RESEARCH REPORT

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LAST ON THE LIST

COMMUNITY SERVICES FOR PEOPLE WITH PHYSICAL DISABILITIES

Virginia Beardshaw

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SUMMARY

Last on the List analyses the health and social support services presently available for disabled people in Britain within the wider framework of national social and community care policy. It attempts to piece together a comprehensive picture of current provision from a wide variety of sources. The report distinguishes between services which provide disabled people with practical help, health care and disability-related services, regardless of the statutory agency responsible for them.

The report describes a piecemeal approach to service development which results in haphazard service delivery to individual disabled people. Similar residential and domiciliary services have been developed by different agencies in parallel, with little attempt to coordinate provision. Aids and equipment supply is split between a number of agencies in a way that creates confusion for both service users and providers. On the health side, the report suggests that there are major inadequacies in the way that both primary and secondary level health services deal with disabled people's general health care. In addition, there is no effective national network of rehabilitation services.

Agencies' failure to agree goals and develop complementary service plans have created considerable problems both for people with disabilities and for the professionals which work directly with them. In the field, these problems of coordination are compounded by failures of communication between professionals and the difficulties they experience in working in partnership with disabled people.

The report stresses the need for change in the way that services are planned, managed and monitored. Options for the future are discussed in the light of current policy developments. Increasing the involvement of disabled people in service design and management is seen as an essential element for future progress.

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My colleague Michaela Benzeval constructed the tables on housing and housing adaptations in chapter three, the map of national rehabilitation centres, and the box on voluntary sector care attendants schemes. My thanks goes to her for her painstaking work, and to Pat Osborne of Crossroads Care Attendants, Community Service Volunteers and the Family Support Services of the Leonard Cheshire Foundation for their help in supplying and checking the information.

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Virginia Beardshaw
May 1988

INTRODUCTION

This report centres on health and social services for people with physical disabilities. It does so within the wider framework of British social and community care policy. From this perspective, it highlights a number of inadequacies in current approaches to service provision with the aim of clarifying some of the key issues which confront policy makers and service providers for disabled people.

Last on the List was written against a background of change and uncertainty. During 1988, community and residential care strategies for priority group members have been the subject of major policy reviews. Fundamental questions about the structure and organisation of services remain to be resolved. Whatever the shape of future provision, however, the report raises issues which must be addressed.

This is because disabled people's position in society is changing, and with it their expectations of the practical help and health care that they receive. We are more than halfway through the international decade of disabled people. The rhetoric — if not always the reality — of integrating people with physical disabilities into the mainstream of social life has wide currency. Health and social service provision must change to foster that integration and enable it to take place.

The services which disabled people use are notoriously fragmented. *Last on the List* has attempted to view them comprehensively by distinguishing between services which provide practical help, services which provide health care and specialist disability services, regardless of the agency involved in providing care. It brings together information from the health, social services, medical, rehabilitation and disability literatures in an attempt to provide an overview of health and social support services for people with physical disabilities. The report does not attempt to survey good practice in the field of disability, since this area is presently being covered by others (Fiedler, 1988). Instead, it attempts to piece together an overview of current provision and practice from a wide variety of sources.

The report's first chapter examines national policy on physical disability within the context of the community care policy developed for all four 'priority groups'. Chapter 2 concentrates on the historical and policy context in which health and social services for disabled people have developed in the post-war period. Chapter 3 describes the present organisation of these services, and discusses some outstanding problems with the quality of the care they deliver. Chapter 4 examines the difficulty of coordinating services, and problems connected with professional practice. It includes three case studies which attempt to illustrate the problems that fragmented services create for disabled people. These cover incontinence services, disabled school leavers and people with multiple disabilities. Each chapter ends with a section giving a summary of its contents and the conclusions to be drawn from them. Chapter 6 contains the report's overall conclusions and recommendations.

Any truly comprehensive study of community care for physically disabled people would cover the entire spectrum of employment services, disability benefits, education, housing and transport as well as health and social support services. *Last on the List* is partial. It concentrates on health and social support services for disabled people because they are both complex and at the same time poorly developed. It highlights the need for considerable changes in the way that these services are thought about and organised. In doing so, it joins a growing literature which documents the inadequacy of our current approaches to disability.

1 COMMUNITY CARE POLICY AND PHYSICAL DISABILITY

Community care is a matter of marshalling resources, sharing responsibilities and combining skills to achieve good quality modern services to meet the actual needs of real people, in ways those people find acceptable and in places which encourage rather than prevent normal living. (DHSS, 1985)

My personal living circumstances do not take into account my future needs, changes and choices. The care support I have available to me is an exception, not the rule. What happens if I want to live somewhere else? Social mobility is an option to most people, even if they choose not to exercise it. Would it mean starting from scratch all over again? Probably so. What are the implications with regard to continuing support if I wish to live with a partner? Must they accept the role of unpaid carer as the price for a relationship? How do we make such normal living choices part of normal provision? (Man with spinal injury, quoted in Creek et al., 1987)

Physical disability: last on the list?

People with physical disabilities were designated a 'priority group' in *Care in Action*, the government's 1981 handbook of policies and priorities for health and personal social services in England. Nevertheless, services for disabled people remain confused and extremely variable, with a distinct lack of good practice nationally. Indeed, a case can be made for considering these services the 'cinderella of the cinderella services'. The field is a neglected one. In essence, it appears that while health and social care for physically disabled people suffers from the same problems as services for the other priority groups, these services have not been a focus for policy attention or innovation to the same extent.

The Royal College of Physicians has commented on the poor services currently available for disabled people, and their disjointed working and patchy coverage (1986a). These criticisms echo those of disabled people themselves (see for example Creek *et al.*, 1987). Nevertheless, schemes for physically disabled people hardly feature in the government's 'Care in the Community' initiative to bring disabled people out of long-stay hospitals, and a recent survey of care support and housing schemes for severely disabled people has underlined the overall poverty of provision in this area as well as a general failure to develop innovative, flexible services (Renshaw *et al.*, 1988; Fiedler, 1988).

Policy documents like *Better Services for the Mentally Handicapped* (Cmnd 4683, 1971), *Better Services for the Mentally Ill* (Cmnd 4683, 1975), *A Happier Old Age* (DHSS, 1978), the Jay Report (DHSS, 1979) and *Growing Older* (Cmnd 8173, 1981) have given a certain focus to planning community care services for the other priority groups. There is no equivalent for physical disability. Perhaps partly as a result, evidence of concerted planning for disabled people by health and local authorities remains sparse. Different reviews of national progress on community care have concentrated on services for mentally handicapped, mentally ill and elderly people, and have not discussed overall progress in developing services for disabled people (Social Services Committee, 1985; Audit Commission, 1986; National Audit Office, 1987). The Chronically Sick and Disabled Persons Act provided a certain focus for service development by local authorities, but provision has been highly variable across the country (Topliss and Gould, 1981).

The national context

This neglect must be seen in the context of a failure to implement comprehensive community care policies nationally. The 'priority' groups have been designated as such precisely because they have traditionally taken second place to acute care in the health service and areas like child care for social services departments. Community care policy was intended to redress the balance through a major shift of resources into long term care. But progress has been disappointingly slow, and there is no convincing evidence to suggest that such a shift has in fact taken place. Major problems of finance and persistent difficulties in coordinating priorities and planning across agencies — as well as the absence of a concerted 'lobby for change' — have seriously impeded progress in many places (Hunter and Wistow, 1987, 90-91). On the ground, public expenditure cuts, professional rivalries, skill shortages and the absence of appropriate training have hampered the formation of new services (Audit Commission, 1986).

Services for all four priority groups remain poorly developed, patchily distributed and fragmented across a bewildering array of statutory and voluntary agencies. Typically, coordination is poor, and information is often inadequate for service users and providers alike. The ideal of flexible, individually-tailored packages of care and of integrated, comprehensive services remains empty rhetoric in most places. Service users and their carers are generally excluded from service planning and monitoring. Service distribution is arbitrary, and services are poorly matched to need. There are major gaps in provision.

Community care services for physically disabled people are subject to this general blight. However, although services for mentally handicapped people, mentally ill people and dependent elderly people are currently far from perfect, the twin pressures of institutional closure and sheer numbers have provided — and will continue to provide — an impetus for change. No such structural pressure exists for physical disability, apart from the representations of disabled people themselves.

Policy confusion

The nub of British community care policy has been the priority placed by successive governments on promoting community-based services to allow the reduction of long-stay hospital provision for the priority groups. These community-based services in essence amount to practical help to permit disabled people to live at home, or in other settings outside large institutions. The policy aim is that community services should be tailored to meet individual needs in a cost-effective way, and that they should make use of a spectrum of care settings and options in order to do so.

In organisational terms this implies changes at two levels. Within the health service it requires a major shift of resources from hospital to community services. It also implies an overall transfer of funds from health to social services. Collaboration on service planning and provision between a variety of agencies — principally health, social services, social security, housing, education, transport and the voluntary sector — is also required. These changes must take place at national, local and field level. They require careful manipulation of the joint planning and joint finance mechanisms (Hunter and Wistow, 1987). In addition, they imply significant changes in training and professional practice.

Very considerable expertise is required to see these changes through. Further, the closure of the large nineteenth century mental illness and mental handicap hospitals at the same time as community services are set up to replace them is itself a process that requires considerable managerial sophistication and commitment as well as inter-agency collaboration if it is to succeed (Korman and Glennerster, 1985).

The demanding nature of the changes required for community care is one reason behind the slow progress on its implementation. Difficulties with joint planning and joint finance and 'perverse incentives' such as open-ended supplementary benefit support for private residential care are others (Audit Commission, 1986 29-48). A further problem is continued controversy over policy objectives.

Community care policy has at least a twenty-five year history in Britain, and has been consistently endorsed and developed by governments of both main parties. Nevertheless, it remains both controversial and contested, with a variety of interpretations available at any one time on what community care means in practice and its implications for disabled people, their families, statutory agencies and voluntary organisations. For some it centres on the better integration of people with disabilities into society, and providing them with better opportunities for ordinary living. For others, community care centres on cost containment and value-for-money considerations. Accordingly, there remains considerable conflict between different agencies and professional and user groups about the kinds of service 'packages' which should be developed under the aegis of community care (Renshaw *et al.*, 1988).

Despite this disagreement, and the ways in which interpretations of community care have shifted over time, the philosophy of 'normalisation', with its emphasis on treating disabled people as valued members of society and/or developing support systems for them that make the fullest possible use of ordinary housing and other 'unsegregated' community services has been a growing influence on service planning during the 1980s. This approach stresses the need to promote autonomy by providing services that enhance individual development and choice (Towell, 1988). Normalisation theory has its origins in the mental handicap field but its influence now pervades the philosophy of care being developed for all four priority groups (Hunter and Wistow, 1987). In the field of physical disability, these ideas are beginning to merge with the demands of disabled people for equal access to normal community facilities and increased domiciliary support to encourage independent living at home (Shearer, 1982; Oliver, 1987).

Disabled people: defining the priority group

Care in Action designates physically and sensorily handicapped people as one of four groups to whom statutory and voluntary agencies should give priority when developing services. The policy handbook comments that these services should aim to allow disabled people to lead full and purposeful lives if possible in the community, and prevent or reduce the effects of their conditions. It singles out services for younger disabled people, their carers and rehabilitation services as in need of special attention (DHSS, 1981, 36-37).

There are around four million people in England and Wales with some significant physical impairment. More than a million of these people need substantial help with mobility and/or the activities of daily life, and are classified as severely or very severely disabled (Warren, 1988). These estimates compare with figures of 120,000 for severely mentally handicapped people, 800,000 for mentally ill people and seven million for people aged sixty five or over (see table 1.1).

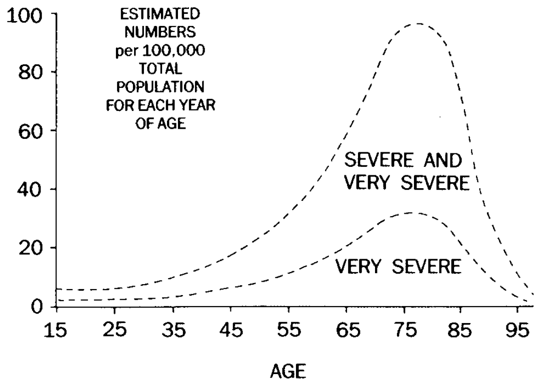
There are, of course, overlaps between the four priority groups. One of the most important is between physical disability and old age: between one-half and two-thirds of physically disabled people are sixty five

TABLE 1.1 · RELATIVE SIZE OF THE PRIORITY GROUPS

People aged 65+[1]	**Severely mentally handicapped people[1]**	**Mentally ill people[1]**	**People with appreciable, severe and very severe physical disabilities[2]**
7 million	120,000	800,000	1.3 million

Sources: *(1) National Audit Office, 1987*
(2) Warren, 1988

FIGURE 1.1. PEOPLE WITH SEVERE AND VERY SEVERE DISABILITIES BY AGE



Source: Royal College of Physicians, 1986b

or over (see figure 1.1). A smaller group has multiple disabilities, where physical impairments combine with mental and/or sensorial handicap or mental illness.

The numbers game

These figures require further explanation and qualification. Current attempts to estimate numbers of disabled people and assess their degree of handicap derive from the Office of Population Censuses and Surveys' national survey of disabled adults living in the community, which took place in 1968, and local surveys undertaken during the 1970s as a result of the Chronically Sick and Disabled Persons Act (Harris *et al.*, 1971; Warren *et al.*, 1978). The results of a new OPCS survey to cover adults and children living in the community and in residential care will be published in 1988.

Most of these surveys distinguish between 'impairment', 'disability' and 'handicap' — impairment being any loss or abnormality of psychological, physiological or anatomical structure; disability being any restriction or lack resulting from impairment; and handicap being a disadvantage resulting from impairment or disability (Warren, 1987). Handicaps are then graded in terms of severity of functional loss on various activity scales — for example, self-care or mobility. Table 1.2 gives an example of one such activity scale.

This approach has developed in an attempt to improve on estimating numbers of disabled people by using diagnostic labels. Diagnostic approaches are limited because disease categories cannot predict levels of dependence: many people with multiple sclerosis, for example, are only minimally impaired, even though the disease itself is one of the major causes of severe disability in young and middle-aged adults. In the same way, substantial impairment — for example limb loss — does not necessarily result in functional disability or handicap.

TABLE 1.2 · SCALE OF SELF-CARE DISABILITY

Very severe in need of special care	1	Toilet help every night and feeding and dressing, or washing and toilet.
	2	Regular nightly toilet help and help feeding/washing/dressing, or much daytime feeding/washing/toilet help.
	3	Bed or chair–fast, or mentally unable to care for themselves — but less help than 1 or 2.
Severe	4	All items difficult or most difficult and some impossible.
	5	Most items difficult or 3–4 difficult and some impossible.
Appreciable	6	Difficulty with some items or help needed with some minor items.
Minor/None	7	Difficulty one or two items.
	8a	(Non–motor): no 'physical' impairment problems but main impairment, sensory, etc.
	8b	(Motor): no self–care difficulty.

Major items —	using WC. Doing up buttons and zips; eating and drinking.
Minor items —	Getting in/out of bed; bath or all-over wash; washing hands and face; putting on shoes and socks, dressing; doing hair (women); shaving (men).

Source: Taylor, 1977 (after Harris)

Nevertheless, this method of classification has been criticised for relating 'handicap' solely to impairment — and thus, by implication, to the functional limitation of individuals — and failing to put sufficient emphasis on the social and physical environments which impose limitations on disabled people, thereby handicapping them (Finkelstein, 1984; Oliver, 1987). Although there is merit in this argument, the OPCS and other surveys based on the tripartite division of 'impairment', 'disability' and 'handicap' are our only source of numerical data on physically disabled people, and accordingly must be used.

A further problem with the tripartite classification is that the formal distinction between 'disability' and 'handicap' is subject to differences of interpretation, and is therefore difficult to observe in practice. In fact, 'disability' is often used as a blanket term to cover both concepts. It is used in this way in this report.

The Harris survey estimated that there were some 3.4 million adults with impairments living in the community in 1968, some 1.3 million of whom needed some support for personal self-care (Harris *et al.*, 1971). A survey conducted by Townsend during the same period produced an estimate of nearly 12 million people with some loss of personal self-care, mobility or household management functioning (Townsend, 1979). The difference in numbers arose because Townsend used a different set of scales to assess disability from those used by Harris. Local authority and other surveys carried out during the 1970s also show marked variations according to the functional criteria used to assess dependence (see table 1.3). What is certain is that the proportion of people who are severely disabled rises with increasing age. Figure 1.1 shows the relationship between disability and old age.

Problems of definition

Any attempt to quantify disability is problematic, and depends on definitions and measures that are more or less arbitrary: slight changes in the way that survey questions are phrased may produce important differences in overall numbers. The physical and social environment in which activity takes place is as much a predictor of disability levels as physical impairment: tasks which disabled people can manage in one setting will involve assistance in others.

It may be that the problems associated with defining disability have contributed to a failure to focus on the needs of physically disabled people as a priority group. There appears to be little general recognition of the numbers of people involved, as well as — in certain quarters — an assumption that overall numbers of younger physically disabled people are small when compared to other priority groups (see, for example, Wagner, 1988, 103). Notably, none of the recent reviews of community care policy included national figures for disabled people (Social Services Committee, 1985; Audit Commission, 1986; National Audit Office, 1987). The forthcoming OPCS disability survey will provide useful, up-to-date figures for planning purposes, which may serve to concentrate attention on the needs of the group as a whole.

Disability: a changing pattern

The Harris survey and those that followed it demonstrated a changing pattern of disability in Britain. They showed that the degenerative diseases of old age greatly exceeded congenital conditions and accidents as the principal cause of impairments. This

TABLE 1.3 · ESTIMATED PREVALENCE RATES AND NUMBERS OF PEOPLE WITH PHYSICAL DISABILITIES[1] BASED ON THE POPULATION OF ENGLAND AND WALES, 1986

All impaired and physically disabled people

Age Group (years)	16–64		65–74		75+		16–75+	
	Prev. per 1000 persons	Number thousand	Prev. per 1000 persons	Number thousand	Prev. per 1000 persons	Number thousand	Prev. per 1000 persons	Number thousand
Source								
Harris[1]	37.5	1,205	221	985	378	1,245	86	3,435
Knight & Warren[3]	41	1,318	223	994	478	1,575	97	3,887
Patrick *et al*[4]	85	2,731	299	1,333	544	1,792	147	5,856
Population in each age group Thousands[5]	32,135		4,458		3,294		39,887	

NOTES:

1. For problems of definition see reference 3 below.
2. Harris, AI, 1971, Handicapped and Impaired in Great Britain, London. HMSO. See Table 2.
3. Knight, R, and Warren, MD, 1978, DHSS Report on Health and Social Subjects 13.
   Physically Disabled People Living at Home: A Study of Numbers and Needs, London, HMSO. See Table 6.5.
4. Patrick, DL, Darby, SC, Green, S, Horton, G, Locker, D, and Wiggins, RD, 1981, Journal of Epidemiology and Community Health, 35, 65-70. Table 2 and personal communication.
5. Population Trends, 1987.

COMMENTARY ON TABLE 1.3

The results of detailed surveys carried out by the OPCS of children and adults with physical disabilities in the community and in hospitals and residential homes should be published later in 1988. These reports will provide accurate and up to date figures. Meanwhile estimates have to be made from the results of earlier studies which used different definitions and methods, and some of which were conducted in one local area only. Table 1.3 presents estimates based on a national sample survey carried out in England, Scotland and Wales in 1968–69 (Harris, 1971), on a study of the results of a small number of selected surveys carried out by local authorities in England in the mid '70s (Knight and Warren) and on a survey in Lambeth in 1978 (Patrick *et al* 1981). The Lambeth survey used a wider definition of disability than the earlier studies and this resulted in doubling the number of people with disabilities in the working age group and substantially increasing the number in the oldest age group. Problems of definition and methodology have been discussed in many papers and reports (eg. Knight and Warren, 1978, and Warren, 1987). Bearing the many limitations in mind it can be seen from the table that it is reasonable to assume that there are about 4 million people in England and Wales with some significant physical impairment or disability, and that over 1 million of these people have severe or very severe physical disabilities.

Source: Warren, 1988

finding was important since rehabilitation services tended to be organised around injury, many of them having their origins in services developed for wounded servicemen.

In the early 1970s, relatively little attention had been paid to 'maintenance rehabilitation' designed to support elderly disabled people at home (Taylor, 1977). Even so, services for disabled people remain slow to digest the implications of this changing pattern: to give one example, in 1986 — fifteen years after the Harris survey was published — the DHSS Artificial Limbs and Appliance Centres (ALACs) were censured for failing to adapt to take account of the fact that more than three-quarters of their users were over 60 and in poor general health, in contrast to the young war-wounded for whom they were established in 1915 (McColl, 1986).

The 1988 OPCS survey will demonstrate a continuation of the trends first established in the early 1970s, along with an overall increase in the prevalence of disabled people in the population. There are two reasons for this — the first being the general increase in the numbers of people aged over 75 in the 20 years since the Harris survey was conducted. The second is that the 1988 survey used a different set of scales for assessing disability than the Harris survey. These are certain to result in higher prevalences of disabled people than the earlier surveys found.

General trends for younger age groups are less certain: declining rates of diseases like poliomyelitis and spina bifida may be balanced by improved survival rates for these and other disabling conditions (Borsay, 1986). However, although there are no comprehensive data on the incidence of congenital impairments, there are indications that the number of children born with major disabilities may be increasing, possibly due to improvements in perinatal care for low birth weight babies (Harrison, 1988).

Distinction by age

Although physically disabled people as a whole are a priority group, services for them tend to be organised by age. Children from birth to sixteen are treated as one group, with disabled people past retirement age as another. In between come people aged 16 to 64, or 'younger disabled adults'. For the health service, at least, this last category is effectively a residual one, covering everyone who falls outside the specialist services developed for children and older people. The Harris surveys suggest that there are presently around 1.2 million people in this group, with some 418,000 of them severely or very severely disabled (see figure 1.4). Numbers of elderly disabled people are, of course, very much larger, with between 2.2 and 3.1 million people aged 65 and over being disabled, an estimated 914,000 of them appreciably or severely.

While this report is concerned with community care services for disabled people as a whole, younger disabled adults are its particular focus. Services for this group are particularly poorly developed, and the problems associated with them have led to British disability services being described as 'the worst in in Europe' (Gloag, 1984). In *Care in Action* they are singled out for special attention. Concentration on the special difficulties experienced by this group illuminates the problems experienced by disabled people and their carers overall, without the additional complicating factors of extreme youth or old age. This report therefore concentrates on disabled people aged between 16 and 64 when considering health and social care services for disabled people in general.

Summary and conclusions

Problems associated with the development of health and social support policies for people with physical disabilities are bound up with the wider difficulties

TABLE 1.4 · PREVALENCE RATES AND NUMBER OF PEOPLE WITH VERY SEVERE, SEVERE AND APPRECIABLE DISABILITIES

Age Groups	Very severe and severe		Appreciable		Total	
	Prevalence per 1000	Number thousand	Prevalence per 1000	Number thousand	Prevalence per 1000	Number thousand
16-64	6	193,	7	225,	13	418,
65–74	34	152,	53	236,	87	388,
75+	91	300,	77	253,	168	553,
TOTALS		645,		714,		1,359,

Table 1.4 presents estimates of the numbers of people in the population of England and Wales with very severe, severe and appreciable disabilities based on the estimates given in the report of the national sample survey carried out in 1968–69 and using the report's definitions of degrees of severity (Harris, 1971, table 9, pages 14–16 and appendix D).

Note: Very severe = Categories 1–3
Severe = Categories 4–5
Appreciable = Category 6

Source: Warren, 1988.

Box 1.1. Statutory expenditure on services for younger physically disabled people

Information on health and local authority spending on the priority groups is hard to come by, and there is very little data on expenditure levels for disabled people. However, a recent report by the Health Economics Consortium at York University gives useful comparative information on health and local authority spending on a range of health and social support services for elderly people and people with mental handicaps, mental illness and physical disabilities. These findings relate to six district health authorities in England, and the local authority areas associated with them. These districts are not a representative sample, and their numbers are too small for the information they give to provide a clear picture of what is happening nationally. Nevertheless, the patterns of expenditure they show are a useful indication of local community care priorities.

The districts were chosen for their diversity. They included a seaside area with a large retirement population (District 1), a London Borough (District 2), a metropolitan district (District 3), a Home Counties District (District 4), a rural area (District 5), and a predominantly rural area with pockets of mining and industry (District 6). Some districts were in RAWP-gaining Regions, others were in RAWP-losing Regions.

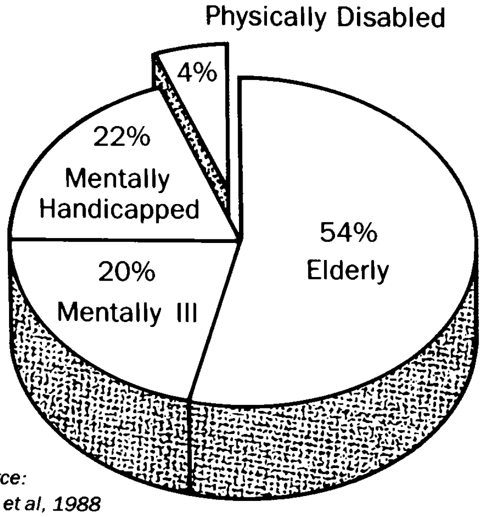
The survey looked at health and local authority spending on hospital care, institutional and residential care, group homes, unstaffed homes, respite care, and community health services — including provision by health visitors, district nurses, community psychiatric nurses, chiropodists, physiotherapists, dentists, psychiatrists and other medical staff. It also covered general community services — including home help/home care services, fieldwork services, luncheon clubs, and laundry schemes, as well as housing, transport and employment services, and occupational therapy. It found that:

- Overall spending on the priority groups was weighted heavily towards institutional care. Taking the six districts as a whole, 73 per cent of all expenditure went on hospital or residential care, with only 18 per cent directed towards community services. 7 per cent of spending went on day care; and 1 per cent each on respite care and group homes.
- There were important differences between the districts in terms of who provided services. In districts 4 and 5 more than 70 per cent of all expenditure on the priority groups came from the health authority, while in districts 2 and 3 local authorities spent more than health authorities did.
- Overall spending on the priority groups varied widely between districts. The average expenditure per head of the total district population was £123 per person, but districts 4 and 5 spent over £160 per person and districts 1 and 3 less than £110.
- However, although spending on elderly, mentally handicapped and mentally ill people showed important variations, expenditure on younger physically disabled people tended to be both more uniform and lower overall (see table below). In addition, the voluntary sector was a much more important service provider for disabled people than it was for older people or people with mental handicaps or chronic mental illness.
- Nowhere did spending on disabled people exceed a 6 per cent share of total priority group expenditure (see pie chart below).

In its section on the policy implications of the study, the survey team commented: "the evidence on services for the physically disabled suggests underfunding and lack of policy".

Source: Gray et al., 1988

TOTAL EXPENDITURE ON THE 4 MAIN COMMUNITY CARE CLIENT GROUPS (%)



Source: Gray et al, 1988

PER CAPITA EXPENDITURE FROM ALL SOURCES ON ALL TYPES OF PRIVISION, BY DHA AND CLIENT GROUP (1985–6)

	Elderly £	Mentally Ill £	Mentally Hand/cppd £	Physically Disabled £	All £
District 1	72	14	10	5	100
District 2	71	41	21	7	140
District 3	72	10	17	6	106
District 4	49	61	54	8	172
District 5	63	30	64	4	162
District 6	60	25	23	5	112
6 District Average	66	24	27	5	123

Source: Gray et al., 1988

and conflicts associated with the implementation of national 'community care' policies for all four priority groups. Even so, people with physical disabilities have received little attention from policy makers at national level, when compared with elderly people, and people with mental handicaps and chronic mental illness. This may be one factor influencing poor service development for this group of people.

Another is the difficulty of defining the size and membership of the priority group. Problems of definition arise because physical disability is not absolute — the effect of an impairment on an individual will vary according to a range of social, environmental and psychological factors. Although it will not resolve all these problems, the forthcoming OPCS survey of disabled people in the community and in residential institutions will provide up-to-date information for planning purposes, and new data on numbers may do something to focus attention on the need to improve provision for disabled people.

Until this new information is available, older surveys provide the only source of estimates of the size of the priority group. These suggest that there are around four million people in England and Wales with some significant physical impairment. More than a million of them need substantial help with mobility and/or the activities of daily life. Some 418,000 of these severely and very severely disabled people are aged between 16 and 64.

2 HEALTH AND SOCIAL SUPPORT: THE HISTORICAL CONTEXT

Parallel monologues

Since 1948, three separate debates have dominated policy discussion on social health and social support for physically disabled people.

The first — which has preoccupied the health service, certain voluntary organisations, and to a much lesser extent local authorities — centres on determining appropriate levels and styles of residential care for severely disabled people.

The second concerns appropriate support for disabled people living in the community. It has been led by organisations of disabled people and their carers, with contributions from academic researchers and statutory agencies.

The third focuses on the vexed question of the purpose and future of rehabilitation services. Debate on this has been conducted almost entirely within the medical and remedial professions, despite representations from disabled people.

In practice, these debates and the service developments that have resulted from them have taken place with very little reference to each other. They are, in effect, parallel policy monologues. As such, they are symptomatic of the absence of a coherent strategy for the development of services for physically disabled people. What follows is an attempt to examine the development of each of the three strands concurrently, and to consider their relationship with each other, and with other aspects of community care policy. Figure 2.1 charts major policy developments chronologically, by listing key events in overall community care policy and the statutory services which had an impact on physically disabled people.

Institutional care

The history of residential care for people with physical disabilities centres on the development of specialist facilities for disabled people aged between 16 and 64. Growth of this kind of provision is relatively recent: although a few institutions for disabled people were built prior to 1945, separate residential accommodation for this group is largely a post war phenomenon (Leat, 1988).

At its inception in 1948, the NHS acquired some 55,000 beds for the 'chronically sick' in England and Wales, approximately 85 per cent of which were used by people over the age of 65. These were essentially a legacy of poor law infirmaries and work-houses, 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. At the same time the National Assistance Act gave local authorities a responsibility to provide accommodation and services for persons who are substantially and permanently handicapped by illness, injury or congenital deformity. Effectively, however, the lion's share of existing provision for disabled people passed to the new health service (Royal College of Physicians, 1986b).

The mix of elderly people and the young chronic sick in long-stay hospital wards was increasingly questioned during the 1950s and 1960s. Specialist geriatric services began to evolve during this time, and there was a parallel move to develop special facilities for younger disabled people. Partly as a result, this period saw a significant development of voluntary sector provision for this group. The Leonard Cheshire Foundation, the Shaftesbury Society, John Grooms, the Spastics Society and others began to provide separate residential accommodation for younger disabled people on a significant scale, subsidised in part by fees paid by local authorities (Harrison, 1988). Only a small number of local authorities themselves developed specialist homes for this group, the first of which opened in 1958. In 1986 there were some 58 of them (Leat, 1988).

Despite these developments, concern about younger disabled people living on geriatric wards and in mental hospital and old people's homes continued, and prompted a series of enquiries and official reports. One of these showed that some 2,000 disabled people between the ages of 15 and 59 lived permanently in geriatric or general hospital wards (DHSS, 1968). These revelations — which came on top of consistent pressure for separate provision from voluntary organisations and the new medical specialty of geriatrics — led the Secretary of State for Health and Social Services to recommend Regional Hospital Boards to establish 25-50 bed hospital units for the 'younger chronic sick'. These were to be sited in hospital grounds with full consultant cover and access to remedial therapy services. The NHS 'Young Disabled Unit' (YDU) building programme began in 1971, with an initial budget of £3 million. By the mid-1980s some 58 YDUs had been built, and they presently house some 10 per cent of all younger physically disabled people in residential care. More are planned (Fiedler, 1988).

The YDU building programme was essentially an attempt to resolve an increasingly embarrassing political problem — the 'unsuitable' placement of younger disabled people in geriatric and general hospital beds — by creating a new type of health service institution. Unilateral action to create NHS facilities meant that NHS, local authority and voluntary sector residential care developed independently of each other, with very limited collaboration at local level (Harrison, 1988). YDUs were established in isolation from developments in domiciliary care for disabled people. Within the health service the YDU building programme amounted to a significant distraction of funds and planning attention from non-residential alternatives (Shearer, 1974; 1982).

Voluntary sector involvement in the provision of residential and other services for people with physical disabilities grew over the same period and remains substantial, with two charities, the Leonard Cheshire Foundation and the Spastics Society, responsible for the largest number of places. Current estimates suggest that the voluntary and private sectors are responsible for just under half of all residential accommodation for people aged 16-64 with physical disabilities (Royal College of Physicians, 1986b). Most voluntary homes' running costs are substantially supported by fees paid by statutory authorities, although capital expenses tend to be funded through charitable donations, making the voluntary sector both a major provider and an important financer of residential care for people with physical disabilities (Leat, 1988).

Critique of residential care

The development of special facilities for younger disabled people began just as the concept of institutional care came under increasing criticism. Goffman's critique of the dehumanising 'total institution' combined with scandals in mental illness and handicap hospitals and a series of critical reports to discredit the large Victorian asylums during the 1960s and 1970s (1961). This analysis, the development of new approaches to mental illness and handicap, plus the increasing costs of maintaining ageing buildings and equipment, were all important influences on early community care policies (Renshaw *et al.*, 1988).

This wider critique contributed to the fact that, virtually from their inception, the health service's YDUs were criticised as 'prisons' by disabled people, who attacked their hospital atmosphere, lack of privacy, and very limited potential to foster personal independence and growth. Voluntary and local authority residential homes came in for similar criticisms. These spawned a continuing series of enquiries into conditions and styles of management, and recommendations for improving the quality of care (Miller and Gwynne, 1972; Inskip, 1981; Canter, 1981; Scott, 1984; Royal College of Physicians, 1986b; Bennion, 1988; Wagner, 1988).

Today, despite considerable growth, the most limited objective of post war investment in institutional accommodation remains unfulfilled: less than one-half of all disabled people aged 16-64 in residential care are in places designed to cater specifically for them. The rest are in old people's homes, psychiatric and geriatric hospitals or ordinary hospital wards (Royal College of Physicians, 1986b). Private residential provision for disabled people is increasing, fuelled by social security board and lodging payments. In practice this usually means care in nursing homes for elderly people, since only a very few private establishments cater exclusively for severely disabled 'younger adults' (Harrison, 1988). Important questions about the quality of care such 'mixed' homes provide remain to be addressed (Owens, 1987).

Community support services

Awareness of the needs of physically disabled people in the community and their disadvantaged position in society developed during the post war period. Self-help groups for disabled people and their families began to be formed in the 1950s, and their numbers increased rapidly in the 1960s and 1970s (Collins, 1976 and see Figure 2.1). The civil rights movement influenced a parallel movement of disabled people in the United States, which had a direct influence on campaigns for improved access to jobs, mainstream education, increases in disability benefits and better support services for disabled people in Britain.

The perception that disabled people were an oppressed minority within a society organised almost exclusively by and for the able-bodied was central to these developments. From this developed a critique of concepts of disability based on medical diagnosis which, by treating disabled people as 'sick', encourage them to become passive recipients of care. Such an approach, it is argued, concentrates on individual impairments and ignores the contribution of social organisation to handicap (Finkelstein, 1984).

The alternative 'social theory of disability' rests on the idea that handicaps are created by society's discrimination against impaired people. As a result, their access to jobs, mainstream education, ordinary housing, transport, and a host of other 'normal' services essential to full participation in society is severely limited. This line of thinking goes on to criticise rehabilitation professionals, the statutory services, and organisations 'for' disabled people for providing services which oblige people with impairments to remain passive recipients of care outside the mainstream of society. It argues for 'enabling' services and improved physical access to allow disabled people to become full participants in community life. A necessary corollary of this is that people with disabilities should take an active part in designing and running the services they use (BCDOP, 1987; Wood, 1988).

Voluntary sector campaigning

In the 1960s and 1970s the growth of voluntary self-help groups concerned with disability gradually resulted in more effective lobbying for improved services and benefits. However, the fragmentation of the voluntary sector into organisations concerned with different disabling conditions, categories and age groups has made the formation of alliances problematic, both at national and at local level. Coordination, too, has been a persistent problem.

This has been exacerbated during the 1980s by tensions between organisations 'for' disabled people — essentially the older established charities established to ease the plight of the blind, deaf and crippled — and organisations 'of' disabled people, which tend to be newer groupings with a more explicit mission to press for the full integration of disabled people into society. This division — which is deepened by the investment that many of the older voluntary organisations have in traditional models of care — has hindered coherent campaigning for improved services for people with physical disabilites.

The 1970 act

Nevertheless, increasing awareness of the needs of disabled people prompted certain local authorities to provide a variety of services for disabled people under section 29 of the National Assistance Act 1948. These included day care, home helps, meals on wheels, aids, telephones, home adaptions, clubs and specialised

FIGURE 2.1. PHYSICAL DISABILITY: MAJOR POLICY DEVELOPMENTS

Year	Community Care Policy	Health Service	Local Authorities
1947			
1948		■ National Health Service takes on 54,000 beds for the 'chronic sick' and elderly.	■ National Assistance Act – Local Authorities given responsibility for 'non specialist' provision
1950			
1952			
1953			
1950s & 1960s			*Limited Growth of Local Authority provision for 'younger chronic sick'*
1959			
1962	■ *Hospital Plan* advocates run down of mental illness and handicapped hospitals and development of community services		
1964			
1966			
1967			
1968		■ Young Disabled Units recommended by health circular HM(68)41	
1969			
1970			■ Chronically Sick and Disabled Persons Act – local authorities recommended to improve services to disabled people and to keep local registeres ■ Local Authority Social Services Act – health, welfare departments united into social services departments
1971	■ *'Better Services for the Mentally Handicapped'* – recommends a move to community based services ■ OPCS survey of physically disabled people in the community published	■ NHS YDU building programme begun	
1970s & 1980s		*Local authority and health authority surveys of disabled people*	
1972		■ Tunbridge and Mair reports on rehabilitation	
1973		■ McMillan report on the remedial professions – recommends greater autonomy ■ Demonstration centres in rehabilitation designated	
1974			
1975	■ *'Better Services for the Mentally Ill'* – large long-stay hospitals to be replaced with 'a local and better range of facilities'		
1976	■ *'Priorities for Health and Personal Services in England'* – recommends a shift of resources from the acute sector towards community care ■ Joint funding mechanism establed between health and local authorities		
1977			
1978	■ *'A Happier Old Age'* – advocates increased use of voluntary and informal sector in the care of the elderly		
1979	■ *'Report of the Committee of Enquiry into Mental Handicapped Nursing and Care'* (Jay Report) – advocates 'normalisation' for mentally handicapped people and the evolution of a 'new caring profession'		
1981	■ International Year of Disabled People ■ *'Care in Action'* designates mentally ill, mentally handicapped, dependent elderly and physically disabled people as priority groups		
1985			
1986	■ Audit Commission Report criticizes slow implementation of community care policy ■ McColl Report on ALACs published	■ *'Physical Disability in 1986 and Beyond'* and *'The Young Disabled Adult'* published by the Royal College of Physicians – underlines shortcomings of medical and other services for disabled people	■ Disabled Persons (Services, Consultation and Representation) Act. Disabled people or their representatives can require local authorities to assess needs
1988	■ Report of Griffiths Review of Community Care ■ Report of Independent Review of Residential Care (Wagner Report)		

	Voluntary Sector	Benefits	Education
1947	■ British Rheumatism and Arthritis Association founded		
1948			
1950	■ Leonard Cheshire Foundation founded		
1952	■ Spastics Society founded		
1953	■ Multiple Sclerosis Society founded		
1950s & 1960s	*Growth of voluntary sector residential provision for 'younger chronic sick'*		
1959	■ Muscular Dystrophy Group founded		
1962			
1964	■ Friedreich's Ataxia Group founded		
1966	■ Association for Spina Bifida and Hydrocephalus founded		
1967	■ Disability Income Group founded		
1968			
1969	■ Centre on Environment for the Handicapped founded ■ Parkinson's Disease Society founded		
1970		■ Attendance Allowance introduced	■ Education (Handicapped Children) Act education services for mentally handicapped children transferred from health to local authorities
1971			
1970s & 1980s			
1972	■ First UK housing with care support scheme begun by Friendship Housing Association Dorset		
1973	■ Crossroads Care Attendant Schemes begun		■ Europe Chair of Rehabilitaton established
1974	■ Disability Alliance and Spinal Injuries Association founded.		
1975		■ Non-contributory invalidity pension ■ Invalid care allowances introduced. ■ Mobility Allowance introduced	■ Open University 'The Handicapped Person in the Community' course introduced
1976			
1977	■ Royal Association for Disability and Rehabilitation formed		
1978			
1979	■ CSV Independent Living Scheme begun ■ Motor Neurone Disease Association and Headway founded		■ Warnock Report recommends greater integration of 'special needs' children in mainstream schools
1981	■ British Council of Organisations of Disabled People founded ■ Association of Carers founded		■ Education Act gives wider choice to parents of 'special needs' children
1985	■ *'Living Options'* published by the Prince of Wales Advisory Group on Disability — emphasises the need for flexible care services in the community		
1986		■ Social Security Act	
1988	■ National Council of Carers and Association of Carers merge	■ Supplementary benefits replaced by income support and social fund loans and payments	

housing. But there was enormous disparity between the types and levels of service provided by different authorities, and provision was often haphazard within them. These inadequacies, the persistent linkage between disability and poverty, and the many anomalies of the disablement benefits system were highlighted as part of a general growth of interest and awareness in the problems of disability during the 1960s and early 1970s. This, and pressure from voluntary organisations, contributed directly to the passage of the Chronically Sick and Disabled Persons Act 1970, as well as the introduction of attendance, mobility and invalid care allowances later in the decade (Topliss and Gould, 1981).

The act originated as a private members bill, and did not reflect a new policy initiative on disability by central government. Instead, it aimed to consolidate the housing and welfare services already being provided on a small scale by certain local authorities, and to make them more widely available across the country.

The 1970 act required local authorities to inform themselves about disabled people in their areas, and to provide them with information about the range of services for which they might be eligible. These included home helps, aids, meals services, and telephones. It also required housing departments to 'have regard to the special needs of chronically sick or disabled persons' when planning future developments, and gave the newly formed social services departments the job of undertaking housing adaptations. In addition, it made recommendations about access to public buildings for people with physical disabilities.

Growth in local authority provision

The Chronically Sick and Disabled Persons Act resulted in a degree of improvement in local authority provision for disabled people. There is evidence that the extent and range of local authority services for disabled people increased during the 1970s (Topliss and Gould, 1981, Borsay, 1986). Its housing requirements also had a certain impact — between 1970 and 1980 local authorities, new towns and housing associations provided 23,000 housing units for disabled people, and adaptations also increased. Home nursing, home help and meals-on-wheels services expanded, as table 2.1 shows, although the effect this

TABLE 2.1 · THE DEVELOPMENT OF HEALTH AND WELFARE SERVICES: ENGLAND, 1970–1986.

Year	Home Nursing (1) (000)	Home help (2,4) (000)	Meals–on–Wheels (3,4) (000)
1970	–	443.2	14,204
1971	1,020.8	–	–
1972	1,841.4	473.9	15,833
1973	2,083.2	524.0	18,147
1974	2,142.8	565.3	21,149
1975	2,401.7	615.0	23,482
1976	2,779.6	652.8	24,346
1977	2,985.4	665.1	24,607
1978	3,157.5	692.9	25,252
1979	3,248.5	730.3	26,181
1980	3,421.0	743.5	27,031
1981	3,367.0	(5) –	27,014
1982	3,433.1	–	27,104
1983	3,551.2	–	27,821
1984	3,550.7	–	28,842
1985	3,522.0	–	29,876
1986	–	–	30,931

Notes

1 Total persons nursed
2 Total cases attended
3 Main meals provided in recipient's home
4 Figures relate to years ended 31 December prior to 1972 and to years ended 31 March thereafter.
5 Discontinued from 1981

Sources: Borsay, 1986
Health and Personal Services for England 1987.

had on physically disabled people as a group is not known. During the same period the voluntary sector pioneered small-scale experiments to provide flexible care support to families with a disabled member — notably care attendants schemes — and a few housing associations introduced housing with care support projects (Shearer, 1982).

Overall, however, the act was substantially vitiated by a combination of uneven implementation by authorities and the public expenditure cuts of the 1970s and 1980s (Borsay, 1986). Since it began as a private member's bill, no additional resources were allocated for its implementation. The introduction of joint finance in 1976 led to some additional funds being available for community care projects, and these resulted in a number of initiatives in housing for disabled people. By the late 1970s, however, research confirmed that local authority spending on disability continued to vary widely across the country (Topliss, 1980). Many of these variations appear to have continued, and the evidence concerning them is discussed in chapter 3.

The 1986 Disabled Persons (Services, Consultation and Representation) Act was drafted partly in an attempt to ensure that local authority provision under the 1970 Act was more precisely matched with need. The act makes provision for disabled people or their authorised representatives to make representations about need for services to the local authority, and obliges the authority to give full details of the needs they accept, the services they propose to provide to meet them, and their reasons for both decisions. It also attempts to ensure that local authorities are informed about disabled school leavers and about the discharge of long-stay patients from psychiatric and mental handicap hospitals, and that assessments of the needs of both sets of people are made. Carers' needs are to be taken into account during assessments, and the act also includes the requirement that local authorities inform disabled people about the services they provide. As yet it is too early to assess the act's impact on service provision, and substantial portions of it remain to be implemented.

Experimentation and innovation

During the 1980s a limited amount of experimentation and innovation in new forms of personal assistance and housing and care arrangments has taken place (Fiedler, 1988). One of the most important developments has been the expansion of care attendants schemes in the voluntary and — on a small-scale — statutory sectors. This form of flexible, client-directed assistance is discussed in detail in chapter 3.

Another significant innovation has been the growth of centres for independent or integrated living (CILs), following the International Year of Disabled People in 1981. CILs are organisations run by people with physical disabilities. Their aim is to work with statutory and other agencies to ensure that disabled people become active participants in designing services which meet their needs. CILs exist to promote integrated living in the community by providing disabled people with the information, counselling, housing, technical aids, personal assistance, transport and access which they need to participate in society. There are six CILs operating in the UK, and more are planned. One of them — the Derbyshire Centre for Integrated Living — is presently collaborating with health and local authorities on the development of local community services and day care for people with physical disabilities (Wood, 1988).

Despite some positive developments, however, a recent national survey of good practice in housing and care support for people with physical disabilities suggests that this kind of innovative service planning for disabled people is thin on the ground. A new range of living options does not appear to have emerged for disabled people in the statutory sector, and the client group as a whole remains a low priority for planners and service providers in both health and local authorities (Royal College of Physicians, 1986; Fiedler, 1988). Innovations are small scale, and tend to remain experimental, outside of mainstream service provision (Leat, 1988). The generality of present day local authority services have been criticised as unimaginative, relying as they do on minimal housing adaptations and inflexible care support (Borsay, 1986).

Rehabilitation

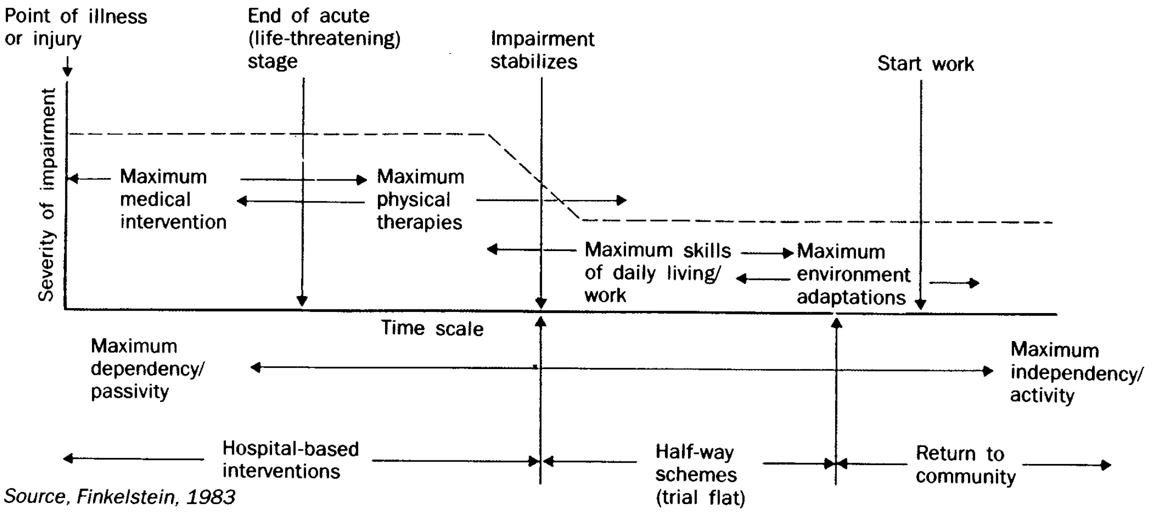
Discussion about rehabilitation services for disabled people has remained largely separate from consideration of their care in the community or in residential accommodation. This separation is artificial, and relates more to the preoccupations of service providers than to the needs of the people they serve. Rehabilitation is an important part of provision for disabled people, and is intended to make a contribution to their independent living in the community. Nevertheless, within the health service at least, discussion on rehabilitation has been confined to the medical and remedial professions, and has tended to resist influences from outside (Blaxter, 1979; Stevens and Warren, 1986). Consequently, little attention has been paid to the need to relate rehabilitation services to care and support in the community, or to coordinate the range of services received by individual disabled people (Partridge and Warren, 1977; Brechin and Liddiard, 1981).

This myopia is reflected in long-standing disagreements over a definition for rehabilitation, and continuing confusion over what rehabilitation services involve (Taylor, 1977). Historically, rehabilitation was led by the medical specialities of orthopaedics and rheumatology, and was limited to physical treatments designed to restore local function and fitness after illness or injury. More recently, a broader definition of rehabilitation has developed, along the lines suggested by the Mair committee who defined it as:

> *The whole complicated process of the restoration of individuals rendered unfit from any cause to a degree of social and economic independence, within the limits imposed by any residual or restriction of function* (1972).

More simply, Agerholm has encapsulated

FIGURE 2.2. THE REHABILITATION PROCESS



Source, Finkelstein, 1983

rehabilitation as 'the process of turning a patient into a person' (1972).

According to these broader definitions, rehabilitation inevitably involves a mix of health and social services organised to promote maximum autonomy (see Figure 2.2). But the full implications of this have yet to permeate service design and delivery, and the narrower definitions have proved tenacious. Perhaps because of this, and the continuing uncertainty about whether rehabilitation is a social or a medical service, rehabilitation services have failed to flourish within the NHS. The care they currently offer is patchy in terms of quality and of geographical spread. In addition, 'therapeutic' models of rehabilitation — with their emphasis on 'treatments' designed to improve individual function — have tended to dominate professional practice, at the expense of models of care which centre on providing support for independent living (Brechin and Liddiard, 1981). Hospital-centred services have been retained at the expense of community ones (Burnard, 1988).

Missing links

Ideally, rehabilitation should involve a spectrum of interlinked services ranging from specialist facilities like spinal injury units, through the physiotherapy and occupational therapy services available to aid recovery in hospital settings, to a great variety of community services designed to support disabled people at home. These can be usefully divided into the cluster of services which aim to effect the best possible recovery from illness or injury — for example intensive physio and occupational therapy in hospital or specialist units — and those aimed at maintaining independent living. These last include housing adaptations, home care services, domiciliary physiotherapy, and aids for daily living. Figure 2.2 illustrates how these services should complement each other at individual case level.

Services do not, however, actually work in this way. Centres specialising in intensive rehabilitation tend to operate in isolation from housing and social care services. This problem is frequently exacerbated by one of physical distance: medical rehabilitation centres, spinal injury units and more specialised services like 'bioengineering' for very severely disabled people are widely dispersed, and their users are therefore often far from home. In these circumstances it frequently proves difficult to organise social care and housing adaptations geared to rehabilitation objectives. These same problems often apply when rehabilitation takes place in general hospital wards. The reasons for these discontinuities are discussed further in chapter 5. Here, the important point to note is that there is presently nothing approaching a comprehensive network of rehabilitation services at national, regional or local level. Three central problems have seriously impeded its development.

Low priority

The first is doctors' general lack of interest in rehabilitation (McLellan, 1987). This relates to the profession's tendency to concentrate on curative medicine in preference to the long-term care of chronic illness and disability. As a consequence, NHS rehabilitation services have developed haphazardly, more as a result of lone clinicians' enthusiasms than from any systematic approach to service development.

The facilities and services currently available owe more to geographical and historical accident than coherent planning: for example, few of the national demonstration centres in rehabilitation are located in Wales, and there are also very few in the north of England (Hamilton, 1984). In addition, although key features of 'centres of excellence' in rehabilitation are in many cases well known, diffusion of their practices is slow and uneven (Brimblecombe, 1976; Langton-Hewer, 1983; Gloag, 1985). There is a tendency for services to deteriorate once individual enthusiasts have moved on.

Rehabilitation services vary greatly between NHS regions (Wood and Holt, 1980; Walton, 1987). This is true both of specialist facilities and generic services. In particular, community-based care has been slow to evolve, with the result that the NHS is only now beginning to consider how to develop physiotherapy and other services to support independent living at home (Partridge and Warren, 1977). The community-based rehabilitation services which are in place are both patchy and diverse, and there is little agreement about either the goals or the methods they should pursue (Burnard, 1988).

Poor evaluation

Dissemination of good practice has been hindered by the paucity of evidence about the effectiveness of different rehabilitation techniques. This relates as much to doctors' lack of interest in rehabilitation as an area of research as to the undeniable difficulties of developing objective outcome measures in this field. Historically, lack of evidence of effectiveness has provided a rationale for lack of investment in rehabilitation techniques, which then continue unassessed (Royal College of Physicians, 1986a). Research by the remedial professions is beginning to break this vicious circle, but progress is slow.

The problem of evaluation is exacerbated by the fact that little scientific attention has been focussed on many of the basic physiological processes connected with long-term disability. As an example, our understanding of spasticity — the inhibition of normal motor function which is a feature of many neurological conditions including cerebral palsy, stroke, traumatic brain injury, multiple sclerosis and Parkinson's disease — is rudimentary. Unsurprisingly in this context, approaches to the best means of overcoming spasticity through rehabilitation remain speculative (Mulley, 1982). Similarly, the absence of scientific evidence about the effects of ageing on long-term disabilities like spinal injuries or poliomyelitis is currently proving an obstacle to the development of effective rehabilitation strategies for older disabled people (GLAD/Living Options, 1987).

Problems in practice

At another level, rehabilitation is beset with problems of professional practice. In theory, rehabilitation means maximising independence and autonomy. It is an active process which involves cooperation between the disabled individual, carers, and professionals. A shared approach to problem solving, as well as agreement over short and long term goals is essential.

In practice, professional attitudes can militate against this cooperation, and undermine individual autonomy and the rehabilitation process (Williams, 1987). The 'partnership' and 'problem solving' models of rehabilitation have been consistently advocated by disabled people, their carers, and some professionals but deep-seated problems of professional practice continue to impede their widespread adoption (Brimblecombe, 1976; Robinson, 1978; Brechin and Liddiard, 1983). In addition, fragmentation of the remedial professions has created very considerable structural barriers to the delivery of a 'holistic' service (Wilding, 1982; Kinsman, 1987). Long-term shortages of remedial staff have contributed to the under-development of community services, and important problems of determining skill-mix and training in these fields remain to be resolved.

Longstanding concern

These underlying problems leave rehabilitation medicine in a cleft stick. In theory, every clinician is responsible for his patients' rehabilitation. In practice, many have little interest in this aspect of care. Lack of expertise and commitment mean that rehabilitation techniques and services remain under-developed. As a result, the post war history of rehabilitation has centred on the efforts of rehabilitation enthusiasts to counter their medical colleagues' indifference to the subject in order to develop an effective NHS disability service. These efforts have been largely unsuccessful.

Concern about rehabilitation is longstanding. Attempts to find a solution initially centred on developing a separate specialty of rehabilitation medicine. The Piercy report first suggested the development of a full-time specialty in 1956, and the main thrust of these suggestions were repeated in the Tunbridge and Mair reports in 1972. At the same time, proposals for regional rehabilitation services based on district general hospitals were made, to cover assessment, specialised therapies, research, training and an information service.

Neither report was acted upon. This was partly because of the remedial professions' resistance to medical supervision, partly because the idea of a separate specialty challenged the convention of individual clinical responsibility for patient care, and partly because of an overall lack of medical interest in the subject (Agerholm, 1972; Lee 1975). Instead, 'Medical Rehabilitation Demonstration Centres' were designated from 1973, in an effort to improve existing rehabilitation methods, and spread good practice by example. At the same time, two university chairs in rehabilitation were founded to enhance the subject's standing, and a training programme was begun (Joseph, 1973; Blaxter, 1979).

No attempt has been made to evaluate this gradualist policy, but its comprehensive failure is evident from the Royal College of Physician's report *Physical Disability 1986 and Beyond* which documents the fragmentary and haphazard array of NHS services presently available for disabled people (1986). This evidence is strengthened by a stream of reports and articles chronicling the poor quality of services available for particular groups of disabled people in different areas of the country, and by the accounts of people with disabilities themselves (Elian and Dean, 1983; Gloag, 1985; Thomas *et al.*, 1987; Creek *et al.*, 1987; Walton, 1987; McLellan, 1987).

There is particular concern about the inadequate services currently available for people with neurological disorders — for example, head injury, stroke, multiple sclerosis and motor neurone disease. This reflects a level of disquiet with the traditional role of neurology, and its heavy emphasis on diagnosis. This meshes with a growing recognition of the inadequacy of current approaches to multiple disability, particularly those involving mental illness or cognitive deficit (McLellan, 1987; Harrison, 1988).

In medical circles, hopes for reform centre on the Royal College of Physician's proposals for a medical disability service. This would be based on NHS health districts, with important specialist and support services provided by regional disability units which would also have educational and training functions. In effect, these proposals amount to improvements in specialist hospital-based services without the development of a specific medical specialty (Royal College of Physicians, 1986a).

The College's proposals have been criticised for concentrating on hospital services, and for neglecting the way in which health services relate to other agencies providing care and social support for disabled people (Thomas *et al.*, 1987). Organisations representing disabled people, in particular, have commented adversely on the absence of attempts to involve disabled users in the design and assessment of services, and on the report's emphasis on medical care at the expense of practical help at home (Spinal Injuries Association, 1987; GLAD/Living Options, 1987).

To sum up, there is growing agreement about the poor quality of the rehabilitation services presently available and on the need for more effective co-ordination of care (Royal College of Physicians, 1986; GLAD, 1987; Harrison, 1988). There is, however, no consensus about the underlying problems which contribute to poor services, or about the respective roles of professionals and disabled people in their future design and development. In essence, service providers are arguing for increased resources to expand existing services. On the other hand service users, carers and the organisations which represent them contend that fundamental changes in approach and design of services are needed before they can effectively support independent living in the community and provide a comprehensive service for disabled people.

Summary and conclusions

Important developments in health and social services for disabled people have taken place during the post war period. One of the most notable has been the development of separate residential facilities for people with severe physical disabilities aged 16 to 64. These were developed by voluntary bodies, the health service and, to a lesser extent, local authorities. These institutions presently cater for an estimated 5 per cent of younger physically disabled people, with an almost equivalent number housed in NHS general or geriatric wards and old people's homes (Harrison, 1988; Leat, 1988). Rehabilitation and domiciliary services have grown up as well, although the evolution of both has been hampered by local and regional variations, and — at times — a lack of commitment by statutory bodies or professional groups.

In practice, however, each of these three strands of provision has developed in isolation from each other, with little or no cross-fertilisation of ideas and no overall planning. Isolated experiments to provide flexible support at home and to combine specialised housing and care support exist, but these have largely failed to become a feature of mainstream provision.

Over the same period, the expectations of people with physical disabilities have begun to change. They — and the organisations which represent them — are working for better integration in society. Improved physical access to public buildings and health service facilities is an important aspect of this. Active participation in setting priorities and designing and monitoring services is another. Achieving participation is, however, proving difficult. Fragmentation and divisions between voluntary bodies concerned with disability have contributed to the problems surrounding collaboration between disabled people and health and local authorities.

Currently, it seems that there is little consensus on future developments. Disabled people argue for a change in emphasis and approach to allow a substantial improvement in the quality and quantity of services available to people in their own homes, while key service providers argue for more resources to improve existing facilities.

3 HEALTH AND SOCIAL SUPPORT SERVICES FOR DISABLED PEOPLE

People with physical disabilities need three kinds of help from the NHS, local authorities and voluntary organisations.

The first is help with household management and self-care. The second is general health care, as is provided by NHS Family Practitioner and Hospital and Community Health Services for the population as a whole. The third is specialist disability services, such as the treatment and rehabilitation facilities provided by spinal injury or stroke units. Comprehensive community services for people with physical disabilities would involve a flexible mesh of all three types of care and support.

Table 3.1 lists the main services available for disabled people in Britain in 1988, according to the type of support they give. The principal agencies which provide these services are shown in brackets.

The table suggests a confused pattern of service provision, with a number of overlaps where health authorities, voluntary agencies and social services departments provide similar sorts of help. In certain areas — the most extreme being provision of aids and equipment — the system is chaotically fragmented across a variety of agencies or sectors of agencies. In others — most notably in the social support category — health authorities and social services departments provide similar services.

What the table does not show is levels of provision. In practice, these are difficult to gauge. There is no comprehensive study which has compared the levels of support disabled people receive from health services and local authorities nationwide. However, a variety of sources suggest that services vary considerably across the country.

The historical and policy context in which these variations developed is sketched in the preceding chapter. The sections which follow describe the main services available to physically disabled people and their carers, and attempt to draw some general conclusions about levels of service provision from the evidence available.

Outstanding problems with the quality of care are discussed as well. In order to better understand their impact on people with physical disabilities and their families four surveys are used. They are York University's survey of 291 severely physically, mentally or multiply disabled young people aged between 18 and 22 and their families who had been in

TABLE 3.1 · COMMUNITY CARE SERVICES FOR DISABLED PEOPLE IN ENGLAND, 1988

General health care	Specialist disability services	Social support
— General Practitioner Services (NHS FPS)	— Physiotherapy (NHS HCHS; NHS FPS)	— Aids and equipment (NHS HCHS; LA SSD; ALACS; RHAs; voluntary sector)
— Dental care (NHS FPS; NHS HCHS; private sector)	— 'Bioengineering' and other specialist disability services (NHS HCHS)	— Personal care (LA; SSD; NHS; HCHS; voluntary sector; private sector)
— Ophthalmic services (NHS FPS; NHS HCHS; private sector)	— Occupational therapy (NHS HCHS and LA SSD)	
— Hospital outpatient care (NHS HCHS)	— Medical rehabilitation units (NHS HCHS)	— Domiciliary physiotherapy
		— Respite care (NHS HCHS; LA SSDs)
— Hospital in–patient care (NHS HCHS)	— Spinal injuries unit (NHS HCHS)	— Domiciliary OT (NHS HCHS; LA HD)
— Home nursing (NHS HCHS)	— Stroke units (NHS HCHS)	— Specially designed housing (LA HD; voluntary sector)
— Chiropody (NHS HCHS)	— Driving for disabled (no set pattern)	— Housing Adaptations (LA HD; voluntary sector)
— Terminal Care (NHS HCHS; NHS FPS; voluntary sector)	— Support for disabled school leavers (no set pattern)	— Incontinence services (NHS HCHS)
		— Counselling and advice (NHS HCHS; LA SSD; Voluntary sector)

Service providers are given in brackets, using the following abbreviations:

ALACS — Artificial Limb and Appliance Centre Services
NHS HCHS — National Health Service Hospital and Community Health Services
NHS FPS — National Health Service Family Practitioner Services
LA SSD — Local Authority Social Services Departments
LA HD — Local Authority Housing Departments

N.B. Distribution of these services varies across NHS districts and regions and local authority areas. It is unlikely that any one health district or local authority provides the full range of services listed here.

contact with the Family Fund (Hirst *et al.* 1984); Exeter University's survey of 383 physically and multiply handicapped young people aged 16 to 25 and their families in East Devon (Tripp *et al.* 1985); the Charing Cross and Westminster Medical School's study of 111 physically and multiply disabled young people aged between 18 and 25 and their families in Paddington and North Kensington and Wycombe health districts (Thomas *et al.*, 1987; Bax *et al.*, 1988); and Thames Polytechnic's study of 77 people with spinal injuries aged 24 to 65+ — all of whom had been treated at Stoke Mandeville Hospital's spinal injuries unit — and their carers (Creek *et al.*, 1987).

Social support services

Support services for disabled people involve assistance with self-care, household management, aids and equipment and relief of carers. The organisation of this kind of help is one of the most complex areas of community care, with considerable fragmentation between agencies, as well as a number of service overlaps. The variety of different providers can be difficult for disabled people and their carers. As a respondent to the Stoke Mandeville study put it:

> *I got very confused by all the terms — community, OT etc., I was never quite sure who was who.*

Despite the number of potential helpers, however, the evidence suggests that the majority of families with disabled members manage with minimal assistance from statutory and other services. For example, only a handful of families in the London and Wycombe survey received help from the formal sector as Table 3.2 shows. There, 98 of the 111 respondents lived at home with their parents or another close relative. Many needed a considerable amount of help with self-care activities: 49 young people needed attention at night, 52 needed help with washing and in getting in and out of the bath, 57 needed to be dressed and 42 needed to be fed. Despite these high dependency levels, only 25 families received any practical help in the home. The bulk of that help came from relatives and friends (Bax *et al.*, 1988).

The same pattern appears in other studies: in a national postal survey of more than 1000 severely and very severely handicapped young adults, 82 per cent of families received no regular help at all, and of the families which did, the majority of help — 70 per cent — was provided informally by friends and neighbors (Hirst, 1982). Similarly, a study of 119 disabled people in Hounslow found that 99 received no regular help from any source (Prior and Linford, 1981). Only 10 per cent of the tetraplegics and paraplegics interviewed in the Stoke Mandeville study received home help services.

Personal assistance

Personal assistance means help with activities like bathing, dressing, feeding and toiletting. Family members provide most of this care for disabled people living in the community, but statutory and voluntary services can augment it, or supply it when informal support is lacking or overstretched.

NHS district nursing services provide personal assistance as well as more overtly 'nursing' care, like changing dressings or giving injections. This help is generally undertaken by minimally or un-trained nursing assistants, rather than by registered or enrolled nurses. In some areas, voluntary sector care attendants schemes also augment the help provided by family members, often with financial support from local or health authorities, or joint finance. A very few care attendants schemes exist to provide all the personal care requirements of severely disabled people. These are mainly organised by the voluntary sector, but a few are the responsibility of statutory authorities (see Lovelock, 1981; Owens, 1987 and Fiedler, 1988). The scope and coverage of voluntary sector care attendents schemes is discussed in detail in box 3.1. In addition, many local authority home help services are beginning to provide personal care, as a supplement to the domestic work that has been their traditional remit (DHSS SSI, 1987). It is possible for all four types of personal assistance to coexist in the same area, providing services for disabled people and other priority group members — notably older people (Owens, 1987).

TABLE 3.2 · SOURCES OF PRACTICAL HELP IN THE HOME: LONDON/WYCOMBE SURVEY OF YOUNG DISABLED ADULTS

Source of Help (n=100)

	Regularly (%)		Occasionally (%)		Never (%)	
	L	W	L	W	L	W
Friends/neighbours	4	4	12	10	84	86
Relatives	4	4	24	18	72	78
Nurse	6	2	2	4	92	94
Care attendant	2	0	0	0	98	100
Home Help	4	4	0	0	96	96

L = London area W = Wycombe area

Source: Thomas et al, 1987

Although all these services provide help with personal care, their style of delivery is distinctly different. Statutory service help is largely restricted to ordinary working hours, with limited or non-existent coverage at evenings, weekends or holidays. Assistance tends to be organised around preordained tasks, rather than client preferences, and is often unpredictably timed. Training has a professional basis, and service delivery reflects professional boundaries — home nurses will not generally undertake domestic tasks which are seen to be the province of home helps, and vice versa. Because of this the intensity and type of assistance may not be well matched to disabled people's needs or preferences, and disabled people may have to put up with a succession of different interventions by a stream of different helpers. In these circumstances, ensuring satisfactory continuity of care can be a problem (Owens, 1987).

Changing needs can also create real problems. Chronic degenerative conditions like rheumatoid arthritis, multiple sclerosis and motor neurone disease require frequent adjustments in the aids and care services provided, to cope with fluctuating or gradually increasing need. In practice, inflexible service arrangements and the difficulties of coordinating care make this very difficult to achieve. A related problem is that people or families with fluctuating needs often find it difficult to 'reactivate' contacts with services when they require help after a period of managing on their own (Creek *et al*, 1987).

Care attendants schemes have grown up to answer some of the deficiencies of statutory services, with the aim of providing more holistic 'client centred' care. Care assistance is more flexibly organised, with clients and their carers providing at least part of the training, and directing task performance. Efforts are made to provide care outside normal working hours. Disabled people can also arrange personal care privately, using their own resources or disability benefits. Currently, attendance allowance will pay for a maximum of 12 to 15 hours of care per week — an amount that will generally be insufficient for the needs of severely disabled people. In practice, however, paying for private care is not a realistic option for disabled people whose income is small — particularly those who rely totally on state income support. People in this position tend to use disability allowances to augment general household income (Harrison, 1988).

Public expenditure on support services for disabled people varies from place to place. Earlier work on local authority provision for disabled people found considerable variations between local authorities on all services, including home helps (Topliss, 1979; Borsay, 1986). This evidence, coupled with studies of service users which suggest both a mismatch of services with levels of user need and a considerable degree of unmet need, reinforces the impression that services for disabled people are patchy in coverage, and that levels of provision vary locally. For younger disabled people and their carers, variation due to differential resource levels can be exacerbated by local policies which restrict services to particular priority groups. In some areas, for example, home helps are only available to older people (Creek *et al.*, 1987). Access to these services may therefore be limited to particular groups of disabled people, and effectively unavailable to others.

Household management

Assistance with household management means practical help with tasks like shopping, cooking, washing and cleaning.

Once again, the bulk of help with housework is provided by informal carers. The local authority home help service is the chief source of statutory assistance, and voluntary and other care attendants schemes also provide household management help. This assistance can be augmented by supplementary services like local authority and voluntary sector meals-on-wheels. Evidence on the coverage given by home help and care attendance services is discussed in the 'personal care' section above. It appears that domiciliary meals provision also varies greatly between local authorities. Rates vary by a factor of more than ten, although some of these differences can be accounted for by socio-economic and demographic differences between areas (Borsay, 1986).

Special housing

Adapted or purpose-built housing can be critical to disabled people's ability to achieve maximum independence. Both personal care and housework can be considerably aided by appropriately designed floorplans, facilities and aids.

The Chronically Sick and Disabled Persons Act gave local authorities powers to assist people with disabilities in carrying out housing adaptations. In addition, the 1974 Housing Act made disability one of the grounds on which house improvement or intermediate grants could be made. Both grants can be used to fund alterations to make the dwelling more convenient for disabled occupants. Initially, these grants were confined to private sector dwellings, but in 1978 housing departments were asked to extend them and pay for the structural renovation of their disabled tenants' homes.

The Department of the Environment also issued guidelines for purpose-built housing for disabled people in 1974. These distinguished between wheelchair and mobility units — wheelchair units being intended for severely disabled people totally dependent on wheelchairs and mobility housing for less severely disabled people who are at least partially ambulant. Housing associations have augmented local authority provision of purpose-built accommodation for disabled people, with certain associations specialising in this field. The role of housing associations has become increasingly important in the last decade as public sector building programmes have declined. Accommodation for physically disabled people currently accounts for some five per cent of all centrally-funded housing association schemes (Harrison, 1988). Local authority and housing association building and adaptation programmes have resulted in a national stock of some 42,000 public sector and 11,000 private sector purpose-built or adapted dwellings. Nevertheless, current estimates suggest that more than three-quarters of a million people with physical disabilities are inadequately housed and that there is a shortage of at least 150,000 purpose-built or adapted dwellings in the public sector (Ounsted, 1987). Levels of provision vary around the country, with marked differences in regional rates for both purpose-built housing and adaptations (Borsay, 1986).

Tables 3.3 and 3.4 show how rates of provision for purpose-built housing and adaptations varied between English regions in 1981 and 1986. They also demonstrate a marked overall decline in the production of public sector purpose-built housing. Between the two years the rate of provision for England dropped sharply from 59.7 new dwellings per 100,000 population in 1981 to 3.9 dwellings per 100,000 in 1986. Housing adaptation rates rose between the same two years — from 144.9 per 100,000 in 1981 to 227.6 in 1986.

Surveys of disabled people suggest that their housing is often inadequate: a national sample of 934 young adults with disabilities living in their parents' home found that more than one-quarter mentioned a need for further housing adaptations (Hirst, 1982). Of the 76 disabled young adults surveyed by Castree and Walker, one-third of those with spina bifida and over one-half of those with cerebral palsy lived in accommodation judged unsuitable for those with severe physical disabilities because the necessary adaptations had not been made (1981).

The housing needs of disabled people can be complex, and in order to achieve maximum independence alterations must be timed appropriately and carried out correctly. In practice, delays and problems are common: over one-quarter of the families in the London and Wycombe survey experienced problems with housing adaptations, and delays of two years for the supply and fitting of grab rails and ramps were not unusual (Thomas *et al.*, 1987, 28). The process can be protracted: needs must be assessed, plans drawn up, approved, work carried out and inspected. Delays and complications associated with more complex work like house extensions can mean that the job takes as long as five years from start to finish (Glendinning, 1986). Problems of coordinating planning between local authority housing and social services departments and explicit or de facto rationing procedures are important contributing factors to delays (Keeble, 1979).

TABLE 3.3 · REGIONAL VARIATIONS IN THE SUPPLY OF NEW PUBLIC SECTOR PURPOSE-BUILT HOUSING. (ENGLAND 1981 AND 1986)

Region (1)	**Wheelchair and Mobility Units ((3), (4), (5))**			
	1981		**1986**	
	Rate per 100,000	**Relative rate (6)**	**Rate per 100,000**	**Relative rate (6)**
ENGLAND	59.76	–	3.91	–
North	63.40	1.06	5.55	1.42
Yorkshire & Humberside	63.94	1.07	6.37	1.63
East Midlands	79.91	1.34	4.77	1.22
East Anglia	49.34	0.83	10.74	2.75
Greater London (8)	55.50	0.93	2.41	0.62
South East	53.21	0.89	3.24	0.83
South West	50.08	0.84	2.33	0.60
West Midlands	81.62	1.37	3.28	0.84
North West	49.87	0.83	2.90	0.74

Notes:

(1) Regions are as defined by the Department of the Environment.
(2) Estimated population mid–1980.
(3) On occasions where local authorities have not supplied the necessary information, it has either been omitted from the table or estimates made.
(4) Wheelchair and Mobility units relate to calendar years.
(5) Number of wheelchair and mobility units completed by local authorities and new towns, housing associations and private sector dwellings.
(6) The relative rate is calculated by dividing the regional rate per 100,000 population by the rate per 100,000 population for England.
(7) Estimated population mid–1986.
(8) Excluding Greater London.

Source: Borsay, 1986.
Department of the Environment and the Welsh Office, 1987.

TABLE 3.4 · REGIONAL VARIATIONS IN THE SUPPLY OF NEW HOUSING ADAPTATIONS (ENGLAND 1986 AND 1986)

Region (1) (4), (5), (6))	**CSDP Adaptations and Renovation Grants ((3),**			
	1981		**1986**	
	Rate per 100,000	**Relative rate (7)**	**Rate per 100,000**	**Relative rate (7)**
ENGLAND	144.97	–	227.60	–
North	95.61	0.66	212.76	0.93
Yorkshire & Humberside	136.69	0.94	191.52	0.84
East Midlands	115.84	0.80	249.04	1.09
East Anglia	145.68	1.00	209.51	0.92
Greater London (9)	264.23	1.82	331.53	1.46
South East	124.53	0.86	156.10	0.69
South West	111.43	0.77	186.96	0.82
West Midlands	152.58	1.05	291.11	1.30
North West	113.42	0.78	239.48	1.05

Notes:
(1) Regions are as defined by the Department of the Environment, where DHSS boundaries are different, C.S.D.P adaptions have been recalculated.
(2) Estimated population mid–1980.
(3) On occasions where Local Authorities have not supplied the necessary information, it has either been omitted from the table or estimates made.
(4) Renovation grants relate to calendar years; C.S.D.P adaptions relate to year ending 31 March.
(5) Number of adaptions assisted in local authority and private sector dwellings.
(6) Number of grants for conversions or improvements and the addition of standard amenities in local authority property; plus the number of house improvement and intermediate grants in the private sector.
(7) The relative rate is calculated by dividing the regional rate per 100,000 population by the rate per 100,000 population for England.
(8) Estimated population mid–1986.
(9) Excluding Greater London.

Source: Borsay, 1986.
Department of the Environment and Welsh Office, 1987.
DHSS, 1987.

Incomplete understanding of a disabled person's needs or poor design can result in a lower than optimal level of independence. The London and Wycombe survey describes a custom-built shower room whose door was too narrow for a wheelchair, with the result that the disabled person for whom it was designed needed assistance for toiletting and washing instead of being able to manage on his own (Thomas *et al.*, 1987, 28). Local surveys of the suitability of adapted and purpose built accommodation for disabled people suggest that this is not an isolated example (Borsay, 1986, 69-77).

Aids and equipment

Aids and equipment supply is the single most confused area of service provision for disabled people. District health authorities, local authority social services departments, Artificial Limb and Appliance Centres (ALACs — until 1991 controlled by a special health authority), regional health authorities and the voluntary sector are all responsible for different aspects of the service. The result is widely acknowledged to be chaos (Wynn Parry, 1986).

Aids supply has developed incrementally over a long period, and the resulting patchwork of services reflects the accretions of history rather than any logical sequence of provision. Table 3.5 illustrates this by showing which agencies were responsible for the issue of aids and equipment in one health district in 1986. Provision by health and social services is inextricably interwoven at local level, with important service overlaps. In theory health authorities provide 'nursing aids' while social services departments are responsible for 'aids for daily living'. In practice this distinction is difficult to sustain — particularly when many severely disabled people are dependent on both for self-care and home management.

This confusion means that getting necessary equipment is a complex, time-consuming and often frustrating business for people with disabilities. One type of hoist is available from social services, another

TABLE 3.5 · DISABILITY AIDS: SOURCES IN ONE HEALTH DISTRICT, 1986

Articles	**Principal Suppliers**	**Occasional Suppliers**
Special chairs and seating	Social services	Health authority
Special beds	Health authority	Social services
Commodes	Health authority	Social services
Bathroom adaptations	Social services	
Incontinence equipment	Health authority	
Wheelchairs		
self-propelled	ALAC*	Social services
indoor electric	ALAC	or health authority
outdoor electric	No provision	
Special heating		
fireguards	Social security	
Hoists and Lifts		
movable	Health authority	Social services
fixed to ceiling and stairs	Social services	
Environmental controls		
simple	Social services	
complex	Regional health authority	
Communication aids	No provision	
Ramps, handrails, kitchen adaptations	Social services	
Building adaptations	Social services and housing (jointly)	

*ALAC: Artificial Limb and Appliance Centre

Source: Harrison, 1988

from the health authority. Some environmental controls come from social services, others need special authorisation from the regional health authority. Other aids are unavailable from any statutory source.

Multiple sources of supply for some items coupled with the absence of provision of others creates a very confusing situation for professionals, disabled people and their carers. These circumstances militate against any one professional's developing a comprehensive knowledge of the range of aids available. Unsurprisingly, therefore, disabled people often have to accept what is on offer from a particular agency, instead of choosing the item of equipment that would best suit their needs. This, poor assessment, and the 'prescriptive' professional practices discussed in chapter 4 undoubtedly contribute to wastage (Thomas *et al.*, 1985). Surveys have demonstrated repeatedly that a very high proportion of aids — up to 50 per cent — in practice go unused (Cochrane, 1982).

Recent attempts at rationalisation have been confined to the wheelchair and prosthetics services provided by ALACs. In 1986, the inefficiency of artificial limb and wheelchair services was criticised by an independent working party, which censured them for failing to provide an adequate service for disabled users (McColl). As a result, ALACs services, which had been run as a separate agency by the DHSS, are now managed as a special health authority. The intention is to integrate them with other district and regional health authority rehabilitation services by 1991, although it is not yet clear precisely how this will be done (DHSS, 1986).

NHS orthotics services are generally considered to require the same kind of root and branch reform, to permit a higher standard of service and better integration with NHS rehabilitation services to develop (Wynn Parry, 1986). The way in which specialist aids and equipment services should be integrated with mainstream NHS and local authority aids provision requires careful consideration at local level if the result is to improve service to users (Langton Hewer, 1988). Presently, research suggests that the quality of provision is not always good. As one example, a review of a clinic for young disabled adults in Newcastle found that 27 per cent of patients examined between 1979 and 1982 had unsatisfactory or worn out appliances (Thomas et al., 1985).

Nothing is known about variations in levels of provision of aids and equipment, but supply is unlikely to be uniform across the country. Because professionals — in particular, hospital consultants, physiotherapists and occupational therapists — control access to different items of equipment there are likely to be significant local variations due to 'provider discretion' (Cantley and Hunter, 1985).

Incontinence services are a specialised branch of aids provision. DHAs supply incontinence pads and other equipment to disabled people who need them. Some health authorities and social services departments provide laundry and/or disposal services to families with incontinent members, but these tend to be restricted in scope. The help that NHS services offer is known to vary markedly from authority to authority, with some districts offering only a very limited range of equipment (Bradshaw, 1977; Parker, 1985). Service quality is also very variable, and the impact of this on disabled people and their families is discussed in Box 4.1

Voluntary sector involvement in this area varies considerably across the country, with local charities at times playing a key role in the dissemination of information about aids and equipment. They also provide grants for items which are not supplied by public agencies — for example, electric outdoor wheelchairs. In some areas voluntary agencies help coordinate services by running stores or showrooms from which aids can be selected. In a few places, voluntary bodies have joined with health authorities and local social services departments to coordinate a joint supply service for disability aids (Fiedler, 1988).

Day care

Day care means day centres and other facilities designed to provide diversion or 'training' for disabled people during the day. In practice, day centres cater for people excluded from the general labour market by their disabilities. Day centre facilities vary widely, as do their definitions of their mission. Some day centres see their function simply as providing respite for carers and a place for disabled people to go during the day. Others aim to teach independent living skills or provide training to return people to paid employment. This last generally involves participation in contract work activities. Some provide a combination of all three activities (Kent *et al.*, 1984). There is a tendency for centres run specifically for physically disabled people to concentrate on offering users company and diversional activities (Carter, 1981).

Day centres are run by local authorities social services departments, DHAs and voluntary organisations. The majority of day centre places for disabled people are, however, provided by social services: in the late 1970s there were some 190 centres intended solely for physically handicapped people in England, only one of which was run by a health authority (Carter, 1981). The number of day centre places for younger physically disabled people in England has remained stable at 9,200 since 1978. Physically disabled people also attend 'mixed' day centres used by other priority group members, and day centres intended for older people may include people with disabilities (Carter, 1981).

In practice, statutory day care provision for physically disabled people is extremely limited, and young disabled adults are relatively disadvantaged compared to other dependent groups (see Table 3.6). This is because disabled people are much less likely than the general population to be in employment, and — at the same time — they are also less likely to have alternative forms of weekday occupation than people with other types of disability (Hirst, 1985).

The quality of day care provision has been criticised in recent years. Day centres traditionally emphasise care rather than self-help, independence and personal development. This has proved to be a particular problem for younger disabled people in 'mixed' groupings, who can find them unstimulating and depressing (Kent *et al.*, 1984). In addition, problems with the timing and availability of transport for day care often limit its effectiveness as a respite service for carers (Martin *et al.*, 1987).

Respite for carers

Respite for carers involves short-term residential placements for disabled people, or, occasionally, schemes which place disabled people with foster families for short periods. Respite care is designed to give carers a break or a holiday, or to provide care during a crisis.

Some NHS YDUs have developed short stay programmes, but commitment to this strategy varies from unit to unit, and it is impossible to gauge levels of provision nationally, or to make comparisons between regions (Harrison, 1988). In many areas respite care arrangements for severely disabled people in practice involve 'social admissions' to acute hospitals (Owens, 1987). The London and Wycombe survey found that carers made little use of respite care. Lack of information appeared to combine with carers' reluctance to use services to cause this (Thomas *et al.*, 1987). The Family Fund survey of severely and very

TABLE 3.6 · DAY–TIME OCCUPATION AND TYPE OF HANDICAP

	Multiple (N=340)	Physical (N=183)	Mental (N=225)	General pop
	%	%	%	%
At home/unemployed	14	34	8	16
Open employment	1	19	1	
Day–centre	18	8	5	
Adult training centre	41	5	56	
Full–time education	21	22	26	29
Other	5	11	5	

Source: Thomas et al, 1985

severely disabled young people found that 29 per cent of the families interviewed made regular use of respite care, although 42 per cent of respondents had made some use of the services when their dependent relative was school age. Users tended to be the most severely disabled people — but nevertheless more than one-half of this group had made no use of respite care (Hirst, 1984).

Counselling and advice

No clearcut arrangements for counselling disabled people presently exist in local authority or health services. In practice, a range of professionals — social workers, general practitioners, health visitors, hospital consultants — engage in different forms of advice giving, according to their personal interpretations of their professional role. The special role of social work in providing advice and counselling for disabled people envisaged by the Seebohm committee has not materialised, and few social workers are adequately prepared to undertake this work (Oliver, 1983). Specialist advice services — for example sexual or genetic counselling — are often inadequate or lacking entirely (Royal College of Physicians, 1986; Langton Hewer, 1988).

Awareness of these gaps is not new: the Warnock Commission, for example, found that sexual counselling was poorly handled in special schools (1978). Voluntary organisations have attempted to fill this gap at both local and national level. Supplying information, advice and mutual support is seen as an important function of self-help groups, and a very wide range of advice, information and peer counselling services are presently offered to disabled people and their carers by voluntary organisations concerned with disability (Collins, 1976; Oliver and Hasler, 1987). There is no information available about their coverage, but since services depend on the existence of effective local disability groups it is certain to vary markedly across the country.

Recent surveys of disabled people suggest that general advice services remain substantially inadequate. This is true both for guidance on sources of practical help, like disability benefits, and for psychological support. One result of this is that there continues to be a problem with take-up of benefits. This is illustrated by the London and Wycombe study, which found that a substantial number of respondents did not receive benefits for which they were eligible. One in five were not receiving the attendance allowance to which they were entitled; one in ten were not receiving mobility allowance; one in three were not claiming non-contributory invalidity pension; one in two were not claiming supplementary benefit and there was poor uptake of the remaining benefits to which they or their carers were entitled, such as invalid care allowance (Thomas *et al.*, 1987,73-74). The Family Fund study found that delay and non take up were largely attributed to ignorance or uncertainty about entitlement rather than negative attitudes about claiming benefits (Hirst, 1985, 206).

General health care

Primary health care

Primary health care for disabled people is provided by NHS Family Practitioner Services, as it is for the population as a whole. Medical care is the responsibility of general medical practitioners (GPs), while responsibility for dental care is divided between general dental practitioners (GDPs) and the community dental services (CDS). In some areas the CDS has assumed a special responsibility for treating members of the priority groups, including making domiciliary visits to people unable to attend dental surgeries and clinics. General dental practitioners also make domiciliary visits and treat people with disabilities. There are few examples of collaboration between the CDS and GDPs to provide comprehensive dental care for the priority groups.

Ophthalmic services are provided by opticians, some of whom will undertake domiciliary visits. Specialised ophthalmology is provided by the hospital service, with domiciliary services available by special arrangement.

Studies of disabled people and their carers suggest a significant degree of dissatisfaction with the care provided by NHS general practitioners. This relates chiefly to GPs' perceived lack of knowledge of disabling conditions and problems related to disability, coupled with their reported lack of interest in disabled patients. In the London and Wycombe study some 50 per cent of families expressed dissatisfaction with GP services, with 30 per cent of families in the Family Fund survey feeling that GPs could be more involved in the health care of their disabled member (Thomas *et al.*, 1985). Evidence from other studies suggests that problems of access to GP surgeries creates difficulties for people with physical disabilities (Martin *et al.*, 1987; Plymouth Guild of Community Service, 1987).

Only a minority of the people surveyed in the Stoke Mandeville study felt that their family doctors were competent to deal with problems connected with spinal injury, or that they were prepared to learn about or take an interest in them. As one respondent put it:

> *I only saw my GP once on discharge — I was getting very stiff — he just said, 'I can't do anything for you I'm afraid, I don't know anything about your situation, go back to Stoke — ask the experts.' I've had no contact since, he didn't want to know, he'd lost interest in me — he made me feel as if he didn't have time for me.* (Creek *et al.*, 292)

A number of the people interviewed found that they became, in effect, their own 'experts' on spinal cord injury:

> *None of them really understand — you just don't get any answers from them. It's quite an odd situation really — you expect them to know and they don't — most of them don't know what they're doing. You've got to be very careful — really I have to say if things are right or wrong, they generally put you off.* (Creek et al., 291)

In contrast, a few respondents commented more positively, suggesting that interest and commitment by GPs can overcome initial lack of knowledge about spinal injury:

> *The doctor I have now is getting to know the hang of me now, he knows how to handle me.*
>
> *The GP was very good. He was thrown in the deep end and knows very little about my condition. In fact, we do talk about things and compromise and anything he doesn't know he will find out.* (Creek *et al.*, 294)

The London and Wycombe study — which concentrated on young people with physical and multiple disabilities, the majority of them congenital — included a medical examination of each of the young adults interviewed. It found that respondents' general health was poor and judged their medical care and health monitoring to be inadequate. Many of the young people in the study had severe health problems that were not being treated. Drug treatments were poorly supervised, and several of the young people who were using drugs for epilepsy had prescriptions which had gone unreviewed for ten years or more. A number were also taking tranquillisers, although the survey team commented that 'the reason for their initial prescription was often difficult to ascertain.' Very few respondents had regular contact with their GP, and the individuals with severe physical or multiple handicaps were the least likely to have regular contact. For many of those who did have regular contact, this simply involved collecting repeat prescriptions. One in three had not seen their general practitioner for over a year and a further one in six for over five years (Bax, 1988).

For dental services, a more mixed picture emerges. Little is known about the contact that disabled people have with dentists, although a number of different sources suggest that access to dentists' premises is frequently a problem. A study of 41 disabled adults attending a rehabilitation centre found that 90 per cent were in need of treatment (Preest and Gelbier, 1977). In the Family Fund survey, however, seven out of ten of the severely disabled residents saw a dentist at least once a year. For a minority, access was a problem and carers were uncertain about whether appropriate care would be provided. (Hirst, 1984 153-6).

In contrast, only just over one-half the London and Wycombe respondents saw a dentist regularly. One-third of the sample had had no dental care for over two years. Respondents with severe multiple handicaps were least likely to receive regular dental attention. Clinical examination found that eleven per cent of the sample needed dental treatment. Carers complained of the unwillingness of high street dentists to treat disabled people, and of the difficulty they experienced in obtaining dental care for their disabled relatives (Thomas *et al.*, 55-6). Access to dental surgeries and health centres was also a problem for respondents to the Stoke Mandeville survey (Creek *et al.*, 1987, 303-4).

Secondary care

Medical supervision of disability

Hospital in-patient and out-patient care for disabled people is provided by DHAs as it is for the general population. This includes specialist supervision of disabling conditions by hospital doctors.

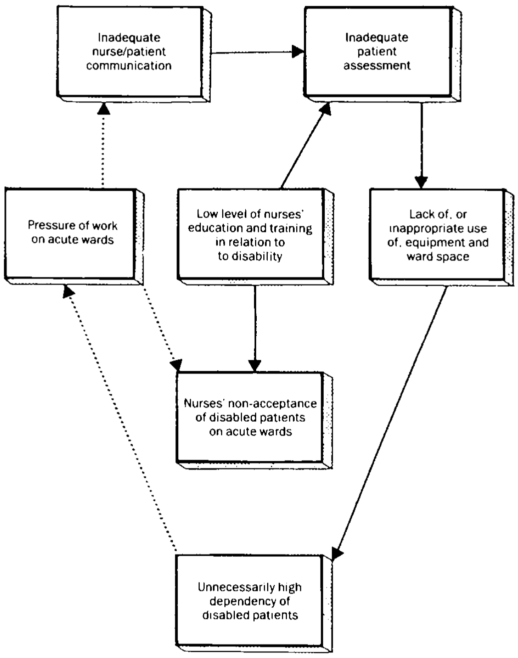
Little is known about levels of hospital specialist provision for disabled people, except that consultant cover in rheumatology, neurology and geriatric medicine — the specialties most concerned with supervising specialist treatment of disabling conditions — varies between NHS regions in a way which does not accord with the prevalence of disability (Hamilton, 1984). Nationally, training in disability medicine is very limited. In 1985 there were only 23 senior registrar posts which gave an accreditable training in rehabilitation, 18 of them in rheumatology. Low levels of training have a number of consequences. It means, for example, that the majority of people below the age of 65 who have strokes are looked after by general physicians with no special training in rehabilitation or neurology, although it is uncertain what effect this has on their care (Gloag, 1985).

Qualitative information is equally sparse. The London and Wycombe study, however, suggests that the quality of care can fall considerably short of the ideal. On clinical examination, two-thirds of the young adults in its sample were found to have current health problems which were not being attended to by the health services. Forty per cent had not seen a hospital doctor for more than two years. These included individuals with deteriorating spina bifida, one of whom had had no direct medical contact for more than three years, even though he had an infected open spinal lesion which was leaking cerebrospinal fluid when examined by the survey team. Another member of this group was obliged to sit well forward in her wheelchair with a cardboard box protecting an unrepaired spinal lesion. Gross oedema of the legs had resulted from this flexed posture.

Many of the young people showed signs of physical deterioration. Preventable skeletal deformities featured in the sample: one in three of the young people examined had definite kypho-scoliosis, which in 17.6 per cent of cases was very severe. Sixty per cent had contractures of the lower legs, and foot deformities were also very common. One-quarter of the respondents had upper joint contractures. One third had skin-care problems, including pressure sores. Preventable deformities and complications of this kind limit independence and complicate personal care, and thus are directly handicapping (Thomas *et al.*, 1987).

In addition, the survey team considered that there were a number of instances in which respondents' diagnoses were incorrect, or only partially correct, and that reassessment would have resulted in the provision of more appropriate services: 'In our view, virtually all the young people would have benefitted from an experienced reappraisal by a team of health professionals'. In one case, failure to revise an initial diagnosis had contributed to the fact that a young woman with sensorineural hearing loss had never been provided with a hearing aid. In another, a young man was known to the health authority as having cerebral palsy when he was in fact primarily mentally handicapped. A failure to update a diagnosis made at birth resulted in his receiving inappropriate services as a young adult. Unsurprisingly in this context, two-thirds of the survey's respondents considered that the medical professions were not sufficiently involved in their health care (Thomas *et al.*, 1987, 33-45).

FIGURE 3.1. CARE OF SEVERELY DISABLED PEOPLE ON ACUTE WARDS



Source: Atkinson and Sklaroff, 1987

Continuity of consultant care also appears to be a problem for people with physical disabilities, particularly when chronic disabling conditions like rheumatoid arthritis, multiple sclerosis and motor neurone disease are involved (Elian and Sean, 1983). Here, sufferers commonly complain of being shunted to a succession of junior medical staff, few of whom are experienced in dealing with chronic disability. Poor communication between consultant and general practitioner about the management of fluctuating or degenerative disorders is a further difficulty: this can be particularly serious for less common diseases like motor neurone disease, which a GP is likely to see only once in fifteen years. Access to out-patient and other hospital facilities is also a frequent problem for disabled people (Plymouth Guild of Community Service, 1987; Martin *et al.*, 1987).

In patient care

NHS hospitals provide in-patient care for disabled people with acute conditions. This care includes acute-phase treatment of disabling disorders as well as of illnesses unrelated to disability. Most of this care takes place in general wards: for example, the acute-phase treatment of multiple sclerosis often takes place on general hospital wards, rather than in specialist neurological units.

Although the area is under-researched, there are indications that disabled people often receive less than optimal care in NHS acute settings. As one disabled person put it:

> *In hospital I enter a world alien to my needs. My illness may be cured, but at a price my dystrophy finds extortionate* (Blackwood, 1978).

Disabled people have a number of concerns about in-patient care. They centre on nurses' lack of awareness of disabled people's needs, and problems of communication with nurses. Ensuring continuity of care can also be difficult for people with special needs. Increased dependence because of the absence of appropriate equipment is an additional area of concern. So are fears of increased disability following hospital admission as a result of dependence in hospital. The development of pressure sores or decreased mobility as a result of in-patient stay are a further worry (Atkinson and Sklaroff, 1987).

Research suggests that these concerns are often justified, and that NHS hospitals are ill-equipped to deal with disabled people. Nurses currently receive very little training about the special needs associated with disability, and this frequently combines with a lack of, or inappropriate use of, specialist equipment to create unnecessary dependence. This can in turn result in increased levels of disability on discharge. The factors involved are summarised in Figure 3.1. Nurses' perceptions of the extra demands created by disabled people on general wards leads them to express a strong preference for special units for disabled people (Atkinson and Sklaroff, 1987).

Some of the respondents to the Stoke Mandeville study found local hospitals unhelpful and ill equipped to cater for their needs, with the result that they relied heavily on the specialist services provided by the spinal injury unit (Creek *et al.*, 1987, 302). Access to hospital facilities and out-patient clinics is another problem area for disabled people, as is transport to and from hospital (Martin *et al.*, 1987).

Terminal care

Care for terminally-ill disabled people is provided by the NHS Family Practitioner and Hospital and Community Health Services, with the involvement of the voluntary sector in some cases. Problems of caring for terminally-ill disabled people in NHS general hospitals have been reported. As with general acute care, hospitals are often ill-adapted to the special needs of disabled people (Owens, 1987, 35). For this reason, the hospice movement has taken an interest in developing care appropriate to the terminal phases of chronic degenerative conditions like motor neurone disease, though the levels at which it provides services for this group is not known (Saunders, 1981).

NHS domiciliary services

District health authorities provide home nursing, health visiting and chiropody — services which are available to everyone requiring domiciliary care, including those with severe physical disabilities. Home nursing involves explicitly 'nursing' tasks like the administration of drugs and dressings, as well as a variety of personal care tasks described above. In practice, there is a complete overlap between home nursing care and that supplied by informal carers. Even the more ostensibly 'technical' nursing tasks are undertaken by carers (Oliver, 1985).

Levels of home nursing and other community health services vary from one health district to another, although there is no systematic information available on how these variations affect disabled people as a group. Community health provision for people over the age of 75 varies greatly between districts, and these variations cannot be explained by local demographic and socio-economic factors (Joyce, 1988). It seems reasonable to assume that a similar degree of variation applies to home nursing and other DHA provision for disabled people, especially considering the large overlap between the two groups.

The Stoke Mandeville study found that levels of provision for NHS domiciliary services varied considerably between health districts, and that services for disabled people could be adversely affected by local policies which give priority to other groups, for example the elderly. A number of the survey's tetraplegic respondents effectively depended on district nursing services to maintain life in the community. They found that the services tended to be inflexible. As one respondent put it:

> *... the problem we have had with the district nurse is that they can only say vaguely when they would come in the afternoon — so there was no way you could rely on them. But the district nurse has been very willing to come in for specific things when I've been in bed — they recently came in every day for a month to dress a sore — so they are very good for that kind of thing.*

Access to community nursing services appears to vary according to provider perceptions about the levels of

FIGURE 3.2. NATIONAL DEMONSTRATION CENTRES IN REHABILITATION IN ENGLAND — 1984

Source: Royal College of Physicians, 1986 family support available for disabled people: individuals with spinal injuries living alone were significantly more likely to receive help from district nurses than those living with relatives regardless of the type of help required (Creek *et al.*, 1987). Fewer than seven per cent of the disabled young people surveyed in the London and Wycombe study — all but a very few of whom were living with close relatives — received help from district nurses, and NHS domiciliary services do not appear to have been a significant source of assistance to families in the East Devon survey. The involvement of community nurses in the care of the severely and very severely disabled young people in the Family Fund survey was minimal: fewer than one in ten of all families had regular contact with domiciliary nursing services (Thomas *et al.*, 1987, 68; Hirst, 1984; Tripp *et al.*, 1985).

Specialist disability services

Specialist disability services are in effect a mixed bag of services and facilities provided exclusively for disabled people. They divide into services for people with a particular medical diagnosis, like stroke, head injury and spinal injury units, and those used by people with a variety of diagnoses and disabilities like medical rehabilitation centres, stoma care and incontinence services.

Specialist facilities

Most of these facilities or services are at the medical end of the rehabilitation spectrum described in chapter 2. As that chapter explained, many specialist facilities owe their existence to individual clinicians, whose enthusiasm for the treatment and rehabilitation of a particular group of disabled people was instrumental to their establishment. The work of Sir Ludwig Guttmann in establishing the spinal injuries unit at Stoke Mandeville hospital during the 1940s and 1950s is an example of this, but there are many others (see for example Brimblecombe, 1977; Langton Hewer, 1983).

The 'charismatic' origins of many specialist disability services largely account for their patchy distribution nationally, which is illustrated for national demonstration centres in rehabilitation in Figure 3.2. In practice, what this means for disabled people is that the availability of expert care varies greatly according to where they live (Hamilton, 1984).

This has two main effects. The first is that disabled people may receive sub-optimal treatment in general hospital wards because they have no access — or delayed access — to specialist treatment. The second is that they may have to travel long distances to regional or national centres to receive expert care (Creek *et al.*, 1987; McLellan, 1987). This is particularly true of 'bioengineering' services for very severely physically disabled people, for which no effective national network presently exists (Wynn Parry, 1986). But it also applies to less highly specialised services intended for larger groups of people — access to stroke units and medical rehabilitation varies even within health districts, and a number of NHS regions are without designated spinal and head injuries centres (Gloag, 1985; McLellan, 1987). In practice, access to specialist

LOCATION OF CROSSROADS AND FSS SCHEMES

North
Carlisle & Eden District (C)
Castle Morpeth (C)
Durham District (C)
Newcastle (LC)
St Helens (C)
South Tyneside (C)
Tynedale (C)
West Cumbria (C)
Windermere (LC)

Yorkshire & Humberside
Calderdale (C)
Dewsbury (C)
Huddersfield (C)

North West
Blackburn/Darwen (C)
Chester (C)
Hyndburn (C)
Lancaster (LC)
Preston (LC)
Ribble Valley (C)
Rochdale (C)
Salford (C)
Stockport (C)
Stratford-upon-Avon & District (C)
Vale Royal (C)
Warrington (C)
West Lancastershire (C)
Wirral (C)

East Midlands
Daventry (C)
Derwent & Wye Valleys (C)
Holme Lodge(Nottingham) (LC)
Mansfield & Ashfield (C)
Northampton (C)
South Northants (C)

South East
Aylesbury (C)
Basildon (C)
Bracknell & District (C)
Braintree & District (C)
Brentwood (C)
Brighton & District (C)
Castle Point (C)
Chatham (C)
Chelmsford (C)
Chiltern (Gerrards Cross) (LC)
Colchester (C)
Cuffley (LC)
Dacorum (Berkhamsted) (LC)
Dartford & Gravesham (C)
Epping Forest (C)
Fareham & District (LC)
Gillingham & Rainham (C)
Gosport (LC)
Guildford (C)
Harlow & District (C)
Maldon & District (LC)
Maidstone (LC)
Mid Surrey (Epsom) (LC)
Milton Keynes (C)
Newbury & District (C)
Oxford (C)
Panshanger (C)
Portsmouth (LC)
Rochester (C)
Rochford (C)
Rushmoor Hart (Aldershot) (LC)
Seaford & Eastbourne (C)
Sheppey (C)
Sittingbourne (C)
Southend (C)
South West Hertfordshire (C)
Spelthorne (C)
Tandridge (C)
Tonbridge, Edenbridge & Sevenoaks (C)
Tunbridge Wells (C)
Thurrock (C)
Uttlesford (C)
Waverley (Godalming) (LC)
Woking (C)

West Midlands
Birmingham (C)
Coventry (C)
Dudley (C)
North Birmingham (LC)
North Warwickshire (C)
Nuneaton & Bedworth (C)
Rugby (C)
Sandwell (C)
Solihull (C)
Warwick & District (C)
Worcester & District (C)
Wolverhampton (C)

East Anglia
Breckland (C)
Broadland (C)
Cambridge City (C)
Cambridge South & East (C)
Fakenham & District (C)
Fenland (C)
Great Yarmouth (C)
Huntingdonshire (C)
Ipswich & District (C)
Mid Suffolk (C)
Norwich City (C)
Peterborough (C)
Suffolk Coastal (C)
Thetford (C)
Waveney (C)
West Suffolk (C)

Wales
Aberconwy (C)
Alyn & Deeside (C)
Arfon (C)
Delyn (C)
Islwyn (C)
Llanelli (C)
Newport & District (C)
Penarth (C)
South Glamorgan (C)
Torfaen (C)
West Glamorgan (C)

South West
Bournemouth & Poole (LC)
Chippenham & District (LC)
Cheltenham (C)
Devizes (LC)
Exeter (C)
North Devon (LC)
South West Wiltshire (LC)
Torbay & District (LC)
Trowbridge (LC)
West Dorset (LC)

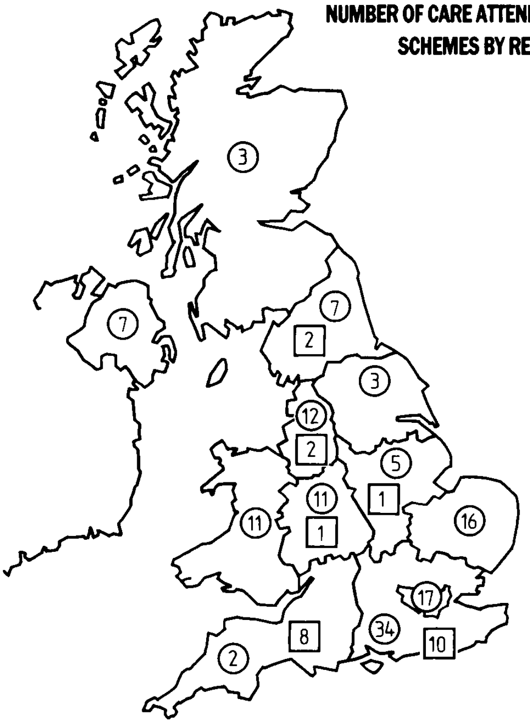
Greater London
Brent (C)
Camden (C)
Croydon (C)
Enfield (C)
Hackney (C)
Hammersmith & Fulham (C)
Hillingdon (C)
Islington (C)
Kensington & Chelsea (C)
Lambeth South West (C)
Merton (C)
Newham (C)
Richmond-on-Thames (C)
Southwark (C)
Sutton (C)
Wandsworth & Putney (C)
Waltham Forest (C)

Scotland
Inverness (C)
Livingston (C)
Skye & Lochalsh (C)

Northern Ireland
Armagh & Dungannon (C)
Belfast East & Castlereagh (C)
Belfast North & West (C)
Belfast South (C)
Craigavon (C)
East Antrim (C)
North Down & Ards (C)

(C) – The Association of Crossroads Care Attendant Schemes
(LC) – Leonard Cheshire Foundation Family Support Services

Box 3.1. CARE ATTENDANT SCHEMES IN THE VOLUNTARY SECTOR: THE NATIONAL PICTURE



NUMBER OF CARE ATTENDANT SCHEMES BY REGION

Community Service Volunteers: Independent Living Schemes

1987

Region	Number of Users
London	42
South East	8
South West	23
Wales	-
Central	22
East	18
North East	8
North West	11
Scotland	11
Northern Ireland	-
TOTAL	143

KEY TO MAP:

□ Association of Crossroads Care Attendant Schemes

○ Leonard Cheshire Foundation Family Support Services

There are three main voluntary sector care attendant schemes which operate in Britain. The Association of Crossroads Care Attendant Schemes was established in Rugby in 1973 with initial funding coming from the television company which produced the Crossroads serial. The Leonard Cheshire Foundation began their Family Support Services (FSS) in 1980 in Bournemouth and Poole, to offer disabled people the choice of an alternative way of life to residential care. The third scheme was set up by Community Service Volunteers and is now known as the Independent Living Scheme (ILS). This started in 1980 as a result of the occasional placement of volunteers to help with the personal care of disabled people in further education during the 1970s. During the 1980s all three organisations have grown in size and now each have schemes operating across much of Britain.

Care attendant schemes provide assistance to families with disabled members or to disabled individuals living on their own. The intensity of help varies: it might take the form of occasionally sitting with the disabled person while other family members go out, or help with daily care and domestic duties. As a result, some clients may receive regular help for several hours a day while others require only a few hours a year. The Leonard Cheshire Foundation estimated that its clients required five hours help per week in 1987 but this average obviously conceals wide variations. The large differences in the amount of help given to individual disabled people means that comparison of the number of clients helped by different services is difficult: for example West Dorset FSS — the largest service — had 350 clients on their books in 1987, but looked after approximately 150 clients per month, with a total of 24,300 hours of care in the year.

In 1986/7, Crossroads had a total of 128 schemes in Britain which helped approximately 9000 clients, 65 per cent of whom were physically disabled and 65 per cent of whom were over 65. In that year they had approximately 900 Crossroads care attendants, who gave over 650,000 hours of care. On average each scheme had approximately 70 clients and 7 paid care attendants, although this again conceals wide variations. The FSS has 24 services which help approximately 1400 clients per month, averaging about 60 clients and 25 paid care attendants each. The map and list of schemes show quite clearly that while both Crossroads and FSS operate in the same regions there is very little overlap between them and that many areas are still without this sort of flexible care assistance. Both types of scheme are mainly funded by statutory authorities. For example about 90% of Crossroads income came from joint finance, health and local authorities and the Department of the Environment. The remainder of their income is made up by fundraising and donations. In addition clients themselves are often asked to contribute if they can.

A different type of scheme to help disabled people in their own homes is the Community Service Volunteers' Independent Living Scheme. This places volunteers into disabled peoples' own homes for 6 months, to do the tasks they would do for themselves, if they were not physically limited. Over half of the users work, others attend further education, but volunteers also help in families where there is a risk of children being taken into care. As can be seen from the table, users are concentrated in London. Location of schemes partly depends on statutory authorities' willingness to help pay the volunteers and supervise them.

disability services of this kind varies both according to local availability and the practices of individual clinicians.

In general, the liaison between hospital and specialist rehabilitation units and community services is poor, and post discharge follow-up can be non-existent. The Stoke Mandeville study comments that:

> ... *rather than follow up and co-ordination of after-care and other services, respondents more often found that discharge meant a marked reduction — or even breakdown — of support and service provision* (Creek *et al.*, 1987, 286).

The survey found that liaison between health and social services housing adaptations was particularly poor. This problem is a general one, and affects large numbers of disabled people and their families (Glendinning, 1986; Owens, 1987). In addition, the studies of disabled young people all comment on the marked reduction of disability services families experienced once respondents were no longer eligible for the care provided by special schools and NHS paediatric departments (Hirst, 1984; Tripp *et al.*, 1985; Thomas *et al.*, 1987).

Remedial therapies

Newly disabled people — those with strokes, head injuries and the like — receive remedial therapies in an effort to minimise the disabling effects of their conditions. But even 'stable' disabling conditions like cerebral palsy, spina bifida and spinal injury are not necessarily static: physiotherapy will be needed periodically. Progressive or fluctuating conditions like multiple sclerosis or rheumatoid arthritis also require flexible inputs of remedial care to minimise disability.

District health authorities organise physiotherapy services for disabled people. The particular pattern of service delivery depends on district therapy managers and clinicians. Little is known about the overall level of service provided for disabled people, except that long-term shortages of skilled staff appear to have hampered service development in many places. In addition, thorough evaluations of the effectiveness of physiotherapy in minimising disabling conditions and preventing deterioration have often not been made.

Recently, certain districts have begun to provide domiciliary physiotherapy and physiotherapists have also been attached to GP practices. These services are in an early stage of development and their impact on disabled people has not been assessed. Recent work suggest that it is, as yet, slight (Burnard, 1988). Only 15 per cent of respondents to the Stoke Mandeville survey received domiciliary physiotherapy after discharge from the spinal unit. Respondents considered that the quality of these services left something to be desired — in some cases it amounted to little more than advice on home exercises.

Evidence from a variety of sources suggests that the physiotherapy service is failing to meet the needs of disabled adults. Provision falls off markedly when disabled young people leave school — the Family Fund survey found that 81 per cent of young adults who had regularly seen a physiotherapist while at school no longer did so once they left (Hirst, 1983). This decline is corroborated in other studies: less than one-third of the young adults in the London and Wycombe study had regular physiotherapy — something that may have contributed to the high level of preventable deformities reported there. Respondents with purely physical disabilities were least likely to receive regular physiotherapy (Thomas *et al.*, 1987). A prior survey of 20 physically disabled teenagers in High Wycombe also suggested that the availability of physiotherapy decreases after leaving school (Enticknap, 1983a,b). Only 14 per cent of the severely and very severely disabled young adults in the national survey received physiotherapy, and physically disabled respondents were more likely to have 'lost' this service on leaving school than those with mental or multiple impairments. Whether or not physiotherapy services continued after school leaving appeared to vary according to local policies and levels of provision (Hirst, 1984).

Summary and conclusions

This chapter has attempted to piece together an impression of the health and social support services available for people with physical disabilities who live in the community. The picture which emerges is a bleak one.

Most disabled people receive little or no practical help from statutory services for their self-care and domestic management. Those who do receive support can experience difficulties with the type and intensity of care given. More flexible services, like care attendants and independent living schemes have grown up over the last decade, but still reach only a small proportion of disabled people. Overall, service development in this area is very confused, and the fact that provision is split between health and social services contributes to this. Advice and counselling for people with physical disabilities is often inadequate. Respite and day care is typically poorly developed.

There is a national shortage of purpose-built and adapted housing for people with physical disabilities. Levels of specialised housing provision vary considerably between different areas. Adaptations to existing accommodation often involve substantial delays. Aids and equipment supply is divided between health authorities and social services departments in a way that creates confusion for service users and providers alike.

On the health side, there appear to be major inadequacies in the way that both primary and secondary health services deal with the general health care of disabled people. These reflect both inadequate levels of provision — as, for example, with dental services in some areas — and an overall lack of expertise in and commitment to disabled people's health needs. These problems are complicated by problems of physical access to primary health care and hospital premises. In addition, rehabilitation services and staffing levels for medical specialties relevant to disability vary across health districts and NHS regions. This contributes to the fact that expert help for problems related to their disability is unavailable locally for many people.

4 CHARTING THE OBSTACLE COURSE

Webs and mazes

Services for disabled people have been repeatedly — and aptly — likened to the maze at Hampton Court. Figure 4.1 illustrates the main agencies and their inter-relationships. Their complexity is such that, on the ground, it is extremely difficult to tailor help to individual needs and preferences. At agency level, lack of coordination on case and programme planning, coupled with confusion or disagreement over service goals, means that collaboration between the NHS, social services and voluntary organisations is often extremely difficult to achieve in practice. These problems are exacerbated when attempts are made to marry health and social care programmes with those of the education and employment services.

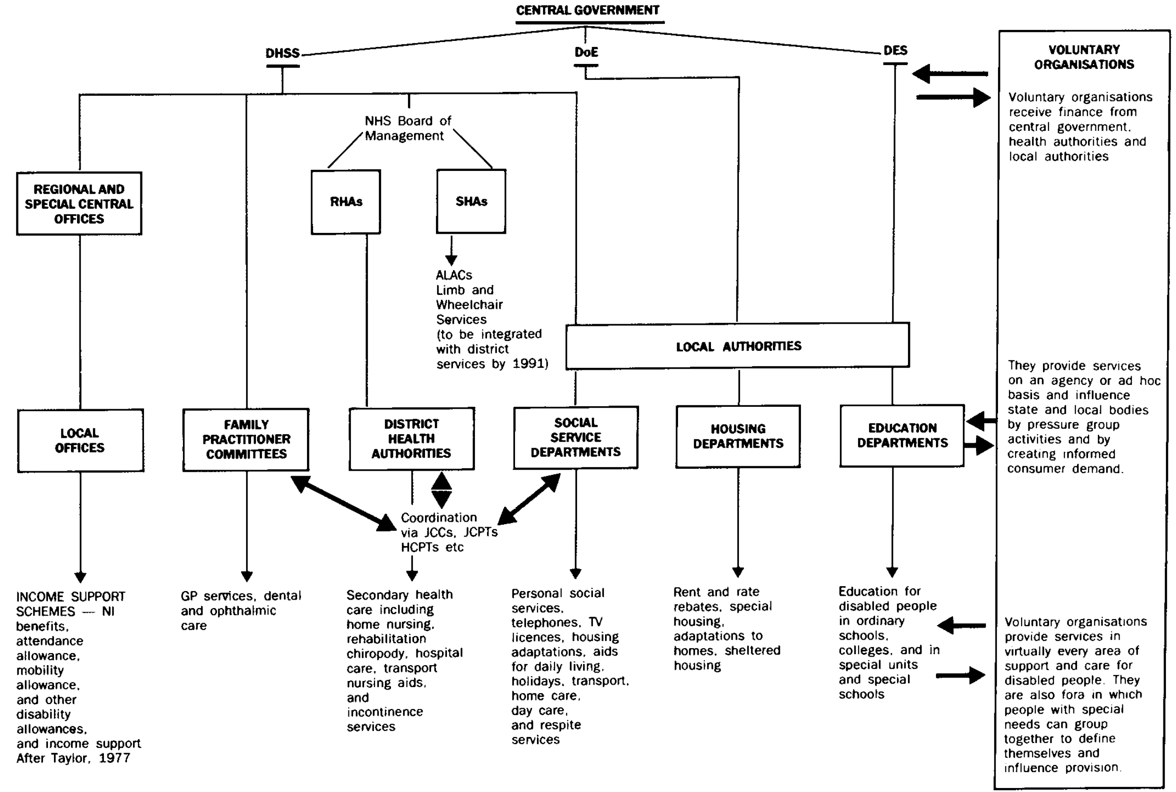
For disabled people this means that services can effectively create barriers to independent living in the community, instead of the active support that they are meant to provide. 'The system' becomes something to be struggled with and fought against, rather than a help for people who already have to cope with crippling impairments.

For their part, service providers have the unenviable task of meeting needs from an inadequate supply of options. At best, this can mean fitting a round peg into a square hole — at worst it means having nothing to offer. Ill-equipped by training to deal with problems of long-term disability and bewildered by the complexities of obtaining services, professionals develop idiosyncratic referral pathways through the maze of services — or, effectively, opt out altogether (Blaxter, 1976; Cantley and Hunter, 1985).

Chapter 3 summarised the evidence about the type of health and social care available to disabled people and their carers. This chapter discusses some of the principal barriers to effective community care for physically disabled people. These centre on the failure of the principal agencies to align planning and service development in order to provide a comprehensive network of services for disabled people. It concentrates on two aspects of this problem: service coordination, and unhelpful professional practices and approaches.

In an attempt to convey how this general policy failure affects physically disabled people and their

FIGURE 4.1 · AGENCIES WHICH PROVIDE HEALTH AND SOCIAL CARE FOR DISABLED PEOPLE



DHSS = Department of Health and Social Security
DoE = Department of the Environment
DES = Department of Education and Science
RHAs = Regional Health Authorities
SHAs = Special Health Authorities

After Taylor, 1977

BOX 4.1. INCONTINENCE SERVICES

PHYSICAL DISABILITY/SOCIAL HANDICAP

Incontinence services epitomise many of the problems of services run for disabled people. They are unglamorous. Worse than that, they are bound up with an aspect of dependence which is both taboo and stigmatising — an area of life that most people fear, and would prefer not to think about.

For disabled people and their carers, incontinence creates problems on a number of levels.

For the individual, incontinence can handicap. It can be an important factor in determining whether children attend mainstream or segregated schools. It can affect a person's employability, marriagability and sexual life.

And incontinence is a major burden for families. It creates a day-in-day-out, year-in-year-out demand for equipment and supplies and a way of disposing of them. It often involves extra washing. This, changing, and managing stocks of supplies and their disposal makes heavy demands on carers, who may nevertheless be reluctant to hand over this aspect of care to outsiders.

Help and expertise

Disabled people and their carers need two kinds of help with incontinence. The first is practical help to lessen the burden it creates. The second is expertise to prevent it, or — when that is impossible — minimise it, and make it as 'undisabling' as possible. Effective help means integrated services.

Multiple provision

Health and local authorities provide help for incontinent disabled people and their families in a number of ways:

- **Aids and equipment:** These include disposable pads or terry nappies, rubber pants, sheets, rubber sheets, equipment for dealing with ileal diversions, special toilet seats and grab-rails, as well as 'training aids' such as special chairs, buzzers and alarms.
- **Laundry service**
- **Disposal service**
- **Expertise:** Incontinence has a number of causes, which include neurological defect, surgical intervention, delayed development and environmental causes. Training and/or appropriate management can help eliminate incontinence, or minimise the disability that results from it.

This help has many sources. Patterns of supply depend on local arrangements, which differ from place to place. Health authorities generally supply pads, disposables and sheets, although choice will generally be limited and preferred items — for examples terry nappies or quality disposables — may have to be purchased privately. Carers may have to collect supplies, or districts may deliver them. 'Training' equipment — and advice on how to use it — may come through health authorities, special schools or voluntary organisations, or may not be available at all. Stoma care equipment is generally available on prescription.

Laundry services may be provided by health and/or social services or may not be available at all. In some cases, second-hand washing machines may be available through social services or voluntary organisations. Disposal services may be organised by health authorities or through local authorities' environmental health departments, but they are frequently not provided.

Multiple experts

Expertise, too, comes from a variety of sources and takes a number of forms. Help to minimise incontinence can come from a range of professionals including hospital specialists, general practitioners, health visitors, teachers, and nurses. Special training programmes may be provided through special schools or voluntary organisations.

To be effective, management interventions and training must be based on accurate assessment and reassessment by people with the skills necessary to follow through with appropriate interventions and practical help. Assessment on its own is not enough.

Unsatisfactory service

Users often find incontinence services unsatisfactory. Studies of disabled people and their families repeatedly suggest a high level of dissatisfaction with an inadequate and inexpert service. One study of multiple sclerosis sufferers found that of 50 users of the service, only seven were pleased with what they received. In 33 of the cases where there was a problem, the nurses doing the interviewing were able to make on-the-spot suggestions for improved management.

These problems relate directly to the fragmentation of services and the number of different professionals involved. Lack of information about services means that families which could use them are unaware of the help they offer. Families who receive help from one part of the service — say, supplies provided by the health authority — may be ignorant of other aspects of it — for example, local authority disposal services. Obtaining appropriate assessment and advice is a persistent difficulty. In any case, certain aspects of the problem — for example, managing faecal incontinence — have received little attention by professionals, despite their serious social consequences.

Experts have pointed out that integration could greatly improve services by making it much easier to tailor provision to individual need. Few of the changes needed would involve extra costs — just better management of services.

Sources: Bradshaw (1978); Parker (1982).

carers, three illustrative case studies are incorporated into this section as boxes 1-3. The first looks in depth at the way incontinence services are organised, and the effect that this has on disabled people and their families. The second examines the problems experienced by disabled school leavers. The third looks at services for people with multiple disabilities, focussing particularly on head injury.

Service coordination

Discontinuities on the ground relate directly to the inability of health authorities, social services departments and voluntary organisations to align plans and programmes for physically disabled people. This problem is, of course, true of planning for all four priority groups: the Audit Commisssion's description of 'two agencies struggling to provide parallel but inadequate services' is apt (1986). Persistent problems associated with determining adequate arrangements for funding community care policies underlie these failures of coordination (Audit Commission, 1986; National Audit Office, 1987).

Discontinuities also reflect the difficulties that agencies, or even different parts of the same service, have in communicating and working effectively together. These problems reflect differences in priorities, ways of working and organisational culture as well as deep-seated professional practices and differences of view (Blaxter, 1979; Hunter and Wistow, 1987).

In many areas, health authorities have taken the lead on priority group planning, but have focussed on services for mentally ill and handicapped people because of the need to close long-stay hospitals. Even within health authorities, however, demands from the acute sector have tended to eclipse those from the priority groups (Hunter and Wistow, 1987). Against this background, services for disabled people have often failed to reach local planning agendas. This failure has had a number of predictable results, including poor planning and poor targetting of resources, as well as the service overlaps, gaps and fragmentation already mentioned.

Agencies have often failed to ask basic questions about what they are trying to achieve for the disabled people they serve. The lack of focus that results is compounded by the fact that user involvement in service design is in its infancy, particularly in the health service (Fiedler, 1988). As a result, user perspectives and priorities are generally absent from the planning process. Thus, even in cases where the main agencies work well together, it is very rare for the full range of health and social care services available for disabled people to be considered comprehensively.

Instead, services are seen as monoliths, and the way in which they relate (or fail to relate) with other services to provide 'packages' of care for individuals is not considered. The development of NHS residential care for young disabled adults, which is described in chapter 2, is a good example of this: there, services were planned without reference either to NHS clinical services for disabled people or local authority and voluntary sector residential provision or to services in the community. Disabled people's views about the new units were discounted (Shearer, 1982). The result is a set of facilities which have largely failed to develop a role for themselves, and which currently pose a set of difficult managerial and quality of care issues (Harrison, 1988). The relationship between the supply of incontinence equipment and expert advice on the management of incontinence discussed in Box 4.1 is another example of health service managers and professionals failing to work together to provide an integrated service for disabled people. In a very real sense, this pattern of provision is the logical outcome of the 'parallel policy monologues' discussed in chapter 2.

'Monolithic' service development can also result in overlaps. Currently, NHS home nursing services, local authority 'home care' or home help services, and voluntary and statutory care attendants schemes all provide disabled people with help with bathing, dressing and other personal care tasks. The three different types of scheme can — and in some places do — coexist in the same geographical area, with great potential confusion about who is doing what for whom. 'Turf battles' between different kinds of care worker are a frequent result, with professionals vying for the authority to supervise care and assume overall control (Owens, 1987).

Agencies' failure to dovetail provision to individual need can also result in unnecessary dependence for people with physical disabilities. This can take a number of forms. At one level, it can mean that because appropriate aids — for example, hoists — are not provided, people need assistance with activities like bathing, which they would otherwise be able to manage on their own. At another, it can mean that, because care support is unavailable in the community, people are admitted to — or remain in — institutions (Finkelstein, 1988).

This kind of problem is exacerbated by the failure of health and local authorities to develop a range of living options for physically disabled people. This has the result that adapted, specialist or sheltered housing, transitional housing arrangements and the like 'silt up' with people who could manage with less support, but for whom appropriate arrangements do not exist locally. Shortages of specialised accommodation for disabled people obviously contribute to this (Fiedler, 1988).

In many places these problems take place against a background of overall service shortage. Shortages coupled with poor targetting of resources result in a mismatch between services and need. In the London and Wycombe survey of 111 physically handicapped young adults from two health districts, the survey team found that while 23.5 per cent of physically disabled and 88.1 per cent of multiply handicapped people were clinically assessed as needing speech therapy, only 5.9 per cent and 23.8 per cent respectively were receiving it. Similarly, while virtually the entire sample were judged to need physiotherapy, only one third received it (Thomas *et al.*, 1987).

Nowhere are the problems of poor interagency

BOX 4.2. DISABLED SCHOOL LEAVERS

Leaving school marks an important transition for everyone. It is a modern 'rite of passage' — a focal point in the process of growing up and forging an identity outside the family circle. The time around school-leaving is important too. Most people make key friendships, become sexually active and take on their first job in the years between fifteen and twenty-five. Many also move away from their parents for the first time. For a number, this move coincides with marriage, or setting up house with a partner.

Young people with disabilities go through this transition too. But for them and their families, leaving school and the sheltered world of children's services can show up the problems of being a grown-up disabled person in sharp relief.

Special schools help integrate services for disabled young people and their families. Remedial therapies are conducted by school staff on school premises in school time. Children's general health is supervised by the school health services, and many schools provide parents and pupils with advice on aids, social services and benefits. Most also provide training in independent living.

When young people leave school, these services stop. At around the same time, paediatric consultants pass responsibility for their young patients to other specialist doctors in the hospital service. Young people with disabilities and their families must construct a new network of services for themselves. At the same time, they must cope with the same sorts of problems as other people their age face: getting a job, making and keeping friends and partners, and living an increasingly independent life.

Young people with disabilities and their families have real difficulties in doing this. Their problems include:

■ **Unemployment:** Many more disabled people are unemployed than people without disabilities. During the 1980s unemployment has been particularly high among school leavers, and higher still for young disabled people. This reflects problems of employability — perceived or real — created by their disability and the fact that disabled people typically leave school with lower qualifications than other people do. Many young people find the the Employment Service less than helpful when trying to find a job.

■ **Nowhere to go:** Physically disabled people have fewer alternatives to paid employment than other people with special needs — there is very little day care for them and training centre places tend to be reserved for people with mental handicaps.

■ **Low incomes:** Even in employment, disabled people earn less than other people do. Their families tend to have lower than average incomes too. This is largely because caring for disabled relatives limits women's capacities to work outside the home, and can effect men's abilities to do overtime or move to obtain promotion.

■ **Extra expenses:** Disability involves extra costs. More expensive transport, special diets, more clothes, extra heating can all be needed. Disability benefits are meant to compensate for this, but the rates are set too low to cover most families' extra expenses. And there are problems with claiming them. There are a host of different benefits payable, and many people find it hard to get information about them. When they do, it's often difficult to understand. Many disabled people fail to take up benefits they are entitled to, generally because they don't know about them.

■ **Isolation:** Disabled young people tend to have fewer friends than their contemporaries, and go out to socialise much less often. When they do go out, problems with access often limit the places they can go to.

■ **Poor social skills:** Young people with disabilities suffer more than their contemporaries do from shyness, lack of self-confidence, and self-doubt. Many of them find it difficult to keep their end up in a conversation — particularly with strangers. More than most, they are uncertain of how to handle new situations and project themselves in a positive way.

■ **Dependence:** Schools are not always as good as they could be in teaching independent living skills. In any case, gains made at school may not carry over to life outside it. This can be because families are unclear about what their children have achieved, or because they are ill-informed about what the school has been aiming at. It may be difficult to transfer skills to the home setting because special equipment or adaptations are lacking. Whatever the reason, the result is that some disabled young people are more dependent on their families than they need to be.

■ **Fewer services:** Physiotherapy and occupational therapy stop altogether for many disabled young people when they leave school. Even when they wish to continue with them, there may be no way they can do so. Specialist medical services are different too. Families can find the transition from paediatric to adult services difficult: continuity of care is broken, and consultants may lack interest or expertise in disability medicine.

■ **Lack of advice:** When families turn to social services departments for help in obtaining benefits, services or aids they often fail to get the help they need. Many report that social workers do not have a great deal of knowledge or expertise in dealing with disabled people and their problems. And young people may need special advice. Many have worries about their sexuality and their capacity to have and bring up children. There is often no one to turn to: sex education in special schools can be poor, and few health authorities or social services departments provide sexual counselling.

■ **No-one to help:** Few families with young disabled members receive any practical help with their care from health or social services.

These problems are inter-related. Together, they present a dismal picture of loneliness, dependence and poverty. Young people with disabilities experience higher rates of depression and other mental illness than their contemporaries. Their depression is fuelled by their isolation, worries about getting a job, perceptions of being a burden and anxiety about their ability to have fulfilling friendships and sexual relationships. Their families experience considerable stress. Parents, in particular, often suffer deep anxiety about their ability to go on coping.

There are around 45,000 physically disabled people between the ages of 16 and 30 in the UK. The special problems of disabled school leavers have been acknowledged for over a decade. The need to do more to fit young people with disabilities for an independent life in the community is widely recognised. So is the need to create a smoother transition between children's and adult services. But the problems that disabled young people experience are symptomatic of more general ones: services are fragmented, ill-coordinated, and inexpert. Special schools are not always adept at preparing young people with disabilities for independent life beyond school. Discrimination by employers and society as a whole affects disabled school leavers' opportunities. Until these things change, problems for school leavers will persist.

Sources: Hirst, 1984; Tripp et al., 1985; Thomas et al., 1985; 1987; Oliver, 1987b working more acute than in rehabilitation, where failure to coordinate community care arrangements and housing adaptations can mean that skills acquired in hospital or during therapy atrophy for want of an appropriate home environment (Creek *et al.*, 1987; Owens, 1987). As well as being a waste of resources, the poor timing of interventions creates unnecessary dependence. Both are an inevitable outcome of present arrangements, where housing adaptations frequently take two to three years to be completed, and where medical rehabilitation facilities remain isolated from community services, with all the problems of coordinating services that this implies (Glendinning, 1984; Creek *et al.*, 1987).

Dislocations of this kind are just as apparent when different parts of the same agency need to relate to one another. The difficulty of dovetailing the activities of local authority social services and housing departments has already been touched on. There is ample evidence, too, that NHS hospital consultants and general practitioners often fail to cooperate effectively on the rehabilitation and continuing medical care of disabled people (Blaxter, 1976; 1979; Bax *et al.*, 1988). The same sorts of difficulty occur when disabled people move from specialist rehabilitation facilities to community services.

Coordination: Papering over the cracks?

No specific arrangements for coordinating the health and social care services received by disabled people presently exist. At an individual level, coordination of services generally falls to disabled people or their carers. Awareness of the problems created by fragmented services has been growing since the mid-1970s. This has led to repeated calls for more and better coordination (Thorpe-Tracey, 19760 Blaxter, 1979; Royal College of Physicians, 1986; GLAD, 1987; Griffiths, 1988). At first, hopes were pinned on particular professionals — specifically social workers and health visitors — to coordinate services at individual case level.

In practice, neither group has undertaken this function. Health visitors — who were identified by the Snowden Committee on the integration of disabled people as possible coordinators for this group — have continued to concentrate on their traditional work with mothers and children under five (Hunter, 1988). Social workers have also largely failed to emerge as service coordinators for disabled people (Oliver, 1984). Some of the reasons for this are historical: since their establishment in 1971, social services departments have concentrated on providing children's and family services. The 'priority' groups have, in practice, had lower priority. This is reflected in the marked tendency for social services departments to allocate physically disabled people to junior staff, and for senior staff with smaller case loads to concentrate on family services (Challis and Ferlie, 1988).

As a result, disabled people's contact with social workers can be less than satisfactory. Only one in five respondents to the London and Wycombe survey of young disabled adults were in regular contact with a social worker, and only one-half of the families were seeing a social worker at all. More than one-half of those whom had had contact with social workers considered them unhelpful. Social workers' failure to understand the needs of disabled people and the emotional impact of caring were particular problem areas, as was their lack of detailed knowledge about benefits and the aids and adaptations available through social services departments (Thomas *et al.*, 1987, 70). Respondents to the Family Fund survey had a poor understanding of the range of help and advice available from social workers, suggesting that their contact with them had been limited in scope (Hirst, 1985, 170-171). A study of community care for severely physically disabled people in Cambridge found that social work involvement tended to be limited to crisis managment and family breakdown (Owens, 1987).

The Stoke Mandeville study found that while 80 per cent of respondants had had contact with hospital-based social workers, only slightly more than half received help from community-based staff on discharge — the time when needs are greatest. Even when contact was made, the quality of service often left something to be desired:

> *[The hospital social worker] was a great help — especially with writing letters. They were very concerned with the after effects — what would happen to you once you got home, what services you would have — that's what I call after-sales service . . . the [community] social worker came twice — but I would have liked much more advice — I could have done with a great deal more help after discharge.*
>
> *Nobody wants to do nothing — we never see the social worker — she came the first weekend dad came home, that was all we saw of her.* (Creek *et al.*, 1987, 308-309)

'Team' approaches

During the late 1970s and early 1980s professional teamwork was favoured both as a way of improving coordination at case level and of achieving improved liasion between agencies. Multidisciplinary community mental handicap teams have been established in many places to coordinate care for mentally handicapped adults, and in some districts health authorities have established teams to manage priority group services — including physical disability — under the 1982 'Griffiths' structure. Little is yet known about the effectiveness of this type of approach. One type of teamwork which has been studied, however, are District Handicap Teams (DHTs), which have been established for disabled children in most areas over the last ten years (Bax and Whitmore, 1985). Their creation was recommended by the Court report in 1976, in order to coordinate health, education and social services for this group.

In practice, the establishment of DHTs has been haphazard. Some teams have only children under five in their remit, others are prepared to see children and young people up to the age of nineteen or twenty. Their composition varies greatly, but has tended to be dominated by health professionals — only one-half of the teams include teachers, and not all include social workers. As such, they do not appear to have achieved the inter-agency liaison role envisaged for them.

BOX 4.3. MULTIPLE DISABILITY

MULTIPLE DISABILITY/MULTIPLE PROBLEMS

Some people with physical disabilities have cognitive, psychiatric or behavioural difficulties as well. We have no idea how many of these people there are, and there are very few services available which take their particular needs into account.

Disease or injury to the brain is a major cause of multiple disability. A host of conditions that affect people at all stages of life can be involved. They include cerebral palsy, meningitis, epilepsy, hydrocephalus, encephalitis, multiple sclerosis, stroke and head injuries which result from accidents or violence.

Multiple Carers

Despite the wide range of people affected, we know very little about how best to help them. The brain is a complex structure, and damage can have a wide and unpredictable set of results. What is becoming clear is that help must be integrated to be effective. Cognitive, physical and behavioural therapies should be planned to reinforce each other, instead of following separate tracks.

Medical and remedial specialties, in particular, are organised in a way that makes it all but impossible to arrange effective care for people with multiple inter–related needs which cross disciplinary boundaries. Neurology – the specialty most involved — has traditionally been preoccupied with diagnosis. It has devoted little attention to alleviating symptoms or developing rehabilitation strategies. Remedial care is split between physiotherapists, occupational therapists, speech therapists and psychologists, making care of the 'whole person' very difficult to achieve.

The problems of people with head injuries illustrate the problems of people with multiple disabilities as a whole. But it is important to remember that this group of people is not the only one with conditions that result in cognitive and physical impairments: others fall through the cracks of existing services in just the same way. People with multiple sclerosis and associated short–term memory loss, for example, can be passed like parcels between neurology, rehabilitation and psychiatry, with no specialty willing to oversee their treatment or provide remedial care.

Head Injury

There are an estimated 70,000 people with severe head injury nationally. A further 2,000 people join their ranks every year. Head injury occurs most frequently to people in their late teens and early twenties. At least fifty years of life with multiple disabilities can lie ahead.

Severe head injury results in brain damage which causes long–term social and cognitive deficits as well as physical impairment. The problems of people with head injury are compounded by the fact that much of this damage can be "hidden": cognitive, emotional and behavioural deficits are not immediately obvious, yet they can have a profound effect on an individual's home and social life, and on his or her ability to work.

We know very little about how to tackle combined problems like this. All that is certain is that people with severe head injury need specialised, integrated rehabilitation, with a team approach that means that lessons learnt with one member of the team are reinforced by every other professional. In practice, this is only available in a very few places round the country — often only experimentally.

Compartmentalised care

The majority of people do without. Instead they get variable amounts of different therapies from a range of professionals: physiotherapists, occupational therapists, psychologists and speech therapists may all be involved. The variety of therapists can create problems of coordination and communication which prove deeply frustrating to people with head injuries and their families. Many respond by opting out before full recovery.

Lack of Support

When formal rehabilitation in hospital or special unit ends there is often very little in the way of remedial training for work or emotional and practical support for carers. This means that families are left to manage alone, or that head injured people end up in residential care. Those with difficult behaviours are very hard to cope with at home, and extremely hard – and expensive — to 'place' long term. There is also very little rehabilitation or remedial treatment available for people whose disturbed behaviour effectively excludes them from conventional centres. Behavioural therapies have been shown to help, but these are often not available in a 'package' with the other therapy that is needed.

In practice, caring for head injured people remains very much a family affair. As a direct result, the families of people recovering from head injury experience very high levels of stress and mental illness.

Sources: Gloag, 1985f; Livingston et al., 1985; Cope, 1985; Owens, 1987; Livingston, 1987; Harrison, 1988; Clouston, 1988; Foxall, 1988.

The tasks undertaken by these teams also varies widely, and there is, as yet, no consensus on their mission or actual functioning. Some undertake assessments only, some provide services, some see their role as coordinating services between agencies. The extent to which they have resolved some of the communication problems characteristic of professionals working across health and social care agencies is unclear, and there is no information on users' views of their work. However, new 'boundary problems' have emerged as the services provided by DHTs have overlapped with those provided by the new community mental handicap teams which have been established in many districts (Bax and Whitmore, 1985).

Plainly, there are dangers in an uncritical reliance on teamwork — or any other 'quick fix' solution — to solve problems which have their roots in a failure to establish clear goals and priorities for service provision between agencies and to agree methods of working. This applies to the case manager approaches to coordinating care which are currently being experimented with as a means of improving care for people with physical disabilities. Hunter points out that the term 'case management' presently has multiple — and at times conflicting — meanings, which revolve around notions of client advocacy, brokerage between agencies to achieve individually tailored packages of care, and value-for-money considerations (1988). A further difficulty is that many of the experiments which aim to improve coordination of services involve adding care managers as 'bolt-on' accessories to existing patterns of provision. Until the more fundamental problems of ensuring collaboration between agencies have been addressed, it is difficult to see such innovations making an appreciable difference for the client group as a whole (see, for example, Glendinning, 1986).

Professional practices

Failures of communication between professionals lead to some of the problems of coordination discussed above. But problems of professional practice are not confined to this one area. Disabled people have argued that rehabilitation professionals encourage dependence (Finkelstein, 1984; Wood, 1988). In effect, this statement encapsulates a number of different arguments about the way that professionals deal with the problems associated with chronic illness or long-term disability. These include problems of communication with clients and poor coordination with other professionals, which combine with rigid approaches to treatment to result in a general failure to adapt interventions to individual needs.

Communicating with disabled people

Long term disabilities and chronic illnesses by definition must be managed and coped with rather than cured. Good management — and good coping — require professional and client to exchange information freely in order to develop the best possible strategy for dealing with particular problems and sets of circumstances. There is ample evidence to suggest that this kind of exchange is the exception rather than the rule. In fact, disabled people and their families demonstrate chronic dissatisfaction with the amount and kind of information they receive from professionals at all stages of the management of disabling conditions (Robinson, 1978).

Problems begin with the way initial information about diagnoses is conveyed to disabled people or their relatives. A considerable body of evidence suggests that this process is often seriously mishandled, with the result that individuals and their families start what must become enduring relationships with health and social services in a less than positive way (Collins, 1978; Robinson, 1978). Subsequently, serious problems can develop when professionals fail to share information about the goals and likely outcomes of treatment regimes or therapy with their patients and their families. These include non-compliance and poor motivation, with the result that less than optimal results are achieved by particular interventions (Bobath and Fennie, 1970; Partridge, 1987). The same sorts of problems occur when professionals fail to share their perceptions of likely progression and outcome with sufferers from chronic degenerative conditions (Williams, 1987).

Communication between professionals

Failure to set and communicate targets also bedevils relationships between professionals. The inability of professionals from different backgrounds to understand each others' perspectives, roles and methods of working has been a pervasive obstacle to the development of community care (Blaxter, 1979; Griffiths, 1988). Its results are all too apparent in confusion over goals, timetables and the details of cooperation on individual cases. These problems occur between members of the same profession as well as between different ones: the management of people with multiple disabilities is a case in point (see box 4.3), as are the often inadequate arrangements made between hospital consultant and general practitioners for the long-term medical care of people with chronic conditions.

Problems of communication are the most extreme in the field of rehabilitation because of the great number of professionals from different backgrounds and agencies involved. Here, the fragmentation of the remedial professions into physiotherapy, occupational therapy and speech therapy is a particular stumbling block to effective care (Wilding, 1982). The fact that different sets of professionals have remits for different aspects of physical functioning means that it is extraordinarily difficult to achieve 'holistic' care for a particular individual (Kinsman, 1987).

The confusion that can result has been dubbed 'the familiar farce of multidisciplinary teamwork' (Finkelstein, 1984). For the disabled person and his or her family, the resulting failures to communicate, align objectives and agree methods of treatment can lead to misunderstandings, uncertainties and — if these are not resolved — considerable frustration. In practice, good teamwork is difficult to organise and administer and all too often proves fragile in the face of staff changes and differences of personal and professional style (Feiger and Schmitt, 1979). In addition, interprofessional rivalries — such as the traditional distrust between doctors and social workers — can be a considerable obstacle to it.

A related problem is the tendency for assessment or diagnostic facilities to be more developed than services to address the problems they reveal. This undoubtedly relates to some professionals' preference for assessing clients at the expense of providing 'hands on' care to meet their needs. This situation is complicated by the fact that many assessment measures exist in isolation from practical 'problem solving' strategies (Brechin and Liddiard, 1982). Disabled people and their carers may therefore emerge from time-consuming testing with only a list of problems. Not surprisingly, many find this disillusioning (Robinson, 1978).

Problem solving and partnership

In recognition of these difficulties, a number of commentators — both disabled and professional — have pointed to the desirability of developing 'problem solving' rather than 'prescriptive' approaches to dealing with disability (Brimblecombe, 1977; Brechin and Liddiard, 1982; Finkelstein, 1984). By definition, an approach of this kind would involve adjusting the traditionally unequal relationship between professional and client to something more akin to partnership. 'Partnership' methods of working involve mutual agreement of long-term objectives and short-term targets, and discussion and agreement on means of achieving them. It also means working closely with carers.

In theory, this kind of approach seems only sensible. In practice, it is proving difficult to achieve. Closer examination suggests that 'partnership' models of working challenge deep-seated professional attitudes and practices, and the power-relationships upon which they are based. Read quotes by two carers:

> *Partnership? I have no trouble with it at all. It all goes like clockwork — till I disagree with something they say.*
>
> *What I think about this partnership lark is that it means that they make all the decisions and I do all the work* (1988).

Plainly, prescriptive styles of working have advantages for professionals, even given that they can involve penalties in terms of limiting the effectiveness of care. Without a major change in the balance of power from professional to client it is hard to see 'partnership' approaches achieving anything more than rhetorical success.

Summary and conclusions

The failure of health and social support agencies to agree goals and develop complementary service plans creates very considerable problems both for people with disabilities and for the professions who work directly with them. Discontinuities of care *within* agencies are just as serious as those that exist between them. 'Quick fix' solutions whereby individual professional workers or teams attempt to manage and coordinate care for individual disabled people are unlikely to be effective while these underlying structural problems remain. In the field, problems of communication between professionals and difficulties associated with developing true 'partnership' methods of working with disabled people are considerable obstacles to effective care.

CONCLUSIONS

This report paints a bleak picture. It highlights substantial inadequacies in the health and social services currently available for disabled people. These are inadequacies both of quality and of quantity: not only are levels of provision inadequate, but the right *kind* of services — ones which enable disabled people to be autonomous and which minimise the burden on carers — often do not exist. Problems of access and a general inability to take disability into account bedevil many of the services that disabled people share with the able-bodied.

Although services have improved since the Chronically Sick and Disabled Persons Act was passed in 1970, the picture nationally is very patchy. Innovations like care attendants schemes have improved the quality of some disabled people's lives, but this kind of care is spread too thinly. The majority of disabled people manage with minimal assistance from services which are ill-equipped to meet their needs.

All four of the 'priority' groups suffer from the paradox that they are in fact low priority. On most policy and planning agendas community care for disabled people ranks lowest of all — squeezed out by institutional closure programmes and the increasing number of older people. This means that resources fail to flow towards services for disabled people — resources both of money and more intangible ones of attention, commitment, expertise and talent.

To some extent, the low priority of these services reflects the position of disabled people in society as a whole: marginalised, stigmatised and discriminated against. The most fundamental criticism of services for disabled people is that — as Blaxter first pointed out a decade ago — they are hypocritical (1979). They set out to 'care for' vulnerable people, but in fact often contribute appreciably to the difficulties that those people face.

Changing climates

But social attitudes towards people with physical disabilities are changing. In a number of important ways disabled people are becoming more integrated into the community. Public access is improving, and the rhetoric — if not the reality — of disabled people engaging as ordinary citizens in all aspects of public life has wide currency (Finkelstein, 1988). The process of integration is by no means complete, but disabled people's own expectations are higher as a result of the changes that have already taken place.

These new attitudes have informed a growing critique of existing health and social support provision for disabled people. It is plain that services have substantially failed to respond to this changing climate (McColl, 1986; Royal College of Physicians, 1986a). Innovations like care attendants schemes and Centres for Integrated Living have, however, given an indication of the way ahead. The experiments in more flexible types of help which have benefitted a few people in the 1970s and 1980s give clear pointers about the kind of services which should become mainstream provision over the next decade (Hunter, 1987).

At the same time, concern about the confusion and lack of progress over the implementation of overall community care policy has prompted a major review of policy options for the priority groups. Both *Community Care: Agenda for Action* and *Residential Care: A Positive Choice* centre on the rights and needs of the individual (Griffiths, 1988; Wagner, 1988). The Griffiths report takes individual need as its starting point, and its proposals centre on 'enabling' social services departments (SSDs) which will — through care management — design, arrange and regulate care, rather than provide it directly. In an attempt to ensure commitment, inter-agency collaboration and high standards locally, Griffiths proposes that a minister should be appointed to promulgate values and to monitor local plans. Receipt of central government funds for community services will be contingent on SSDs' producing plans which adhere to centrally agreed values and standards and which are genuinely collaborative, while taking into account local circumstances. Close cooperation between statutory, voluntary and private sectors is to be encouraged.

The Wagner report on residential care contains an important new principle:

> *People who move into a residential establishment should do so by positive choice. A distinction should be made between need for accommodation and need for services. No one should be required to change their permanent accommodation in order to receive services which could be made available to them in their own homes* (1988, 114).

It goes on to endorse the idea of local authorities taking the lead in the strategic planning of accommodation and support services, and to suggest that the introduction of a system of community care allowances to allow people with special needs to purchase care services directly should be given careful consideration (1988, 115). Griffiths, too, gives a cautious go-ahead to SSDs to experiment with voucher schemes or credits which individuals can use to purchase domiciliary care (1988, para. 39).

The approach to accommodation and social support outlined in the two reports is one that could offer a constructive way forward for people with physical disabilities. In particular, it offers the potential for far greater user-participation in service design and delivery, with the possibility of direct user control of services becoming a general option through community care allowances. The way would also be clear for SSDs to contract out services to be run by organisations of disabled people, or their representatives. These developments could, in time, do much to alter the relationship between professionals and people with disabilities, leading to more genuine partnership.

But both reports are silent on the critical question of funding community care: resource levels are for central government to determine. Unless adequate funds become available it is likely that the 'managed care' approach put forward by Griffiths will be less about developing packages of services tailored to individual need and more about strict rationing of inadequate resources. Although this problem affects all four priority groups, it will be particularly acute for disabled people, because services for them are so poorly developed. A further difficulty is that SSDs, as presently organised, have a poor track record in terms of developing services for people with physical disabilities. A new commitment will be hard to generate overnight, especially considering the extent of the upheaval involved if the Griffiths proposals are implemented in full, and the continuing pressure of psychiatric and mental handicap hospital closure as well as the growth in the population of frail elderly people (Hunter and Judge, 1988). Furthermore, even under the new arrangements important interfaces would remain — the most notable being between SSDs and housing authorities and between SSDs and primary and secondary health care. Problems of integrating care across them are likely to be persistent.

Towards a comprehensive service

Regardless of what happens to community care policy at national level, it is plain that we must begin to think more clearly about what providing comprehensive health and social support for disabled people means. This report identifies general health care, social support and disability services as key areas for service provision. Any attempt to construct a comprehensive service for disabled people must concentrate on developing all three — and on improving the way in which they inter-relate.

Social support

Services which deliver practical help to disabled people are currently very confused. The fact that provision is split between health and social services contributes substantially to this, as does the fact that many people who receive support services are obliged to do so in residential settings. This, and the gaps in present provision, mean that it is currently impossible to say with certainty how a model service would be organised, or to determine the 'weightings' to give to different service elements within it.

More flexible forms of assistance have begun to replace conventional home nursing and home help services for a few people. Under the present all-or-nothing arrangements many more manage with very little help from statutory services — or end up in residential care. Lack of expertise hampers the effectiveness of many services, and a failure to coordinate care hinders others. It is clear that few service providers have really thought through the implications of what it means to support disabled people in living autonomously (Bennion, 1988). Many of the counselling and advice services needed by disabled people and their families are absent altogether.

Further development of flexible domiciliary care arrangements is one obvious way ahead for services which aim to help disabled people. The innovation and experimentation that has taken place in this area during the 1970s and 1980s has given clear indications of the potential of these approaches for improving the practical help that people with physical disabilities receive. Greatly improved coordination between health authorities, social services departments and voluntary organisations will be essential for any worthwhile improvements in this area. Current arrangements, which permit SSDs, NHS community services and voluntary organisations to operate parallel systems for the same types of services, are untenable.

To be effective, cooperation between agencies must extend to planning, designing, allocating and monitoring the practical help that disabled people receive. To ensure that services are appropriate and offer value-for-money, it will be important to involve disabled people in their design and management (Wood, 1988).

The same considerations apply to aids and equipment supply. Coordinated planning and joint management of services are necessary to ensure that the chaos and wastage of present arrangements does not continue. The integration of ALACs into district health authorities by 1991 offers a good opportunity for a comprehensive overhaul and upgrading of the system at local level. It will be important for ALACs services to be seen as components of an overall system of aids, equipment and orthotics supply. The inolvement of disabled people in designing, managing and monitoring new arrangments will be an essential part of ensuring quality of service.

Health care

This report highlights major inadequacies in the way that both primary and secondary health services deal with the health care of disabled people. These reflect both inadequate levels of provision — as, for example, with dental services — and an overall lack of expertise in and commitment to disabled people's health needs. These difficulties are complicated by problems of physical access to primary health care and hospital premises. In addition, communication problems between general practitioners, hospital doctors and other health professionals can impede the effective management of long-term disability. At individual case level, 'prescriptive' styles of care can militate against the development of effective coping strategies (Williams, 1987).

Changing this will involve a considerable effort in health service organisation, as well as substantial investment in staff training, improved facilities and better access to and within buildings. Improvements in the way that health care is delivered to disabled people are clearly necessary whatever changes are made in overall community care policy. Indeed, it would be unfortunate if changes in national policy aimed at enhancing local authorities' role in community care deflected attention from the need for change within the health service.

Three types of change are required. The first is adaptations to existing premises and careful planning of new facilities to make them fully accessible to disabled people. This applies to hospital and other secondary health care facilities and as well as to general practitioners' premises.

The second is for general practitioners and hospital specialists to agree clearer strategies for managing long-term disabilities and chronic illnesses. Where appropriate, these should be backed up by clinical protocols and monitored by a system of medical audit. All such strategies should be developed with the aim of involving disabled people in their own health care and in the prevention of handicaps resulting from their physical impairments. 'Handover' arrangements between paediatric and adult services should be clearly established.

At district and Family Practitioner Committee level the aim should be to ensure that general practitioners have clear referral pathways for problems connected with physical disability. Responsibility for providing dental care and other services for disabled people should be clearly defined. General practitioners should, where appropriate, establish lists of disabled people whose health needs regular monitoring, and develop systems to ensure that this takes place.

Arrangements like these would go some way towards preventing the kind of neglect documented in chapter 3, while improving the quality of care generally available. In addition, improved training on the health needs of disabled people must take place. Consideration should also be given to the appropriate care of disabled people as hospital in-patients, with the aim of minimising increases in disability that result from hospital stays and improving care overall.

Disability services

There is a danger that rehabilitation services will atrophy further if health service managers and clinicians interpret changes in community care policy to mean that responsibility for disabled people lies elsewhere (McLellan, 1988). The task over the next few years will be for rehabilitation professionals to begin to determine what care and help they are most effective at giving disabled people. This will involve critical appraisals of rehabilitation approaches and techniques, and their effectiveness in consultation with disabled people themselves. Only then will it be possible to determine what network of medical rehabilitation facilities is needed, and the level at which it should be developed.

Presently, no such network exists. A hotch-potch of special units and hospital services cope with some of the medical rehabilitation needs of some disabled people, depending on where they live round the country. These often fail to make links with primary health care, social services departments or voluntary organisations, and their impact is thereby reduced. There is no consensus about how rehabilitation professionals can most effectively operate in the community (Burnard, 1988). There are also very considerable problems associated with integrating the care given by remedial professionals (Kinsman, 1987).

Perhaps the best way of beginning to rationalise this state of affairs is to develop local rehabilitation policies, based on district health authorities (Royal College of Physicians, 1986a). A necessary preliminary for this would be to determine which services are available locally, which are provided regionally and which are unavailable (Langton Hewer, 1988). Any services developed subsequently would need to take account of the importance of integrating rehabilitation with the strategies for practical help being developed in the community. The overall aim must be to provide integrated care for people with disabilities which allows them to live as independently as possible. For this reason, it will be important for rehabilitation services to be organised locally, and to use distant specialist facilities sparingly.

'Prescriptive' professional approaches can limit the effectiveness of rehabilitation. Once again, a considerable investment in training is required. So are changes in professional practice which foster rather than inhibit integrated care. The fragmentation of the remedial professions, and the problems of ensuring integrated care through 'multidisciplinary teamwork' need to be addressed.

Preventing disability

Being serious about preventing handicap is an essential part of any comprehensive strategy on disability. This means action at a number of levels and settings: developing effective perinatal and accident and emergency care are areas for intervention, as are thorough genetic screening and counselling services. Accident prevention programmes are equally important, as are the acute services which undertake hip-replacement and other disability reducing procedures. A national strategy for disability prevention is required, along with the commitment to implement it at local level (Impact Foundation, 1986).

Developing effective strategies for preventing existing disabilities from worsening are crucial: the joint contractures and pressure sores discussed in chapter three provide a case in point. Improvements in many of the services discussed in this report would fall under this heading: an integrated and expert aids and equipment service could prevent many impairments becoming handicaps, as would speedy adaptations to disabled people's homes.

Care and action

Change for the better requires action on a number of fronts. The first is political: disabled people and their organisations must not permit their needs to remain last on the list. This means overcoming many of the divisions in the disability movement in order to present a coherent view of how services should develop in future. It will also involve developing new, genuinely collaborative ways of working with professionals and statutory and voluntary agencies to improve existing services and create new ones (Wood, 1988). Health and social services managers will need to accept these new approaches as a basis for creating appropriate services for disabled people and making them easier to use. Professionals, for their part, must begin to change obstructive work methods and develop expertise that is genuinely useful to disabled people.

Many of these changes will be facilitated if a reorganisation of community care involves a change of focus from agencies to individuals. This requires a clear new direction from central government and sustained leadership both centrally and at agency level. New skills will be required from managers and from case workers in the field. But change for the better will still be possible even if this 'cultural revolution' fails to take place. The main message of this report is that change is badly needed.

BIBLIOGRAPHY

Abberley (1987), 'The Concept of Oppression and the Development of a Social Theory of Disability', *Disability, Handicap and Society,* 2:1, 5–19.

M. Agerholm (1972), 'Rehabilitation', *The Lancet*, August 12, 329–330.

C. Aitkin and J. Walker (1986), *Care of Disabled People in the Community*, University of Edinburgh, Edinburgh.

C. Aitkin (1981), 'Psychological Aspects of Disability', *Psychiatry in Practice*, September, 22–34.

C. Aitkin et al (1982), 'Research Aspects of Rehabilitation After Acute Brain Damage in Adults', *The Lancet*, November 6, 1034–1036.

F. I. Aitkinson and S. A. Sklaroff (1987), *Acute Hospital Wards and the Disabled Patient*, Royal College of Nursing, London.

J. Apley (ed.) (1978), *Care of the Handicapped Child*, Heinemann Medical Books, London.

Association of Crossroads Care Attendant Schemes (1987), *National Statistics April 1986–March 1987*, ACCAS,Rugby.

Audit Commission (1986), *Making a Reality of Community Care*, London, HMSO

Audit Commission (1987), *Community Care: Developing services for people with a mental handicap*, Occasional Papers number 4, London: HMSO

M. Bax, D. Smyth and A. Thomas (1988), 'Health care of physically handicapped young adults', *British Medical Journal*, 296, 1153–1155.

M. Bax and K. Whitmore (1985), *District Handicap Teams: Structure, Functions and Relationships,* Community Paediatric Research Unit, Westminster Children's Hospital, London.

BCDOP (1987), *Comment on the Report of the Audit Commission – 'Making a Reality of Community Care'*, British Council of Organisations of Disabled People, London.

C. Bennion (1988), *Choosing to Live Independently: A study of people with disabilities living in residential accommodation*, Spastics Society, London.

T. B. Benson and E. Williams (1979), 'The younger disabled unit at Fazakerley Hospital', *British Medical Journal*, 2, 369–371.

P. Blair (1982), 'Therapists voice fears over reorganization', *The Times Health Supplement*, No 18, 5 March, 5.

M. Blackwood (1978), 'A cry from the heart', Nursing Times, special supplement *Disability without Handicap*, 74:33, 22–23.

M. Blaxter (1976), *The Meaning of Disability: A Sociological Study of Impairment*, Heinemann, London.

M. Blaxter (1979), 'Principles and Practice in Rehabilitation', in Sir Alec Merrison (Chairman), *Report of the Royal Commission on the National Health Service*, Cmnd 7615, HMSO, London, pp 441–455.

B. Bobath and N. R. Finnie (1970), 'Problems of Communication between Parents and Staff in the Treatment and Management of Children with Cerebral Palsy', *Developmental Medicine and Child Neurology*, 12, 629–635.

A. Borsay (1986), *Disabled People in the Community: A Study of Housing, Health and Welfare Services*, Occasional Papers on Social Administration 80, Bedford Square Press/NCVO, London.

A. Borsay (1986), 'Personal Trouble or Public Issue? Towards a model of policy for people with physical and mental disabilities', *Disability, Handicap and Society*, 1:2, 179–195.

M. D. Brock (1976), 'The Problem Family', *Child: care, health and development*, 2, 139–143.

J. Bradshaw (1978), *Incontinence: A burden for families with Handicapped Children*, Disabled Living Foundation, London.

A. Brechin and P. Liddiard (1981), *Look at it this Way: New Perspectives in Rehabilitation*, Hodder and Stoughton in association with the Open University Press, Sevenoaks.

A. Brechin et al (eds) (1981), *Handicap in a Social World*, Hodder and Stoughton in association with the Open University Press, Sevenoaks.

F. S. W. Brimblecombe (1976), 'How about Parents as Partners?' *Social Work Service*, 9, 19–21.

F. S. W. Brimblecombe (1977), 'The Honeylands Project', *The Journal of Maternal and Child Health*, September, 361–366.

S. Brisenden (1987), 'A Response to Disability in 1986 and Beyond: a report of the Royal College of Physicians', *Disability, Handicap and Society*, 2:2, 175–182.

S. Brisenden (1986), 'Independent Living and the Medical Model of Disability', *Disability, Handicap and Society*, 1:2, 173–178.

British Medical Association (1968), *Report of a Working Party on Aids for the Disabled*, BMA, London.

J. C. Brocklehurst et al (1978), 'How much physical therapy for patients with stroke?', *British Medical Journal*, 1, 1307–1310.

I. Bromley et al (1987), *Physiotherapy services: a basis for development of standards*, King's Fund, London.

J. Campling (1984), 'Disability: "On our own terms"', *Community Care*, 5 April, 25–26.

H. Canter, R. Barnitt and S. Buckland (1981), *This is their Home: A study of residential homes for adults with physical disablement*, DHSS, London.

C. Cantley and D. Hunter (1985), 'People Processing: Towards a Typology of Selected General Practitioner Referral and Admission Practices in Care of Elderly People', *Ageing and Society*, 5, 267–288.

T. Cantrell et al (1983), *Prisoners of Handicap*, Rehabilitation Department, Southampton University.

J. Carter (1981), *Day Services for Adults: Somewhere to go*, National Institute Social Services Library No 40, George Allen and Unwin, London.

R. Carus (1980), 'Motor neurone disease: a demeaning illness', *British Medical Journal*, 16 February, 455–456.

B. J. Castree and J. H. Walker (1981), 'The Young Adult with Spina Bifida', *British Medical Journal*, 283:6298, 1040–1042.

D. Challis and E. Ferlie (1988), 'The Myth of Generic Practice: Specialisation in Social Work', *Social Policy* 17:1, 1–22.

A. Chamberlain and I. Blomfield (eds), *Younger Disabled Units: Report of the conference held in Leeds in October 1982*.

E. Clouston (1988), 'Heads you lose', *Guardian*, 20.4.88, 21.

G. M. Cochrane (1982), 'Hidden resources for rehabilitation and care of the disabled', *Journal of the Royal Society of Medicine*, 75, 89–95.

J. R. Cole (1985), 'Rehabilitation of the Severely Brain–Injured Patient: A Community–Based, Low–Cost Model Program', *Arch Phys Med Rehabil*, January 1985, pp 38–40.

M. Collins et al (1976), *Kith and Kids: Self–Help for Families of the Handicapped*, Souvenir Press, London.

K. Cooke and D. Lawton (1985), *SPRU Reprints 8*, Social Policy Research Unit, University of York.

Council of Europe (1986), *Rehabilitation of disabled people. Activity Report 1985–1986*, Council of Europe, Strasbourg.

Council of Europe (1984), *A coherent policy for the rehabilitation of disabled people*, Council for Europe, Strasbourg.

G. Creek, M. Moore, M. Oliver, V. Salisbury, J. Silver, G. Zarb (1987), *Personal and Social Implications of Spinal Cord Injury: A Retrospective Study*, Thames Polytechnic, Eltham.

M. Croxen and V. Finkelstein (1984), 'Vocational Rehabilitation: A USA/UK Cross–Cultural Perspective', *Rehabilitation Literature*, 45:11–12, 370–374.

L. Davidson (1987), 'Major changes ahead for ALACs', *The Health Services Journal*, 97:5042.

Department of the Environment/Welsh Office (1987), *Local Housing Statistics England and Wales*, HMSO, London.

DHSS (1973), *The Remedial Professions. Report by a Working Party set up in March 1973 by the Secretary of State for Social Services*, HMSO, London.

DHSS (1972), *Rehabilitation. Report of a Sub–Committee of the Standing Medical Advisory Committee*, HMSO, London.

DHSS (1981), *Care in Action: A Handbook of Policies and Priorities for the Health and Personal Social Services in England*, London, HMSO.

DHSS (1985), *Government response to the second report from the social services committee*, 1984–5 session: community care. Cmnd 9674. London, HMSO.

DHSS (1987), 'Health Services Management: Review of Artificial Limb and Appliance Centre (ALAC) Services', HN(87)9.

DHSS (1987b), *Domiciliary Services, Meals, Aids and Adaptations – Year ending 31 March 1986, England*, DHSS, London.

DHSS Social Services Inspectorate (1987), *From Home Help to Home Care: An analysis of policy, resourcing and service management, Summary Report*, London.

D. Dick (1982), 'The management of rehabilitation services after reorganisation', *British Journal of Occupational Therapy*, 45:4, 115–116.

Disability Alliance (1987), *Poverty and Disability: Breaking the link*, Disability Alliance, London.

P. Drummond (1986), 'Disability: a force to be reckoned', *The Health Service Journal*, 96:5017, 1226–1227.

J. Dyer (1982), 'Diversity in districts', *Remedial Therapist*, 4:14, 20.

Economist Intelligence Unit (1973), *Care with dignity. An analysis of costs of care for the disabled*, National Fund for Research into Crippling Diseases, Horsham.

M. Elian and G. Dean (1983), 'Need For and Use of Social and Health Services by Multiple Sclerosis Patients Living at Home in England', *The Lancet*, 14 May, 1091–1093.

J. Evans (1984), 'The Independent Living Philosophy', *Spinal Injuries Association Newsletter*, 31, 10–11.

Family Focus (1983), *Parental Involvement in the Assessment of Children with Special Needs*, Coventry.

S. M. Feiger and M. H. Schmitt (1979), 'Collegiality in Inter–disciplinary Health Teams', *Social Science and Medicine*, 13A, 217–229.

B. Fiedler (1988), 'A Fair Slice of the Cake', *Community Care*, 4.2.88, 30–31.

B. Fiedler (1988), *Living Options: Housing and care support services for people with severe physical disability*, Prince of Wales Advisory Group on Disability, London.

S. N. Finkelstein, J. Hutton and J. Persson (1987), 'Assessing Technology for Rehabilitation: Three cases and three countries', *International Journal of Technology Assessment in Health Care*, 3, 375–385.

V. Finkelstein (1983), *The Many Faces of Rehabilitation: audio cassette notes and student notes and study guide for Open University course on the handicapped person in the community*, Open University Press, Milton Keynes.

V. Finkelstein (1984), 'Are rehabilitation services needed?', in T. Lobstein and the Namibia Support Committee Health Collective (eds), *Namibia: reclaiming the people's health*, AON Publications, London.

V. Finkelstein (1984), *Schemes for Independent Living*. Paper presented to the Medical Disability Society, British Council of Organisations of Disabled People, London.

V. Finkelstein (1988), 'Changes in Thinking about Disability', paper presented to South Glamorgan Study Day 'New Approaches to Disability', unpublished.

B. Firth (1975), 'General Practitioners and Social Help for the Handicapped', *Journal of the Royal College of General Practitioners*, 25, 21–26.

A. M. Fox (1975), *They get this training but they don't really know how you feel: Transcripts of interviews with the parents of handicapped children*, Action Research for the Crippled Child, Horsham.

M. Foxall (1988), *Multiply Handicapped People*, Gloucester Health Authority, unpublished paper.

F. Frazer (1988), 'Let's get off our backs before we stick our necks out...', *Therapy Weekly*, 14.1.88, p.6.

F. Frazer (ed.) (1982), *Rehabilitation within the community*, Faber and Faber, London.

A. A. Gatherer (1981), 'Support in the home', in R. F. A. Shegog (ed.), *The impending crisis of old age – A challenge to ingenuity*, Nuffield Provincial Hospitals Trust in association with Oxford University Press, Oxford, pp 55–67.

E. Gilchrist and M. Wilkinson (1979), 'Some Factors Determining Prognosis in Young People With Severe Head Injuries', *Arch Neurol*, 36, 355–359.

C. Glendinning (1983), *Unshared Care: Parents and their disabled children*, Routledge & Kegan Paul, London.

C. Glendinning (1986), *A Single Door: Social Work with Families of Disabled Children*, Allen and Unwin, London.

D. Gloag (1984), 'Unmet need in chronic disability', *British Medical Journal*, 289, 211–212.

D. Gloag (1985), 'Needs and Opportunities in Rehabilitation. Introduction and a look at some short term orthopaedic rehabilitation', *British Medical Journal*, 290:6461, 43–46.

D. Gloag (1985b), 'Needs and Opportunities in Rehabilitation. 'Rehabilitation in rheumatic diseases', *British Medical Journal*, 290:6461, 132–136.

D. Gloag (1985c), 'Needs and Opportunities in Rehabilitation. Aids and the Environment *British Medical Journal*, 290:6461, 220–223

D. Gloag (1985d), 'Needs and Opportunities in Rehabilitation. Severe Disability: 1 – Tasks of rehabilitation', *British Medical Journal*, 290:6461, 301–303.

D. Gloag (1985e), 'Needs and Opportunities in Rehabilitation. Severe disability: 2 – Residential care and living in the community', *British Medical Journal*, 290:6461, 368–372.

D. Gloag (1985f), 'Needs and Opportunities in Rehabilitation. Rehabilitation of the elderly: 1 – Settings and services', *British Medical Journal*, 290:6461, 455–457.

D. Gloag (1985g), 'Needs and Opportunities in Rehabilitation. Rehabilitation of the elderly: 2 – Mind and body', *British Medical Journal*, 290:6461, 542–544.

D. Gloag (1985h), 'Needs and Opportunities in Rehabilitation. Rehabilitation of patients with cardiac conditions', *British Medical Journal*, 290:6461, 617–620.

D. Gloag (1985i), 'Needs and Opportunities in Rehabilitation. Rehabilitation after stroke: 1 – What is the potential?', *British Medical Journal*, 290:6461, 699–701.

D. Gloag (1985j), 'Needs and Opportunities in Rehabilitation. Rehabilitation after stroke – 2: Language and memory training and the requirements of rehabilitation services ', *British Medical Journal*, 290:6461, 768–771.

D. Gloag (1985k), 'Needs and Opportunities in Rehabilitation. Rehabilitation after head injury – 1: Cognitive problems', ', *British Medical Journal*, 290:6461, 834–837.

D. Gloag (1985l), 'Needs and Opportunities in Rehabilitation. Rehabilitation after head injury: 2 – Behaviour and emotional problems, long term needs, and the requirements for services', *British Medical Journal*, 290:6461, 913–916.

D. Gloag (1985m), 'Needs and Opportunities in Rehabilitation. Occupational rehabilitation and return to work: 1 – General Services', *British Medical Journal*, 290:6461, 1135–1138.

D. Gloag (1985n), 'Needs and Opportunities in Rehabilitation. The time is now: education and organisation of services', *British Medical Journal*, 290:6461, 1333–1336.

R. E. A. Goble and P. J. R. Nichols (1971), *Evaluation of a disabled living unit*, Butterworths, London.

E. Goffman (1961), *Asylums*, Harmondsworth, Penguin.

J. Goodall (1988), 'Living Options for Physically Disabled Adults – A Review', *Disability, Handicap and Society*, 3:2.

C. J. Goodwill and A. A. Chamberlain (1988), *Rehabilitation of the Physically Disabled Adult*, Croom Helm/Sheridan Medical Books, London.

P. Gordon (1979), *Living in Units for Young Disabled People*, King's Fund, London.

B. M. Graveling (1982), 'Management of Rehabilitation Services', *Physiotherapy*, 68:6, 194–195.

A. M. Gray, A. Whelan and C. Normand (1988), *Care in the Community: A study of services and costs in six districts*, Centre for Health Economics, University of York.

R. Griffiths (1988), *Community Care: Agenda for Action*, DHSS, London.

Lady Hamilton (1984), *Am I living in the right place? The distribution of health care*, The Harding Award, RADAR.

Hampshire Centre for Independent Living (1986), *Source Book Towards Independent Living: Care support ideas*, Hampshire.

A. I. Harris (1971), Handicapped and Impaired in Great Britain, HMSO, London.

J. Harris and J. Simon (1985), 'The Head Injuries Rehabilitation Centre', *Occupational Therapy*, April, 109–111.

J. Harrison (1988), *Severe Physical Disability: Responses to the challenge of care*, Cassell, London.

S. P. Harrisson (1977), *Families in Stress*, Royal College of Nursing, London.

I. R. Henderson (1972), *The Case for a Unified Service for Rehabilitation of Disabled People*, British Council for Rehabilitation of the Disabled, London.

E. Helander (1980), 'Towards a Multipurpose Rehabilitation Therapist', *Rehabilitation*, 1 pp 26–29.

E. Henke (1968), 'Motor Neurone Disease – a Patient's View', *British Medical Journal*, 21 December, 765–766.

A. Henshall (1980), *Rehabilitation in the West Midlands. The report of the Rehabilitation Working Group*, West Midlands Council for the Disabled.

S. Hewett (1976), 'Research on Families With Handicapped Children – An Aid or an Impediment to Understanding?', *Birth Defects: Original Article Series*, XII:4, 35–46.

M. Hirst (1983), 'Young people with disabilities: what happens after 16?', *Child, health and development*, 9, 273–284.

M. Hirst (1984), 'Education after 16 for young people with disabilities', *Youth and Policy*, 2, 37–40.

M. Hirst (1985), 'Dependency and family care of young adults with disabilities', *Child: care, health and development*, 11, 241–257.

M. Hirst (1985b), 'Social security and insecurity: Young people with disabilities in the United Kingdom', *International Social Security Review*, 3, 258–272.

M. Hirst (1987), 'Careers of Young People with Disabilities between Ages 15 and 21 Years', *Disability, Handicap and Society*, 2:1, 61–74.

R. Holland, J. Crawford, C. Peberdy (1986), *Towards a better service for people with a severe physical disability in the Basingstoke and North Hampshire health Authority; A survey of needs*, Basingstoke and North Hampshire HA.

A. Hopkins (1984), 'Practical Help', *The Lancet*, June 23, 1393–1396.

B. Hudson (1987), 'Granted on condition...', *The Health Service Journal*, 19 November, 1354–1355.

B. Hudson (1987), 'Return to the Poor Law?', *The Health Service Journal*, 29 October, 1256–1257.

B. Hudson (1987), 'Strategy in Suspense', *The Health Service Journal*, 10 December, 1438–1439.

D. J. Hunter (ed)(1988), *Bridging the Gap: Case management and advocacy for people with physical handicaps*, King's Fund, London.

D. J. Hunter and G. Wistow (1987), *Community Care in Britain: Variations on a Theme*, King's Fund, London.

D. J. Hunter and K. Judge (1988): *Griffiths and Community Care*, Briefing Paper 5, King's Fund Institute, London.

D. J. Hunter, N. P. McKeganey and I. A. MacPherson (1988), *Care of the Elderly: Policy and Practice*, Aberdeen University Press, Aberdeen.

R. Illsley (1981), 'Sociological aspects', in J. Kinnaird, Sir John Brotherston and J. Williamson (eds), *The Provision of Care for the Elderly*, Churchill Livingstone, Edinburgh, pp 211–216.

Impact Foundation (1986), *Preventing Disability in the United Kingdom: A summary of the conclusions of the National Seminar on the Prevention of Disablement*, The Impact Foundation, Brighton.

H. Inskip (1981), *Family Support Services for Physically and Mentally Handicapped People in their own Homes*, Bedford Square Press/NCVO, London.

D. A. Jackson (1987), 'Where is the Physiotherapy Profession Going?', *Physiotherapy*, 73:11, 590–591.

P. Jay (1984), *Coping with Disability*, Disabled Living Foundation, London.

Sir K. Joseph (1973), 'Strategy for the Development of Medical Rehabilitation Services', *Rheumatology and Rehabilitation*, XII:3, 105–115.

M. Joyce (1988), *Community Care for the Elderly: A Research Report*, Public Finance Foundation, Discussion Paper 15, London, NIESR.

C. L. Kaufmann (1986), 'Role Obligations and Health Status in Chronic Disease: the experience of men and women with arthritis', *Disability, Handicap and Society*, 1:3, 261–271.

U. Keeble (1979), *Aids and Adaptations*, Occasional Papers on Social Administration 62, Bedford Square Press, London.

A. Kent et al (1984), *Day Centres for Young Disabled People*, The Royal Association for Disability and Rehabilitation, London.

King's Fund (1980), *An Ordinary Life: Comprehensive, locally based residential services for mentally handicapped people*, Project paper 24, King's Fund, London.

King's Fund (1982), *Reviewing Disabled People in Residential Care – what do we mean? Report of two workshops held at the King's Fund Centre*, King's Fund Reports, London.

King's Fund Institute (1987), *Promoting Innovation in Community Care: From small scale developments to mainstream provision*, King's Fund Institute, London.

R. Kinsman (1987), 'When the team fails, the conductor may succeed', *Geriatric Medicine*, September, 62-66.

R. Knight and M. D. Warren (1978), *Physically Disabled People Living at Home: A Study of Numbers and Needs*, HMSO, London.

N. Korman and H. Glennerster, (1985), *Closing a Hospital: The Darenth Park Project*, Bedford Square Press, London.

D. Kuh et al (1986), 'Disabled Young People: making choices for future living options', *Social Services Research*, 15, 57–86.

N. G. Kutner (1987), 'Social ties, social support, and perceived health status among chronically disabled people', *Social Science and Medicine*, 25:1, 29–34.

R. Langton Hewer and M. Holbrook (1983), 'The Bristol Stroke Unit', *Health Trends*, 15, 15–18.

R. Langton Hewer (chair) (1988), *The Challenge of Disability in Avon: Report of a working group on services for the physically disabled – January 1988*, Frenchay Health District, Bristol.

D. Leat (1988): 'Residential Care for Younger Physically Disabled Adults', in I. Sinclair (ed) *Residential Care: The Research Reviewed – Literature Surveys commissioned by the Independent Review of Residential Care*, NISW/HMSO, London.

R. H. Lee (1975), 'Medical Rehabilitation: Policy–Making in the English Health Service', *Social Science and Medicine*, 9, 325–332.

W. Lewin et al 'Long–term outcome after severe head injury', *British Medical Journal*, 2, 1533–1538.

K. Lind (1982), 'A synthesis of studies on stroke rehabilitation', *Journal of Chronic Disability*, 35, 133–149.

Living Options/GLAD (1987), *Response to the Report of the Royal College of Physicians: Physical Disability in 1986 and Beyond*, Living Options/GLAD, London, Unpublished paper.

M. G. Livingston, D. N. Brooks, and M. R. Bond (1985), 'Patient outcome in the year following severe head injury and relatives' psychiatric and social functioning', *Journal of Neurology, Neurosurgery and Psychiatry*, 48, 876–881.

S. Lloyd–Bostock (1976), 'Parents' experiences of official help and guidance in caring for a mentally handicapped child', *Child: care, health and development*, 2, 325–338.

J. Loring (1978), 'Integrated Therapy, Education and Child Care' in J. Apley (ed.), *The Case of the Handicapped Child*, Heinemann Medical Books, London.

R. Lovelock (1981), *. . . Friends in deed*, Portsmouth Polytechnic and Hampshire Social Services, Portsmouth.

I. McColl (Chair) (1986), *Review of Artifical Limb and Appliance Centre Services*, Volumes 1 and 2, DHSS, London.

D. L. McLellan (1987), 'Physical Disability in 1986 and Beyond: a response to Simon Brisenden', *Disability, Handicap and Society*, 2:3, 285–288.

J. Martin and M. Bone (1985), *OPCS Surveys of Disabled people in Great Britain*, OPCS unpublished paper.

G. Martin, A. Pfingst, J. Golding (1987), *Constructing Services for People with Severe Physical Disabilities in Bloomsbury District Health Authority: A study of needs and services*, Bloomsbury DHA, London.

S. Mattingly (ed.) (1981), *Rehabilitation Today in Great Britain*, Update Books, London.

E. Miller (19..), *Recovery and Management of Neuropsychological Impairments*, John Wiley & Sons, Chichester.

P. Mitchell (1986), 'A change of ministerial heart', *Contact*, 49, 23.

A. Mitchison (1987), 'An arm and a leg', *New Society*, 6 March, 26.

G. P. Mulley (1982), 'Avoidable Complications of Stroke', *Journal of the Royal College of Physicians of London*, 16:2, 94–97.

Multiple Sclerosis Society (1986), *Residential Care Review*, Submission to the DHSS Residential Care Review.

E. Murphy (1987), 'Community Care I: problems', *British Medical Journal*, 295, 1505–1508.

E. Murphy (1988), 'Community Care II: possible solutions', *British Medical Journal*, 296, 6–8.

National Audit Office (1987), *Report by the Comptroller and Auditor General: Community Care Developments*, HMSO, London.

D. Nelson (1987), 'A disabling policy', *New Society*, 10 April, 15.

P. Newrick and R. Langton Hewer (1984), 'Motor neurone disease: can we do better? A study of 42 patients', *British Medical Journal*, 289, 539–542.

P. J. R. Nichols (1976), *Rehabilitation Medicine*, Butterworths, London.

P.J.R. Nichols (1975), 'Some Psychosocial Aspects of Rehabilitation and their Implications in Research', *Proceedings of the Royal Society of Medicine*, 68, 537–545.

J. Oliver (1985), 'Eight days a week', *Nursing Times*, January 16.

J. Oliver (1985b), 'Who cares for the carers?', *Self Health*, No 8, September.

M. Oliver (1983), *Social Work with Disabled People*, Macmillan, London.

M. Oliver (1986), 'Social Policy and Disability: some theoretical issues', *Disability, Handicap and Society*, 1;1, 5–17.

M. Oliver (1987), 'Re–Defining disability: A Challenge to Research', *Research, Policy and Planning*, 5:1, 9–13.

M. Oliver (1987b), 'Some reflections on disabling services: Transition to Adulthood', unpublished paper presented to Further Education Unit Conference, Thames Polytechnic, Eltham.

M. Oliver (1988), 'Social Policy and Disability: The Creation of Dependency', unpublished paper.

M. Oliver and F. Hasler (1987), 'Disability and Self–help: a case study of the Spinal Injuries Association', *Disability, Handicap and Society*, 2:2, 113–125.

M. Oliver (1988), 'Flexible Services', *Nursing Times*, 84:14, 25–29.

M. Oliver (1988b), 'Social Policy and Disability: The creation of dependency', unpublished paper prepared for the OECD.

M. C. O'Mahony et al (1987), 'The Register of Children with Special Needs – An Approach', *Public Health*, 101, 9–15.

M. Oswin (1978), *Holes in the Welfare Net*, Bedford Sqare Press, London.

M. Oswin (1977), 'Physically handicapped children in long-stay hospitals', *Child: care, health and development*, 3, 349–355.

D. Ounsted (1987), *Wheelchairs: No handicap in housing*, National Federation of Housing Associations, London.

P. Owens (1987), *Community care and severe physical disability*, Bedford Square Press, London.

C. Parker and M. Hirst (1987), 'Continuity and change in medical care for young adults with disabilities', *Journal of the Royal College of physicians of London*, 21:2, 129–133.

G. M. Parker (1984), 'The case for an integrated incontinence service for disabled children', *Community Medicine*, 4, 119–124.

'The Provision of Aids and Equipment', *Health Visitor*, 57, 44–45.

C. J. Partridge (1984), 'Recovery from Conditions Involving Physical Disability', *Physiotherapy*, 70:6, 233–235.

C. J. Partridge and M. D. Warren (1977), *Physiotherapy in the Community*, Health Services Research Unit, University of Kent, Canterbury.

D. L. Patrick et al (1981), 'Screening for disability in the inner city', *Journal of Epidemiology and Community Health*, 35, 65–70.

D. L. Patrick, H. Peach, I. Gregg (1982), 'Disablement and care: a comparison of patient views and general practioner knowledge', *Journal of the Royal College of General Practioners*, 32 429–434.

Piercy Report (1956), *Report of the Committee of Enquiry on the Rehabilitation Training and Resettlement of Disabled Persons*, Cmnd 9883. HMSO, London.

C. Porter (1984), *Social work specialisation and people with physical disabilities*, University of Edinburgh, Edinburgh.

B. Price (1986), 'Giving the patient control', *Nursing Times*, 82:20, 28–30.

G. Pugh and P. Russell (1977), Shared Care, *National Children's Bureau*, London.

RADAR (1986), 'Disabled Persons (Services, Consultation and Representation) Act 1986. Brief Explanation of Sections', *RADAR Bulletin*, 152, 1–5.

J. Read (1987), 'The Structural Position of Mentally Handicapped Children, Adults and their Carers: Some implications for practice' in Central Council for Education and Training in Social Work, *Policy, Politics and Practice: Training for work with mentally handicapped people*, CCETSW, London.

J. Renshaw et al (1988), *Care in the Community: the first steps*, PSSRU, University of Kent, Canterbury.

T. Robinson (1978), *In Worlds Apart*, Bedford Square Press, London.

Royal College of Physicians (1986), *Physical Disability in 1986 and Beyond*, Royal College of Physicians of London.

Royal College of Physicians (1986), *The Young Disabled Adult: The Use of Residential Homes and Hospital Units for the Age Group 16–64*, Royal College of Physicians of London.

B. M. Samuels (1987), 'Physiotherapy in the Eighties: The challenge of change', *Physiotherapy*, 73:11, 584–586.

C. Saunders et al (eds) (1981), *Hospice: the living idea*, Edward Arnold, London.

C.J. Scott (1984), 'Hospitals for the Disabled?' *International Rehabilitation Medicine*, 6, 166–169.

Scottish Home and Health Department (1983), *Prostheses, Orthoses and Aids for the Disabled*, HMSO, Edinburgh.

Scottish Hospital Advisory Service (1976), *Rehabilitation at Geriatric Hospitals and Assessments Units*, SHAS.

Sharp Report (1974), *Mobility of Physically Disabled People*, HMSO, London.

A. Shearer (1974), 'Housing to fit the Handicapped', in D. M. Boswell and J. M. Wingrove (eds), *The Handicapped Person in the Community*, London, Tavistock.

A. Shearer (1981), *Disability: Whose Handicap?*, Basil Blackwell, Oxford.

A. Shearer (1982), *Living Independently*, Centre on Environment for the Handicapped/King's Fund, London.

Sheffield Regional Hospital Board (1962), *Final Report of Ad Hoc Committee on Rehabilitation*, Sheffield.

F. W. Skinner (ed.) (1969), *Physical disability and community care*, Bedford Square Press, London.

C. W. E. Smith (1977), 'Care of the Young Chronic Sick and Disabled', *Update*, 14:5, 503–512.

D. S. Smith et al (1981), 'Remedial therapy after stroke: a randomised controlled trial', *British Medical Journal*, 282, 517–520.

Snowden Report (1976), *Integrating the Disabled*, National Fund for Research into Crippling Diseases, London.

Social Services Committee, 1984/85 session (1985). *Second Report. Community Care with Special Reference to Adult Mentally Ill and Mentally Handicapped People*, London, HMSO.

Southmead Health Authority (1987), 1986/87 Handbook.

Spinal Injuries Association, (1987), *Comments on the Royal College of Physicians' Reports on Disability*, SIA, London.

M. Stacey (1980), 'Charisma, power and altruism: a discussion of research in a child development centre', *Sociology of Health and Illness*, 2:1, 64–90.

I. Starks (1987), 'Where is the Physiotherapy Profession Going?', *Physiotherapy*, 73:11, 592–594.

R. S. Stevens and M. D. Warren (1986), 'Sharing Knowledge and Experience of Disability', *Journal of the Royal College of Physicians of London*, 20:2, 133–135.

P. C. Swain (1988), *A Scandanavian Study Tour of Services for Physically Handicapped People: Denmark, Sweden and Finland*, Exeter Council for Independent Living, Exeter.

The Prince of Wales Advisory Group on Disability (1985), *Living Options*, King's Fund, London.

D. Taylor (1977), *Physical Impairment: social handicap*, Office of Health Economics, London.

A. Thomas, M. Bax, K. Coombs, E. Goldson, D. Smyth, K. Whitmore (1985), 'The Health and Social Needs of Physically Handicapped Young Adults: Are they being met by the statutory services?', *Developmental Medicine and Child Neurology*, 27:4, Supplement 50.

A. Thomas, M. Bax and K. Whitmore (1987), *The provision of support services for the handicapped young adult*, Department of Child Health, Charing Cross and Westminster Medical School, London.

R. Thorpe–Tracey (ed.) (1976), *Integrating the Disabled. Report of the Snowdon Working Party*, National Fund for Research into Crippling Diseases, Horsham.

E. Topliss (1979), *Provision for the Disabled*, Basil Blackwell and Martin Robinson, Oxford (2nd edition).

E. Topliss and B. Gould (1981), *A Charter for the Disabled*, Basil Blackwell and Martin Robinson, Oxford.

D. Towell (ed.) (1984), 'Managing psychiatric services in transition', *Health and Social Service Journal*, October 25, centre 8.

J. Tripp et al (1987), *Disability in Society*, Exeter Health Authority.

Tunbridge Report (1972), *Rehabilitation: Report of a Sub–committee of the Standing Medical Advisory Committee*, HMSO, London.

D. T. Wade and R. Langton Hewer (1987), 'Epidemiology of some neurological diseases', *International Rehabilitation Medicine*, 8, 129–137.

G. Wagner (1988), *A positive choice: Report of the Independent Review of Residential Care*, NISW/HMSO, London.

D. Walker (1987), 'A synoptic history of health and related services 1970–1985', *Community Medicine*, 9:3, 265–273.

L.M. Wallace and A. G. Learmouth (1986), *A Survey of Adults with Chronic Physical Disabilities: Perceived Needs, Problems and Use of Services*, South Birmingham Health Authority.

J. Walton (1987), 'Spending more on turning patients into people', *British Medical Journal*, 295, 1012–1013.

A. W. M. Ward (1979), 'Physiotherapists – career patterns and attitudes', *Health Trends*, 11, 14–17.

H. M. Warnock (Chair) (1978), *Report of the Committee of Enquiry into the Education of Handicapped Children and Young People*, Cmnd 7212, HMSO, London.

M. D. Warren (1972), 'Rehabilitation', The Lancet, July 15, 135–136.

M. D. Warren (1979), *Changing capabilities and needs of people with handicaps: A two year follow–up study*, HSRU, University of Kent, Canterbury.

M. D. Warren (1985), 'The Canterbury Studies of Disablement in the Community: Prevalence, needs and attitudes', *International Journal of Rehabilitation Research*, 8:1, 3–18.

M. D. Warren (1987), 'The Prevalence of Disability: Measuring and Estimating the Number and the Needs of Disabled People in the Community', *Public Health*, 101, 333–341.

M. D. Warren (1988), 'Estimated prevalence rates and numbers of people with physical disabilities' and 'Prevalence rates and numbers of people with very severe, severe and appreciable disabilities'. Personal communication.

Weekly Hansard, 'Disabled people', 23–27 June 1986, 1388, 88.

P. West et al (1984), 'Public Preferences for the Care of Dependency Groups', *Social Science and Medicine*, 18:4, 287–295.

P. Wilding (1982), *Professional power and social welfare*, Routledge & Kegan Paul, London.

B. T. Williams and A. Lambourne (1973), 'The younger chronic sick: how many beds?', *British Journal of Preventive and Social Medicine*, 27, 129–136.

J. Williams (1985), 'Last Ditch Rehabilitation', *Public Health*, 99, 215–218.

J. Williams (1987), 'Parkinson's Disease from a Patient's Point of View', *Public Health*, 101, 343–350.

P. H. N. Wood (1978), 'Symposium: The young chronic sick', *Journal of the Royal Society of Medicine*, 71, 437–441.

P. H. N. Wood and P. J. Lennox Holt (1980), 'The development of strategic guidelines for regional planning of rehabililitation services', *International Rehabilitation Medicine*, 2, 143–152.

R. Wood (1988), 'Disabled People Point the Way Forward', *Social Work Today*, 21.1.88, 16-17.

Working Party on Psychological Services for Adults with Physical Disabilities (1987), *Draft Structure of Report*, The British Psychological Society, London.

World Health Organisation (1981), *Disability prevention and rehabilitation*, World Health Organisation, Geneva.

C. B. Wynn Parry (1986), 'Rehabilitation: Long–Term Issues', Appendix II to *Review of Artificial Limb and Appliance Centre Services*, volume I, *The Report of an Independent Working Party under the Chairmanship of Professor Ian McColl*, HMSO, London.

E. Younghusband et al (eds) (1970), *Living with handicap*, The National Bureau for Co–operation in Child Care, London.

United Nations (1977), *Rehabilitation for the Disabled*, Department of Economic and Social Affairs, United Nations, New York.

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