

THE DISABLED IN SOCIETY

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The Disabled in Society⁽¹⁾

In Britain about 1½ million persons, or 3 per cent of the population, are found in groups officially described as disabled or handicapped.⁽²⁾ Over a million live at home. The Ministry of Labour lists 654,000 persons on the Disabled Persons Register.⁽³⁾ There are approximately 450,000 disablement pensioners from the two Great Wars and nearly 200,000 industrial injury disablement pensioners.⁽⁴⁾ The local authorities' registers contain the names of 110,000 blind, 30,000 partially-sighted and 205,000 other disabled and handicapped persons, the great majority of whom live at home.⁽⁵⁾ There are many persons with long-term mental or physical handicaps, probably about 200,000 who reside in hospitals, particularly those for the chronic sick and mentally ill, or in residential Homes or hostels.⁽⁶⁾ They include 65,000 subnormal and severely subnormal patients in psychiatric hospitals. Altogether 90,000 subnormal and severely subnormal and another 71,000 mentally ill or psychopathic

(1) A lecture given at the Royal College of Surgeons on 5th May 1967 under the auspices of the Greater London Association for the Disabled. It owes much to Sally Sainsbury, who carried out the survey on which it is largely based. See her book, Registered as Disabled, London, Bell, 1970.

(2) The figure is a conservative estimate which allows for double - or multiple - counting of the same persons in some of the categories listed in the rest of this paragraph. Judging from research in other countries, for example, Denmark and Sweden, a figure of 6 per cent of all adults aged 21-64 is likely to be reached when disability is defined broadly. Allowing for a smaller proportion of children but a much larger proportion of the elderly the figure for the whole population would probably be higher. See, for example, Andersen, B.R., Fysisk Handicappede i Danmark, Socialforskningsinstituttets Publikationer 16, Copenhagen, 1964, pp.55-56. / On the basis of a major survey carried out by the Government in 1969, 1.1 millions in Britain aged 16 and over were estimated to be very seriously, severely or appreciably handicapped, and a further 1.9 millions were impaired but needed little or no support for normal everyday living activities. Harris, A., Handicapped and Impaired in Great Britain, London, HMSO, 1971.

(3) Ministry of Labour Gazette, April, 1967, p.308.

(4) Report of the Ministry of Pensions and National Insurance for the Year 1965, Cmd. 3046, London, HMSO, 1966.

(5) For England and Wales, Report of the Ministry of Health for the Year 1965, Cmd.3039, London, HMSO, 1966, pp.127-30. Figures for Scotland obtained from Home and Health Department and added.

(6) About 48,000 of those living in council or supported voluntary Homes in England and Wales are described as "handicapped". See Report of the Ministry of Health for 1965, op.cit., p.124.

persons living at home have mental health service provided by local health authorities.⁽⁷⁾ The Supplementary Benefits Commission (formerly the National Assistance Board) pays allowances to 138,000 incapacitated persons living at home who are not receiving sickness or other insurance benefits.⁽⁸⁾ There are 76,000 handicapped children of whom about 32,000 are physically handicapped in special schools or units.⁽⁹⁾ Other administratively-defined categories might be added. There is considerable duplication in these figures. Their very fragmentation and the confessed inability of the Ministry of Health to give "comprehensive national statistics"⁽¹⁰⁾ forces us to ask whether we are doing all we should to develop our understanding of handicap and disability and whether the services to meet the needs of the disabled are adequate.

In this lecture I shall describe the results of a survey carried out between 1964 and 1966 from the University of Essex. This was carried out in London, Essex and Middlesex by Sally Sainsbury, a Research Officer at the University, under my guidance. The Greater London Association for the Disabled generously commissioned the work in the belief that it would contribute to the task of thinking out afresh the roles that should be played respectively by local authority and voluntary organisations as a result of the reorganisation of London government. Our data cover one group of the disabled in the three local authority areas - those registered in the "general classes" of the physically handicapped - that is, excluding the special groups of blind, deaf and hard of hearing. A sample of men and women on the registers was visited and a total of 211 persons were interviewed, the majority being in London. Eight per cent of the original sample refused an interview and another 3 per cent were too ill to give information. The average interview took over two hours.

(7) England and Wales, Report of the Ministry of Health for 1965, op.cit., p.119.

(8) In March 1967 the total had reached 144,000 (Private communication, Ministry of Social Security). Most of them "are persons incapacitated since birth or early childhood and living with their parents". Report of the National Assistance Board for the year ended 31st December 1965, Cmnd.3042, London, HMSO, 1966, p.13.

(9) Education in 1966 - Report of the Department of Education and Science, Cmnd. 3226, London, HMSO, 1967, p.44.

(10) Health and Welfare: the Development of Community Care, Cmnd.1973, HMSO, 1963, p.31.

The survey was thus relatively modest in numbers of persons and of areas covered. This fact should be borne in mind throughout the following report. Moreover, registration with a local authority is voluntary and some kinds of disabled persons do not see why they would benefit by registering. Other disabled persons are not advised by Government and local authority departments and voluntary organisations to do so.

Our sample does not adequately represent certain kinds of handicaps such as blindness, deafness and mental illness or subnormality. Only five per cent were war or industrial disablement pensioners. Nonetheless, a wide range of persons were included, some with multiple handicaps. As many as 45 different kinds of handicaps were represented. There were rather more women than men. Nearly half were married and another third widowed, separated or divorced. Some were in their teens, twenties and thirties but two-fifths were middle-aged (45-64) and another two-fifths elderly (65+). The main source of income for nearly a fifth was derived from employment; two-fifths depended primarily on retirement pensions, nearly a fifth on sickness benefit and the rest on national assistance, disablement pensions and unemployment benefit.⁽¹¹⁾

The chief conclusion of the study is that there is an imbalance between the impulses of the disabled towards integration into ordinary social and occupational life and the segregative practices of society. One wants what the other largely fails either to recognise or translate into real opportunity. Although a majority of the persons registered with the local authorities are severely incapacitated and a majority middle-aged or elderly most emphasise physical and economic independence and integration in work and society. They are usually realistic about their limitations but believe they could lead an approximately normal life if only they could obtain more help with physical aids, housing, transport and employment. In general they regard special clubs or residential Homes and special workshops as second-best, like other symbols of separate disability status. By contrast, society tends to give weak support to the principles of economic

(11) Many of those receiving retirement pensions and unemployment or sickness benefits were also receiving supplementary national assistance. People receiving personal disablement benefits (war or industrial injury) were also eligible to receive national insurance benefits.

independence and social integration or participation and fairly strong support, some of it unwitting, to the enforced dependence and social segregation of the disabled.

This conclusion naturally requires qualification, for the supporting arguments are by no means entirely consistent. It depends on a wide variety of evidence about the actual situation of the disabled - their environment, work and income and their relationships with family and social services. There is lamentably little factual knowledge. I shall endeavour to present some of the more important strands of evidence in this lecture. A necessary first step is to discuss the underlying concept of disability and explain why new definitions and measures are essential both for knowledge and policy.

The Meaning of Disability

What do we mean when we say that someone is disabled? First, there is anatomical, physiological or psychological abnormality or loss. Thus we think of the disabled as persons who have lost a limb or part of the nervous system through surgery or in an accident, become blind or deaf or paralysed or are physically damaged or abnormal in some particular, usually observable, respect.

Second, there is chronic clinical condition altering or interrupting normal physiological or psychological processes, such as bronchitis, arthritis, tuberculosis, epilepsy, schizophrenia and manic-depression. These two concepts of loss or abnormality and of chronic disease tend in fact to merge for although a loss may be sustained without disease, disease long-continued usually has some physiological or anatomical effect.⁽¹²⁾ Among the persons whom we interviewed a wide range of conditions were represented. About 31 per cent specified rheumatoid arthritis, osteo-arthritis or just arthritis and between four per cent and 13 per cent in each instance specified the after-effects of poliomyelitis,

(12) See also the analysis by Nagi, S.Z., "Some Conceptual Issues in Disability and Rehabilitation", in Sussman, M.B., (ed.), Sociology and Rehabilitation, Washington D.C., American Sociological Association, 1966, particularly pp.100-103.

disseminated sclerosis, bronchitis, epilepsy, coronary thrombosis or were amputees or hemiplegics. For both meanings of disability the clinical reference-object is the normal human body, of like sex and age.

A third meaning is functional limitation of ordinary activity, whether that activity is carried on alone or with others. The simplest example is incapacity for self-care and management, in the sense of being unable or finding it difficult to walk about, negotiate stairs, wash and dress, for example.⁽¹³⁾ But this principle of limitation can be applied to other aspects of ordinary life. By reference to the average person of the same sex an estimate can be made of the individual's relative incapacity for household management and performance of both general social roles as husband, father or mother, neighbour or church member, say, and of specific occupational roles.

A fourth meaning is a pattern of behaviour which has particular elements of a socially deviant kind.⁽¹⁴⁾ This pattern of behaviour is in part directly attributable to an impairment or pathological condition - such as a regular physical tremor or limp, or an irregularly occurring fit. But it is also attributable to the individual's perception of his condition and his response to others' expectations of him. Thus, activity may not only be limited, but different. And it may be different as much depending on how it is perceived by the individual and others as on its physiological determination. Two people with an identical physical impairment may differ greatly in their behaviour, one acting up to the limit of his capacities and the other refraining from actions of which he is capable. Alternatively a man with little or no impairment may play the disabled "role". Sociologists have recently paid increasing attention to the concepts of the sick role and of illness behaviour.⁽¹⁵⁾ Society

(13) An attempt to develop a measure of this was made in "Measuring Incapacity for Self-Care", in Townsend, P., The Last Refuge, London, Routledge, 1962, pp.464-476.

(14) Goffman, E. Stigma: Notes on the Management of Spoiled Identity, Englewood Cliffs, NJ, Spectrum Books, 1963; Freidson, E., "Disability as Social Deviance" in Sussman, M.B., Sociology and Rehabilitation, Washington DC, American Sociological Association, 1966. More generally see Becker H.S., Outsiders: Studies in the Sociology of Deviance. The Free Press, New York, 1963, particularly Chapters 1 & 2.

(15) See, for example, Mechanic, D., "The Concept of Illness Behaviour", Journal of Chronic Diseases, Vol.15, 1962; Mechanic, D., "Response Factors in Illness: The Study of Illness Behaviour", Social Psychiatry, Vol.1, Aug. 1966.

expects the blind or the deaf or the physically handicapped to behave in certain approved or stereotyped ways. We all know of instances of people assuming deafness or handicap. They may adopt whole patterns of behaviour. Individuals can be motivated towards such behaviour when their physical or neurological condition does not compel it. A family or a sub-culture can condition it. There are cultural differences in disability behaviour. People of different nationality or ethnic group vary in their stoicism in face of pain and handicap.⁽¹⁶⁾ All this can be a fascinating focus for inquiry.

Finally, disability means a socially defined position or status. The actor does not just act differently. He occupies a status which attracts a mixture of deference, condescension, consideration and indifference. Irrespective of a disabled individual's specific behaviour or condition he attracts certain kinds of attention from the rest of the population by virtue of the "position" that the disabled, when recognised as such, occupy in that particular society. There are countries and populations which do not recognise or identify mild forms of subnormality, schizophrenia or infirmity, for example. In working-class British society euphemisms for certain handicaps are used. Someone has "nerves" or is "hard of hearing" or is "a bit simple". So far this would mean that deviance simply is not recognised or clearly distinguished. But the technical, conclusive and stigmatising labels are avoided. A place is not taken in a rank or a hierarchy. This can, of course, have its advantages. Some people can continue to be treated as ordinary members of the community. To identify or register them as disabled may entitle them to certain special benefits or professional treatment but it may also separate them from society and encourage people to look on them if not as a race apart, like lepers, then with aloof condescension. Disability can imply inferior

(16) See, for example, Zborowski, M., "Cultural Components in Responses to Pain", Journal of Social Issues, Vol. 8, 1952; Jaco, E. G. (ed.) Patients, Physicians and Illness, New York, The Free Press, 1958.

as well as different status.⁽¹⁷⁾ The extent to which an individual belongs to special groups or clubs, has special sets of relationships with doctors and nurses and social workers, relies on particular forms of income and sheltered forms of occupation and is patronised by voluntary organisations will all determine his particular position and status or the extent to which he is integrated into the social fabric. Of much of this doctors, social workers and administrative personnel may be unaware. While the sociologist would not pretend to be able to advance medical knowledge, casework and administration as such, it is his responsibility to develop this aspect of knowledge.

Operational Measures of Disability as a Guide to Action

It would be possible to assemble a large number of data on each of these interpretations of disability. All of them have implications both for our understanding of disability as well as the means with which to offer help and service. Clinical particularisations are essential if pathology is to be investigated or arrested but there can be unfortunate social and administrative consequences. The proliferation of specialist consultants for particular diseases or disabilities and of statutory and voluntary organisations gives emphasis to the separateness rather than the similarity of many disabled conditions with consequential confusion, fragmentation of effort and injustice. Some conditions receive favourable publicity and attention. Others, with worse effects, are neglected. The thalidomide children have attracted vastly more public sympathy than children suffering from subnormality or congenital syphilis. The Spastics Society has an income of around £2m but the National Society for Mentally Handicapped Children only £40,000.⁽¹⁸⁾

One consequence is inconsistency of assessment. How do we assess degree of disability so as to determine level of pension or of other needs? The

(17) The "dependent and segregated status [of the disabled] is not an index merely of their physical condition; to an extent only beginning to be recognised it is the product of cultural definition - an assumptive framework of myths, stereotypes, aversive responses, and outright prejudices, together with more rational and scientific evidence." Ten Broek, J., and Matsen, F.W., "The Disabled and the Law of Welfare", California Law Review, Vol. 54, No.2, May 1966, p.814.

(18) According to the Charity Commissioners the Spastics Society received £1.8m in 1962, and the National Society for Mentally Handicapped Children £39,000 in 1964.

McCorquodale Committee on the Assessment of Disablement repeatedly referred in its report to the principle that assessment should be determined by "means of a comparison between the condition of the disabled person and that of a normal healthy person of the same age",⁽¹⁹⁾ but took no steps to apply the principle empirically. The Committee did not obtain information systematically about disabled persons and healthy persons of equivalent age. Nor did the Committee try to examine the rationale of current medical assessment. They largely confined their attentions to amputations and loss of limb or eye and did not, even for these minority disabilities, seek empirical justification for percentage assessments. For example, they accepted the loss of four fingers and of a leg below the knee (leaving a stump of between $3\frac{1}{2}$ and 5 inches) each as equivalent to 50 per cent disability. We might question the logic of both rate and equivalence. The loss of three fingers, the amputation of "one foot resulting in end-bearing stump", the amputation "through one foot proximal to the metatarpo-phalangeal joint" and the loss of vision in one eye were all regarded as equivalent to 30 per cent disability.²⁰ In refraining from exploring the functional, psychological and social effects even of different kinds of limb amputation they failed to take advantage of the growing body of knowledge and research methods developed by the Social Sciences in the last 20 years. The same kind of criticisms might be made of the more general ^{and rather different} definitions of disability currently used by the Ministries of ^{Social Security} Pensions, Labour and Health.⁽²⁰⁾ Britain is still largely governed

(19) Report of the Committee on the Assessment of Disablement (the McCorquodale Report), Cmd 2847, London, HMSO, December 1965.

(20) In awarding war pensions and industrial injuries disablement pensions the Ministry of Pensions bases assessments on comparison between "the condition of a disabled person and that of a normal healthy person of the same age. Assessment on this basis measures the general handicap imposed by loss of faculty. Loss of faculty may be defined as the loss of physical or mental capacity to lead a normally occupied life and does not depend on the way in which the disablement affects the particular circumstances of the individual. A normally occupied life includes work as well as household and social activities and leisure pursuits." Report of the Committee on the Assessment of Disablement, op. cit., p.4. To be admitted to the Ministry of Labour's Register of Disabled Persons an applicant must (1) "be substantially handicapped on account of injury, disease (including a physical or mental condition arising from imperfect development of any organ) or congenital deformity, in obtaining or keeping employment or work on his own account otherwise suited to his age, qualification and experience; the disablement being likely to last for twelve months or more; (2) desire to engage in some form of remunerative employment or work... and have a reasonable prospect of obtaining and keeping such employment or work..." Finally, local authorities are empowered by Section 29 of the National Assistance Act, 1948, to promote the welfare of persons who are blind, deaf or dumb and others "who are substantially and permanently handicapped by illness, injury or congenital deformity or such other disabilities as may be prescribed by the Minister". Registers are compiled on this basis from a variety of sources.

in its conduct towards the disabled by the source rather than the effect of disability. Too little effort has been made to develop functional indices, based on questions about individual capacities. Such indices are difficult to develop and have to be treated with caution. But they are implicit in nearly all official definitions and have been partly but unsystematically used in some medical and administrative procedures. For example, the information supplied by doctors on a form used by the Ministry of Labour includes the kind of conditions which doctors believe the disabled person should avoid in his employment. The information does not adequately reflect either the general or specific capacities of the disabled person although some "functional" information is given.⁽²¹⁾ Britain is not alone in having failed to size up to this problem.⁽²²⁾ If we did apply functional measures it is likely that we would identify between 3 per cent and 6 per cent of adults under pensionable age as physically or mentally handicapped. A recent Danish survey established that around 6 per cent of adults were physically handicapped. There was little difference between the rates for men and the rates for women but both rates increased sharply in the fifties. About 3 per cent in the twenties and thirties were disabled and 7 per cent in the forties, but by the late fifties the figure reached 17 per cent, topping 20 per cent in the early sixties.⁽²³⁾ In Sweden disability pensions reach 2½ per cent of the adult population. The rate also rises sharply in the fifties and early sixties. But some of the less disabled may not qualify for such pensions.

We developed a crude index of incapacity to manage personal and household activities which involved assessing 23 tasks and activities.⁽²⁴⁾ Each activity was scored two if it could not be done at all and one if it could be done only with difficulty. Altogether as many as 17 per cent of the disabled in the three counties were very severely incapacitated (scoring 23 and over), ~~making 53 per cent altogether.~~ Another 36 per cent were severely incapacitated (scoring 15-22). making 53 per cent altogether. Only 11 per cent were slightly incapacitated (scoring 6 or less). Incapacity tended to increase with age. Only a third of those younger than 45 were severely or very severely incapacitated in our sense, compared with nearly half those aged 45-64 and nearly two-thirds of those aged 65 and over.

(21) The Medical Report form includes a section which allows the doctor to indicate whether an individual can use upper limbs (shoulders, arms, hands, fingers and touch) and lower limbs (walking, standing, sitting only, hurrying, balancing, climbing stairs, climbing ladders), and can kneel, stoop, push and pull and lift and carry. The extent of hearing and vision also can be noted. The need for better functional assessment was recognised by a Working Party of the British Council for Rehabilitation of the Disabled reporting in 1964: The Handicapped School-Leaver, London. British Council for Rehabilitation of the Disabled.

(22) See, for example, Hess, A.E., "Old Age, Survivors and Disability Insurance: Early Problems and Operations of the Disability Provisions", Social Insurance Administration, U.S. Dept of Health, Education and Welfare, 1964, pp. 1-10.

(23) Andersen, E.B., Physical Handicaps in Denmark, part 2, Socialforordningsinstituttets Publikationer 16, Copenhagen, 1964, pp. 55-56.

(24) Including going up and down stairs, getting about house, washing and bathing, dressing and putting on shoes, cutting toe nails, brushing and combing hair, going to toilet on own, cleaning floors, cooking a hot meal, seeing, speaking and hearing and organising thoughts in lucid speech.

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This kind of approach allows us to compare persons with multiple disabilities. Nearly half the sample had at least two. It also allows us to begin comparing the effects of different disabilities and the ways in which the extent of incapacity changes over time. Very little work has been done on this. Nearly 20 per cent had disabilities which were quickly progressive and another 40 per cent slowly progressive. Many were prone to depression and feared increasing dependence on others. Some people found that their capacities fluctuated according to the nature of their condition and changes in the weather. Even those whose disabilities were quickly progressive found there were periods of recovery or restoration of capacity. In all this I am stressing the relativity of disability, like the relativity of intelligence. ^{for example in illness or after accidents,} There are times when most of us cannot walk or cannot dress or cannot speak. Many of us have a "permanent" limitation of some kind. It is appropriate therefore to ask to what degree the disabled are more incapacitated than ourselves as a way of asserting a common involvement and preparing the ground for a rational examination of their occupational and social opportunities.

Housing

The first major problem is that of housing. We found that the disabled live in housing which is in some respects worse in basic facilities than the rest of the community. Only a fifth of the sample were owner occupiers compared with over two-fifths of the total population. ⁽²⁵⁾ Their incomes were usually small. Half were council tenants. Over time they had qualified for a council flat or house. But some had been recently placed in houses or flats erected between the wars rather than in the last 20 years and a number were in flats other than on the ground floor. About a quarter were tenants in private housing and in general these had the worst facilities. Altogether 30 per cent had no hot water supply, 23 per cent no bath and as many as 21 per cent no WC indoors. We met people who had to get water from a well or a pump in the garden or a tap in the back yard; who had to share a miserable lavatory with other households or get to one across a yard or to the bottom of a garden along a broken path. Inability to use a WC

(25) For national figures of tenure see Donnison, D.V., The Government of Housing, Harmondsworth, Penguin Books, 1967, p. 186.

was universally regarded as being the greatest personal indignity. As many as 20 per cent of the persons in the sample lived in homes which were deficient of three or more ^{basic} facilities.

Stairs pose a critical difficulty. Seventy-four per cent of the persons in the sample had to climb or descend at least one flight of stairs to the entrance of their homes or inside from the WC or kitchen to the living-room. Thirty-three per cent had to negotiate stairs both outside and inside. One partially-sighted woman who was an epileptic had to mount a flight of steps from her basement flat with no handrail and the fourth step missing. Five per cent had to use lifts to reach their council flats on the upper storeys. This minority all complained that the lifts frequently broke down with sometimes disastrous effects so far as they were concerned. Councils who place disabled and elderly persons on the higher storeys of blocks of flats under the assumption that lifts secure constant access seem to be mistaken.

Against basic structural deficiencies or difficulties such as these the efforts of welfare authorities to introduce adaptations inevitably seem puny. Adaptations had in fact been carried out in just under half the homes of the sample, some by individuals and hospital authorities and a few by voluntary organisations but the majority by the welfare departments of local authorities. Most of these were of a simple kind: handrails on stairways and in passages and lavatories; ramps up single steps; lavatory seats raised; a few doorways widened and a few electric light switches lowered and electric points raised. There is no doubt that such alterations can make life a lot easier and there is scope for a massive expansion of activity.

Twenty-four per cent specified adaptations which they felt needed to be carried out by the local authority but many others had been told or believed they lived in accommodation which was unsuitable for satisfactory adaptation. We asked the disabled about a variety of facilities which they could not use because they were ill-placed or ill-designed. Seventy per cent could not open and shut windows; 42 per cent and 40 per cent respectively could not reach gas and electric meters; 22 per cent were unable to use a cooker and a similar proportion could not use taps, use a sink and reach any cupboards.

These are disconcerting statistics.

The problem is partly one of standardising certain kinds of units so that they can be introduced into homes quickly. But there is a limit to opportunities of standardisation. Chairbound persons need to have a low sink in the kitchen but an arthritic housewife who cannot stand or bend needs a high stool and a fairly high sink. Moreover, physiotherapists may prefer obstacles to remain for particular persons so that limbs and muscles are properly exercised. Individual solutions will always to some extent be necessary. The problem is also one of devising an effective administrative plan and implementing it quickly. In instances which were all too rare welfare officers had achieved just this. But do local authorities complete a detailed schedule of household deficiencies ~~and difficulties~~ when a disabled person is newly registered? And can they organise a blitz on the dwelling so that improvements are introduced simultaneously over a very short period and not piecemeal over many months, with all the disruptive and depressing effects this can have on a household? I suspect we are going to need local authority work teams which are seconded to welfare departments by housing departments with the blessing of local trade unions.

Adaptations sometimes achieve much less than they are supposed to achieve. We met persons who used a handrail to help them along a passage and down a couple of steps into a kitchenette but who could not carry a tray of food back and felt obliged to eat meals off a draining board. Nearly all the ramps which had been installed or which could be laid across outside steps could not be used by the disabled individual without help. One woman said that when she tried to go in her wheelchair down a short ramp into her kitchen without help she could not control it and went headlong into the opposite wall. The main problem for wheelchairs, as much in new council flats as old private properties was manoeuvrability. There was rarely sufficient space in kitchens and living rooms and lavatories to turn round or go easily through doorways and along passageways.

Here the insistent question is how the disabled can be transferred to good housing which first has modern amenities and which second does not pro-

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vide obstacles to persons with limited mobility. The question of special design or adaptation - for that is the real question - is secondary. ~~Some~~ Some of the persons whom we interviewed wanted to transfer from council homes which were unsuitable structurally or in their siting. Others who rented privately owned homes had applied for council flats. Altogether 16 per cent were on council housing lists, more than half of them for at least two years and a few for over 10 years. Half the owner-occupied homes needed major improvements, some of which would be possible to finance or subsidise under existing legislation if only local officials took the initiative to assist applications and organise builders and decorators. I suspect that new scales of priorities have to be drawn up by health and welfare departments on the one hand and housing departments on the other. The former should have responsibility for allocating and administering a high proportion of the accommodation for the disabled and elderly.

Community Care Services

The second major problem is personal and household help. Nearly a fifth of the disabled persons whom we interviewed were unmarried and many others were widowed, divorced or separated. We found that 15 per cent lived alone and had no relatives in the immediate vicinity. Another 10 per cent lived alone and the relatives in the vicinity could not provide all the services that were needed. Finally, around a third of the sample were people who lived with husbands and wives or relatives but who were not employed and were alone for substantial parts of the day. Some had to wait from 8am to 5 or 6pm for a hot drink and meal. Others reported falls and other accidents which left them lying waiting for help until a relative returned in the evening.

4 For care in illness and regular care in the household substantially more persons relied on family help than ^{on} all the health and welfare services put together. For example, during their last illness 66 per cent had been looked after by relatives while 10 per cent had gone into hospital (21 per cent looked after themselves, 2 per cent were looked after by neighbours and 1 per cent by friends). Again, 75 per cent had meals prepared for them by relatives and 9

per cent received them occasionally or often in the week from a meal delivery service. Friends and neighbours furnished valuable, usually supplementary, help to nearly half the sample, mainly by shopping, preparing a meal or cleaning.

The health and welfare services were nonetheless a major source of help. Thirty per cent had a home help, 9 per cent meals delivered to them, 13 per cent were visited regularly by district nurses, 10 per cent had chiropody services at home and another 25 per cent had chiropody elsewhere, and 2 per cent in each instance were helped by the home bathing and borough laundry services. Altogether nearly half the sample had at least one domiciliary service, of whom half had two or more services. In London rather more than a half and in Essex and Middlesex rather less than two-fifths of the sample had one or more services. In addition people were in touch with welfare departments and voluntary agencies. Eighty-four per cent said they had been visited at least once, a quarter three or more times, by the welfare officer in the previous twelve months, the other 16 per cent claiming not to have been visited. Three-quarters of the visits were said to be routine, lasting from 10 to 30 minutes, but 6 per cent were in connection with holidays, 8 per cent alterations and 7 per cent aids or gadgets. The welfare departments maintain what is at present mainly a referral service. Thirty per cent were in touch with a voluntary agency of some kind. For two-thirds of them this meant membership of a club. For a third or more it meant occasional or regular visits, some routine checks on present circumstances, some inquiries about means, aids, alterations, food parcels and so on. Proportionately more of ^{those who were only slightly or moderately incapacitated} ~~the less than the more disabled~~ were in touch with voluntary agencies.

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Doctors and medical social workers in hospital played an important role in referring patients for welfare services. It was not our purpose to investigate medical and hospital care but a substantial number were in close contact with a GP. Over half had seen one within the previous month and as many as a quarter said they were visited regularly. There were a fifth, however, who had not seen their GP in the previous 12 months. A few very incapacitated persons would have liked regular consultations. Others spoke of the problems of getting to hospital outpatient departments.

Despite this range of services we found evidence of considerable need. A third as many disabled people again as were receiving a home help, meals delivered at home and a district nurse expressed a wish for such a service. The majority were very severely or severely incapacitated by the strict standards that were applied. There was a huge latent demand for home bathing, laundry, chiropody and optical and dental services and between 10 per cent and 20 per cent of the entire sample in each instance expressed a desire for these services. Others did not express a desire for such services but by objective assessment seemed to require them. Thus a fifth of those who were severely incapacitated lived alone and did not have a home help. They did not always feel the need for such help. Among those getting the service as many as a fifth (or 6 per cent of the entire sample) received more than 8 hours help per week but half received it for only between an hour and three hours and half of them felt the need for more frequent visits.

Some of those living alone did not ask for meals to be delivered because the ^{service} meals had a poor reputation. Only a third of the people having meals said they were hot when they arrived. Many warmed them up though a few could not use the cooker and ate them cold. A third said the meals were usually delivered before 11am. Again, although some received meals five days a week over half received them only twice a week. An inquiry into the diets of a sub-sample suggested that in a quarter to a fifth of instances they were unsatisfactory.

, local authorities

One function of the National Health Service/and other agencies is to provide aids for the handicapped. A large array of aids, from wheelchairs, tri-cycles, crutches, sticks and surgical corsets to special eating utensils, long-handled combs and "permanent" collars and ties were being used by persons in the sample. The lack of really satisfactory false legs and aids to mobility, despite the far greater numbers having difficulties with legs than with arms, was repeatedly drawn to our attention. Sixty-four per cent of the sample were affected by disability in the lower limbs only and another 28 per cent were affected in both lower and upper limbs. Only 3 per cent were affected in the

upper limbs only.⁽²⁶⁾ As many as 65 per cent of the men and 70 per cent of the women in the sample used some aid to get about outdoors and nearly as many indoors. Most of the persons with artificial legs who were interviewed had a great deal of trouble either because stumps were sore, or because they suffered from phantom pains. All found walking indoors and outdoors difficult. Leg supports or substitutes such as crutches and wheelchairs are remarkably cumbersome. The value of aids should not be minimised. We made various calculations which showed that average incapacity to undertake a range of tasks was reduced by over a quarter by aids already available. It became possible for people to do more tasks. Incapacity could be further reduced. But there is little doubt that by any rational assessment the top priorities are more good housing, better community services and more generous motorised transport. Ingenuity and research are important but even more important is the willingness to finance services and transport.

In 1956 the Piercy Committee pointed out that expenditure on the disabled by local authorities was not substantial. "It is clear that only the fringes of the field have yet been touched. The Act gives local authorities very wide permissive powers to make provision for the welfare of disabled persons, and on the evidence received there is no doubt that there is a need for a fuller and better provision and scope for considerable development."⁽²⁷⁾ The Committee recommended an Exchequer grant for these services but this was not accepted. The Ministry of Health later spoke of steady progress and tried to reassure the public, although from the vantage point of history I believe the attitude adopted by the department will be seen as grudging. It did not even match the cautious and unimaginative approach to reform, of the Piercy Committee. In 1963 the Ministry acknowledged that up to a year or so earlier "the development of local authority welfare services [for the physically handicapped] had been very uneven and a number of authorities had not even made schemes for the deaf or dumb or for the general classes."⁽²⁸⁾

(26) It is interesting to note that in 1965, 17,163 artificial legs but only 2,736 artificial arms were supplied under the National Health Service. Annual Report of the Ministry of Health for 1965, *op. cit.*, p. 165.

(27) Report of the Committee of Enquiry on the Rehabilitation, Training and Re-Settlement of Disabled Persons, Cmd 9883, London, HMSO, 1956, p. 26.

(28) Health and Welfare: The Development of Community Care, *op. cit.*, p. 31.

The fact that there are far more disabled persons requiring welfare services than are registered has been lamented officially for years. Yet between 1957 and 1965 the numbers of blind, deaf and physically handicapped persons registered with local authorities in England and Wales grew by only 74,000 to 288,000 or six per 1,000 population. The total includes nearly 148,000 physically handicapped other than the blind or deaf, or 3 per 1,000 population. Yet the variations between local authorities are inexplicably wide. The numbers of generally handicapped persons on the registers per 1,000 population range from 0.8 in Chester, 1.2 in Portsmouth, 1.3 in Oxford and Southport, 1.4 in the North Riding, Coventry and Leicestershire, 1.5 in Staffordshire and 1.7 in Kent, at the lower levels, to 6.9 in Lincolnshire (Holland), 7.1 in Glamorgan, 7.2 in Hastings, 7.9 in Bath, 8.2 in West Bromwich and 10.7 in Kingston-upon-Hull, at the higher levels.⁽²⁹⁾ If all authorities were to register proportionately as many as the top ten authorities another 150-200,000 would be added nationally to the registers. It is quite evident that the problem has scarcely begun to be identified, still less met.

Employment

The third major problem is occupation. Thirteen per cent of the total sample of 211 were in paid open employment and another four per cent were employed ^a in/sheltered workshop or at home. More than a quarter of those below pensionable age were in paid employment, some of whom were severely incapacitated. Over half of the 33 persons below pension age who were employed were not registered on the Ministry of Labour's Disabled Persons Register. Some who were employed full-time had been told by Disablement Resettlement Officers at the Employment Exchange that they were unsuitable for work and found work for themselves.

(29) Calculated on the basis of information kindly supplied by the Ministry of Health.

There was an air of near-desperation in the attitudes of many persons below pensionable age to their need for a paid job. As many as 25 per cent expressed a wish for employment. At least half of these did not seem on the face of it to be too incapacitated to obtain a job. If our figures are broadly representative then there are 28,000 on the local authority registers seeking paid employment, 16,000 of them full-time employment. A number in the sample had difficulties in getting work because they could not obtain appropriate transport. The disabled still find it difficult to qualify for specially designed tricycles and adapted cars, especially if their disability is progressive and they have to convince Ministry officials that it is more difficult than it used to be to get to and from work. Some who do qualify find that by contrast with modern vehicles on the roads the tricycles and cars are inferior even in standards of comfort and possibly unsafe. Until recently they were not fitted with heaters, so many of the older vehicles are still grim to drive in winter.

It is difficult in some respects to understand why more of the disabled on the local authority registers who are not at work than who are at work are seeking it, for in status, pay and conditions it is often so unattractive. The disabled tend to be given light assembly work, packing, filing, cleaning and storekeeping. Some are in so-called designated employment, as car park attendants and lift attendants.⁽³⁰⁾ The average wage of the men in the sample in full-time employment in 1965 was £14 compared with £19 at that time in London and the South East.

A disproportionately large number of those in employment were in unskilled and semi-skilled jobs. Some who had accepted paid work at home, making up rosettes or flower-holders and packing toys by the gross, for example, had to work extremely long hours for very little money. In all the instances we came across the average earned was less than three shillings an hour. The local authorities play little role as protective or referral agents for the disabled and most home-work is contracted privately.

(30) According to the Ministry of Labour's information on designated employment for August 1964, all but a small minority of the 2,769 lift attendants and 2,584 car park attendants were registered disabled.

The true situation is disturbing. Nine per cent of those on the Ministry of Labour's Disabled Persons Register are unemployed, compared with 2 per cent nationally.⁽³¹⁾ But this greatly underestimates the scale of the problem. The Ministry declares in effect that many of the long-term unemployed who are not on the Disabled Persons Register have personal handicaps because of age or physical or mental condition.⁽³²⁾ There are substantial numbers of disabled on the local authority registers seeking work who are not listed at the local employment exchanges. Some of them will presumably be assessed by the Disablement Resettlement Officers as unsuitable for admission to the Ministry's Disabled Persons Register.⁽³³⁾ And no doubt there are substantial numbers of other disabled persons on no official register who are in a similar position. It is time we recognised that this situation is absurd and unjust and should be remedied. The numbers of the genuinely unemployed are being under-represented.

Current activity on behalf of the disabled is not encouraging. Some of the persons we interviewed spoke enthusiastically about the efforts made by Disablement Resettlement Officers. But more spoke of discouragement and many had made no use of the special services.⁽³⁴⁾ Training at Industrial Rehabilitation Units is difficult to secure and when secured is not always as up to date

(31) Ministry of Labour Gazette, April 1967.

(32) This was stated of 80,000 of the 104,000 men unemployed for six months or more in a special inquiry carried out in 1964. "Second Inquiry into the Characteristics of the Unemployed", Ministry of Labour Gazette, April, 1966. In a special study of the unemployed who were receiving assistance in June 1956 the National Assistance Board found that a majority had some specific physical handicap. Moreover, they also found that only 72 per cent of the men and 50 per cent of the women with physical handicap were registered as disabled persons with the Employment Exchange. Report of the National Assistance Board for 1956, Cmnd. 181, London, HMSO, 1957, p.42.

(33) The history of registration is puzzling. In 1950 the register reached a peak of 936,500 but then declined, in some years rather sharply (the figure for 1966 being 654,000). In 1957 the Ministry explained that only part of this decline was attributable to a falling off in the numbers of disabled Servicemen. Many disabled persons did not renew their registration, either because they felt secure enough in their employment, or because the DROs, supported by the Disablement Advisory Committee Panels, were interpreting disability more strictly "so as to exclude the lightly handicapped". There is also the fact that soon after registration started employers persuaded some of their employees to register to help meet the three per cent quota. Even if persons who stay with one firm do not re-register they are still counted in the quota. This is plainly unsatisfactory, for some are no longer disabled or have remained no more than marginally disabled. See Annual Reports of the Ministry of Labour for 1949-60, particularly for 1949, (Cmnd. 8017), 1957 (Cmnd 468) and 1960 (Cmnd. 1364).

(34) Some have called for an independent review of the work. Members of staff of the Ministry fill the post of DRC by rotation, serving for five years. They then move on to other work. There is no established training course. Lady Hamilton, "Integrating the Physically Handicapped", New Society, 5th May, 1966.

as it might be. Little or no help is given in particular to retrain women and older men. Sheltered workshops are few and far between and get too little subsidy and managerial investment to be successful. In any event disabled persons often feel that such employment is to be avoided at all costs. Work in the home would be welcomed by a large proportion of the disabled but depends on skilful organisation. Local authorities have permissive powers to operate home-working schemes. Few do so. The disabled need work-finders and transport-organisers and work-flow teams more than occupational therapy as understood in the narrow sense of that term. Some occupational therapists spend a lot of time finding employment for handicapped persons and some uncertainty between them and the DROs about division of function might well be investigated.⁽³⁵⁾

The quota of disabled persons is one of the most important instruments of policy. All employers with more than 20 employees must employ three per cent of disabled persons. Only 52 per cent of firms in fact satisfy the quota.⁽³⁶⁾ Recently it was also revealed that fewer than three per cent of Government employees are disabled. There is no doubt that there are many sympathetic employers who are prepared to go to considerable lengths to help a disabled person. We were given instances of people being given time off and having working hours and conditions adjusted. On the other hand there is no doubt that some employers abuse the provisions of the Disabled Persons (Employment) Acts by persuading some lightly handicapped persons applying to them for jobs to register as disabled persons so that they can meet their quota. Others in practice pay low wages and offer inferior working conditions to the disabled. Discrimination is perhaps practised unconsciously more often than consciously. Nonetheless, the quota is a more effective means of assuring employment than designated employment, Remploy and sheltered workshops. It also encourages ordinary forms of employment, which the disabled prefer.

(35) Jefferys, M., An Anatomy of Social Welfare Services, London, Michael Joseph, 1966, pp.63 and 238.

(36) The percentage varies from 67 per cent in Wales to 59 per cent in the North-West to 49 per cent in the Midlands and 45 per cent in London and the South-East. Information for 1st July 1966 kindly supplied in a private communication by the Ministry of Labour.

It seems important to liberalise the conditions under which persons can qualify for admission to the Register. In broad principle official help should be given to all persons seeking employment, whatever their sex or age and whatever doubts may exist about their capacity to hold employment. This part of the Ministry of Labour's work needs to be imaginatively expanded. The ultimate aim would be the integration of all disabled persons wanting work into open employment. Various forms of subsidy and encouragement to employers might be tried. An immediate step could be the manipulation of Selective Employment Tax in favour of disabled employees.

Income

← A fourth problem is low level of resources. We have seen that relatively few disabled persons on local authority registers owned their own homes and that those in paid employment had relatively low earnings. In general the disabled in the sample had low incomes. Altogether 60 per cent of households had a total income of less than £10 a week and another 26 per cent less than £20. (A third of the households, it should be remembered, contained three or more persons.) Three-quarters had less than £50 savings. Nearly half depended partly or wholly on national assistance and about 5 per cent might have qualified for supplementary assistance had they applied for it. There is no doubt that a disproportionate ^{large} number of the disabled are in poverty or on its margins.

Social security benefits for the long-term disabled are not related to

limitation of capacity except secondarily and there is no consistent system of extra allowances for constant attendance or personal support and help. There are anomalies as between different kinds of allowances. ⁽³⁷⁾ A man with a wife and two children who is bedfast or chairbound because of multiple sclerosis, say, will receive £8 15s a week if he is on sickness benefit (including family allowance) or under £10 a week, plus a rent allowance if he is on national assistance. ^{Yes} a man in similar family circumstances who is incapacitated after an industrial injury may receive a pension of £6 15s plus dependants' and other allowances making a total of £18 5s. Moreover, if this man was once awarded an industrial injury disablement pension of 100 per cent and is rehabilitated so that he can take paid employment again he continues to receive the pension of £6 15s. If he happens to fall sick he receives exactly the same as the first man, that is, £8 15s, plus his pension of £6 15s. ⁽³⁸⁾ A disabled housewife is in the worst plight. If her husband is in full-time work she will usually get nothing, not even national assistance. Thus disablement for her family can be a disaster, especially if her husband's earnings are small or barely cover the normal day-to-day needs of the household.

The Disablement Income Group is rightly calling for the introduction of a national system of disability pensions. I believe that a generous pension should be introduced for both men and women based on the principle of limitation of capacity, as ascertained by the kind of functional assessment discussed earlier. This would be difficult to work out in practice but seems to be fairer and less arbitrary than any alternative, such as a pension based on the principle of limitation of earning power. The 100 per cent pension might be fixed initially at 30 per cent of average industrial earnings, which would be just over £6 at the present time. There would be additional allowances for dependent adults and children. The pension could be permanent or temporary according to the degree of certainty about the condition, as under the Swedish system. ⁽³⁸⁾ These benefits would be supplemented by a system of allowances for

(37) For a clear account of some of these see Willmott, P., "Social Security in Disablement" in Hunt, P. (ed.) Stigma: The Experience of Disability, London, Geoffrey Chapman, 1966.

(38) English translation of National Insurance Act, 25 May 1962, Swedish Ministry of Social Affairs, 1963.

constant attendance and personal help. This system of benefits would normally apply upon the termination of six months earnings-related sickness or unemployment benefit or earlier in instances of undoubted long-term handicap. Earnings-related supplements would continue to be paid to disabled persons over retirement age, as to all other retired persons under the Labour Party's scheme for National Superannuation which is to be introduced before 1970. Persons disabled in middle or late-middle age would also receive earnings-related supplements to reflect extra contributions made in working life. I would hope that this system would largely overtake special war and industrial pension levels. Discrimination between people disabled in war, industry and civil life is distasteful as well as being an administrator's and a lawyer's nightmare.

The present Government's provisions must surely be regarded as ~~unjustifiable~~ and makeshift, because earnings-related benefits cease after six months. ~~Even among wage-earners with low earnings~~ The long-term sick will be worse off under the new scheme than the short-term sick. And there is a kind of hiatus implicit in present legislation, earnings-related supplements ceasing after six months of sickness and an unconditional flat-rate allowance of 9s being awarded by the Supplementary Benefits Commission after two years of sickness. A man who has been unemployed though disabled is not entitled to this extra allowance.

The Problems of Integration

There are of course many other problems ^{and} ~~which need to be discussed~~. I have only touched on what seem to be the major ones. How ^{quite} ~~real~~ are they? Have I skirted those which matter even more to severely disabled persons? It is reasonable to ^{suppose} ~~suggest~~ that personal relationships with members of ~~their~~ families and with friends and the physical struggle to participate in many activities concern the disabled much more than campaigning for more home help, motorised wheelchairs and even a modern council flat or house on the ground-floor. But politics and the organisation of

professional services are not aspects of life which are unconnected with private relationships. The institutional fabric which we have created and within which we live shapes our behaviour and values. We would be unwise to discount ~~it~~^{it}. However much we struggle to avoid allowing the wider social and political structure to influence our views, it causes us to treat some people, even in our own families, as inferiors or as redundant. And it causes the objects of our indifference or of our self-righteous pity to underestimate their rights. They need to complain and assert themselves, even more for our sake than their own.

I hope I have sketched sufficient evidence to show that as a society Britain has what amounts to an elaborate system of discrimination against the disabled. We do not ensure they have good housing, adequate community services, employment with dignity or an adequate income. We do not even think it necessary to count their numbers. ⁽³⁹⁾ I venture to suggest these are facts, not opinions, which we must take into our reckoning.

What ~~stands~~^{stood} out in this largely depressing ~~report~~^{survey was} is the warmth and strength of many of the personal relationships of those who ~~are~~^{were} disabled. Many of the people whom we interviewed had close friends or neighbours who were concerned about them. Nearly half were married, as I have said, and another third were widowed, separated or divorced. On the one hand, we found evidence of marital strain. Nearly a tenth of those with a husband or wife who was alive were now separated or divorced. The rate seems to be a little higher than in the general population of comparable age. Another tenth, particularly wives, had marital difficulties of one kind and another. On the other hand, the great majority seemed to be content or, indeed, richly rewarded in their marriages. They could count on devoted support and they contributed a great deal themselves. Much the same is true of relationships with other members of the family, though it does seem that disability reduces the scope and therefore the inter-

changeability of contacts with the extended family. Relations are

(39) ~~It was in the following year, 1966~~ [In 1968, partly as a consequence of pressure from the Disablement Income Group, The Child Poverty Action Group and other bodies, the Minister of Social Security, Mrs Judith Hack, announced the research which culminated in a survey of the handicapped and impaired in Britain by The Office of Population Censuses and Surveys: Social Survey Division. See Harris A. Handicapped and Impaired in Great Britain, London, HMSO, 1971]

concentrated among a few people. What is disturbing is the lack of adequate relief for many wives and husbands and sons and daughters who give personal and household care. Community services are required to provide a temporary substitute or a permanent relief for relatives who are under excessive strain.

How can this principle of participation or involvement in family and other primary-group relationships be extended to employment, recreation and welfare? There is a gulf, in effect, between private and public life for the disabled. There must be no illusions. Major improvements in the circumstances of the disabled cannot be secured by modest increments in legislation or services. A gradual reconstruction of the attitudes and values of society is required which can proceed only in relation to the reduction or elimination of many forms of social prejudice and superiority - involving colour, old age and economically unproductive work, for example, as well as handicap or disability. The fundamental difficulty here for individuals and society is one of recognising diversity without ordering groups of people in superior and inferior social ranks.

I have tried to argue the relatedness of disability to the human condition. There are features of disability such as pain, shyness, awkwardness and abnormality which are known to us all. We have met some of them in our illnesses; we may carry some of them with us in our everyday lives and most of us can expect to encounter them in old age even if we are not thrust face to face with them by ill-luck in youth or middle-life. We have to come to terms with the condition, to recognise it frankly and not to banish it from sight and mind. This involves recognising that there are creative outcomes and original ways of looking at life as disabled persons as well as permanent limitations and idiosyncrasies. As one disabled person who has written sensitively about the problems has said, "If those of us who are disabled live as fully as we can, while being completely conscious of the tragedy of our situation.....then

somehow we can communicate to others an awareness that the value of the human person transcends his social status, attributes and possessions or his lack of them" (39)

This principle of relatedness, integration or participation has to be applied in various ways. The work of many different statutory and voluntary agencies has to be merged or coordinated if the universality of many of the problems of disability are to be recognised and met. Such emphasis as there is on separate organisations, separate services and separate institutions for the blind, the deaf, the epileptic and the subnormal may need to be reduced. Such emphasis as there is on separating the disabled from the non-disabled in sheltered workshops, residential institutions, housing and clubs may need also to be reduced. The possibility of rearranging and consolidating the work of the local authorities in a major new family service in which the disabled can participate and inviting voluntary agencies to play a vital supplementary role, is one which the present Seeborn Committee could do much to make real. But there must be more central direction and strategy, beginning with a determined attempt to identify numbers and introduce new pensions, employment opportunities and access to good housing. In this, as in many other respects, we require imaginative leadership as well as popular goodwill, interest and effort.

(39) Hunt P., "A Critical Condition", in Hunt P(ed) op. cit. p.148.

(40) Titmuss R.M. "Social Work and Social Service: A Challenge for Local Government", 1966.