Wales. These were left over from Poor Law infirmaries and workhouses which had been administered by local authorities since 1930. They housed a mixed population of disabled and elderly people, many of whom had no need of medical care. Additionally, the 1948 National Assistance Act gave local authorities a responsibility to provide residential facilities for people 'handicapped' by illness, injury or congenital impairment (Royal College of Physicians, 1986).

Throughout the 1950s and 1960s concern over the mix of elderly and disabled people in long-stay hospitals prompted the development of separate facilities for elderly and younger (below retirement age) disabled people. In 1968 the Secretary of State for Health and Social Services instructed Regional Hospital Boards to set

up special units for the 'younger chronic sick' within the grounds of general hospitals. In 1971 the NHY Young Disabled Unit (YDU) building programme began with an initial budget of 3 million pounds. By the mid-1980s some fifty-eight YDUs had been built. They presently house around 10 per cent of all younger physically disabled people in residential care (Fielder, 1988).

During the same period there was a significant growth of voluntary sector residential provision. The Leonard Cheshire Foundation, the Shaftesbury Society, John Grooms, the Spastics Society and others began to provide residential accommodation for younger disabled people. Much of the funding for this expansion came from local authorities, which were allowed under Part 3 of the 1948 National Assistance Act to finance support for disabled people in privately-sponsored residential homes (Harrison, 1987). Current estimates suggest that the voluntary and private sectors are responsible for just under half of all the residential accommodation for people with 'physical' impairments who are below retirement age (Royal College of Physicians, 1986). Few local authorities run residential homes for disabled people, of which there were sixty- eight in 1986 (Leat, 1988).

The YDU building programme, local authority and voluntary and private sector residential provision have all developed independently of each other with little collaboration at the local level (Harrison, 1987). The YDUs have been established in isolation from community-based services for disabled people. They are a consider- able drain on the limited economic and human resources available to the NHS and their continued support tends to inhibit the development of community-based alternatives.

Despite the growth in institutional provision in the mid-1980s, less than half of all disabled people of working age living in institutions were in places designed specifically for them. The majority were in old people's homes, psychiatric and geriatric hospitals, or ordinary hospital wards. Also, private residential provision for disabled people has increased, fuelled by social security board and lodging payments. Public expenditure on private sector residential care, as a result of these entitlements, rose from £12 million in 1979 to £489 million in 1987 (Land, 1988). Government plans to transfer these resources to local authorities with explicit encouragement to purchase non-residential services have been postponed. Moreover, because there are only a very few private establishments which cater exclusively for younger disabled people, this usually means accommodation in a nursing home for elderly people (Harrison, 1987).

Rehabilitation and Integration

The rehabilitation services which are currently available are highly discriminatory and do a major disservice to disabled people. This is not to deny that some people have benefited from this provision, and that more could do so if more and better services were provided, but we are concerned here with what is actually being offered.

At present rehabilitation is not only a product of institutional discrimination against disabled people; it is also a central component in the discriminatory process. It refers to 'a piecemeal welfare system of professionals and services' specifically designed to 'help' disabled people learn how to cope with 'impossible social, financial, housing and environmental difficulties', which would be totally unacceptable to any other section of the community. In most cases the only part a disabled person is expected to play in the rehabilitation process 'is an inherently dependent one' (Brechin and Liddiard, 1985, pp.2-3). Indeed, if the economic and social barriers which confront disabled people were removed the need for rehabilitation in its present form would be greatly reduced, if not eliminated altogether (Finkelstein, 1980).

Historically, rehabilitation has been dominated by the medical and remedial professions associated with orthopaedics and rheumatology, and until fairly recently was limited to the restoration of lost abilities after illness or injury (Beardshaw, 1988). Today, however, many disabled people have to endure rehabilitation regardless of the cause of their impairment, whether it is newly acquired or present from birth. One is therefore talking of both 'rehabilitation' and 'habilitation'.

Over the years definitions have shifted away from overtly medical concerns toward a preoccupation with the 'whole individual', or the balance between the medical and the social. The Scottish Health Services Council, for example, concluded that

> rehabilitation must. ..take cognizance of the individual and his environment, in order to restore him to his former status or balance' (Scottish Health Services Council [1972] quoted in Beardshaw, 1988, p.20).

Brechin and Liddiard (1985) have suggested that what is actually being described here is the 'promotion of a state of health or well being such as we all might strive for, disabled or not' (Brechin and Liddiard, 1985, p. 2).

Within this broader framework several writers have argued that health and well-being depend only minimally on medical intervention and more substantially on the broad social and cultural context (Brisenden, 1985; Ilsley, 1981; Oliver, 1983,

1990). But in this area medical and therapeutic approaches still dominate professional thinking (Royal College of Physicians, 1986) at the expense of other approaches which promote independent living (Brechin and Liddiard, 1985; SIA, 1987). As a result, current provision is patchy, in both quality and geographical spread, hospital-based services have been retained at the expense of community-based ones (Beardshaw, 1988; Harrison, 1987; Royal College of Physicians, 1986), and functional assessments remain crucial to the process of resource allocation (Glendinning, 1990).

Central to the traditional view of rehabilitation is the notion that individual disabled people should be subject to functional assessments by professionals in order to determine need. The importance of this process has been strongly re-emphasised in several recent Government statements on community-based provision. For example, the White Paper Caring for People states that the allocation of community services is to be based upon professional assessments

of what the individual can and cannot do, and could be expected to achieve, taking account of his or her personal and social relationships. All agencies and professions involved with the individual and his or her problems should be brought into the assessment process when necessary (HMSO, 1989b, pp. 18-19).

This has a number of important discriminatory implications for disabled people. Those who need community-based support will be subject to more scrutiny and control by state officials. Comprehensive assessments by social workers and other professionals will have to be made into the individual and family circumstances of disabled people seeking support before access to services is granted. These assessments might include 'mobility, personal care, financial affairs, leisure' and 'employment'. Moreover, since social services departments are to establish and publish 'criteria of eligibility for assessment and the way in which their assessment processes will work' (HMSO, 1989b, p. 20), those receiving services will inadvertently have their economic and social circumstances made public.

In addition, recent changes to the welfare system mean that there is little scope for disabled people to challenge professional wisdom in the assessment process or service allocation. As Glendinning (1990) notes, this represents a significant loss of rights for disabled people. Under the old social security scheme (see Chapter 5), those applying for means-tested social security payments in order to buy essential services had an automatic right of appeal to an independent tribunal if they were dissatisfied with the outcome of their application. There is no right of appeal and no mechanisms for questioning the decisions of social services staff under the new system (Glendinning, 1990). This is important because historically professionals' perceptions of need are frequently at odds with those defined by disabled people

and their organisations (Davis, 1990a; Oliver, 1983; GMCDP, 1989; Sutherland, 1981), and disputes between disabled people and professionals over the form and levels of service considered appropriate are not uncommon (Glendinning, 1990).

It may be argued that there is little or no need for appeals procedures and mechanisms which challenge professional wisdom within health and social support systems because disabled people and their organizations are to be involved in the planning and delivery of services at every level. To date, however, this has proved extremely difficult to achieve and recent events would suggest that it is unlikely to happen in the immediate future. The idea that disabled people and their organizations should collaborate meaningfully in the planning and running of services for disabled people was first proposed in the early 1970s by a number of disabled writers (see for example UPIAS, 1976). Over the following decade this idea became more influential and was enshrined in statute in the Disabled Persons (Services Consultation and Representation) Act 1986 (Warburton, 1990).

It is evident, however, that with only one or two notable exceptions this has not taken place. A recent Department of Health and Social Services Inspectorate report which examined the extent to which the Act had been implemented in a one-in-three sample of social services departments, found that while some authorities had made some improvements, 'for many there is much to do.' Many local authorities attributed the lack of progress to a lack of resources, although local authority support grants have recognized the need for spending in this area (Warbuton, 1990, p.1).

As for Section 10 of the 1986 Act, which requires local authorities to co-opt people with specialist knowledge of disability to council committees, there was evidence of widespread discrimination. The report noted that there was 'a gap between intent and practice'. Although Section 10 specifically requires local authorities to consult with organizations of disabled people when making co-options, some authorities 'thought' they were operating according to the law by consulting with voluntary organizations concerned with disability. Only one London borough indicated a positive stance toward organizations of or for disabled people; other respondents did not distinguish between the two. Two authorities, one of which was a London borough, reported that it was not council policy to make co-options on to representative committees. Another said that it had individual disabled people on various committees, but added that such representation is 'cosmetic' (Warburton, 1990, p.30).

This should not be surprising, since organizations of disabled people have received little support from central Government. The British Council of Organizations of Disabled People (BCODP), the national umbrella organization of eighty

organizations of disabled people with a total membership of over 200,000 received a paltry £30,000 from the Department of Health in 1989/90. By contrast, the Royal Association for Disability and Rehabilitation (RADAR), the national equivalent for the more traditional organisations for disabled people, received £233,000 (Hansard, 1990a). Historically, organisations for disabled people have represented the interests of disabled people to Government and are 'used and supported by Government for this purpose'. They often 'lack direct contact with disabled people and are very inadequately accountable to them' (Large, 1981, unpaged).

Moreover, organisations of disabled people have not been formally involved in the recent social services review, despite the response to an earlier report on 'community care' by BCODP (BCODP, 1987), and their repeated calls for more accountability in service provision, which have been ignored. Although social service departments are encouraged to 'consult' with disabled people when preparing their plans for community-based services under the new proposals, they are not obliged to demonstrate that disabled people have actually been involved in the planning process (HMSO, 1989b, pp.42-3). Complaints procedures are to be established, but as Glendinning (1990) notes, this is not the same as ensuring that users and potential users are fully involved in specifying and monitoring standards of quality.

If services are to move away from welfare paternalism, it is essential that they adopt and are seen to adopt a collaborative approach between users and providers. Disabled people must also have easy access to a wide range of interlinked provision. These should include specialist facilities such as spinal injury units, occupational and physiotherapy services in hospital settings to aid recovery, and a variety of facilities specifically concerned with independent living (Beardshaw, 1988). As for the latter, these can be summarised within the framework of 'the seven needs' identified by the Derbyshire Coalition of Disabled People (DCDP): information, counselling, housing, technical aids and adaptations, personal assistance, transport, and physical access (DCC, 1986; Davis, 1990, 1990a).

Housing, transport and physical access are examined in the following chapter; here we look at information and counselling, technical aids and adaptations and personal assistance.

Information, Counselling and Advice

Information is fundamental to any decision, and indeed has been described as 'the fourth right of citizenship'. In addition to the general information that all people need, in an able-bodied society disabled people need specialist information. The lack of this information is as discriminatory 'as a narrow door or a flight of stairs'

(DCC, 1986). Moreover, in view of the extreme economic and social difficulties faced by the majority of disabled people, information on its own may not be used to its full effect without counselling help (Davis, 1990). Hence there is an urgent need for a national network of information and counselling agencies.

It is evident, however, that many disabled people do not have access to this type of service. Previous chapters have shown that disabled people and their families have only a limited knowledge of education systems, employment opportunities and social security benefits. With medical data, research shows that a large proportion of disabled young adults know very little about their impairments (Anderson and Clarke, 1982; Barnes, 1990; Brimblecombe et al., 1985). People with newly-acquired impairments often receive insufficient information and counselling to understand their changed circumstances (Morris, 1989; Oliver et 01., 1988). There is also substantial evidence that disabled people and their families have only limited knowledge of community-based health and support services and technical aids and equipment (Martin, White and Meltzer, 1989; Morris, 1989; Oliver and Hasler, 1987; Oliver et al., 1988). Indeed, this general lack of information 'seems to be as common in the 1980s as it was during the 1950s, 1960s and 1970s' (Morris, 1989, p. 33).

Whilst this might be partly explained by the cumulative debilitating psychological effects of institutional discrimination on disabled individuals in other areas, in education and the labour markets for example, it is also due to the 'professionalisation' of disability. As noted earlier, within the context of the welfare system disabled people are confronted by a bewildering array of professionals, those whom Davis has termed the 'denizens of the disability industry' (Davis, 1990b). This not only presents problems stemming from inter-disciplinary communication, and to some degree rivalry, but it also contributes to the process of 'mystification' (Wilding, 1982).

It has been well documented elsewhere that each profession or specialisation tends to assume a language, a set of policies and a code of practice which give professional respectability and status to its work and its practitioners. Preservation of status would appear to depend upon the maintenance of a 'decent gulf between professionals and clients' (Wilding, 1982). This is an inevitable consequence of the traditional paternalistic model of professional work and is an important element in the discriminatory process. All too often professionals confront disabled people who seek their services with their own definition of the problem which substantially ignores the views of those seeking help (Morris, 1989; Oliver et 01., 1988; Sutherland, 1981; UPIAS, 1976). Consequently, disabled people find getting appropriate information not only unnecessarily intimidating but also problematic. Moreover, without this information they face great difficulty in gaining any

measure of control over how their needs should be met, or even whether their needs will be met at all (BCODP, 1987; Oliver, 1983; Oliver et al., 1988; Wilding, 1982).

There is no uniform approach to advice and counselling services for disabled people within health authorities or in local authorities' social services departments. This task is usually performed by a variety of professionals, such as GPs, social workers, health visitors and hospital doctors, according to their individual interpretation of their professional role. The Seebohm Report (1968) suggested that it should be undertaken by social workers, but this has not materialised. Few social workers are trained for this type of work (Oliver, 1983), and early evidence suggests that they are reluctant to work with disabled or elderly people (Rees, 1978).

Under Section 9 of the 1986 Disabled Person's Act local authorities' social service departments are obliged to give disabled people information relevant to their needs. But this seems to have had little impact on social services personnel. Many appear to think that producing and distributing handbooks or funding information services run by voluntary agencies is all that is required. There is a need for more supervision in this area within social service departments, since it is evident that staff do not take this role seriously and are not fully informed of the wide range of equipment and services currently available (Parratt, 1989). A Department of Health Social Services Inspectorate report published in 1990 concluded that 'it was discouraging that so little had been done by social services departments to provide relevant information in suitable formats for disabled people' (Warburton, 1990, p. 3).

Self-help groups have attempted to fill this gap both locally and nationally. Their emergence over the last couple of decades has been partly in response to the perceived shortcomings of the health and social support services. There are three main differences between self-help groups and other service agencies. First, a common problem or predicament is shared by all or most of the members, and for disabled people this is the experience of discrimination. Secondly, there is reciprocity of helping amongst most of these members and, thirdly, the group is self-managing (Robinson and Henry, 1977). A wide range of advice, information and peer counselling is offered to disabled people and their families by self-help groups (Oliver and Hasler, 1987).

Yet the overwhelming majority of these 'organisations of disabled people' receive little or no financial support from local authorities, and those which do are under the constant threat of having it withdrawn. Cuts in local authority spending that resulted from the introduction of the Community Charge or Poll Tax meant that

many self-help groups had their funding drastically reduced (Disability Now, 1990a).

For example, the Derbyshire Coalition of Disabled People, one of the best known and most successful self-help organisations in Britain, had £24,000 cut from its annual budget of £48,000 half way through the financial year. Since the funds are allocated periodically over twelve months and used up almost immediately, this amounted to a 100 per cent cut in revenue. As a result, four of the seven part- time staff employed specifically to give peer counselling and advice were made redundant. The Derbyshire Centre for Integrated Living had £100,000 deducted from its annual grant of £420,000. The only way redundancies were avoided was by staff working shorter hours. Remarkably, the other two groups supported by funds from Derbyshire County Council's Equal Opportunities Department, namely women and ethnic minorities, did not have their budgets reduced at all (Davis, 199Oc).

Technical Aids and Equipment

Functional impairment can be overcome by the provision of suitable technical aids and equipment (DCDP, 1986). The inability of the British welfare system to provide appropriate aids and equipment for people who experience functional impairment is an important part of institutional discrimination. It not only limits their ability to participate in the mainstream economic and social life of the community but heightens their dependence on others.

The latest estimates suggest that 69 per cent of disabled adults use some form of special equipment. This includes wheelchairs and walking aids, surgical aids and appliances (such as surgical braces and artificial limbs), aids to help vision, hearing and incontinence, small equipment and gadgets, and special furniture and other equipment to help with personal needs. Not surprisingly the use of special equipment increases with severity of impairment (Martin, White and Meltzer, 1989). It should be noted that the OPCS researchers did not count spectacles as special equipment because most disabled adults, 89 per cent, used glasses 'whether they had a seeing disability or not' (Martin, White and Meltzer, 1989 p. 51).

The OPCS survey recorded a significant level of unmet need in this particular area. For example, 7 per cent of people with mobility problems thought that they needed equipment which they did not have, 13 per cent of those with visual impairments said that they needed vision aids, 29 per cent of those with hearing impairments needed hearing equipment, and 17 per cent of the people with continence impairments thought that their current arrangements were inadequate. Also, about a quarter of those with impairments affecting physical dexterity in reaching or

stretching felt they needed small aids and gadgets that they did not have (Martin, White and Meltzer, 1989, Chapter 5).

In addition, given the methodological limitations of the OPCS survey, discussed in detail in Chapters 2 and 4, these findings have to be treated with the utmost caution. The real level of unmet need is likely to be far higher than these estimates. To establish whether disabled people needed any equipment which they did not have, individuals with only 'relevant' impairments were shown a card with a list of special aids on it. They were then asked:

> Are there any aids such as those listed on this card which you think would help you but that you don't have at the moment? (Martin, White and Meltzer, 1989, p. 46).

There was no room for discussion or clarification of what the items listed on the card actually were. Indeed, the OPCS researchers themselves appeared somewhat sensitive about their methods on this issue. When explaining their findings, they said that the low proportions of unmet need 'could' indicate that people were 'relatively satisfied' with their present situation, 'but is probably, at least in part, a reflection of the lack of knowledge people have about what sort of equipment is available' (Martin, White and Meltzer, 1989, p. 49).

Beardshaw (1988) has shown that technical aids and equipment supply make up the single most confused area of service provision for disabled people. District health authorities, local authority social service departments, Artificial Limb and Appliance Centres (ALACs) - which till 1991 were controlled by a special health authority, namely the Disability Services Authority (DSA) - regional health authorities and the voluntary sector are all responsible for different aspects of the service. The result is 'chaos' (Beardshaw, 1988).

The supply of special equipment has evolved in an ad hoc fashion over along period. The result is a hotchpotch of provision delivered by a variety of sources, with important service overlaps and omissions. Theoretically, health authorities provide medical aids, while social services departments are responsible for 'aids for daily living'. In reality, however, this distinction is difficult to sustain, particularly since many people use both these things for personal and domestic support. Hence, some equipment is available from social services, while alternatives are provided by health authorities. More- over, some essential special aids are generally unavailable from any statutory authority (Beardshaw, 1988).

It can easily be seen, therefore, that getting equipment is complex, time-consuming and often frustrating, and that multiple sources of supply for some items, coupled

with the absence of provision of others, causes confusion for disabled people and their families. Poor assessment procedures and the prescriptive professional practices mentioned above undoubtedly contribute to this. Because professionals control access to different items of equipment, there are frequently significant local variations due to 'provider discretion' (Cantley and Hunter, 1985).

In general, the quality of provision is not good. Often disabled people feel compelled to accept what is offered from a particular agency instead of choosing an item that would best suit their needs (Beardshaw, 1988). For example,' the Association of Spina Bifida and Hydrocephalus (ASABH) has reported that nine out of ten young people with spina bifida are given wheelchairs that are unsuitable or unsafe (McColl 1986). Many people suffer long delays before getting the equipment they need (Oliver et 01., 1988), and maintenance and upgrading are a constant problem (McColl, 1986). A recent review of clinics for disabled young adults found that 27 per cent of users examined had unsatisfactory or worn out equipment (Thomas et al., 1989).

Voluntary sector involvement in this area also varies greatly. Local charities sometimes playa key role in disseminating information about special aids and equipment, and provide funds for items which are difficult to obtain through public agencies. In some areas they help coordinate services by running stores or showrooms from which aids can be selected. In others voluntary bodies have joined with health authorities and local authority social service departments to coordinate a joint supply service for disabled people (Fielder, 1988).

However, in addition to questions about the organisation of technical aids supply, the crucial issue of what is actually being provided also needs to be addressed. Much of the equipment provided by the state sector is simply not good enough. The provision of wheelchairs is an important example. Although wheelchair and artificial limb supply services were censured by an independent working party in 1986 for failing to provide an adequate service (McColl, 1986), and a quasi-independent body, the DSA, was set up a year later to coordinate provision, little changed.

A recent report by the Institute of Health and Economic Affairs concluded that the provision of wheelchairs and other special aids has become stuck in a '40-year time warp' due to the state's mono- poly of services for disabled people. Drawing attention to the technological advances which have transformed the lives of disabled people in other countries, the report states that the wheelchairs pro- vided by the British welfare system are of such low quality that they would not be offered on the open market (Galasko and Lipskin, 1989).

The standard-issue NHS wheelchair was designed in the 1930s. It is heavy and difficult to manoeuvre. Lightweight wheelchairs are generally unavailable through the NHS. Although some people engaged in sporting activities manage to obtain them through the DSA, the majority who want this type of machine have to buy it themselves or get financial help from charities. Lightweight chairs can be obtained through the Department of Employment as long as they are considered necessary for employment. To obtain one in this way the disabled person has to 'prove' that s/he needs it for work.

However, even the provision of lightweight wheelchairs does not give wheelchair-users optimum mobility or independence. To travel any distance they are still dependent upon an ambulant companion. Research shows that at best about 25 per cent of wheelchair-users can push themselves no more than 200 yards in an average urban environment (Segal, 1986). To achieve meaningful independence, therefore, a range of powered wheelchairs capable of indoor and outdoor use should be available by right to all those who need them. Although in 1990 the DSA was given a £1 million grant toward providing powered wheelchairs on the NHS (Massie, 1990), this proved inadequate. Moreover, a recent report by the National Consumer Council warned that there is a danger that the situation will get much worse because of the abolition of the DSA. From April 1991 overall responsibility for the supply of wheelchairs and other. equipment was returned to local authorities, along with two years' funding to meet disabled people's equipment needs. Once this money is spent, and the amount available is generally regarded as insufficient, wheelchair providers will have to compete with other areas of the NHS for funding (NCC, 1991). Hence, the majority of wheelchair-users will remain dependent upon others.

Personal Assistance

Many disabled people need a comprehensive and flexible system of personal assistance with things they cannot do independently. If independent living is to become a reality then the scope of this assistance needs to go beyond supporting disabled people in their home and 'extend into the community to facilitate social integration' (DCC, 1986, p. 2).

Discrimination occurs when disabled people are unable to secure the appropriate assistance to achieve social integration. As we have seen in previous chapters, only rarely are disabled people able to obtain the necessary support within the context of the workplace. In this section we demonstrate that these facilities are unavailable to the majority of disabled people within the community as a whole.

At present there is no national comprehensive and flexible support system for disabled people. For the last couple of decades the principal function of the health and social support services has been to provide assistance for the families, friends and neighbours of disabled people who provide unpaid informal support, rather than providing services directly for disabled people themselves (Parker, 1990). Government estimates suggest that there are around 4 million people, the majority of whom are women, providing informal assistance of one kind or another specifically to disabled people (Martin, White and Meltzer, 1989).

The main personal support services are organised around supplementary help with 'self-care', 'household management' and the 'relief of carers'. Most disabled people are therefore forced to be dependent on family members, friends and relatives 'at great personal, physical and fiscal cost to all concerned' (HCIL, 1990, p. 12). A comprehensive service is only provided if informal support is lacking or overstretched. Also, this service is usually a combination of statutory and voluntary provision and is never guaranteed. It is no substitute for disabled people's right to a personal support system. Moreover, the organisation of these services is one of the most complex areas of community provision, with considerable fragmentation between agencies as well as a number of important service overlaps and omissions. This causes major difficulties for disabled people and their families when trying to gain access to them (Beardshaw, 1988).

As a consequence, the overwhelming majority of families with a disabled member or members manage with minimal assistance from statutory and voluntary agencies. Government estimates suggest that overall 60 per cent of disabled adults need some form of personal and/or domestic assistance. Twenty-two per cent need some form of personal assistance with self-care: washing, dressing, using the toilet etc.; 58 per cent need help with household management, e.g. cooking, washing up, shopping and book-keeping. Of those who require a 'lot of help both day and night', only 28 per cent receive it from formal sources, namely statutory, voluntary or private agencies. Of the remainder only 20 per cent get this type of support (Martin, White and Meltzer, 1989).

The type of help given takes many forms and is delivered by a variety of professionals from a range of organisations in both the public and the private sectors. These include district health authorities, local authority social service departments and voluntary agencies, both national and local. With specialist services, the OPCS survey found that of the disabled adults living in the community, only 7 per cent had access to a health visitor, 11 per cent to a chiropodist, 10 per cent to a physiotherapist and 1 per cent to a social worker. The OPCS study only reported on whether disabled people had been visited in their own homes by these professionals within a 12-month period; the frequency of the

visits was not recorded, nor was the level of user satisfaction with the services given. Additionally, researchers recorded a significant amount of unmet need in each of these areas from people who were not receiving them (Martin, White and Meltzer, 1989).

For self-care, as well as medical care such as in changing dressings and giving injections, NHS district nursing services sometimes provide help (Beardshaw, 1988). Although in a given year 16 per cent of disabled adults living in the community were visited by a district or community nurse at least once (Martin, White and Meltzer, 1989), the amount of personal assistance given is not known.

Most help with housework is provided by families and friends. Although some 'care attendant' schemes (see below) provide assistance with domestic duties, the local authority home help service is the chief source of statutory provision. Indeed, in some areas local authority home helps now provide personal assistance as a supplement to their traditional domestic role. This can be augmented by supplementary services like local authority and voluntary sector meals on wheels. According to the OPCS survey, only 14 per cent of disabled adults living at home had a home help and 4 per cent received meals on wheels (Martin, White and Meltzer, 1989). Support for these services varies greatly between local authorities. With meals on wheels, for example, rates vary by a factor of more than ten (Borsay, 1986). In addition, they are usually only provided to people who live alone and to those in the older age-groups. Almost no one under the age of fifty receives meals on wheels (Martin, White and Meltzer, 1989).

Many services are organised around the needs of the provider rather than those of the user. Statutory provision is usually restricted to 'office hours', with coverage limited or non-existent in the early mornings, evenings, at weekends and during holidays.

Service delivery tends to be structured around predetermined tasks instead of user preferences and is often unpredictably timed (Begum, 1990; Morris, 1989). Service providers are professionally trained, and provision usually reflects professional boundaries and interests. A visit by a social worker, for example, does not mean that a disabled person's personal or domestic needs are being met. Those receiving services are often subject to a succession of interventions from a variety of people. The result is that disabled people are denied the right to organise their daily lives in the same way as the rest of the population. They have little or no control over who enters their homes or what professional helpers do once they get inside (Wood, 1990).

Additionally, if disabled people are to integrate into the community then they need services which are able to respond quickly to changing need. The inflexibility and poor coordination of existing provision makes this almost impossible. A related problem is that people or families with changing needs often find it difficult to 'reactivate' contacts with services when they require help after a period of managing on their own (Oliver et al., 1988).

In some areas voluntary sector 'care attendant' schemes supplement assistance provided by family members and statutory authorities. There are only a handful of schemes catering for all the personal assistance needs of disabled people. With one or two exceptions (see Owens, 1987; Fielder, 1988), these are mostly organised by the voluntary sector. Funding for voluntary sector provision is provided from statutory and charitable sources, with the lion's share coming from the former. Users themselves are also asked to contribute if they can afford to (Beardshaw, 1988).

The Association of Crossroads Care Attendants, the Leonard Cheshire Foundation's Family Support Services (FSS) and the Community Service Volunteers' Independent Living Scheme (ILS) are the three major voluntary sector care-attendant scheme providers. The first two are mainly concerned with providing assistance for families with a disabled member, but in a minority of cases they do provide services to disabled individuals living alone. There is wide variation in the level of assistance given. It can take the form of volunteers occasionally sitting with the disabled person while other family members go out, or regular help with a range of daily tasks. While some areas of the country are well covered by these schemes there are many which are not (Beardshaw, 1988).

The ILS is slightly different in that it places volunteers into disabled people's own homes for a six-month period. Over half of the users work, and others are in further education. Volunteers also help in families where there is a risk of children being taken into care. Although there are schemes throughout Britain, facilities are concentrated in the London area. In 1988, for example, 143 people were helped by the ILS: forty-two of them lived in London (Beardshaw, 1988).

Originally conceived by a disabled person, care-attendant schemes have evolved in response to some of the deficiencies of statutory provision with the aim of providing a more holistic user-centred service. In general, they are more flexibly organised, with assistance available outside office hours, and users and informal helpers are partly responsible for the training and supervision of volunteers. However, they are primarily a voluntary service. Pro- vision is often unreliable and unpredictable (Begum, 1990) and ultimate control does not rest with users or their families (Mason, 1990). The FSSs, for example, are normally run by management

committees comprising local dignitaries rather than by organisations of disabled people. In addition, their availability is largely determined by the willingness of statutory authorities to provide financial support (Beardshaw, 1988).

There has been an abundance of ideas from disabled people and their organisations which could easily overcome these difficulties, such as the Self Operated Care Scheme (SOCS) pioneered by Hampshire Centre for Independent Living (HCIL). The basic principle of the scheme is that a grant is paid to individuals who then employ their own personal assistants (PAs) in their own homes. The great advantage of the scheme is that the routine is decided by the disabled people themselves, 'which truly enables them to lead a life of their own choosing' (Brisenden, 1985, p. 10). In 1986 the HCIL devised a pilot scheme for disabled people who do not wish to be involved in the formalities of employing PAs, but want control of staff in their home. This involved a shared management arrangement with a third party. Members of the Derbyshire Coalition of Disabled People (DCDP) have experimented with a care cooperative involving 'professional' personal assistants and disabled people. These and similar schemes could be developed, but the major obstacle to their growth is the lack of Government support and funding (HCIL, 1990, p. 12).

Disabled people can arrange personal assistance privately using their own resources or disability benefits. But as we have seen in previous chapters, paying for private help is not a realistic option for the overwhelming majority of disabled people. They are, therefore, reliant upon unpaid informal helpers, some of the consequences of which are discussed in the following section.

The Carers' Movement and Respite Care. The emergence of the carers' movement has added a further twist to the discriminatory spiral. The failure of the present system to provide appropriate support for disabled people not only discriminates against disabled people but also against those who are charged with the responsibility of providing that support, namely their families, friends and neighbours. Giving help to a disabled family member or friend can be both economically and socially demanding. Informal helpers are sometimes forced to give up their jobs and their social lives in order to provide support for those who need it. This is a situation which the overwhelming majority of disabled people neither want nor expect:

Given free will and the ability to exercise that free will most adult disabled people would choose to respect and value the relation- ships that they enjoy with their relatives and friends rather than compromise them by imposing demands that exceed natural bounds (HCIL, 1990, p. 15).

The economic and emotional tensions ensuing from this largely enforced relationship have created significant socio-political divisions where there should not and need not be any. A strong and articulate 'carers' movement' has emerged which adds a further dimension to the discrimination encountered by disabled people.

Rock (1988) has noted that 'caring' today is big business, not in terms of paid work, but in organisation and campaigning. A number of carers' organisations regularly raise thousands of pounds for a growing membership to provide economic and social support for their members. The need for this support is not in doubt and many disabled people are thankful that they alone do not have to provide it. But many disabled people are expected to be grateful that someone is 'mindful' of their needs. As Rock (1988) notes, the word 'carer' is now synonymous with self-sacrifice and martyrdom, whilst the disabled person is often perceived as the cause of suffering and a burden. This view arises because most often the disabled person is the silent partner in the relationship (Rock, 1988, p. 4).

One illustration of the influence of the carers' movement is the increasing emphasis in official policy statements on the importance of 'respite care' as a valued feature of community-based provision (see the Government White Paper Caring for People [HMSO, 1989b]). It usually means moving disabled people out of their homes, while their regular informal helpers remain there temporarily freed of their 'care' responsibilities (Large, 1990a). The implications are that the 'overburdened, manipulated and abused, self-sacrificing' carers 'desperately' need a break from their 'over demanding, ungrateful and manipulative dependents', namely disabled people (HCIL, 1990, p. 14).

Thus respite care is another term for 'crisis management', but it would not be necessary if disabled people received adequate and stable personal support. The tensions which precipitate the need for crisis management would not arise if 'caring' or the provision of personal assistance were seen as a form of work with contracts of employment for both parties. While voluntary and unpaid personal assistants have to continue, often unaided, the need for respite care will increase and the position of the disabled person will continue to be both 'marginalised and invisible' (Rock, 1988, p. 4).

Conclusion

It is evident that the health and social support systems currently available to disabled people are a product of, and a major contributor to, institutional discrimination. They are organised around the traditional assumption that disabled people are unable to take charge of their own lives. This is clearly reflected in the

ideology of community care as espoused by a succession of policy-makers and recent developments within the personal social services as a whole. It is particularly significant that demands by disabled people and their organisations for self-management have been ignored in official circles while the role of professionals has been re-emphasised and indeed strengthened. In terms of funding, services for disabled people are accorded a low priority within the present health and social support system, and the bulk of financial resources are spent on professionals' salaries and traditional facilities. The effect of this on disabled people's lives is usually negative.

Although the negative consequences of life in residential institutions are well known, many disabled people are still forced to endure it. Residential facilities continue to be supported by a variety of agencies at the expense of community-based ones. Disproportion- ate support for medical rehabilitation persists within the various welfare structures, while facilities which actively promote social integration go greatly under-resourced. Comprehensive assessments of disabled people and their families by professionals remain central to the process of service allocation, and professional power within welfare bureaucracies continues to go unchallenged. Although lip-service is paid to the idea of meaningful collaboration between service users and providers, notably with the introduction of the 1986 Act, this has yet to materialise. There is evidence of widespread disregard for the law within local authorities, which has largely been ignored by central Government, and organisations of disabled people have received little financial and political support. Disabled people's opportunities for economic and social integration are severely restricted because of the lack of specialist information, appropriate technical aids and equipment, and a comprehensive personal assistance service. Although the 1986 Act required local authorities to give relevant information to disabled people in a suitable and appropriate format, in the main this has not taken place. In some cases information and advice is provided by user self-help groups, but official support has proved tenuous and unpredictable. Technical aids and equipment supply is split between a number of agencies in a way that creates confusion for all concerned. There is evidence in this area of widespread unmet need among disabled people and it was shown that some of the technical equipment currently available from the state sector does not make for maximum independence.

There is no national comprehensive personal assistance service for those disabled people who need it, and most of this work is done by unpaid, informal helpers, namely families and friends. Existing provision comes from a variety of sources, takes several forms and is mainly organised around supplementary help for informal helpers, the majority of whom go unaided. This policy discriminates not only against disabled people but against informal helpers. It has created

unnecessary social and political divisions between the former and the latter, which compounds the discriminatory spiral in which many disabled people find themselves. Although there has been a number of solutions put forward by disabled people and their organisations which could easily overcome these problems, they have largely been ignored.

Current policies regarding health and social support systems for disabled people not only fail to provide them with the necessary services to live independently within the community, but also deny them the dignity of independence in personal relationships and in their own homes. Without a radical restructuring of the present system this is unlikely to change.