THE AUTHOR

GORDON CAMPBELL

The Rt. Hon. Lord Campbell of Croy

Having been a soldier, diplomat and parliamentarian in turn, Gordon Campbell continues to be active in the House of Lords and in business.

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H.M. Queen Elizabeth
The Queen Mother Fellowship
1981

Disablement
Problems and prospects in the United Kingdom

GORDON CAMPBELL
(Lord Campbell of Croy)

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INTRODUCTION

It is a great honour for me to have been selected to be the first incumbent in this new Fellowship and to have been asked to contribute a monograph on this subject. Disability and its effects upon our national life are not only matters of clinical importance for the professions involved but also of increasing concern to the general public.

'The disabled' have become a prominent topic in public affairs during the past fifteen years. The designation of 1981 as the International Year has attracted and concentrated even more attention. My object in writing the chapters which follow has been to bring together all the main strands of a diverse subject for the benefit of readers who do not necessarily have medical or technical knowledge, but who seek the information most likely to help them to assess the issues that arise and to apprehend the significance of developments as they occur. Expressed in another way, lightheartedly, this is an endeavour to supply 'everything you wanted to know about the disabled and were too shy to find out (including why they are continually being mentioned by all those politicians) and more that may surprise you'.

ACKNOWLEDGEMENT

I am extremely grateful for the help and wise advice which I have received from Professor Archie Duncan.

I

RECENT HISTORY

THE CONCEPT OF COMPREHENSIVE CARE AND provision for severely disabled people of all kinds, no matter what the cause of disability, has only been current for about fifteen years. In that time there has been a considerable change in public attitudes although anomalies have continued in one form or another.

The reasons for the different treatment of some disabled people, before the mid–1960s, in contrast to the treatment of other disabled, are not difficult to find. In the period since 1914 the war-disabled left by two world wars have naturally formed the category of handicapped people of primary concern to the nation during the post-war years. Twenty years had hardly passed after the first war before the other started. Although the toll was not as great, the young men in the Second World War again became the most vulnerable part of the population. Families discovered that their members aged between 18 and 35 were most at risk, with those in their early 20s being more likely to become casualties.

It should not be surprising that for about twenty years after each of the world wars the war-disabled should have received most attention. The fact that the nation as a whole owed a debt to them was especially acknowledged by the older generations, most of whom had not been involved in the fighting. In particular the elderly, amongst whom there is always a high proportion of disabled (for example, from arthritis), did not expect to receive as much consideration as the young people who had survived with incapacitating wounds. Similarly young children who had been handicapped from birth or early youth owed their freedom (in contrast to what the Kaiser or Hitler had in store), in the nation's eyes, to the age group in each war who had manned the front line by providing most of the men in the warships, combatant divisions, and aircraft.

Twenty years after the Second World War, continuing peace enabled more public attention to be turned to other kinds of disabled people in the community. Remarkable changes had by that time been brought about in health and social security in Britain. The two state systems, National Insurance (N.I.) and the National Health Service (N.H.S.), were introduced and developed. Supported by the National Assistance scheme (N.A.), they formed the main components of a 'welfare state' which gave the impression that all forms of illness and personal misfortune were adequately provided for. That is what the large majority of the population thought during those post-war years when the schemes were getting under way. In fact there were serious gaps, as we shall see.

Amongst disabled people, those disabled in war were being treated and assisted with priority, aided by fully supporting clinical and financial arrangements. This reflected public opinion during that post-war period. The interests of the war-disabled and individual cases were also well looked after by such organizations as the Royal British Legion, the British Limbless Ex-Servicemen's Association, and institutions for the war-blinded.

There was one other category of disabled person which received some recognition and preference. This consisted of the disabled who had been injured at work and could benefit from industrial injuries legislation.

Someone who was handicapped as a result of an accident when he was engaged in his occupation was regarded as deserving a measure of compensation. The reasons for this can be readily understood. Anomalies were none-the-less created. Two men previously engaged in exactly the same work could be equally disabled through accidents, one accident being at work and the other elsewhere. Both could no longer continue with their original jobs. Because his accident had been at work, one man would receive financial compensation considerably more than anything the second could expect.

For reasons which have already been explained, the difference between the treatment of those who had been disabled in war or at work and the people who had been disabled with similar severity from other causes was very marked. Ex-servicemen with permanent injuries of a minor kind attributable to their service were classified in a category such as 20 per cent disabled. As such they were usually eligible for a small pension and could expect special attention for any trouble arising from the impairment in question. There were no such arrangements for people with similar disabilities sustained in other circumstances.

Where there was severe disability, the war-disabled could qualify for a constant attendance allowance. It was not available to people who were just as severely incapacitated from other causes. Another example of the difference in treatment was to be seen in invalid transport. Disabled war-pensioners who were eligible for such transport were normally supplied with small cars. If they were unable to drive themselves, they could nominate someone else to drive for them. In contrast the usual form of transport supplied for the N.H.S. patient was a single-seater three-wheeler, a vehicle which became the subject of much controversy because of alleged inadequacies.

By the mid-1960s the uneven effects of the state systems and the omissions were becoming apparent to a wider section of the public. The general increase in prosperity since the war was no doubt another reason for exploring areas where further progress might be made in helping the less fortunate in the community. Let us briefly examine the framework which had been constructed by the legislation on health and social security passed by Parliament in the late 1940s. This is important in order to appreciate the curious situations which could arise for various categories of disabled.

The system of National Insurance, which has operated in its present form since the entry into effect of the 1946 Act and which greatly expanded the previous national insurance scheme, was inspired by the Beveridge Report.[1] After the very high unemployment in the 1930s, Lord Beveridge had concentrated upon insurance against loss of employment and upon leaving employment at retirement age. The whole emphasis was on employment or lack of it. The individual and his employer insured while he was at work against loss of income when he was unable to work or ceased to work.

Consequently the National Insurance scheme was by no means a complete system of social security. It applied only to those in employment or available for employment. The scale of benefits was payable in accordance with the contribution records of individuals over periods of time. These benefits constituted compensation for loss of earnings upon loss of employment, for example for the reasons of unemployment, sickness, maternity, or retirement.

The National Health Service and its Scottish counterpart were established in 1948 as a state system. Private practice was simultaneously expected to continue and to use some of the facilities. The N.H.S. was to be paid for out of general taxation, although provision was made for grants from the N.I. Fund at the discretion of Ministers. Every resident in the country was eligible for treatment within the service (subject to waiting lists). The borderline was drawn with some difficulty at the category of foreign merchant seamen whose vessels were temporarily at U.K. ports.

The Service was to be free to the patient at the time of treatment, although of course it was not in the true sense 'free'. It was to be paid for by virtually everyone—the money coming from indirect taxes, (e.g. in those days purchase tax and excise taxes) as well as from direct taxation (e.g. income tax). Charges were later levied on certain items and these have been increased over recent years as the cost of the N.H.S. has risen. Attention was indirectly drawn by this process to disablement in 1968 when exemptions from charges for prescriptions were being considered. It became clear that there were no records of the disabled and chronically sick for whom it was intended to grant exemption. No realistic estimate could even be made of their numbers.

The two systems described above, National Insurance and the National Health Service, were separate although there is no doubt that they were bundled together in the minds of the general public. There was a financial connection between them arising from the power granted to the Government in the 1946 Act (Section 37) to make payments from the N.I. Fund. For the first eight years about 9 per cent of the cost of the N.H.S. was thus met by N.I. In 1957 the N.I. financial supplement was converted to part of the weekly stamp contribution, rising at the same time to meet 14 per cent of the total cost. In recent years the N.H.S. has been paid for in the following approximate proportions: 84 per cent from general taxation, 9 per cent from N.I. funds and 7 per cent from charges.

The N.I. system applied to individuals who had worked, were working, or were available for work. Everyone in the country capable of work was expected to have a N.I. number. This gave the comforting impression that everyone in the country was covered, whatever the circumstances. In fact N.I. provided only a national register of the employed and the employable. Furthermore, N.I. benefits were available only to those who had a qualifying contribution record—those who had worked or had been available for work—as in any other insurance scheme.

People who had been severely disabled from birth or youth and who were too incapacitated to be able to work were not in the N.I. system. They were not registered. They had no N.I. numbers. Moreover there was no record of such people. The number of these very seriously handicapped people could not even be estimated. After the wartime identity card system ended there was no register of the nation except what might be compiled from the periodical census (which did not provide information about disability). N.H.S. cards were held by only part of the population, usually as and when required. They were not in any case expected to be universal as private practice was continuing. So no one knew how many severely disabled people, too helpless to work, were being looked after at home, as best could be done, by families and friends. Others who were in hospitals or institutions could, of course, have been accounted for. The total number of severely disabled, however, was unknown and could not even be guessed with any accuracy.

For some of the severely disabled the N.H.S. could with difficulty provide help in the form of beds and treatment. The only possible financial addition to private sources consisted of limited payments from National Assistance which were subject to a test of means—logically because N.A. constituted the 'safety net' paid for by taxpayers to ensure that no one in the country would starve. The tariff of payments was accordingly not much more than subsistence level. (N.A. was transformed in 1966 to 'Supplementary Benefits' with a Commission assuming, until 1980, functions similar to those previously carried out by the National Assistance Board.)

Local government councils had certain functions in health and social services, and discretionary powers under the National Assistance Act, 1948. Their effect, however, in helping the disabled was haphazard and piecemeal, as discussion during the passage through Parliament of the 1970 Chronically Sick and Disabled Persons Act underlined.

In the 'welfare state' of the 1950s, outlined above, the position of a disabled housewife was completely ignored. The large majority of wives did not find it worthwhile to contribute to N.I. separately from their husbands even when they were doing full-time jobs themselves. If a housewife was struck by serious disablement, there was no allowance or other arrangement derived from her husband's N.I. to pay for help in the home or to compensate the husband for taking necessary time off work.

As it became increasingly apparent that there were serious gaps in the health and social security system, relatives and friends of severely disabled people, together with those in public positions who were concerned, took up the cudgels. Letters appeared in the press. Questions were asked in Parliament. Information given in reply showed that the provisions were as inconsistent as had been feared. The disabled and their families started communicating with each other. Organizations were formed to represent what were called the 'civilian' disabled.

One of these organizations, probably the most representative of the categories then overlooked by the national schemes, was the Disablement Income Group (D.I.G.). Its first chairman was a disabled housewife, Mrs. Megan du Boisson, and its first office was in her house at Godalming. It officially became an association and was registered as a charity in the summer of 1967. Its Scottish counterpart established an office in Edinburgh. It is sad to relate that Mrs. du Boisson survived only another two years and did not live to see some of D.I.G.'s aims accomplished.

Meanwhile, in Parliament, the Government responded to the concern being expressed by announcing in October 1967, that the Government Social Survey would immediately carry out an inquiry into numbers of severely disabled in the country.[2] This announcement recognized the enormous gap in services to the disabled and the complete absence of information about some of the most helpless categories. The results of the inquiry, known as the Amelia Harris Report after the Principal Research Officer who led it, were published nearly four years later, in May 1971, by the Office of Population Censuses and Surveys. The inquiry had used the method of sampling, but its figures were nevertheless regarded as accurate enough to be very significant and virtually to have supplied estimates which previously it had been impossible to formulate. The Report did not extend to Northern Ireland and was restricted to people aged 16 and over living in private households. Information about children and people living in hospitals and other institutions could be obtained, as required, from other sources, e.g. schools and medical records. Thus it was at last feasible to make realistic total estimates of the numbers of handicaped and impaired people in England, Wales and Scotland.

The Amelia Harris Report performed another very useful service. It considered and adopted a classification of degree of handicap consisting of eight principal categories. As a result it was possible to estimate the numbers of very severely disabled (Categories 1, 2 and 3) divided between men and women.

Among the civilian disabled were some, vaguely delineated, whose severe handicaps were caused by continuous incapacitating illness. These people are unable to do an ordinary job, either permanently or for long periods, although they are not suffering from a distinct physical disability. They have become known as the 'chronically sick' and a category of handicapped people.

The principal aim of individuals and organizations who were pressing the cause of the unidentified and uncounted civilian disabled was a basic system for all severely disabled people in the country, regardless of the cause of disablement. There was no intention of subtracting anything from the status and treatment of the war-disabled. In order to convey reassurance on this point and to make common cause, D.I.G. approached the British Legion at an early stage (in November 1967). On the whole organizations representing various kinds of disabled have tried to co-ordinate their activities and, where appropriate, act in concert.

In the 1960s, disabled people and those who were helping them found they had no less than seven separate Ministries to deal with. The two most involved were the Ministries of Health and Social Security which were not brought together and amalgamated into a new Department until 1968.

The year in which prospects for the civilian disabled brightened considerably was 1969. There was a perceptible change in the attitude of the Government of the time, particularly in Parliament where Ministers had been sympathetic but apparently unable to support or initiate positive action. The change was most clearly illustrated in November when the M.P. who was first in the annual ballot for Private Members' Bills, Mr. Alf Morris, chose the disabled as the subject for his Bill. The Government were prepared to help with drafting the Bill if it stayed within certain limits of finance and the granting of powers. This more forthcoming approach was in notable contrast with the Government's previous opposition to unobjectionable Private Members' Bills on the disabled, even those incurring no public expenditure. As recently as the beginning of the same year, on January 24th 1969, the Government had for example stopped a Bill of this kind after its Second Reading debate by forcing a division in the Commons and requiring the Government side of the House to vote against it.[3]

What was the explanation of this change of heart? It could be ascribed to a determination to find ways of adapting or supplementing the existing systems to help the kinds of case whose problems and difficulties, it had become clear, were outside the compass of those systems. No doubt political advice to the effect that advantages were to be gained by a more positive approach by the Government were offered and heeded, though it should be remembered that the parliamentary pressure on this subject during the previous three years had come from all parties and had not been politically partisan.

Another factor, which may have been the most important consideration, was that the sections of Whitehall concerned, particularly in the Treasury, had satisfied themselves about one particular argument which had been advanced in aid of the disabled. This was that improvements did not necessarily involve extra public expenditure. Indeed it was usually cheaper for the Exchequer to enable a disabled person to be looked after at home, with special help, than to keep him in hospital. Beds in the N.H.S. hospitals were, in any case, badly needed for patients of all kinds. If money were authorized to be used in other ways, such as in the form of attendance allowances intended to meet local care and services, the total of expenditure need not be affected. Moreover the large majority of severely disabled people wanted to be as independent as possible and outside hospital. Encouragement in these directions would be good for them. It was not more money that was needed so much as new imaginative schemes to use the funds available to the best advantage of the disabled and the nation.

An additional system of financial help paid to individuals duly followed in the early 1970s. In particular invalidity benefit and attendance allowance were introduced and developed. For some of these new benefits, for example the attendance allowance, payment of N.I. contributions were not a necessary qualification. (A list of some of the principal benefits related to disability which exist now, in 1981, is contained in Appendix I.).

The Private Member's Bill, which became the Chronically Sick and Disabled Persons Act, 1970, applied mostly to action to be taken by local authorities. It did not oblige local councils to provide services for the disabled. Instead it was, in the parliamentary sense, permissive. Councils could do as much or as little as they each considered was appropriate and consistent with their finances.

When the ballot for Private Members' Bills takes place once a year in the House of Commons, it is the first six Members only, in the order drawn, who can expect to be allotted the time needed on the Floor of the Commons and in committee for the passage of a Bill which is complicated, controversial, or objectionable in any way to the Government. (There is no difficulty about the necessary time being found later in the other House, the Lords.) The Member who has been fortunate in coming top of the list, however, must produce his Bill in good time for a Second Reading in the Commons little more than two months after the ballot. When the Bill on disablement was first seen and debated early in 1970, it had been drafted to apply to England and Wales. Two Scottish M.P.s immediately gave notice that they would introduce an equivalent Bill for Scotland, by another method open to Private Members, unless the original Bill was extended to Scotland. This was a matter in which the Government eventually gave help by drafting the necessary amendments in time for the Report Stage (after the detailed examination in Committee). The Bill was thereby extended to Scotland before completing its passage in 1970, though argument continued until 1972 on whether additional amendments for Scotland were still necessary to Clauses 1 and 2.[4]

The particular importance of the Chronically Sick and Disabled Persons Act, 1970, was that it had been drafted, introduced, amended and passed with the acquiescence and assistance of the Government of the day. Although many of its provisions appeared to impose 'duties' upon local councils, the implementation was left to the discretion of those councils. Their attention was directed to the functions which many of them were already carrying out to varying extents—some hardly at all. In future local authorities were expected to provide services to disabled people in their homes, such as practical assistance, meals, and a telephone. There were also provisions about access to public buildings and facilities for severely disabled persons in public places. During the immediately following years there was some disappointment amongst interested observers who had not recognized the permissive, enabling nature of the Act, when they found that local government councils were not doing everything in the Act immediately.

In particular there were misunderstandings about Section 1. The impression gained currency that the councils were obliged by its terms to locate and identify every disabled person resident in their areas. This would have required something like a mini-census. In fact Section 1 required them 'to inform themselves of the number of persons', falling into certain categories, who were resident within their areas. There was no question of compiling a register with names and addresses. The Amelia Harris inquiry had produced estimates by sampling and no doubt many local councils regarded that method as meeting the requirement accurately enough, bearing in mind that the numbers would in any case not remain constant.

With the reorganization of local government in the mid-1970s, the functions in the 1970 Act were assumed by the new authorities as follows. In England and Wales the councils of non-metropolitan counties and of metropolitan districts now have these responsibilities, in company with the London boroughs. In Scotland the regional and islands councils inherited the functions.

The 1970 Act also legislated for new buildings, intended to be used by the general public, to incorporate adequate arrangements for access for disabled people, subject to what was 'both practicable and reasonable'. In this matter, as in the local authorities' duties to provide certain personal services, the Act contained no means of enforcement. This absence of any way of achieving compliance has predictably been a continuing cause of criticism from groups representing the interests of disabled people.

After 1970, however, considerably more attention was called to the need for access to public buildings, whether within the responsibility of local government and other public authorities or not. An example of this was a motion placed on the Order Paper of the House of Commons by M.P.s of all parties regretting the inadequate provision of facilities for disabled people at the new National Theatre. This reflected a growing awareness that questions of access to buildings ought to be considered at a very early stage; and a feeling that it should be possible for disabled people to circulate with others in ordinary life.

During the 1970s additional financial benefits were introduced, as already mentioned, to fill gaps in welfare services. Thus the invalidity benefit and attendance allowance helped the severely disabled housewife and other categories who had previously qualified for little or no assistance.

A very significant feature was that these new benefits were non-contributory. In other words the previous requirement was being abandoned that payments of this kind had to be within the N.I. system and available only to participants who could make contributions. This was a signal advance towards a fairer system for all disabled people in their different circumstances and regardless of the causes of their disablement. To that extent the general situation was improved, although it was still complicated and irrational owing to the miscellaneous conditions attaching to benefits, including the apparently haphazard liability to taxation and the effects on other benefits unrelated to disability.

2

FACING REALITIES

INTERNATIONAL YEAR

IN 1976 THE UNITED NATIONS PASSED A resolution proclaiming that 1981 be designated as the International Year of Disabled People (I.Y.D.P.). The United Kingdom was a sponsor of the motion when it was proposed and so has been seen as an active supporter of the idea from the beginning. There have been previous International Years for particular subjects, the purpose no doubt being to attain impact and increase publicity by concentrating on a cause in every country at the same time. In the resolution the United Nations offered five principal aims:

Helping disabled people in their physical and psychological adjustment to society

Promoting all national and international efforts to provide disabled people with proper assistance, training, care and guidance; to make available opportunities for suitable work and to ensure their full integration in society

Encouraging study and research projects; projects designed to facilitate the practical participation of disabled people in daily life, for example by improving their access to public buildings and transportation schemes

Educating and informing the public of the rights of disabled people to participate in and contribute to various aspects of economic, social, and political life

Promoting effective measures for the prevention of disability and for the rehabilitation of disabled people.

The International Year includes all forms and degrees of disability. In theory it therefore extends from a slightly disabled person with virtually no handicap to a completely paralysed person requiring mechanical respiration. In practice those who will be regarded as of main concern will understandably be disabled people who are considerably handicapped in relation to ordinary life. They include, in addition to locomotor handicap, the deaf, blind, partially sighted, speech-impaired, mentally handicapped, or mentally ill.

This raises the whole question of what we mean by 'the disabled' when we are considering integration in the community (where this is possible), or benefits, services, and other help. A very large proportion of the categories included in the U.N. resolution do not have handicaps severe enough to prevent them living ordinary lives without special help. Someone can be disabled, and perhaps obviously so, and yet not be handicapped. In contrast another person may be suffering a severe handicap without obvious signs of a disability.

The United Nations clearly did not wish to leave anyone out. Moreover the intention must be, in the U.K. as elsewhere, greatly to increase public awareness of different kinds of disablement; and to spread knowledge about how the disabled can themselves contribute to life and what the able-bodied can do to cooperate.

A descriptive list of the causes of the principal kinds of disability and handicap to be found in the U.K. is contained in Appendix III. The onset of old age frequently brings frailty and other disabilities. Most people will accept the prospect that, if they happen to live to their 70s or 80s, some impairments may be experienced. We must accordingly recognize that a large proportion of 'the disabled' are elderly people who have become frail or handicapped only with age. Because people are living longer, the proportion of the elderly in the population is increasing. The Registrar-General's estimates suggest that in 1981 about 15 per cent of the population are over the age of 65; and 5·7 per cent over the age of 75. The last figure indicates that there are about three million people in the country over 75.

Largely because women tend to live for longer than men, very severely disabled women considerably outnumber the same category of men. For example the Amelia Harris Report, in its estimates for adults in Great Britain, produced the figures of 45,000 for men and 113,000 for women in the very severe categories (1, 2 and 3).

Arthritis is one of the crippling ailments which particularly afflict the elderly and many of them are sufferers from it. While great advances have been made in the relief of arthritic conditions in recent years by the development of artificial joints leading, for example, to the insertion of new hips, one of the greatest boons to mankind would be the discovery of a cure for this painful and disabling infirmity.

We have observed above that the proportion of elderly people in our population has been increasing and that age must be expected to bring frailty and handicap. The proportion is likely to continue to increase over the next few years at least. Because the United Nations' criteria for the International Year embrace everyone with any degree of disability or impairment, the number of people in the U.K. who qualify for the purposes of the Year is much greater than the general public would expect. All who can be the separate approach to the situation of children in under-developed countries. The United Nations Children's Fund (U.N.I.C.E.F.) has been campaigning on the basis that one in ten of children born in deprived areas of the world are born with, or acquire, impairments that will interfere with their capacities for normal development. People who are poor and out of reach of the most essential human services are, U.N.I.C.E.F. points out, far more likely to be affected by the main causes of childhood disability: poor nutrition, problems at birth, diseases, infections, and accidents. The ratio is accordingly high in those countries.

MENTAL DISABILITY

It has been difficult for members of the public to understand and accept mental illness unless they have met it amongst their families or friends. It can cause severe disability although this may not be recognizable in strangers in public places. Indeed someone with a severe mental illness may, in close proximity, give to a stranger simply an impression of eccentricity, blankness, or aggression. Familiarity with such disorders has not in the past been common because until a few years ago the standard treatment for serious cases was detention in a home or institution.

Advances in medical knowledge over the past 30 years have transformed the kind of existence which sufferers can lead. It is now possible for a large proportion of those who previously had been locked up to circulate in the community, observing a prescribed regime of drugs, without unacceptable risk to themselves or others. Close or distant supervision may be needed, as well as a limited or protected environment. Such a regime is invariably better for the mentally disabled person than being institutionalized. It also relieves pressure on scarce mental nursing resources.

described as 'disabled' are included, although most of these people are not really handicapped for ordinary life. If they are elderly, they are likely to be retired from work and will not have been taken by surprise when their faculties started to fade.

There is a drawback, indeed a danger, in this approach. The man in the street would not recognize, or credit as disabled and needing his special concern, the majority of this sizeable section of the population. It may well do harm to the interests of handicapped people of working age if too much is made of the total number of people with any kind of disability.

If we eliminate disabilities that have arrived with old age and those disabled people who have virtually no handicap, the figure becomes greatly reduced. We should surely concentrate on the core of severely disabled people, of working age or below, who have real handicaps. Success in enabling them to lead their lives alongside able-bodied people also gives encouragement to the less handicapped to overcome their smaller problems.

There is accordingly no particular significance in the estimate of 5 million 'disabled' in Great Britain, though that figure can be substantiated by adding up every degree and category of impairment. To suggest that one in ten of the population ought to be the subjects of our special attention during the International Year is to court disbelief. The interest and concern of the general public will be more readily engaged if attention is drawn to the smaller groups with serious handicaps. Whether those handicaps are obvious does not matter—and some of them may not be, for example, if they are mental or respiratory. Increasing the knowledge and understanding of the man in the street about such disorders should be our aim.

We are here considering a course of action at home in the United Kingdom. It should not be confused with

What this welcome trend does require is a matching increase in knowledge and understanding by the general public. This will not be easy to achieve. The mentally ill are not what most of the public have in mind as disabled people—and they will not immediately recognize them as such. Common misunderstandings do not help. For example, one of the most serious and disabling illnesses, schizophrenia, for which the cause and cure are still being sought, is widely thought to be solely a Jekyll and Hyde phenomenon. As a result the word is misused and does not evoke the care, sympathy, and consideration which it should. If one achievement only could be attained in the International Year, it would be enough if Members of Parliament could be restrained from misusing 'schizophrenia' to describe the behaviour of their political adversaries!

Serious mental handicap, usually entailing subnormal intelligence, is also a disabling condition. It is very different from mental illness and requires different treatment. Here again there is much to be done to enlighten the general public and to explain the associated problems.

AIDS AND EQUIPMENT

Wheelchairs and other aids and appliances are supplied, as they become available, through the N.H.S. to handicapped people who qualify for them. There is an electronic device known as 'possum' (also as 'environmental control equipment') which enables someone with very limited movement to control lighting, heating, door-locking, and other functions, including even the telephone if necessary. The equipment is fitted to suit the kind of movement available to the individual disabled person. It can, for example, be controlled by finger, chin movement, or by blowing air. With its call system for attendance, possum makes looking after someone at home much more easy for a family.

Equipment in the home, including hoists and rails, can make a great difference to ordinary life for many handicapped people. Local government authorities have discretion to provide help with adapting houses for easier occupation by such people; and the criteria for assessment for payment of local rates have recently been altered by Parliament to ensure some relief for adaptations carried out for this purpose.

That part of British industry which designs and manufactures aids and equipment holds periodical exhibitions and conferences in different parts of the country. There are also Appliance Centres, some of them mobile. The aim must always be to keep the manufacturers on the one hand, and the professions and the disabled on the other, as well informed as possible about needs and the latest developments in design and technology.

The United Kingdom has had a high reputation for standards of artificial limbs, calipers, and other equipment to replace or assist parts of the body. Care and attention to detail in individual cases must continue to be the hallmarks of this service.

ACCESS

If disabled people are to circulate and share ordinary life with the rest of the community, obstacles and hazards must be removed from their paths. Ramps for wheelchairs are needed as alternatives to steps, and lifts as alternatives to stairs. There must also be lavatory facilities for disabled people in public buildings.

The 1970 Act attempted to introduce these features as requirements in all buildings open to the public (not only publicly owned, such as libraries and museums, but also privately owned, such as shops). Since there was no method of enforcement in the Act, it has had the effect of formulating a code of good practice rather than stipulating an obligation. The Government should now be seeking ways of strengthening the requirements where new buildings to be used by the public are being proposed.

DISABILITY AND NEED

The seriously handicapped in the population of Great Britain cover a wide range of afflictions and circumstances. Here are some illustrations: the deaf and dumb woman aged thirty, travelling by bus to her work, who does not appear to be disabled to the conductor or to other passengers; the autistic child who is unable to speak or communicate; the businessman in his forties who has become partially paralysed, with an impediment of speech, as the result of a stroke six months ago; the arthritic woman in her sixties who cannot stoop and can walk only with difficulty; the epileptic young man who may collapse without warning in a fit although he is keeping strictly to his prescribed medical regime; the teen-age girl in a wheelchair with continually wobbling head and distorted arm movements.

It is to be hoped that these and other conditions and manifestations (where they are visible) will be regarded as part of the scene in ordinary life by more and more of the population. Greater public awareness will make circulation much easier for handicapped people, even if their handicaps are not immediately apparent.

Authorities responsible for social services, whether in central or local government, are working amongst the elderly, the needy, and people who are for various reasons disadvantaged or in poverty. The categories needing assistance overlap. Entitlement to benefits becomes complicated. In considering the problems of handicapped people, let us bear in mind that an individual's situation will certainly be worse if it is combined with old age, poverty, and living alone.

3

PREVENTION

A GREAT DEAL OF SUFFERING COULD BE AVOIDED and pressure on our health and social services could be eased, if the proportion of disabled people in our population could be reduced in the future. Prevention of disability is one of the principal aims of the International Year of Disabled People, as expressed in the United Nations resolution. While no one will dissent from this theme, some of the possible remedies are delicate subjects on which there are divided views, as we shall see. Prevention can conveniently be considered in four parts: accidents, research into causes and cures, health education, and ante-natal care.

ACCIDENTS

As regards accidents at work, employers have a duty to apply safety measures to lessen their likelihood to a minimum. Accidents in or about the home could be reduced by finding better ways of advising and warning families. The Royal Society for the Prevention of Accidents is actively engaged in seeking improvements in safety where the daily lives of citizens are concerned. The design and integrity of buildings, plant, and goods are by law subject to standards and inspection. Warnings are issued to the public if certain products on sale are found not to conform in any particular affecting safety.

In addition special vigilance is required in looking out for the need to modernize or augment legislation, as new products appear, in order to improve safety in the home. There are regrettably more accidents in homes than anywhere else, from such causes as fires (some from inflammable clothing), scalding, fumes from plastic furniture, and straightforward cases of falling downstairs or off stepladders. More education, caution, and care are needed. There is still a great deal to be done in informing households, in acceptable ways, about the risks to children (especially in kitchens) and in advising the elderly.

It is our roads, however, which are the scene of the accidents which cause most damage to the human frame, besides fatalities, in relation to the numbers of people using the roads. A high proportion of those injured in these accidents have severe head injuries which cause permanent disablement of some kind. The proportion of deaths and serious injuries amongst motorcycle riders is greater than for other road vehicles. It is tragic that most of these riders (pillion too) are under 30 in age.

This brings us immediately to the controversy about whether the wearing of seat-belts should be compulsory. Some years ago the wearing of helmets by the riders of motorcycles was made compulsory by Parliament, against some strong objections including the wish of Sikhs to be allowed to wear turbans in accordance with the practice of their religion. Manufacturers of motorcars have for some years been obliged by law to provide belts for front seat passengers. There have also been from time to time in recent years debates in both Houses of Parliament without a positive decision being taken to make the use of them compulsory. At the time of writing a Transport Bill is passing through Parliament and an addition has been made to it requiring front seat passengers under the age of thirteen to be secured by seat-belts when a road vehicle is in motion. It is possible that a further provision will be added, before the Bill is enacted, making the wearing of seat-belts compulsory for everyone in the front seats of moving cars or lorries.

The argument in favour of the compulsory wearing of seat-belts is that they do undoubtedly lessen the dangers of serious injury in road accidents. Reputable estimates have been made showing that the numbers of deaths and disabling injuries from road accidents would be much reduced. Although the public have for some time been exhorted to 'belt up', this injunction is disregarded by a very large proportion of drivers and front seat passengers. Against compulsion by law it is strongly argued, by people who feel passionately about freedom, that the citizen should be allowed to make his own decisions in this matter; and that to introduce another motoring offence, which would be difficult for the police to handle, would bring the law into disrepute. What exemptions would there be? Would pregnant women be one such category? Would the full rigour of the law be directed against someone who had stepped into his car to move it only three metres to a parking space?

The views on both sides of this issue have been sincerely held. It does now seem, however, that a decision will be taken by Parliament in the foreseeable future to make the wearing of belts compulsory in front seats. That a substantial reduction can in this way be made in the suffering and distress caused by road accidents is the obstinate fact which ultimately will influence most parliamentarians.

RESEARCH

The prevalence of severe disability in the national community can also be significantly reduced by research leading to the discovery of the causes of crippling diseases and other disorders, and of the cures for them. Methods of alleviation and of inoculation against particular illnesses can also be discovered and put into practice.

Looking back over the past forty years we can perceive remarkable successes, for example in mastering polio and tuberculosis. These we must hope can be emulated by continuing efforts in research into incapacitating scourges, such as multiple sclerosis, arthritis and severe mental illness.

There are many voluntary bodies in the country whose purpose, amongst other things, is to raise funds for research in various medical fields. Cancer in all its forms seems to be of most concern to the public, understandably because of its unpredictable onset and malignant threat to life. While funds collected voluntarily should be spent in the ways promised at the time when they were raised, there appears to be scope for more co-ordination to achieve effective research in those directions most likely to curb lethal or crippling illnesses, or successfully to replace defective or missing parts of the body. In this last connection much progress has been made in the technique of transplanting kidneys, though many people who could benefit are waiting for the appropriate occasion to arrive for a transplant.

The Government should play an influential part through the guidance and financial help given to medical research, without seeking to dictate programmes in detail.

There are two Chairs of Rehabilitation Studies in the United Kingdom. One is the Europe Chair at Southampton University, established to commemorate entry into the European Economic Community (E.E.C.) in 1973. The other is in Edinburgh University and is financed by charitable trusts. More could be created with advantage to the country as a whole.

HEALTH EDUCATION

Since 1968 there have been Health Education Units working closely with the Health Departments. Through them and in other ways successive governments have issued health warnings to the public. Probably the most obvious of these has been on the subject of the connection between smoking, lung cancer, and the aggravation of respiratory illnesses.

Health Departments have also encouraged public immunization schemes in order to spread protection against severe and crippling diseases or conditions. A good example is vaccination against rubella (German measles), not in itself a serious illness. Because rubella during pregnancy gives rise to the serious risk of damage to the unborn child, it is a sensible precaution to make sure that as many girls as possible are immunized before they reach their teens. This is a simple way of preventing distress and suffering arising from avoidable disability.

There are a very few people in the population who sustain damage from the process of immunization against one illness or another. In some cases this consists of severe injury to the brain. Every effort should continue to be made to discover ways of identifying these members of the public before a vaccination scheme is started. A state scheme for vaccine damage does provide compensation for a person who has suffered permanent or very severe damage as a result of vaccination under a programme within public policy. Those damaged before birth through vaccination of their mothers are included.

The immunization programmes in the U.K. have led to the virtual elimination of some dangerous and disabling diseases and a great reduction of others. The benefits which they have bestowed greatly outweigh the injuries regrettably caused by the comparatively rare side-effects. (We are not here considering the advantages and disadvantages of immunization against illnesses which are not normally dangerous.)

It must be emphasized that a health education service cannot be expected to achieve dramatic results by itself. Indeed a 'nannying' attitude to the public would receive little response. Much can be obtained in addition from tactful reminding that every citizen has a certain responsibility to the community in which he lives to take reasonable trouble and precautions in order to keep himself well and to avoid unnecessary risks to health.

ANTE-NATAL CARE

Health Departments and the medical professions have encouraged women to attend clinics regularly for examination during pregnancy. Warnings are given about risks to the unborn child. Regular attendance, if it can be achieved despite work and household responsibilities, increases the chances of a healthy baby being born. It is especially important to make the first visit early in a pregnancy.

Recently there have been considerable advances in the techniques of recognizing and diagnozing abnormalities in the foetus. Where severe brain damage, mongolism (Down's syndrome) or a totally incapacitating defect are identified, difficult decisions may have to be taken. Since one option is abortion, this is a controversial subject and no attempt will be made to prescribe solutions in these pages. What can be suggested, with little argument, is that in each case the parents should be given the opportunity to choose a course, after receiving counsel from the medical team and as good a picture as possible of the child's future if born alive.

The subject of selective abortion nonetheless deserves amplification because prenatal diagnosis has reached the stage where several crippling disorders, including spina bifida, cystic fibrosis and mongolism, can be identified within the first six months of pregnancy. The facts and issues have been lucidly explained and considered by Professor H. Harris.[5]

The intricacy and cost of the advanced techniques have restricted their use hitherto to those who can afford them or to certain groups or families where a high risk of abnormality is known to exist. They are also normally embarked upon only when the parents concerned have already made clear that they are prepared to consider abortion. There will undoubtedly be pressure in coming years, as technology advances, for prenatal diagnosis to be extended to more sections of the population. The difficulties in taking decisions about abortion, except where religious or personal views preclude it, will remain; and indeed the numbers of decisions to be made in these circumstances are likely to increase. It is therefore worth considering briefly some of the main factors involved.

There are some parents of greatly disadvantaged children who have found a new purpose and dedication in raising a completely helpless or mentally defective child. Other parents' lives have been wrecked, often including their marriages, by the worry and tied slavery required for personal care, day and night, over many years. It must be recognized that there are factors, such as the availability of money and resources and the size of the existing family, which influence each situation.

To appreciate the difficulties of some decisions we should consider Huntington's chorea, a disorder affecting about one in 20,000 in the population. A congenital illness involving heredity, its symptoms do not appear until after the age of 30. About half of the children of someone afflicted are likely to have it too—and those children may be born before a parent develops the symptoms. What sensitive counselling must be required with families confronted with these problems and what difficult personal decisions they may have to take!

Professor Harris points out that selective abortion could be regarded as assisting natural selection. For example it is estimated that about 65 per cent of potential mongol infants are spontaneously eliminated by miscarriages in early pregnancy.

4

MOBILITY

FOR MANY SEVERELY DISABLED PEOPLE WHO cannot walk, or who can walk only a few paces with difficulty, the use of a private vehicle prevents them from being house-bound. Whether they can aspire to living a normal life, or indeed can obtain and keep a job, may well depend upon the availability of such transport. The disabled person may be the driver or someone else may drive if it is not a single-seater. The vehicle may have to be adapted for a particular disability.

In addition, these and others with less severe disabilities, encounter considerable difficulties with public transport unless the airports, trains, stations, buses etc., have been designed with their problems in mind. Both the availability of private transport to certain categories and the suitability of public transport are important factors in attempting to improve the integration of disabled people with the able-bodied. It is convenient to consider each in turn.

PRIVATE CARS

For at least thirty years the Government have recognized the need for special road vehicles for certain disabled people who would otherwise have little or no mobility. Small cars or single-seater 3-wheelers were provided free to applicants, subject to the necessary medical examination. There were also arrangements for maintenance, and repair and allowances and official contributions towards the costs. A major change in the system was introduced at the end of 1977 when the scheme called 'Motability' was announced.

Before that change there had been continuing controversy about the suitability and safety of the 3-wheel road vehicle. Whatever the facts and arguments, it was not trusted by all the users or prospective applicants. Furthermore the disabled person was isolated, without a helper, in the vehicle.

Motability is a voluntary organization, which came into being with the blessing of the Government, to help disabled people to make best use of the mobility allowance after the introduction of that allowance in 1978. Two schemes are offered, one for leasing cars at favourable rates and the other for owning a car by hire-purchase. The disabled people must have been medically proved to be eligible for mobility allowance during the periods of the schemes (usually about four years). The schemes have been generally welcomed as providing more flexibility.

In the three years since Motability started, 14,500 contracts have been concluded and about 11,000 cars are on the road as a result of the organization's work. It is now supplying electric wheelchairs as well as cars.

Who is eligible for mobility allowance? This is now the key to financial help with a private road vehicle. Entitlement seems to depend on a claimant's 'virtual' inability to walk. It is accepted that respiratory illnesses and afflictions not directly affecting the legs can prevent walking. This is an advance but it makes the borderline between award of the allowance and rejection very unclear to applicants and the public.

The procedure is for a claim to be sent to the Mobility Allowance Unit. The applicant is required to be seen by a doctor who makes a report. If the allowance is refused on the basis of the report there is a right of appeal to a medical board and, after that, to a medical appeal tribunal.

Before 1978 decisions on eligibility for a 3-wheeler or a small car (the latter usually for war-disabled) were more directly related to a double amputation or the loss of use of both legs. The present arrangements take account of a wider range of disabilities and so are more difficult for the public to comprehend. It is therefore even more important that they should observe the same standards throughout the country.

There are two particular matters affecting the disabled motorist which need attention. The first is the effect of taxation. The 1981 Budget selected road transport for increased taxes (e.g. petrol and licence). If the Government wish to protect the severely disabled from the effects of this deliberate action, they should continue to adjust mobility allowance accordingly. They have in their hands this countervailing measure; and they did increase the allowance by nearly 14 per cent in the same Budget.

The second matter arises from the spread of self-service petrol stations. Should these become universal, or almost so, the severely disabled driver will be facing the hazards of being stranded. Some special arrangements for help should be made at some of the self-service stations and an appropriate sign should be clearly visible to indicate this availability.

PARKING

One of the anxieties which press upon the individual in a modern town or city is the parking problem. For disabled people it dominates the whole question whether to use a car or not. The schemes to help disabled people in recent years, however, have caused considerable controversy because they were open to widespread abuse. Local authorities have had the power to issue badges (usually orange discs) for windscreens, together with an orange square label for the back of a car. Both carried the easily recognizable wheelchair sign.

In the first period of enthusiasm, some local authorities appeared to issue these badges to people broadly in the categories equivalent to the classification (for war-disabled) of 50 per cent and above. This was probably too wide a distribution for the real needs. The badges exempt a car from payment at a parking place and are valid in the area of most other local authorities (not in central London). In addition traffic wardens have sensibly been prepared to allow cars with these badges to park for reasonable periods on a single yellow line when parking spaces were not available. There are even thought to be some local authorities who permit an orange badge to park on a single yellow line at any time!

The abuse which has naturally worried the public has been the parking of such cars, with the privileges of the badges, by able-bodied drivers when a disabled person has not been a passenger. Local councils have improved the situation by requiring the nominated disabled person's name to be on the orange disc. The disc should only be in place when that person is in the vehicle. Unfortunately the badge at the rear is stuck to the glass and normally is not removable. This rear badge is not necessary and ought to be abolished.

Central London does not accept the orange disc scheme. One part, Westminster, has its own 'white card' scheme, similar in effect. The card is issued to people in or above the category of 85 per cent disabled, or if they have been examined by the Council's medical officer and found to have serious difficulty in walking. There again the name appears on the card, which is supposed to be removed from the windscreen when the disabled person is not using the car.

Reform of the parking scheme for the disabled is needed, starting with guidance from the Government to local authorities. In general eligibility should be tightened and police and traffic wardens encouraged to check the occupants of a car against the name on the disc. An improved system will help the disabled because it will enjoy greater confidence amongst the general public.

PUBLIC TRANSPORT

Turning to public transport, the railways have always produced problems for severely disabled people. The doors of coaches have been too narrow for wheelchairs, so that a paraplegic has normally had to travel in the guard's van. Fortunately the most modern trains, recently designed and built, have wider doors which give better access. For less disabled people the steps up and down from a platform have been both obstacles and hazards. Because coaches and platforms cannot be drastically altered in design, the principle to be observed with rail travel is that British Rail should be informed in good time about the proposed journey of a severely disabled person. British Rail, for their part, are ready to take as much care and trouble as they can, given enough notice.

Underground trains and buses are not suitable for the severely disabled, in the conditions of a busy urban area. There always seem to be steps, besides escalators, at underground stations. It is true that some stations have now been provided with access arrangements for wheelchairs, but this is less than satisfactory for travellers who are not familiar with the lines concerned and do not know which stations are accessible. Though a helping hand may assist with the steps on to a bus, both there and in the tube involuntary jostling cannot be avoided. Rush hours, of course, produce extreme conditions.

Nonetheless people with less severe disabilities expect to travel by underground or bus and should be helped to do so. Recently special seats have been made available for the elderly or disabled on the London underground and on buses. This should be encouraged and emulated elsewhere. One of the fruits of a successful International Year of Disabled People in 1981 should be greater awareness of certain handicaps which can be assisted by consideration and help to strangers.

When disabled people have to travel by air, they meet different problems. Most airports and airlines now have arrangements to enable wheelchairs to pass through airports and to have direct access to aircraft. Here again the system will normally work well if reasonable notice is given. It should also be recorded that a small minority of airlines are notoriously bad in handling wheelchair or similar passengers.

A particular problem for disabled people at airports, including those who can walk short distances, is the length of some corridors from a terminal building to a departure gate. Whether a passenger is suffering from severe asthma or has limited movement of the legs, he probably needs to pause and rest even if the total distance is not too long for him. At present there is a dearth of seating at intermediate points. What the airports do provide, however, is a wheelchair and attendant for someone who cannot walk these distances and who has given enough notice. This poses the present unsatisfactory choice, for someone who can manage ordinary life on his feet, between a difficult walk and calling for a wheelchair.

It would be in the interests of the airport authorities to make more seating of suitable kinds available in the appropriate places. There would then be fewer calls for wheelchairs and attendants.

A small vehicle with an electric motor called a 'buggy' has been introduced at Gatwick to transport disabled people over some of the long distances there. This is helpful but the numbers may not be enough to meet all the requirements without notice, and alternative assistance is still likely to be needed.

5

EMPLOYMENT

FOR MOST PEOPLE WHO ARE HANDICAPPED BY A disability there is a great psychological benefit to be gained from having an occupation or job. To be able to perform work that is useful to others can often be the best medicine for a condition. To be able to earn a living, where that is possible, can in some cases make all the difference between a disabled person remaining part of the community or gradually lapsing into seclusion and an empty life.

When someone has become seriously disabled while of working age, early rehabilitation of a psychological kind is of extreme importance. It is not enough to help with training or preparation for future suitable work. The disabled person concerned needs to start in such work as soon as possible after reaching the expected state of recovery. There have been too many cases in which the man or woman has returned to the labour market but remained unemployed for many months. The unfortunate effect is discouragement and a feeling of being useless. As time passes the disabled person becomes less and less capable of starting work again.

When considering work for the disabled, therefore, there should be priority for helping to launch into employment again those people who have become available for work immediately after a disabling incident or illness.

REGISTER SCHEMES

Over the last 35 years practice in the United Kingdom has been guided by the Disabled Persons (Employment) Act, 1944, and its quota system. The Act requires employers of twenty or more persons to recruit 3 per cent of their workforce from a register of disabled persons kept by the Ministry of Labour (later transformed into the Department of Employment) and, since 1974, by the Manpower Services Commission. The Act was clearly intended at the time to be of help principally to the war-disabled in the post-war years. It has nonetheless applied to disabled people of all kinds, although it has never been thought realistic or prudent to try to enforce it. Employers would be antagonized by enforcement and the disabled would then tend to be regarded by them as unwelcome.

In practice the quota scheme has simply held out 3 per cent as an aim to be achieved if possible. Replies to Parliamentary Questions during the past two years have revealed that employers of all kinds, including Government Departments, have fallen short in reality of the percentage prescribed. It is not surprising that the question whether the quota scheme should be continued has been under review by the Manpower Services Commission.

There are too many variable factors in this quota scheme to enable it to be applied with fairness. For example some industries can more easily than others employ handicapped people without danger to them or to other employees. The degree of handicap is not stipulated. One employer could therefore fill his 3 per cent with people who were all only slightly disabled, while another employer was making a great effort to employ 1 per cent of seriously disabled. The latter might well be performing a better service for the community than the former.

At a time of high unemployment in the country as a whole, it is naturally less easy for disabled people to find places at work. Whether or not some form of quota scheme is continued, requiring every significant employer to play a part, a policy of encouraging and persuading industry and commerce is more likely to succeed than a policy of enforcing percentages. Some companies have satisfactorily and sensibly steered people with certain handicaps to work in particular sections. For example some textile factories retain places in their visual inspection department (for faults or quality) for the deaf and dumb. Arrangements in that area can be made completely safe, even though the employees cannot speak or hear. The manufacturers are likely to benefit from the acute sight with which deaf people are often equipped.

More should be done in research, with Government assistance, to find such areas where people with particular disabilities can be suitably and successfully employed.

It must also be recognized that there are some disabled people who do not want to be registered as such even though they wish to work and are looking for jobs. They do not want to be labelled, usually because they think it will reduce their chances or because they wish to be considered to be completely normal employees. A scheme based upon the Employment Service's Register cannot accordingly be comprehensive. The register is a voluntary one and is separate from any register kept by a local government council (for its functions under the National Assistance Act or the Chronically Sick and Disabled Persons Act).

This register, kept now by the Manpower Services Commission, is open to a disabled person who 'on account of injury, disease or congenital deformity is substantially handicapped in obtaining or keeping employment, or undertaking work on his own account of a kind which, apart from that injury, disease or deformity, would be suited to his age, experience and qualification'. The person has to be likely to remain disabled for at least a year and to be actively looking for employment, with some prospect of obtaining it. Part of the register is reserved for severely disabled people who are unlikely to be capable of obtaining and keeping a job in ordinary employment if competing with able-bodied people.

Operating such a scheme of registration will always run into complications. For example a man may lose a finger in an accident and become slightly handicapped as a result. If he is a professional pianist that handicap may have to alter his occupation and way of life. Similarly another man who is left with a hand tremor after an illness may think little of it unless he happens to be a watchmaker. In that occupation he becomes severely handicapped. These are extreme and unusual examples. They do nevertheless illustrate why rehabilitation and resettlement are needed in many cases where a disability seems small but where the effect upon a particular job is great, with the result that skills and qualifications can no longer serve the individual concerned.

RESETTLEMENT

Disablement Resettlement Officers (D.R.O.s) form part of the Government's Employment Service and are widely available to assist and advise disabled people, whether they are on the register or not. There are also nearly thirty Employment Rehabilitation Centres which run courses to help disabled people to prepare for training and suitable work. The D.R.O.s help in the allocation of places. D.R.O.s can also provide technical aids to help registered disabled people to work.

The intention of all the official schemes and arrangements operating within the Government's control appears to be to prepare disabled people, if possible, for work in 'open' employment alongside the able-bodied. This is an admirable intention. There will always, however, be cases of people so handicapped that they cannot possibly carry out their work in normal conditions. Their prospects and interests must on no account be ignored or overlooked.

What is known as 'sheltered' employment is provided by voluntary organizations, local authorities, and the organization sponsored by the Government called Remploy. The jobs are mostly in workshops and about 14,000 disabled people are at present so employed. Again the D.R.O.s have responsibilities for nominating people for places. This system can be criticized as segregation when now-a-days the merits of 'integration' form a popular theme. In certain cases, however sheltered employment makes all the difference between whether a disabled person can find work or not. It has a part to play in the system, provided that sensitive control can be maintained over the allocation of places and the graduation of employees to the world outside when they are ready and equipped for it.

The Manpower Services Commission embarked upon the 'Fit for Work' campaign in the autumn of 1979 with the message 'Disabled Workers are Good Workers'. The campaign was supported by the Confederation of British Industries (C.B.I.) and the Trade Union Congress (T.U.C.); and there was a related awards scheme to give recognition to firms with constructive and effective policies in the employment of disabled people. A campaign of this kind helps to draw attention to disabled people and the contribution they can make. The awards system certainly ought to be continued. The Companies Act passed in 1980 is helpful in this connection because it requires, for the first time, that companies employing more than 250 include in their annual reports information on their policies on recruitment, training and career development of employees with disabilities. It is to be hoped that Government Departments and official bodies and agencies who are employers on a similar scale will also be required to publish reports on the same lines.

In addition to the official system and services outlined above, there is the National Advisory Council on the Employment of the Disabled. The advice and views which this body offers to the Government are not normally made public, but it can be presumed that candid and critical comments are made by this means from outside the official circle.

One difficult aspect of this subject which must be kept under review is the regulation of earnings. If a disabled person has little or no source of income and is unable to earn a living, he is supported by the social security system or other benefits and allowances. That constitutes the safety net which we have all come to expect to be available in such cases. Should the disabled person then be able to earn some money, there is a limit to what is described as 'therapeutic' earnings, if the official support is not to be reduced. That limit is now £15 a week.

From the point of view of rehabilitation and incentive to acquire and keep a job, a handicapped person should be given every reasonable chance to retain any earnings. While the social security system must remain an essential element for those in need of it, the therapeutic earnings limit should be raised as and when the economic situation permits. Similar action has been taken in raising the limit for earnings of retirement pensioners (now at £52 a week) and the present Government undertook to abolish that limit altogether when circumstances were favourable.

Where disabled people are concerned, there are clearly delicate matters of judgment to be considered. Nonethe less the good effects on a disabled person of being able to earn money for a job well done merit special consideration.

6

EDUCATION AND TRAINING

THE WHOLE SUBJECT OF THE EDUCATION OF handicapped young people has been under public discussion in recent months in the light of the report of the Warnock Committee, which spent four years, from 1974 to 1978, reviewing the special education arrangements existing in England, Wales and Scotland.[6] The Government published comments upon the report in two white Papers, one for England and Wales (*Special Needs in Education*) and the other for Scotland (*Special Educational Needs in Scotland*).[7]

At the time of writing two Government Bills are also passing through Parliament. One applies to England and Wales and deals with this subject only. The other, for Scotland, is a general Education Bill to legislate on several matters including handicapped children.[8]

SCHOOLS

The Government have cautiously accepted the main theme of the Warnock Committee, namely, that there should be a considerable move towards integration of handicapped children with able-bodied children in ordinary schools. For over thirty years the local education authorities, with a duty to provide education for all children, have segregated the severely disabled in special schools where there were arrangements to cater for their disabilities. Children were placed in different categories in accordance with their particular handicaps. This system, the Warnock Committee pointed out, had become less flexible than it should be. Some children had more than one handicap; and they were all likely to fare better if they were considered in accordance with their needs and potential rather than only on the basis of their handicaps.

It was accepted by the Committee and by the Government that there will always be some children who are so handicapped that they cannot sensibly be taught in an ordinary school alongside able-bodied children. There will consequently still be a role for special schools in any future system. Wide support has emerged for the principle of the Warnock recommendations. Not surprisingly, the legislation now before Parliament allows for educating handicapped children in ordinary schools and for reducing the numbers of places in special schools. As a consequence more teachers will need to have some training in the needs of handicapped children and, as the Warnock Committee recommended, parents of disabled children should be closely consulted about their schooling. Both handicapped children and the able-bodied with whom they will be mixing at school should benefit from being at school together. In particular able-bodied children should become accustomed to accepting handicapped children as normal, so acquiring this enlightened and realistic outlook early in life. Special equipment and the adaptation of buildings may be needed while the change of policy is being carried out in future years. There is no reason to assume that these will lead to substantial extra costs because the number of special schools, which have been expensive, will be diminishing.

The Warnock Committee recommended that 'a duty should be imposed on local education authorities to maintain a record of children whom they judged to require special educational provision not normally available in the ordinary school, subject to the proviso that no child should be recorded without prior assessment by a multiprofessional team'. The two Bills before Parliament duly provide for this principle of 'recording' in the cases of certain seriously handicapped children. (While the Scottish Bill retains the word 'record' the other Bill uses different wording with the same effect.) They should both enable a system of discreet supervision to be introduced. Some severely disabled young people would in future be expected to attend ordinary schools. At the same time no child with a particular problem would be left to sink or swim in the world of the able-bodied.

Criticism will no doubt be heard, even if the new system proves to be very effective in carrying out this purpose. Such criticism can be expected to be on the lines that more disabled children, or all of them, should be integrated in ordinary schools. Nothing but complete integration will be regarded as enough by some critics. These observers will be motivated by what they think to be in the best interests of children, but they will be oversimplifying the situation because unfortunately there will always be a number of children so handicapped as to be completely helpless or almost so. For example a child who is paralysed except for a slight movement in one hand cannot realistically be catered for in an ordinary school. In his case an education can be provided only by special arrangements designed to suit his circumstances. This was recognised by the Warnock Committee. It does not detract from the new objective to which the Committee pointed, namely, the inclusion in ordinary schools of as many handicapped children as can benefit from this integration and can be catered for with special equipment and other help.

There will be differences of opinion about the degree of 'integration' which can best be achieved. Our aim should nevertheless be the careful steering of children to what is likely to be the most satisfactory for them in each individual case, after full consultation with parents, medical advisers and others concerned.

HIGHER AND FURTHER EDUCATION

If a young person, while severely disabled, has successfully completed secondary education and obtained a place in further or higher education, he should be generally prepared for the new regime of a college. A student who becomes severely disabled after school is a different matter and is almost certain to find it difficult to take up the reins again.

Besides the allowances which a disabled student may be eligible to receive arising from his handicap, he may claim a special allowance (for disabled students) for additional expenditure caused by his disability. In England and Wales a local authority responsible for student grants has discretion to pay this modest allowance up to a maximum (in 1981) of £235 per year. In Scotland it is the Scottish Office which dispenses these student grants centrally.

Within the last few years the National Bureau for Handicapped Students has been established as a voluntary body to help disabled students, particularly with information about their prospects and entitlements. The Royal National Institute for the Blind provides grants to visually handicapped students towards expenditure incurred in full time courses of higher or further education.

Where disabled young people are not embarking on higher or further education, they may need or seek more knowledge or training. Local authorities have the power to provide grants for correspondence courses and these can be of considerable help to a handicapped person. The Training Services Division of the Manpower Services Commission provides free training and financial support in certain circumstances related to improving employment prospects. Here again handicapped young people have opportunities of benefiting, depending upon their individual situations.

Two developments now in prospect are likely to help handicapped students considerably towards fulfilling their potential after school age. One, already discussed, is the new system for schools to be introduced following the Warnock Report. It will lead to greater preparedness amongst students. The other is the increase in awareness by the general public of the needs of disabled people, which the International Year is helping to bring about.

7

RECREATION AND SPORT

IF A HANDICAPPED PERSON IS TO LEAD AS normal a life as possible, he or she should be given every opportunity of using leisure outside the home. We have already considered the significance of mobility. Provided that appropriate transport can be used, disabled people can enjoy and benefit from the countryside. They can also make visits to places of outstanding beauty, to historic buildings, museums, galleries, and to places of entertainment. It must be emphasized here again that such visits will be restricted and cause disappointment if the buildings concerned are not suitably appointed with access and facilities for seriously handicapped people.

Besides such recreation there is a range of sport in which disabled people can compete. Not only do these activities provide encouragement, satisfaction, and pleasure to those taking part, but they are likely to improve their health in general. Before mentioning some of them a word of caution must be registered. Some of these sports may be excellent for certain kinds of handicapped people. Others may be inappropriate or dangerous. Medical advice should be taken first to ensure that a disabled person is not attempting something unsafe or harmful for his particular condition.

Swimming can be good exercise or relaxation for many handicapped people. Even when their ability to move limbs is restricted, immersion in water in a suitably arranged pool can prove to be an enjoyable and healthy recreation.

In recent years groups have been formed all over the country to provide riding on horses or ponies for disabled people. This outdoor activity can also be beneficial, but here it is essential to determine first whether it is safe or sensible for particular disabilities. Where children are concerned this is an ideal way of bringing disabled and able-bodied together. They will learn to co-operate in overcoming difficulties.

Archery has also become popular in recent years amongst the handicapped. It can be carried out with great success from a wheelchair. Paraplegics in wheelchairs have shown that they can compete with each other in a number of athletic events. In Great Britain this has been fostered in particular by the initiatives and enthusiasm of Stoke Mandeville Hospital. International Paraplegic Games have now become a part of the world's calendar of events.

There is, of course, even more scope for severely disabled people in indoor sports such as table tennis and darts. Exponents confined to wheelchairs can excel in these, especially if they have skill and determination. Although, to be fair, they ought at some of these games to be matched against each other, rather than against able-bodied opponents, the staging of practice and contests should have the satisfactory effect of bringing together disabled and able-bodied people.

Remarkable agility can be developed by people in wheelchairs with the result that wheelchair dancing is spreading as a social pastime for them.

An organization called Physically Handicapped and Able-bodied (P.H.A.B.), amongst its activities, successfully arranges sports meetings and camps for equal numbers of physically handicapped and able-bodied young people.

No attempt will be made here to catalogue all the various kinds of sport which disabled people have successfully taken up. Two of them, although not within the reach or resources of everyone, are worth special mention. They are sailing and car rally driving. The fact that remarkable prowess is being achieved by handicapped enthusiasts in these sports is most heartening to the disabled fraternity as a whole.

The more that is done to promote and increase recreation and sport for disabled people, the more easily will those people participate in other aspects of ordinary life. The initiatives and early efforts to promote such activities can usefully come from able-bodied members of the community.

8

PROSPECTS FOR THE FUTURE

ALTHOUGH SECTION I, OF THE 1970 ACT PLACED a duty upon the relevant local authorities to discover the numbers of disabled people in their areas, it is still not possible to assess, over the country as a whole, the size of the task of providing services for those with handicaps needing help and attention. A few local authorities have been able to make lists with reasonable accuracy, sometimes after door-to-door enquiries undertaken by volunteers. Others have felt that they have not the financial resources to make more than an estimate of numbers after some form of sampling. Central government could compile records of those receiving various benefits and allowances, but this would show part of the picture only. Completion of all local authority surveys is necessary to provide a nationwide count or register.

It is not surprising that leading members of bodies representing disabled people have been urging that the patchwork of local authority surveys should be completed to a minimum standard over the whole country. For most local councils it would be an inordinate expense to carry out a kind of mini-census. There is scope here, however, for more voluntary work. Those members of the public who now gallantly offer themselves, for sponsorship, to undertake long distance runs or other feats, steering the money collected to good causes, could expediently direct their energy to other challenges such as visiting every dwelling in a street or district to collect the information needed about disabled people. They would bring in the sponsorship money too. Such voluntary effort would help the cause of the disabled in a very effective way.

The piecemeal introduction of new forms of financial help for disabled people—improvements in themselves because they met identified needs—has created a complex web of benefits and allowances (the principal ones related to disability can be seen in Appendix I and others of general application are in Appendix II). The conditions attached to them, the rules of eligibility for them and the appeals procedures loom as daunting obstacles to many disabled people and their helpers.

Let us consider the example of the non-contributory invalidity pension for housewives. To be eligible applicants have to prove, first, that they are incapable of paid employment, and second, that they are incapable of 'normal household duties'. The 'test' which is applied to household duties seems to produce arbitrary results since a large number of applicants who failed the test have succeeded on appeal. It also discourages the women concerned from trying to do more in the house and so achieving some degree of rehabilitation. Reflecting the disquiet surrounding this process, the National Insurance Advisory Committee has advocated either abandoning the household duties test or introducing another form of test.

Clearly some rationalization of the whole system of financial help should be attempted in the not too distant future. It is understood that the Government are considering what many of the voluntary organizations have been proposing, a general disablement benefit which would not depend upon the occupation of the individual or the cause of impairment. Ministers should be given every encouragement to prepare a new system on these lines and to publish the results as a consultative document before taking decisions. There should be no reason for concern about the interests of the war-disabled. It should be unquestioned that nothing should be subtracted from the real value of their pensions and benefits. They are now a small and diminishing group (whose ranks we hope will not be augmented by warfare in the future).

Another complication about the present system is that some benefits are taxed and others are not. The Government have announced that they intend to make more of the benefits taxable in 1982 (not war-pensions). The aim is no doubt to use the individual's tax return as the simplest way of apportioning fairly between the affluent and the less well off, even though it means giving with one hand and taking back with another.

If it ever happens a thorough rationalization would be possible upon the introduction of a tax credit scheme (sometimes known also as negative income tax) covering the whole national system of personal taxation and personal subsidies and allowances. One of its intentions would be to reduce means tests to not more than one per person, preferably the equivalent of an individual's tax return. In favour of such a scheme it is argued that it would greatly simplify the present profusion of payments in both directions between individuals and the public purse under a confusing number of headings. The present Government have set themselves the task of moving to a tax credit system, as a future reform, but have indicated that it is still some years away because of the initial cost.

In any new system much will still depend upon the relevance and reliability of medical examinations and certificates. Again it is to be hoped that improvements can be made to rationalize the number of examinations which have to be carried out for official purposes.

As we have seen in the chapter on Prevention, there are good prospects of reducing the incidence of severe handicap, although there will be a larger proportion of the population in the older age-groups than hitherto. We can look forward with confidence to a declining proportion of disabled people amongst those of working age and under. There will still be special problems, some of them new. For example it is estimated that there are about 2,000 people in Britain in their teens or older suffering from spina bifida. Because of success in treatment they have survived to ages beyond those previously expected for this congenital abnormality.

Research and medical care will continue to improve the lot of severely disabled people. Perhaps the greatest advance that can be hoped for in the next few years is in public attitudes. The International Year is helping. The more able-bodied people there are who can recognize disabilities and act or help accordingly, but with sensitivity, the more people with severe handicaps there will be who can live ordinary lives in the community. Quite apart from possible changes to rationalize the systems which have evolved, as described above, the Treasury and the Health and Social Security Departments should keep the whole deployment of financial help and resources for disabled people under review to ensure that public expenditure is in the forms most needed. We must expect more handicapped people to be living in their own homes rather than in institutions. That should certainly be our aim. The proportion of financial support in direct personal benefits and the proportion to be extended in other ways, for example through local government services, must be adjusted from time to time to achieve the greatest effect with the money available.

The Pearson Commission[9] pointed out that the biggest single source of compensation for injury and bereavement in this country is our social security system. Payments do not depend on whether an injury was due to anyone's fault, as distinct from civil liability in tort or, in Scotland, delict. Usually the law of tort requires payment of compensation only when the person who caused the injury was at fault (normally by his insurers). The Commission's recommendations on future 'no-fault' compensation schemes (meaning payment out of a fund regardless of whether anyone is at fault) are extremely relevant to the rationalization and simplification of the social security system.

We have recorded in Chapter 1 that in the 1960s disabled people and their helpers found that they were having to deal with several departments of central and local government. Although the situation has improved since then, the division of responsibilities between different authorities can still be perplexing. A move in the right direction was the designation of a Minister for the Disabled. He has been one of the junior Ministers in the combined Department of Health and Social Security (D.H.S.S.) and has had other duties as well. One of his functions should be to arrange for all the official services concerned with the disabled to be working closely together. If possible disabled people, or their representatives, should each be required to have only one point of communication with the state system.

There has also been some confusion in the past about responsibilities for the supply of aids and appliances. For example, the Education Departments have provided aids for pupils in special schools, while the Department of Employment can supply aids to help a disabled person to obtain or keep a job. Appliances have also been available from local authorities and voluntary bodies, besides hospitals and appliance centres. Here again more can still be done to rationalize the system in the interests of efficiency and availability to disabled people.

A most useful service for severely handicapped people is the provision of information of particular relevance to them. There are organizations already doing good work of this kind. One is the Disabled Living Foundation, based in London. Another is the Scottish Information Service for the Disabled, in Edinburgh. These organizations publish information on aids and equipment, social and recreational facilities and educational opportunities. They also organize meetings and study groups in addition to providing information direct to enquirers. Special telephone arrangements are also now being devised to enable disabled people in their homes to be in direct and immediate touch with information points and to make contact with services, especially in emergencies. This is a personal service which could be expanded rapidly in the next few years.

Easy access to the kind of information which they need is a very helpful factor in enabling more severely handicapped people to live outside institutional care.

There are now a great many voluntary organizations and societies who are active in the interests of disabled people. Some are identified with particular disabilities, such as multiple sclerosis. There are also pressure groups, most of them of recent origin, campaigning on behalf of the disabled in general or of particular categories. There is no doubt that they have had an impact upon elected representatives, departments and the general public. The pressure groups will mostly want to continue their activities on their own. As regards the majority of voluntary organizations, however, more is likely to be achieved in the future for the benefit of disabled people through better coordination with official bodies working in the same fields and with the professions involved.

There is no more appropriate time for closer cooperation of this kind than the International Year. 1981 should not, of course, simply be regarded as a single period of intense and concentrated attention and activity. Rather should it be treated as a time during which great acceleration in progress should be attained. It is to be hoped that the impetus will be carried on for many years to come.

We have already noted that for several years the importance of making public buildings accessible for disabled people has been accepted in principle. Regrettably there have been no legal or other sanctions available to induce those responsible for buildings about to be constructed to conform.

The Government should set themselves a special duty in the next few years to insist upon access for disabled people to buildings used by the public. This is what the country will demand sooner or later and it should be enforceable when new proposed buildings are at the design stage. Because of its wide application to private developers and owners as well as public authorities, this is a nettle which the Government should grasp. It is too much to expect a Private Member's Bill in Parliament to deal with the complications of planning legislation, building regulations, enforcement provisions and perhaps the introduction of new offences. An improvement of this kind, making access arrangements enforceable for new public buildings, would be one of the most rewarding actions which a Government in this country could now take in the improvement of daily life for severely disabled people.

In these days of high unemployment and of gloomy predictions that it will continue, there is one bright feature for several categories of physically handicapped people. The micro-chip and the computer may have replaced numbers of men and women in work, but they can provide work for the disabled in their homes. There are a number of jobs, including programming, which can be done in isolation because the equipment is linked by line with an external system. Many of those with physical handicaps severe enough to render them immobile develop the aptitude required for this kind of work with computers.

Whether further opportunities of suitable employment occur or not, we can be confident that severely disabled people will make even more remarkable contributions to the community than they have in the past. It is important that they should be enabled to help themselves. Many of them have astonishing achievements to their credit. More will be able to fulfil their full potential when the rest of the community recognize, encourage, and understand them.

APPENDIX I

Some of the principal benefits in 1981 related to disability, in weekly amounts

Invalidity benefit: N.I. contributory; *£26 and £15.60 dependant, £7.50 each child.*

Non-contributory invalidity pension: Not N.I. contributory; *£16.30 and £9.80 wife, £7.50 each child.*

Non-contributory invalidity pension for married women: Not N.I. contributory; *£16.30*

Attendance allowance (for disabled requiring daily care and attention from another person): Not N.I. contributory; *£21.65 (day and night), and £14.45 (day or night).*

Invalid care allowance (for another person who attends a severely disabled relative, not a husband): Not N.I. contributory; *£16.30.*

Disablement pension (War): Not N.I. contributory *£44.30 (100% Private Soldier).*

Disablement benefit (Industrial): Not N.I. contributory; *£44.30 (100%).*

Mobility allowance: Not N.I. contributory; *£14.50.*

NOTE. Payment depends on conditions for qualifying. Rules for tax, means tests and loss of other benefits vary for each benefit.

APPENDIX II

Benefits in 1981 of general application, not directly related to disability, but important to disabled people with small incomes, in weekly amounts

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Sickness benefit: Contributory; *£20.65 plus additions for dependants and children.*

Unemployment benefit: Contributory; *£20.65 plus additions for dependants and children.*

Retirement pension: Contributory; *£27.15 single, £43.45 married.*

Child benefit: Non-contributory; *£4.75 per child.*

Supplementary benefit, normally covers rent as well: Non-contributory; *£21.30 single, £34.60 married.*

Family income supplement: Non-contributory; *takes parents' income up to £67, additions for children.*

Rent rebates: Non-contributory; *scale depending on income, disability increases rebates.*

Rate rebates: Non-contributory; *scale depending on income, disability increases rebates.*

APPENDIX III

Main causes of impairment

1. Diseases of blood and blood forming organs
    e.g. haemophilia
2. Mental, psycho-neurotic and personality disorders
    e.g. mental illness
    psychosis
    debility
    mental subnormality
3. Diseases of central nervous system
    e.g. poliomyelitis
    strokes
    multiple sclerosis
    epilepsy
4. Diseases of circulatory system
    e.g. congenital heart disease
    rheumatic fever
    coronary disease
5. Diseases of respiratory system
    e.g. bronchitis
    emphysema
    asthma
6. Diseases and disorders of digestive system
7. Diseases of genito-urinary system
8. Disorders of sense organs
    e.g. deafness
9. Diseases of skin and cellular tissue
    e.g. dermatitis
    psoriasis

10. Diseases and disorders of bones and organs of movement
    e.g. rheumatoid arthritis
    muscular distrophy
11. Congenital malformations (present from birth, not necessarily hereditary)
    e.g. spina bifida
12. Injuries
    e.g. birth injuries
    burns
    injuries from accidents, war, violence
13. Senility
14. Amputations
15. Blindness
16. Neoplasms (tumours)
    e.g. cancer (malignant tumours)
17. Endocrine diseases
    e.g. diabetes
18. Allergic diseases
19. Nutritional diseases
20. Metabolic diseases
21. Parasitic diseases

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