PHYSICAL IMPAIRMENT: SOCIAL HANDICAP

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As employed in this paper the term impairment refers to physical defects and the loss of normal bodily mechanical functions. Disablement is a consequence of impairment. It involves reductions in functional abilities such as gripping a pen or climbing stairs and or decreased performance in more complex activities like washing or self feeding. Handicap is used as a social term describing the effects of impairments or disabilities on a person's interaction with others and his or her ability to keep a satisfactory place in the community. Usually handicap stems directly from disability although in some instances this may not be the case. For example, an unsightly impairment could in practice be handicapping without causing disability.

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Introduction

Britain's one and a half million physically handicapped people do not form a homogeneous group. It is wrong to regard them as a discrete section of the population with identical difficulties and interests; for just as the basic abilities, learnt skills and other personal characteristics of 'normal' people vary very widely so too do those of persons who happen to have a disabling condition. In addition, someone who suffers the painful limitations imposed by, for example, rheumatoid arthritis may need help very different from that required by individuals with epilepsy, multiple sclerosis, chronic bronchitis, a spinal injury, blindness[1] or a combination of such afflictions. And factors such as the age at which an individual is affected, the duration of his or her condition, whether or not it remains stable, improves or becomes progressively worse and whether or not family and or other community support is available are all critical determinants of the personal experience of a given impairment in day to day life.

Yet consciousness of wide variations in the causes and consequences of physical defects or limitations should not obscure the fact that most of the people who suffer them share some common disadvantages. Awareness of this point has grown significantly during the last decade, partly as a result of the increasing realisation that handicap may be seen as a social state which may arise from but is different in nature from the specific impairments or disabilities that a person may suffer. Restricted mobility, loss of income (often coupled with increased basic living costs) and the over protective or other prejudices of able-bodied members of the population are all examples of phenomena which frequently tend to deny disabled people a personally satisfactory place in the community around them.

Traditional disease orientated approaches to understanding disability have often failed to reveal these universal aspects of physical handicap, a shortcoming which this paper attempts to remedy by offering an integrated picture of both its medical and its social characteristics. It describes the measurement, causes and where it is possible the prevention of impairment and handicap and also analyses the structure and organisational problems of the services available for the assistance and rehabilitation of disabled people, the total cost of which was around £3,000 million in 1976–77.[2]

One of the main objectives of this study is to highlight the changes in the pattern of physical impairment in Britain during the twentieth century and to indicate how increases in disability related to chronic, degenerative illnesses of middle and later life have created new demands on the NHS and allied agencies, particularly at the primary care level. The resulting tensions may be eased through a full understanding of the separate, although complementary, contributions of medicine and social support to the wellbeing of disabled people and a positive definition of the role of family doctors and other professionals in providing relevant services.

Measuring disability

The start of the present decade brought with it two related developments of particular importance in the field of physical handicap. The first was the passing of the 1970 Chronically Sick and Disabled Persons Act which has been seen by many commentators as a major turning point in the provision of services for disabled people. The second was the publication of a report entitled 'Handicapped and Impaired in Britain' (Harris *et al* 1971) which contained the results of a major national survey carried out by the Social Survey Division of the Office of Population Censuses and Surveys in the late 1960s.

This study, although it owed much to earlier work such as that conducted by Townsend (1967) and, more directly, that of Jefferys and her colleagues at Bedford College (Jefferys *et al* 1969), may be regarded as the first and still by far the most important comprehensive source of statistics on disability in adults in this country. Figure 1 illustrates some of the OPCS findings which indicate that in the British population aged over 16 living outside institutions there are around three million people with physical impairments. Of these it is probable that over a million are handicapped, that is significantly disadvantaged in their lives because of the reductions in their physical abilities resulting from their impairments.

Some two thirds of those affected are females, a bias related to the age structure of the overall population and the age specific impairment rates shown in Figure 2. When linked to the data yielded by studies of disability in childhood like the National Child Development Study of the National Children's Bureau (Davie *et al* 1972) and the survey carried out in the Isle of Wight in the 1960s by Rutter, Tizard and Whitmore (1970) and the estimated populations of residential care institutions for the elderly and physically disabled provided by Topliss (1975) the OPCS figures suggest that there are in total around one and a half million handicapped people in Britain, as described in Figure 3.

Handicapped in what context?

The work of Harris and her colleagues, which also contains a wealth of information on the living conditions and economic circumstances of physically handicapped adults, has many valuable aspects. Where similar studies have been undertaken, as in the case of the better local authority surveys conducted in response to Section 1 of the Chronically Sick and Disabled Persons Act which obliged local government bodies to identify disabled people within their boundaries, little has been added to the overall picture provided by the OPCS (Brown and Bowl 1976).[3]

However, it is necessary to realise the limitations of the government investigation. These stem both from the exclusion of children and, more importantly, people in institutions from its sample and also from the fact that the types of activity restriction it surveyed were largely

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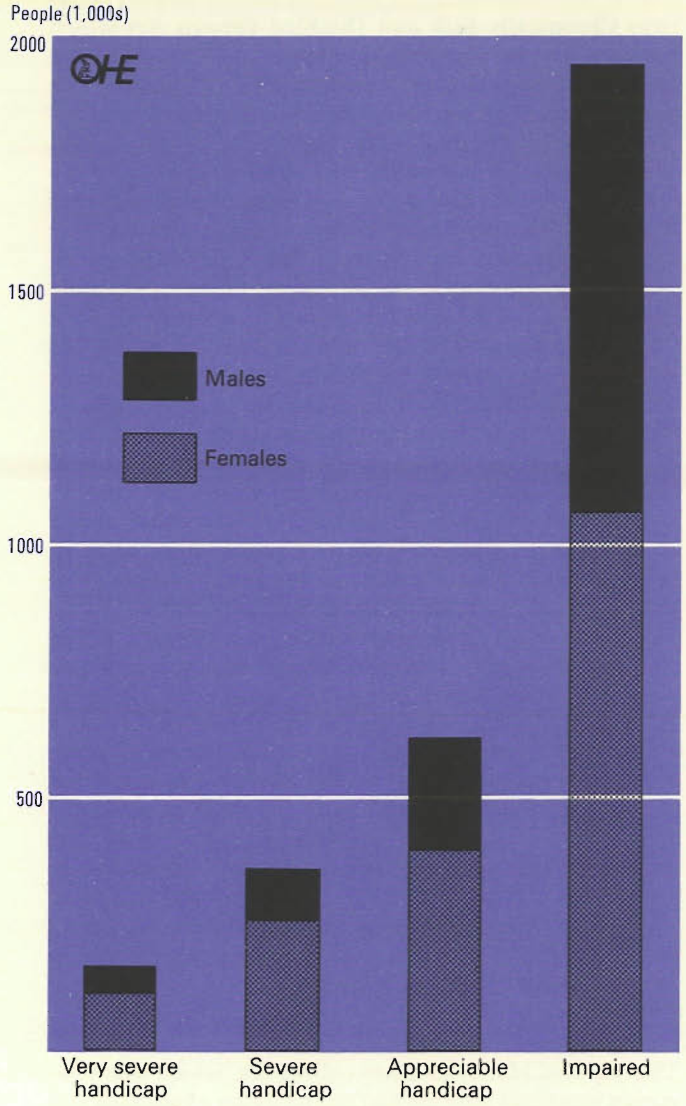
[1] In this paper physical disabilities are defined as all forms of disability, including sensory defects, resulting from bodily impairment other than conditions usually termed mental illness or handicap. However, most of what is said applies to the unfortunate minority who suffer both physical and mental disabilities.

[2] This total excludes the cost of retirement pensions paid to disabled people.

[3] Some local authority surveys have been of value in terms of being an educative exercise in themselves and a means of identifying disabled individuals. Work such as that at Canterbury has also produced useful insights through, for instance, demonstrating the surprisingly rapid rate of 'turnover' in the handicapped population. The latter is related to movements of individuals, the temporary nature of some complaints and the relatively high death rate in the older sections of the population.

Figure 1 *Handicapped and impaired adults in the community*

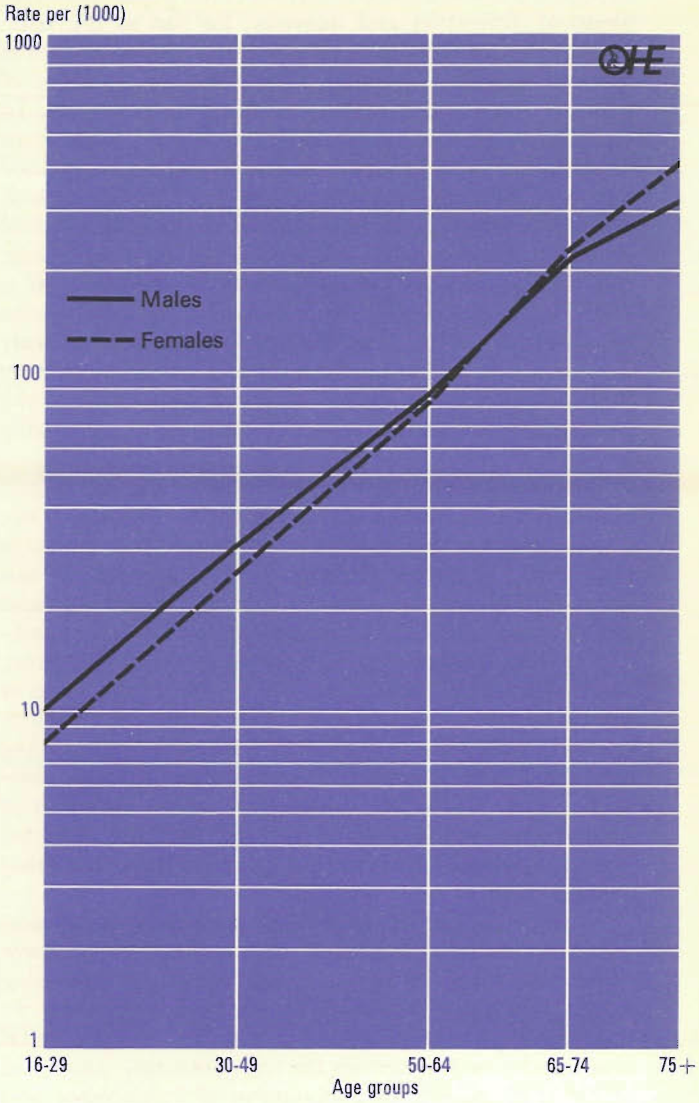


Notes The Harris criteria of 'handicap' were:

Very severe:	In need of permanent special care. For example, bedfast or chairbound, unable to feed or use the lavatory independently.
Severe:	Finds most activities in daily living difficult, some impossible.
Appreciable:	Can do a fair amount independently but some tasks difficult and help needed in a few areas.
Impairment:	Either no difficulty in self-care or only minor problems.

Source Harris 1971

Figure 2 *Age specific impairment rates per 1000 people in the community*



Notes In the population aged 16–50 approximately 49 per cent of the total are females.

In the population aged over 75, 69 per cent are females.

Source Harris 1971

LOG SCALE

related to impaired peoples' capacities to care for themselves in their domestic environments. As the OPCS researchers pointed out their results tended to understate the prevalence of certain types of physical limitation which do not interfere with self-care, such as deafness, and may not indicate the extent of handicap in other fields.

The significance of the Harris survey's focus on domestic self-care is demonstrated in Table 1, which places the figures it gave on people of working age against those provided by enquiries in other countries which employed various different definitions of 'handicap'. As may be seen the British estimates appear low when compared with the Australian rates which are based on the recorded prevalence of 'chronic limiting conditions' (Ehrlich *et al* 1969) and Danish data which rested on the identification of diseases or impairments which would result in an 'unskilled, unmarried worker, without support from his surroundings and with mental reserves and energy a little below average, having difficulty in coping with daily life on an equal footing to others' (Anderson 1964). Both the American (Haber 1968) and Israeli (Nizan and Avidor 1968) surveys centred on the employment status of disabled people, with the latter's 'vocationally handicapped' and the former's 'severely disabled' equating to inability to hold full-time employment.

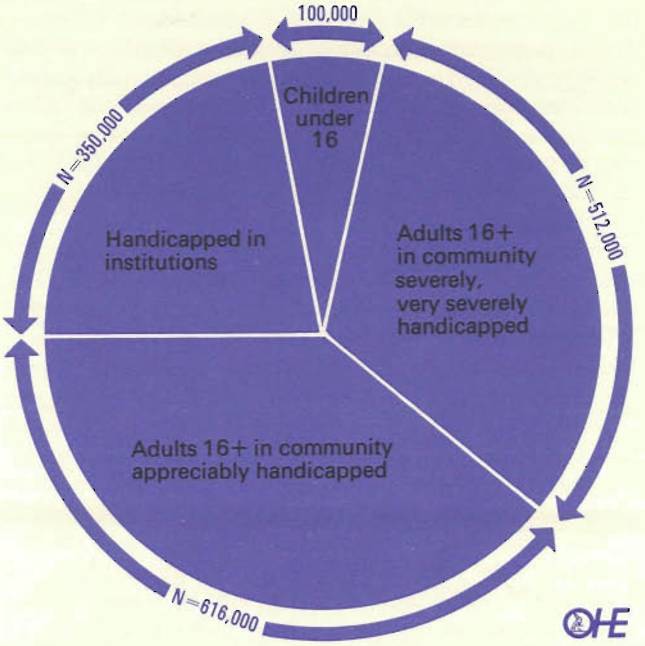
One of the more interesting points to draw from this body of information, particularly that contributed by the United States' Social Security Administration, is that there is a strong positive link between the degree of occupational handicap experienced by people of a given level of disability and factors like low social status and poor educational background (Haber 1973). The OPCS results mirror this to an extent in that they reveal the low incomes of and high unemployment rate amongst disabled people but they give no clear picture of the interaction between disadvantages.

Terminology

Awareness of the limitations of existing knowledge (and concern about what is already known) has in recent years led to efforts to make more precise the terminology used in the study of physical limitation. Also attempts have been made both to refine the techniques used to assess the capacities of disabled individuals and to create comprehensive classifications of impairments and handicaps. However, there are still substantial differences between many of the schemes used and advocated by the various academic researchers, fieldworkers and administrative bodies active in the area. The current debate in this context is of interest in that it may influence possible future developments such as the introduction of a more unified system of disablement incomes.

Figure 4 links the ideas of disease, impairment, disability and handicap into a continuum which extends from an individual physical event on the one hand through to a socially defined result on the other. It indicates that introduction into the state of handicap is a behavioural consequence of disability as it affects a subject's capacity to play a personally acceptable social role although other factors, such as the degree to which an individual is perceived as impaired or handicapped by others, may influence such processes.

Figure 3 *Number of physically handicapped people in Britain*



Source OHE estimates based on various sources

Table 1 *Prevalence of disability, handicap, limitation, or impairment in five countries*

Study population	*Percentage of specified population*
USA, 1966 (age 18–64)	
Disabled	17·2
Severe	5·9
Occupational	4·9
Secondary	6·4
Australia, 1968 (age 15–64)	
Chronic limiting condition	8·4
Denmark, 1961–62 (age 15–61)	
Physically handicapped	6·5
Great Britain, 1968–69 (age 16–64)	
Impaired	3·9
Handicapped	1·2
Israel, 1965–66 (men age 14–64, women age 14–59)	
Vocationally handicapped	2·9

Source Haber 1973

Today this basic approach is widely accepted although some commentators fear that a naïve application of it may have undesirable effects. It is possible, for example, that it could impose an inappropriate emphasis on trying to make disabled people's life-styles comply with stereotyped images of what is thought 'normal' for non-disabled people. Conversely, it might encourage some people to adopt the Utopian viewpoint that given the appropriate social setting all handicap is avoidable, whatever a person's limitations.

In addition some concern has been expressed as to the value of the concept of disability. Warren (1974) has linked the terms impairment and handicap directly, leaving 'disability' free for use as a broad general term. This was in effect the approach adopted by Harris (1971) and subsequently by Agerholm (1975), although the latter has also argued that there should be a division between extrinsic and intrinsic handicap, that is handicap caused primarily by adverse environmental factors as opposed to individual limitations.

The underlying reason for such variations is that some authorities see 'handicap' as including any form of activity restriction from being unable to wash or dress independently to being unable to find employment or form adequate social contacts whilst others regard the latter only as handicap and describe the former as disability. Clearly the importance of such a semantic dispute is limited. But if it is accepted that the major practical benefit to be gained from a clear description of the process of disease or injury leading through to social disadvantage is that it may help to reveal to what extent and in what way impaired individuals' problems may be solved or reduced by complementary medical and social assistance then the format used in Figure 4 is on balance the most appropriate one.

Assessment, assignment and classification

Schemes for assessing disabled people's capacities against what is in effect a simple list of functions such as the ability to grip a pen and composite acts like independent feeding have been available for several decades. For instance, a comprehensive assessment procedure for 'grading' servicemen (known as PULHEEMS) was developed for armed forces use during the Second World War and subsequently adopted for civilian application by Warren (1956). However, since the start of the 1960s a number of more sophisticated attempts have been made to construct schemes for measuring and categorising individuals' impairments, disabilities and handicaps. These have been made along a number of different lines.

Table 2 *Index of self-care handicap (After Harris)*

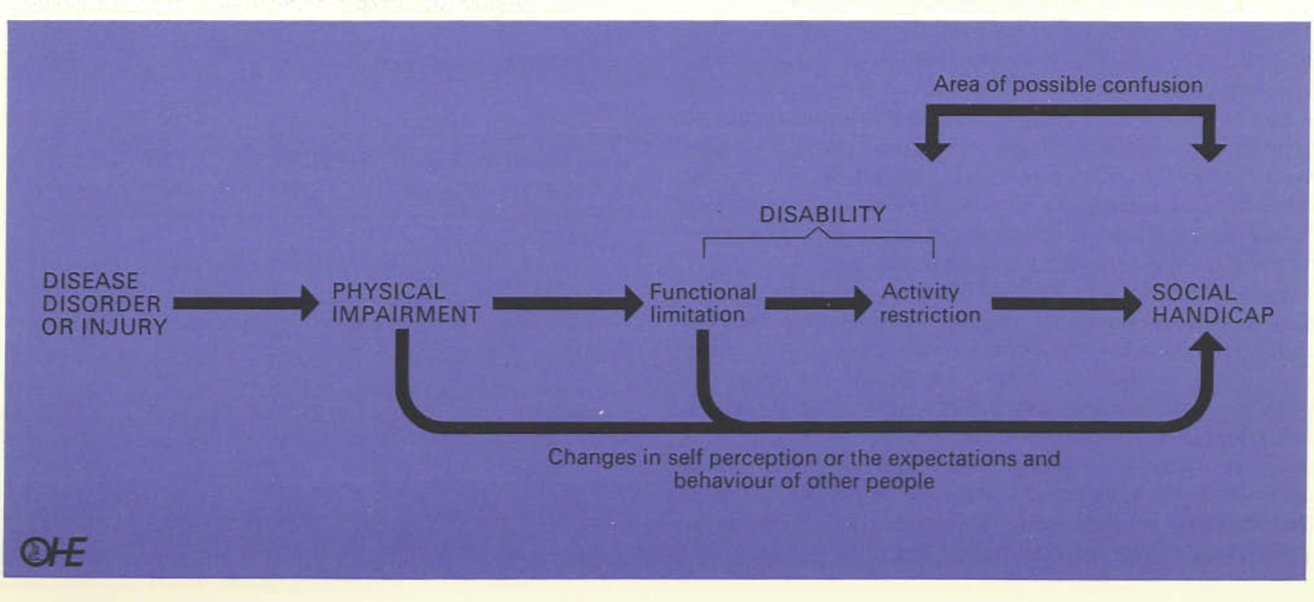
Very severe in need of special care	1. Toilet help every night and feeding and dressing, or washing and toilet.
	2. Regular nightly toilet help and help feeding/washing/dressing, or much daytime feeding/washing/toilet help.
	3. Bed or chair-fast, or mentally unable to care for themselves – but less help 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 Harris 1971

Figure 4 *The terminology of physical limitation*



For example, the OPCS survey (Harris *et al* 1971) hinged on the use of the index of functional loss and activity restriction outlined in Table 2. Work like that of Jefferys (1969) and Sainsbury (1973) employed a similar approach, all three projects involving the development of carefully defined schedules for assigning individuals to particular performance related subgroups. Recent research (Williams 1976, Bebbington 1977) has aimed at simplifying this process of categorisation by arranging the items in the indices of disablement on a single hierarchical scale of severity. It has been argued by Townsend (1973a and 1973b) that such tests of functional loss could be of special value in improving the administrative identification of disabled people entitled to graded income support in that they represent a significant advance over the methods currently employed in, say, the industrial injuries scheme. This view is discussed further in Appendix 1 of this paper.[4]

A second important contribution is the work of Agerholm (1975), described in Table 3. This involves the measurement of an individual's physical limitations via a battery of indicators of mixed nature, some referring to impairments, some to functional loss and some to social limitations. The cumulative score which results may be used as an indicator of handicap, Agerholm's 'classification' thus being in the strict sense simply a procedure for categorising impaired people's difficulties and disadvantages on a relatively arbitrary basis. Its main advantages lie in its comprehensiveness and simplicity. The scheme is potentially usable by a wide range of personnel including field workers like health visitors or occupational therapists and Agerholm (1976) has pointed out that the basic structure may be extended to give either more detailed information about the causes of disabilities or the positive 'strengths' of the individuals who suffer them.

A final approach to have been developed in the past few years is that of Wood (1975) and his colleagues, which was prepared with a view for possible inclusion in the next (1979) revision of the WHO International Classification of Diseases. As Table 4 shows this comprises two indices, one a linked code of impairment and disability and the other a detailed breakdown of handicap. It is in many ways the most logically consistent system available and is particularly important in that it is designed to give detailed clinical information about the causes of an individual's disabilities[5] coupled with a description of associated handicap analysed strictly by its main social components. Hence it combines being a true classification of impairment and handicap from both a medical and a sociological viewpoint. But there are arguably unsatisfactory aspects of Wood's proposals, particularly in respect of the disability code. Furthermore his scheme would probably be difficult for anyone who has not received special instruction to use, although the handicap scale by itself could be more widely employed.

Thus the main conclusion to draw from this brief review of the alternative classifications of physical disability currently being advanced is that none appear ideal in all circumstances. The concept of a universal scheme for use throughout the health and social services is in some ways attractive even if it would be likely to suffer some of the disadvantages traditionally associated with

Table 3 *Classification of intrinsic handicaps (After Agerholm)*

Handicaps	*Handicap components*
1. Locomotor	a) Impaired mobility in environment.
	b) Impaired postural mobility.
	c) Impaired manual dexterity.
	d) Reduced exercise tolerance.
2. Visual	a) Total loss of sight.
	b) Impaired visual acuity (uncorrectable).
	c) Impaired visual field.
	d) Perceptual defect.
3. Communication	a) Impaired hearing.
	b) Impaired talking.
	c) Impaired reading.
	d) Impaired writing.
4. Visceral	a) Disorders of ingestion.
	b) Disorders of excretion.
	c) Artificial openings.
	d) Dependence on life-saving machines.
5. Intellectual	a) Mental retardation (congenital).
	b) Mental retardation (acquired).
	c) Loss of learned skills.
	d) Impaired learning ability
	e) Impaired memory.
	f) Impaired orientation in space or time.
	g) Impaired consciousness.
6. Emotional	a) Psychoses.
	b) Neuroses.
	c) Behaviour disorders.
	d) Drug disorders (includes alcoholism).
	e) Antisocial disorders.
	f) Emotional immaturity.
7. Invisible (Vulnerability)	a) Metabolic disorders on permanent therapy (eg diabetes, cystic fibrosis).
	b) Epilepsy and other unpredictable losses of consciousness.
	c) Special susceptibility to trauma (eg to pressure sores, to haemorrhage).
	d) Intermittent prostration (eg vertigo, migraine, asthma).
	e) Severe pain disorders.
8. Aversive	a) Unsightly distortion or defect of body.
	b) Unsightly skin disorders or scarring.
	c) Abnormal movements of body (athetosis, etc).
	d) Abnormal smell or noise.
9. Senescence (Ageing)	a) Reduced 'plasticity' of ageing process.
	b) Slowing of physical or mental function of ageing process
	c) Reduced recuperative powers of ageing process.

Source Agerholm 1975

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[4] The industrial injuries scheme is based on assignments of impairments like the loss of an eye or foot to a particular category of disability.

[5] Wood (1977a, 1977b) has pointed to the disadvantages of recording data on handicap which does not include information on the underlying cause of disability. The DHSS General Classes Register of Handicapped Persons recently switched to recording the severity of handicap of registered people (defined by Harris criteria) rather than the disease(s) or impairments suffered. Hence it is no longer possible to derive from these figures estimates of the impact of particular conditions.

Table 4 *Classification of impairments and handicaps (After Wood)*

Headings for main impairments and disability groupings
Mental and behavioural.
Special senses.
Internal organs and special functions.
Head and trunk.
Limbs – mechanical.
Limbs – paralysis.
Limbs – other motor.
Limbs – sensory disturbance, disfigurement, others.
Limbs – transverse deficiencies.
Limbs – longitudinal deficiencies.

Handicaps	*Example items*
I – Independence (physical)	Difficult or impossible to wash hands and face, use lavatory, bath.
M – Mobility	Confined to house (bedfast, chairfast), able to get out only if accompanied, or with or without significant difficulty.
O – Occupation	Ceased employment because of disability (premature retirement, housewife) or otherwise not employed (temporarily sick, other retired). At work in occupational centre, normal job.
S – Social integration	Living alone, have television or telephone, go to clubs, have had holiday in previous four years.
E – Economic self-sufficiency	Costs of disabilities, levels of income from all sources.

Source Wood 1975

IQ testing. But in practice information needs and gathering capacities vary widely at different points in the system. Perhaps the most positive approach is therefore to stress that the primary requirement at the present time is to clarify the objectives and potential outcomes of interventions in spheres like medical and linked social rehabilitation and then to adopt 'custom built' assessment and classification methods designed to maximise their efficiency. This involves welcoming a certain degree of plurality although it may be noted that all the schemes described above share the underlying principle that the mechanical causes of disability differ in nature radically from its social consequences (DHSS 1976b). It is probably more important to stress this basic philosophical unity than to dispute the practical details of its application.

Causes of disability: a changing pattern

In individual terms many of the economically most costly and personally most challenging cases of physical disability occur amongst children and young people. It is both reasonable and understandable that much concern is concentrated on the problems of people like those affected by the thalidomide tragedy who will have to face many difficulties throughout their lifetimes, whatever the support provided by other members of society. However, it is also important to realise that in numerical terms those who become disabled before middle life form only a very small proportion of the total number of handicapped people. Most physical limitation occurs amongst people aged 50 years or more and stems from causes quite different from those most commonly associated with disability in the school age population.

In the first few years of life the available national and international data indicates that approaching two-thirds of serious physical handicap is caused by spina bifida and hydrocephalus, cerebral palsy (which includes spasticity) and muscular dystrophy (Bradshaw 1976, RCB 1970, Swedish Institute for the Handicapped 1975). And the main risk of becoming handicapped during the later years of childhood stems from accidents either in the home or on the roads.

But as Figure 5 illustrates, the Harris survey found that amongst adults of all ages living outside institutions the main causes of impairment are conditions like arthritis, stroke and bronchitis. Even in people of working age alone the OPCS data presented in Figure 6 show that only a little over 15 per cent of all severe and appreciable handicap is associated with complaints experienced in childhood or with traumatic injury and/or amputation.[6]

Bias in the overall prevalence of physical disability towards the older sections of the population and towards causation linked to chronic degenerative disease has become more marked as the twentieth century has progressed. Coupled with this changing pattern has been the demographic ageing of the population, the control of infectious diseases like poliomyelitis and tuberculosis and the development of medical techniques capable of correcting or preventing some forms of inborn impairment. It is also significant that Britain no longer has large numbers of young war-wounded people and that despite the fact that accidents still cause approaching 5,000 cases of serious long-term disablement each year[7] overall improvements in working conditions and an increased regard for safety coupled with medical advances has meant that the rate of civilian disability

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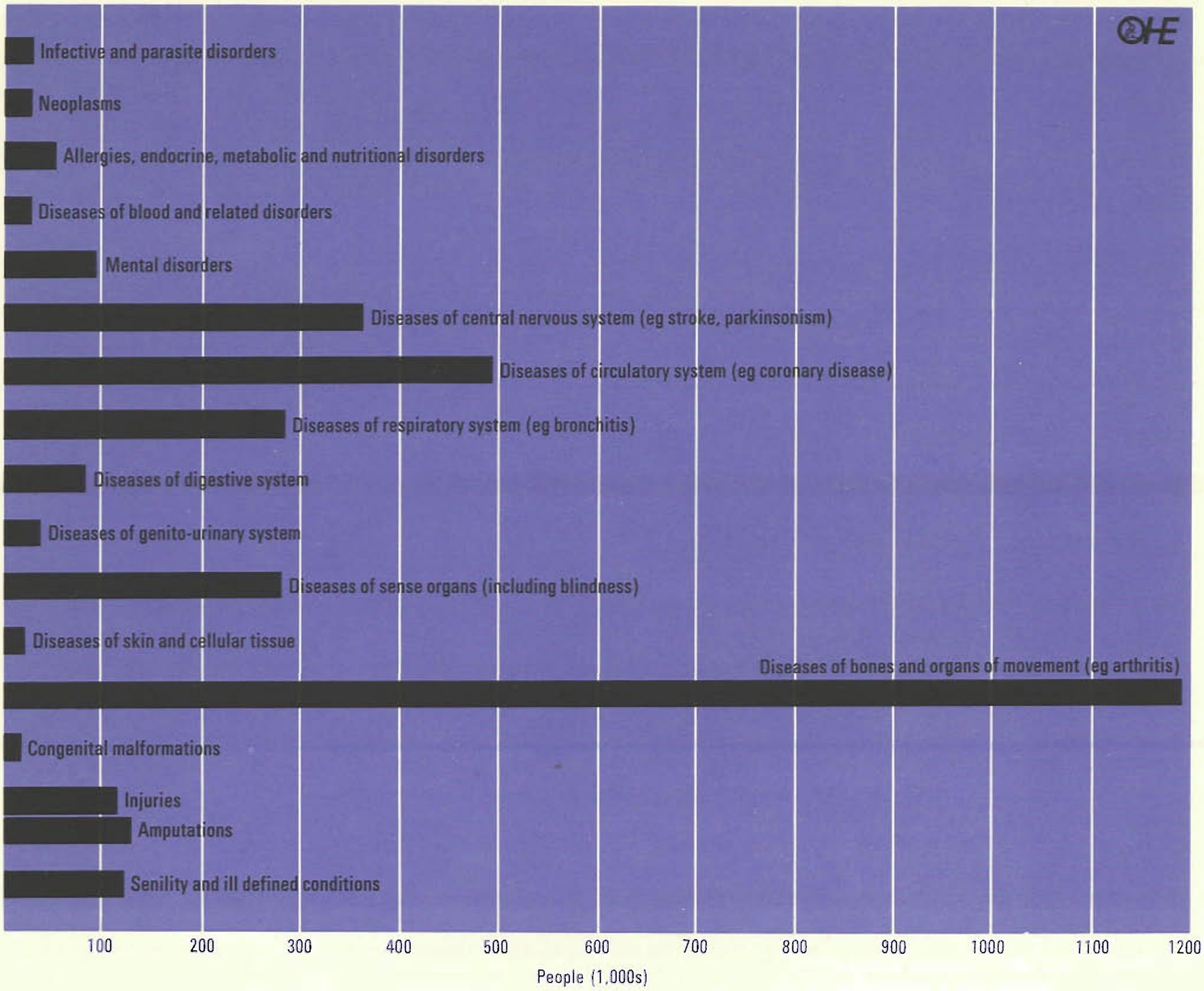
[6] In the population as a whole, peripheral vascular deficiency is the underlying cause for 60 per cent of all lower limb amputations. Only 10 per cent occur subsequent to trauma (DHSS 1976).

[7] Available statistical sources do not allow accurate determination of the volume of physical handicap related to current levels of accidents. This figure is based on marriages of data from Hospital Inpatient Enquiries and the Registrar General backed by specific studies such as that of Field (1976) on head injuries and balanced against overall numbers of people known to be handicapped. There are, for instance, some 15,000 fractures of the skull, spine or trunk caused by traffic accidents each year and about 20,000 lower limb fractures. However, it is clear from the Harris survey and the numbers of physically handicapped people in institutional care that most of the individuals affected recover at least sufficiently to be independent in self care. Field (1976) estimated an annual rate of 1,500 people left with major impairments after head injuries, over two-thirds of which probably stem from road traffic accidents.

Figure 5 *The main causes of physical impairment in adults*



Note to Figures 5 and 6 Because the Harris survey was confined to those outside institutions it may have tended to understate the impact of those conditions most likely to cause very severe disability. The main group likely to have been so affected is that of neurological conditions like stroke, parkinsonism and multiple sclerosis.

Source Harris 1971

caused through accidents in general has probably dropped considerably since before the First World War.

The above observations raise a number of important points. For example, they suggest that exaggerated attention tends to be paid to impairment related to injury as opposed to that stemming from disease. One aspect of this imbalance, which may help to perpetuate its existence, is that in injuries where 'fault' can be established compensatory awards may be made by the courts. Such payments are often well above the level of support (usually determined on non-compensatory principles) available to people disabled in other circumstances, a bias which in some contexts might adversely affect aspects of service provision.[8] Similarly, it may be argued that if public and political interest concentrates too exclusively on the problems of the younger disabled, then there is a danger that the changing causal pattern underlying physical handicap in the community will not be fully perceived. This in turn would be likely to confuse thinking about topics like the objectives of medical rehabilitation 80 per cent of which, Wood (1977a) has noted, is devoted to assisting those past retirement age to live independently. It may be that because disablement in childhood is often taken as a universal model the development of chronic disease and consequent physical limitation in elderly people is sometimes seen as an entirely separate issue from that of disability experienced

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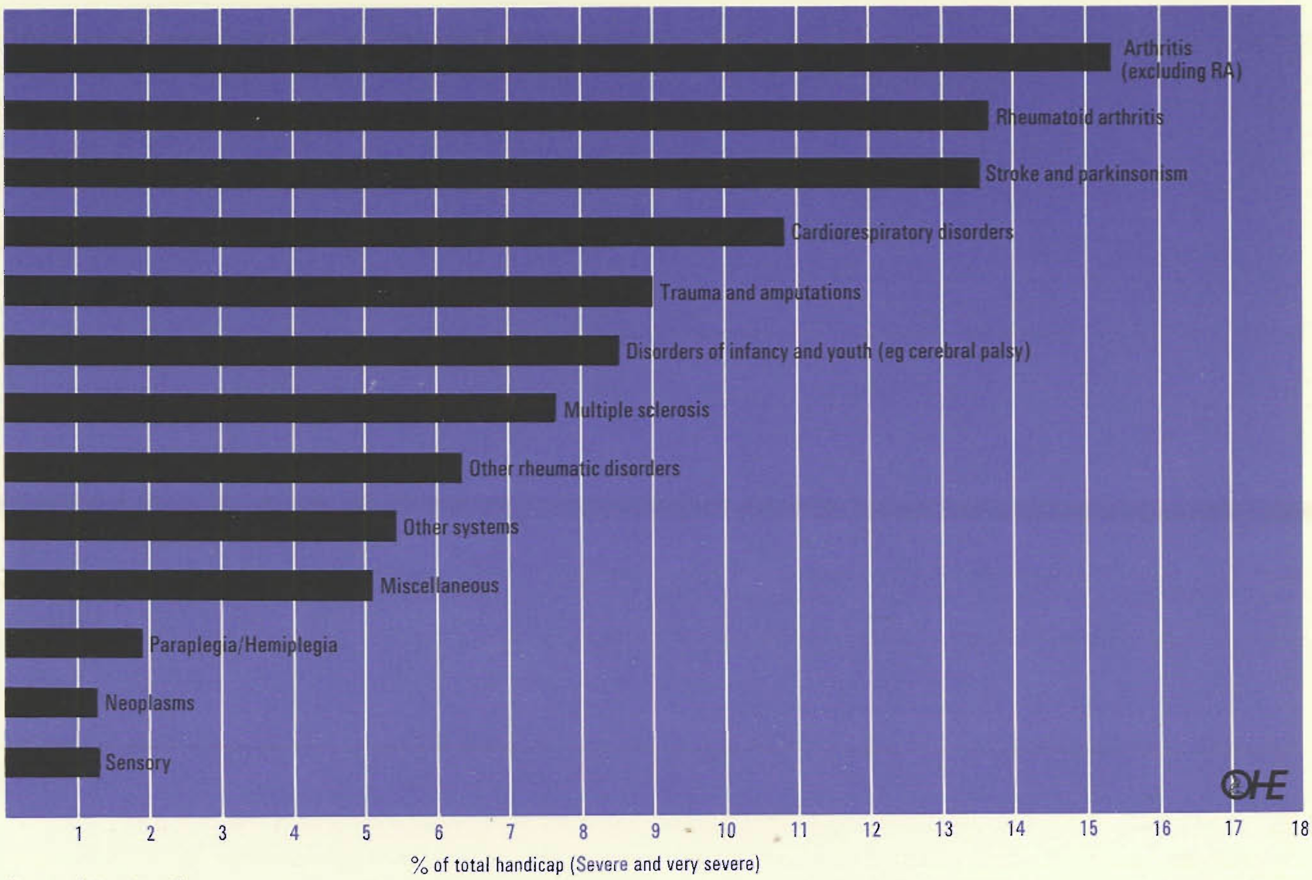
[8] The desirability of special compensation for possible whooping-cough vaccine damage is a relevant area. It may be thought to be in some ways unfortunate that the terms of reference of the Royal Commission on Civil Liability (the Pearson Commission) focussed on issues related to accidental injury rather than on society's responsibilities towards impaired people in general, regardless of cause or fault.

Figure 6 *Main causes of severe and very severe handicap in adults of working age (16–65)*



Source Wood 1976

in younger individuals and the resulting preventable handicap wrongly accepted as an inevitable part of ageing.

In fact many of the economic and social issues relating to the rehabilitation of older persons are similar to, although by no means identical with, those affecting people of working age. If any group of physically disabled people is to be considered atypical because of age it is young children because they will undergo their formative experiences and the transition from childhood to adulthood with their limitations. By contrast people who become impaired later have to readjust their expectations and their previous life style to accommodate their changed situation. This requires mental and physical rehabilitation rather than the primary habilitation needed by children although even the latter group shares many fundamental problems with disabled persons of all ages, like a tendency to be isolated from the social life of their peers.

Another significant point to be drawn from an accurate picture of the predominant causes of physical impairment in modern Britain is that although its consequences may demand social intervention its existence is usually the result of diseases which require medical treatment. Even where cure or effective control cannot be achieved medical skills are often needed to alleviate symptoms like pain or to determine prognosis, knowledge of which plays an important part in the process of individual adjustment.

It is interesting to note in this context that Harris and her colleagues found that approaching 80 per cent of physically handicapped people were being prescribed medicines and that over 50 per cent had seen their family doctors during the month prior to the survey. These results are an indicator that, unlike the case in most instances of mental handicap, there is a significant medical contribution to be made within the overall pattern of support for physically disabled individuals although this is not to suggest that all medicine prescribing and all expectations of medical aid are appropriate. Indeed, part of the social process of handicap may be an undue dependence on medical or other professional services which it is necessary to break in order to achieve rehabilitation (Agerholm 1972). Thus the limitations of the role of the medical profession in relation to physical disability need careful definition, both as to the variable needs of individual patients and at the level of inter-professional contact.

Prevention

In its broadest sense the prevention of physical handicap covers a vast range of interventions from those designed to reduce the initial occurrence of impairment to those intended to make a disabled person's life more acceptable. Examples of the former include the introduction of safety belts, crash helmets and speed restrictions in order to lessen the number and severity of road accidents and attempts to limit cigarette smoking. The latter is a very significant cause of disabling disease in modern Britain. The control of working environments is also of major importance in reducing the incidence of some forms of impairment. For instance, much deafness is related to exposure to high noise levels in industry[9] whilst the health dangers of coal mining (of which pneumoconiosis is the best known) have in the past at least been so great that they probably largely account for regional variations such as the high Welsh male handicap rates found by the OPCS.

However, this section confines its analysis of prevention to two areas in which conventional medical skills are of central importance. The first is the primary prevention of disabling conditions at or around birth and the second is the treatment of chronic complaints of later life.

Impairment at birth

Over the past few decades medical efforts to reduce the incidence of disablement in children have produced encouraging results. For example, immunisation has provided the means of virtually eliminating poliomyelitis. Surgical techniques have proved valuable in correcting many forms of congenital deformity, from relatively minor conditions like polydactyly through to serious heart disorders. The extension of child health services has reduced the risk of conditions like congenital dislocation of the hip or impaired hearing passing unnoticed early in life and so for lack of corrective or compensating intervention causing otherwise avoidable problems later. Complaints like asthma and epilepsy may be partly controlled by modern medicines. And in the case of visual impairment the reduction of maternal syphilis and gonorrhoea to very low levels has removed what previously used to be the main cause of blindness in newborn children whilst the modern management of oxygen therapy for neonates has eliminated the risk of visual damage caused by retrolental fibroplasia,[10] although not without attendant costs (Cross 1973, Silverman 1977).

In addition there is good reason to believe that further improvements in pre and post-natal care and obstetric services coupled with specific preventive measures could cut the current prevalence of physical impairment in young children significantly, probably by over 20–25 per cent in the coming 10 to 15 years (Alberman 1977). The two most important spheres in which such progress is likely to occur are the prevention of spina bifida and of cerebral palsy.

At the start of the 1970s considerable concern was being expressed about the rising prevalence of severe disability associated with spina bifida (which affects around 1·5 per thousand live births in Southern England and 4·5 per thousand in Northern Ireland). Lorber (1971) reported a two-year survival rate of well over 60 per cent of spina bifida cases receiving intensive modern care as compared with one of only 15 per cent amongst those cared for in a traditional manner. Many of the additional survivors suffered multiple impairments. But subsequent experience soon began to indicate a decline in spina bifida survival rates (DHSS 1974). Such findings imply that doctors became more selective in using sophisticated life preserving techniques, confining their application to those cases with a relatively good prognosis.

More recently, however, new approaches to spina bifida have become available, based on prenatal diagnosis followed by the offer of abortion (Lancet 1977) and it now appears that such provisions will be made available nationally within the relatively near future. Such a development might not only help to eliminate a major cause of inborn physical impairments but could also lessen the distress associated with the birth of children with conditions incompatible with life, like anencephaly. Yet any form of prevention based on screening followed by abortion is not without difficulties, both practical and ethical.

The situation with regard to reducing the incidence of cerebral palsy (which affects around 40,000 children in Britain – Bradshaw 1975) is rather more straightforward. In Sweden, for instance, where prenatal obstetric and paediatric care is amongst the most sophisticated in the world, both infant mortality and the incidence of cerebral palsy in young children are around half the British levels. In the period 1955–70 the Swedish cerebral palsy rates dropped by over 40 per cent whilst the prevalence of spastic diplegia[11] in young children dropped 60 per cent (Hagberg and Hagberg 1975).

The records of centres of excellence in Britain, such as the Hammersmith and University College hospitals, suggest that similar results could be achieved in this country were resources made available. Thus the benefits of applying existing knowledge in this field to prevention are potentially considerable (Polani 1973, Loring 1977). This has been recognised in France where a programme designed to reduce all forms of impairment of perinatal origin was initiated at the start of the 1970s, in part as a result of studies indicating the positive economic benefits likely to accrue to such measures (Wynn and Wynn 1976). Yet in Britain obstetric services are currently losing resources in real terms although this trend is to an extent balanced by falling numbers of births and hence declining work loads (DHSS 1976a).

There are two main points to draw from such observations on the opportunities for the primary prevention of conditions like spina bifida and spastic diplegia. First, the extent to which the prevention of birth impairments is possible is even today generally underestimated. As more techniques become available (such as prenatal screening for sickle-cell anaemia or thalassaemia and the control of Duchenne muscular dystrophy by genetic

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[9] Some 4 to 5 per cent of the total adult population suffer impaired hearing.

[10] Of the numbers of blind people on local authority registers in England in 1975 only 3 per cent were aged under 20 as opposed to over 70 per cent aged over 65.

[11] The term 'cerebral palsy' may be taken to include all forms of spasticity. Spastic diplegia refers specifically to palsied lower extremities.

counselling backed by prenatal diagnosis) health authorities both in Britain and abroad will come under increasing pressure to develop policies designed to ensure that they are used as productively as possible throughout populations rather than just amongst relatively rich or informed subgroups. To a large extent measures to achieve such a goal must hinge on attempts to educate people about the facilities and options open and to help them make clear decisions on the ethical and other issues involved. Relevent decision making should therefore be seen in terms of participative, general public involvement in the field, not as the strict preserve of health care professionals.

Second, there is some danger that in the future increased emphasis on the desirability of preventing congenital disability coupled with falling overall incidence rates could increase the subjective distress associated with the individual cases which will continue to occur and could even contribute to a process of stigmatisation of handicapped children and their parents or a feeling of guilt on the part of the latter. Efforts aimed at encouraging primary prevention in this context will therefore need to be balanced by the creation of a positive awareness that with adequate facilities the great majority of people with even severe physical disabilities can lead a happy and worthwhile life.

Prevention in later life

By far the most common forms of physical impairment are those associated with chronic, often progressive disorders like the cardio-vascular diseases, Parkinsonism, bronchitis and, most prevalent of all, the rheumatic disorders. Although complaints in this category may affect relatively young individuals – multiple sclerosis and Stills' disease are outstanding examples – most sufferers are in their 50's or over. Thus increases in the proportion of older people in the population since the turn of the century have raised the overall prevalence of physical disability in the community, despite declines in age specific rates. This trend will probably continue throughout the 1980s because of the growing absolute number of very elderly persons.

The immediate prospects for primary prevention in this sphere are, in the nature of ageing, limited. Although life-style changes and the further improvement of working conditions have significant long-term potential they are unlikely to influence rates of impairment incidence in older people within current planning horizons, that is the next 10 to 15 years.[12] Thus even though it is false to argue that the prevention of the onset of handicapping conditions in middle life merely delays the problem until old age and is therefore of little value (exactly the same could be said of primary prevention in newborn children) it is true that for the moment its relevance is limited. Rather most medical efforts are devoted to secondary and tertiary intervention, that is to stopping where possible the progress of disabling conditions and/or alleviating the physical and social distress associated with them.

Medicines prescribed by family doctors play a major role in this process. Since the 1940s a considerable range of products have become available which, although they generally do not 'cure' in the sense implied by traditional medical models of disease, can make life easier for sufferers and if used appropriately can reduce disability and so sometimes prevent handicap. Examples include those medicines employed to reduce high blood pressure, anti-Parkinsonian agents, antibiotics used to control exacerbations of chronic bronchitis, the range of anti-inflammatory and pain-killing drugs used in rheumatology and the anti-depressants and improved anxiolytic sedatives introduced in the last 10 to 15 years. The relevance of the latter to physical handicap is not only that they may help to control psychiatric problems in a limited number of cases but also that they may be of value in, for instance, helping people in physical distress to sleep.

Technological changes of this nature coupled with the demographic ageing of the population have created a situation in which an increasingly significant element in the workload of the average family doctor is the treatment of potentially handicapping conditions. Although other factors, such as the increased rate of presentation of some forms of psychiatric disorder and the rapid growth of local authority social service departments, may to an extent have disguised the underlying trend towards the management of chronic disabling disease as a central element of general practice there can be no doubt that it is a phenomenon of major importance. Its implications regarding the desirable future relationship between family doctors and those working at secondary levels in the field of rehabilitation and/or other spheres of medicine are discussed later in this paper, as are possible patterns of development in the links between NHS services and those of other welfare agencies.

But a point to make in the immediate context of prevention is that family doctors are likely to be in contact with a person suffering a physical impairment long before it becomes seriously disabling and so potentially handicapping and long before other professions are involved.[13] Thus they are in a potentially ideal position to not only provide routine medical care as and when it is needed but to help people to adjust to the prospect of disability before it actually affects them and so take early measures to ensure as satisfactory a way of life as possible. In addition at later stages in a disease process minor changes in an individual's capacity to live normally may be an early indication of physical deterioration which might be controllable by prompt medical treatment. Awareness of such possibilities is likely to advance further the shift in medicine (already initiated by the effective control of most acute infections) away from the traditional emphasis on crisis intervention and cure and more towards understanding the long-term behavioural effects of both sickness and health care itself.

Nevertheless it is important to retain a balanced view. Recognition of the fact that there should be a broader concept of disease than that generated by an exclusive concentration on aetiology, pathology and semeiology should not detract from awareness of the achievements of conventional medicine in the past or the future potential of even an improved application of existing knowledge. One example of this lies in the field of urinary incontinence, the existence or otherwise of which may be a deciding factor in allowing some older disabled people a satisfactory way of life. A significant number of cases are related to untreated urinary infection (Cameron 1977) and thus are at some stage potentially preventable by appropriate medical care. The development of joint replacement surgery, and especially total hip arthroplasty, provides another illustration of the way in which 'mechanical' medical techniques can provide dramatic benefits with significant social implications, even though the latter may be lost if insufficient economic resources are devoted to elective surgery to ensure that it becomes available without such a long delay that a person's normal way of life is destroyed (Taylor 1976). It would be a sad irony if a growing awareness of the social aspects of physical handicap diverted attention in such a way as to lead to a reduction of efforts to utilise primary methods of eliminating or avoiding the conditions which give rise to it.

Even today, caring for disabled people, especially those who happen to be elderly, is often thought of in terms of primarily providing individuals with shelter against the world through separating them from the rigours of day to day life. However, modern thinking on the relationship between physical impairment and the possible resultant experience of handicap emphasises the need to help disabled people to live in a manner which they consider satisfactory and worthwhile. Seen in this light 'care' should usually involve the retention by those in receipt of it of a maximum possible degree of personal responsibility and freedom of action.

The process of assisting disabled people to face the stresses and difficulties of active day-to-day living rather than encouraging individuals with limited physical abilities to play a passive, dependent role is often referred to as being one of 'normalisation' or 'integration'. Yet these terms should be used with caution as they tend to be subject to misunderstandings. As the recent report of the Snowdon Working Party (1976) stresses the integration of disabled people in the community should not involve abandoning all forms of special support along with segregated institutional provisions. Rather it hinges on helping severely impaired individuals to make the most of their abilities through, say, offering special work or special educational facilities alongside those for 'normal' people. 'Normalisation' may thus be regarded as the process of enabling disabled persons to live as satisfactorily as possible within the values of their society given their abnormal limitations which have to be recognised and accepted, even if this means adopting some imaginative and unusual way of 'coping'.

In recent years the principle of integration, in the sense of recognising the undesirability of isolating disabled people, has been acknowledged in government publications and circulars relating to most areas of social policy including housing, transport, employment and education. (See, for example, DES 1974, Department of the Environment 1974, Department of Employment 1974). Although in some cases the extension of community care has been severely limited by resource shortages there would seem to be relatively little fundamental conflict between the ultimate objectives of official policies and those of most voluntary organisations and pressure groups advocating reform.

This also appears to be the case in the sphere of health care although there are still some areas of disagreement. For example, the priority given to capital investment in hospital based special units for the disabled (DHSS 1976) has been questioned by some advocates of complete integration.[14] However, the most significant problems in this area relate to organisational topics like the structure of services supplying aids for disabled people and to uncertainties as to the relative contributions to be expected of medically and socially orientated services in supporting physically handicapped individuals. These issues are discussed below with specific reference to rehabilitative care. They in turn raise questions relating to the incomes of disabled people which are developed in Appendix I of this paper.

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[12] The chemotherapeutic prevention of strokes in at-risk subjects may also cut disability rates although it would be unwise at this stage to attempt to estimate the likely impact of such techniques.

[13] A follow-up survey in one London borough (unpublished) showed that all the disabled individuals identified as potential new social service clients by an investigation carried out under Section 1 of the CSDP Act were already known to their family doctors. The work of Blaxter (1976) also supports this view. This suggests that general practitioners' records could be a valuable source of information for other agencies seeking to identify disabled persons although Warren (1976) has noted difficulties in this context.

[14] Between 1971 and 1976 capital spending of £7 million (£ November 1974) was allocated for special units for the younger disabled. Between 1977–78 and 1979–80 £0·5 million per annum capital spending was identified as reasonable in the 'priorities document'. It is this allocation which has been questioned although there is no disagreement on other related issues such as the need to give capital priority to the establishment of a spinal injuries unit in Southern England. The construction of this has now commenced in Salisbury.

Problems of diversity – the example of aids and appliances

As Figure 7 and Table 5 show the range of facilities available for disabled people is wide. Its essential elements include the health care offered by the NHS, the support given by local authority social services and allied departments, the employment provisions now under the Manpower Services Commission and the income maintenance schemes administered by the DHSS. In addition voluntary organisations play an important role both in providing general services and support designed for specific groups of sick or impaired people. Overall one recent study (Blaxter 1976) found 59 organisations and branches of organisations operating various types of help relevant to disability within the relatively small city of Aberdeen alone.

Two major factors have promoted this diversity. The first is that because physical limitations may expose individuals to special problems in virtually all areas of normal activity, from finding a suitable house or job to arranging a holiday or establishing a satisfactory sexual life, the number of bodies involved in care is naturally large. The second is many services have evolved over several centuries. Because of political, economic and allied pressures the usual pattern of development has been one of gradual incremental change rather than radical restructuring which although advantageous in some respects has led to much structural differentiation and division of function.

The result is an overall pattern of support which is widely criticised because of inefficiencies associated with overlaps of activity and poor liaison in service provision, inadequate planning and considerable complexity. One of the costs of the latter is that it may not only dispirit and confuse disabled people seeking help but that it may also make them excessively reliant on professional guidance. Since loss of self-esteem may exacerbate the behavioural consequences of disability in both adults and children alike (Fox 1977) and 'learnt helplessness' may perpetuate indefinitely dependence on professional intervention unnecessary complications in service provision are likely to be highly counterproductive. They undermine the capacity of disabled people to take an active part in determining their own life styles and the pattern of support they receive, so making impossible the type of 'do-it-yourself' care considered desirable by many authorities.

An area often taken to typify many of the problems associated with the complexity of services for disabled people is the supply of aids and appliances. In the past considerable confusion has been caused by the division of responsibilities in this area between local authority social service departments, voluntary bodies (sometimes acting as agencies for local authorities), NHS hospital and community services, the Artificial Limb and Appliance Centres and the Departments of Employment and Education.[15] Despite the fact that in recent years efforts have been made to improve services (like the employment of increasing numbers of occupational therapists by social service departments) the system still has many inefficient and wasteful aspects (Keeble 1976).

These relate largely to a lack of skill necessary to assess the likely value of aids to disabled people leading to inappropriate provision on the one hand and inadequate supply on the other. Often administrative costs (including social workers time) relative to the value of items delivered or adaptations carried out are extremely high (Simkins 1977). It has been suggested that the range of items like wheelchairs available is inadequate and difficult to obtain (Agerholm 1977a, 1977b) and that in many cases people with orthoses like calipers are unhappy with the design or have not been correctly fitted (Jay 1977).

Several commentators have argued that to counter these problems it is necessary to integrate the centrally funded Appliance Centres (of which there are 23 in England and Wales, all but seven of which also deal with artificial limbs) into the main NHS structure, as is already the case in Scotland. This might be an initial step in establishing an Area or District based service offering not only skilled fitting and allied services but also serving as a 'resource centre', providing knowledge about aids and their applications to professionals such as family doctors as well as to members of the public directly. But official reaction to ideas of this sort has been negative. Wood (1977a) has accused the DHSS of, in one instance, censoring the publication of such views. One reason for such a response could be the fear that if the administration of services for the disabled currently funded directly by central government were to pass to a greater number of relatively independent local bodies expenditure could rise dramatically, not just through increased manning and numbers of premises but also because pressures towards supplying higher quality aids and appliances, and so subsequently increased demand, would be more difficult to resist. However, other factors may also be relevant to official reluctance to integrate the Appliance Centres into the NHS, including perhaps the perceived interests of civil service staff and those of the war disabled for whom the ALACs were first established.

In addition it should be remembered that the undesirable and/or inadequate characteristics of certain aspects of services for physically disabled people are sometimes subject to exaggerated attacks. This may, for example, be the case with regard to much of the controversy on mobility allowances and the planned withdrawal of invalid tricycles.[16] Even though overstated criticisms

[15] The Department of Education and Science purchases aids for use in special schools. The Disabled Persons (Employment) Act gives the Department of Employment the power to supply aids necessary for a disabled person to obtain or keep a job. However, although its expenditure on aids is rising, being in the order of £100,000 in 1975–76, this service is limited. The Snowdon Working Party recommended its extension and some authorities report an undue reluctance to supply aids before a person has definitely got work, leading to 'Catch 22' situations.

[16] Concern has been expressed in Parliament about the withdrawal of the Invacar scheme (which cost nearly £8 million in 1976–77) following the government's decision not to supply adapted four-wheelers as advocated in the Sharp Report of 1974. Instead, it has introduced the mobility allowance which eventually will be available to approaching 200,000 people as opposed to a total of 50,000 beneficiaries under the pre-existing scheme. Its cost will be in real terms at least three times greater than that of the former arrangements. So far debate has centred on the problems of younger severely disabled people who will not be issued with a vehicle this year (although special vehicle hire-purchase arrangements have been made and help from other sources like the Department of Employment should be available for people wishing to travel to work). But in the future the mobility problems of people over retirement age, who are not to receive the mobility allowance, may come to be seen as a key issue.

Figure 7 *Services for disabled people – the pattern in England*

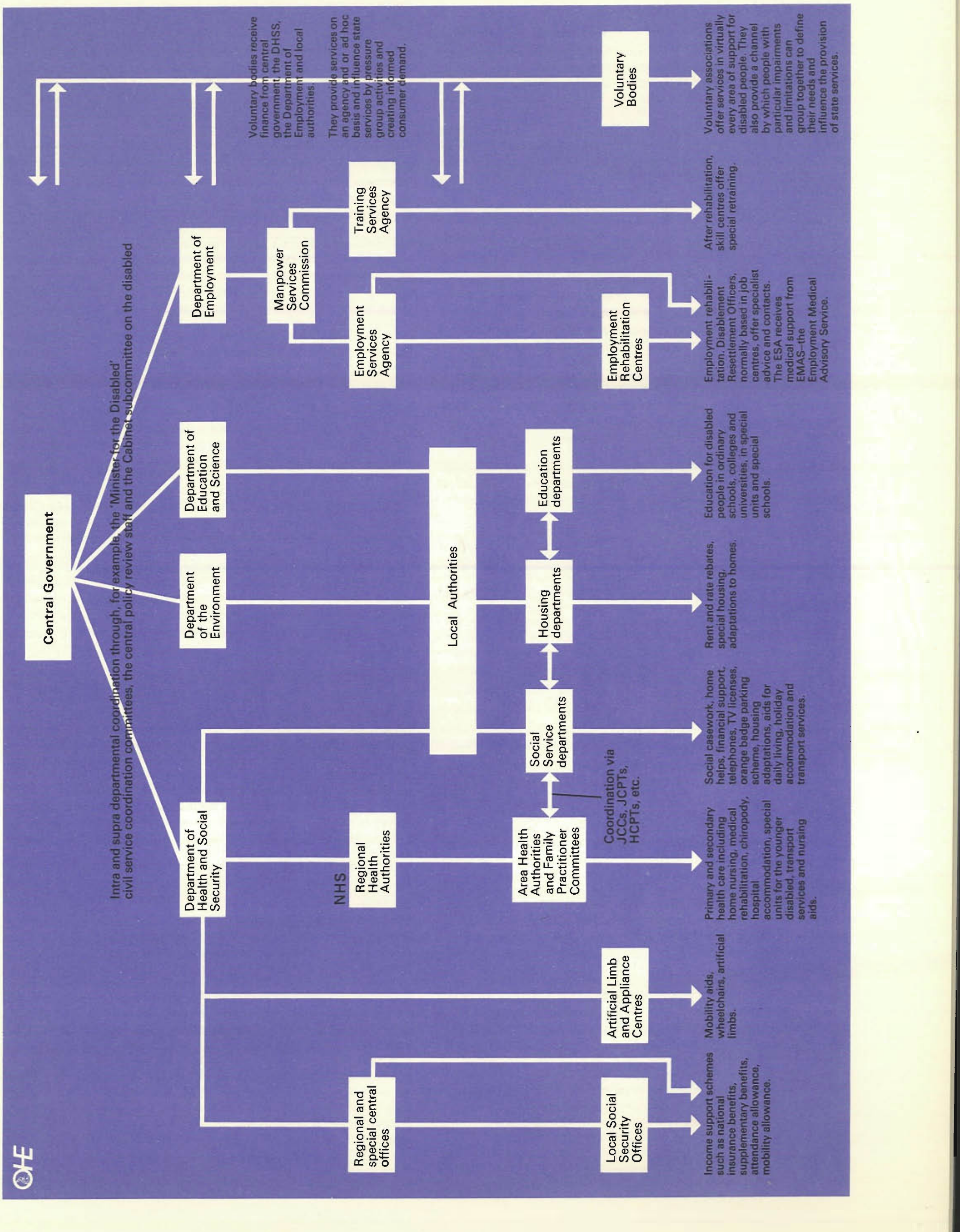

Table 5 *Services for disabled people*

Accommodation

The availability of suitable housing is an important factor in aiding physically handicapped people to live outside institutions and maintain satisfactory contact with the rest of the community. It is thus disturbing that in the late 1960s the OPCS found that over 800,000 handicapped or impaired people were in need of rehousing, a reflection of the fact that before the CSDP Act the only responsibility local housing authorities had in this field was to provide residential care under Part III of the 1948 National Assistance Act. Since the start of the 1970s efforts have been made to extend the range of housing available to physically handicapped people although improvements have so far been limited. In the period 1970–75, for example, only a little over one purpose built dwelling was completed for every 400 people defined by the OPCS as in need of rehousing (CCD 1976).

In 1974 the important distinction between 'wheelchair' and 'mobility' housing was introduced. The latter term refers to accommodation which is suitable for both disabled and non-disabled people but has characteristics like a level entrance, wider than conventional doorways and at least one bedroom on the entrance floor. Wheelchair housing is designed more for people who are or will be confined for most of the day to wheelchairs, there being a potential demand for around 80,000 such units.

Issues related to accommodation for disabled people which have been of recent concern include the lack of provision in many new towns, the poor quality of the data available on major housing adaptations conducted by local authorities (overall spending on which went up by over 180 per cent between 1973 and 1976) and the difficulties encountered by handicapped people who wish to purchase their own homes. In the latter area there are problems associated not simply with low incomes but also with getting pension payments accepted as income for mortgage purposes. However, the Housing Corporation now encourages the concept of housing associations for disabled people, a move which could go some way to solving problems in this context.

One of the most significant lacks of provision in the field of housing for handicapped people in Britain is the shortage of accommodation providing a level of support midway between the minimal services available in conventional sheltered housing and the care given in residential institutions. Schemes like the Fokus flats in Sweden, the Danish 'collective houses' and the Crossroad care attendance in Rugby all offer potential models of the manner in which accommodation designed to fill this need could be provided.

Education

Many children with physical impairments attend normal schools and are never classified as handicapped and in need of special education. Even of those that are, around half of the approximately 20,000 individuals concerned (this total excludes children with sensory impairments like deafness and many with combined physical and mental handicap) are placed in ordinary schools. But the remainder are in non-integrated special schools.

This situation has recently attracted both attention and criticism, a fact reflected by both Section 10 of 1976 Education Act which requires handicapped children to be educated in ordinary schools unless this is impractical and the current work of the Warnock Committee which is investigating the education of both physically and mentally handicapped children (this last group make up the great majority of the 150,000 children in special schools). Although resource restraints may limit the rate of progress and although the attractions of total integration for some groups of handicapped children may have been overstated by some enthusiasts there can be little doubt that future policy should be aimed at helping a greater proportion of physically handicapped pupils out of special schools. Recent work from the Institute of Education (Cope and Anderson 1977) indicates that in many instances partial integration involving special units or classes in ordinary schools may be an effective approach which could help to improve the disappointing academic record of traditional educational facilities for physically handicapped children.

The poor performance of the latter is to an extent indicated by the low proportion of physically handicapped students proceeding to tertiary education. However, there have recently been attempts to remedy this through, for instance, the establishment of the National Bureau for Handicapped Students and the work of the Open University. In addition to those in specialist colleges there are currently 250 disabled full time students in British Universities (Gunn 1976) whilst the Open University has had approaching 1,000 disabled students registered with it.

Employment

There are currently around half a million individuals on the Department of Employment's register of disabled people. Amongst this group unemployment stands at about three times the national average although it may be that of those disabled people who do not choose to register a greater proportion are in work (probably rather less than 50 per cent of the total number of disabled people of working age register with the Department).

A central element in the 1944 Disabled Person's (Employment) Act was the provision that all employers of 20 or more staff should employ at least 3 per cent registered disabled people. This requirement still stands (and has received recent emphasis) but in practice it has proved difficult to implement. Field (1977) has pointed to the failure of nationalised industries, local authorities and central government departments to meet their quotas whilst the Snowdon Report (1976) argued in favour of a number of reforms. These included differential weighting for quota purposes by severity of handicap and the creation of a Disabled Employment Tax designed to fund a system of compensation for those employers making special provision for disabled workers.

Aspects of the cost, structure and limitations of the employment rehabilitation services are discussed in the text of this paper. Their main elements include some 500 Disablement Resettlement Officers who operate mainly from Job Centres (some DROs use a hospital base and a small minority specialise in areas like the employment of the blind) backed by residential Employment Rehabilitation Units and various vocational training facilities. Sheltered employment is provided via local authorities and Remploy Ltd which together offer over 13,000 such jobs. Key criticisms relate to the quality of DROs, the range of occupations and training offered and poor liaison between health and employment services.

Income

Civilian disablement cash benefits and the broad problems relating to the maintenance of physically handicapped people's incomes are examined in Appendix 1 of this paper. In general it may be argued that the importance of this area relates to the desirability of disabled individuals retaining authority and choice in their relationship with those who provide them with essential goods and services. Where it is possible to purchase the latter directly tendencies towards excessive bureaucratic and professional dominance can be checked and the individual's autonomy protected. There is, therefore, sometimes a genuine conflict of interest between the various advocates of 'cash' and 'care' although ideally both types of support should be provided in a manner designed to promote their complementary interaction.

Mobility

Interest regarding the mobility of physically handicapped people has recently centred on the controversy surrounding the withdrawal of three-wheel trikes (Invacars – see text footnote 16). However, mobility can be influenced by many other disparate factors. These include the availability of aids like calipers and wheelchairs, the provision of hand rails and ramps in public and private buildings, whether or not high kerb stones are used in roadways, the design of public transport vehicles like buses and trains and the attitude of staff and other transport users.

Thus traditionally the mobility of disabled people has been affected by the decisions of a great number of public and private agencies none of which carries overall responsibility in the field. The Chronically Sick and Disabled Persons Act has not entirely remedied the consequent lack of clear policy even though the situation of disabled people has improved through the introduction of innovations like the orange disc parking scheme.

may stem from reforming zeal rather than destructive sensationalism they not only tend to denigrate the achievements of all those working in the field but they may also sap the confidence of handicapped individuals who may thus not benefit from the support available as much as would otherwise have been the case.

In this context it may be pointed out that despite debate as to the impact of the 1970 Chronically sick and Disabled Persons Act (which did not create 'earmarked' financial provision to meet disabled people's needs, which were themselves left loosely defined) local authority expenditure on aids, adaptations and telephones alone under Section 2 of that Act reached nearly £9 million[17] in 1975–76 (Ennals 1977). Although this represents only a small proportion of total spending it shows a growth in real terms of 90 per cent since 1972–73. And in the case of wheelchairs, which since 1971 have been supplied by Appliance Centres on the recommendation of either a general practitioner or a hospital doctor, a recent survey found that only about 10 per cent of users found them not very satisfactory (Fenwick 1977). Despite criticisms like the long delivery period experienced by many clients (who may not be in a position to effectively judge some other aspects of service quality) this finding suggests that the situation is not as bad as some commentators believe.

On a more general level another balancing factor is that much of the structure of services established during the 1950s and 1960s was built upon reforms introduced at around the end of the Second World War. Since the beginning of the 1970s many innovations including the Seebohm restructuring of social services, the 1974 reorganisation of local government, the NHS and the Department of Employment and the appointment of a 'Minister for the Disabled', have been introduced. Despite the fact that individually legislative measures such as the 1970 Chronically Sick and Disabled Persons Act have already borne considerable fruit it may be argued that insufficient time has passed for these steps to display their cumulative effect upon service provision. The significance of the innovations of the 1970s will probably only be clearly seen in the 1980s and the 1990s.

Rehabilitation

The need for further evolution within the overall format established in the first half of the 1970s may be well demonstrated with reference to rehabilitative services in Britain. This is not least because the term 'rehabilitation' in its current usage lacks precise meaning and has considerable emotional overtones, a factor which has contributed to much diffuse discussion of the topic but little clear understanding of the specific objectives of rehabilitation. For example, the Report of the Mair Committee (Scottish Home and Health Department 1972) defined rehabilitation as 'the restoration of patients to their fullest mental, social and physical wellbeing', so providing a linguistic umbrella broad enough to include all the activities involved in health care.

Nichols (1974, 1976) has argued that rehabilitation should more appropriately be described as the 'many physical, social and organisational aspects of the after care of patients who require more than short-term, definitive treatment'. It would thus include activities ranging from the functional retraining and subsequent re-employment if possible of, say, a young person injured in a road accident or an older individual who has suffered a stroke to the longer-term treatment and assistance needed by someone with a chronic disease like bronchitis or arthritis.

However, even this more precise application of the term may be thought to need certain qualifications, particularly with regard to its social implications. For in the case of someone hurt in a road accident or otherwise acutely ill rehabilitation clearly involves equipping them to resume their normal (although perhaps modified) social role as, for example, a wage earner and/or provider of domestic care. It is the bridge between being in a state of sickness in which normal responsibilities are suspended and being well which Agerholm (1972) has described as the process of patient turning into person. But if models of intervention applicable in the above instances are used in cases where someone with a chronic progressive condition is in fact seeking long-term help in gradually adjusting to increasing limitation, that is maintaining their way of life through managing to adapt to their disability, then an inappropriate pattern of care may often result. Traumatic events like the admission of older people in particular to hospital based assessment and rehabilitation units frequently at best reflect the failure of the NHS and allied agencies to provide earlier, less disturbing care in the community. At worst they demonstrate that inappropriate 'rehabilitation' can be the first stage of transforming a person into a patient.

This observation suggests that much conventional thinking on the prevention of handicap and the management of disability is not relevant to people suffering the most prevalent forms of physical impairment in Britain today such as those associated with rheumatic disease and strokes. More emphasis should be placed on 'maintenance rehabilitation'. This requires a shift in service emphasis away from institutional support and crisis intervention towards greater reliance on community based primary care.

A major reason why the current pattern of rehabilitative care is inadequately geared towards the needs of people suffering chronic disabling illness is that it developed largely in response to the problems associated with the wartime emergencies of the first half of the twentieth century and, to a lesser extent, to the requirements of particular civilian working groups like coal miners. The Lord Robert's Workshops, for example, which played a pioneer role in providing sheltered work in the voluntary sector, were first established to help meet the occupational needs of men returning from the Boer War. The influx of injured soldiers during the 1914–18 conflict stimulated pioneer rehabilitative regimes in military orthopaedic hospitals and the formation of the Artificial Limb Service. The first of the Government Training Centres (there are today over 40 renamed Skill Centres) was established in 1919 to help meet the occupational retraining needs of disabled soldiers. Similarly the first Industrial Rehabilitation Unit (there

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[17] Estimated total spending including holidays, etc was £15 million in 1975–76. Volume growth projected at 9 per cent between 1975–76 and 1979–80 in the 1976 Consultative Document on priorities.

are now some 25 Employment Rehabilitation Centres) was opened in 1943, partly in connection with government interest in employing disabled people in the war effort. The latter also led to the formation of the Tomlinson Committee in 1942 and the subsequent Disabled Persons (Employment) Act of 1944.

There have of course been significant developments in rehabilitative services since that time. The work of the Piercy Committee in the mid 1950s led to legislative innovations and in the 1960s there were efforts to more closely link medical and employment retraining through combined centres like Garston Manor. A small number of hospital based Disablement Resettlement Officers have been established, and more recently the Manpower Services Commission has introduced further reforms including attempts to give Disablement Resettlement Officers a more attractive career structure. But much of the basic approach to medical and employment rehabilitation assumed in earlier provisions has persisted and their development has been in reality little influenced by consumer demand, market pressures or new planning initiatives. For instance, the services of the Department of Employment still remain disturbingly isolated from those of the NHS (Brewerton and Nichols 1977).[18]

Medical attitudes – Tunbridge and after

Many commentators have suggested that the traditional approach of the medical profession in the field of rehabilitation has been too narrow and isolated, a view to an extent reflected in the work of the Tunbridge Committee (DHSS 1972). The report of the latter (which although unimplemented is a useful source of information and has served to stimulate much debate and interest) contained concepts which ran counter to the widely accepted view that rehabilitation should be seen as an integral part of all medical practice. Rather it argued in favour of a separate hospital based service. The Committee, which was a Sub-Committee of the Standing Medical Advisory Committee of the Central Health Services Council, suggested that access to beds in the proposed hospital rehabilitation departments needed the control of a specialist consultant, partly in order to prevent inappropriate use related to factors like the lack of detailed knowledge amongst many hospital and family doctors of up-to-date rehabilitation methods.

The thinking of the Report thus represented a radical revision of past ideas and a recognition of previously poor performance of the health service which challenged the interests of some groups within the medical profession. But critics argued that the defects of the Committee's work included a failure to see the need for and analyse the potential of community based services or to fully comprehend the role played by para-medical workers such as physiotherapists and occupational therapists. Nor did it investigate in any depth the significance of the developments in personal social services at the end of the 1960s, the growing autonomy of which had radical implications for the practice of most forms of non-acute medicine. These faults, which stemmed in part from an inadequate appreciation of the changing pattern of causes of impairment in the community, undoubtedly contributed to the Report's lack of subsequent influence on policy formation although this might also have been related simply to lack of medical interest in the plan to form a new speciality (Lee 1974).

The government's reaction to the Tunbridge publication was to announce in 1973 the allocation of funds for a four-year programme for the formation of rehabilitation demonstration centres which would act as foci of interest on a Regional or sub-Regional level and serve as a driving force in the development of services. The academic standing of rehabilitation was encouraged by the financing of Chairs in the subject in the faculties of medicine at the Universities of Southampton and Edinburgh. The then Secretary of State for Health and Social Services, Sir Keith Joseph, also pointed to the future need to develop a better understanding of issues like 'the correct balance between rehabilitation in the hospital and community, and the question of who should be in overall charge of the rehabilitation services' (Joseph 1973).

Some commentators doubt the relevance of creating academic Chairs and demonstration centres to efforts to resolve such important questions. Yet it should be remembered that at present little is known of the value of rehabilitative techniques. For example, Nichols (1976), has argued on the basis of a DHSS survey of the use of physiotherapy that in some instances it is little more than an expensive form of social support, although when appropriately employed it is of undoubted value to many disabled people. If research at such centres can help to provide indicators of the outcome value of rehabilitative interventions it could at least provide a basis for more rational service planning even though a careful analysis of the field may already suggest several variables likely to be major considerations in any future development of rehabilitative care.

The latter topic is discussed in following sections of this paper. However, in the immediate context of medical attitudes it is relevant to note that in the period subsequent to the Tunbridge Report both the Royal College of Physicians and the Royal College of General Practitioners have made arrangements for extending medical training in the sphere of rehabilitation. To an extent such moves reflect an acceptance of the need for more specialist knowledge in the area although this is not to say that the desirability of a hospital or consultant dominated system has been agreed. Rather, opinion appears to have swayed more in favour of community based services, perhaps coordinated from rehabilitation clinics incorporating aid centres. Some two years before the reorganised NHS came into being Warren (1972) noted that its new structure could accommodate developments along these lines, possibly linking in innovations like improved chiropody services, the importance of which in maintaining the mobility and independence of many disabled people may have been underestimated until recently (Age Concern 1976).

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[18] Lack of direct economic incentives may be one reason why employment rehabilitation appears to be less efficiently organised in Britain than it is in countries like West Germany where insurance based systems operate (Wilson 1977). However, this point is to an extent balanced by the possibility that the favourable economic climate in Germany has been a significant factor and also by the fact that the British insurance based worker compensation scheme for industrial injuries operating before the Second World War was not entirely successful.

Such an approach need not undermine awareness of the need for a strong medical input in rehabilitative care in areas like the initial determination of diagnosis, and prognosis and the prompt delivery of definitive care when it is required. Indeed it may improve it at the primary level, where most disabling illness is treated, by encouraging closer links between family and hospital doctors, occupational therapists and other remedial therapy staff. It has been pointed out (Norman *et al* 1975) that the Tunbridge Committee's objections to direct general practitioner access to sophisticated rehabilitative services would be obviated by a closer rapport between such individuals. The existence of improved inter-professional liaison at the primary care level would in the long-term help to maximise the explicitly medical contribution of family doctors to the care of people with chronic disabling complaints whilst minimising the risk of their becoming involved in the long unproductive dialogues with external agencies which often occur when there is poor communication and inadequate role definition.

Disablement in society: the future

As societies become technically more advanced and the methods of production employed within them more complex so the day-to-day lives and expectations of individuals within the population become more varied. In as much as this implies the breakdown of narrow definitions of what is 'normal' and a growing realisation of the mutual dependence of all members of the population this prospect is a desirable one for disabled people. It suggests first that the community around them will become more tolerant of deviance and so accept people with any form of limitation more easily and second that impaired people themselves will become more flexible in their attitudes and so find a broader range of life styles acceptable.

Benefits from such developments could accrue in many ways. For example, most individuals will probably become increasingly able to accept that disabled persons have sexual desires which if they are to be met may need special assistance (Greengross 1975, Stewart 1975). In the field of employment increased social flexibility could help to decrease employer prejudice against people with physical limitations on the one hand and, on the other, help handicapped people themselves to realise that a satisfactory life style need not centre on 'work' in the conventional sense. And with regard to leisure and recreation a wider awareness of the needs and abilities of everyone in the community, not just those who are 'normal', will probably encourage more sensible attitudes to problems like ensuring ease of access to public buildings or the unnecessarily rigid restrictions sometimes placed on impaired people in the interest of causes like reducing postulated fire risks.

However, acceptance of the value of greater social flexibility should not be taken to conflict with the desire of most people to maintain public order generally. There is little point in introducing legislation designed, for example, to help increase the mobility of disabled people if all older and/or weaker persons are restricted in their activities by the fear (realistic or otherwise) that they will be assaulted on the streets. An example of the difficulties in this area is the reported withdrawal in some urban areas of visual distress indicators for disabled persons living alone because of fears that if used they might attract burglaries.

The future of disabled individuals in Britain will therefore to an extent hinge on the community's capacity to combine the breakdown of restrictive and irrational prejudices with the maintenance of a core of common values and mutually respected objectives. This central theme of the need to balance the virtues of collective authority and purpose against those of stimulating personal freedom and independence of action underlies many aspects of the topics considered below. These are a brief analysis of the costs of rehabilitative and supportive services followed by a discussion of the problems inherent in their further development and the possible future role of voluntary bodies in this process.

The economics of care

Tables 6a, 6b and 6c show the costs of and probable future trends in spending on government financed services for disabled people. The available data suggests that total UK expenditure in this field in 1976–77 was

Table 6a *Costs of centrally funded services for disabled people in 1976–77 (£ current)*

i) Personal health and social services

	England	*Scotland*[1]	*Wales*
Artificial limb and appliance centres	£4,858,000 of which salaries of 1,036 staff are £3,292,000	NA	£200,200 of which salaries of 49 staff are £187,300
Supply and repair of artificial limbs, appliances, etc	£18,335,000 of which Hearing aids £ 6,005,000 Artificial limbs, etc £12,016,000 Surgical boots £ 313,000	£3,295,000 of which Hearing aids £ 657,000 Artificial limbs £1,462,000 Invalid tricycles and cars £1,176,000	£1,866,000 Hearing aids £234,000 Artificial limbs £851,000 Surgical boots £ 13,000 Invalid tricycles and cars £768,000
Supply and repair of invalid vehicles, wheelchairs, etc	£16,519,000 of which Invacar scheme £7,821,000	NA	NA
Private car allowances	£2,080,000	£130,000	£150,000
Other	£137,000 of which essential aids £ 62,000	NA	£91,000
Gross Total Appropriations in aid	£41,926,000 £ 422,000	£3,475,000 £ 54,000	£2,307,200 £ 5,200

ii) Employment Services (UK)

Remploy Ltd – Grants	£17,135,000
Capital loans	£ 2,580,000
Local Authority	
Grants for employment and training of serously disabled people	£ 5,260,000
Capital grants	£ 968,000
Voluntary Bodies	
Grants for employment and training of seriously disabled people	£ 758,000
Capital grants	£ 232,000
Allowances for seriously disabled people whilst training	£ 290,000
Other administrative costs	£ 464,000
ESA budget	
Employment Rehabilitation Centres	£ 9,715,000
Other rehabilitation services	£ 647,000
Gross Total	£38,049,000[2]

Notes

1) In Scotland, artificial limb and appliance centres are financed as part of the NHS.

2) To this total must be added that proportion of the approximately £299,000,000 spent by the Training Services Agency on services for disabled people. This probably brings total Department of Employment spending in the area to around £50 million.

Source Supply Estimates 1977–78

Table 6b *Estimated (revenue) cost of selected NHS and Local Authority services used by elderly and disabled people for the year 1975–76 and illustrative projection to 1979–80 (England £ Million 1976)*

	1975–76	*1979–80 (Illustrative projection)*	*Annual growth rate (%)*
Geriatric inpatients	255	290	3·5
Geriatric outpatients	5	9	
Non-psychiatric day patients	9	11	5
Home nursing	72	92	6
Chiropody	11	12	3
LA residential care	174	189	2
Home helps	112	120	2
Meal services	17	18	2
Day care	21	26	4
Aids, adaptations, holidays, etc	15	21	9
Centrally funded services	37	39	1·5

Note These figures are estimates subject to revision (see DHSS 1977). They are rounded and adjusted from £ November 1974 prices.

Source Priorities for Health and Personal Social Services in England. HMSO 1976

Table 6c *Costs of disability benefits in £1976 for the year 1975–76 and estimated numbers of people receiving them in the years 1975–76 and 1980–81 (UK)*

	Cost £ million 1976	*Number of recipients 1975–76 (1,000s)*	*Number of recipients 1980–81 (1,000s) estimated*
Invalidity benefit	514	470	475
Industrial disablement benefit	167	200	200
Attendance allowance and invalid care allowance	110	205	295
Non-contributory invalidity pension	20	105	205
Mobility allowance	8 (in first full year 1976–77)	10	130–150
Supplementary benefits paid to disabled people (estimates)	450 ±	1,500 ±	?
War pensions disablement widows	297	321	270
and others		110	85
Retirement pension	5,507	8,070	8,520

Notes Retirement pensions, which are received by over 50 per cent of all impaired persons, are included for comparative purposes although it is debatable whether or not retirement pension should be regarded as a disability benefit. Projections of the numbers of recipients are given because costs will vary with real increases in the value of benefits which are not predicted in government publications.

Source Cmnd 6721–11

approaching £3,000 million, around two-thirds of which was devoted to social security benefits for disabled people. This figure is exclusive of other spending which may indirectly benefit significant numbers of people with physical limitations (like retirement pensions) and certain items like the cost of medicines used in treating disabling conditions[19] although in balance the NHS and social service expenditure shown helps to maintain some services of general benefit to older persons.

Thus despite the fact that according to EEC figures Britain's overall health and welfare spending is low both absolutely and proportionately compared to that of most of the richer countries of Europe it is clear that this country is already making a considerable economic effort in support of the handicapped population. This should be remembered in the face of the sometimes bitter public attacks made on the inadequacy of services although it may of course be pointed out that volume of expenditure implies nothing about its effectiveness.

For example, one area for legitimate concern is the ratio of spending on residential as opposed to community services. Over 60 per cent of NHS and local authority current expenditure identified under the general heading of being for the elderly and/or disabled goes to the former. Despite recent policy statements (DHSS 1977) there is likely to be little shift in this ratio over the next few years notwithstanding verbal stress on the importance of community support. Indeed on the capital budget side the current decline in investment in day care facilities is sharper than that in new residential provisions.

Some commentators have expressed surprise about the apparent lack of emphasis on improving community facilities. It has been pointed out that a number of studies, perhaps the most important of which was 'Care with Dignity' (EIU 1974), have indicated that economic savings would accrue from additional measures designed to bring disabled people out of institutions into the community. This is even so with very severely handicapped people such as polio victims dependent on respirators (Adler *et al* 1974, Creese and Fielden 1977).

Yet as far as existing provisions are concerned there are some balancing points to be considered in the context of these findings. For example, if marginal cost rather than average cost comparisons are made then the benefits of transferring limited numbers of patients from residential to community care appear small. And it may also be the case that over a critical period expenditure on alternative services may have to rise before any savings from residential care reduction could be reaped, a phenomenon which presents a barrier to major change in times of limited economic expansion. Only in instances where care is extended to greater numbers of people than previously served are the economic benefits of community support likely to be realised, and even then historical experience suggests that rising expectations associated with such changes would drive up unit costs from their initial level and so reduce savings.

These comments should not be taken to suggest that improvements in care and support aimed at giving disabled people as full a life as possible in the community should not be considered an important priority. But they do suggest that the economic basis of arguments in favour of such social development may be weaker than some enthusiasts admit. If this fact is not understood clearly then desirable reform might be slowed through its advocates becoming discredited.

Similar considerations are relevant to the employment of severely disabled people in sheltered surroundings. This is again sometimes supported on economic grounds which may be questioned because they understate the costs of providing jobs. For example, as Table 6a shows, the Supplies Estimates for 1977 indicate that Remploy Ltd received approximately £20 million in government support in 1976–77. This represents about £2,500 for each of its 8,000 disabled employees and is a total sum in excess of all local authority expenditure on aids, adaptations and holidays for disabled persons for that year. Despite the fact that in this instance such costs have to be offset against probable savings in other areas, notably social security payments, this observation is a strong pointer to the conclusion that an undue emphasis on capital intensive support to keep disabled people in 'productive' employment could deprive other areas of care of adequate funding.

Hence even though it may be that the provision of conventional sheltered employment is in some circumstances justified it seems, on economic as well as social grounds, that it would be more desirable to encourage younger disabled people to wherever possible develop special intellectual or otherwise labour intensive skills which may be employed in ordinary, albeit possibly slightly adapted or flexibly run, workplaces. Similarly in the context of individuals who become impaired in or around middle life the strongest economic arguments in favour of allocating resources to assist their continued occupational activity relate to the benefits to be gained from keeping professional and allied specialised knowledge within the pool of human capital.

These observations imply that in the field of employment rehabilitation there is still a need to shift the main focus of official activity away from those areas once thought fit for disabled soldiers to aspire to towards those traditionally awarded a higher status in the community. But in recognising this it also has to be accepted that although there may be a strong moral or social case for providing very severely disabled people with limited skills and intellects with suitable jobs the economic return of doing so for the community as a whole, particularly in times of significant overall unemployment, is unlikely to be positive. Indeed, the same is true regarding the extension of any other form of care. Although Topliss (1975) has argued that economic self-interest has led society to give support for people who are physically handicapped this observation appears hard to substantiate. Compassion coupled with political reasons for introducing popular reforms appear to be more likely motivations although this explanation might seem objectionable to disabled people who reject overt pity as stigmatisation.

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[19] Which is in the order of one-third of total NHS pharmaceutical costs.

Planning care for chronically sick and disabled persons

Given a realistic understanding of the monetary costs and benefits of providing services for disabled people it is not surprising that Britain's poor economic performance has significantly inhibited the development of care and support in recent years. For instance, much of the dissatisfaction and difficulty associated with the implementation of the Chronically Sick and Disabled Persons Act has resulted from financial problems. Many local authorities have been criticised for not expanding services rapidly enough to satisfy rising public expectations.[20] Yet in the main policy makers were faced with the choice of increasing expenditure at such a rate as to possibly threaten the national economy or to finance new provisions by transferring resources from other client groups or community services. Although recent measures such as the joint funding arrangements between NHS and Local Authorities may be seen in some instances as a device to encourage the latter to provide services in accordance with central government prompting it is clear that in many cases it has been overall restrictions on public spending which have proved the major growth limit.

Economic difficulties may also have delayed the appearance of tangible benefits from the more sophisticated local authority and health service planning systems introduced in the 1974 reorganisations and muted the gains which might have been expected from the more coordinated inter-departmental and central government planning procedures started at about the same time. Despite the fact that there is an impressive list of central government achievements which have been accomplished or initiated since Alfred Morris became 'Minister for the Disabled' the overall quality of services in the field has not apparently improved to a similar degree.

However, factors other than the purely economic have also slowed progress. Some of these relate to the nature of the new management arrangements introduced in the early 1970s and to efforts to improve the professional status of groups such as the various types of remedial therapist. Although there are sound long-term arguments in favour of encouraging such changes their short-term effect may have been to strengthen hierarchical power structures and to encourage the avoidance of risk rather than innovation and initiative. And another reason why the improvement of services has proceeded at an uncertain pace has been a lack of understanding of the nature of disability and of the objectives of care.

In as much as the range of problems faced by handicapped people is extremely wide (the difficulties encountered by severely impaired school leavers are quite different to, for example, those of a disabled mother trying to raise a family) no simple model of ideal service provision could ever be adequate. But the data presented in this paper suggests that by far the largest subgroup of disabled people today are those aged between 50 and their mid 70s who suffer a chronic illness. Greater conceptual clarity relative to the needs of these individuals could do much to improve the quality of current planning.

People in this group usually have a long-term need for medical treatment to control the condition(s) which impair and so potentially handicap them. The objective of social and medical support is normally to prevent their decline in behavioural terms rather than to promote recovery from their ailments. It is because of the need of chronically sick people for a permanent network of support which does not interrupt their involvement with day-to-day life that more stress should today be placed on the value of community based, complementary health and social support.

Various approaches to the coordination of such a pattern of services have been advocated. For example, the Snowdon Working Party (1976) urged the development of a stronger role for health visitors in relation to disabled people although the practicality of this suggestion may be questioned. Overall it appears to be family doctors who are best placed to not only provide the definitive medical treatment needed (initiating and monitoring the use of more sophisticated secondary services where appropriate) but also to direct individuals who are likely to suffer increasing physical limitation to seek support from other agencies before their problems escalate to a crisis stage. This is not to argue that there should be any form of direct medical authority over personal social services or allied local authority provisions, as there was before the Seebohm reorganisation.[21] But family doctors should be seen as being at an important 'gateway' to social support for chronically sick people and their role tailored appropriately.[22]

The emergence of primary health care teams may be seen as a step towards recognising the significance of long term, disabling illness in general medical practice and the creation of an efficient system of care. Yet major problems still exist. Not only is there poor coordination of treatment within service sectors (the risk of iatrogenic disease in elderly disabled people stemming from inadequately monitored multiple medication is just one aspect of the undesirability of disjointed primary and secondary health care interventions) but there is still much antagonism between health and social workers. In part this is due to differing role perceptions and working conditions coupled with factors like inherent conflicts in statutory responsibilities (Ratoff *et al* 1974). But often discord is also generated by an inadequate appreciation of the chain of events linking physical impairments and social handicap and a failure to understand that unless social and medical support are combined in a balanced manner in cases of handicap related to chronic illness then a wasteful and inappropriate use of resources will occur. This point is illustrated in simplified form in Figure 8.

It may also be thought that the type of primary care team fashionably advocated in the late 1960s and early 1970s is in fact of dubious desirability. Not only have such arrangements been difficult to establish in many parts of the country, especially in urban areas like

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[20] And as such may have caused distress. Even so, discontent is a motor behind improved service provision.

[21] The Seebohm reorganisation established social work departments as being independent from the authority previously exercised by Medical Officers of Health.

[22] Other independent contractors have significant potential contributions to make to the care of chronically sick and disabled people. The high street pharmacist could develop an important monitoring role whilst there is a need to extend dental facilities for people with restricted mobility through the appropriate adaptation of surgeries.

London (RCGP 1977), but they appear to be of very limited popularity amongst some groups of paramedical and social workers (see, for instance, HVA 1977). Indeed, it could be argued that an inappropriate emphasis on solving liaison and communication problems by the formation of teams and on solving the consequent leadership disputes by creating pressures designed to induce 'consensus leadership' may in the long run lessen both individual committment and reduce the advantages of interprofessional interaction by suppressing the expression of contrasting views.

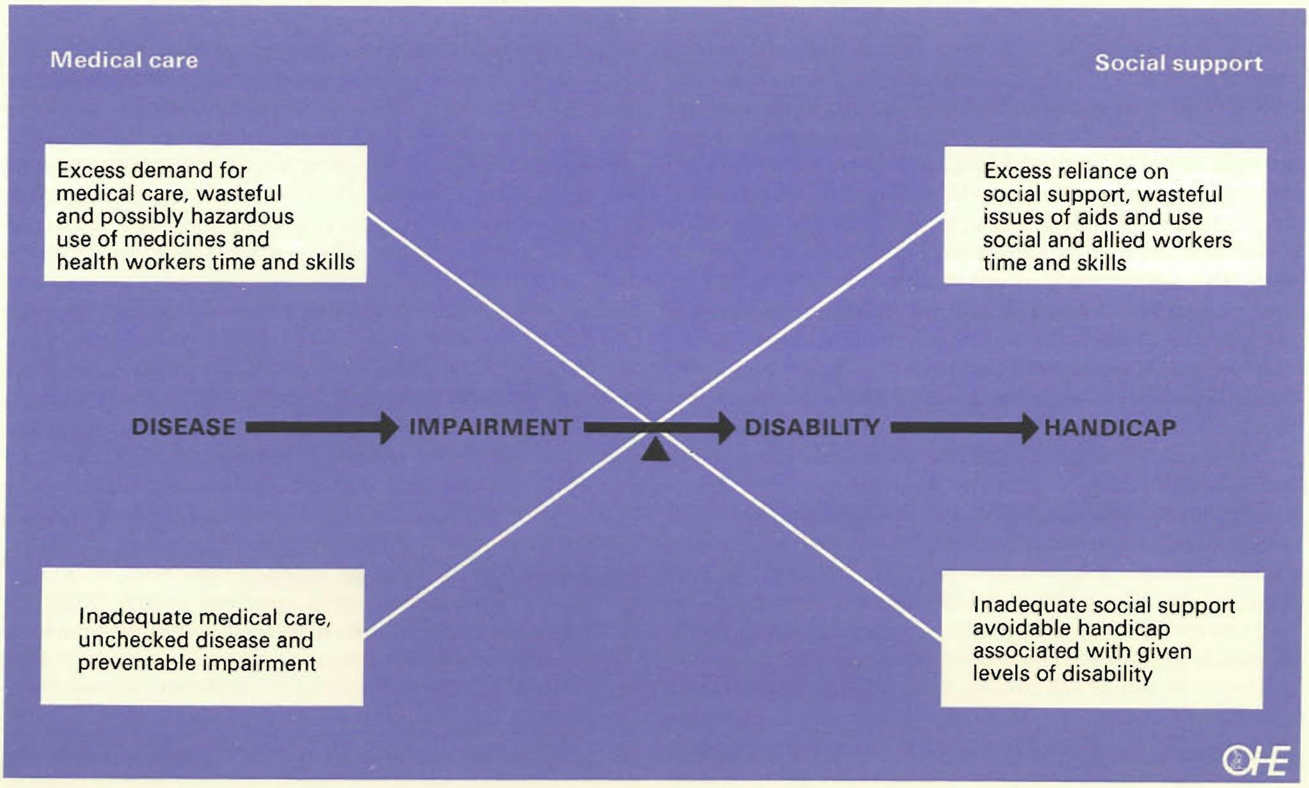
'Do-it-yourself' care

The above observation suggests that although the development of specialist interdisciplinary groups based on hospitals, aid centres or rehabilitation units may be a desirable goal (especially if their members are prepared to travel to patients' homes or local health and community centres to conduct assessments) perhaps more attention should be paid at the primary level to establishing clear functional demarcation lines between the individuals and organisations providing services for disabled people. If such an approach were adopted it could do much to focus the attention of bodies like Health Care Planning Teams on key issues like the promotion of inter-agency communication and record linkage and the build up of respect and rapport between field workers in all professional groups. It could also help to generate an awareness that in complex areas like the support of chronically sick persons efficiency depends to some considerable extent not on perfecting formal organisational and procedural details but on stimulating personal enterprise and a sense of mutual confidence amongst both service providers and service consumers.

The participation of disabled persons in determining and organising the pattern of care available to them is of great value if the receipt of the latter is to be seen as an acceptable facet of responsible adult existence. It may be achieved at a number of levels ranging from the planning of individual support and treatment régimes jointly by therapists and their clients to the involvement of disabled consumers with health service management bodies and organisations like CHCs. In addition the collective efforts of physically impaired people working through voluntary associations may provide care directly and influence state services by introducing new ideas and standards.

Guthrie (1976, 1977) has argued that in the future the latter will come to be clearly seen as the key role of voluntary organisations. This is partly because economic pressures are likely to restrict voluntary efforts to relatively small scale projects coupled with pressure group activities. The Crossroads Care Attendance Scheme in Rugby is one possible model for the future. Another example of a current voluntary organisation backed experiment which might eventually serve as a guide to the development of state services is the establishment of centres where disabled people can receive advice about the entire range of services available to them (Hannam 1977). This could reduce the confusion related to structural complexity and so increase handicapped individuals' sense of self-reliance and independence in seeking the rights to which they are entitled.

Figure 8 *The balance between medical and social care*



Conclusions

Provisions for assisting disabled individuals in Britain to overcome their disadvantages have emerged over the course of the last two centuries as a result of the largely uncoordinated efforts of many different agencies. Perhaps inevitably their growth has been influenced more by political expediencies, sectional pressures and fashions in sentiment than it has by clear analysis of the causes of physical limitation or the complex problems it generates. This has resulted in the evolution of a system of care which is needlessly complex, frequently lacks defined objectives and which has reacted only slowly to changes in the pattern of disability and handicap experienced in the community. The significance of many of the recent developments described in this paper, such as the efforts which have been made to define and measure the prevalence of impairment and its consequences more precisely and the reorganisations which took place in the NHS and social care in the early 1970s, is that they were initial steps towards the establishment of more efficient and appropriate forms of support.

There can be no doubt that since the passing of the Chronically Sick and Disabled Persons Act at the start of this decade many improvements have been made in the pattern of care. These include the introduction of several new social security benefits, increased recognition of and provision for disabled people by local authority social service departments, research into areas like the quality and efficacy of aids and appliances, attempts to stimulate comprehensive approaches to the mobility and housing of disabled people and the extension of the work of the Family Fund.

But the impact of these measures on consumer experience and the quality of services in the field may not yet have had its full effect. Also it is clear that in many instances they are only piecemeal advances unlikely to achieve the more ambitious objectives envisaged by the advocates of, for example, a universal compensatory disablement income scheme or community based rehabilitation services.

To an extent continuing deficiencies in such areas are a function of Britain's economic problems and the resource restrictions affecting welfare agencies. Yet with regard to rehabilitation in particular they in some cases also stem from outdated organisational arrangements and an inadequate perception of the needs of disabled people. This is related to a widespread failure to comprehend the significance of the increasing predominance of conditions like arthritis and stroke as causes of disability.

The great majority of the population can today expect to live their first few decades free of physical limitation. Even more will do so as techniques for the prevention of congenital and allied handicaps improve and industrial and road safety precautions are strengthened. However, they will survive to face physical limitations in later life. And as these gradually develop they will need complementary medical and social support to help them cope with their disadvantages and prevent the loss of their self-respect and position in the community. Such 'maintenance' rehabilitation is quite different from the pattern of crisis medical treatment followed by intensive functional or occupational retraining traditionally seen as appropriate for someone impaired by injury.

This has important implications in a number of areas. For example, it has led to a questioning of some current aspects of rehabilitation for employment and the supply of mobility aids like wheelchairs. It should also help to focus attention on the potential role of family doctors in support of individuals disabled by chronic degenerative disease. They are in an ideal position not only to give continuing medical care but to make contacts between people in an early stage of impairment and other services. However, it is unlikely that their full potential in this sphere can be exploited without adequate back-up resources such as local aid centres, more direct links with DROs and specialist rehabilitation teams prepared to work in the community rather than in institutions. The development of such facilities would appear to be a major task for new NHS planning bodies like the Health Care Planning Teams.

An improved appreciation of the nature of chronic illness and its handicapping behavioural sequelae could also reduce confusion in areas such as the care of older disabled people. Despite the fact that the expectations of and difficulties encountered by an impaired man in his twenties or thirties will be quite different to those of a similarly limited woman in her sixties or seventies there should be no doubt that provided both retain their mental faculties they face similar social problems. The positive attitude now usually taken to the rehabilitation and support of younger disabled people should also be applied to those in later life who may too often be dismissed as 'geriatric' or thought to be suffering inevitable consequences of old age.

In addition a better understanding of the fact that much medical intervention should be designed to influence the behavioural effects of chronic illness rather than to cure in a conventional sense may help to encourage rational attitudes towards cooperation between the health and social services and to the use of potent modern medicines. The appropriate employment of the latter amongst populations suffering incurable disabling conditions can only be fully determined in the light of their overall contribution to an individual's capacity to maintain a personally satisfactory way of life. This requires medication régimes to be carefully planned and monitored, ideally at the primary care level. The need for this is particularly great in cases where people with multiple complaints are receiving treatment from various sources.

Finally, a wider public knowledge of the way in which physical impairment is most commonly caused and how it may exacerbate pre-existing social disadvantages would not only allow disabled people themselves to gain a more accurate picture of the difficulties they encounter and the measures they may take to surmount them. It might also lead more members of the currently non-disabled population to realise that permanent physical impairment should no longer be regarded as a phenomenon likely to affect only an unfortunate minority of the population. Most individuals will eventually suffer it in some form. Thus it is in the ultimate interest of the community as a whole to encourage the measures designed to help disabled people avoid serious social handicap.

Appendix 1 Disablement incomes

Low income and physical disability are linked in a variety of complex ways. Harris and her colleagues estimated that in the late 1960s about a quarter of all impaired people had incomes below supplementary benefit rates whilst more recently the Disability Alliance (1977) calculated that around half the population of impaired individuals live on incomes at or around supplementary benefit level. Further, financial problems may be exacerbated by costs incurred as a result of being disabled (Baldwin 1977, Hyman 1977). These may include raised expenditure on items like heating, diet, clothing and transport as well as the price paid by other members of a disabled child's or adult's family in terms of earnings forgone during the time spent in helping the person concerned.

It is thus clear that physically impaired people are likely to be in need of financial assistance from the rest of the community. It is perhaps less obvious that the pattern of social security benefits available for such individuals has an important influence on both the demand for and the efficacy of rehabilitative and other supportive services. Cash assistance may sometimes obviate the need for professionally administered services. And the terms upon which it is provided may act as either an incentive or disincentive to a disabled person to return to or find paid employment.[23]

As with other services for disabled people the present structure of cash benefits has been largely influenced by historical factors. Piecemeal development over the course of the twentieth century has led to a system characterised by its considerable complexity and apparent inequity, the latter stemming from the fact that the various schemes shown in Table 7 were founded on a variety of disparate principles and, more importantly, on deliberate preferences for certain groups. For example, blindness is an impairment which has traditionally attracted a relatively favourable share of the total resources devoted to the support of disabled people (although this is not to deny that it is potentially a very handicapping condition) whilst the war disabled have tended to be more generously treated than their civilian counterparts.

The War Pensions Scheme, like that for Industrial Injuries established in 1948, has a central compensatory pension based on a graded assessment of the recipients' degree of impairment. Entitlement is not affected by other income and it is backed by an array of other payments for particular handicaps or losses. The National Insurance scheme, by contrast, provides only compensation for lost income (which is not earnings related) in the form of invalidity pensions and allowances, the former converting into retirement pension at the appropriate age.

The attendance and mobility allowances introduced in the 1970s may, although their payment is not dependent on insurance status and the latter is not available to those over retirement age, serve as supplements to basic National Insurance provisions. But overall they do little to redress the imbalances in the economic support received by the various sections of disabled people in the community, the existence of which appears unjust to many observers.

Another source of adverse comment stems from the fact that many disabled people have to fall back on the supplementary benefit 'safety net'. This is undesirable because there is still some of the stigma of poor law relief associated with supplementary benefit which may account for why Harris found that many impaired people who might have claimed it because of their poverty had not done so. It has also been pointed out by the National Consumer Council (1976) that the supplementary benefit system is inefficient. This in part because of the costs of abortive claims and also, more significantly, because of the need to make detailed enquiries about the situation of applicants which even so may not lead to them receiving the full amount to which they are entitled.

In response to concerns such as these there is widespread support amongst organisations representing physically disabled people for the concept of a universally available disability income payable as 'of right' to all substantially impaired individuals regardless of the cause of their impairment or their personal financial status (although it could be 'clawed back' through the tax system). This would extend the principle of compensatory payments for disability *per se* to the entire community.

The specific schemes advocated in this context comprise an array of benefits of which such a universal disability income would only be one part (see, for example, Disability Alliance 1975). Townsend (1973a) has argued that tests of functional ability could provide the basis for assessing the percentage of the full disablement payment to which each individual would be entitled although there are some doubts as to whether such indicators could in practice be fair and efficient measures of the handicapping effects of disability which vary as between persons and communities.

Bolderson (1975) has commented that there might be significant social costs associated with 'psychological and physiological means testing' whilst it may also be argued that none of the schemes put forward which involve introduction of a compensatory disability income would be likely to prove less complex than the present arrangements. Recently Donnison (1977) has pointed to the difficulty in defining the border lines between disadvantage related to physical impairments and other forms of social disadvantage and to the possibility that other reforms, such as the introduction of some form of tax credit system, would appear to have priority over changing the current pattern of disability benefits. Indeed, merely to attempt to lift the physically handicapped out of the supplementary benefit 'net' whilst leaving the basic system unchanged could contribute to a further stigmatisation of the 'undeserving poor' left in receipt of such assistance.

Nevertheless the concept of a universal compensatory pension for disability is in many ways an attractive one

[23] In this context it is interesting to note that increases in the total rehabilitation period for fractures of the lower leg apparently followed changes in benefit schemes during the 1960s (Sommerville 1974). There are marked variations in the duration of total disability following injuries amongst civilians as opposed to members of the armed forces (Nichols 1975) and individuals such as professional footballers (Wilson 1977). However, income is by no means the only variable involved in such cases and thus simplistic conclusions as to the costs and benefits of increasing financial support for disabled people should be avoided.

Table 7 *Cash benefits for disabled people (civilian schemes)*

Benefit		*Rate (weekly)*		*Comments*
		From November 1976	*From November 1977*	
Invalidity pension and allowance	*Invalidity Pension*			Invalidity benefits replace national insurance 'sick pay' after 28 weeks of incapacity for work. Some 450,000 people are currently in receipt of invalidity pension which is not taxed but is subject to an earnings limit of £9 per week (£10 from November 1977) and cannot be paid in conjunction with most other forms of national insurance or industrial injury benefit. Payment stops at pensionable age although the additional invalidity allowance for younger people (designed to compensate for lack of savings) is continued. Qualification for these benefits is dependent on national insurance contributions and a statement from the claimants own doctor.
	Recipient	£15·30	£17·50	
	Adult dependent	9·50	10·50	
	1st child	6·45	7·40	
	Subsequent children	5·95	6·90	
	Invalidity Allowance			
	Age under 35	£3·20	£ 3·70	
	35–45	2·00	2·30	
	45–60*	1·00	1·15	
	*55 for women			
Non-contributory invalidity pension	Recipient	£ 9·20	£10·50	The non-contributory invalidity pension (NCIP) was introduced in late 1975. It is a non taxed, non means tested benefit payable to people of working age who have been incapable of work for 28 weeks or more but who do not qualify for normal national insurance benefits through, for example, never having been in the workforce. In the main this benefit (which is subject to earnings limit) serves only to reduce its recipients' reliance on supplementary benefit although they are also credited with national insurance contributions and may also become entitled to rate and rent assistance. However, from November 1977 up to 40,000 previously unaided disabled housewives will become entitled to NCIP.
	Wife*	5·60	6·30	
	1st child	6·45	7·40	
	Subsequent children	5·95	6·90	
	*In November 1977 some disabled housewives will become entitled to NCIP in their own right. Wives may earn up to £35 without affecting husbands' NCIP (£40 from November 1977).			
Mobility allowance		£5·00	£7·00	Mobility allowance was first introduced at the start of 1976 and since then has been phased in for increasing numbers of people. Eventually every disabled person who has been or will probably be virtually unable to walk for a year or more and who is aged over five and under retirement age will become entitled to it (ie around 200,000 individuals). It is not subject to an earnings limit, does not affect the payment of other benefits but is taxed. Entitlement is determined by medical examination by a board doctor backed by appeal procedures for anyone who feels that their claim may have been wrongly rejected. Mobility allowance rises by 40 per cent in November 1977, as opposed to 14 per cent for most other benefits.
Attendance allowance	Lower rate	£ 8·15	£ 9·30	The Attendance Allowance is a tax free benefit which was first paid in 1971. It is without means test, qualification resting on an individual's need for extensive day *or* night (lower rate) or day *and* night (higher rate) care. Only children under two are not eligible and attendance allowance payments are ignored when a subject's entitlement to other payments (including retirement pension) is calculated. Currently around 250,000 people receive it, a total which will probably rise to some 300,000 by the end of the decade. Medical assessments are conducted by board doctors.
	Higher rate	12·20	14·00	

Benefit		*Rate (weekly)* *From November 1976*	*From November 1977*	*Comments*
Invalid care allowance	Recipient	£ 9·20	£10·50	Invalid care allowances (ICAs) were first paid in mid-1976. They are provided for people of working age who give up paid employment to look after disabled relatives although married women looking after their husbands or other members of their families do not qualify. ICA is not means tested or subject to insurance contributions but it is taxed, subject to an earnings limit and taken into account when other entitlements like supplementary benefits are calculated. However, as in the case of NCIP recipients are credited with national insurance contributions. Government forecasts indicate that 11,500 people may be entitled to ICA, most of them single women.
	*Wife/Housekeeper	5·60	6·30	
	1st child	6·45	7·40	
	Subsequent children	5·95	6·90	

*Married women living with their husbands are not entitled to this benefit.

		From November 1976		*From November 1977*		
		Ordinary rate	*Long term rate* (under 80)*	*Ordinary rate*	*Long term rate* (under 80)*	*Comments*
Supplementary benefit	Married couple	£20·65	£24·85	£23·55	£28·35	Although originally envisaged only as a 'safety net' supplementary benefit represents the largest single section of social security provision after retirement pensions. Basic benefits under the supplementary scheme are termed 'allowances' and 'pensions', depending on whether the recipient is of or over working age. Qualification is purely on level of income. Each individual is allowed £1,200 of capital before this is taken into account in determining payments. (Additional amounts are assessed on the basis of £50=25p per week income). Living costs like rent or mortgage interest repayments are added to the basic rate as may be allowances for special expenses for items such as heating, which take the form of weekly exceptional circumstances allowances (ECAs), or clothing and bedding provided for by lump sum exceptional needs payments (ENPs). Other entitlements, such as free prescriptions and fares to hospital, accompany receipt of supplementary benefit which in 1975 was drawn by between 1·5 and 2 million people of pensionable age (probably the majority of whom were impaired or handicapped) and some 250,000 younger disabled persons. Even so a significant minority of disabled people do not take up the benefits to which they are entitled, partly because supplementary benefit has in the past at least had a degree of 'poor law' stigma attached to it.
	Single persons living alone	£12·70	15·70	14·50	17·90	
	Other persons					
	18+	£10·15	£12·60	£11·60	£14·35	
	16–17	7·80	—	8·90		
	13–15	6·50	—	7·40		
	11–12	5·35	—	6·10		
	5–10	4·35	—	4·95		
	Under 5	3·60	—	4·10		
	Blind Persons					
	Married couple					
	1 Blind	£21·90	£26·10	£24·80	£29·60	
	Both Blind	22·70	26·90	25·60	30·40	
	Single person					
	18+	£13·95	£16·95	£15·75	£19·15	
	(reduced rates for children)					

*+25p per week for those aged over 80 years

ECAs: *Examples:* Heating allowances for health reasons 70p per week minimum, £2·10 maximum (80p and £2·40 after November 1977) Diet allowance £1·75 for people with conditions like peptic ulcer or ulcerating colitis, in other cases 75p (£2·10 and 90p after November 1977). Laundry, central heating, unusual clothing wear and tear or telephone bills may all be subject to an ECA.

ENPs: No fixed scale.

		Rate (weekly)		
Benefit		*From November 1976*	*From November 1977*	*Comments*
Industrial disablement benefit	100 per cent	£25·00	£28·60	Under the industrial injuries scheme people who suffer loss of ability for work or lesser physical and/or mental reduction in faculty for more than 26 weeks resulting from work related injury or disease are entitled to either a lump sum payment or (if their disablement is classified as more than '20 per cent') a weekly pension. About 200,000 people currently receive the latter. As in the case of the war pensions scheme it is paid in addition to other earnings and benefits like the retirement pension and may be accompanied by one or more of several other benefits such as the special hardship allowance paid when a subject is unable to return to his or her previous normal work and a constant attendance allowance for those in need of extensive care. In total the benefits received by someone suffering disablement stemming from industrial injury or disease may be very much greater than those available to an equivalently disabled person whose condition is related to disease or injury otherwise classified.
	Unemployability supplement	£15·30	£17·50	
	Special hardships allowance (maximum)	10·00	11·40	
	Constant attendance allowance (normal maximum)	10·00	11·40	
	Exceptionally severe disablement allowance	10·00	11·40	
	Note: These benefits are approximately equivalent to those payable under the war pension scheme. However, in some instances the provisions of the latter are more generous.			
Local Authority benefits	Housing grants normally cover up to half the eligible expense of alterations or improvements. Rate rebates and rent rebates and allowances are calculated on a complex scale which favours disabled poeple. They may be payable to people whose income is too high to qualify them for supplementary benefit.			Local authorities may provide several forms of what in effect are cash benefits to disabled people, mainly in the form of grants for housing improvements and adaptations, rent rebates and allowances and rate rebates. Structural housing alterations for disabled people may also be financed by social service departments or, in the case of disabled council tenants, be carried out by housing departments directly. In some instances disabled house owners may qualify for combinations of aid such as an intermediate grant plus social service department assistance. Rate exemption in respect of improvements made for the purpose of supporting disabled people may also be available. This is distinct from the rent rebates and allowances and rate rebates which may be available. The uptake rate of the latter is amongst the lowest of all benefits. People should apply via housing offices (whatever the type of their accommodation) unless they are already in receipt of supplementary benefit.
The Family Fund	No fixed scale			The Family Fund, originally formed to aid the victims of the thalidomide tragedy, may help the families of any disabled child under 16. The aid it gives is not formally means tested and people are requested to ask for whatever they most need. Claims are decided largely on the basis of a social workers report which should take into account the families overall social and economic circumstances. The work of the Family Fund appears to show that such open-ended schemes are not abused by clients and that they may be a desirable model for future development.

Note Information and advice about all benefits for disabled people other than those under the heading of local authority benefits may be obtained from local Social Security offices. Housing grants and rent and rate aid may be discussed at the local housing offices, contactable via the Town Hall. The address of the Family Fund is Beverly House, Shipton Road, York YO3 6RB. Independent advice is obtainable through bodies like the Citizens Advice Bureau or the local Community Health Council.

and it may well be that political opinion will swing in its favour.[24] And even if the most pressing current objective is seen as the uprating of existing provisions it certainly appears unduly pessimistic to argue that the basis and organisation of today's system of economic aid for disabled people cannot be substantially improved in the future.

Cash support in rehabilitation

A major restructuring of disability benefits would provide an opportunity to link social security benefits more positively to the pattern of rehabilitative care available in this country. As a DHSS team which visited several European countries at the start of the 1970s commented, Britain appears backward in this field (DHSS 1972). The Netherlands, for instance, has a far more comprehensive system of joint medical and social assessment and economic compensation for disabled people. This provides not only in some instances what is in effect short-term partial incapacity benefit but also, more generally, long-term partial incapacity payments which enable someone who has a permanent reduction in earning capacity to combine benefit and earnings. In this country the relatively low 'therapeutic earnings limit' associated with the payment of invalidity pension may sometimes, through a 'poverty trap' effect, act as a barrier to occupational rehabilitation.

The 1974 White Paper 'Social Security Provision for Chronically Sick and Disabled People' recognised that there was a lack of information regarding the role of cash benefits in policies aimed at employment rehabilitation. But it made little attempt to assess their significance in this area on even a theoretical basis. For example, the government document stated that 'better (social security) provision for the severely disabled must come before further provision for the less severely disabled' without apparently recognising that a more flexible system of support for the latter group might speed rehabilitation and in the long term free resources for the severely handicapped. It might also have pointed out that both in Britain and abroad there is even less data available on the part played by cash assistance in enabling the rehabilitation or preventing the dishabilitation of impaired persons in later life.

Income support for disabled individuals at or around retirement age may be seen as desirable not simply in terms of maintaining their purchasing ability as such but more positively in allowing individuals to retain the status and independence of someone who can pay for the special goods and services they require to assist them to adjust to their gradually increasing physical limitations. This view is supported by the fact that, although professional groups often stress the helplessness and social inadequacy of the people for whom they care, there is evidence that impaired people themselves often see cash support as the most important type of help (DHSS 1976c). It would be naïve to suppose that there are many areas in which the problems of allocation could ever be resolved by exclusive policies of either cash provision or professional control. But it may well be worthwhile to explore further the possibilities of extending market-like patterns of distribution in fields like the supply of home helps or aids.

Appendix 2
Sources of information

Income support

Advice may be obtained from local social security offices, listed in telephone books under Health and Social Security. Explanatory leaflets should be available from post offices. Voluntary bodies with a particular interest in this field are:

The Disability Alliance, 96 Portland Place, London W1. 01–794 1536
The Disablement Income Group, Attlee House, Toynbee Hall, 28 Commercial Street, London E1. 01–247 2128

Both these organisations produce publications describing the range of financial and allied support available to physically impaired people. Useful examples include *The Disability Rights Handbook for 1977* from the Disability Alliance and *The ABC of Services and Information for Disabled People* from DIG.

Social services, housing and education

Provisions in these areas are the responsibility of Local Authorities and departments may be contacted through the Town Hall. Hospitals and family doctors should be able to arrange a meeting with a social worker, who will be able to explain the facilities available. He or she may also be able to advise people about how to get in touch with other local authority bodies such as the housing department which administers rent and rate rebates and allowances.

Voluntary organisations

There are many independent associations of and for people with particular types of disability and or illness. Two which may be of particular value as sources of information are:

The Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London W1. 01–637 5400
The Disabled Living Foundation, 346 Kensington High Street, London W14. 01–247 2128

A useful guide for parents of disabled children is *Help Starts Here* prepared by the Voluntary Council of Handicapped Children and published by the National Children's Bureau, 8 Wakely Street, London EC1.

The address of the Family Fund is at the foot of Table 7.

People trying to find out about the services available and the rights to which they are entitled may wish to contact their district Community Health Council 'shop' or the local Citizens Advice Bureau. Addresses are obtainable from the telephone book or, in the case of CHC's, from health service staff.

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[24] Discussion of this topic will be stimulated by the publication of the Pearson Commission's report on civil liability.

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