

An aid scale for disabled children

* EXCLUDING THOSE

The announcement by Sir Keith Joseph, in the wake of the campaign by *The Sunday Times* and MPs, including Mr Jack Ashley, that £3m would be given to the Joseph Rowntree Memorial Trust to help severely congenitally disabled children, including the thalidomide children, seems to be wrong on all counts: many severely handicapped children are excluded; benefit should take the form of weekly or monthly payments rather than a lump sum; the total of £3m is therefore much too small; and the task of administration would be best undertaken by a statutory body.

Which families should qualify for Government help? Sir Keith has rightly decided that children other than thalidomide children should be included but has referred only to children with "very severe" disabilities "found to be present at birth or immediately after". But some major disabilities are not in practice identified in early infancy and only come to light, or develop, much later.

Muscular dystrophy, for example, may not become apparent until a child begins to walk and severe mental handicap may not be diagnosed among children under five, or even under 10. The reported incidence is only 0.5 per 1,000 under five years of age, compared with 3.5 per 1,000 at 15-19. As the Tunbridge Committee stated in its recent authoritative report on *Rehabilitation*: "Disability in children is rarely easy to analyze in the early years. The early identification of disability is best achieved by a periodic developmental assessment for all children."

Can assessments after infancy, therefore, and reassessments to take account of changes in severity of disability, be included in the proposed scheme? Should financial aid be withheld from parents of children disabled, say, after a road accident or a long illness? Unless questions such as these are answered from the start by the Government itself an arbitrary and inequitable system is bound to result.

The scale of the problem is still largely guesswork. In spite of a variety of studies of handicap in recent years, information about handicapped children is inadequate. The lack of reliable estimates of the number of disabled caused the Government to commission a survey in 1968-69. The third report on that survey, making an implicit case for a disability pension and showing that about 70,000 disabled adults are not drawing but are entitled to supplementary benefit, has just been published. Handicapped children under 16 were excluded from the survey, and estimates of their numbers are uncertain. The table below sums up the figures that can be gleaned or estimated from different Government reports. There is an overlap between some of the estimates, for example, between those in the care of local authority mental health services and those awaiting admission to special schools and a few small groups such as the physically handicapped in ordinary schools and in hospitals, have not been included. Altogether there are over 150,000 handicapped children known to different services. This is in fact the minimum figure officially assumed by the DHSS but many handicapped children are not known to any service, and the rate varies between areas. Greater efforts have been made in Scotland than in England to locate the handicapped and, through the Scottish Home and

Number mentally handicapped children in hospital ..	7,100
Registered blind ..	2,300
Registered partially sighted ..	3,300
Registered deaf and partially deaf	6,300
Handicapped (general classes) on local authority registers ..	15,700
Number physically handicapped and delicate children in special schools ..	19,500
Number of educationally subnormal children in special schools ..	59,000
Additional number attending special schools, formerly training centres	21,400
Number educationally subnormal children awaiting admission to special schools, and those receiving education in their own homes ..	(a) 10,400
Number in care of local authority mental health services ..	31,000
(a) England and Wales only.	

Health Department admits there is still some way to go, far more physically handicapped children have been registered than in the whole of England, despite the much smaller population. According to Scottish experience there should be 80,000 to 100,000 handicapped children who are mentally handicapped, deaf, blind or partially sighted, on the English local registers. In fact there are fewer than 6,000.

According to functional criteria the total numbers of children with every kind of handicap in the population are likely to lie between 300,000 and 500,000. Our estimate is 400,000. This figure is based on information from areas where special efforts have been made to register the handicapped, research surveys of children, and rates per 1,000 population of certain types of handicap among people between the ages 15 and 19.

For example, in the comprehensive National Child Development Study, which included medical examinations, but did not establish functional effects, 2.6 per cent of seven-year-olds were found to have various congenital disorders of a serious kind, and another 1.6 per cent were in need of special educational treatment, were injured after accidents or had progressively disabling illnesses or were severely or partially deaf. Applied to all children under 15 the combined total of 4.2 per cent represents over 550,000 children.

The pattern of handicap is changing. During the past 50 years cerebral palsy and spina bifida have begun to replace poliomyelitis and heart disease as principal causes of handicap. The change is, of course, based largely on the development of new drugs and methods of surgery but also on the acceptance by more of the medical profession and of the public of malformation, at least among children. The numbers of handicapped children who survive the critical weeks after birth is likely to increase steadily.

Little is known about numbers with different degrees of handicap. Some children may be only mildly handicapped and require little more parental supervision and maintenance than children who are not handicapped. Others place severe psychological, physical and financial demands on their parents. Some need special aids, frequent replacements of shoes and clothing, a special diet, a specially designed home environment, or regular subsidies for transport.

What form should financial aid take? The attendance allowance can be paid to the parents of severely handicapped children of two years of age and over, but by April 1972 only 11,600 awards had been made for children under 10 in Britain and the allowance is one for attendance and not other

special needs. The provision of aids by social service departments, which would reduce financial needs, is also still on a tiny scale. Finally, the Royal Commission on civil liability and compensation for personal injury and death, which was set up under Lord Pearson by the Prime Minister just before Christmas, cannot fill the gap in policy. The terms of reference are sadly restricted.

While forms of compensation might be preserved in law for liabilities which can be traced, such a system is plainly unsatisfactory as a method of providing financial support for all those in need and according to degrees of need. Liability cannot be traced in most instances, it is not related uniformly to need, courts vary in their decisions and inflation quickly reduces the value of any award. Instead, a strong argument can be made for an allowance which can be paid at a special rate, and which could be varied according to degree of handicap. The advantage over lump sum compensation of a special allowance for handicapped children, which could be paid like a supplementary family allowance, is that it can be changed from time to time to allow for any changes in the condition of the child, the economy or society's perception of need.

The administration of grants or allowances for handicapped children must be based on a wide range of expertise and be accountable directly to the public. Any voluntary association concerned with the handicapped would find it impossible to assess even all congenitally disabled children. The Government is being unfair in asking the Rowntree Trust to attempt the task. Elaborate enquiries will have to be made in all parts of the country and information collected. The needs of children and their parents will have to be carefully weighed, with full opportunity for appeal and public discussion of the principles upon which payments are made. The closest contacts with health, welfare and social security services will be necessary.

The allocation of £3m is significant because Sir Keith tacitly acknowledges that under the present law a fair outcome of the dispute between the Distiller's Company and the parents of the thalidomide children cannot be guaranteed—or cannot be achieved without special Government measures. There are difficulties in finding an equitable solution for the future as well as the present needs of these children. But for each one of them there are another 1,000 handicapped children, some of whom deserve as much, or even more, financial aid.

The Government should therefore announce a comprehensive policy to replace what is little more than an ineffectual gesture. It should appoint an advisory committee, perhaps linking with the committee advising on the attendance allowance, to supervise its introduction. The Rowntree Trust's administration of the first £3m could be treated as an integral part of the first phase of that work. But no one should be under any illusion that less than the expenditure of 30 times this figure should be committed annually if families are to receive adequate financial support for handicapped children.

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