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PROBLEMS OF SOCIAL INTEGRATION FOR PARAPLEGICS IN SCOTLAND

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INTRODUCTION

MEDICAL advances have so prolonged the life of the paraplegic that it has become increasingly important to provide for his social and economic independence. In the U.K. the passing in 1970 of the Chronically Sick and Disabled Persons Act highlighted growing concern that the needs of the disabled have been neglected. The Sponsors of the 1970 Act explained in early debates that their aims were to make it possible for the handicapped 'to participate in industry and society according to their ability' (Mr. A. Morris, M.P.).

We have been conducting a survey in the West of Scotland to examine the requirements of paraplegics living at home, to see what local services are provided for them and how far these help paraplegics to be integrated members of the community. This could be of particular importance as not all of the sections of the 1970 Act apply to Scotland.

SUBJECTS

Fifty paraplegics living in the West of Scotland were visited and personally interviewed. The paraplegics were living in the City of Glasgow and neighbouring counties (fig. 1). Glasgow, with a population of one million, is the most densely populated city in Scotland and the area of the survey has a population of about two million. The sample was drawn from several sources, including the two hospitals in Scotland which specialise in the care of patients with spinal injuries, Philipshill Hospital, Glasgow, and Edenhall Hospital, near Edinburgh. Several were contacted via the Scottish Paraplegic Association. There were 44 male and 6 female paraplegics aged 16-62 years. All had been paraplegic for at least a year and 34 had been paralysed for less than 10 years. Thirty-four per cent. had cervical lesions, 50 per cent. had thoracic lesions and 16 per cent. had lumbar lesions. The most common lesion was at the lower thoracic level and was complete. Of those with cervical lesions eight had incomplete lesions and four of these could use their arms and hands. One man with a lower thoracic incomplete lesion was able to walk with the aid of calipers and crutches, but all others relied on a wheelchair.

The group appeared to be very similar to other groups studied elsewhere, in age, sex distribution, cause of injury and distribution of lesions (Guttmann, 1965, 1967; Thompson & Murray, 1967; Gehrig & Michaelis, 1968).

EMPLOYMENT

Before disablement the majority of the 50 paraplegics were in paid employment (37) and only one man was unemployed. Most of the working group were

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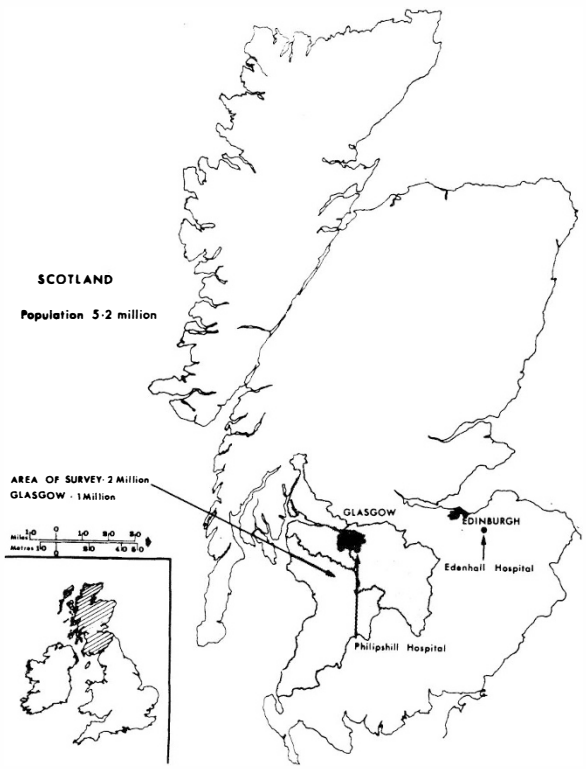

FIG. 1

The survey area (stippled), comprising the City of Glasgow and the counties of Dunbartonshire, Renfrewshire, Lanarkshire and Ayrshire.

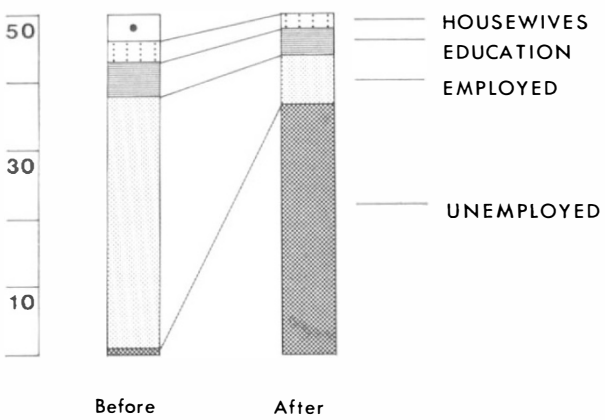

FIG. 2

Occupations before and after disablement. The vertical axis indicates the number of paraplegics. ●: military service (3); pre-school child (1).

manual workers. The effect of disablement on the pattern of employment has been considerable, leaving only seven paraplegics working. There were in addition four students and two women who were housewives able to run their homes unaided. Thirty-seven of the group were unemployed (fig. 2). Of those who were working, four had the same type of occupation as before disablement and were professional and skilled workers. Two paraplegics were in sheltered employment. Not all the paraplegics who were unemployed were seeking work. Several said that they did not wish to work and seven were physically unfit. There were, however, 13 paraplegics who had unseccessfully tried to obtain employment, and of these six had cervical lesions. No individuals with cervical lesions were in employment.

There were 44 paraplegics who were potentially employable when discharged from hospital. However, only 21 had been in contact with a Disablement Resettlement Officer (D.R.O.) in their local office of the Department of Employment

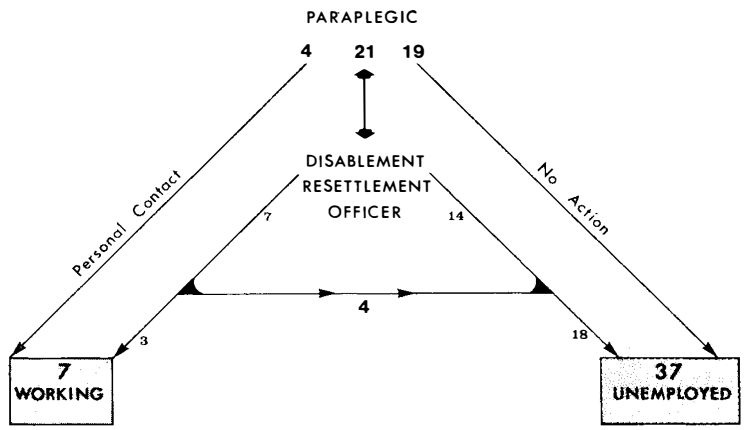

FIG. 3

Employment services. The involvement of the disablement resettlement officers with the paraplegics shown in Figure 2 as either employed or unemployed after disablement.

(fig. 3). The D.R.O. assists disabled people to obtain and keep suitable work, although registration is voluntary. In many cases, however, the contact between the paraplegic and the D.R.O. was minimal because the D.R.O. could offer little hope of finding employment in the area. Few paraplegics obtained work for themselves, but at least 19 paraplegics, for whom employment might have been, were never referred to a D.R.O. Of the seven who found work through the D.R.O., four resigned at an early stage and only one remained in the job obtained for him. The others gave medical reasons for leaving or complained that the work offered was unsatisfactory or badly paid.

The Department of Employment offered industrial rehabilitation and six attended an Industrial Rehabilitation unit although two refused the offers. Of those who attended a unit, three later undertook training (table I). The paraplegics who received industrial rehabilitation were males under 25 years of age at the time of injury; most had experienced some form of training and were skilled workers. Two-thirds of the group not offered industrial rehabilitation (23), however, stated

that they did not want to work. Thus in the total group of potential workers, there were 13 who were trying to obtain work and 10 of these had never had a chance of retraining.

TABLE I

Rehabilitation made available to the Paraplegics and its effect upon their Employment

Employment rehabilitation		
Offered		8
refused	2	
attended re-training centre	6	
work obtained	5	
not seeking work	1	
Not offered		36
Not seeking work		24
Still seeking work		13

Comparison with Other Reported Groups of Paraplegics. There was a marked difference between the employment statistics of our group and those reported from elsewhere. Guttmann (1962) reported that 66 per cent. of all paraplegics discharged from Stoke Mandeville were employed; this included some in further education and in part-time occupations. In 1965 and 1967 he amplified these findings and reported that if he discounted patients who had retired and were over age, who were under treatment in hospital, physically unfit or had died, then only 14·6 per cent. were not working at all. This compares with our figure of 60 per cent.

Even more remarkable differences were found on considering the problem of employment of quadriplegics. None in our group, which included nine complete and eight incomplete lesions, was working, although one was receiving further education. A study of 188 quadriplegics discharged up to 1968 from Stoke Mandeville found that 44 per cent. were in remunerative employment and 7·4 per cent. were students (Robinson, 1971). A survey carried out at the Institute of Rehabilitation Medicine, New York University Medical Center, on 131 quadriplegics aged 18-60 years, who had been patients between 1962 and 1967 found 34 per cent. were employed and 47 per cent. were receiving higher education (Siegel, 1969).

The poor employment situation that we have found in the West of Scotland is related to a local unemployment rate above the national average. Nevertheless, it may also be related to poorer facilities compared with more prosperous areas.

The figures also suggest that many paraplegics were not referred to a Disablement Resettlement Officer and few were offered employment rehabilitation. Moreover, those who did use these services were generally dissatisfied with the type of work offered. Studies elsewhere have revealed similar situations. Robinson (1971) found that only 11 out of 84 employed quadriplegics had obtained work through the D.R.O. and only two had received employment rehabilitation. A recent survey of work and housing for the disabled in Great Britain found that of 146 unemployed who sought help from the D.R.O., five obtained work through this service (Buckle, 1971). The difficulties that the paraplegics in our group have had over employment indicates the necessity of further development of the rehabilitation services.

SOCIAL WORK SERVICES

In the U.K. the welfare of paraplegics is the concern of medical social workers and local authority social workers, together with the hospital medical teams and general practitioners (fig. 4). We examined aspects of the social work services which have recently been clarified by the Chronically Sick and Disabled Persons Act (1970).

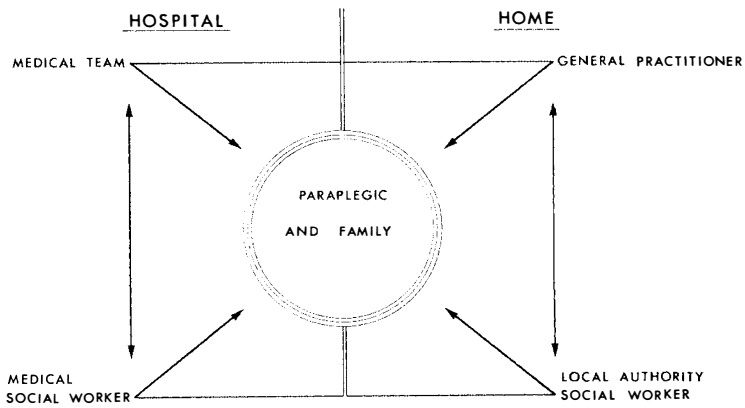

FIG. 4

Diagram of liaison between doctors and social workers in the care of the paraplegic and his family.

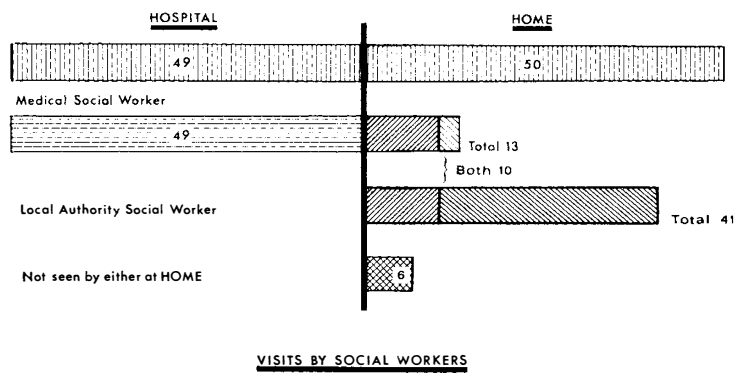

FIG. 5

Contact between social workers and paraplegics in hospital and at home. The central vertical bar divides visits in hospital on the left from those at home, on the right.

- Total number of paraplegics who could have been visited in hospital and at home.
- Visit by medical social worker in hospital.
- Visit by medical social worker only.
- Visit by local authority social worker only.
- Visits by both medical and local authority social workers.
- Visit by neither social worker.

Contact between Social Workers and Paraplegics. Forty-nine of the paraplegics underwent a long period of initial hospital treatment (fig. 5). A medical social worker saw all of them during that time. The situation, however, was less satisfactory when they were out of hospital. Forty-one paraplegics were visited at home by a local authority social worker, but of the nine who had no contact with their local authority there were three still visited by the medical social worker alone, even though they had returned home. Thus six had no contact with either worker once they had left hospital.

Within this group of six there were obvious cases of need, even for simple measures like adaptations in the home. This failure could have been overcome if the patients had been automatically registered as disabled persons with their Local Authority at the time of leaving hospital.

Under Section 1 of the Chronically Sick and Disabled Persons Act (1970), which came into force on 1st October 1971, local authorities must assess the numbers and needs of chronically sick and disabled persons in their area and publicise the services which are available to them. This should provide the social services with a comprehensive register of disabled persons which was not achieved under previous legislation. Section 1 of the Act does not, however, extend to Scotland and as a result we feel that some disabled people may remain unknown to local authorities and fail to receive services which they might need. Moreover, services available to the disabled will continue to vary from area to area in Scotland, although implementation of the Section should help to overcome these problems in England and Wales.

Services available to the Paraplegic at Home. Section 2 of the Chronically Sick and Disabled Persons Act (1970) makes provision for the disabled at home by requiring that local authorities consider the need for facilities in the home. This is the first time that legislation has detailed services to be provided for disabled persons where the need is appropriate. Thus Section 2 provides for:

(*a*) practical assistance in the home
(*b*) wireless, television, library or similar recreational facilities
(*c*) lectures, games, outings, recreational facilities outside the home and educational facilities
(*d*) assistance in travelling to use services outside the home
(*e*) assistance with home adaptations
(*f*) holiday facilities
(*g*) meals at home or elsewhere
(*h*) telephone or any special equipment necessary for its use.

This section, like Section 1, does not apply to Scotland.

Many paraplegics already had one or more of the facilities specified (fig. 6), but there were some cases of need and there was little evidence that local authorities were going to assist with their provision. The most noticeable inadequacy was in the provision of telephones: 13 had no telephone and some of these were alone in their homes. Under normal circumstances 74 per cent. ownership for telephones would be considered high (The Family Expenditure Survey for 1968 showed only 29 per cent. of British households possessing this amenity (Source: table 194 British Labour Statistics)), but Section 2 of the 1970 Act recognises the telephone as an essential facility for the disabled.

Thirty-four paraplegics possessed either an invalid vehicle or an adapted car; three others lived with a car-owner, but 13 paraplegics had no form of transport readily available to them. We found no evidence of local authorities providing transport services in accordance with Section 2 (*d*) of the Chronically Sick and Disabled Persons Act.

Some paraplegics (11) had been on holidays arranged by welfare or voluntary organisations, but 18 others had not been away, mainly because of cost and uncertainty. Many of our group were neither aware of accommodation for the disabled offered by local authority holiday homes, nor of published information on holidays for the physically handicapped.

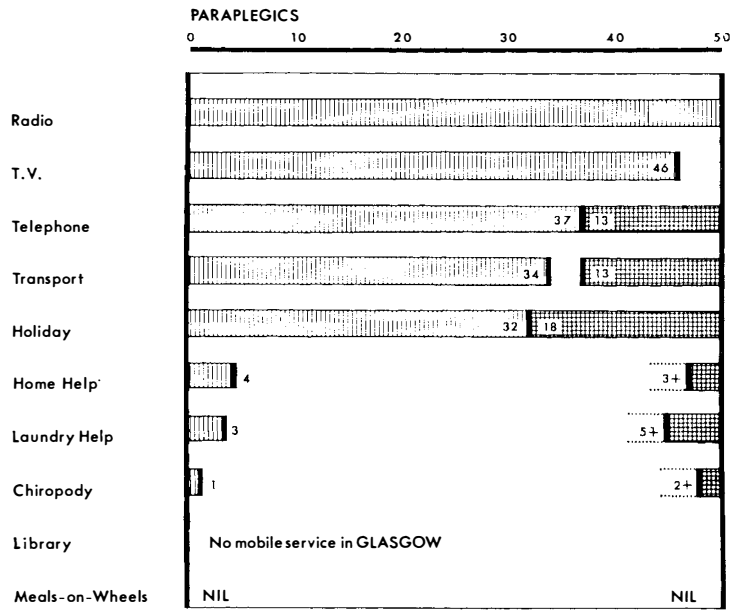

FIG. 6

The provision of some of the facilities covered by the Chronically Sick and Disabled Persons Act (1970). The number of paraplegics is indicated on the horizontal scale.

Facilities provided personally or with assistance.
Facilities lacking.

The assessment, among the group of paraplegics, of other needs which were not covered was more difficult. A number of paraplegics, besides those who indicated, might have benefited from some services if they had been more widely available.

Problems such as these are to be found on a wide scale throughout Great Britain. A survey of the handicapped and impaired in a quarter of a million households estimated that although three out of four drew on at least one service, there remained 2000 very severely handicapped and 90,000 others who were living alone and not receiving services (Buckle, 1971). A writer reviewing this survey found consolation in the Chronically Sick and Disabled Persons Act and commented that

the situation revealed in the report might soon be improved as a result of it (*Lancet*, 1971). We are concerned that improvement is less assured in Scotland where the provision of these services is not guaranteed by legislation.

SUMMARY

A survey has been carried out to examine the facilities available to a group of disabled people living in Scotland. Fifty paraplegics, living in Glasgow or the surrounding counties, were visited and interviewed.

The degree of unemployment in the group (74 per cent.) was far greater than has been reported in other surveys and no quadriplegic was in remunerative employment. Although the general unemployment level in the area is high, services to help the disabled gain employment were only partially utilised.

Liaison between social workers was not always successful. Some paraplegics were visited at home by both a medical social worker and a local authority social worker, while others were not supported by either. There is no apparent attempt by local authorities to identify the disabled as is required in England under Section 1 of the Chronically Sick and Disabled Persons Act (1970). Several paraplegics lacked facilities which are covered by Section 2 of the Act. It would appear that the exclusion of Scotland from Sections 1 and 2 of the Chronically Sick and Disabled Persons Act may widen the differences between the two countries as the Scottish legislation is less specific.

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REFERENCES

BUCKLE, J. R. (1971). *Work and Housing of Impaired Persons in Great Britain.* (Part II of *Handicapped and Impaired in Great Britain.*) H.M. Stationery Office.

GEHRIG, R. & MICHAELIS, L. S. (1968). Statistics of acute paraplegia and tetraplegia on a national scale. *Paraplegia*, **6**, 2, 93-95.

GUTTMANN, L. (1962). Our paralysed fellowmen at work. *Rehabilitation*, **43**, 9-17.

GUTTMANN, L. (1965). Services for the Treatment and Rehabilitation of Spinal Paraplegics and Tetraplegics in Great Britain. *Trends in Social Welfare*, 319-336. Oxford: Pergamon Press.

GUTTMAN, L. (1967). History of the National Spinal Injuries Centre, Stoke Mandeville Hospital, Aylesbury. *Paraplegia*, **5**, 3, 115-126.

LEADER; LANCET (1971). Help for the handicapped. *Lancet*, **1**, 1169.

ROBINSON, R. S. (1971). Survey of Employment for Quadriplegics (United Kingdom). National Spinal Injuries Centre, Stoke Mandeville Hospital, Aylesbury, Buckinghamshire (privately circulated).

SIEGEL, M. S. (1969). *Planning for Employment for the Quadriplegic.* Proc. 17th Veterans Admin. Spinal Cord Injury Conference New York, 230-233.

THOMPSON, M. A. & MURRAY, W. A. (1967). *Paraplegia at Home: A Pilot Survey.* Edinburgh and London: E. and S. Livingstone.