

Briefing

DISABILITY IN BRITAIN— THE PROCESSES OF TRANSITION

Following a proposal originally made by the representative of the Libyan Arab Jamahiriya, the General Assembly of the United Nations decided late in 1976 that 1981 should be proclaimed the International Year of Disabled Persons (IYDP). The UN's intended aims for the year include increasing global awareness of the abilities and needs of disabled people; encouraging their fuller integration into their communities; improving preventive services; and stimulating 'more positive' attitudes generally.

There can be little reasonable doubt that such goals are desirable, especially in relation to those parts of the world where questions about disability have received little political or public attention. Yet the relevance of IYDP to disablement in Britain may to a degree be questioned. For example, the problems caused by various types of physical, intellectual and cognitive/emotional impairments can differ widely in nature. And their alleviation or solution is in many instances likely to emerge only after a considerable period of effort. It is possible that a single year of 'action' with broad, ill defined goals could in practice draw attention away from or mask the need for sustained, painstaking, unglamorous labour aimed at improving the lot of each discrete section of the disabled population.

Similarly in helping to provide an open platform for virtually any group or individual to expound on problems relating to 'the disabled', IYDP could sometimes add to the confusion in an already complex social and political field. Some authorities (Oliver 1981, Shearer 1980) have suggested the IYDP may prove to be destructive in as much as it could encourage a needlessly passive image of disabled persons as, in a sense, parasites dependent on the care and compassion of the 'able'. It has been argued in this context that initial uncertainties as to whether the International Year should be designated *of* or *for* disabled persons reflected some ambiguity in the minds of its planners.

Such criticisms of and cautions about IYDP are not without content and should not be entirely discounted. However, there appears in balance to them to be a fairly widespread feeling amongst disabled individuals that the Year offers an important opportunity for explaining their needs and aspirations to the public in general and to influential, but often sadly ill informed, sub groups like media commentators and politicians. Indeed, given the cold economic climate currently prevailing in Britain, which may threaten to deprive disabled people of some of the limited gains in living standards they made during the previous decade or so, IYDP may in fact be thought of as a rather opportune event.

In the light of these last considerations, therefore, this *OHE Briefing* is offered in support of the International

Year. Its goals are to present outline data about the nature and occurrence of disablement in modern Britain; to provide a background understanding of the demographic, social and economic developments which led up to the current situation; and to discuss some of the ways in which social interventions and medical or pharmaceutical advances might in future help to lessen the hardships associated with disablement in this and other countries.

The language and meaning of disablement

In popular usage terms like 'the disabled' and 'the handicapped' have no consistent meaning. The former is if anything probably most often used to refer to people with physical limitations – typically the not necessarily representative minority of that population who are confined to wheelchairs. The latter may more often be employed to describe individuals with intellectual impairments or some forms of mental illness (Weir 1981).

Even amongst professional workers there is no universally adopted terminology, although that shown in Table 1 and Figure 1a has gained a significant degree of acceptance, particularly in circles concerned with physical medicine. It is largely based on the work of Wood and his colleagues of the Arthritis and Rheumatism Council Epidemiology Research Unit, who made an important contribution to the recently published WHO classification of impairments, disabilities and handicaps (WHO 1980). As Figure 1b illustrates this scheme can be applied to potentially disabling mental as well as physical states.

Table 1 *The terminology of disablement (as employed in this paper)*

Impairment

This describes specific physical damage whether to the nervous system or to any other part of the body.

Disability

Disability is the immediate consequence of impairment. It can be divided into functional limitations (for example, loss of ability to grip) and activity restrictions (for example, loss of ability to write, wash or feed oneself). The terms disability and disablement can also refer generally to the processes of impairment/disability/handicap described by the disability spectrum.

Handicap

In this paper handicap is used to refer to an individual's loss of a satisfactory social role, whether in their work, leisure or domestic lives. However, in certain instances, as in the widely used phrase 'mental handicap', it has a less precise meaning.

Figure 1a *Disablement – the basic model*

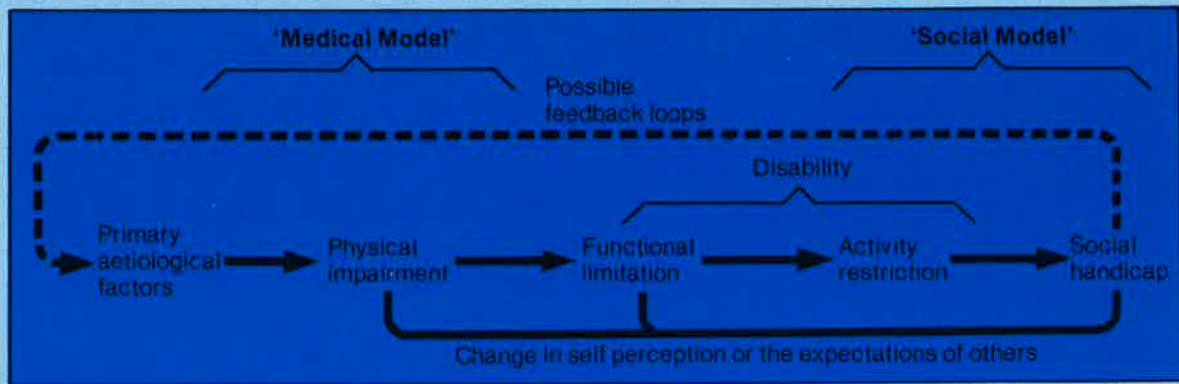
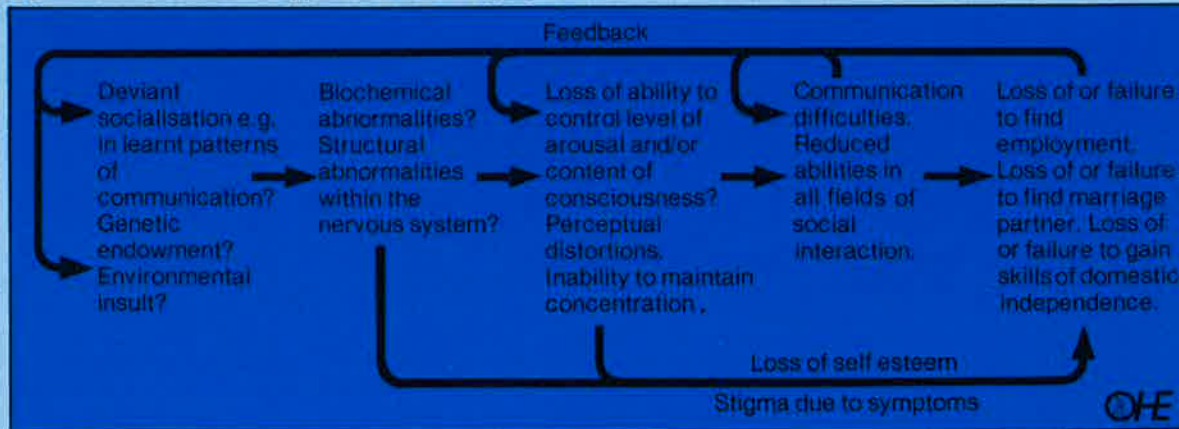


Figure 1b *An illustrative application to schizophrenia*



Source: OHE 1979b

A detailed discussion of the complex practical and theoretical problems associated with classifying and assessing various types of impairment and linked disabilities and social handicaps would be beyond the scope of this short paper. But two points are worth special emphasis.

The first is that perhaps the most crucial distinction to be drawn from Figure 1a is that made between impairment – that is any abnormality of bodily function which leads to physical (e.g. locomotor or sensory), intellectual or other mental disabilities – and handicap, the consequence of impairment and/or disability as experienced by individuals attempting to fulfill their normal social roles. These phenomena are in a sense quite distinct, so much so that traditional ‘medical’ images of disablement orientated towards the disease/impairment end of the disability spectrum may ignore altogether social considerations. Similarly some social models of disability may discount as irrelevant medically orientated factors underlying a given social handicap.

But it is a central contention of this *Briefing* that an integrated view of the disability spectrum is a pre-requisite for the emergence of optimal patterns of care and support for disabled persons. Without it, later sections argue, appropriate boundaries of authority between professional groups and their clients cannot be adequately drawn.

The second point is that it might be suggested that the model outlined in Figure 1a is flawed in as much as it could be interpreted as laying excessive weight on factors within the disabled individual as being ‘the problem’. Writers such as Finkelstein (1980) have argued that disability generally can be seen as ‘a special form of discrimination or social oppression’. Together with organisations like the Union of Physically Impaired Against Segregation he suggests that it is the environment in which disabled persons find themselves that should be seen as the root cause of their major social difficulties.

There is considerable force in this view. In the past ‘rehabilitation’ was all too often regarded as purely a

process by which individuals were trained to adapt themselves and their expectations to the world as it happened to be, never the reverse. Even today such attitudes can be found although efforts are being made to understand disablement in terms of the overall social and economic evolution of the community and of specific environmental barriers, like avoidable restrictions on disabled people in public buildings. Some disabled people now argue that they have a ‘right’ to access and a ‘right’ to an adequate income in the same sense that in civilised society all its members have, say, a ‘right’ to own property.¹

However, with regard to the disability spectrum model adopted in this paper it would be wrong to assume that the disabled individual is intended to be seen as somehow isolated from, or passive in, his or her social, or indeed physical, environment. Attempts to prevent impairing diseases or accidents must, just as much as interventions aimed at controlling disability or avoiding handicap, obviously be based on a sound understanding of the continuous interaction between ‘at risk’ subjects and their surroundings.

Also, in balance to descriptions of disability/handicap as a presumably preventable form of social oppression, it would seem wise to avoid the supposition that social changes alone might one day lead to a utopian state in which all disablement can be meaningfully said to be eradicated. The reality of the problems faced by people with conditions like severe Down’s syndrome or chronic schizophrenia or incontinence associated with mental impairment in old age is such that the provision of sustained individual care and support aimed at alleviating their distress and compensating for their (and often their family’s) undeniable loss and disadvantage seems to be the most relevant response a civilised society can make.

1 It is of note in this context that strong people are not normally said to be acting out compassion when they refrain from robbing their weaker fellows. Rather they are said to be behaving in accordance with civilised values.

Figure 2a Death rate of infants under 1 year per 1000 live births and live birth rate per 1000 population, England and Wales, 1841 to 1980

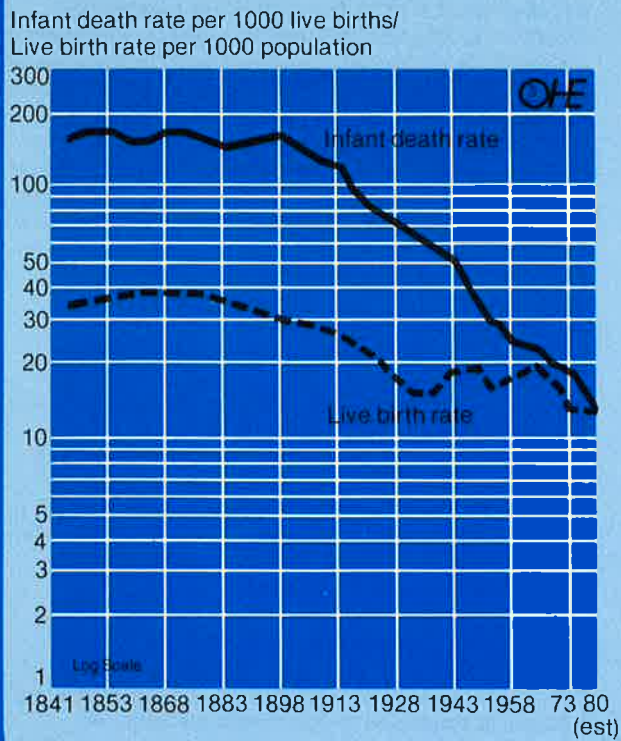
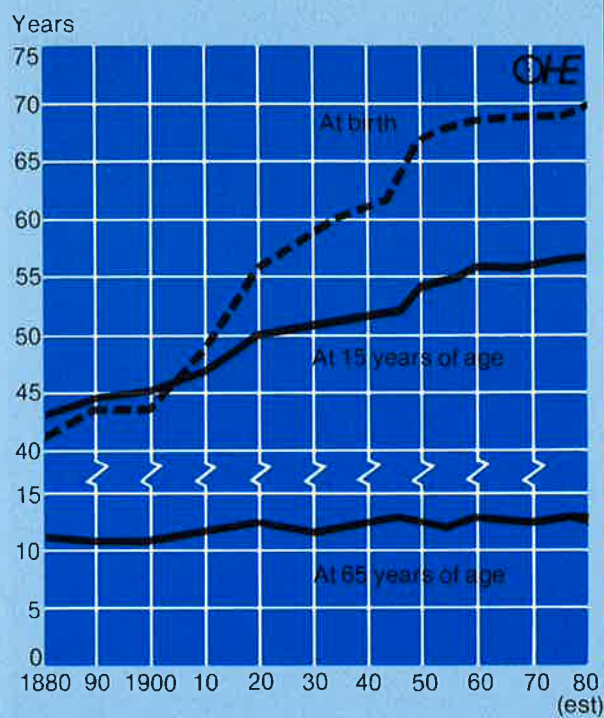


Figure 2b Life expectancy at birth, at 15 years and at 65 years of age for males, 1880-1980. England and Wales.



Source: Registrar General

The disability transition

The pattern of disablement now seen in Britain differs fundamentally from that which existed in this country a century ago, and that which still exists in most of Latin America, Asia and Africa. An understanding of the disability transition which underlies this shift and divides the disablement problems of the 'developed' and 'less developed' states helps the formation of appropriate beliefs and expectations about disabled people and the types of care and support they need in Britain today.

Demographically, the outstanding characteristic of the rich industrialised nations is that they have low, stable death rates and low, slightly less stable fertility rates as compared with poor, agrarian based societies. These usually have high, fluctuating mortality levels and high, more stable, fertility. The change from the latter to the former is normally termed demographic transition, although this should not be thought of as an entirely uniform process. Different cultures have experienced it, or may in future experience it, at different stages of their progress and in different ways. For example, France underwent demographic transition early, in the eighteenth century. Whilst Japan's population structure has still not fully taken on a post transitional form, despite very rapid changes in the last few decades.

However, for the purposes of this *Briefing* Britain's experience may be thought to typify demographic transition. As Figures 2a, 2b and 3 show, the last hundred years have seen a drop in infant and child mortality leading to a rise in average life expectancy, coupled with declining fertility and, consequently, a marked increase in the proportion of the population in the older (65+) age groups. A point to stress is that environmental changes such as clean water supplies and improved sanitation and diet, affordable because of industrialising Britain's late nineteenth century wealth, were the initial and main motors underlying this change. Modern medicines like antibiotics, vaccines and oral contraceptives were only of fundamental significance towards the end of the process.

These demographic and associated health developments – the most important of which has been the control of many forms of infectious illness, like tuberculosis – have

Figure 3 The age structure of the UK population, 1900 and 1980

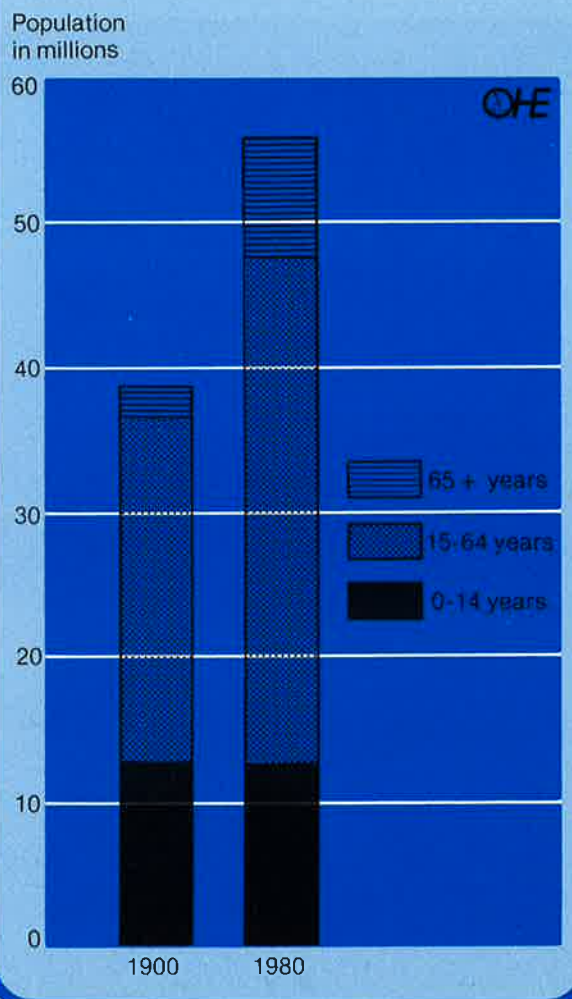
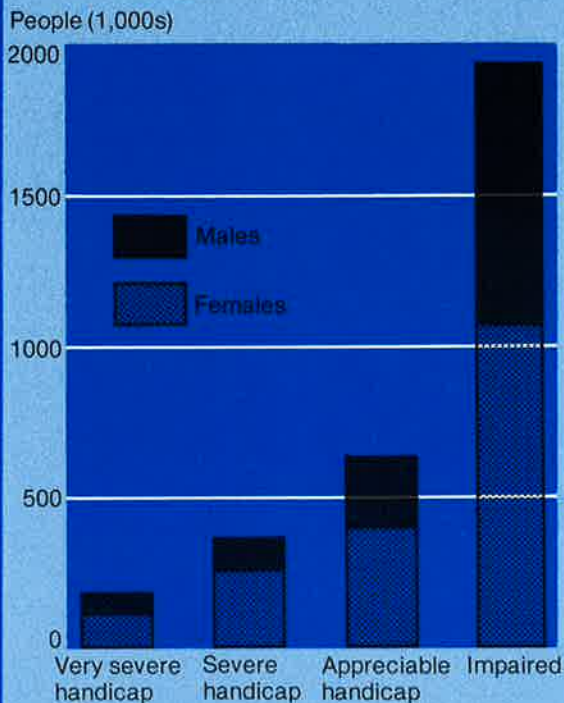


Figure 4 *Handicapped and impaired adults in the community*



Notes The Harris criteria of 'handicap' were:

Very severe: In need of permanent special care. For example, bed-fast or chairbound, unable to feed or use the lavatory independently.

Severe: Find 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

OHE

in turn promoted a dramatic shift in the incidence and causes of the most frequent types of disability in society. This may be termed disability transition (Taylor 1979a).

Most people can now expect to live through their first five decades of life free from physically incapacitating impairment. Diseases like multiple sclerosis, which strikes the relatively young and is not yet effectively treatable, are today an exception. Even the burden imposed by traumatic injury has been cut, in part because of the enhanced capacity of surgery to repair the consequences of events like road accidents and in part because Britain has avoided involvement in a major war for approaching forty years. But instead the population survives in proportionately large numbers to face the chronic disabling conditions of later life. These include Parkinson's disease, arthritis, bronchitis, heart diseases and the neurological impairments caused by strokes.

In the fields of psychiatric distress and intellectual impairment disability transition has perhaps been less clearly marked, although factors like reduced family size, the changed nature of work and the gradual demystification of mental disablement associated with effective treatments have all significantly affected the nature of such states. And as with physical impairment the ageing of the population has had a strong influence. The various forms of dementia are now the most common problem facing the psychiatric services.

Disablement in modern Britain – the figures

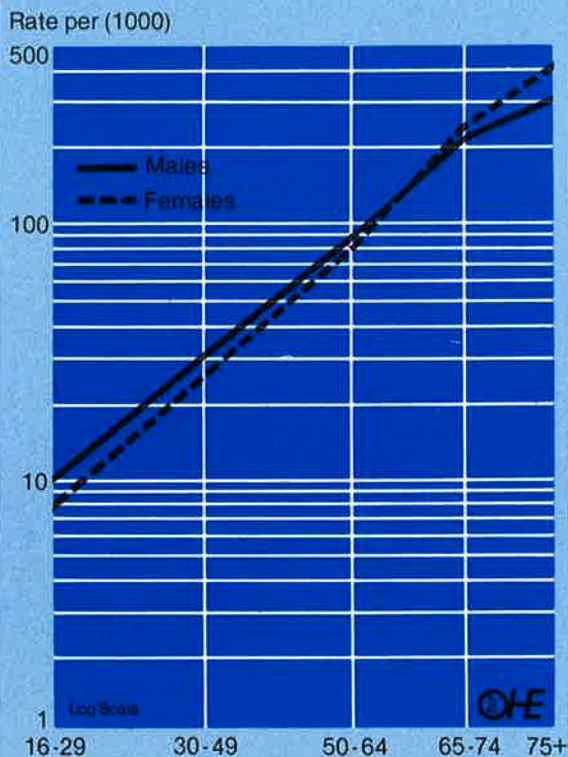
The first national survey of handicap and impairment in Britain was conducted by Harris and her Office of Population Census and Survey (OPCS) colleagues in the late 1960s. This had the main goal of assessing potential demand for new social security provisions then being planned (Harris et al 1971). They reported that just over 3 million people over sixteen living outside institutions (8 per cent of those 'at risk') were impaired in some way. Of these roughly 1 million were said to be handicapped, which in the context of the OPCS' work meant that their ability to care for themselves adequately was somehow reduced.

Figure 4 illustrates these findings, whilst Figure 5 emphasises the close relationship between age and disablement revealed by Harris. Figure 6 shows that even in younger handicapped people (those aged 16-65) it was most often 'degenerative' states often associated with ageing which were the cause of disablement.

For the practical purposes for which this survey was designed, that of identifying people needing special assistance in their home context, its results were of unquestionable value. Similar investigations conducted subsequently, such as many of the local authority surveys commissioned in response to the requirements of the 1970 Chronically Sick and Disabled Persons (CSDP) Act, have confirmed its general findings (Warren 1980, 1981). For example, Warren and Knight (1978) calculated on the basis of an aggregated collection of CSDP surveys that only 0.5 per cent of the population under 16 is appreciably or severely handicapped in Harris terms as compared with 1 per cent of those aged 16-64, 7 per cent of those aged 65-74 and 30 per cent aged over 75. Hunt (1978), in an OPCS survey of the elderly at home, also confirmed this age gradient in disablement, although arguing strongly that nine out of ten old people can in fact get around reasonably well. She claimed that in today's society the conventional retirement age is not for most people a reasonable indicator of the start of physical old age. Seventy five or older is more appropriate.

Yet the Harris criteria of handicap ignored many problem areas important to younger persons in particular like, say, employment difficulties. Also individuals with many forms of sensory or mental incapacity would not have been identified. And children and people living in institutions were outside the scope of the enquiry. Thus the OPCS work cannot be said to provide a fully comprehensive view of the occurrence or nature of disablement in modern Britain. Additional sources of information include specialised epidemiological studies, data from abroad and

Figure 5 *Age specific impairment rates per 1000 people in the community*

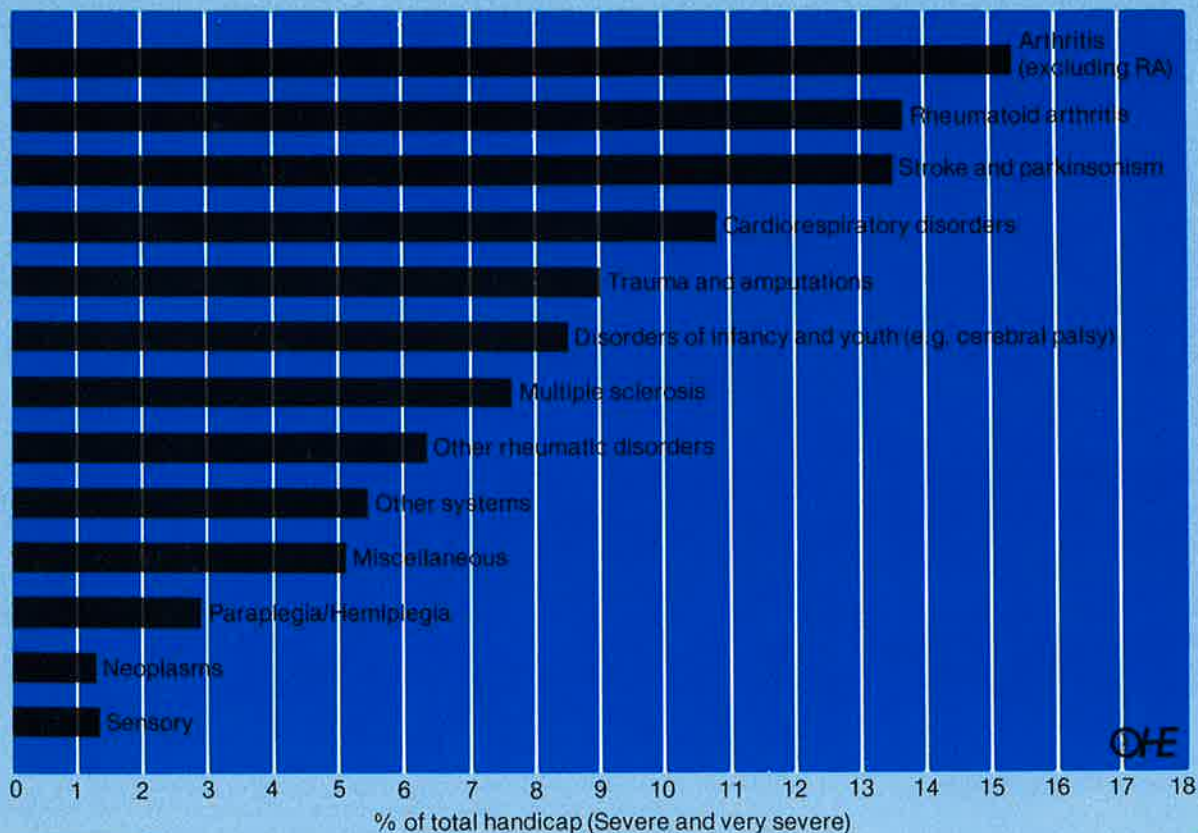


Notes In the population aged 16-50 approximately 49 per cent of the total are females.
In the population aged over 75, 69 per cent are females.

Source: Harris 1971

OHE

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



Source: OHE 1977

more broadly based British surveys such as Townsend's (1979) *Poverty in the United Kingdom*.

Regarding the first of these areas, OHE has over the past twenty years collected information on many diseases from a wide variety of sources. Its work almost without exception suggests that impairment rates are higher than the Harris survey might be taken to indicate. For instance, the latter found 22,000 people to be impaired by Parkinson's disease. The OHE estimate (OHE 1974) is in the order of 70,000. For multiple sclerosis the relative figures are 24,000 as against 50,000 (OHE 1975). For epilepsy, 21,000 as against some 300,000 (OHE 1971). And Harris reports 55,000 people impaired with asthma, only about one tenth of the number who have the disease in some form (OHE 1976).

Data relating to conditions like hearing impairment or migraine (OHE 1972) shows even more striking discrepancies. Whilst with regard to mental impairments the OPCS research shows only 100,000 people so affected living in the community. In totality, however, the population with forms of dementia alone is probably in the order of 700,000 (OHE 1979a). Three hundred thousand or more are severely disabled. That for severe mental handicap is in excess of 150,000 (OHE 1978), and that for long term, potentially disabling, schizophrenia over 100,000 (OHE 1979b).

Turning to surveys conducted abroad, these would again suggest that the impairment rates reported by Harris were low and that different handicap criteria would reveal, as might be expected, a much greater working age population of disabled persons. A notable illustration is provided by the work of the United States Social Security Administration, which has included disability related to employment in its investigations. It suggests that one American in seven of working age can be considered disabled, with people belonging to racial minorities and/or of low educational status being especially at risk (Haber 1973).

The overlap between various forms of material and social disadvantage and biologically based impairments is also suggested in Townsend's (1979) research, although in

general the Black report (1980) stressed the inadequacy of British data relating disablement and social class. Townsend reported handicap and impairment rates three times higher than those found by Harris *et al*, with both his figures and those of the General Household Survey implying that one in ten of the total population is significantly limited in either self care or the undertaking of household tasks.

In summary, it therefore appears that it is not possible to form an absolute, clear cut picture of the size and make up of Britain's disabled population. Rather, the context in which disability is being studied has first to be defined. For the purposes of this paper, which is primarily orientated towards looking at the problems of persons sufficiently impaired to require help even in basic independent living, Table 2 shows the number handicapped to be in the order of 2.25 million. But Table 2 also indicates that if difficulties such as those linked to occupation and poverty are considered the population 'at risk' is at least twice and possibly four times greater.

Transitions in care?

In feudal and medieval Britain support for the poor (who often became sick and/or disabled) and the sick and disabled (who even if not born in poverty were likely to die in it) was provided only by their families and/or their immediate communities, backed sometimes by the institutions of the church. However, the start of the seventeenth century saw the beginning of more formal, secular influence in this field with the passing of the 1601 Poor Law Act.

Against a background of gradually weakening religious authority, in part related to the start of the 'agrarian revolution' and changing patterns of land ownership in Tudor England, this empowered local government to provide food, shelter and where appropriate work for poor, and disabled, people. Such services were to be paid for by a locally raised rate.

For upwards of two centuries this system, operating in conjunction with informal familial and related support networks available in the community, worked tolerably

Table 2 *The numbers of disabled people*

<i>Physical disability</i>	
Significantly or severely handicapped in a normal domestic environment	There are probably around 1.6 million people in this category today. Some 300,000 are in institutional care and 100,000 are children. This group is strongly heterogeneous in that the interests and problems of, say, the 100,000 or so registered blind may differ considerably from those of the similar number of wheelchair bound people. But recently awareness of common needs in relation to issues like income support has grown.
Disadvantaged in some situations	According to Harris' criteria some 2 million adults come into this category. But other acceptable approaches would put the figure nearer to 5 million. It is of note, for example, that some 4 per cent of the entire population suffers some form of hearing impairment.
<i>Emotional/cognitive disability</i>	
Significantly or severely handicapped in a normal domestic environment	There are perhaps 500,000 people in this group, some 60 per cent of whom suffer some form of dementia. In addition conditions like schizophrenia and the depressive psychoses affect several hundred thousand individuals at any one time, although with modern attention many experience only acute distress rather than long term major disablement.
Disadvantaged in some situations	Epidemiological research suggests that in any one year at least 5 million people in Britain suffer a temporary period of mental illness. The number whose 'life chances' are significantly impaired by such conditions (through, for instance, a consistent inability to withstand the mental stress of work, academic or family life) is unknown but probably high, in the order of at least a million individuals. In addition there are perhaps 350,000 mildly demented people.
<i>Intellectual disability (mental handicap)</i>	
Significantly or severely handicapped in a normal domestic environment	There are around 150,000 severely 'mentally handicapped' people according to official data, about a third of whom are children. However, only 20,000 or so are completely incapable of self care in an appropriate environment. Some 70 per cent of all mentally handicapped adults are continent, ambulant and do not need constant supervision.
Disadvantaged in some situations	Mild mental handicap, as defined by conventional IQ criteria, affects around 1.25 million people in Britain. Most are not, however, officially so identified. This may be in some respects a good thing, although it means that unidentified intellectual impairments may underlie many events in the employment, educational and general social markets.

Note: There may be overlaps between all three categories of handicap and impairment.

well, although it should not be assumed that the lot of 'paupers', 'lunatics', 'idiots' or 'cripples' was particularly desirable in the near subsistence economy of Britain 200-300 years ago. Unchecked disease and premature death often went hand in hand with superstition and irrational prejudice. Simple stupidity may have been (or be) more acceptable in unsophisticated rural communities than it is in twentieth century Britain. But visible, gross physical abnormality or bizarre behaviour, especially in a stranger or persons otherwise not thought entitled to receive support from the local rate, was likely to give rise to reactions ranging from derision to hostility to even overt hatred or terror of those so 'marked out by God or the Devil'.

By the early 1800s the processes of industrialisation and the shift of population off the land had accelerated to a point where the old Poor Law system was virtually overwhelmed, at least in urban areas. At the same time increased mobility exacerbated social problems by weakening family and related caring capacities. Victorian Britain's official response was to place more overt emphasis on social control in its Poor Law arrangements. In effect out-door (community) care was abandoned and segregated, near punitive workhouses substituted. Many sick and disabled persons who had the misfortune to be poor either found themselves in such conditions, or in the Poor Law hospitals and local authority asylums built during the nineteenth century. Figure 7 shows the steady increase in mentally ill residents of such institutions, a rise paralleled at a rather later date by increases in the institutional confinement of intellectually impaired people.²

Hence as Britain entered the present century it was

2. In addition to providing shelter for vulnerable people who would have found it difficult to survive unaided in a society shifting towards an urban, industrial pattern of life and work institutionalisation of 'the mentally handicapped' was in part a paradoxical effect of Victorian science. Poorly formed ideas about inheritance and evolution led to a fear that free circulation of certain sections of the population would undermine the 'genetic stock' of the British community (OHE 1978).

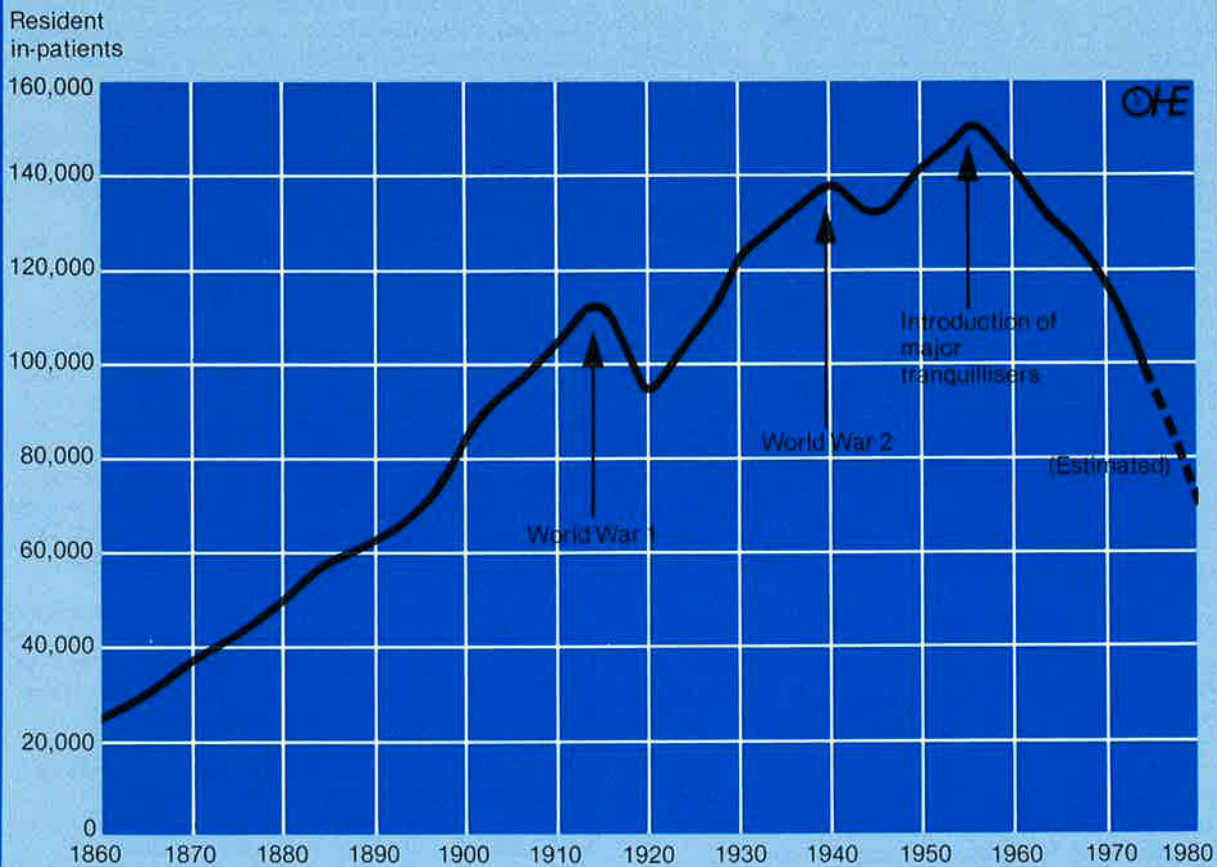
developing a pattern of care which made many groups of disabled persons more separated from the rest of the community than had previously been the case. In part this, like the growth of charities and insurance funds, was an attempt to compensate for fractured patterns of informal community support and to face up to the new types of problem brought on by industrialisation and the first stages of demographic/disability transition. But it represented an in some ways unfortunate inheritance of concepts and facilities for subsequent generations of services to be based on.

The formation of Britain's NHS in the 1940s followed on from the final break-up of the old Poor Law system in the late 1920s and the extension of local government health care provisions in the following decade. In integrating the latter with the previously poorly linked or discrete services given by family practitioners and private and public hospitals it offered the possibility of a radically new, less segregated, pattern of care and support for sick and disabled people, particularly as the 'welfare state' promised a whole range of additional forms of help in areas like income, housing and education.

In practice, however, progress was limited. It is of course true that most people benefited from Britain's increased wealth in the 1950s and 1960s, as did the populations of other economically expanding developed nations. It is also true that new medical technologies, mainly vaccines and medicines, led to enhanced control of infections such as polio and tuberculosis and conditions like arthritis and blood pressure. They also helped to initiate new patterns of care. For instance, the mid 1950s commencement of a fall off in the mental illness hospital population shown in Figure 7 was in a considerable part facilitated by the introduction of major tranquillisers. But with regard to services for the disabled overall the period 1948-1970 may be thought of as in many ways disappointing. The main underlying reasons for this may be summarised as follows:

a) Services for the support of disabled and chronically ill

Figure 7 *In-patients resident in mental illness hospitals – England and Wales 1860-1980*



Source: Taylor 1979a

people were not the major priority set for the NHS and kindred welfare services at the time of their formation. Rather acute care and the abolition of ‘reservoirs’ of curable illness were the central perceived goals.

b) The implications of ‘disability transition’ were not understood, even by those working in the area of rehabilitation. The dominant model of disablement remained that either of the ‘crippled’ child or the wounded soldier, both of who need services are very different from the type of maintenance rehabilitation required by older persons with progressive illnesses.

c) The fragmented organisational structure of the welfare state made the provision of adequate care difficult. NHS services were (and to some extent still are) split between hospital, family practitioner and community services, in addition to which there are facilities such as the Artificial Limb and Appliance Centres administered by DHSS. Local authority departments such as housing and social services were (are) separate again as were (are) employment services. And charitable and voluntary services can come from a bewildering number of sources.

d) The political and general social environment remained in a sense hostile to suggestions which would entail changing fundamentally living conditions and the ways of life open to disabled people. This was in part because of a lack of basic information, in part because of superstitions or other forms of inhibition which made topics like sex and, say, the intellectually impaired adolescent seem ‘taboo’ or disturbing and in part because of economic restraints. Also organisations like charities claiming to represent ‘the disabled’ or ‘the elderly’ often failed to express their interests clearly and/or pursued sectional interests at the expense of the overall disabled population. Charities receiving state grants may also have served to confuse people’s perceptions of their ‘rights’ to and the financial basis of some types of care.

e) The growth of health and other welfare services was associated with increasing problems of professionalisation.

These included demarcation disputes between various disciplines and potentially destructive processes related to concepts such as Illich’s ‘social iatrogenesis’ and Seligman’s ‘learnt helplessness’. At centre, these imply that professionals sometimes undermine instead of building up disabled people’s own sense of authority and independence, taking unnecessary control of their clients’/patients’ lives and helping to break up vital informal support systems in the community.

Appropriate help – current issues

Against the above background developments at the start of the 1970s such as the Seebohm reorganisation of the social services (despite its negative association with ‘genericism’ and the loss of specialist skills), the passing of the Chronically Sick and Disabled Persons (CSDP) Act and the reorganisation of local government and the health service can all be seen as measures in some degree relevant to the improvement of services for disabled people. Throughout the decade debate on topics like ‘integration’ and ‘normalisation’ developed, and a growing intellectual basis for more effective and humane forms of care, perhaps particularly for severely disabled younger persons, was established.³ In several areas genuine service improvements emerged.

³ This debate has been, however, somewhat confused and lacking in sociological or economic foundation. It may in this context be useful to explore Max Weber’s theory of social exclusion (which postulates that exclusive behaviours are essential to the function of most human groupings) in the context of disablement. It casts light both on the mechanisms by which inappropriate segregation can occur, and also shows that in certain circumstances disabled people themselves need to display or may benefit from exclusive behaviour. Total ‘inclusion’ is a concept of questionable value, although many commentators use such terms in so undefined a manner that it is difficult to understand precisely what they are advocating. Perhaps the most valuable point to stress is that situations in which disabled persons are ‘out of sight’ and so liable to be deprived of what are seen as basic rights common to their peers in the general community, as in closed institutions or even isolated family care, are obviously undesirable.

Table 3 Social Security Benefits for Disabled People (1975-83) cost in £millions 1980 and numbers claiming (100,000s)

	1975/76	1980/81	1983/84 (projection)
Invalidity Benefit	£735 (470)	£1034 (650)	£1140 (670)
Industrial Disablement Benefit	£237 (200)	£246 (200)	£260 (200)
War Pensions (Disablement and Widows)	£424 (110)*	£368 (90)*	£360 (75)*
Attendance and Invalid Care Allowance	£146 (200)	£214 (300)	£500 (180)
Non-contributory Invalidity Pension	£19 (105)	£90 (170)	
Mobility Allowance	£- (-)	£109 (190)	(220)
Supplementary Benefits for Disabled people	£215 (-)	£190 (-)	£230 (-)

*Figures in parenthesis relate to numbers claiming War Pension for Disablement only.

Source: Cmnd 8175.

For instance, new forms of economic assistance were introduced, including the attendance allowance (1971), non contributory invalidity pension (1975), mobility allowance (1976) and the invalid care allowance (1976). Table 3 provides data relating to such payments, which in constant terms rose in value by more than three times in the 1970s and now stand at over £2,000 million (£1980). Social service spending on provisions like aids and adaptations covered by the CSDP Act climbed even more swiftly. Yet as Table 4 summarises it is an unfortunate truth that there remain significant limitations in virtually every aspect of the help British society provides for its disabled members. These have if anything increased as a result of the country's current economic situation.

The impact of the latter can be seen in a number of areas, from certain political responses towards the disabled (for instance, that they should not be 'insulted' by being 'denied participation' in the financial stringencies the community is having to suffer) to the practical problems being faced by care providers such as social service departments (SSDs) and the limited scope of legislative reforms which have been presented for consideration by Parliament in IYDP. In this last context it is of note that neither of the two measures recently before the House, one a private members bill mainly representing a strengthening of the CSDP Act's provisions an access and the other a government response to the Warnock report's recommendations on integrated education, involve any mandatory allocation of new (or reallocation of established) resources. Whatever their theoretical significance their practical value is not likely to be great in the immediate future.

Regarding the problems faced by the LA social services recent reductions in spending (a roughly 7 per cent 'real term' cut in 1980-81 probably followed by a further small drop this year - Cmnd 8175) have threatened those forms of care supplied to disabled people under section II of the CSDP Act. These include home helps, aids and adaptations to the home, telephones and assistance with holidays.

Commentators such as Topliss (1980) and Keeble (1981) stress that even before the late 1970s there were major variations between different LA's levels of provision. Since then additional inequities, such as locally determined charges for services, have been imposed and some areas have simply frozen the supply of new, or even effectively withdrawn existing, facilities. The number of people not

receiving the full help the CSDP Act might theoretically entitle them to can realistically be estimated as being in hundreds of thousands.⁴ Despite attempts to challenge local authorities which fail to meet their albeit ill defined statutory obligations (Keeble 1981), this situation is unlikely to be remedied in the foreseeable future.

The economic crisis also means that, despite joint funding arrangements between health and local authorities, extensions in community based provisions for groups like the mentally disabled will be limited. Given the virtual freeze on NHS resources the prospect of reducing inappropriate dependence on institutional care seems to have receded.

Possible alternatives or supplements to the existing pattern of support for disabled people who are trying to live independently in the community include increasing their financial benefits, so enabling the direct purchase of needed services, and encouraging informal or voluntary care. Both these strategies have attractions. The first, for instance, may in opening up the opportunity for a more market orientated allocation of care resources increase disabled people's control of their own lives and so counter bureaucratic and excessive professional dominance. The second might act in similar manner as far as limiting 'official' interference is concerned.

But neither are without disadvantages as well. Individuals cannot always make informed choices, and there may well be limits to the acceptability of market behaviour and the principle of 'caveat emptor' in relation to the care of the disabled. Families, volunteers and charities can be authoritarian and insensitive, just like some bureaucrats, doctors, nurses and social workers. And neither raising disablement incomes nor expanding significantly charitable or other forms of non-state support is likely to be possible without public sector resource costs.

For example, even where a disabled individual has a relative willing and able to help them significant income losses and personal sacrifices may often be incurred. Compensation, either in cash benefits or in the form of back-up services like the Crossroads Care Attendance Schemes now in operation, needs public money (Osborne 1981). And any idea that there is a sufficient reserve of voluntary labour or capital available to make major inroads into today's central care problems is of somewhat dubious validity.

Not only might disabled persons themselves question the desirability of being dependent on such potentially capricious aid (Large 1981). The financial position of many charities, a significant proportion of which already require central or local government funds to survive, is such that they are unlikely to be able to independently extend their services to any great degree. Recent appeals regarding value added tax payments and competition between NHS and charitable fund raising activities underline this point.

It thus appears inevitable that whatever the strategy adopted key improvements in social and allied care for disabled people in Britain will depend on political decisions regarding its funding, and so in turn will involve choices between priorities right across the spectrum of state activities. But in a time of high unemployment, when the economy cannot in conventional terms productively employ all the 'able bodied' labour available, it may be difficult to convince policy makers of the wisdom even of investing in areas like jobs for younger, less severely disabled individuals. And suggestions such that often costly rehabilitation should be aimed at successful retirement rather than a return to work or that 'man hours' can as deservedly and profitably be devoted to old women as they can young men may be harder still to implant in the 'mind' of government, however strong that the case for such views may actually be (Taylor 1979b).

⁴ Topliss (1980) mentions Cambridgeshire, Buckinghamshire and Lincolnshire as being poor care providers in 1978. Keeble (1981), whilst working on a joint project involving 14 national charities, was involved in cases of failure to assess needs or to supply or to continue supplying statutory assistance in localities including Wandsworth, Hampshire, Essex, Oxford and Richmond.

Table 4 *Services for disabled people*

Access/Mobility

Provision in this area cannot be the responsibility of one single service giver. Significant factors range from the availability of aids like wheelchairs to the provision of ramps in public and private buildings, the removal of high kerb stones, the appropriate design of public transport vehicles like buses and the judicious placing of 'street furniture'. The 'mobility allowance' provides significant financial support for around 200,000 very severely disabled younger people. It has risen relatively rapidly in value in the last few years, in line with the high costs of motoring reflected in the 'motorability' scheme for disabled drivers. But many less disabled persons capable of walking only short distances, or who happen to be over retirement age, receive no special assistance.

Education

Officially some 2 per cent of Britain's school age population (a little under 200,000 individuals) are classified as handicapped, although perhaps 15-20 per cent are in need of some form of special educational help. Over 80 per cent of the former group are in segregated schools. Following the Warnock report government has moved towards recognising the need to 'integrate' more fully the education of many such children with that of their able bodied peers, both on academic and social grounds. However, some commentators (see, for example, Low 1981) fear that lack of economic resources and confused philosophies of support mean that little real progress is likely to be made in the foreseeable future.

Employment

Of the half a million plus individuals on the MSC register of disabled people over 15 per cent are unemployed, about twice the national average figure. At present the quota scheme established by the 1944 Disabled Persons (Employment) Act is under review, as has been the future of the Disablement Resettlement Officer Service and that of certain Employment Rehabilitation Centres. Yet it seems unlikely that any radically new pattern will emerge. A key point is that government policy generally has concentrated on 'lubricating' the existing employment market rather than attempting to create significant numbers of jobs 'tailor made' for groups like mildly mentally handicapped people. A case can be made for a considerably more interventionist policy, especially in periods of lower overall employment levels. However, this may involve regarding 'jobs' as commodities in themselves, rather than merely a means to producing valued goods.

Housing

In the period 1970-75 only one purpose built dwelling was completed for every 400 disabled individuals defined by the OPCS as in need of rehousing. Since then, with economic recession, the rate of provision of either new homes or even of adaptations may have dropped. For instance, *Shelter* recently noted that in 1980 the number of 'starts' on disabled housing units was down by about a third on the previous year. In the case of home adaptations the recent imposition of charges by a number of authorities may have discouraged some clients from proceeding with requests for such assistance.

Income

Financial support for disabled persons and their families increased through the 1970s, although groups such as the Disability Alliance and the Disablement Income Group still stress the need for a comprehensive disability income designed to cover the special expenses that disability imposes as well as lost earning capacity. Estimates of the additional costs of such a scheme vary between £1,500 million and £3,000 million. Its advantages would include the possible elimination of inequities relating to assessment for benefits like housewives non-contributory invalidity pension (married women are at present subject to particularly stringent criteria) and the poverty trap suffered by partially disabled people of working age. A government study of this area has recently been re-initiated, and should eventually lead to a green paper.

The role of medicine and medicines

The role of medical interventions in the context of disablement is often misunderstood, both by disabled people themselves and by those working in health and other welfare services. Commonly held doubts and misconceptions centre on questions like the poor past record of some older hospitals for impaired/handicapped people, and the consequent fear that inappropriate institutionalisation may stem from the exercise of unjustified medical control; the supposition that it is the 'fault' of modern medicine that so many people survive to be disabled; and the belief that the hazards of modern medicines are such that they may in themselves prove to be a major cause of disablement.

Such uncertainties are understandable and not without foundation, particularly in regard to some aspects of medical authority over the people they work with and the patients who doctors derive their social status from by helping. Also it is true that in some cases sophisticated medical care prolongs lives which involve much suffering. Yet as data presented earlier in this paper implies it was environmental change, not medical progress, which initially led to the disability transition of the last century or so. In respect to the dangers of medicines it is again true that there are examples, most notably the thalidomide tragedy which affected some four hundred British families, of pharmaceuticals promoting physical or mental impairment (OHE 1980).

But in balance to this last point recent experience seems to suggest that (as in the recent debates over topics like whooping cough vaccination, the risks of minor tranquillisers and anti-peptic ulcer medicines, the control of severe nausea in pregnancy, and the possible use of interferon in cancer) such 'medical' stories can be wrong or exaggerated. Factors involved include the commercial interests of the media and the career interests of individuals.

More importantly it can in addition be argued that the contributions of medicines, vaccines and surgery in fields like arthritis, the control of blood pressure and heart disease, epilepsy, asthma, Parkinson's disease, schizophrenia, depression, polio, venereal diseases and tuberculosis have already done much to help prevent the 'social death' of people who otherwise would have lived in considerable pain and isolation. Future research may bring gains such as the further prevention of circulatory diseases and strokes, alleviation of potentially damaging addictions and the control through immunisation of conditions like malaria and leprosy, which are still major causes of impairment in much of the world.⁵

A detailed analysis of the risks and benefits of medical care in relation to disablement would once again be beyond the scope of this short paper. But some key points can briefly be considered under three headings:

Primary prevention: *that is, prevention of impairment either by avoiding or eliminating primary aetiological factors.*

Secondary prevention: *defined as limiting the disabilities which a given impairment may give rise to by its treatment or correction.*

Tertiary prevention: *avoiding social handicap consequent on the disadvantages imposed by impairments and disabilities.*

Primary prevention tends to receive more popular attention than the other forms, especially with regard to its possibilities amongst babies and children. This is in many ways reasonable. Obviously reductions in impairments like congenital deafness (by rubella vaccination), neural tube defects (through prenatal screening and possibly dietary

⁵ The multinational pharmaceutical industry has played and will play a central part in such progress, together with scientists in academic and medical environments. For instance, the major tranquillisers resulted from a primary initiative by a French company. The enhanced control of asthma is largely a result of British research by a company which recently incurred heavy losses in trying to improve still further its products. Levodopa, used in Parkinsonism, was isolated before the first World War by the Swiss company which participated in its introduction into the therapeutic armory in the late 1960s. Current research on prostacyclins in relation to atheroma stems from investments made largely by a British company.

supplements for 'at risk' women), Down's syndrome (pre-natal screening), cerebral palsy and some other forms of mental handicap (better pre-natal and obstetric care) are desirable. And it is true that in certain instances UK services could be improved. For example, the rubella vaccination programme has in some respects been disappointing. And Down's syndrome screening is often obtainable only by mothers aged over thirty nine or forty despite the fact that an impressive case for its availability to younger women, say thirty five and over, can be made.

But there are some cautions to be noted. In certain cases the risks of screening or other techniques are significant and/or the costs of such procedures genuinely prohibitive. This may apply, for instance, in the case of recent calls to extend screening for adolescent scoliosis to all children (Leaver et al 1981). Also, despite support from organisations such as the Spastics Society, the recent (1980) report from the House of Commons Social Services Committee on preventing perinatal and neonatal mortality (and impairment) might be accused both of overstating the case for some forms of sophisticated intervention and of simplifying the social, economic and epidemiological issues involved to an excessive degree (Chalmers 1981, Cmnd 8084, Baird 1980).

It may also be suggested that as regards adults, amongst whom chronic illnesses are by far the main cause of disablement, the opportunities at present open for primary prevention are limited mainly to areas like improving work and road safety, assisting people to avoid eating and drinking excessively and eradicating cigarette smoking.⁶ This last would significantly affect some impairment rates, but overall the impact would not be as great as some commentators imply. In addition it should also be noted that primary prevention by life style changes is by no

6 It is in some ways a reflection of questionable values that the most common link made between smoking and disability relates to women endangering unborn children by using cigarettes in pregnancy. This is not to deny the hazards of the latter. But smoking is, in addition to the major preventable cause of premature mortality, the cause of much bronchitis, emphysema and heart disease. This burden is likely to fall more and more on women in the future.

means always the 'good buy' it is frequently assumed to be. Bury and Wood (unpublished) have noted that when it is possible 'cure' might often be cheaper.

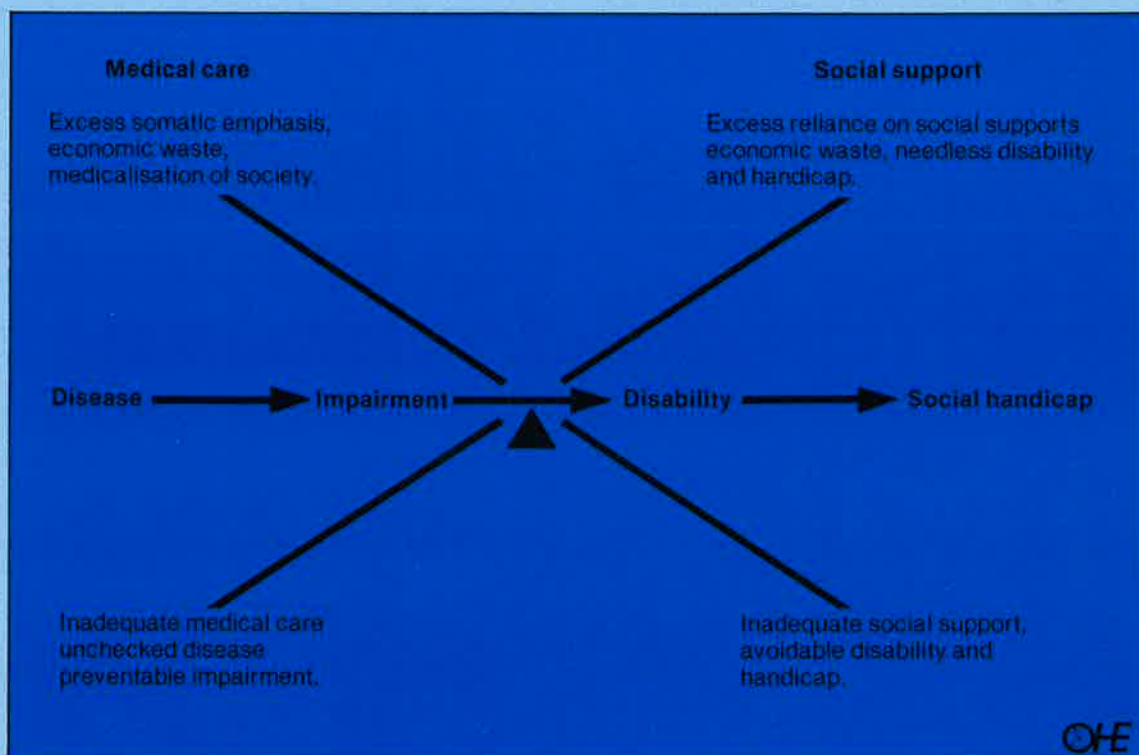
Turning to secondary prevention 'maintenance rehabilitation' of people with chronic and potentially progressive conditions should be considered by far the most important challenge confronting the medical services. Diabetes is an example of the type of condition where good medical advice and the prompt control of symptoms may help to stop disabilities (and more severe secondary impairments) emerging. Nevertheless, in some instances secondary prevention may lead not only to the avoidance of disability and subsequently handicap but also to the virtually complete correction of a given impairment. One of the most celebrated examples of interventions which may fall into this category is total hip replacement.⁷

However, too much emphasis should not be placed on the purely mechanical aspects of treatment. To be fully effective even joint replacement needs to be coupled with rehabilitative training at a functional level and help with the individual's re-entry into the social world. In this context the 1971 Harris survey figures showed that 80 per cent of all impaired persons in that sample were being prescribed medicines, and 50 per cent had seen their family doctor in the month prior to being questioned. These observations stress the potential importance of the gateway role that doctors in general and general practitioners in particular may play in providing a path to contacting other welfare services.

Tertiary prevention – the avoidance of social handicap – is the area in which traditional medical authority is most

7 It has been calculated that in economic terms the overall costs of hip replacements are outweighed by benefits in a ratio of around 4:1 (Taylor 1976). This may make the apparent shortfall of NHS facilities in some localities difficult to understand. But an important general consideration in the economics of disablement is that the section of society which bears the costs of care is often not that which experiences the benefit. For instance, the state pays for health care from taxes from the 'able bodied'. But it is the disabled and their families who receive the main benefit, whether in terms of reduced distress or increased income. Such transfers are inherent to most forms of disability care and the questions 'whose cost?' and 'whose benefits?' underly many policy debates.

Figure 8 The care balance



likely to be challenged. This is often for good reason. For 'medical' models of disablement which focus only at the disease/impairment end of the disability spectrum are virtually bound to lead those who use them to ignore many vital social needs of disabled individuals. Turning 'people into patients' can obviously be extremely destructive.

But at the same time a failure to adequately integrate medical knowledge and skills into the overall pattern of support available to 'the disabled' can lead to ineffective services and needless distress. To take a simple example from psychiatry, a proportion of people with schizophrenia have extremely low tolerances to certain forms of social stress which they experience as distressingly intrusive. Attempts to 'normalise' their lives by 'including' them more extensively in ordinary social interaction are unlikely to be successful. Institutional support may sometimes offer a desirable form of sanctuary. It is thus to be hoped that phenomena like inter-professional disputes over status do not stand in the way of the formation of comprehensive views of the entire disability spectrum and appropriate, flexible boundaries of service interaction. Aspects of the need for a 'care balance' based on this observation are illustrated in Figure 8.

Conclusions – after IYDP

The outline of the development of care and support for disabled people in Britain presented in this *Briefing* can, after Finkelstein (1980), broadly be seen as a three phase progression. The first, pre-industrial, stage may be described as based primarily on informal familial and community care of the type available in relatively stable but poor, religiously oriented, agrarian communities. The second, which is not yet completed, rested on greater state intervention and professional control and, to a degree, greater physical protection/isolation of 'the disabled' from the rest of the community. This phase coincided with increased population mobility, the partial break-up of the 'extended family' and the linked processes of demographic and disability transition.

The third stage of care development, which in Britain can be conveniently said to have begun in the late 1960s/early 1970s, involves compensatory processes of 'de-segregation' and 're-normalisation' of disabled people's lives. Although there should be no question that government funded and professionally run services can be dispensed with today's care transition involves more emphasis on informal support through, for instance, helping families to cope with their disabled members problems more effectively; accepting where possible that disabled adults are ultimately in charge of and responsible for their own lives; and making the social environment one suited to the needs of all those dependent on it for their survival, 'able' and 'disabled' alike.

In simple terms the challenge facing Britain currently relates to whether or not this third stage development can in practice be achieved. Some commentators fear that economic recession already threatens to force such redistributive progress into reverse, as recent examples taken from the fields of social security payments and the implementation of the Chronically Sick and Disabled Persons Act provisions on identification and care may indicate.

However, it is in reality probably more sensible to think of such problems as temporary set-backs rather than the reversal of a long term historical process. Current campaigns on topics like freedom of access for disabled persons enjoy considerable public support, as do proposals in favour of comprehensive disability incomes and enhanced local authority services (Weir 1981).⁸ The evidence tends to suggest that social and economic forces underlying the more recent changes discussed above (which the model given does not explain) are still intact and fairly robust.

When the situations of individual sub-groups of the disabled population are focused on more specifically it also becomes apparent that interactions between disadvantages lead to unique sets of problems to which the simple, three phase paradigm has little direct relevance. Instances of this relate to the experience of disablement in immigrant sub-groups (who face special problems of population ageing and rapid family structure change); to care deficiencies affecting inner city populations; to the particular difficulties of disabled women; to the needs of the minority of the population aged 65-75 who are disabled but often regarded as 'merely elderly'; and to the difficulties confronting groups such as those with mild intellectual impairments who are not seen as disabled and have to compete directly with their more fortunate peers for basic requirements like jobs and housing.

Analyses of areas like these clearly show that Britain (like most other developed societies) cannot yet claim to have broken the ancient links between low social status, poverty and disability. Unemployment amongst the mildly mentally handicapped is one, albeit inadequately monitored, example. The mobility problems of people who become disabled between 65 and 75, in absolute terms the period of maximum disability onset, provide another. Their incomes have fallen because of retirement. They cannot claim the mobility allowance available to the younger disabled. And they cannot take advantage of the transport concessions available to able bodied pensioners. It is because old age itself has low status overall that such specific disablement issues are not considered a matter of major public concern.

It would be beyond the scope of this *Briefing* to attempt to prescribe solutions to such problems. But in conclusion it may be worthwhile to stress the importance of the role that local and national politicians must play in developing effective systems of support for disabled persons. This is despite the fact that their knowledge of this field is, with a few notable exceptions, limited. This is so even at national level, notwithstanding the measures of support that institutions like charities and the All Party Disablement Group can offer to MP's and the expert advice potentially available to bodies such as the Social Services Committee.

In respect to the goals of the International Year of Disabled Persons it may thus be that if it succeeds only in underlining the significance of disablement as a political topic and the need for a transition in political attitudes and knowledge, it should be considered a success. Perhaps one way to achieve these ends in Britain would be a strengthening of the social research and policy analysis capacity available to Parliament. The establishment of an Institute of Health and Social Services Research along lines proposed by the recent Royal Commission on the NHS, but operating independently of the civil service and reporting directly to MPs, could perhaps be the type of vehicle required. Such a strategy would have special appeal if recently announced cuts in government statistical services reduce the future flow of information to commentators wishing to sensitise further the 'body politic' to social issues like those of disablement in Britain.

⁸ The preparedness of better off, middle class, respondents to the survey quoted to pay higher rates was perhaps understandably lower than that of poorer people. The middle class were also less in favour of comprehensive disablement incomes but more in favour of 'integrated' education. Perhaps working class experience of being 'losers' in school coloured their views on the latter topic to some degree.

References

- Baird D. (1980) *Brit J of Obs and Gny*, 1080, p 1057-67
- Bury M.R. and Wood P.H.N., Prevention and its Relationship to Chronic Illness. *Draft paper*
- Chalmers I. (1981). Personal communication.
- Cmnd 8084. Reply to the Second Report from the Social Services Committee on Perinatal and Neonatal Mortality.* HMSO, London.
- Cmnd 8175 (1981) The Government's Expenditure Plans 1981-82 to 1983-84.* HMSO, London.
- DHSS (1980). Inequalities in Health. The Report of a Research Working Group. DHSS London.
- Finkelstein V. (1980). Attitudes and Disabled People: Issues for Discussion. World Rehabilitation Fund, Washington. D.C.
- Haber L.D. (1973) *Health and Society*, 51, 3pp 319-36
- Harris A.I., Cox E. and Smith R.W. (1971). Handicapped and Impaired in Great Britain, *Part 1*. HMSO, London.
- Keeble U. (1981). Personal communication.
- Large P. (1981). Personal communication.
- Leaver J.M., Alvik A. and Warren M.D. Prescriptive Screening for Adolescent Idiopathic Scoliosis. *Draft paper*.
- Low C. (1980). *New Society* 55, 957, pp 460-61
- OHE (1971) Epilepsy in Society. OHE, London.
- OHE (1972) Migraine. OHE, London.
- OHE (1974) Parkinson's Disease. OHE, London.
- OHE (1975) Multiple Sclerosis. OHE, London.
- OHE (1976) Asthma, OHE, London.
- OHE (1977) Physical Impairment: Social Handicap. OHE, London.
- OHE (1978) Mental Handicap. OHE, London.
- OHE (1979a) Dementia in Old Age. OHE, London.
- OHE (1979b) Schizophrenia. OHE, London.
- OHE (1980) A Question of Balance. OHE, London.
- Oliver M. (1981) Personal communication.
- Osborne P. (1981) *Contact*, Spring issue, pp 13-14.
- Second Report for the Social Services Committee, Session 1979-1980.*
- Perinatal and Neonatal Mortality. House of Commons Paper 663-1* HMSO, London.
- Shearer A. (1980). *Guardian*, 31/12/80
- Taylor D.G. (1976) *Proc of Roy Soc Lond*, 192 pp 145-55
- Taylor D.G. (1979a) *In Medicines for the Year 200.* Eds. Teeling-Smith G. and Wells N.E.J., OHE, London.
- Taylor D.G. (1979b) *In Disability.* Eds. Kenedi R.M., Paul J.P. and Hughes J., Macmillan, London.
- Topliss E. (1980) *Paper given to RADAR Conference on the Chronically Sick and Disabled Persons Act, 1970-80,* RADAR, London.
- Townsend P. (1979) *Poverty in the United Kingdom.* Penguin Books, Harmondsworth.
- Warren M.D. and Knight R. (1978) *Physically Disabled People Living at Home. A study of Numbers and Needs.* HMSO, London.
- Warren M.D. (1980) *Paper given to RADAR Conference on the Chronically Sick and Disabled Persons Act, 1970-80* RADAR, London.
- Warren M.D. (1981) Personal communication.
- Weir S. (1981) *New Society* 55, 946 pp 7-10
- WHO (1980) *International Classification of Impairments, Disabilities and Handicaps.* WHO, Geneva.

Office of Health Economics

The Office of Health Economics was founded in 1962 by the Association of the British Pharmaceutical Industry.

Its terms of reference are:

To undertake research on the economic aspects of medical care.

To investigate other health and social problems.

To collect data from other countries.

To publish results, data and conclusions relevant to the above.

The Office of Health Economics welcomes financial support and discussions on research problems with any persons or bodies interested in its work.

Office of Health Economics

12 Whitehall London SW1A 2DY.

Telephone: 01-930 9203.

This *Briefing* was researched and written by David Taylor.