

Wanted: A Policy for Disabled Children and Adults

How the Story Began

Criticism of both Labour and Conservative Governments for their inability to develop a sufficiently generous and comprehensive policy for the disabled has been gathering momentum, and now takes a new, and possibly highly significant, form. The letter to the Prime Minister printed above was signed by 68 specialists whose work in a professional or voluntary capacity puts them in touch with the needs of handicapped children and adults. The unity which is demonstrated, although expressed in general terms, is new and encouraging.

There are three main groups among them: heads of voluntary associations concerned with the handicapped; university professors of Paediatrics, Child Health, Child Development and Social Administration; and heads of research institutes and units. There are also representatives of both Labour and Conservatives in the House of Commons and the House of Lords. Although many signed as individuals, some heads of voluntary bodies, including those of the Multiple Sclerosis Society, National Association for Maternal and Child Welfare, Invalid Children's Aid Association, National Association for the Welfare of Children in Hospital and the Society for the Aid of Thalidomide Children, specifically sought the endorsement beforehand of their executive committees or trustees.

The letter was sparked off by the Government's response to the outcome of the public discussion about the thalidomide children. Once it was known that a sum of at least £10m. (later £20m.) would be settled by the Distiller's Company on about 400 thalidomide children, Sir Keith Joseph announced that £1m would be granted in the first instance to the Joseph Rowntree Memorial Trust to pass on to the parents of severely

congenitally handicapped children. But there are probably between 80,000 and 100,000 such children and the sum is, therefore derisory, amounting to little more per family than an exceptional needs grant for clothing.

Moreover, there are many other children, and adults, who are handicapped to the same or to an even more severe extent as the result of either disease or accident. For example, large numbers of children have hip diseases, chronic disease of the kidneys, malignant tumours or leukaemia; and many others are severely handicapped after accidents in the home or on the roads. There is a risk of creating three widely different financial categories among children who are all severely handicapped; thalidomide children entitled to the largest sums; severely congenitally handicapped children qualifying for small grants; and other handicapped children entitled to nothing. The same kind of anomalous situation already applies to adults, depending on whether their disability originated in war, at work or in the home and is frequently criticised. Although the Labour Government reorganised personal social services and introduced legislation on the attendance allowance, and the Conservative Government went on, as Mr. Heath says in his letter printed above, to introduce invalidity pensions and extend the initial scope for the attendance allowance and other benefits, no attempt has yet been made to review the different sums that are paid to, or on behalf of, people of equal disability and to examine evidence of the needs and living standards of the disabled.

A rational and comprehensive system of allowances and a co-ordinated programme governing occupational and community services have yet to be worked out. Since 1965 the Disablement Income Group has campaigned for an equitable system of income for all the disabled and such a system still seems far away. And although the growth of expenditure on local

authority health and personal social services is currently rapid, the Government has not yet produced a controlled programme of priorities and is planning to reduce substantially the rate of growth, as Table 1 shows.

TABLE 1

Planned expenditure on local authority health and
personal social services

	£m	per cent increase over previous year	expenditure as per cent hospital expenditure
1971-72	453	10.0	29
1972-73	499	10.2	30
1973-74	542	8.7	31
1974-75	565	4.3	32

Source: Public Expenditure to 1976-77, Cmd. 5178, December, 1972, p.71.

Below, the case for a comprehensive policy is divided into three parts: estimates of the number who are disabled; how a system of allowances and pensions might be developed according to degree of disability; and how a more comprehensive and uniform system of care and occupation might be created by the local authorities.

1. The Number of Disabled

There are at least three sources of information about the numbers of children under 16 who are handicapped. First, registration in local authorities, particularly Scotland, where the strongest efforts have been made to locate the handicapped suggest a total for the United Kingdom of at least 200,000 under 16. The department of Health estimates cautiously that the number is 150,000. Second, the National Children's Bureau found

*Strongest efforts perhaps,
but applying only to children.*

*Chronically Sick &
Disabled Act not
enforced yet.*

in a survey of seven year olds that 2.6 per cent were congenitally handicapped and another 1.6 per cent had been injured after accidents, had progressively disabling illnesses, were severely or partially deaf or were otherwise in need of special educational treatment. If these two percentages are applied to children of all ages a total in the United Kingdom of more than 500,000 children is reached. However, some will be only slightly handicapped. Third, a research team directed by Michael Rutter and Jack Tizard in the Isle of Wight, found that 1.1 per cent of children aged 10-12 were severely or moderately handicapped, another 2.2 per cent slightly handicapped and a further 2.4 per cent impaired without it affecting their principal daily activities. If the first two percentages are applied to children of all ages, totals for the country of over 150,000 and 300,000 respectively are reached. These and other sources of evidence lead to the conservative conclusion that there are at least 400,000 children in the United Kingdom whose activities are restricted because of handicap, 150,000 of them substantially or seriously.

For people aged 16 and over the Government's national survey carried out by Amelia Harris and her colleagues, produced the following estimates of degree of handicap:

Very severe	157,000
Severe	357,000
Appreciable	616,000
Total	<hr/> 1,130,000

Of these about 400,000 were under 65 and 730,000 over 65. Another 1,942,000 were estimated to be impaired, but needed little or no support for normal everyday living activities.

These estimates are now being used extensively as a basis for planning, though many local authorities have undertaken their own surveys to establish local prevalence.

2. Allowances to be based on degree of handicap

No country has yet been able to establish an equitable system of income for the disabled. Some countries, including Sweden and the Soviet Union, have tried to build comprehensive schemes based mainly on the principle of compensation for loss of earning power. This principle has proved difficult to apply. It has led to substantial numbers of the disabled being left out of the schemes and also to crude and arbitrary simplification of rates of payment.

In every country there are disabled people who have been handicapped from birth or childhood and have never worked. There are people who have been disabled in adult life but have either had a number of jobs at lower rates of earnings during a gradual onset of disablement or, like married women and the chronically ill, have not held a paid job for years. It is difficult to establish what "wage" should be compensated. It is also difficult to argue that a wage earned say in 1972 and compensated in 1973 should be compensated in just the same way in every succeeding year to 1973 and beyond. Should people receive fixed earnings related disability pensions in late middle age and after reaching the pension age, especially if they were first disabled at 20 or 30? How can an earnings-related scheme cover not just one or two but several categories of degree of disability, and how can it cover people whose disability gets gradually more severe over periods as long as 10 or 20 years? As time passes, and depending on the point in the life cycle at which disability occurred, peak or average or theoretical earning power seems largely irrelevant to the question of determining for the rest

of life the living standards of disabled people, especially at times of inflation and rapid social change.

Two developments in Britain strongly support the establishment of an entirely new system, based on the principle of degree of functional handicap or disability. First, a succession of research studies by teams at the University of Essex, Bedford College, St. Thomas' Hospital, the London School of Economics, and the Social Survey division of the Office of Population Censuses and Surveys have shown how questions about everyday activities can be used to discriminate fairly reliably between people with different degrees of disability even when they are suffering from widely different clinical conditions. Work by the National Children's Bureau and the team completing the survey in the Isle of Wight suggest that similar questions might also be used for children, though they would have to be adapted for very young children. Included might be questions about difficulty experienced in getting in and out of bed, climbing stairs, washing hands and face, dressing, tying string and stretching to an overhead shelf, getting to the shops and joining in ordinary conversation. Groups of questions and tests can be applied by people trained in their use who need not be doctors to find whether the individual falls substantially short of being able to undertake the activities normal for someone of his age. Allowances of 20 per cent, 30 per cent and so on of the full rate of disability might be paid to reflect degree of disability. The full 100 per cent rate might be fixed at a rate corresponding with that for 100 per cent disablement in the industrial injuries scheme (currently £11.20 but going up to £12.80 in October 1973).

Second, experience of the administration of a new benefit adds immeasurably to the case. The war pensions and industrial injuries

disablement schemes have used percentage assessment for many years and cover 371,000 and 208,000 people respectively. However, these schemes are limited mainly to men experiencing certain types of disability in early adulthood and are based on the strange guidance of the McCorquodale Committee which was over-conscious of physical impairment. In 1965 this Committee refrained from studying the effects upon individual activity of the loss of different bodily functions and recommended, for example, that the loss of three fingers, the amputation of "one foot resulting in end-bearing stump", the amputation "through one foot proximal to the metatarsophalangeal joint" and the loss of vision in one eye should all be treated as equivalent to 30 per cent disability.

The new attendance allowance scheme represents a departure from this tradition. All types of disability and people of any age except infants under the age of two are covered. Moreover, two degrees of severity of disability have so far been identified using a type of functional assessment like that used in the research studies. The report completed by a doctor includes questions about an individual's capacity without help to change position whilst in bed, get out of bed, walk, use stairs, dress and undress, wash, bathe, eat, drink and go to the toilet.

The Prime Minister seems to envisage the extension of the attendance allowance to only about a quarter of a million (or just over a fifth) of the severely or appreciably disabled by 1974-75. A much higher proportion could be covered in the next two years. For example, the constant attendance allowance under the war pension scheme is now paid at five separate rates.

There seems then to be a strong argument for using functional assessment more generally. There are two important qualifications. Attendance allowances are only intended to be a contribution to the costs of attendance and although functional assessment is used to determine eligibility it

could be used to determine entitlement to a minimum income or pension as well. And though there are problems in covering certain disabilities, especially those like epilepsy or asthma, which may be only temporarily, if devastatingly, incapacitating, they can be overcome. Allowance could be made for frequency and severity of attack and also any restriction or need for supervision that has to be placed on the ordinary range of activities.

Disability allowances would partly replace basic social security allowances. The costs of the scheme outlined here would be approximately £250m. - £300m. per annum or about one-eighth of the cost of retirement pensions. This estimate is based on the numbers of handicapped found to be in different categories in the Government's survey, with an addition for children, and on the assumption that about half any entitlement would be offset by any retirement pension received.

Such a system would be very attractive. Disabled adults would have a right without test of means, to the allowance and would have no disincentive to work; indeed they would have a minimum income to meet basic expenses, if they did choose to work, and the allowance would bolster their low earnings. The disabled elderly would receive allowances additional to the standard rate of retirement pensions to meet the needs of and compensate for, disability. Parents of disabled children would be entitled to an addition to the family allowance to meet the needs of their children.

The system would not preclude the development of other types of allowance including earnings-related supplements and any standardised forms of compensation worked out by the Pearson Commission to reflect liabilities of employers and others. For example, under the industrial injury and war pension schemes there are, in addition to basic disablement pensions and attendance allowances, unemployability supplements and a

whole range of different allowances for treatment, invalidity, clothing, comforts, age, lowered standard of occupation and exceptionally severe disablement. What is now required is Government commitment in principle to a comprehensive scheme based on degree of disability and urgent attention to the job of working out a detailed scheme.