# Living With Cerebral Palsy

A Study of School Leavers Suffering from Cerebral Palsy in Eastern Scotland

by

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Foreword by Professor R. W. B. Ellis

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## Foreword

With increasing specialisation within the medical and social services, the handicapped individual is likely to pass through the hands of numerous agencies between birth and adulthood. There is a real danger that unless positive steps are taken to ensure liaison between these agencies, each may be working to some extent in a vacuum, unaware of what has gone before or of the late results of efforts applied in the medical or educational field in infancy and childhood. Even in the case of the normal individual, the information available to the obstetrician, paediatrician, general practitioner, infant welfare worker, educationist, school medical officer, youth employment officer and industrial medical officer is not always passed on or used to full advantage. This book is particularly welcome since it correlates studies made in early life on patients with cerebral palsy with the status and social adjustment of the same individuals when they become adult.

The problem of fitting handicapped patients for life in the community after leaving school is one which is likely to increase as the prospects of survival become greater. The adequate provision of sheltered workshops or niche employment is an important part of the answer. In a largely materialistic society, gainful employment tends to be correlated with status, and social adjustment is likely to be best when economic independence can be achieved. But in planning facilities of all types for the handicapped, it is essential to have factual information both as to the numbers involved and the effectiveness of training in early life in making adjustment to a competitive environment possible. In a recent report on 'The Young Chronic Sick' (1964) the Scottish Health Services Council drew attention to the urgent need for reliable information on the numbers and potential of those with each type of disability in the community. This study helps to provide the basic data with regard to the handicap of cerebral palsy in Scotland, and so should have far-reaching effects in influencing planning of social services and possible manipulation of the industrial or home environment to meet individual needs.

#### **Richard W. B. Ellis**

#### CHAPTER 1

## Introduction

THERE IS a voluminous literature describing the causes of cerebral palsy in childhood, its early manifestations and the types of treatment which may be offered. Few studies discuss the fate of patients once they outgrow childhood and come to seek employment or vocation in adult life, yet any plans to provide facilities for sheltered employment, vocational advice, diversionary activities and home help on a wide scale should be made only when the need for these services has been adequately assessed.

The studies available indicate that many young adult patients find great difficulty in obtaining work. D'Avignon and Gardeström (1958) showed that of 55 patients between the ages of 16 and 20 years in Sweden, only six were in open employment, 15 were in training for employment or still at school and 34 (approximately 62 per cent) were unemployed. In Denmark, Hansen (1960) studied 1,127 patients over the age of 15 years. Of these, 649 were unemployed (approximately 57.5 per cent), 10 per cent were in employment which was either skilled or required some training and 12 per cent were in unskilled employment; 4.5 per cent were housewives (Table I).

#### TABLE I

Employment of patients suffering from cerebral palsy over the age of fifteen years in Denmark (From Hansen, 1960)

				Number	Approximate percentage
Skilled employment or er	nployme	nt requ	iring		
some training				113	10
Unskilled employment	•••			132	12
Housewives				51	4.5
Under training			•••	175	15.5
Unemployed				649	57.5
Unknown			•••	7	•5
				1127	100

Including the patients who were in training at the time of his survey, Hansen estimated that 35 per cent of the adult patients he studied would be more or less independent. He found that not quite 90 per cent of the 245 patients with known occupations (excluding housewives and patients under training) were mildly physically handicapped. The majority suffered from spastic hemiplegia, but between

10 and 11 per cent of patients with moderate physical handicap were earning their living. Hansen commented:

'It is seen clearly that patients with mono- and hemiplegia, to some degree also patients with paraplegia, manage best occupationally, while the possibilities are considerably poorer for patients with diplegia and to an even higher degree for patients with tetraplegia and athetosis.'

Crothers and Paine (1959) followed up 1,401 patients who had been referred for paediatric consultation between 1930 and 1950 to the Children's Medical Centre, Boston. They found that 40 (approximately 27 per cent) of 148 patients over 21 years of age were competitors with unhandicapped people and that 11 (approximately 7 per cent) were competitors with concessions. More patients suffering from hemiplegia were competitive than were those suffering from other types of cerebral palsy. Whereas almost one-third of the 57 patients with hemiplegia over 21 years of age were competitive, only 10 per cent of the 20 adult patients suffering from spastic paraplegia, triplegia or tetraplegia were in this category. Twenty per cent of the 30 patients suffering from extrapyramidal cerebral palsy were competitive.

The authors noted that, particularly in extrapyramidal cerebral palsy:

'employability seems to depend not only on intelligence but also on motor function, speech and presentability.'

Several of the patients they studied were in jobs which would normally have been carried out by people of lower intelligence.

In the survey carried out in Dundee and the surrounding districts by Henderson and his colleagues (1961) there were 48 patients ascertained over the age of 15; of these 17 obtained full-time employment (approximately 35 per cent) though a further 7 (approximately 15 per cent) were classified as potentially employable. In this study the severe effect of combinations of mental and physical handicap was emphasized (Kerr *et al.* 1961).

More optimistic accounts of the possibilities of patients suffering from cerebral palsy finding employment have appeared. The majority of these are based on the study of selected series of patients. For example, Holoran (1952) reported that 8 of 17 educable children over the age of 16 years were employed, 5 were in training and 4 were unable to work; yet even on the basis of experience with these selected patients she commented:

'From these small groups of children who have left school it would appear that any complete schemes for dealing with cerebral palsy must include sheltered workshops and home industries.'

In Scotland increasing interest has been taken in the employment problems of handicapped young people in recent years. A study of almost 1,000 youths who were mentally handicapped or suffered from a variety of physical handicaps, including cardiac disease, tuberculosis, deafness, impaired vision and chronic respiratory disease, was made in Glasgow by Ferguson and Kerr (1960). Relatively few of these patients were classified as suffering from cerebral palsy though 5 girls and 7 boys were handicapped by spastic diplegia. Ten girls and 14 boys suffered from

epilepsy. The authors commented, however, that:

'The proportion of young people who were working was highest amongst those handicapped by defective vision or defective hearing and lowest amongst the sufferers from spastic diplegia.'

Ferguson and Kerr were impressed by the relative success of physically healthy, mentally handicapped patients in obtaining and holding employment, but commented on the difficulties of placing patients in suitable employment who had combinations of physical and mental handicap. They showed clearly that the success or failure of handicapped youths in obtaining employment did not depend only on the severity of their mental and physical handicap but was also influenced by many other factors. Youths with congenital abnormalities seemed less often successful than those suffering from acquired disease. The educational achievement of patients was an important determining factor and this in turn was influenced by the frequency of their absence from school due to illness. The material and psychological conditions of the home were also important. Patients living in satisfactory material conditions, and stable families with sympathetic parents had better chances of success in employment than those coming from unsatisfactory homes.

Though a number of pioneering schemes to provide training facilities, sheltered work and occupation for young adults suffering from cerebral palsy have been established in Scotland, the lack of accurate statistics about the numbers of patients requiring special facilities to help them to obtain and hold suitable work has been a handicap to planning on a large scale. In 1960 it was suggested to the Scottish Council for the Care of Spastics that a research programme should be instituted to try to obtain information about the numbers of patients able to work in open employment, in sheltered conditions and in diversionary pursuits, and the number who were unemployable. The Council supported the research enthusiastically and it began in May 1962.

There had been two surveys in the previous ten years designed to ascertain the prevalence of cerebral palsy amongst children living in Edinburgh, Dundee, Perthshire and Angus. As a result of these, groups of children had been ascertained which were thought to be representative of those suffering from cerebral palsy in the general population (Ingram 1955, 1964, Henderson 1961).

The broad plan of the present investigation was to find out what had happened to the patients ascertained in the Edinburgh survey (1952-53) and in the Dundee survey, which included patients from Dundee itself and small towns within easy reach of Dundee with populations of over 3,000, after they had left school. These patients had been ascertained in 1954-55 in the survey by Henderson and his co-workers (1961).

It was thought that accurate knowledge of the number of patients who obtained employment in open competition or in sheltered conditions or who failed to obtain employment would provide some idea as to the extent of the employment difficulties of patients suffering from cerebral palsy. We hoped, in addition, to explore some of the many reasons why patients with cerebral palsy were unsuccessful in finding employment. Our aim was to provide information for those planning to help patients suffering from cerebral palsy to find work, either by giving them the advice they needed to find employment in open competition or by organising sheltered workshops and other similar facilities. Necessarily, our studies were limited in scope because the numbers of our patients are limited. On the other hand, our series are probably representative of patients suffering from cerebral palsy in the general population

There are quite elaborate statutory and voluntary provisions designed to help the handicapped and to provide for their welfare in Scotland. Unfortunately implementation of the various Acts concerned with provision of welfare facilities is generally inadequate.

#### Government Services for the Disabled in the United Kingdom

Responsibility for the care of the disabled in the United Kingdom is divided between the Ministry of Health, the Ministry of Labour and Local Authorities. In Scotland the Health Services are administered separately by the Scotlish Home and Health Department under the Secretary of State for Scotland.

#### Medical Services for the Disabled

The National Health Act of 1944 provided disabled people with a free comprehensive medical service. Rehabilitation is now regarded as part of the national responsibility of medical practice. Since 1948, all appliances for disabled patients including wheelchairs and invalid cars have been provided by the National Health Service.

In 1949 hospitals were further encouraged to develop their rehabilitation centres. Larger hospitals were required to nominate one of their medical staff to supervise their rehabilitation services and were encouraged to provide, where possible, physiotherapy, remedial gymnastic and occupational therapy departments for in- and outpatients. Provision was to be made for regular conferences between the medical staff, almoner and disablement resettlement officer for patients leaving hospital who needed advice on employment.

There are no separate facilities for children's rehabilitation. In any case, children over twelve years are generally in adult wards.

#### **Employment Services**

Under the Disabled Persons (Employment) Acts of 1944 and 1948, the Ministry of Labour was given certain powers to assist disabled people to find employment.

(a) The Minister has to maintain a register of disabled people. Registration is voluntary but the person registering must be disabled within the meaning of the Act and likely to be so for at least twelve months. He must also be over school leaving age, resident in the United Kingdom and seeking work there. The applicant must have a reasonable (a very elastic term) prospect of obtaining work. Registration must be renewed after ten years, but the applicant may apply to have his name removed from the register at any time.

(b) Every employer of twenty or more people must employ a quota, at present 3 per cent, of registered disabled people. The Government itself employs  $4\frac{1}{2}$  per cent of disabled persons.

(c) The Minister was empowered to reserve certain kinds of work, known as designated employment, for registered disabled people.

(d) The Acts made provision for the appointment of Disablement Resettlement Officers (D.R.O.) to carry out the special orders of the Act. The D.R.O. provides the link between the medical rehabilitation provided by the National Health Service and the Employment Service. Every Employment Exchange has a D.R.O. attached to it.

The D.R.O. advises disabled people and helps them to find employment. To do this effectively he must have a good liaison with local employers and with colleagues in the Employment Exchange. Where necessary he can obtain medical advice and guidance on a standard form from the appropriate medical staff and can arrange for a medical assessment in exceptionally difficult cases. The D.R.O. may interview patients in hospital or such places as Industrial Rehabilitation Units. The effectiveness of the help given to disabled persons necessarily depends on the ability and enthusiasm of the D.R.O.

(e) The Minister is also responsible for the provision of Sheltered Workshops for those who are employable but too disabled to work under normal conditions.

As well as setting up Government Sheltered Workshops, known as Remploy factories (see p. 7), the Minister can give grants to voluntary organisations (see p. 7) and Local Authorities who provide sheltered employment for the disabled. In certain cases individual disabled people can be given grants to set up in business.

(f) National and Local Advisory bodies were established to advise the Minister on the problems of disabled people, and to report on problems connected with the Register and the quota system referred to them.

(g) The provision of courses in industrial rehabilitation.

(h) The provision of vocational training where necessary, by setting up Government training centres, subsidising centres run by voluntary organisations or giving grants to certain trainees at approved technical colleges.

#### Youth Employment Office

The Ministry of Labour also runs a Youth Employment Service which advises young people under 18 years of age on employment problems and helps to place them in suitable occupations. Youth Employment Officers give careers talks to schools in their neighbourhood and interview school leavers. They co-operate with the D.R.O. and voluntary organisations in trying to find suitable work for young disabled people.

#### **Local Authorities**

Local Education Authorities are required to provide certain services for disabled school children, such as medical inspection and treatment, special educational treatment and further education. Special education may be provided by means of extra coaching in an ordinary school, attendance at a special school or hospital school, or by home tuition. Local Education Authorities also give assistance with fees and maintenance for young disabled people to attend residential training centres.

The National Assistance Act, 1948, in addition to grants to those in need, made Local Authorities, under the guidance of the Ministry of Health and the Secretary of State for Scotland, responsible for the welfare of the permanently or substantially handicapped. Local Authorities have to maintain a register of handicapped people and an advisory visiting service.

Local Authorities are also expected to provide some form of occupational therapy for the severely disabled. In addition to organising social clubs, outings and holidays Local Authorities may provide, where necessary, hostels for disabled people attending training courses or employed in sheltered workshops.

#### **Financial Assistance**

The National Insurance Acts of 1946-60 provided many disabled people with unemployment and sickness benefit. Those who did not qualify for these allowances could, where necessary, obtain grants from the National Assistance Board.

#### Local Conditions in Edinburgh, Dundee and Small Towns

The employment prospects and social lives of patients will depend to a large extent on local economic conditions and the extent to which local authorities and voluntary bodies have provided for the welfare of the handicapped.

### Edinburgh

Edinburgh, with a population of 468,378 according to the 1961 Census, is the capital of Scotland, and as such is the main administrative centre for Scotland and the centre of the Scottish Legal System. It is also an important centre for Banking and Commerce, Insurance and Investment. Edinburgh has never had a serious employment problem as it has a wide variety of industry within its boundaries, including publishing, printing, electronics, textiles and light engineering of all types. It has a good labour supply, excellent transport facilities, (including the Port of Leith), a University and good schools, and so has little difficulty in attracting new industry. Edinburgh's unemployment rate is well below the average; in January 1963 it was 3.3 per cent and in July 2.2 per cent, as compared with 5.9 per cent and 4.3 per cent for the whole of Scotland.

Scotland's main employment problem, although less acute in Edinburgh than elsewhere, is lack of craft apprenticeships and progressive jobs for young boys. This problem has been aggravated within the last year or two by the increase in the number of school leavers due to the post-war 'population bulge'. Unfortunately there has not been a corresponding increase in the pool of jobs available. The resulting unemployment has tended to affect older children between 16 and 17, who have drifted from job to job and have a poor industrial record, rather than the school leaver. Only 10 per cent of the children in Scotland who left school in June 1963 were still without work by the end of August. The proportion for Edinburgh was only 6.9 per cent, and the other towns included in the Survey also had a level of unemployment for recent school leavers below the national average (Dundee 7.1 per cent, Angus 5.8 per cent and Perth 6.5 per cent).

#### Facilities in Edinburgh for Handicapped Adults

Senior Occupation Centres. Edinburgh Corporation run two Senior Occupation Centres, one for men and one for women. Many patients have to attend them on a part-time basis owing to the demand for places. There are, however, plans for another centre.

*Remploy.* There is one sheltered workshop run by Remploy Ltd., a corporation set up by the Ministry of Labour, which takes people who by reason of their disability are prevented from working in open employment. Many employees are disabled as a result of war injuries or accidents at work.

Industrial Rehabilitation Unit. This unit, run by the Ministry of Labour, serves the whole of the East of Scotland. The object is to rehabilitate patients who have been in hospital for long periods and who, as a result of their illness, may not be able to return to their former work. The course lasts for a maximum period of 12 weeks. It is not very suitable for patients who suffer from cerebral palsy with multiple handicaps, who require a long period of habilitation rather than rehabilitation.

Edinburgh Cripple and Invalid Children's Aid Society Work and Recreation Centre at Simon Square. A work centre for disabled adults was opened by this Society in November 1960, and patients are referred to the centre by their general practitioners. There are no medical assessment clinics attached to it, but assessments of patients' capabilities are made by occupational therapists before they start in the centre. Patients come to the centre from 10 a.m. to 4 p.m. from Monday to Friday, and transport is provided by voluntary workers for the more severely disabled. The centre has ratients with different handicaps, such as poliomyelitis, heart disease and disseminated sclerosis. Some patients have cerebral palsy and these are referred to the Scottish Council for assessment if they are considered suitable for sheltered training. Simon Square is not a treatment centre although it has a therapeutic and purposeful atmosphere, and industrial contract work is undertaken supervised by occupational therapists. It provides long-term rehabilitation, and social workers attached to the clinic try to find employment for those who are considered ready for it. Many patients, however, will only be suitable for sheltered work while others will remain at the work therapy level. The need for such a centre in Edinburgh is shown by the increasing number of patients attending the centre. In January 1961 there were 79 patients in the workroom and by December 1962 there were 141.

Scottish Council for the Care of Spastics. The Scottish Council is the only association which caters specifically for patients suffering from cerebral palsy. It helps patients with cerebral palsy from all over Scotland from its headquarters in Edinburgh. At first the council was mainly concerned with children of school age; accordingly in 1948 the council, with the help of the Scottish Branch of the British Red Cross Society, opened Westerlea School (which is in Edinburgh) for educable children suffering from cerebral palsy. All the children were assessed by a team of consultants in orthopaedics, paediatrics and psychology. Each child was given training and treatment by occupational therapists, physiotherapists and speech therapists working under the consultants, in addition to formal education. Later a Social Service Department was added.

It was evident from the increasing number of adults who came to the school for advice and help in finding work that there was a need for something more than treatment to encourage personal independence. Many severely handicapped adults lacked the ability to cope with open employment under ordinary conditions and so had no occupation. It was felt that in order to give these adults some purpose to work for, a sheltered workshop should be established. A small beginning was made in 1957, when adult group sessions were started by the speech and occupational therapy departments. It soon became apparent that it would be some time before patients would be ready for paid employment even in a sheltered workshop (Levin 1964).

In May 1959, 'Rhuemore', a large dwelling house in Corstorphine (a prosperous part of Edinburgh), was bought to be used as an out-patient clinic and a training centre for adult patients. Thirty-four patients were registered for training after a preliminary assessment by a team of doctors, therapists and social workers. Training included cooking, housework, gardening, woodwork, reading and writing. Five adults graduated to a more intensive course than the others and attended  $5\frac{1}{2}$  days a week, keeping normal office hours. These patients were to form the nucleus for the sheltered workshop. It was decided that a laundry (initially a bagwash service) would provide a variety of jobs which would develop the different abilities of the patients, such as feeding the machines themselves, clerical and reception work, folding, cleaning and general portering jobs. The Ministry of Labour approved the scheme and provided 75 per cent of the capital cost of the Workshop, and training allowances for a period of 13 weeks for each trainee. Three female patients started training in August 1961, and the Laundry was opened to the public in October 1961. The Laundry has gradually expanded and now employs 9 patients and 1 trainee. The patients are supervised by an experienced laundry manageress and an assistant.

In addition to the disabled people working in the laundry, and laundry trainees, 8 patients attend 'Rhuemore' five days a week from 9 a.m. to 5 p.m. for work therapy, and 28 more handicapped patients attend for occupational therapy. Some of them, including laundry workers, also have speech therapy and physiotherapy. The main obstacle to expansion at present is lack of space and the need for hostel accommodation for patients whose homes are not within daily travelling distance.

Edinburgh and District Parents' Association. This group run a centre for children suffering from cerebral palsy. A group of severely handicapped young adults meets there three days a week and also attends an evening club once a week. Some teenagers from special schools, and some who have recently left school, also attend this club. The association provides transport to and from the centre where this is necessary. It also organises holidays for severely handicapped young people in the summer months.

There are also sheltered workshops in Edinburgh for the blind and for wounded

ex-servicemen, but we know of no patients suffering from cerebral palsy who are employed in them.

### Dundee

Dundee, with a population of 182,959 according to the 1961 Census, is the fourth largest city in Scotland. Situated on the north bank of the river Tay it is traditionally the centre of the jute industry, which is a fluctuating one and dependent for its prosperity on the international situation and Government protection. Since the war, attempts have been made to stabilise Dundee's economy by the establishment of new light industries, and in 1945 it was scheduled as a Development District. An industrial estate was built with assistance from the Board of Trade, and light engineering firms were encouraged to start up factories. There are now about 30 factories on the estate, manufacturing such things as business machines and refrigerators; nevertheless almost a quarter of Dundee's labour is still employed in the jute industry. Dundee's unemployment rate is at present below the Scottish national average, 3.5 per cent in July, 1963 as compared with 4.3 per cent for the whole of Scotland, and it is not considered by any means a 'black spot' for unemployment. The present low rate is to some extent dependent on the continued prosperity of the jute industry, and on the shipbuilding yard which is at present holding its own.

#### Facilities in Dundee for Handicapped Adults

Senior Occupation Centres. There is a Senior Occupation Centre for boys and a class for about 12 senior girls attached to the Junior Occupation Centre. There are plans for extending these.

Dundee Invalid and Cripple Children's Aid Society. The society runs a Residential Training School for handicapped girls. The course lasts two years and consists mainly of dressmaking, with some English and Commercial subjects. The centre caters for all types of handicapped girls but is unsuitable for most patients suffering from cerebral palsy, who find it difficult to reach an adequate standard in sewing. The occupational therapists from the centre also visit patients in their homes and give them some diversional therapy.

*Remploy.* There is a sheltered workshop run by the Ministry of Labour on similar lines to the Edinburgh factory, but it is difficult to gain admission to this as there are few vacancies and the management are reluctant to take anyone under 21 years of age.

Facilities for the Blind. There is a sheltered workshop for the blind and partially sighted.

### **Small Towns**

The small towns included in the Survey are, strictly speaking, not all small. Arbroath and Perth rank as large burghs, but they are small compared with Edinburgh and Dundee. Five of the towns, Arbroath, Brechin, Forfar, Monifieth and Montrose are in Angus and the other, Perth, is the county town of Perthshire.

*ARBROATH* is Scotland's smallest large burgh, with a population of 19,553. It is situated on the coast north of Dundee and has a thriving tourist trade in addition to being a fishing port and the centre of a rich agricultural community. In the past it has been dependent on jute but is now turning to light engineering for its source of employment. It had an unemployment rate of 3.4 per cent in July, 1963, showing an increase of 1 per cent over the previous year's figure.

*BRECHIN*, with a population of 7,114, had an unemployment rate of  $2 \cdot 1$  per cent for July, 1963. Its main industry is agriculture but there is a textile and a machine tools factory. There is little hope of attracting new industry to the town because of the small labour force and heavy transport costs, so that if the existing factories were to contract then employees would be forced to find work elsewhere.

FORFAR, with a population of 10,252, is the county town of Angus and the market town for the surrounding agricultural district. Twenty per cent of its working population are employed in the jute industry, but firms are now turning to other lines. In recent years agricultural engineering and fruit and vegetable processing firms have been established in the town and so have provided a greater variety of jobs. There is very little unemployment at present and it had the lowest rate of all the towns in the present Survey—0.9 per cent in July, 1963.

*MONIFIETH*, with a population of only 3,475, joins on to Broughty Ferry (a suburb of Dundee) and is mainly residential. It has a textile machinery factory which is a subsidiary of a Dundee firm, a foundry, and a number of nurseries and market gardens.

*MONTROSE*, with a population of 10,702, is situated on the coast north of Arbroath and is a seaside resort, the main attraction of which is its very fine stretch of beach. Its shipbuilding and textile industries are contracting and, in spite of the existence of a chemical factory, a distillery and a flour mill, there is need for new light engineering industry to be attracted to the area. Employment in Montrose is to some extent seasonal, owing to the tourist trade and a fruit and vegetable canning factory, and this is reflected in the relatively high unemployment rate of 5·3 per cent for January, the highest rate for any town in the Survey as compared with 3·4 per cent in July, 1963. Even making allowances for seasonal fluctuations, unemployment in Montrose seems to be increasing: the figure for July, 1963 shows an increase of 0·6 per cent over that for July, 1962. Despite the worsening of the employment situation, only two of 83 children leaving school in June, 1963 were still unplaced by September.

*PERTH*, with a population of 41,196, is a large burgh and the administrative centre for the county of Perth. Perth has a healthy, well-balanced economy, good transport facilities, including a harbour and docks, and is the centre of a rich agricultural community. Its industries include whisky distilling, which has recently expanded, glass manufacture, textiles, building and civil engineering, dyeing, cleaning, printing and publishing. It is also an important centre for the insurance business. Unemployment is well below the national average, at 1.8 per cent in July, 1963, and is

likely to remain at a low level as industry is expanding rather than contracting and the outlook for the future is good.

#### Facilities for Handicapped Adults in the Small Towns

There were no facilities for handicapped adults in the small towns, nor were any of the patients living in small towns in the present Survey attending Training Centres in other parts of the country, although one patient had been to the Industrial Rehabilitation Unit for a brief period.

The lack of facilities for disabled people in small towns demonstrates the obvious difficulties encountered by Local Authorities with limited financial resources and a scattered population in providing statutory welfare services as compared with authorities in large urban areas. These difficulties are discussed further in Chapter VIII.

#### Other Residential Training Centres Available to Patients

It is sometimes possible to obtain vacancies for cerebral palsy patients in residential training centres in other parts of Scotland and England. These facilities are, of course, available to patients in Dundee and the small towns as well as Edinburgh.

*Red Cross House, Largs.* This is a residential training centre run by the Red Cross for disabled men and women, and patients are accepted from all parts of Scotland. Initially it was a training centre, but it was found that many trainees were incapable of working in open employment and a sheltered workshop has now been built to meet the needs of these patients, whose training would otherwise seem rather purposeless. A hostel for the sheltered workshop is nearing completion and there will be accommodation for 12 females and 17 males in it. Patients between the ages of 16 and 35 are accepted, suffering from varying disabilities including cerebral palsy, but blind patients and those suffering from idiopathic epilepsy and rapidly progressive disease are not accepted. There are plans for a similar centre in Inverness.

The Spastics Society (England). This society runs a training centre in Hertfordshire specifically designed for patients suffering from cerebral palsy. Although the society is prepared to consider taking Scottish patients its waiting list is very long, and when a vacancy occurs it is found that many patients are reluctant to go so far from home.

### CHAPTER 2

## Classifications and Methods of Study

### The Classification of Cerebral Palsy

The classification of cerebral palsy (Table II) used is that suggested by Balf and Ingram (1956).

Neurological diagnosis	Extent
Hemiplegia	∫Right
	Left
Bilateral hemiplegia	
Diplegia	
Hypotonic	Paraplegic
Dystonic	Triplegic Tetraplegic
Rigid or spastic	Tetraplegic
Ataxic diplegia—	
Hypotonic	Paraplegic
Spastic (	Triplegic
,	Tetraplegic
Ataxia—	Predominantly unilateral
	Bilateral
Dyskinesia—	
Dystonic	Monoplegic
Choreoid	Hemiplegic
Athetoid	Triplegic
Tension	Tetraplegic
Tremor	
Other forms of cerebral	palsy including mixed forms

## TABLE II Classification of Cerebral Palsy

*Hemiplegia* is unilateral paresis of the limbs, commonly affecting the upper limb more severely than the lower. The paresis is usually associated with spasticity and a tendency to flexion contracture. In most congenital cases and those arising in early childhood growth is retarded in the affected limbs so that these are shorter and thinner than those on the unaffected side. Vasomotor disturbances may occur though their severity is not necessarily proportional to the severity of the paresis or to the degree of dwarfing of the limbs. Athetosis, slow writhing involuntary movements of the distal parts of the affected limbs, particularly the fingers and hand, occurs fairly frequently in hemiplegia in childhood. Sensory disturbances in the affected limbs are common. These most commonly impair two-point discrimination, kinaesthesia and fine position sense of the limbs. Appreciation of light touch and pin-prick is usually unimpaired. Epilepsy occurs in between one-third and one-half of patients.

Patients suffering from *bilateral hemiplegia* show tetraplegic paresis more severe in the upper limbs than in the lower, associated with greater or lesser spastic increase of tone and usually some flexion contractures. There is usually severe involvement of the bulbar musculature, with feeding difficulty and dysarthria in consequence. Most patients are mentally defective, epileptic and severely microcephalic. Developmental malformations are commonly associated. The total disability exceeds the summation of two hemiplegias because of the involvement of the bulbar musculature. A greater motor impairment of the upper limbs than the lower differentiates bilateral hemiplegia from diplegia.

Patients suffering from *diplegia* (a poorly derived term devised by Sigmund Freud), suffer from more or less symmetrical paresis of the limbs, more severe in the lower limbs than the upper, which dates from birth or shortly afterwards. Fine movements of the fingers and toes are almost invariably impaired. There is usually a marked increase of muscle tone and relative dwarfing below the waist. Mental impairment, epilepsy and strabismus, usually convergent in type, are common. Between a third and a half of patients are found to be born prematurely in most reported series. A number of arbitrarily defined stages in development of diplegia may be recognised in a high proportion of patients (Ingram 1955).

Patients suffering from *ataxic diplegia* show weakness and inco-ordination of voluntary movement with intention tremor and inability to perform rapid repeated movements, particularly with the distal parts of the limbs. There is unsteadiness and a tendency to walk on a broad base when in the erect position. In addition there is paresis of voluntary movement more severe in the lower limbs than the upper, commonly associated with spastic increase of tone, and pyramidal signs. The increase of muscle tone shown by patients suffering from ataxic diplegia varies greatly from case to case. In patients who are predominantly ataxic and in whom paresis is not severe, muscle tone may be diminished rather than increased and ataxia is more prominent than paresis. On the other hand there are patients tend to walk on a narrower base than those with more pronounced ataxia, their muscle tone is higher, and their biceps, triceps, supinator, knee and ankle jerks tend to be brisker. The majority of patients are mentally retarded.

Patients suffering from *ataxia* show weakness and inco-ordination of movement usually associated with intention tremor and impaired balance as their presenting features. Ataxia may be symmetrical or predominantly unilateral. There is generalised hypotonia, and frequently gross hyper-extensibility of the digits may be demonstrated. The biceps, triceps, supinator, knee and ankle jerks are usually depressed and the plantar responses are flexor. Patients suffering from congenital ataxia rarely have nystagmus and the Romberg test is usually negative. As in ataxic diplegia a high proportion of patients are mentally retarded.

In *dyskinesia* involuntary movements of the limbs produce the major disability. The types of involuntary movements which occur in dyskinesia are classified as suggested by Perlstein (1952). Dystonic movements are those which involve the proximal parts of the limbs more than the distal. They are slow and writhing in quality, and they tend to place the parts of the body which they affect in the opisthotonic posture. Choreoid movements also affect the proximal parts of the limbs, but they are much more rapid than those classified as being dystonic. They often seem to throw the limbs into bizarre postures and may also affect the trunk and face, resulting in sudden erratic changes in posture, respiratory rhythm and in grimacing. Athetoid movements affect the fingers and toes predominantly though in severe cases the wrist, forearm, and occasionally even the elbows may be affected. The movements are slow and writhing, they are accentuated by voluntary activity but are absent at rest. They are often best seen as extension and abduction of the fingers and thumb when the child reaches for objects. Sudden involuntary variations of muscle tone, commonly a generalised hypertonus termed tension affecting both the flexor and extensor muscle groups, also occur in dyskinesia. The whole limb becomes stiff during attempted voluntary movement, and bizarre postures may occur transiently as a result. Tremor may also occur in dyskinesia. It is different from the other forms of involuntary movement discussed as it is rhythmic, though its rhythm varies greatly from case to case. Tremor usually affects the distal parts of the limbs more obviously than the proximal and is almost always more obvious when involuntary movement is attempted. Tremor is rarely the major cause of motor disability.

Most patients suffering from dyskinesia show a number of different types of involuntary movement. Thus patients who have suffered from kernicterus frequently show a mixture of dystonia, choreoid movements and athetosis, frequently associated with tension. Epilepsy is less frequent amongst patients suffering from dyskinesia than in those suffering from other types of cerebral palsy, and mental retardation is also less prevalent.

Patients suffering from other types and mixed types of cerebral palsy are those who are not conveniently classified in the categories already defined. Thus, some patients with involuntary movement superimposed on diplegia cannot be conveniently classified in either the category of 'diplegia' or 'dyskinesia', and it is useful to classify a few patients whose findings are changing rapidly as they mature in the category of 'other' if their findings cannot be accepted confidently as belonging to any particular type of cerebral palsy.

#### Severity of Cerebral Palsy

It is difficult to assess the severity of cerebral palsy in the various categories by uniform criteria, for each type of cerebral palsy affects the patient in different ways. For example, in hemiplegia the major motor handicap is the paresis and incoordination of the affected hand, whilst in diplegia the major handicap is the paresis of the lower limbs and the consequent effect of this on gait. When we attempted to assess the severity of physical handicaps, we used the criteria of Mitchell (1961) in order to obtain a reasonably uniform, if arbitrary, measure of physical handicap. 'In assessing whether patients were mildly, moderately or severely handicapped consideration has been given to the total physical disability and not merely to the motor dysfunction. No definite criteria have been laid down for the three categories of severity, because it is difficult to choose criteria which will apply equally to all types of cerebral palsy, so the assessment is based on the observer's general impression and is therefore liable to a certain amount of subjective error. Nevertheless, such a rough grading of the patients is useful as a general indication of the degree of disability, provided its limitations are appreciated.'

Patients classified as mildly affected were those capable of living normal lives from the physical standpoint, though some activities demanding a high degree of physical skill might be impossible for them. Moderately severely affected patients suffered from some limitation of normal activity as a result of their physical handicaps; for example, they might require a stick as an aid to walking or be unable to climb stairs without help. Severely affected patients were those who required assistance in all but the simplest everyday activities. They could not dress themselves, for example, and most of them could not walk without help. It was often difficult to decide how much of an individual patient's handicap was physical and how much mental, and necessarily the classification of patients by physical disability is somewhat arbitrary. However, classification in this way probably gives some idea of our clinical assessment of the patient's physical handicap. To their motor handicap in many instances are added the handicaps of mental impairment, epilepsy, sensory loss, behaviour disturbances, psychiatric and social difficulties, the severity of which it is difficult to score on any arbitrary scales.

Intelligence had been assessed by a number of different psychologists using different tests in Edinburgh, but we are fortunate in having access to results of previous psychometric assessment in all our patients. In Dundee, Perth and Angus patients had been studied more systematically by a psychologist (Dr. June M. Cockburn) during the original survey, and the results of her tests were made available to us.

Patients were classified by intelligence as follows:

I.O.

110+	Superior intelligence
90-110	Average intelligence
70–90	High grade defective
50-70	Moderately severely mentally defective Mentally handi-
-50	Severely mentally defective $\int$ capped or defective.

We also classified patients by their degree of attractiveness, for obviously, as in potential employees who are not handicapped, appearance may be an asset or a drawback when the individual seeks work. Necessarily, our assessment is entirely subjective, but in fact there seemed to be a very wide measure of agreement amongst those who met them as to which patients were attractive, which unattractive or worrying to look at, and those whose appearance was unremarkable. We divided patients into three categories, those who were positively attractive and likely to find their appearance an asset when they sought work, those whose appearance was unremarkable, and those whose appearance was likely to be a drawback because they grimaced and drooled, were badly deformed, hydrocephalic, or had associated abnormalities.

Speech defects were classified in three groups. In the first were those patients with no detectable disorder of speech; in the second were those with mild speech disorders whose speech was not normal but was intelligible, and those with moderately severe speech defects whose speech was partly intelligible to strangers; in the third category were those with severe speech defects who were largely unintelligible or had such limited speech that they could not communicate their ideas.

#### **Classification of Employment**

Patients were considered to be in open employment when they were in full competition with people who were not handicapped, and holding jobs in which no allowances were made for their disabilities. Patients were considered to be in niche employment when they were doing work which could have been done better by an unhandicapped person, and when they kept their jobs only because allowances were made for their handicaps. Many patients in niche employment had obtained their jobs through family influence or special agencies concerned with the employment of the handicapped.

A good example of niche employment was that of Case 65, who was employed as a clerk in a light engineering firm with a particularly good record for giving employment to disabled people. He was of average intelligence but suffered from dyskinesia and was moderately physically handicapped. His writing was very poor and slow. This had impeded his progress at his physically handicapped school. When he first started work he was tried out as an apprentice but was too slow and not up to the required educational standard. However, a job was made for him as a clerk in the Estimating Department. A normal employee would have been dismissed as being too slow, but allowances were made for his disability. It was hoped that in time he might improve and gradually acquire some knowledge of the workings of his particular department. The firm's main reason for employing him was philanthropic but his good appearance and pleasant manner were to his advantage. His father was a partner in a business firm and so he enjoyed a fairly high standard of living and could afford to dress reasonably well.

By sheltered employment was understood work carried out in establishments recognised as sheltered workshops by the Ministry of Labour. These included workshops under the auspices of Remploy and the St. Jude's\* laundry staffed by patients suffering from cerebral palsy, organised and run by the Scottish Council for the Care of Spastics in Edinburgh. Patients in training for posts in sheltered workshops and similar establishments were classified as being in sheltered training. Patients in Red Cross House at Largs, which specializes in the training of handicapped people for industry, and those in the training scheme of the laundry at Rhuemore Outpatient \* Named after St. Jude, the patron saint of lost causes.

Department run by the Scottish Council for the Care of Spastics, for example, were placed in this category. Patients classified as unemployed were those without work at the time of the survey. A few of them had been employed in earlier years, usually for short periods.

#### Methods of Study

The patients studied were those ascertained some ten years previously in Edinburgh during an investigation of the prevalence of cerebral palsy in the city amongst children born between 1938 and 1952, carried out in 1952-53 (Ingram 1955), and those ascertained in a similar study made in Dundee and the counties of Perth, Angus and Kinross, of the prevalence of cerebral palsy amongst children and young adults under the age of 21 on the 31st March 1955, made by Henderson and his colleagues in 1954-55 (Henderson 1961).

In both surveys a total ascertainment of patients suffering from cerebral palsy was attempted rather than a sampling survey. Information was obtained in three main ways. Firstly, all doctors, clinics and hospitals likely to have treated children suffering from cerebral palsy were asked to notify them. Amongst those contacted were medical officers, nurses, general practitioners and health visitors in the School Health Service, the Maternity and Child Welfare Services, those working in private schools and all hospitals with paediatric beds or outpatient clinics. Information about patients was also obtained from investigations concerned with other research projects, and from the staff and records of the Scottish Council for the Care of Spastics.

Secondly, the case-notes of patients suffering from disorders which might have resulted in or been associated with cerebral palsy were studied. Records of children suffering from mental retardation, epilepsy, club feet, visual and hearing defects and those with histories suggesting birth injury, rhesus incompatibility, meningitis, hydrocephalus, intracranial abscess or tumour and head injury were obtained from a wide variety of clinics, schools and hospitals. In Edinburgh approximately 8,500 casenotes of patients of this type were studied.

Thirdly, and most important, in both surveys active ascertainment was attempted by the investigators themselves. In Edinburgh, for example, approximately 4,000 children were inspected in schools for the mentally and physically handicapped, schools for normal children, and institutions for the mentally defective, the blind and the deaf. Others were seen in a variety of paediatric, orthopaedic, ophthalmological, infant welfare and school medical clinics. The aim of these inspections was to find children in whom more detailed examination seemed worth while.

In the Edinburgh survey, detailed family and personal histories of the patients were taken from parents or guardians, and the affected children were carefully examined, usually on two or more occasions. Psychological assessments could not be made routinely; they were usually available from other sources in children of school age, but when they were not available they were obtained by referring the patients to psychologists working in Edinburgh hospitals or for the Edinburgh Education Department. Details of school performances were sought routinely from teachers and as much information as possible was obtained of behaviour abnormalities at home and in school. Details about the child's attitude to his disability, to his family and to other children were sought. An attempt was made to describe the home background in each case, but it was difficult for a rather inexperienced doctor in the course of a few interviews to gain any clear impression of the stresses and strains resulting from the presence within a family of a child suffering from cerebral palsy.

In Dundee a more comprehensive assessment of patients was attempted by a team consisting of doctors, social workers, a psychologist and an expert in social medicine. Patients were seen by a paediatrician, orthopaedic surgeon, ear, nose and throat surgeon, ophthalmologist and psychologist, and their parents were interviewed by a social worker. As a result of these studies, more accurate information was available about the medical handicaps of the children in the Dundee study, and the psychological and social aspects were investigated more systematically.

A summary of the information about each patient which was obtained during the original surveys in Edinburgh and Dundee was made using special proformas. This summary contained details of the development of motor, adaptive and linguistic behaviour and information about the diagnosis, severity of physical handicap, and associated disabilities such as hearing or visual difficulties, epilepsy and mental subnormality.

On the basis of the assessment of total physical handicap, including associated disabilities and the child's educational and social adjustment, a prediction was made about the likelihood of his being able to work in open employment or sheltered conditions, or of his being unemployable.

#### **Contacting Patients**

During this follow-up study, attempts were made to contact all the patients in Edinburgh who had been born between 1938 and 1947 inclusive. We did not, however, attempt to follow-up all the patients ascertained in the Dundee area, since we excluded from the follow-up study those living in isolated rural conditions in the counties of Perth, Angus and Kinross. The patients studied were those born between 1937 and 1947 inclusive whose parents had been domiciled in Dundee in 1955, or in smaller towns readily accessible from Dundee, *viz.*, Montrose, Brechin, Forfar, Arbroath, Monifieth and Perth.

#### **Description of Interviews**

The first approach was made to the parents of the patients. In most cases a cyclostyled letter was used, but in others personal letters were written. In these the purpose of the study was explained and the co-operation of patients and their relatives requested. The patients and parents were asked to allow the social worker to visit them at home, or to visit her. Where possible, the first interview took place with the parents or parent only. The length of the interview varied from about half an hour to an hour and a half.

The following information was sought from parents:

(1) Extent of patient's physical handicap and speech defect, if any.

- (2) Patient's relationships with other people.
- (3) Parents' interpretation of the diagnosis.
- (4) Parents' assessment of the patient's major handicaps.
- (5) Parents' assessment of the patient's employability and, where appropriate, the suitability of his present job.
- (6) Information about patient and comments on his progress.
- (7) Parents' account of hospital treatment and physical therapy, if any, and its value to the patient.

The following information was sought from patients:

- (1) Diagnosis.
- (2) Patient's account of his own, his parents' and other people's reactions to his disabilities.
- (3) Account of his handicaps.
- (4) Assessment of independence.
- (5) Assessment of employability.
- (6) Opportunities for social life.
- (7) Account of the result of hospital treatment, physical therapy and work-training.
- (8) Employment history and method of finding work.

Information was also sought from patient, parents or appropriate outside sources.

- (1) Medical history, e.g. epilepsy, other physical handicaps, psychiatric symptoms.
- (2) General intelligence and appearance.
- (3) Independence in personal care.
- (4) Home background and social class.
- (5) Education—tests taken and standard reached.
- (6) Present occupation and means of support of the patient.
- (7) Opportunities for social life.

The majority of parents were very co-operative and welcomed an interest being taken in their children. Interviews with parents varied in quality depending to a great extent on their intelligence, and their attitude to their child's disability. It was, however, possible to obtain some information from all the parents seen, even from two who turned the social worker away. It was not always possible to obtain worthwhile information from patients, who were either too mentally handicapped to answer questions at all, or who were capable of answering only simple questions. Very few could give accounts of reactions to their disabilities. Many patients, although able to answer questions, tended to be defensive and reserved. The proforma was generally filled in at the time of interview.

When letters were returned 'unknown at this address' or were not returned, visits were made to the houses by the social worker who tried to find out where the patients were now living. Sometimes it was possible to obtain the patient's new address from subsequent occupants or from neighbours, or it was possible to learn from them more vaguely what had happened to the family sought.

When this method of finding patients proved unsuccessful, attempts were made to find them by contacting institutions for the mentally handicapped, rehabilitation centres, hospitals and statutory authorities, such as the local education authority, housing authority, Youth Employment Officer, etc. to see if the patient's present domicile was known.

Only four of the 26 patients in open employment in Edinburgh gave permission for the social worker to contact former employers. In Dundee, three patients in open employment gave permission to contact previous employers. Their reluctance to have the social worker contact their employers was understandable for many of the latter had not regarded the patients as handicapped. Employers who were contacted were telephoned rather than written to as it was felt that the response to a postal questionnaire would be poor. All employers contacted were interested and cooperative. The majority answered questions over the telephone but four of the employers in Edinburgh granted personal interviews. Inevitably, because a high proportion of the patients had been in unskilled work for only a short time years earlier, employers were unable to give much useful information about them (see Chapter V).

#### CHAPTER 3

## The Survey Samples

As a result of the survey in Edinburgh (1952-53), 208 patients were ascertained who had been born between 1938 and 1952 and were resident in Edinburgh at the beginning of January 1953. The distribution of patients by year of birth is shown in Table III.

			mber of Pat	ients	Prevalence per 1,000			
Year of Birth	Popula- tion*	Hemi- plegia	Diplegia	All types	Hemiplegia	Diplegia	All types	
1938	6749	10	3	17				
1939	6574	3	8	13	0.819	0.563	1.945	
1940	6209	3	0	8				
1941	6099	4	2	10				
1942	6388	4	4	13	0.631	0.578	1.839	
1943	6538	4	5	12				
1944	6533	7	11	24				
1945	5993	4	3	9	0.930	1.028	2.546	
1946	7902	8	7	19				
1947	8900	8	7	21				
1948	7700	6	4	14	0.871	0.996	2.448	
1949	7500	7	13	24				
1950	7200	5	3	11				
1951	7100	1	6	8	0.330	0.566	1.132	
1952	6900	1	3	5				
1938-52	104285	75	79	208	0.719	0.757	1.991	

\*Based on figures obtained from Edinburgh Education Authority and the Registrar General.

It will be seen that the prevalence of cerebral palsy varied between 1.132 per 1,000 of the total child population in the three-year period 1950-52 inclusive and 2.546 per 1,000 in the three-year period 1944-46. Prevalence figures are low in the younger age group predominantly because of the technical difficulties of ascertainment. It is likely that there is a real difference, however, in the prevalence of cerebral palsy in the years 1938-1943 and 1944-49. The high prevalence in the latter period may be explained in a number of ways. Firstly a larger number of small premature babies with cerebral palsy survived in the later period, secondly there was diminished mortality from infections amongst patients with very severe cerebral palsy as antibiotics became more widely used, and thirdly, as a result of the wider use of antibiotics in the treatment of the cerebral complications of infectious diseases, more patients survived to show cerebral palsy.

In Dundee and the counties of Perth, Angus and Kinross, the prevalence rates are very similar to those found in Edinburgh (Table IV). They are as high as, if not higher than, most comparable rates found in recent regional surveys of cerebral palsy in school children, and it seems likely that ascertainment in both surveys was adequate and that the patients studied were reasonably representative of those suffering from cerebral palsy in the community. As explained already, patients living in isolated conditions in Perth and Angus were excluded from the present study, which is confined to those living in small towns with populations of over 3,000 within easy travelling distance of Dundee.

TABLE IV The prevalence of cerebral palsy according to age in Angus, Perth and Kinross (*Henderson*, 1961)

	Ag	ge in years	
	0-4	5-14	15-18
Number of cases	50	133	37
*Population (Angus, Perth and Kinross)	32,400	65,000	23,400
Prevalence	1.54	2.04	1.28

\*Estimate provided by the Registrar-General, Scotland, for the end of June 1955.

#### The Patients Studied

One hundred and forty-six patients were ascertained during the Edinburgh study of 1952-53 who had been born between 1938 and 1947 inclusive. Fifty-five patients were ascertained in Dundee and 31 in the small towns (Table V). It will be seen that the sex ratio of males to females amongst Edinburgh patients is approximately 3:2, similar to that found in the small towns, whereas the ratio is almost 1:1 in Dundee. When the series are combined, there are 135 male and 97 female patients.

Two patients, both from the Edinburgh series, were excluded on account of misdiagnosis. The first, a girl diagnosed as suffering from ataxic diplegia, became progressively disabled following the 1952-53 survey, and a second diagnosis of progressive spino-cerebellar ataxia with dementia was made. She died at the age of 20 years having been bedridden for the last 18 months of her life. The second misdiagnosed case was a boy suffering from post-encephalitic Parkinsonism, whose disease seemed arrested at the time of the original survey but who subsequently

		burgh	Du	ndee	Small	towns	A	LL
	Male	Female	Male	Female	Male	Female	Male	Female
Total patients in original surveys	89	57	28	27	18	13	135	97
Excluded because of mis-diagnosis Died after original	1	1	0	0	0	0	1	1
survey	3 8	4	2	1	1	3	6	8
Untraced Traced patients in present surveys	8 77	48	2 24	25	16	10	117	83

 TABLE V

 The fate of patients in original survey in Edinburgh, Dundee and Small Towns

deteriorated rather rapidly and died as a result of hypostatic pneumonia at the age of 15 years. Fourteen of the 230 patients who did suffer from cerebral palsy ascertained in the original surveys had died before the follow-up study. Sixteen patients were untraced, 12 of them in the Edinburgh series and four amongst those ascertained in Dundee and small towns. Two hundred of the patients from Edinburgh, Dundee and small towns were traced and information was obtained about them—125 of these came from Edinburgh, 49 from Dundee and 26 from small towns.

#### **Deaths of Patients Suffering from Cerebral Palsy**

In the 10 years which elapsed between the initial ascertainment of patients in Edinburgh and their follow-up study, and in the 8 years which elapsed between the ascertainment of patients in Dundee and small towns and their follow-up, 14 died, giving a yearly fatality rate per thousand of 6.6. Eleven of the 14 patients who died were considered to be severely physically handicapped, giving a yearly mortality-rate per thousand of 31.2 for severely physically handicapped patients only. These figures may be compared with the yearly mortality-rate in the Edinburgh school population between 1952 and 1961 of 0.4 per thousand approximately (Tait and Boog Watson 1962). The difference between the mortality rates for children of the general population and those suffering from cerebral palsy is similar to that found by Schlesinger *et al.* (1959). They reported that the mortality amongst patients aged between 6 and 17 years suffering from cerebral palsy was about 13 times greater for males and 17 times greater for females than amongst children in the general population.

Crothers and Paine (1959) reported that 14 per cent of 847 patients, selected by hospital referral and born between 1916 and 1955, were dead by 1956. The highest death-rate was in patients suffering from 'spastic tetraplegia', a category which comprises tetraplegia, diplegia and bilateral hemiplegia as defined in the present study. Deaths occurred most commonly between the ages of 5 and 20 years.

In the present study it was found that 12.5 times more Edinburgh children aged between 5 and 25 years who suffered from cerebral palsy died than all Edinburgh school children (Table VI).

	Total number of patients	Total number of deaths	Yearly rate per 1,000	Number of severely handi- capped patients	Number of deaths among severely handi- capped patients	Yearly rate per 1,000
Edinburgh	144	7	5	24	7	29
Dundee	55	3	6.8	9	1	11
Small towns	31	4	16	5	3	75
Combined series	230	14	6.6	38	11	31.2

TABLE VI Yearly fatality rate per 1,000 patients in Edinburgh, Dundee and Small Towns

It will be seen from Table VII that, as in Schlesinger's survey, the proportion of females suffering from cerebral palsy who died is surprisingly high. There were in fact 6 males and 8 females, a reversal of the sex ratio found in living patients. Seven of the 8 females who died had been classified as suffering from bilateral hemiplegia, as were 3 of the 4 who died in Dundee and small towns. There appears to be a group of female patients severely affected by bilateral paresis of the limbs, usually more severe in the upper limbs than the lower, who are liable to die as a result of epileptic attacks, pneumonia or associated congenital anomalies. It will be seen from Table VII that pneumonia, epileptic attacks and congenital abnormalities are responsible for the majority of deaths.

Age at death	Sex	Diagnosis	Severity	Associated disabilities	Prediction	Cause of death
Edinburgh 15	F	Bilateral hemiplegia	Severe	Gross men- tal defect. Epilepsy	Institution	Status epilepticus
20	М	Diplegia	Severe	Cortical blindness. Gross mental defect	Institution	Pneumonia
15	М	Dyskinesia	Severe	Gross men- tal defect. Hearing loss	Institution	Pneumonia
10	F	Bilateral hemiplegia	Severe	Multiple congenital anomalies. Gross men- tal defect	Institution	Pneumonia Congenital heart disease
12	F	Bilateral hemiplegia	Severe	Multiple congenital anomalies. Gross mental defect. Epilepsy.	Institution	Pneumonia
18	М	Dyskinesia	Severe	Severe bulbar in- volvement	Institution	Post operative death
14	F	Bilateral hemiplegia	Severe	Gross men- tal defect	Institution	Pneumonia
Dundee ?	М	Diplegia	Slight	Gross men- tal defect	Unemploy- able	Pneumonia
15	М	Diplegia	Slight	Epilepsy	Possibly Niche employment	Status epilepticus
14	F	Bilateral hemiplegia	Severe	Gross men- tal defect. Severe scoliosis	Institution	Pneumonia
Small Towns 18	F	Bilateral hemiplegia	Severe	Epilepsy Extreme physical emaciation	Institution	Progressive deteriora- tion
21	F	Bilateral hemiplegia	Severe	Epilepsy. Gross men- tal defect. Gross sco- liosis. Micro- cephalic Brachy- cephaly	Unemploy- able	Pneumonia
17	М	Bilateral hemiplegia	Moderate	Gross men- tal defect. Epilepsy. Scoliosis	Institution	?Status epilepticus
13	F	Diplegia	Severe	Gross men- tal defect. Epilepsy	Institution	?Status epilepticus

 TABLE VII

 Deaths of patients occurring between 1953 and 1963 by type of cerebral palsy and cause of death.

#### TABLE VIII

# Untraced patients by sex, social class, diagnosis, severity of physical handicap, associated disabilities, prediction for employment and last information about them.

	Year of Birth	Sex	Social Class	Diagnosis	Severity	Associated dis- abilities	Prediction	Last information
Edin- burgh	1938	F	111	Dyskinesia	Moderate	_	Open em- ployment	Moved. Address unknown.
	1947	Μ	IV	Dyskinesia	Mild	—	Open em- ployment	Moved to Yorkshire.
	1946	М	v	Ataxia	Moderately severe	Over- activity	Possibly open em- ployment	Moved. Father in Regular Army.
	1941	F	V	Right hemi- plegia	Moderately severe	_	Sheltered employ- ment	Moved. Address unknown.
	1947	М	III	Diplegia	Moderately severe	Defects of feet	Open em- ployment	Moved. Address unknown.
	1938	М	v	Left hemiplegia	Moderately severe	_	Open em- ployment	Moved. Address unknown.
	1944	M	Ш	Ataxia	Mild	Defective vision	Open em- ployment	Gone to U.S.A.
	1944	M	IV	Left hemiplegia	Mild		Open em- ployment	Moved. Address unknown.
	1939	М	IV	Diplegia	Moderately severe	Psychiatric	Open em- ployment	Gone to London.
	1947	F	IV	Ataxic diplegia	Moderately severe	Psychiatric	Sheltered employment	In U.S.A.
	1938	М	IV	Right hemiplegia	Moderately severe	Defective vision	Sheltered employ- ment	'Vanished into thin air'.
	1947	F	111	Left hemiplegia	Moderately severe	Focal epi- lepsy. Over- activity	Sheltered employ- ment	Family emi- grated to Australia.
Dundee	1944	F	v	Left hemiplegia	Slight	Myopia	Open em- ployment	Moved. Address unknown.
	1947	M	III	Tetraplegia	Slight	Epilepsy	Unemploy- able	Moved to London.
·	1942	М	II	Choreo- athetosis	Slight	None	Open em- ployment	Moved. Address unknown.
Small Towns	1947	М	IV	Left hemiplegia	Slight	None	Open em- ployment	Moved South.

#### **Untraced Patients**

It will be seen from Table VIII that 12 of the Edinburgh patients, 3 of those from Dundee and 1 from the small towns were untraced. Three of those in Edinburgh were known to have gone abroad and could not be contacted. The approximate whereabouts of 7 patients was known, but in 9 it proved quite impossible to find out where they had moved, in spite of efforts to trace them through housing

Edinburgh							
Year of		Hemi-		Dyskin-			
birth	Sex	plegia	Diplegia	esia	Other	Totals	
1938 1939 }	M F	7 4}11	$\binom{4}{6}$ 10	0 0}0	$\frac{1}{-}$	$12 \\ 10 $ $\}$ 22	
1940 \ 1941 }	M F	$\frac{4}{3}$ 7	<mark>4</mark> _}4	$1 \\ 1 \\ 2$	$\frac{1}{2}$ }3	$\frac{10}{6}$ 16	
1942 1943	M F	$\frac{4}{4}$ 8	$\frac{7}{3}$ 10	$\frac{1}{2}$	$\frac{1}{1}$ 2	$13 \\ 10$ 23	
1944 1945	M F	$\frac{7}{5}$ 12	$\frac{9}{6}$ 15	$\frac{2}{-}$ 2	$\left \begin{array}{c}0\\2\end{array}\right _2$	$18 \\ 13 \\ 31$	
1946 \ 1947 \	M F	$12 \\ 1$ 13	$10 \\ 5 \\ 15$	$\frac{2}{2}$ 4	$\frac{-1}{1}$	$24 \\ 9$ 33	
TOTAL	M F	$34 \\ 17 $ 51	$34 \\ 20 $ 54	$\binom{6}{5}$ 11	3 6}9	$\begin{array}{c} 77\\ 48 \end{array}\} 125$	
Dundee							
1938 <u> </u> 1939	M F	$\frac{6}{-}$ 6	$\frac{3}{3}$ 6	$\frac{-}{1}$ 1	_}-	$\binom{9}{4}$ 13	
1940 <b>}</b> 1941 <b>}</b>	M F	$\frac{2}{4}$ 6	$-\frac{1}{4}$	$\frac{1}{1}$ 2	$\overline{1}$	$3 \\ 10 $ 13	
1942 <u> </u> 1943	M F	$\frac{2}{2}$ 4	$\frac{1}{-}$ 1	-}-	_}-	$\frac{3}{2}$ 5	
1944 <u>1945</u>	M F	$\frac{3}{-}$ 3	$\frac{2}{-}$ 2	$\frac{1}{1}$ 2	$\overline{\frac{1}{1}}$	$\left\{\begin{array}{c} 6\\2\end{array}\right\} 8$	
1946 } 1947 }	M F	$\frac{2}{3}$ 5	$\frac{1}{2}$	$\frac{1}{1}$	$\frac{1}{1}$	$\frac{3}{7}$ 10	
TOTAL	M F	$15 \\ 9$ 24	$\binom{6}{9}$ 15	$3 \\ 4 $	$\overline{\overline{3}}$	$24 \\ 25 $ $49$	
Small Towns		,	,	,	,	,	Grand Total Edinburgh, Dundee and Small Town
1938 1939	M F	$\frac{3}{1}$ 4	_}-	_}-	_}-	$\frac{3}{1}$ 4	$24 \\ 15 $ 39
1940 1941 }	M F	$2 \\ 1 \\ 3$	$2 \\ 3 $	$\frac{1}{-}$ 1	$\overline{1}$	$\frac{5}{5}$ 10	$\frac{18}{21}$ 39
1942 1943	M F	$1 \\ 1 $	_}-	_}-	_}-	$1 \\ 1 \\ 2$	$17 \\ 13$ 30
1944 1945 }	M F	$1 \\ 1 $	$1 \\ 1$	_}-	_}-	$\frac{2}{2}$ 4	$\frac{26}{17}$ 43
1946 1947 }	M F	$\frac{3}{3}$	$\frac{1}{-}$ 1	$\overline{1}$	$\frac{1}{-}$	$\frac{5}{1}6$	$32 \\ 17 $ $49$
TOTAL	M F	$10 \\ 4$ 14	$\frac{4}{4}$ 8	$\frac{1}{1}$ 2	$1 \\ 1$	$\frac{16}{10}$ 26	$117 \\ 83 \\ 200$

TABLE IX Distribution of traced surviving patients by diagnosis and year of birth in Edinburgh, Dundee and Small Towns

authorities, local hospitals, National Health Service Executive Councils and various voluntary bodies.

It will be seen that all 4 of the patients who were untraced from Dundee and the small towns were considered to be mildly physically handicapped, as were 3 of those from Edinburgh. The other 9 Edinburgh patients were classified as having moderately severe physical disabilities but none was classified as being severely disabled. The prediction was for open employment in 11 patients and for sheltered employment in 4, while 1 patient in Dundee was considered unemployable. Thus the patients who were untraced comprised a group of relatively lightly physically handicapped patients, most of whom were likely to obtain employment. Their exclusion from the follow-up study makes the numbers of employed patients in it smaller than would have been the case had they been included. The fact that so many of the patients who moved house were lightly handicapped is in itself interesting; possibly an equal proportion of the parents with moderately or severely handicapped children would have moved had their children been less gravely disabled.

The larger proportion of diplegic patients in the Edinburgh survey compared to that found in the series from Dundee and small towns is interesting, though no ready explanation for the difference can be offered (Table IX).

The similarities between statistics for Edinburgh, Dundee and small towns are more striking than their differences (see Table X). The Edinburgh survey contains a rather higher proportion of patients considered to be mildly physically handicapped; speech defects are found rather less commonly in the Dundee and small towns series; on the other hand, the proportions of patients found to have epilepsy in Dundee and Edinburgh were remarkably similar. Various explanations could be offered for the fact that fewer patients were thought to have an attractive appearance in Dundee and surrounding small towns than in Edinburgh! In all three series there is a high proportion of patients suffering from hemiplegia among those classified as mildly physically handicapped. For example, in Edinburgh, 39 of the patients in the group of 71 considered to be mildly physically handicapped suffered from hemiplegia, and 26 from diplegia. Only 4 of the 57 Edinburgh patients suffering from hemiplegia were considered to be severely physically handicapped, whereas 11 of the 54 who were suffering from diplegia were placed in this category. A relatively high proportion of patients suffering from dyskinesia were found to be of average intelligence, and this is compatible with the observations of most published studies—that intelligence is more often spared in dyskinesia than in the other types of cerebral palsy (Woods 1957).

The distribution of patients living in Edinburgh, Dundee and small towns by the type of school they last attended is shown in Table XI. No severely physically handicapped patients attended junior or senior secondary schools. Even amongst mildly physically handicapped patients, mental impairment appears to have been the factor which determined the need for special schooling in most cases who could not manage ordinary school. Of the 83 patients in schools for the physically or mentally handicapped only 12 were of average intelligence.

Compared with Edinburgh and Dundee there is a lack of special schools in the country districts. There is one school for the mentally handicapped in Perth, special classes attached to ordinary schools in Forfar, Arbroath and Montrose, and Junior Occupation Centres in Forfar, Montrose and Perth, but there is no provision specifically for physically handicapped children. It will be seen from Table XI that only approximately 8 per cent of 26 patients in the small towns were at schools for the mentally handicapped. A greater percentage of patients attended schools for the

Patients by diagnosis, severity of physical handicap, intelligence, presence or absence of epilepsy, speech defects and appearance, in Edinburgh	of physical	handicap, ir	telligence, pr	resence or a	bsence of epile	epsy, spe	ech defect	s and apl	jearance, in Ed	nburgh
	Ċ	Severity	Severity of physical handicap	handicap	14	itelligenc	Intelligence quotient		Epi	Epilepsy
LJiagnosis	Nex	Mild	Moderate	Severe	+06	70-90	50-70	-50	None	Present
Hemiplegia	∑⊔ ∶	25) 39	6) 8 3( 8	3 4	12) 14	9 18	4) 7	9) 12	24) 31	10) 10) 20
Diplegia	י∑⊔ :	15 15 16	11	8 11 11	6) 6) 12	7 13	12) 12) 16	9 13	25 41	9  13
Dyskinesia	י∑ר :	2 1 3	6 6 6	5 7 0 7 0	0 7 6 6	112	5 11 1		8 90 90	0 0 1 t
Other	ւ Ծ և :	1 <u>3</u>	5 5 6		1 7 - 1 - 1	$\frac{3}{1} 4$	- <u>-</u>	<u> </u>	21 31 4 7	$5 \overline{)} 2$
TOTALS	Zµ ∶	44 71	22) 37	11 6 17	32	20) 37	17) 29	18) 27	58) 87	19) 38
Approximate per cent	ч∑н :	57 57 57	$\frac{28}{37}$ 30	14( 12) 13	$28 \\ 21 \\ 26 \\ 3 \\ 3 \\ 3 \\ 3 \\ 3 \\ 3 \\ 3 \\ 3 \\ 3 \\ $	$\frac{1}{26}$ 30	$22 \\ 25 \\ 23 \\ 23 \\ 23 \\ 23 \\ 23 \\ 23 \\ $	$\begin{bmatrix} 23\\ 18\\ 18 \end{bmatrix} 20$	$\binom{75}{60}$ 67	25 40) 32
			i	Appearance	ce			Spee	Speech Defects	
Diagnosis			Asset	Unre- markable	Dis- advantage	, H	Not present	Mild N	Moderate Severe	Total
				(¢;						

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Е	
[AB]	

 $\begin{array}{c} 77\\ 48\\ 99\\ 99\\ 100\\ \end{array} 100 \end{array} 100$ 34) 51 177 51 200 54 56 11 6 9 6 9 8 13 5 13 10 10 10 10 ŝ 2 ÷  $\overline{-1}\overline{0}\overline{0}\overline{0}$  $\begin{array}{c} 13\\ 6\\ 6\\ 17\\ 13\\ 13\\ 15\end{array}$ 2 <u>vu40w---</u> 25) 41 16) 32 32) 32  $\begin{array}{c} 117\\ 110\\ 12\\ 12\\ -\\ -\\ -\\ 2\\ 2\\ 2\\ 2\\ 2\\ 2\end{array}$  $\begin{array}{c} 31\\ 21\\ 40\\ 43\\ 43\\ \end{array}$  $\begin{array}{c} 24\\17\\17\\31\\35\\33\end{array}$ 15 19  $\begin{array}{c} 100\\ 16\\ 9\\ 9\\ 1\\ 1\\ 1\\ 1\\ 1\\ 2 \end{array}$ 23) 38 15) 38 31) 30 ÷ ÷ ÷ ÷ ÷ ÷ ÷ Approximate per cent. ... : : ÷ ÷ TOTALS ... ÷ ÷ ÷ ÷ (Hemiplegia) (Other) ... (Diplegia) ... (Dyskinesia)

		Severity c	Severity of physical handicap	andicap		Intelligenc	Intelligence quotient		Epilepsy	, sd
Diagnosis	Sex	Mild	Moderate	Severe	+06	0602	50-70	-50	None	Present
Hemiplegia Diplegia Dyskinesia Other	ΣμΣμΣμΣμ	F 9 0 m 0 1 1 1	r004-0 10			×00111	8888 - 18	00mm   -   -	0L440WIW	8442
TOTALS	Σц	${11 \atop 9}$ 20	$10 \\ 10 \\ 20$	$\begin{pmatrix} 3\\6 \end{pmatrix}$ 9	<b>4</b> <b>8</b> <b>12</b>	$\left  \begin{array}{c} 11 \\ 3 \end{array} \right\rangle 14$	$\frac{4}{7}$ }11	5 $7$ $12$	15) 17) 32	9) 8) 17
Approximate per cent	Σıl	45-8 36	41.7 40	12.5 24	16.7 32	45.8 12	16.7 28	20.8 28	62-5) 68-0) 65	37.51 34 32.0) 34
(Diagnosis)		Ad- vantage	Appearance Unre- markable	Dis- advantage		No defect	Speech Defects Intelligible but defective	ts Unin- telligible		Total
(Hemiplegia)	:	04	۲ ۲	9		13				15
(Diplegia)	÷	- I c	- 61 4	' ব <b>ে</b>		2014	1010			00
(Dyskinesia)	÷	4 <del></del> C	ן ר <del>-</del>	40-		- 19 0	1-1	4   <del>-</del>		v w Z
(Other)	÷	1   1		- 10		- 1	a : 🛏	-		t   m
TOTALS	:	3 8 11	9 8 17	$\begin{array}{c} 12\\9\\9\end{array}$		17) 13] 30	$   \begin{array}{c}     4 \\     7 \\     7 \\   \end{array}   \begin{array}{c}     4 \\     11 \\     7 \\     11   \end{array} $	5 8		24) 49 25) 49
Approximate	:	12-5	37.5	50		70.8) 61	, 16.7) <sub>22</sub>	12.5 116		100

TABLE Xb

29

			Severity of physical handicap	of phy:	sical ha	undicap		Intelligence quotient	quotient		Epi	Epilepsy
Diagnosis		Sex	Mild	Moderate		Severe	+06	06-02	50-70	-50	None	Present
		Σır	64	4		1		4		1 5	4 00	6
Diplegia	:	Σ⊔		- "		7	-0		4-	I <del></del>	4 r	ı <del>-</del>
Dyskinesia	:	. Zu	- 1 -	— с			4	1		-	51	«
Other	:	ւ∑ււ				5 1 1		1 1 1			1 1	
TOTALS	:	Σц	7 7}14		7 3 3	2	$\left\{ \begin{array}{c} 4\\ 6 \end{array} \right\} 10$	<u>5</u> }5	3 8	2 1 3	8 7	5 <sup>8</sup> / <sub>3</sub> }11
Approximate per cent		Σц	43.7 70.0}53.8	8 43.7 30.0	38-4	$\frac{43.7}{30.0} \} 38.4 \ \frac{12.6}{-} \} 7.6$	$25.0 \\ 60.0 \\ 38$	$\begin{array}{c} 25 \cdot 0 \\ 60 \cdot 0 \\ \end{array} \Big\} 38 \cdot 4  \begin{array}{c} 31 \cdot 2 \\ - \\ \end{array} \Big\} 19 \cdot 2  \begin{array}{c} 31 \cdot 2 \\ 30 \cdot 0 \\ \end{array} \Big\} 30 \cdot 7  \begin{array}{c} 12 \cdot 6 \\ 10 \cdot 0 \\ \end{array} \Big\} 11 \cdot 5$	$\frac{31.2}{30.0}$ } 30.7	12.6 10.0 1	$1.5 \qquad \begin{array}{c} 50\\ 70\end{array} \right\} 57.6$	$7.6 \begin{array}{c} 50\\ 30 \end{array} \} 42.3$
									Cmoodb dofacts	ofacto		Total
(Diagnosis)	sis)		A van	Ad- vantage	Appearan Unre- markable	Appearance Unre- Dis- narkable advantage	ge	No defect	Intelligible but defective		Unintelligible	I Ulai
(Hemiplegia)	a) .		:	20	4-	4.		6.	-		1	0.4
(Diplegia)	:	:	:	110	-0	- 0 -		401	11-		7	t 4 4
(Dyskinesia)	(1	:	:	<b>0</b> I	<del>,</del>			n				t
(Other)		:	:	4 1 1		1 1 1		· ·			111	
TOTALS	:		:	2 5}7	37	$\frac{7}{3} \Big\} 10 \qquad \frac{7}{2} \Big\} 9$	6	11 8 8		3355	2 2 -	$16 \\ 10 \\ 26$
Approximate	lte		18.	7 26.9	37.5	18.7 26.9 37.5 38.4 43.75 34.6	.34.6	68-8) 73 80 7 73		18.7 19.2	12.5 7.6	00

30

	Number	Senior second- ary	Junior second- ary	Phy- sically handi- capped	Men- tally handi- capped	Junior Occu- pation centre	Home tuition	No educa- tion	Insti- tution	Total
Edinburgh	n 125	6	22	24	24	6	0	6	13	101
Dundee Small	49	6	14	16	42	6	2	2	12	100
Towns	26	15	54	0	8	0	4	4	15	100
All	200	7	24	19	26	5	1	5	13	100

TABLE XI Percentage of patients by town and type of school last attended

mentally handicapped in Dundee (over 40 per cent) than in Edinburgh (24 per cent). 2 of the Dundee patients were assessed to be of average intelligence, and a further 8 (almost 16 per cent) were thought to have intelligence quotients of 70-90, whereas in Edinburgh no patients of average intelligence had attended schools for the mentally handicapped, and only 8 (over 6 per cent) showed intelligence quotients of between 70 and 90. 10 mildly physically handicapped patients had attended schools for the physically handicapped.

It is thought that where possible physically handicapped patients should be encouraged to attend ordinary schools and mix with their non-handicapped contemporaries; and it would be interesting, if it were feasible, to select a number of patients with similar handicaps and intelligence, send half of them to a special school and half to an ordinary school, and discover which group fared better when they left school in terms of work and social adjustment.

#### CHAPTER 4

## Social Life and Personal Relationships

Information about social life and personal relationships was obtained where possible from patients. Patients were encouraged to talk freely about themselves, and questions were directed as unobtrusively as possible towards the aspects of their lives in which the social worker was interested. Many patients were reluctant to disclose their lack of social life. Information from the survey was supplemented where possible by teachers, social workers, therapists, doctors and psychologists who had come to know the patients.

Patients were grouped into seven categories according to the type of social life they led (Table XII).

- (1) Patients leading a normal social life for their age, sex and social class (over 21 per cent).
- (2) Patients leading a restricted social life (approximately 25 per cent).

Patients in these two categories were accepted by their contemporaries on equal terms. The main differences between the two groups were that patients in category 1 lived fairly active lives, independent of their parents, though in the great majority of cases still living at home, while those in category 2 led rather quieter lives and were more dependent on their families than normal for their age.

- (3) Patients who attended clubs for the disabled and whose friends were also disabled (over 11 per cent).
- (4) Patients who attended clubs for the disabled but whose social life was otherwise confined to their immediate family circle (7 per cent).
- (5) Patients whose social life was confined to their immediate family circle (about 20 per cent).
- (6) Patients who never left the house for social activities (over 4 per cent).
- (7) Patients in institutions for the mentally handicapped (12 per cent).

Cate- gory	Total num- ber of pat- ients	(1) Normal life	(2) Restricted	(3) Club and handi- capped friends	(4) Family circle and handi- capped club	(5) Family circle only	(6) Home- bound	(7) Institu- tion	Total
Edinburgh	(125)	22	26	14	6	16	6	10	100
Dundee	(49)	21	16	12	12	23	2	14	100
Small Towns	(26)	19	34	0	0	30	0	16	99
All	200	21	24.5	11.5	7	19.5	4.5	12	100

TABLE XII Percentage of patients by town and type of social life

Severity of Physical Handi- cap	Total num- ber	(1) Normal Circle	(2) Re- stricted	(3) Handi- capped club and handi- capped friends	(4) Family circle and handi- capped club	(5) Family circle only	(6) Home- bound	(7) Insti- tution	Totals
Mild	(107)	34	36	7	1	16	1	5	100
Moderate	(66)	9	16	19	16	30	1	9	100
Severe	(27)	0	0	11	8	11	26	44	100
Total	(200)	21	24.5	11.2	7	19.2	4.2	12	100

TABLE XIII Approximate percentage of patients in Edinburgh, Dundee and Small Towns by severity of physical handicap and type of social life.

Each category was then examined to find the major factors determining the type of social life led by the patients in the survey.

It will be seen from Table XIII that a high proportion (approximately 70 per cent) of mildly physically handicapped patients were in categories 1 and 2, in which they were accepted by their contemporaries on equal terms. Seven per cent were in category 3 in which they had handicapped friends and went to a handicapped club, and 23 per cent had more limited social contacts. Only 25 per cent of those with moderate physical handicaps and none of those with severe physical handicaps were in categories 1 and 2.

Approximately 44 per cent of the patients of average intelligence were in category 1, about 37 per cent in category 2 and 11 per cent in category 3 (Table XIV). Just over 6 per cent were in category 4. It seems that in those categories which comprise patients with any social life outside their family circle, the severity of physical handicap more than the degree of mental handicap determines the amount of social contact available to the patient. This is well illustrated by two patients one a boy who was in category 1 despite an I.Q. of less than 50, and the other a girl of average intelligence in category 3.

Case 204 was a mildly physically handicapped youth who was severely mentally handicapped and had been in an institution for a brief period. He came from a very poor home in one of the city's most notorious slums inhabited mainly by petty criminals. His father was a casual labourer and some of his brothers had been 'in

 TABLE XIV

 Patients by intelligence and social life in Edinburgh, Dundee and Small Towns (Approximate Percentage)

I.Q.	Total num- ber	Normal (1)	H Restricted (2)	andicapped club and handi- capped friends (3)	Family circle an handi- capped club (4)	d Family circle only (5)	Home- bound (6)	Institu- tion (7)	Total
90+	(53)	44	37	11	6	2	0	0	100
70–90	(54)	22	38	15	11	10	0	4	100
50-70	(47)	10	15	18	8	41	2	6	100
-50	(46)	4	2	2	2	30	17	42	99
Total	(200)	21	24.5	11.5	7	19.5	4.5	12	100

trouble' with the police. Despite his very low mentality, he was accepted by the other boys in the neighbourhood as one of the gang, and could thus be said to lead a normal social life for his particular environment.

*Case* 171 was a severely physically handicapped girl of 18 years of average intelligence. Her social life was restricted by her difficulty in getting about. She walked rather precariously with the aid of two sticks, and getting on and off buses was a slow, sometimes hazardous undertaking. This girl was very anxious to be accepted as a normal teenager and was interested in clothes, hair styles, and pop records. She could not dance, although she made spirited attempts to do so at her handicapped club, and felt very out of things when she went to a party given by non-handicapped teenagers.

In categories 5, 6 and 7, however, the degree of mental handicap appears to be the deciding factor which determines how severely limited social relationships will be. Over 40 per cent of the patients in category 5 were mildly physically handicapped, but one-third were severely mentally handicapped and in the combined categories 6 and 7 over two-thirds were severely mentally handicapped.

*Case* 139 was a typical example of a girl whose social life was restricted by her mental rather than by her physical handicap. She was 19 years old and attended a Senior Occupation Centre. The family lived in a council house and her father was a tradesman. She was mildly physically handicapped but severely mentally handicapped and could not read or write. She had no difficulty in getting on and off buses but needed someone to tell her which bus to take and where to get off. In fact she never went out alone except to the local shops where she was known. Possibly in a less sheltered environment she might have developed a little more self-confidence.

#### The Differences in Social Life Encountered in Edinburgh, Dundee and Small Towns

There were no special social facilities for handicapped people in the small towns. Dundee and Edinburgh had a number of social clubs for disabled people. Apart from sheltered workshops and training centres (see chapter I), which in themselves provided workers with social contacts, Edinburgh had an Adult Spastic Club which met one evening a week during the winter months. The Club was run by a committee elected by the members, and a social worker was present in an advisory capacity. Transport for more disabled members was provided by the local Parents Association.

Edinburgh Cripple Aid Society also ran social clubs for disabled adults and provided transport where necessary.

There was also a club run by voluntary workers for disabled people but which included unhandicapped young people among its membership. Edinburgh and District Parents Association ran a teenage club for young people suffering from cerebral palsy, some of whom were very severely handicapped.

Dundee had social clubs attached to its special school and occupation centre, and in addition evening classes were held for former pupils. Dundee Invalid and Cripple Children's Aid Society ran a club for disabled people which was attended by nonhandicapped young people. Dundee Parents Association was hoping to start a social club for patients suffering from cerebral palsy. Social clubs in Dundee had one great disadvantage over most clubs in Edinburgh in that regular transport was not provided for more disabled patients. The facilities offered had obvious effects on the social life of patients in the different towns (Table XII).

The seven categories were also examined by the social class of the patients' parents (Table XV). A rather higher proportion of patients in social class III led normal or somewhat restricted social lives than in social classes IV and V or I and II. The difference is not statistically significant. It is possible, however, that parents in social class III provide their children with a more secure background in the economic sense than those in social classes IV and V, and resist the temptation to overshelter them more often than some parents in social classes I and II, who tend to have smaller families. Comparing the differences in social class between patients in Edinburgh, Dundee and the small towns, only one Dundee patient, now in an institution, came from social class I and II as opposed to 14 per cent in Edinburgh and over 7 per cent in the small towns. On the other hand 50 per cent of patients in small towns came from social class III as opposed to 30 per cent in Edinburgh and approximately 36 per cent in Dundee.

	ΤA	BL	E XV	
Social	life	by	social	class

Secial	Nina	-		Ap	proximat	e Percent	age		
Social class	Num- ber of patients	Normal circle		Club and handi- capped friends	Family circle handi- capped club	Family circle only	Home- bound	Institu- tion	Total
I & II III IV & V All classes	(21) (69) (110) (200)	10 26 20 21	28 30 20 24.5	5 9 14 11-5	14 9 5 7	28 15 20 19·5	5 2 6 4.5	10 9 15 12	100 100 100 100

#### **Family Relationships**

There was a strong tendency for patients to be over-dependent on their parents. Category 1 was the only category in which this was not so at the time of the survey, though many had been very dependent on their mothers when they were younger, in some cases necessarily so because of their physical disabilities, as, for example, in case 191.

Case 191 was a normal child until he acquired a right hemiplegia following measles encephalitis at  $5\frac{1}{2}$  years. During the acute stage of his illness he became blind and paralysed, and lost the power of speech. His condition gradually improved, but on returning home he became very difficult and demanded constant attention from his mother. His speech was almost incomprehensible, and although he could feed himself with his left hand he could not dress himself. Naturally he was much more dependent on his mother than normal for a child of his age, but as he grew older and his condition gradually improved he grew more independent. He is now 16 years old and leads a normal social life. He found himself a job and he goes on holiday with friends of his own age.

Rather more than half the patients in categories 3 and 4 were considered overdependent on their mothers, in the sense that they expected to be looked after like children and were incapable of forming relationships with other people without their help. The over-dependence was still more marked in Category 5, especially among Edinburgh patients. No Edinburgh patients in this category were considered to be able to make a normal relationship with other people. In 6 cases the relationship with the mother was considered to be infantile and in 11 over-dependent. One patient (*case* 69), an epileptic, was aggressive and beyond control, and in Case 154 the mother had left home.

*Case* 3 was a good example of an Edinburgh patient in category 5 who, although 24 years old, was still treated by his mother like a small child. He was moderately physically handicapped and also mentally handicapped. Apart from two days a week at a centre for therapy he spent his time with his mother and her friends. His mother even told him which particular cake to eat at tea time. His complete lack of concentration made it unlikely that he could work even in a sheltered workshop, but he would have benefited from a wider social circle. He seemed happier when he was admitted to an institution for a period following a nervous breakdown.

The situation was rather different in Dundee and the small towns where lack of clubs restricted patients, some of whom might have been capable of a wider social life, to their immediate family circle. All patients in this category in Dundee and small towns were over-dependent on their parents and two were aggressive. It was thought that about half the patients in this category in these areas would have benefited from attendance at clubs, but the majority would have needed transport.

Case 114/D was a moderately physically handicapped girl of dull normal intelligence, aged 25, living in Dundee. She had a job in niche employment assembling samples, and was seen to and from her work by her father, for though she walked unaided she was a little unsteady on her feet. She never went out in the evening because it was considered unsafe. Her father had once or twice taken her to a club for handicapped people, but he was in poor health and found it rather burdensome. She was completely out of touch with all her old friends as she could never arrange to do anything with them.

Case 203/ST was a rather unprepossessing, moderately handicapped young man, aged 21, who lived in a small town. He was of average intelligence and had been to a senior secondary school. He was quite independent, in that he could travel about on his own, but despite this he had no real friends. He was becoming more and more introverted and felt that no-one wanted to be friends with him because he was handicapped. Had there been a club in the neighbourhood for handicapped people, where he would not have felt inferior to the other members, this might have helped him to lead a less lonely life.

We had a definite impression that patients were less often over-protected when there were other children in the home, and possibly the number of patients who were persistently over-protected and 'babied' would have been less had there been fewer only children. It is probably significant that in category 1 only four patients, three of them girls, were only children.

# School Life

Twenty-eight patients never went to school or had been there for only a short time. Forty-nine were thought to have led normal school lives, 77 were shyer than average and 46 were noticeably 'odd men out', being either aggressive or solitary. Five patients in category 7 had been aggressive and difficult at school. Four of these came from homes where somewhat uninhibited aggression was the usual pattern of behaviour.

#### **Relationships with the Opposite Sex**

One hundred and eighty-six of the 200 patients in the survey were of marriageable age, being between 16 and 25 years, but only 4, 1 male and 3 females, were married. Had the patients been normal, approximately 18.4 per cent of the males and 33.4 per cent of the females would be expected to have married by the time of the survey, according to figures given by the Registrar-General for Scotland, 1962. This extremely low marriage-rate is some indication of the way in which patients suffering from cerebral palsy were at a disadvantage when it came to attracting members of the opposite sex. A lower marriage-rate of youths suffering from handicaps other than cerebral palsy was also noted by Ferguson and Kerr (1960). The majority of handicapped people appeared very much aware that they were at a disadvantage in attracting the opposite sex. Even very mildly handicapped patients were often very shy and sensitive. They not only tended to look less attractive, but the majority of them had less well-paid jobs if they were employed, and their long-term prospects were not as good as their contemporaries'. All the patients in category 1, apart from 3 who had not left school, courted members of the opposite sex. Four were married although 1 was separated from her husband at the time of the survey. Nine considered themselves engaged officially or unofficially. Eight patients in category 2 had not left school. Twenty-two of the 41 others were thought to be too shy and aware of their disabilities to go out alone with members of the opposite sex.

Two patients in category 3 went out regularly with each other. The man had been engaged to 2 other handicapped girls and was emotionally very immature. The others were interested but too shy or lacking in initiative to take anyone out. Many of the patients in this category were discouraged from taking people out either because of their physical difficulty in getting on and off buses, or because of lack of mental ability to count change at the cinema, read the destination of buses and carry out similar activities normally taken for granted. Only 6 of them were in paid employment so that the majority of them had little money to spend on their entertainment, compared with their more affluent normal contemporaries, and spent most of their evenings at home watching television. Club night was for many their only regular night out in the week and it consequently played an important part in their lives, even although many of them appeared to take a very passive part in it.

All patients in category 4, with the exception of one very withdrawn male, were interested in members of the opposite sex, but were either too shy or lacked the

opportunity for making friends in the normal way. Patients in categories 5, 6 and 7 lacked opportunities for mixing with members of the opposite sex.

Two unmarried female patients were known to have had babies, and another was pregnant at the time of the survey. One of the girls whose physical handicap was mild, but who was mentally handicapped, became pregnant and subsequently married a partly disabled labourer of low intelligence and had three children by him within three years. One girl of low intelligence had been placed in an institution because she was considered to be in moral danger. Her family have now taken her home. Another deaf girl with little intelligible speech caused her family much embarrassment by accosting strange men in the street and waving to them from her window.

Two boys, one who had been admitted to an institution for mental defectives, and another on the waiting list for admission, were known to have homosexual tendencies. Both had extremely disturbed home backgrounds. One was the eldest of three illegitimate children. The mother of the second had died and his father had become an alcoholic, rejecting the boy. Both were very lightly handicapped so that cerebral palsy would not appear to be the major factor contributing to their sexual deviation. One boy had been temporarily placed in an institution following a breakdown caused by his girl friend leaving him.

*Case* 123 suffered from a mild left hemiplegia and was of dull normal intelligence. Her parents had separated when she (an only child) was a baby, and she lived with her mother who went out to work. The girl's mother was very indulgent, gave her a lot of pocket money and never expected her to do any household chores. Her schooling was rather disrupted as they moved about a good deal but she attended a Junior Secondary School until, following an attempted suicide, she was transferred to a school for physically handicapped children. Since leaving school she has never worked although she has been assessed as capable of light factory work. She was quite attractive but very untidy, and her main interest in life was boys. Her mother let her stay in bed all morning and never made her do the housework. After a series of rows with her mother she went into rooms, but her mother continued to give her money. She became friendly with a young married man and as a result of this association had a baby girl. Her mother has taken most of the responsibility for looking after the child and the girl has continued to live as she did before.

#### **Hobbies and Occupations**

A high proportion of patients watched television for hours each day, and no home visited in the course of the survey was without a set, often the largest and latest model. In many houses it was the focal point of the room. Playing records was another very popular way of passing the time, as it is with many non-handicapped teenagers. Many patients gave their record players rather rough treatment so that they were frequently out of commission.

Many of the men in categories 1 and 2 played some sort of sport, though possibly not as regularly or with as much skill as their contemporaries. Cycling was also popular; one mildly physically handicapped boy in category 1 had driven his motor scooter all over Europe on his summer holidays, and one young man in category 2 could drive his own car, having been taught to do so by his father who was a qualified driving instructor.

Only 5 male and 6 female patients mentioned dancing as a hobby. Others described how they had gone to dance halls, had been made to feel acutely different and social failures and had not returned.

Few patients read for pleasure. Many were too severely mentally handicapped and others found the turning of pages difficult and burdensome. The majority probably lacked the attention span necessary for rewarding reading. One girl played bingo three nights a week. One boy spent quite a lot of time drawing and painting. Another bred budgerigars.

Membership of the Church and associated clubs provided a number of patients with social outlets which they would otherwise not have had. One man was an ardent Mormon; a girl was a member of the Church of Pentecost; another was a keen member of the Salvation Army and went to every local meeting. Though mildly physically handicapped she was not prepossessing in appearance, was of poor intelligence, and it is doubtful whether she would have had as much social contact had it not been for her church activities.

# Money

The majority of patients who were working earned less than their contemporaries. As seen in Chapter V, most were in jobs which demanded little skill or physical strength and were, therefore, badly paid. Those in niche employment tended to be paid less than those in open employment. Although patients and employers were not asked specifically about wages, it was evident that the small sums they earned were a frequent cause of discontent. Two patients in niche employment were known to be receiving nominal payment for their services. Both were over 21 but were doing the work usually done by a very junior employee.

Patients in sheltered workshops earned wages agreed by the appropriate wages council—most were earning the national minimum. Patients in sheltered training were paid as trainees by the Ministry of Labour—their allowances were less than the wages of fully trained workers.

Patients who were unemployed received an allowance from the National Assistance Board, and if they attended a centre for daily therapy they received a small sum in addition to National Assistance which provided them with an incentive to attend regularly.

Even patients of low intelligence seemed to be able to manage their own money at the pocket money level. Most patients handed their wage packet to their mother, and were given pocket money in return, with which they paid bus fares and entertainment, and such things as cosmetics, sweets, records and some clothing. Some also saved for their holidays. Some of the boys spent a good deal of money on betting.

Apart from patients in residential training centres and institutions, very few patients lived away from home and had to manage their own finances. One male patient in open employment supported a wife and family. Only 4 patients, 2

male and 2 female, lived in lodgings. One man in open employment (Case 134) earned a reasonable wage and seemed to manage well financially; another (Case 89) worked in a sheltered workshop—he was mentally handicapped but preferred to live independently from his parents. One female (Case 114) had quarrelled with her mother and lived on National Assistance in squalid lodgings, while the other (Case 123), nominally living on National Assistance, was in fact largely supported by her mother. Other patients lived at home with parents or relatives. Although patients in open and some in niche employment might manage on their own, other patients would need some form of supervision of the sort provided in hostels.

#### Holidays

As far as holidays were concerned, patients could be divided into four groups: the largest group (34 per cent), containing patients with all degrees of handicap, went on holiday with parents or close relatives; another group (20 per cent), containing 3 with severe physical handicaps, went on holidays arranged for the disabled or with Youth Organisations; a third group, of whom all were mildly or moderately physically handicapped (over 23 per cent of all patients), went on holiday alone or with a friend; lastly, some patients (over 23 per cent) never went away for a holiday. The reason for this appeared mainly financial, although there were 6 patients who required so much care and attention that holidays were not feasible. Two patients had gone into hospital for a short period so that their parents could have a holiday, but some parents were reluctant to leave their children even for a brief period.

# CHAPTER 5

# Employment

The percentages of patients in Edinburgh, Dundee and the small towns by employment are shown in Figure 1.

At the time of the survey there were 43 patients in open employment, 32 in niche employment, 5 in sheltered employment and 14 in sheltered training. Eighty-eight were unemployed. Eighteen were still at school. The employment experiences of patients in Edinburgh, Dundee and in small towns will be described.

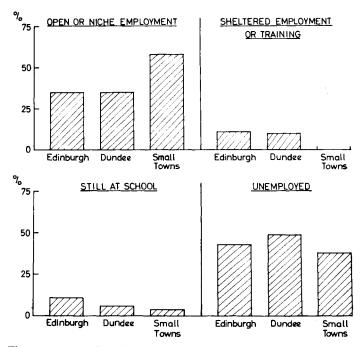


Fig. 1. The percentages of patients employed in Edinburgh, Dundee and Small Towns.

# Edinburgh

# **Patients in Open Employment**

There were 21 males and 5 females in this category. It will be seen from Table XVI that the majority were in unskilled jobs requiring no special qualifications.

Eight of the 21 males were in industry; 6 of these were unskilled factory workers or labourers, 1 was a skilled engineer having completed a normal five-year

#### TABLE Patients in open employment

Case No.	Age	Social class of parents	Occupation of patient	Diagnosis	Severity	I.Q.	Last School attended	Appearance
MALE 100	17	IV	Assistant warehouseman	Left hemiplegia	Mild	53	Mentally handicapped	Unremarkable
191	16	111	Builder's labourer	Acquired right	Mild	80	Junior Secondary	Unremarkable
199	16	v	Factory worker	hemiplegia Right hemiplegia	Mild	80	Mentally handicapped	<b>D</b> isadvantage
22	16	Ш	Temporary clerk (Clerical Grade of	Diplegia	Mild	70 to 90	Junior Secondary	Advantage
27	17	IV	Civil Service) Junior clerk (Commercial	Ataxic diplegia	Mild	90 +	Junior Secondary	Unremarkable
79	16	IV	office) Junior clerk	Left hemiplegia	Mild	<b>90</b> +	Junior Secondary	Advantage
113	16	111	Junior clerk	Right	Mild	<b>90</b> +	Junior	Advantage
163	15	ш	Apprentice	hemiplegia Right	Mild	70 to 90	Secondary Junior	Advantage
11	24	Ш	butcher Engineer	hemiplegia Acquired	Mild	90+	Secondary Junior	Advantage
11	24	111	Engineer	left	IVITIC	90+	Secondary	Auvantage
85	23	Ш	Section Manager, Poultry	hemiplegia Acquired left hemiplegia	Mild	<b>90</b> +	Senior Secondary	Advantage
47	18	IV	factory Jobbing joiner	Diplegia	Mild	96	Junior Secondary	Unremarkable
128	19	v	Factory worker	Diplegia	Mild	50 to 70	Mentally handicapped	Disadvantage
134	24	111	Factory worker	Left hemiplegia	Mild	70 to 90	Mentally handicapped	Advantage
39	24	111	Clerk in commercial	Right hemiplegia	Mild	<b>90</b> +-	Junior Secondary	Advantage
62	19	П	office Stockbroker's clerk	Diplegia	Mild	<b>90</b> ±	Junior Secondary	Advantage
71	22	IV	Shop	Left	Mild	<b>90</b> +	Junior	Unremarkable
200	24	v	assistant Shop	hemiplegia Diplegia	Moderate	70	Secondary Physically	Advantage
20	24	v	assistant Bus conductor	Acquired left	Mild	72	handicapped Mentally handicapped	Unremarkable
182	22	Ш	Relief porter	hemiplegia Ataxia	Mild	70 to 90	Physically handicapped	Advantage
151	20	v	Pantry man	Ataxic	Moderate	77	Mentally	Disadvantage
180	21	111	Merchant Navy	diplegia Right hemiplegia	Mild	<b>90</b> +	handicapped Senior Secondary	Advantage
EMAL 183	.Е 18	v	Comptometer operator	Diplegia	Mild	90+	Junior Secondary	Advantage
8	24	111	Clerk	Ataxic	Mild	<b>90</b> +	Junior	Unremarkable
193	18	11	Clerk	diplegia Diplegia	Mild	61	Secondary Mentally	Advantage
96	20	IV	Addresso- graph operator	Diplegia	Mild	90 +-	handicapped Junior Secondary	Unremarkable
19	20	v	Married woman and housewife	Left hemiplegia	Mild	63	Mentally handicapped	Disadvantage

Speech Defect	Epilepsy	How job obtained	Length of time in job	Patient's account of job	Parent's opinion of job	Number of previous jobs	Patient's attitude to disability	Parent's attitude to patient
			100	01 100	0) 100	<i>J003</i>	to assubility	to patient
MALE Marked	None	Youth Employment Officer	l year	Satisfactory	Satisfactory	0	Sensitive	Fluctuate
None	None	Youth Employment Officer	l year	Satisfactory	Satisfactory	1	Doesn't consider handicapped	Realistic
None	None	Advertise- ment	3 months	Satisfactory	Satisfactory	1	Doesn't consider	Un- realistic
None	None	Advertise- ment	l year	Very satis- factory if passes examination	Very satis- factory if passes examination	0	handicapped Doesn't consider handicapped	Denies handicar
Present	None	Advertise- ment	2 years	Satisfactory	No prospects	0	Doesn't consider	Denies handicar
None	None	Youth Employment	2 months	Satisfactory	Satisfactory	0	handicapped Doesn't consider	Realistic
None	None	Officer Advertise- ment	l year	Satisfactory	No prospects	0	handicapped Defeatist	Realistic
None	None	Advertise-	3 days	Satisfactory	Good	0	Realistic	Realistic
None	None	ment Direct application	4 years	Very satis- factory	prospects Very satis- factory	1	Doesn't consider	Realistic
None	None	Friend	4 years	Satisfactory	Satisfactory	2	handicapped Doesn't consider handicapped	Realistic
None	Present	Friend	3 years	Satisfactory	Satisfactory	0	Doesn't consider handicapped	Over- protectiv
None	None	Direct application	No in- formation	Satisfactory	Satisfactory	No in- formation	Doesn't	Denying
None	None	Youth Employment Officer	8 years	No prospects	Dead	0	Sensitive	Dead
None	None	Labour Exchange	2 years	Satisfactory	Satisfactory	2	Doesn't consider handicapped	Denying
Present	None	Youth Employment Officer	4 years	Satisfactory	No prospects	0	Doesn't consider handicapped	Denying
Present	None	Advertise-	5 years	No	Satisfactory	1	Sensitive	Over-pr
Present	None	ment Social worker	8 years	prospects Satisfactory	Don't care	0	Sensitive	tective Rejectin
None	None	Direct application	3 years	Satisfactory	Satisfactory	2	Doesn't consider	Denying
None	None	Direct application	2 years	No prospects	No prospects	3	handicapped Doesn't consider handicapped	Realisti
Present	Present	Father	2 years	Unsatis-	Unsatis-	0	handicapped Realistic	Over-
None	Present	Direct application	l year	factory Satisfactory	factory Satisfactory	2	Doesn't consider handicapped	ambition Denying
FEMALI						_	••	<b>.</b> .
None	None	Direct application	3 years	Very satis- factory	Very satis- factory	0	Doesn't consider handicapped	
None	None	Sister	7 years	Satisfactory	Satisfactory	2	Over- driving	Over- ambitio
None	Present	No infor- mation	No infor- mation	No infor- mation	Satisfactory	No infor- mation	Unrealistic	Over- protecti
None	None	Advertise- ment	11 years	Satisfactory	Satisfactory	2	Doesn't consider handicapped	Denying
							nandicannad	

# XVI at the time of the survey in Edinburgh

#### TABLE Patients in niche employment

Case No.	Age	Social class of parents	Occupa- tion of patient	Diagnosis	Severity	I.Q.	Last school attended	Appear- ance	Speech Defect	Epilepsy
MAL 7	E 16	II	Jobbing Gardener	Right hemiplegia	Mild	56	Mentally handicapped	Unremark- able	None	None
124	21	v	Handy man	Diplegia	Moderate	69	Mentally handicapped	Advan- tage	None	None
67	24	Ш	Labourer	Left	Moderate	74	Physically	Unremark-	Present	Present
65	18	П	Clerk	hemiplegia Dyskinesia	Moderate	90	handicapped Physically	able Advan-	Present	None
167	21	III	Printing machine	Right hemiplegia	Mild	90+	handicapped Junior Secondary	tage Unremark- able	Present	None
21	22	١v	operator Jobbing	Dyskinesia	Moderate	70 to 90	Physically	Unremark-	Marked	None
132	18	v	gardener Jobbing gardener	Acquired left hemiplegia	Mild	70 to 90	handicapped Junior Secondary	able Unremark- able	None	None
FEM 108	ALE 17	Ш	Clerk	Right	Mild	87	Junior	Advantage	None	None
100	17	111	CICIK	hemiplegia	WING	07	Secondary	Auvaniage	None	Hone
106	16	111	Addresso - graph operator	Dyskinesia	Moderate	92	Junior Secondary	Unre- markable	Present	None
165	17	IV	Emboss- ing machine	Right hemiplegia	Moderate	90+	Physically handicapped	Advantage	None	Present
57	23	V	operator Factory worker	Diplegia	Mild	63	Mentally handicapped	Dis- advantage	None	None
66	18	111	Factory worker	Diplegia	Mild	73	Mentally handicapped	Advantage	None	None
102	21	v	Factory	Other	Moderate	57	Physically	Dis-	Present	None
103	23	v	worker Factory worker	Diplegia	Mild	50	handicapped Mentally handicapped	advantage Unre- markable	Present	None
206	23	11	Recep- tionist	Right hemiplegia	Mild	75	Physically handicapped	Advantage	None	Present
170	19	IV	Shop assistant	Right hemiplegia	Mild	70 to 90	Junior Secondary	Advantage	None	Present
30	23	111	Altera- tion hand	Ataxia	Mild	78	Physically handicapped	Advantage	Present	None

apprenticeship and 1 was the section manager of a small poultry factory. Two of the patients had started off as apprentice tradesmen (Cases 191 and 47) but had not reached the required standards, especially on the theoretical side. One boy (Case 47) was an 18-year-old of average intelligence suffering from mild diplegia. He went to a Junior Secondary School where he was able to keep up with his class with some special coaching. He was badly behaved in class and very inattentive. His father was an invalid and his mother was unable to discipline him. On leaving school he became an apprentice joiner, but he became discouraged when he failed examinations at night

#### XVII at the time of the survey in Edinburgh

How job obtained	Length of time in job	Patient's account of job	Parent's opinion of job	Number of pre- vious jobs	Patient's attitude to disability	Parent's attitude to patient	Remarks
MALE Youth Employment Officer	6 months	Satisfactory	Temporary	0	Doesn't consider handicapped	Over- ambitious	Part-time. Simple job for handicapped youth
Social worker	6 months	Satisfactory	Satisfactory	2	Over- driving	Over- ambitious	Poor manipula- tion: more than normal
Father	5 years	No prospects	Satisfactory	5	Unrealistic	Realistic	supervision Father foreman; slow and clumsy
Social worker	2 years	Satisfactory	Unrealistic	0	Realistic	Un- realistic	Writing slow, job made for him
Disablement Resettlement Officer		Satisfactory	Satisfactory	2	Realistic	Over- protective	Job for disabled
Father	4 years	Satisfactory	Satisfactory	0	Sensitive	Over-	Passenger
Social worker	6 months	Satisfactory	Not interested	1	Defeatist	protective Rejecting	Work carefully selected
FEMALE Youth Employment Officer	6 months	Satisfactory	Satisfactory	1	Sensitive	Over- ambitious	Slower than average. Careful not to worry
Social worker	3 months	Satisfactory	Satisfactory	0	Doesn't consider handicapped	Realistic	Poor writing. Can't lift stationery.
Social worker	3 months	Satisfactory	Satisfactory	0	Sensitive	Over- protective	Easily upset Occasional fits
Youth Employment Officer	7 years	Satisfactory	Not interested	0	Doesn't consider handicapped	Rejecting	Can't count
Youth Employment Officer	2 years	Satisfactory	Satisfactory	0	Sensitive	Realistic	Special job
Friend	5 years	Satisfactory	Satisfactory	1	Sensitive	Realistic	Sitting job
Disablement Resettlement Officer		Satisfactory	Satisfactory	3	Doesn't consider handicapped	Over- protective	Illiterate
Social worker	3 years	Very satis- factory	Satisfactory	4	Doesn't consider handicapped	Realistic	Takes fits; special job made for her
Youth Employment Officer	2 years	Low pay	Satisfactory	4	Sensitive	Bitter	Can't work in all departments
Aunt	1½ years	Low pay	Low pay	2	Unrealistic	Over- protective	Can't use scissors

school and gave up his apprenticeship. He is now a jobbing joiner with the same firm.

Six of the 21 males and 4 of the 5 females worked in offices. All but one had been to Junior Secondary Schools and were of average to dull normal intelligence. One office worker (Case 193) had an I.Q. of 61 and had been to a school for the mentally handicapped; unfortunately her mother refused to give details of her daughter's employment, except that she worked in an office. All the 4 office workers under the age of 18 were attending evening classes in English and book-keeping and 2 were sitting examinations for the clerical grade of the Civil Service. The chances

Case No.	Age	Social class of parents	Occupation of patient	Diagnosis	Severity	<i>I.Q</i> .	Last school attended	Speech Defect	Epilepsy
MALE			Et	Distanta	14:14	54	Man (a 11a)	NT	N
76	24	I	Factory worker	Diplegia	Mild	54	Mentally handi- capped	None	None
89	24	v	Factory	Right	Moderate	50 to 70	Institution	Present	None
			worker	hemiplegia					
158	18	v	Laundry worker	Diplegia	Mild	57	Mentally handi- capped	None	None
FEMA									
58	18	III	Laundry worker	Right hemiplegia	Moderate	53	Mentally handi- capped	Present	Present

of success were remote for one boy (Case 113), who was just able to hold down a junior office job but was likely to find promotion hard to attain. The comptometer operator (Case 183) had not had any training for her work and therefore could not be considered skilled. Six of the male patients worked in shops or in the public service, 2 as shop assistants (Cases 71 and 200), 1 as a pantry boy (Case 151) clearing away dirty glasses in a buffet, 1 as a relief porter (Case 182) and 1 as a bus conductor (Case 20). One school leaver had just started work as an apprentice butcher, and it was too early to assess his progress in a job which would require some skill and physical stamina (Case 163). One patient whose handicap was not obvious at the time of the survey was a deck-hand in the Merchant Navy, and had presumably passed the necessary Medical Board (Case 180). One woman was married to an epileptic husband who was unemployed at the time of the survey (Case 19). She had three small children and was expecting her fourth, but her domestic standards were low.

#### **Patients in Niche Employment**

Seven males and 10 females were considered to be in niche jobs (Table XVII), posts in which special allowances were made for their various handicaps, and in which they were not expected to compete on equal terms with their non-handicapped workmates. More allowances were made for some patients than others, and no-one was in a job which needed any special skill or training. Two male patients were

#### XVIII workshops for the disabled in Edinburgh

Appear- ance	How job obtained	Length of time in job	Patient's account of job	Parent's opinion of job	No. of previous jobs	Patient's attitude to disability	Parent's attitude to patient	Supervisor's repor on patient's work
MALES Un remark- able	Disable- ment Resettle- ment Officer	Four years	Satis- factory	Satis- factory	2	Sensitive	Realistic	Very efficient Doesn't nee supervision. N physical difficut ties. Slightly men tally retarded
Dis- advant- age	Dis- ablement Resettle- ment Officer	Six years	Unsatis- factory	Don't care	0	Unreal- istic	Reject- ing	Needs supervision Lacks concentra- tion. Slowed dow by mental and phy- sical handicaps
Un- remark- able	Social worker	Eighteen months	Very satis- factory	Satis- factory	0	Defeatist	Realistic	Very willing b needs great deal supervision. Ver forgetful. Diff culty with balance
FEMALE Un- remark- able	S Youth Employ- ment Officer	Eighteen months	Satis- factory	Satis- factory	1	Sensitive	Over- protec- tive	Very slow and in clined to be lazy Once shown ca carry job throug without super vision

employed as labourers in industry; both were part of their firm's quota of disabled employees. One youth (Case 67), employed because his father was a foreman in the same firm, was unable to push heavy barrows which other labourers had to do as part of their work; he was also off sick more often than would be tolerated in the normal employee. The other (Case 124) was constantly having to be shown ways of overcoming his difficulties in manipulating objects. Four of the 10 female patients were doing unskilled work in industry. Two were employed in a cardboard-box factory doing simple repetitive work. Neither of these girls could read or count, and therefore needed more careful supervision than other employees. One female was employed in a clothing factory picking basting threads off finished articles (Case 66), and one in a confectionery factory as a packer (Case 102). Most of the packers in the factory were young girls who had just left school and who soon graduated to other tasks; this patient remained a packer although she was now 21 years of age—an example of the poor prospects of many of the jobs held by patients suffering from cerebral palsy.

Six patients, 2 males (Cases 65 and 167) and 4 females (Cases 106, 108, 165 and 206), were employed in offices. They were relatively more intelligent than the majority of patients in niche employment, 4 being of average and 2 of dull normal intelligence. Three of the female office workers were under the age of 18 and two of them were in their first jobs, which had been found for them by social workers of the Scottish Council for the Care of Spastics after a period of assessment and

Case Age Social Di No. parents of Di AALES V D 53 23 V D 143 22 IV R 145 16 11 D 150 17 V A di	Diagnosis	Severity	I.Q.	Last school	Purpose of training	Supervisor's report on	Patient's	Parent's
parents           20         V           23         V           23         V           1         V           11         V           17         V						Drogress	attitude to	attitude to
20 V 20 V 10 10 10 10 10 10 10 10 10 10 10 10 10				attended	)		disability	patient
> 2 1 >	Diplegia	Moderate	80	Physically	Sheltered work	Is very slow and requires	Unrealistic	Unrealistic
2 1 >	Diplegia	Severe	70	capped Physically handi- capped	Sheltered work	Lacks concentration. Lacks concentration. Very variable—at times adopts a "couldn't care less" attitude. Very slow. Loss heart if work piles up and mixes orders.	Unrealistic	Rejecting
н >	Right hemiplegia	Moderate	+06	Physically handi- capped	Sheltered work	<b>U</b> NO	Sensitive	Over- protective
>	Dyskinesia	Moderate	+06	Physically handi- capped	Sheltered work	supervision. Very immature. Resents criticism—lacks con- centration and needs con-	Defeatist	Over- protective
	Ataxic diplegia	Moderate	06	Physically handi- capped	Sheltered work	Natur supervision. Needs constant supervi- sion. Very distractable. Doesn't finish things off	Unrealistic	Don't care
>	Diplegia	Mild	53	Mentally handi- capped	Sheltered work	property. Lacks concentration. Needs continual supervi- sion.	Defeatist	Realistic
33 17 III A	Ataxia	Moderate	67	Physically handi- capped	Sheltered work	Maturing a little. Was very childish and un- happy at school. Not ready for sheltered work yet as still reluctant to be classed as a handicapped	Unrealistic	Over- protective
0 III 91 E1	Dyskinesia	Moderate	70 to 90	Physically handi- capped	Sheltered work in laundry, eventually openemploy-	Very good worker.	Realistic	Over- protective
0 III 81	Diplegia	Severe	+06	Physically handi- capped	Sheltered work Sheltered work as book-keep- er if transport arranged	Certain amount of intelli- gence but gets very muddled. Shortsighted in vision and in seeing what to do. Poor at	Sensitive	Dead
18 V D	Diplegia	Moderate	70 to 90	Physically handi- capped	Niche employment	organistic action of constraints and work. Personality problem in addition to clumsy hands and poor balance. "Very bossy" with handicapped people. Gets on better with non-handicapped	Over- driving	Unrealistic

training. One had occasional epileptic fits which might have led to her dismissal by the average employer, and the other had very bad handwriting and hesitant speech. The female over 18 worked as a receptionist in a large firm. The work was not enough to occupy a normal employee full time but was very suitable for this girl who could not have coped with a busy job, but who was attractive, well-groomed and had a pleasant manner with people.

Three male patients were employed out-of-doors in simple work, as jobbing gardeners with the Parks Department of Edinburgh Corporation (Cases 7, 21 and 132). All three were slow and needed continual supervision. Two were fairly adequate but one was so handicapped that he was able to do very little more than pick up bits of rubbish.

Two young women worked in shops; one was employed in a large chain store where it was usual for the assistants to work on all the different counters in turn. She was not able to work on the counters dealing with heavier types of goods as she could not lift things with two hands. The other young woman worked as an alteration hand; although she could not use scissors she was good at running little errands for the other alteration hands, such as matching buttons.

# Patients in Sheltered Workshops

Four patients, 3 male and 1 female (Table XVIII), were employed in sheltered workshops for the disabled (recognised as such by the Ministry of Labour). Three patients (Cases 89, 158 and 58) required a great deal more supervision than that given under normal working conditions. All three worked at such a very slow pace that they would not have held down a job in open or niche employment. The female worker had been employed in a commercial laundry but had been dismissed as unsuitable after two weeks. The other male patient (Case 76) was reported to need no supervision and to be a good worker in sheltered conditions but had previously failed to hold two niche jobs. His parents hoped that a period in steady sheltered employment would be of benefit and were fortunate in being able to make suitable arrangements for him.

#### **Patients in Sheltered Training**

Ten patients, 6 males and 4 females, were in sheltered training (Table XIX). It was hoped that one (Case 173) might eventually find niche or even open employment. Despite involuntary movement she was a good ironer but lacked the selfconfidence to work in a less sheltered atmosphere. One other female (Case 98) would have been more suited to sheltered work in that her hands and feet were very clumsy, but she did not get on well with other handicapped people as she tended to be rather aggressive and managing. It was felt that a job in niche employment would be more suitable for her if one could be found. The aim with the other eight patients was to fit them for sheltered work. Three of the male patients were at a residential training centre run by the Red Cross in the West of Scotland, and the remainder attended the centre of the Scottish Council for the Care of Spastics in Edinburgh. One patient (Case 171) was brought to work by car because of her difficulty in walking even with

# TABLE Analysis of Edinburgh patients not in institutions, at present

Case No.	Age	Social Class	Diagnosis	Severity (	<i>I.Q</i> .	Last School attended	Type of job
MALI 73	ES 21	v	Diplegia	Mild	<b>50</b> +	Mentally	Factory worker
72	20	v	Ataxia	Mild	71	handicapped	
12	20	v	Ataxia	Milu	71	Mentally handicapped	1. Van boy
							2. Labourer
							3. Labourer
							4. Factory worker
							5. Relief porter
8	18	I	Left hemiplegia	Mild	75	Mentally	6. Van boy Photostat operator
9 <b>9</b>	17	IV	Diplegia	Moderate	81	handicapped Physically handicapped	Assistant watch and clockmaker
157	18	v	Diplegia	Mild	70 to 90	Junior	1. Lift attendant
						Secondary	1. Boot repairer
							3. Message boy
							4. Shop assistant
							n bhop ussistant
							5. Warehouseman
187	16	111	Right hemiplegia	Mild	90+	Junior	6. Telephonist Jeweller's assistant
	ALES		Kight hemplegia	INITIO	<b>70</b> +	Secondary	Jewener 5 assistant
5	24	IV	Left hemiplegia	Mild	<b>90</b> +	Junior	Factory worker
15	18	v	Left hemiplegia	Mild	59	Secondary Mentally	Factory worker
101	19	v	Ataxic diplegia	Mild	84	handicapped Physically	1. Factory worker
						handicapped	2. Laundry worker
							3. Domestic cleaner
114	23	v	Diplegia	Moderate	75	Junior Secondary	1. Factory worker
						Secondary	2. Dish washer
							3. Bus conductress
							4. Waitress
162	20	v	Right hemiplegia	Mild	79	Junior Secondary	1. Laundry worker
							<ol> <li>Shop assistant</li> <li>Factory worker</li> </ol>
195	21	v	Left hemiplegia	Mild	70 to 90	Junior	1. Factory worker
			F <b>3.</b> •		•	Secondary	2. Factory worker
							<ol> <li>Factory worker</li> </ol>
							<ol> <li>Waitress</li> <li>Factory worker</li> </ol>
166	24	ш	Ataxic diplegia	Mild	70 to 90	Physically	6. Factory worker 1. Factory worker
100				111111		handicapped	
166	24	111	Ataxic diplegia	Mild	70 to 90		

# XXa

## unemployed, who have been employed previously

How job obtained	Length of time in job	Reasons for dismissal	Patient's attitude to disability	Parent's attitude to patient	Chief barrier to re-employment
MALES Youth Employ-	1 month	Too slow	Doesn't consider	Over-protective	Mental handicap
ment Officer Direct application	3 months	Too slow	handicapped Doesn't consider handicapped	Rejecting	Unpredictable behaviour
Youth Employ- ment Officer	l month	Inefficient; unsuitable for working with			_
Direct application Direct application		machinery Inefficiency Did not like night shift			_
Direct application Direct application Father		Temporary employme Slow and inefficient Pilfering	Defeatist	Over-protective	Emotional
Father	6 months	Redundancy	Sensitive	Bitter and over protective	Lack of co- operation with Employment
Youth Employ- ment Officer	6 months	Unpunctuality	Unrealistic	Unrealistic	Agencies Low intelligence
Advertisement	2 weeks	Not up to standard	_	—	_
Youth Employ-	6 months	No prospects	—	—	—
ment Officer Advertisement	2 weeks	Left of own accord. Work		—	—
Advertisement	6 months	too heavy Left of own accord. Wages too low	—	—	—
Advertisement Advertisement	2 weeks 6 months	Too slow Redundant	Sensitive	Realistic	Immaturity
FEMALES Youth Employ- ment Officer	1 week	Adverse working conditions	Realistic	Dead	Epilepsy
Youth Employ- ment Officer	5 weeks	Too slow	Defeatist	Realistic	Mental handicap
Youth Employ- ment Officer	3 weeks	Too slow	Defeatist	Unrealistic	Inertia and low intelligence
Youth Employ- ment Officer	6 weeks	Adverse working conditions	—		
Mother Youth Employ- ment Officer	3 months 3 months	Temporary employme Moved to another town	nt — Unrealistic	Rejecting	Pregnancy
Direct application	1 <sup>1</sup> / <sub>2</sub> years	Left of own accord to get better wages	—	—	
Direct application	6 months	Moved back to Edinburgh	_	—	—
Direct application Direct application	6 months 6 months	Shop closed down Adverse working conditions	Doesn't consider handicapped	Over-indulgent	Not interested in work
Advertisement Social worker	1 month 1 year	Redundant Dismissed for		_	
Advertisement	3 weeks	frequent absence Working conditions		Denies handicap	
Advertisement	4 months	too heavy Adverse working conditions	handicapped —		needed at home
Advertisement	5 months	Adverse working conditions	—		
Advertisement	l year	Wages too low	—		-
Advertisement Advertisement	1 year 14 months	Illness Illness in family	_		
Youth Employ- ment Officer	2 weeks	Fits and too slow	Realistic	Unrealistic	Epilepsy
Youth Employ- ment Officer	2 weeks	Fits and too slow	_	_	—

#### TABLE Patients unemployed who had never

Case No.	Age	Social Class	Diagnosis	Severity	<i>I.Q</i> .
MALES					
3	23	11	Diplegia	Moderate	50 to 70
17	19	IV	Right hemiplegia	Moderate	-50
26	15	IV	Diplegia	Severe	-50
205	16	III	Diplegia	Mild	67
105	20	v	Bilateral hemiplegia	Severe	-50
115	18	V	Ataxia	Moderate	70 to 90
119	16	v	Left hemiplegia	Mild	-50
126	20	Í	Diplegia	Severe	-50
155	16	ĪV	Diplegia	Severe	40
197	19	ÎV	Dyskinesia	Mild	63
204	20	v	Left hemiplegia	Mild	45
FEMALES					
10	16	IV	Diplegia	Moderate	-50
28	21	V	Ataxia	Moderate	53
38	24	IV	Diplegia	Severe	-50
40	23	IV	Diplegia	Mild	66
60	18	111	Diplegia	Moderate	-50
97	21	ĪV	Left hemiplegia	Mild	-50
136	19	I	Dyskinesia	Severe	90+
117	24	III	Right hemiplegia	Mild	-50
116	16	III	Ataxic diplegia	Moderate	90+
123	20	ш	Right hemiplegia	Mild	79
125	22	v	Dyskinesia	Mild	54
130	18	III	Left hemiplegia	Severe	72
139	19	Ш	Diplegia	Mild	-50
160	22	Ŷ	Right hemiplegia	Mild	-50
176	15	ш	Left hemiplegia	Mild	78
202	15	IV	Dyskinesia	Severe	-50
107	16	III	Diplegia	Severe	70

the support of sticks, but the other patients used public transport.

The main reasons for these patients being unsuited to open or niche employment were that they were slow, lacked concentration and needed constant supervision. Four of them were considered to be of average intelligence and only two had an intelligence quotient of less than 70. The physical defect was considered to be mild in degree in one (Case 159), moderately severe in seven and severe in two patients.

# Patients Unemployed at the Time of the Survey

Patients who were unemployed at the time of the survey could be divided into three main categories.

Firstly, those who had at one time been employed, even for brief periods. Secondly, those who had never been employed but lived at home, and thirdly those who were

#### XXb worked but were not in an institution

Last school attended	Prediction	Chief reason for unemployment
MALES		
Private tuition	Occupational therapy	Low intelligence and complete lack of concentration
Junior Occupation Centre (excluded)	Institution	Severe mental and physical handicap
Ineducable	Institution	Severe mental and physical handicap
Mentally handicapped	Possibly sheltered work	Mental handicap and epilepsy
Ineducable	Institution	Severe mental and physical handicap
Physically handicapped	Sheltered work	Low intelligence and extreme with- drawal
Mentally handicapped	Occupational therapy	Severe mental handicap
Ineducable	Institution Institution	Severe mental and physical handicap
Ineducable Mentally handicapped	Sheltered work	Severe mental and physical handicap Mental handicap and over-protection at
Mentally handicapped	Sheltered work	home
Institution	Institution or H.M. prison	Mental handicap and uncontrolled be- haviour
FEMALES		
Ineducable	Institution	Severe mental handicap and severe epilepsy
Home tuition	Possibly sheltered work	Mental handicap and over-protection at home
Ineducable	Institution	Severe mental and physical handicap
Mentally handicapped	Possibly sheltered work	Mental handicap and severe epilepsy
Home tuition	Occupational therapy	Severe mental handicap
Ineducable	Institution	Severe mental handicap and over- protection
Physically handicapped	Occupational therapy	Severe physical handicap
Junior Occupation Centre	Occupational therapy	Severe mental handicap
Physically handicapped	Possibly open employment	Lack of co-operation with employment
	after training	agencies and unrealistic approach
Physically handicapped	Open employment	Over-protection at home—no interest in working
Mentally handicapped	Possibly sheltered work	Mental handicap and epilepsy
Home tuition	Occupational therapy	Severe physical handicap
Junior Occupation Centre	Occupational therapy	Severe mental handicap
Junior Occupation Centre	Possibly sheltered work	Severe mental handicap and epilepsy
Junior Secondary	Open employment after	Low intelligence and lack of self-
Lunian Occurrentian Contra	period of training	confidence
Junior Occupation Centre Physically handicapped	Institution Occupational therapy	Severe mental and physical handicap Severe physical handicap

living in institutions for the mentally handicapped because of severe mental defect, behaviour aberrations or adverse environmental factors.

The employment experiences of those who had worked at some time are summarized in Table XX a. It will be seen that 13 patients, 6 male and 7 female, had been employed for periods ranging from one week to 18 months, but were out of work at the time of the survey. Eleven of the 13 patients were considered to be only mildly physically handicapped and only 2 had I.Q.'s of less than 70. None of the patients had been employed in work requiring skill or special training.

All were capable of doing some form of work, either in niche or sheltered employment and in one case possibly open employment. Two male patients were said to have been apprentice jewellers or clocksmiths, but as both were dismissed after six months as redundant their success seems to have been very limited. Two male patients

	Case No.	Age	Sex	Diagnosis	Severity	<i>I.Q</i> .	Education	Remarks
	29	18	M.	Right hemi- plegia	Mild	-30	Junior Occupation Centre	Very severe mental retardation
	42	22	М.	Diplegia	Severe	-50	None	Needs complete nursing care
	41	16	М.	Diplegia	Severe	-50	None	Very severe mental and physical handi- cap
	48	18	М.	Right hemi- plegia	Severe	-50	Junior Occupation Centre	Very severe mental and physical handi- cap
	94	15	М.	Left hemi- plegia	Mild	80	Mentally handi- capped	Psychopathic be- haviour. Epileptic.
	110	18	М.	Right hemi- plegia	Mild	36	Junior Occupation Centre	Epileptic. Mental retardation with general depression and apathy
	122	20	М.	Diplegia	Mild	33	Junior Occupation Centre	Violent behaviour
	135	22	М.	Ataxic di- plegia	Mild	64	Mentally handi- capped	Unpredictable be- haviour. Parents both dead
	153	16	M.	Diplegia	Moderate	-50	Junior Occupation Centre	Epileptic. Severe mental retarda- tion. Parents di- vorced
	161	19	М.	Diplegia	Severe	-50	None	Needs complete nursing care. Con- dition deteriorating.
	168	20	М.	Right hemi- plegia	Severe	-50	Junior Occupation Centre	Violent behaviour
	174	18	М.	Diplegia	Severe	50 to 70	Junior Occupation Centre	Severely physically h a n d i c a p p e d . Simple-minded
_	49	17	F.	Ataxia	Moderate	-50	None	Severe mentally defective. Over- active and restless. Suffers from grand mal epilepsy

 TABLE XXc

 Patients in institutions for the mentally defective

had held six jobs. One (Case 72) was the third illegitimate child of a mother who had since married and 'settled down'. The patient lived with his grandparents in old tenement property and felt rejected by his mother. He was on a waiting list for institutional care on account of unpredictable behaviour, poor intelligence and a bad home environment. The other (Case 157) had unrealistically high opinions of his own capabilities. He was a mildly physically handicapped youth of dull normal intelligence who had been at a Junior Secondary School. He made a good impression at interviews and had little difficulty in obtaining employment, but his problem was to keep it. Three of his jobs only lasted two weeks, but as he remained longest as a lift attendant he was being encouraged to look for work of this type in niche employment. The 4 other males had had only one job. One (Case 73) had worked for a month in a brewery when he first left school, but had not been able to keep up with the other bottlers and had been dismissed. He appeared quite content to stay at home exercising the dog and doing a small unpaid paper round in the afternoons. He could, however, be

employed in a sheltered workshop after some initial training in work habits. The two other male patients (Case 88 and 99) would be suitable for sheltered work; one has not co-operated with employment agencies and the other's family have moved to another area where there are at present few facilities for handicapped people.

Five of the 7 female patients had been employed in more than one job. All of them had worked in factories at one time, and one (Case 114) said she had also been a bus conductress in spite of being moderately physically handicapped. Four had attended Junior Secondary Schools (Cases 5, 114, 162 and 195), and it will be seen from Table XXXII that 3 of them had disturbed home backgrounds and psychological problems, and that the other was a mild epileptic whose general health was poor. Her father had died recently and she was staying at home while her mother went out to work. She was attractive in appearance and seemed to have no difficulty in obtaining work in open employment. Case 5 was an epileptic and sheltered work would be the most suitable type of employment for her. She attended a work therapy centre for adults with mixed handicaps four afternoons a week and looked after the house in the mornings for her step-father. She led an isolated life and felt frustrated by her double handicap. The prospects of open employment for Case 162 would have been good if she had been sufficiently interested in working. The moderately physically handicapped girl (Case 114) was expecting a baby and was consorting with a low type of casual labourer. She might in future obtain niche employment provided she was prepared to co-operate with employment agencies and improve her appearance. The three females who had been to special schools (Cases 15, 101 and 166) would be suitable for work in a sheltered workshop after a period of training. One (Case 166) had the additional handicap of epilepsy.

Twenty-eight patients, 11 males and 17 females, who were not in institutions had never worked (Table XX b). Eighteen of them, 8 males and 10 females, were thought to be incapable of work even in sheltered conditions, because of very severe mental or physical handicap or both, though 8 were thought likely to benefit from treatment in occupation centres. Three of the 8 considered suitable for occupation centres were confined to their wheel chairs (Cases 107, 136 and 130) and would have required transport to and from work, and the other 5, 2 males and 3 females, lacked powers of concentration to such an extent that employment even under sheltered conditions was impracticable. Seven patients, 3 males and 4 females, could probably be employed in sheltered training; 4 suffered from epilepsy in addition to their other handicaps. At the time of the survey 3 of these patients were attending a centre four days a week for work therapy (Cases 115, 205 and 28). One (Case 160) was at a senior occupation centre, 2 were at home all day and were said to be helping with the housework (Cases 40 and 125), and 1 (Case 197) attended work therapy sessions spasmodically-he was very overprotected at home and was not encouraged to find an occupation.

It was thought that 3 female patients might find niche employment after some initial training and assessment. Two were very reluctant to undertake any training (Cases 116 and 123), especially as part of it included housework. The other (Case 176) had recently left a Junior Secondary School where she had been in a modified

TABLE Open Employment—

								Open Emplo
Case No.	Age	Social Class of parents	Occupation of patient	Diagnosis	Severity	I.Q.	Last school attended	Appearance
MALES 69/D	17	III	Apprentice chef	Left hemiplegia	Mild	Average	Junior Secondary	Unremarkable
88/D	22	IV	Labourer in jute mill	Right hemiplegia	Mild	Average	Juniot Secondary	Unremarkable
49/D	24	v	Labourer	Right hemiplegia	Mild	Dull Normal	Junior Secondary	Advantage
50/D	21		Labouter in jute mill	Athetoid	Mild	Average	Mentally handi- capped	Disadvantage
35/D	24	V	Storeman	Right hemiplegia	Mild	Average	Physically handi- capped	Unremarkable
FEMALI 113/D	ES 22	V	Finisher in jute mill	Hemiplegia	Mild	Dull Normal	Mentally handi- capped	Advantage
89/D	16	IV	Machinist	Hemiplegia	Mild	Average	Junior Secondary	Advantage
109/D	22	IV	Weaver in jute mill	Hemiplegia	Mild	Average	Junior Secondary	Unremarkable
20/D	20	V	Clerk	Right hemiplegia	Mild	Average	Junior Secondary	Advantage
32/D	21	V	Factory worker	Diplegia	Mild	Mental handicap Grade I	Mentally handi- capped	Unremarkable

class. She had had several unsuccessful interviews for work and it was thought that she would be prepared to undergo a training course.

Thirteen patients, 12 males and 1 female, were in institutions for the mentally defective at the time of the survey (Table XX c). All were mentally handicapped, the majority severely so, except one boy of dull normal intelligence who was an epileptic, could be violent and was a danger to the public. Only one patient had previously been in employment, a 22-year-old male who suffered from mild ataxic diplegia. He had been employed for a short period as a milkboy but had been dismissed when he had been found sleeping in one of the firm's vans. He was classified as a high-grade mental defective but his behaviour was impulsive and unpredictable (Case 135).

#### XXI Dundee Survey

Speech Defect	Epilepsy	How job obtained	Length of time in job	Patient's account of job	Parent's opinion of job	No. of pre- vious jobs	Patient's attitude to dis- disability	Parent's attitude to patient
MALES None	None	Direct application	l year	Very satis- factory	Very satis- factory	2	Doesn't con- sider handi- capped	Realistic
None	None	Father	2 years	Satis- factory	Satis- factory	2	Doesn't con- sider handi- capped	Realistic
None	None	Former employer	8 years	Satis- factory	Satis- factory	2	Doesn't con- sider handi- capped	Realistic
Present	None	Friend	1 year	Satis- factory	Satis- factory	1	Sensitive	Realistic
None	None	Direct application	5 years	Satis- factory	Not in- terested	6	Doesn't con- sider handi- capped	Not interested
FEMALI None	ES None	Direct application	6 years	Satis- factory	Satis- factory	3	Sensitive	Bitter
None	None	Sister	1 year	Very satis- factory	Very satis- factory	1	Doesn't con- sider handi- capped	Realistic
None	None	Direct application	1 year	Satis- factory	Satis- factory	4	Doesn't con- sider handi- capped	Realistic
None	None	Youth Em- ployment Officer	6 years	Satis- factory	Satis- factory	2	Doesn't con- sider handi- capped	Realistic
Present	None	Labour Exchange	3 weeks	Satis- factory	Satis- factory	2	Sensitive	Fluctu- ating

# Dundee

#### Patients in Open Employment

There were five males and five females in open employment in Dundee (Table XXI). All patients in this category were mildly physically handicapped and 7, 4 males and 3 females, were of average intelligence. Four of the males were employed in industry, 3 as labourers and 1 as an assistant storekeeper. All the labourers were in light jobs. For example, Case 88/D was an odd job man in a jute mill; he had tried more skilled work as a setter but said that he had not been able to 'get the knack' and was a bit slow. Another boy, Case 50/D, drove a

TABLE Niche Employment—

Case No.	Age	Social Class of parents	Occupation of patient	Diagnosis	Severity	I.Q.	Last school attended	Appearance	Speech Defect
MALES 99/D	24	III	Bond clerk	Left hemiplegia	Mild	Dull Normaı	Mentally handi- capped	Advantage	None
2/D	19	111	Factory worker	Diplegia	Mild	Dull Normal	Physically handi- capped	Unre- markable	None
73/D	20	IV	Shop assistant	Right hemiplegia	Mild	Average	Mentally handi- capped	Unre- markable	None
111/D	24	III	Messenger	Left hemiplegia	Mod- erate	Mental handicap Grade I	Mentally handi- capped	Unre- markable	None
FEMAL 114/D	<b>ES</b> 25	·	Factory worker	Diplegia	Mod- erate	Dull Normal	Mentally handi- capped	Unre- markable	Pre- sent
40/D	20		Dish washer	Left hemiplegia	Mild	Dull Normal	Physically handi- capped	Unre- markable	None
112/D	23		Clerk	Diplegia	Mild	Average	Senior Secondary	Unre- markable	None

truck in a different mill. The storeman, Case 35/D, had had a variety of jobs (unskilled) in the first two years after leaving school, but seemed to have been more settled since then. He had been with his present firm for five years and had graduated from stores labourer to storeman. The apprentice chef, Case 69/D, worked in the restaurant of a large department store. He had joined the store as a messenger and had seen the vacancy advertised on the staff notice-board. His main anxiety was that recurring dermatitis might lose him his job.

Four of the 5 females also worked in industry. One, Case 109/D, was a skilled weaver in a jute mill. Another, Case 113/D, was a finisher in another mill and ranked as semi-skilled; she had been in the same mill since leaving school eight years previously. One girl, Case 32/D, was learning spinning although she was mentally handicapped and had recently been discharged from an institution. Her first job on discharge had been weighing but this had only lasted a week because, as her aunt explained, she was no scholar (in other words, she had difficulty in reading the figures on the weighing machine). It is doubtful whether she will be able to remain in her present work for long. The other factory worker, Case 89/D, was a semi-skilled machinist employed making mattress covers. She worked in the same factory

# XXII

Dundee Survey

Epil- epsy	How job obtained	Length of time in job		Parent's opinion of job	No. of pre- vious jobs	Patient's attitude to dis- ability		Employer's comments
MALE: None	S Youth Em- ployment Officer	8 years	Satis- factory	Satis- factory	0	Over- anxious	Over- pro- tective	Bad writing. Can't hold telephone and write
None	Youth Em- ployment Officer	1 year	Satis- factory	Un- satis- factory	2	Deny- ing	Realis- tic	Not allowed to do all jobs, e.g. working saw
Pre- sent	Youth Em- ployment Officer	6/12 months	In- secure	No pros- pects	5	Un- realistic	Un- realistic	Arithmetic has to be checked. Slow at tying parcels
None	Social worker	8 years	Satis- factory	Satis- factory	0	Deny- ing	Real- istic	Job made for him under very strict supervision
FEMA None now	LES Direct application	2 weeks	Satis- factory	Satis- factory	2	Sensi- tive	Over- pro- tective	Sitting job for disabled person
Pre- sent	Father	9 months	Very satis- factory	Satis- factory	3	Deny- ing	Over- anxious	Allowances made for slowness. Has fits
None	Disable- ment Re- habilitation Officer	1 year	Satis- factory	Satis- factory	4	Sensi- tive	Real- istic	Given only one job at a time. Careful not to fluster

as her sister, but as the firm were always prepared to take her back after fairly frequent periods of absence it must be assumed that she was efficient at her work. She had worked for five weeks as a stocktaker in a confectionery factory, but had found it too heavy, had had to be on her feet all the time and quite often had to lift heavy boxes. She sat most of the time in her present job. One female, Case 20/D, worked in a busy printer's office as a clerk. She had been there six years and had studied bookkeeping at night school.

# Patients in Niche Employment

Four males and three females were considered to be in niche employment (Table XXII). Only one male patient worked in a factory (Case 2/D). He was employed in a poultry factory but was not allowed to use the band-saw and was unable to push heavy loads. Two male patients worked in offices. One, Case 99/D, a mildly handicapped young man of dull normal intelligence, was employed as a clerk and was part of the office's quota of disabled persons. He was a very bad writer when he first came but had improved, although he was still slow and could not hold the telephone and write at the same time, which could be awkward. He had been in the

attitude tient	dead nate)	50		otective
Parent's atti to patient	Parents dead (Illegitimate)	Rejecting	Realistic	Over protective
Patient's attitude Parent's attitude to disability to patient	Becoming more realistic	Unrealistic	Realistic	Unrealistic
Supervisor's Report on progress	Concentration very poor but improving. Needs constant supervision. Main handicap very poor speech and constant drooling	Handicapped by poor education and limited intelligence. Lacks con- centration and needs con- stant supervision. Will require a sedentary job	Doing very well. Main difficulty will be transport to and from work	Not making any progress. Has severe epileptic fits. Continually off sick
Purpose of train- ing	Sheltered work	Sheltered work	Niche	Occupa- tion at home
Last school attended	Mentally handi- capped	Mentally handi- capped	Physical-Niche ly handi- capped	Mentally handi- capped
I.Q.	Dull Normal	Mental handicap Grade I	Average	Mental handicap Grade I
Severity	Moderate Dull Nor	Diplegia Moderate Mental handica Grade	Severe	Athetoid Moderate Mental handica Grade I
Case Age Social Diagnosis Severity No. Class	Right hemi- plegia	Diplegia	Athetoid Severe	Athetoid
Social Class		>	>	2
Age	21	18	LES 16	19
Case No.	21/D 21/D	28/D	FEMALES 6/D 16	18/D

TABLE XXIII

Patients in Sheltered Training-Dundee Survey

same office since leaving school. The other office worker (Case 111/D), was employed as a messenger boy although he was 24 years old. The job had been made for him by a kindly management. He was mainly employed running messages for the other members of staff. He was moderately physically handicapped as well as mentally handicapped but was very contented with his job. One male patient, Case 73/D, was employed as a shop assistant in a men's outfitters. Although a mildly physically handicapped boy of average intelligence his arithmetic was poor and his calculations had to be double checked. He was also slow at tying parcels.

One female, Case 114/D, was an unskilled factory worker. She was on the Disablement Register and was employed by the factory as part of the quota. She worked in a carpet factory assembling samples but had been idle for four months before finding this job. When she first left school she had been employed for eight years in a hat factory, first as a measurer and then as a cloakroom attendant, but the hat factory had closed down. Another female patient, Case 112/D, a mildly handicapped girl of average intelligence who had been to a Senior Secondary School, worked as a clerk in the office of a large factory. She had passed her Scottish Higher Leaving Certificate in four subjects but her present job could have been done by someone with less education. She was on the Disablement Register and her employers were careful not to fluster her and give her too much to do at one time. She had, when she first left school, been a clerical officer in the Civil Service, but had been unable to cope with the responsibility and the pressure of work, and as a result had a nervous breakdown. The other female in niche employment, Case 40/D, worked as a dish washer in a restaurant. She was mildly physically handicapped and of dull normal intelligence but found it very difficult to find employment as she was a fairly severe epileptic. She had had three jobs in factories but had been dismissed because her seizures upset the other workers. Although her present employers are most understanding and are friends of her father, it is doubtful whether they will be able to keep her because of the increasing frequency of her fits and the amount of crockery she has broken.

#### **Patients in Sheltered Workshops**

Only one Dundee patient, Case 55/D, worked in a sheltered workshop. He was moderately physically handicapped, of dull normal intelligence and had no other handicaps. He worked as an inspector of industrial gloves and was reasonably efficient though his work was rather erratic. It had been difficult to find suitable work for him even in the sheltered workshop. He had been taken on at the age of 19 after his mother, who felt very bitter about the situation, had appealed to her Member of Parliament to help her son find work.

#### **Patients in Sheltered Training**

Four Dundee patients (Table XXIII), 2 males and 2 females, were in residential sheltered training. The male patients were in centres outside Dundee; both came from broken homes and were moderately physically handicapped (Cases 21/D and 28/D). It is hoped that the centres will be able to employ them in sheltered workshops when they have finished their training. The two girls were at a residential training

TABLE XXIV           Unemployed. Never workel but not in Institution—Dundee Survey           Case No. Age Parents' Diagnosis Severity I.Q. Last School Prediction Social           Class           MALES         Right         Mild         Mental         Mentally         Fendiction           71/D         16         V         Athetoid         Moderate         Null         Mentally         Employable           71/D         16         V         Athetoid         Moderate         Null         Mentally         Niche           91/D         17         11         Athetoid         Moderate         Normal         Scondary         Niche           91/D         17         11         Diplegia         Moderate         Normal         Scondary         Niche           91/D         17         11         Diplegia         Moderate         Normal         Scondary         Niche           91/D         16         11         Diplegia         Moderate         Normal         Scondary         Niche           80/D         16         11         Diplegia         Moderate         Normal         Mentally         Sheltered           88/D         22         1V         Left	V Left hemiplegia	V I oft	III Other	111 Other	Diplegia	Severe	Moderate Mental handicap Grade I		Home Tuition Physically	Niche Sheltered n Unemployable	oyable Severe mental and physical handicap. Lack of training facilities for the disabled. Mental handicap and lack of intelli-
	16	16	16	71	Ξ			Diplegia	Right Severe hemiplegia Moderate Diplegia Moderate	Left Moderate Dull hemiplegia Moderate Dull Left Mild Mental hemiplegia Severe Mental hemiplegia handicap	Grade 1AthetoidSevereMentalJuniorAthetoidSevereMentalJuniorDandicapCarade IICentreCentreCrade IIModerateDullMentallyhemiplegiaModerateDullMentallyLeftMildMentalMentally

centre in Dundee. One, Case 6/D, was severely physically handicapped but of average intelligence, and was making good progress in dressmaking. She was attractive, had a very pleasant manner and so might find niche employment if transport could be organised. The other, Case 18/D, was moderately physically handicapped but was mentally handicapped and a severe epileptic. Dressmaking was too difficult for her but it was felt that she would benefit from a period away from home, where she lived with her widowed mother, aunt and grandmother and had no opportunity of meeting people of her own age.

#### **Unemployed Dundee Patients**

Three patients, 1 male and 2 females, were unemployed at the time of the survey but had worked at one time. The male, Case 23/D, was moderately physically handicapped and fairly severely mentally handicapped. When he left school, where he was in the mentally handicapped section, it was suggested that he should go to the Senior Occupation Centre, but his father refused to send him there and insisted that he should have an office job. The mother had died some time before and the father was very bitter about his son's disabilities, which he refused to accept, and he was very aggressive towards anyone in authority. Despite his son's obviously handicapped appearance the father did manage to get three jobs but he did not keep them longer than four weeks. In two cases his employer dismissed him but in the other the father took him away after half a day because he thought the work dangerous. For the last six years the boy had had no occupation and seemed to fill in his days going to the pictures.

One of the 2 females who had worked, Case 24/D, was mildly physically handicapped and mentally handicapped. Her appearance was rather marred by a facial paralysis. She was on the Disablement Register and shortly after leaving school had been employed by a wholesale warehouse owner to prepack small quantities of fruit and vegetables for the retail market. Unfortunately, this new line was not a commercial success and as there was no other job which would have been suitable for her, she became redundant. She has been unemployed for over two years, except for a short rush job in a factory. This girl might find niche employment after a prolonged period of training and assessment. The other female, Case 16/D, was moderately physically handicapped but was of average intelligence. When she left school she did a dressmaking course but although she understood the theory she found that she could not put into practice what she had learnt. She stayed on at the centre as a housemaid for two years but this was not a success; on the one hand she felt she was being made to do too much, and on the other the rest of the staff felt that she did not pull her weight. She was finally dismissed for asking for too much time off. Since then she has been unable to find work but appears to be fairly content to stay at home and look after neighbours' children while they are out at work. She would be able to work in a sheltered workshop, but she disliked being segregated with other handicapped people and would not be prepared to live in a hostel.

#### Patients Who Had Never Worked

Fourteen patients, 6 male and 8 female, had never worked but were not in an institution (Table XXIV). One male, Case 91/D, had been at a Junior Secondary

				Patients from Dundee in Institutions	lee in Institutions	
Case No. Age	Age	Diagnosis	Severity	I.Q.	Education	Comment
MALES 46/D	23	Right hemiplegia	Mild	Mental handicap Grade II	Institution	Severe mental defect. Occasional outbreaks of violence.
0/17	52	Double hemiplegia	Severe	Mental handicap Grade III	Nil	Gross mental and physical defect. Needs complete nursing care.
96/D	52	Tetraplegia	Severe	Mental handicap Grade III	Nil	Gross mental and physical defect. Needs complete nursing care.
14/D	18	Left hemiplegia	Moderate	Dull normal	Physically handicapped	Temporary patient following severe nervous breakdown.
FEMALES 25/D	16	Right hemiplegia	Moderate	Mental handicap Grade II	Institution	Severe mental defect. Became difficult for mother to cope with in confined space of tenement type home.
3/D	52	Diplegia	Severe	Mental handicap Grade III	Nil	Gross mental and physical defect. Needs complete nursing care.
47/D	25	Athetoid	Severe	Mental handicap Grade III	Nil	Gross mental and physical defect. Needs complete nursing care.

TABLE XXV

School where he had taken a modified course. He was a mildly handicapped boy of dull intelligence and had a good appearance but rather apathetic manner. His home environment, however, made it difficult for him to adopt a realistic attitude towards finding work. His father was an engineer but was unemployed because of depressive neurosis, and the atmosphere at home was not a happy one. The mother was very proud of her elder son who had a good job as a football coach in New Zealand, and was anxious that her other son should get a 'nice' job, not something in a factory. It was thought that he would be able to manage a simple repetitive job after a period of training and assessment and that he would benefit from living away from home.

Two other unemployed male patients, Cases 71/D and 80/D, would have been able to work in sheltered employment after a period of training; both were moderately physically handicapped and of dull normal intelligence but one had the additional handicap of occasional fits, and was feeling his idleness more keenly since his younger brother had left school and found work as a van boy. Two patients, Cases 17/D and 5/D, attended a Senior Occupation Centre which seemed to cater for their needs. Both were mentally handicapped and one was moderately physically handicapped, while the other, though mildly physically handicapped, was a severe epileptic and occasionally violent. His mother was very anxious for him to gain admission to a sheltered workshop but this would have been unsuitable because of his difficult behaviour. The other patient, Case 75/D, had been at home since he left a Junior Occupation Centre. He was severely mentally and physically handicapped but had appreciated diversional therapy which he had attended once a week for a period, and it was felt that he would benefit from some form of group therapy.

Two of the female patients were too severely handicapped to be capable of benefiting from any form of therapy; one, Case 74/D, was bedridden and the other, Case 4/D, was confined to the house. Two patients had other disabilities in addition to cerebral palsy. One, Case 68/D, a mentally handicapped girl with a mild left hemiplegia, was deaf and had little intelligible speech. She had been a boarder at a school for the deaf and then went to a residential training centre for three-and-a-half years, since when she has lived with her grandparents as both her mother and father go out to work. She could not travel alone but might be able to work under sheltered conditions provided there was a residential hostel attached to the centre. The other, Case 70/D, was blind in addition to being moderately physically handicapped and mentally handicapped. She had been to a sight-saving school and could read simple books in Braille. She had a home teacher for the blind once a week, but otherwise spent her time doing the housework and shopping on her own when it was not necessary to cross the street. It is difficult to suggest an alternative routine though if transport could be arranged she would benefit from some form of group therapy. One moderately physically handicapped girl, Case 66/D, who was also mentally handicapped, appeared suitably placed at a Senior Occupation Centre, and another, Case 83/D, suffering from similar disabilities, was on the waiting list for a vacancy. Another patient, Case 93/D, a moderately severely physically handicapped girl who was severely mentally handicapped and suffered from epilepsy, might have been able to go to an occupation centre. She was never allowed out alone and had sat at home since

Case No.	Age	Social Class	Occupation of patient	Diagnosis	Severity	<i>I.Q.</i>	Last School attended	Appearance
MALES 236/ST	16	III	Apprentice welder	Right hemiplegia	Mild	Average	Junior Secondary	Advantage
309/ST	15	v	Factory worker	Hemiplegia	Mild	Average	Junior Secondary	Unremarkable
246/ST	18	IV	Labourer in jute mill	Diplegia	Mild	Average	Junior Secondary	Unremarkable
FEMAL 239/ST		v	Factory worker	Diplegia	Mild	Mental handicap Grade I	Junior Secondary	Advantage
353/ST	20	IV	Married woman	Left hemiplegia	Mild	Average	Senior Secondary	Unremarkable
258/ST	21	III	Clerk	Right hemiplegia	Mild	Average	Senior Secondary	Advantage
355/ST	23	III	Shorthand Typist	Left hemiplegia	Mild	Average	Senior Secondary	Advantage

leaving school with embroidery as her sole occupation. Another mentally handicapped but mildly physically handicapped girl has remained at home since leaving school. She might be able to work in sheltered conditions if allowed to develop more selfconfidence, but her mother was extremely over-protective and never let her go out alone.

#### **Patients in Institutions**

Four males and 3 females were in institutions. From Table XXV it will be seen that all of them were severely mentally handicapped, except for one male patient, Case 14/D, of dull normal intelligence, who was a temporary inmate owing to a severe nervous breakdown. This boy, who was partially sighted, had recently completed a training course in a sheltered workshop for the blind and had been made an approved worker. His progress had been very slow and he had only just reached the required standard. His nervous breakdown had been precipitated by being jilted by his first girl friend.

#### **Small Towns**

# **Open Employment in the Small Towns**

There were 3 males and 4 females in open employment in the small towns

#### XXVI ment in the Small Towns

Speech Defect	Epilepsy	How job obtained	Length of time in job	Patient's account of job	Parent's opinion of job	No. of previo jobs	Patient's attitude us to disability	Parent's attitude to patient
MALES None	None	Father	5 months	Satis- factory	Satis- factory	0	Doesn't con- sider handi- capped	Realistic
None	None	Youth Employment Officer	1 month	Satis- factory	Satis- factory	2	Doesn't con- sider handi- capped	Over protective
None	None	Youth Employment Officer	2 years	Unsatis- factory	Unsatis- factory	0	Sensitive	Over protective
FEMAL None	ES None	Direct application	6 years	Satis- factory	Satis- factory	1	Doesn't con- sider handicapped	Realistic
None	None	Does not apply		Does not apply	Does not apply	3	Doesn't con- sider handi- capped	Realistic
None	None	Direct application	5 years	Very satis- factory	Very satis- factory	0	Doesn't con- sider handi- capped	Realistic
None	None	Advertise- ment	5 years	Satis- factory	Satis- factory	1	Doesn't con- sider handi- capped	Denies handicap

(Table XXVI). They were all mildly physically handicapped and with the exception of one mentally handicapped girl (Case 239/St.) were of average intelligence. The 3 male patients worked in industry. One, Case 236/St, was serving a five-year apprenticeship in welding and attended day-release classes once a week at a Technical College. His parents had been very anxious that he should learn a trade but had had some difficulty in finding an opening for him. His employer was a close friend of his father but even so he will have to be reasonably efficient to complete his apprenticeship. Another male was a labourer in a jute mill, Case 246/St. He had been with the same firm for four years, but had failed to obtain more skilled work and had become discouraged at the thought of remaining a labourer. The other male, Case 309/St, had had some difficulty in finding work, and had been idle for six months after leaving school till he obtained temporary work packing calendars over the Christmas period. He was then taken on for a trial period in a bakery but the work was too heavy. He had been in his present job, making wooden boxes, for four weeks and seemed satisfied with it.

Only one female was employed in a factory. She had a simple job as an 'in-giver' (handing threads to a weaver) and had been in the same mill for six years. The other females had been to Senior Secondary Schools and worked in offices. One was a

#### TABLE

Patients in Niche Employment

Case No.	Age	Social Class	Occupation of patient	Diagnosis	Severity	I.Q.	Last school attended	Appear- ance	Speech Defect
MALES 207/ST	19	III	Assistant Storeman jute mill	Right hemi- plegia	Moderate	Dull Normal	Junior Secondary	Unre- markable	None
351/ST	23	III	Shop assistant	Hemi- plegia	Mild	Dull Normal	Junior Secondary	Unre- markable	None
242/ST	18	III	Factory worker	Right hemi- plegia	Mild	Mental handi- cap Grade I	Junior Secondary	Advantage	None
243/ST	16	IV	Labourer	Right hemi- plegia	Mild	Dull Normal	Junior Secondary	Unre- markable	None
263/ST	16	11	Factory worker	Diplegia	Mod- erate	Dull Normal	Mentally handi- capped	Unre- markable	None
FEMALI 215/ST	ES 22	111	Invoice typist	Other	Mild	Average	Junior Secondary	Advantage	None
204/ST	22	III	Telephon- ist recep- tionist	Diplegia	Mod- erate	Average	Senior Secondary	Advantage	None
254/ST	18	111	Shop assistant	Diplegia	Mod- erate	Average	Junior Secondary	Advantage	None

married woman who had held three clerical jobs for periods varying from 18 months to three years. She had stopped working when she started a family. She was able to type but admitted that she was slower than average and had mainly done reception work. Another girl, Case 355/St, was a shorthand-typist in a professional office. One girl, Case 238/St, had started a Teacher's Training Course in Dundee, but she had left after seven weeks as she had had to live in a hostel, had been homesick, and also was frightened that she could not manage the work. Since then she has worked in her home town as a wages clerk for a large engineering firm.

#### Patients in Niche Employment in the Small Towns

Five males and 3 females were considered to be in niche employment in the small towns (Table XXVII). All were unskilled workers except one girl who was a typist.

#### XXVII

in the Small Towns

Epil- epsy	How job obtained	Length of time in job	Patient's account of job	Parent's opinion of job	No. of pre- vious jobs	to dis-	Parent's attitude to patient	Allowances made in job
MALES Not since 10 years	Youth Em- ployment Officer	2½ years	Satis- factory	Satis- factory	2	Sensi- tive	Real- istic	Job made to suit him.
Pre- sent 12-14 years	Known by owner	6 years	Satis- factory	Satis- factory	1	Sensi- tive	Bitter	Can't take any respon- sibility. Given simple jobs. Can't lift.
Pre- sent	Disable- ment Re- settlement Officer	1 year	Satis- factory	Satis- factory	4	Doesn't con- sider handi- capped	Real- istic	Light job for disabled person
None	Youth Em- ployment Officer	l year	Un- satis- factory	Un- satis- factory	4	Sensi- tive	Real- istic	Light job for disabled person
None	Youth Em- ployment Officer	2 days	Satis- factory	Satis- factory	1	Denieș handi- cap	Real- istic	Simple factory job with supervision
FEMA None	L <b>ES</b> Father	6 years	Un- satis- factory	Un- satis- factory	0	Sensi- tive	Real- istic	Simple job. Not able to do as much as other clerkesses.
None	Youth Em- ployment Officer	5 years	Very satis- factory	Satis- factory	8	Real- istic	Real- istic	Sitting job for disabled person
None	Direct application	3 years	Satis- factory	Satis- factory	0	Sensi- tive	Real- istic	Not suitable to work at all counters

Four of the male patients worked in industry and were part of their firm's quota of disabled persons. All the patients were doing light labouring jobs which offered no prospect of advancement. One boy, Case 243/St, had been driving a small trolley in a scrap metal yard for the past 15 months and felt that he was in a dead-end job. It was one of those jobs where there was not quite enough work to keep him fully occupied. His employment history was fairly typical of this type of apparently mildly physically handicapped boy. He worked for one week as a creel boy (tying wool on the looms) in a local carpet factory but was dismissed because the work was too fine for him. He then went as office boy to the firm where his father worked and might have stayed there if a well-intentioned family friend, against the advice of his parents, had not persuaded him to work in his butcher's shop with the hope of becoming an apprentice. He lasted a week there. By this time he had a large-size chip on his shoulder which was not helped by his twin brother leaving home to join

Case No.	Age	Diagnosis	Severity	1.Q.	Education	Remarks
MALES 223/St	15	Other	Mod- erate	Mental handi- cap Grade I	In- stitution	Placement unsuitable but lack of facilities in neighbourhood for special schools. Suspicion of ill treatment at home before admission.
312/ST	21	Di- plegia	Severe	Mental handi- cap Grade III	Nil	Gross mental and physical defect. Patient illegitimate. Mother died shortly after child's birth.
309/ST	22	Di- plegia	Severe	Men- tal handi- cap Grade III	Nil	Gross mental and physical defect. Requires complete nursing care.
FEMALES 208/ST	21	Di- plegia	Mod- erate	Men- tal handi- cap Grade III	Nil	Third illegimate child of a certified mentally defective mother.

#### TABLE XXVIII

#### Patients in Institutions in Small Towns

the Merchant Navy. Another male patient, Case 351/St, worked in a shop. Although he had been there for six years he still had to be carefully supervised; he also had difficulty in lifting anything heavy, and as the shop dealt in electrical equipment this was a great disadvantage.

The three females were all of average intelligence. Two worked in offices, and 1, Case 215/St, in the firm where her father worked. She had taken a secretarial course when she first left school, but her typing had been slower than average and she had been unable to get up any speed in shorthand, although she had mastered the theory. Since then she had been employed as an invoice typist, a job which was normally left to the junior employee, and was very conscious of the fact that she had not been promoted to keeping the books as was the usual practice with typists in that office. The other office worker, Case 204/St, worked in a firm which took a special interest in providing employment for local disabled people. She operated an internal switchboard and directed people to the various departments, but since she walked with a stick, she was not expected to move from her chair. One of the firm's vans called for her each morning and she was allowed time off for her weekly physiotherapy treatment. One girl, Case 254/St, was a shop assistant in a chain store. She always worked at the same counter where the goods were pre-packed and easy to handle.

### Patients in the Small Towns Who Were Unemployed at the Time of the Survey

Three male patients were unemployed at the time of the survey but had worked

for periods varying from six months to three years. Their continuance in employment seems to have depended on the attitude of their employers rather than on their own abilities. One moderately severely physically handicapped boy, Case 251/St, who was also mentally handicapped, was unemployed for 18 months after leaving school until a friend of the family gave him niche employment in the drawing office of his small engineering firm. Unfortunately the employer died after the boy had been there only two years and he was soon after declared redundant. Since then he has not been able to find work and his cousin, with whom he lived, would not let him go to a training centre in the South of England because she did not think it would lead to any work in their neighbourhood.

Another mildly physically handicapped boy (Case 221/St), who was mentally handicapped, was employed for two years when he first left school as a street orderly. He was fortunate in having an understanding foreman, but when this man left his successor was less patient and had the boy dismissed. His father was a very aggressive man and so his attempts to find employment for his son were not successful. The boy could work under sheltered conditions but his father, who maintained that there was nothing wrong with the boy, would not be prepared to co-operate with any employment agency.

The other male patient, Case 203/St, was moderately physically handicapped, but was of average intelligence and had been to a Senior Secondary School. Despite the fact that he stayed at school till he was 18 years old he did not get a leaving certificate, and he explained this as due to repeated absence through illness. When he left school he became a clerk in an office where his father had a good position. While in this office he went to day release classes at a College of Commerce where he passed some examinations in English, History and Arithmetic. He left the office after three years because he wanted to be independent. He was taken on as a clerk by a garage very near his home and thought that he was doing well until, at the end of six months, he was given a week's notice. It transpired that, although he was quite intelligent, he was very slow and only did the equivalent of half-a-day's work. He might have kept the job in spite of this if he had not been disliked by his immediate superior.

# Patients Who Had Never Worked

Three patients, 1 male and 2 females, had never worked but were not in an institution. All 3 were epileptic and 1, Case 237/St, was also blind. The blind girl would have benefited from going to an Occupation Centre if transport could have been provided, and the other two might manage sheltered work if their fits were sufficiently controlled.

#### **Patients in Institutions**

Four patients, 3 males and 1 female, were in institutions (Table XXVIII). All were severely mentally handicapped except one high-grade defective (Case 223 St) who had been sent there because he had not been able to cope with an ordinary school, and at that time there were no special schools in the neighbourhood. There was also some suspicion of ill treatment at home but this was never proved. He went home for holidays and received regular visits from his parents, so that it would seem that either the suspicions were unfounded or the parents' attitude had changed.

# **General Remarks**

## Attitude of Patients, Parents and Employers to Employment Problems

The majority of patients in open employment appeared to be reasonably satisfied with their work, though few had chances of promotion. The lack of future opportunity did not seem to cause great concern to younger patients, but at least four of those over the age of 18 years were dissatisfied with their present employment and worried about the future. For example, one had been a box repairer in a brewery for eight years but was frightened to seek other work lest he became unemployed (Case 134). Another was a relief porter working only occasional shifts and earning little (Case 182).

None of the female patients or their parents appeared dissatisfied with their present jobs, possibly because low wages are more easily accepted by single women than by men, who may at some time expect to have to support a wife and family. Since only 7 of the males, and 1 female employee gave permission for employers to be interviewed, it was difficult to form any real impression of employers' reactions. Probably the best guide to employer's satisfaction with the patient's work is the length of time that the job has been held. It will be seen from Table XXVI that 19 of the males had held jobs for more than a year, 9 for more than three years and 4 for more than five years. Nine of the 10 women in wage-earning employment had held their present posts for six years, and 1 clerk (Case 8) had been with the same firm for seven years.

Only 5 patients in niche employment admitted to being dissatisfied, 4 because of low wages and 1 because he felt that he might be dismissed (Case 73/D). Twenty-four of the parents were satisfied with the employment of their children. One (Case 111/D) felt, realistically, that there were no prospects in her son's present job. Another (Case 2/D) thought his son's work too heavy. Another (Case 243/St) felt that her son did not have enough work to do and he might be considered too old for it when he became 18.

Unlike the employers of patients in open employment, the employers of patients in niche employment were prepared to make allowances for the patients' disabilities. In general, they seemed realistic about what they could expect the patients to do, and were satisfied with them as employees.

Two patients in sheltered workshops appeared dissatisfied with their present jobs. One patient (Case 89) considered he had to stand too long. The other (Case 55/D) found the work monotonous.

Only 4 of the 14 patients in sheltered training (Cases 150, 159, 173 and 21/D) appeared as satisfied with the prospect of sheltered work as those actually engaged in it. Two other male patients (Cases 53 and 143) had tried unsuccessfully to find other work and were now resigned to working in a sheltered workshop. Four patients (Cases 25, 33, 98 and 18/D) were very reluctant to be classed as handicapped persons. Three were too immature (Cases 145, 28/D and 18/D) to be considering the future.

Only 4 of the patients in Edinburgh who were unemployed at the time of the Survey, but who had been employed, appeared to be actively looking for work. All

4 patients (Cases 72, 86, 157 and 187) were male. One other patient (Case 99) was said to be looking for work but did not co-operate with employment agencies. One male patient (Case 73) and 5 female patients (Cases 15, 101, 114, 162 and 195) appeared quite content not to be working, and 2 other patients suffering from epilepsy (Cases 5 and 166) had looked for work but had become discouraged. Two patients who were unemployed at the time of the Survey but had never worked, were looking for work. Another patient (Case 123) considered employable was staying at home looking after her illegitimate baby. The majority of the 18 patients considered incapable of work, even in sheltered conditions, seemed reasonably contented with their routine. One male patient (Case 3) felt very frustrated at being so dependent on his mother and would have preferred to return to the institution where he had been for a short time. Another patient (Case 204) and his parents were very bitter at his not finding a job. Three female patients of average or dull normal intelligence (Cases 107, 130 and 136) were too severely physically handicapped to be employed, even in sheltered workshops, and consequently sometimes found time hung heavily upon them. On the other hand, only one of the patients (Case 205) who could probably find work in sheltered conditions seemed anxious to find work; the remainder were uninterested.

The situation was not quite the same in Dundee and the small towns, where there were fewer facilities for assessing cerebral palsy patients and no training centres catering specifically for them. A number of patients came for a period of assessment at the Scottish Council for the Care of Spastics but many of them could not live on their own and therefore were unable to have a full assessment. The six patients who had held jobs were said to be looking for work, but the impression gained was that most of them had become discouraged by repeated failure. One patient (Case 203/St) had only recently lost his job but the others had been idle for at least a year.

Three male patients who had never been employed (Cases 71/D, 80/D and 91/D) were looking for work in a fairly passive way. Two male patients and 1 female patient in Dundee attended Senior Occupation Centres (Cases 17/D, 5/D and 66/D). Other patients would have benefited from such centres had they been available. Only 1 patient (Case 74/D) was so handicapped that she could derive no benefit from any form of occupational therapy.

#### **Methods of Obtaining Employment**

Methods of finding employment varied greatly. The ways in which patients had obtained their current employment are indicated in Table XXIX. It will be seen that 20 of the 43 patients in open employment found their present work as a result of answering advertisements or making direct applications, and 9 obtained work through friends or relatives. At least 4 of these patients might not have found jobs in open employment without this help.

Twelve of the 32 patients in niche employment obtained their jobs through the Youth Employment Officer, and 4 through the Disablement Resettlement Officer. In one of these cases the Disablement Resettlement Officer was the patient's uncle, which was not a disadvantage! Seven patients had been helped to find work by a social worker. Only 1 patient (Case 111/D) in Dundee found work in this way and the social worker concerned was a voluntary worker with business connections.

Seven obtained work through relatives or friends. Two female patients had obtained niche employment by direct applications to employers—both were on the Disablement Register.

	Open	Employ	yment	Niche			Sheltered Workshops		
	Edin- burgh	Dun- dee	Small towns	Edin- burgh	Dun- dee	Small towns	Edin- burgh	Dun- dee	Small towns
Advertisement	7	_	1		_	_		-	
Direct application	6	4	2	_	1	1	_		_
Youth Employ-	-		•	-	•				
ment Officer	5	1	2	5	3	4	1	_	-
Disablement Re-				2	1	1	2		
settlement Officer	-	-		2	I	1	2	-	-
Labour Exchange	1	1	-		-	-	-	—	-
Relative or friend	4	4	1	4	1	2	-	1	
Social Worker	1	_	-	6	1	-	1	_	-
No information	1	-	-	-	-	-	-	-	-
Total	*25	10	6	17	7		4	1	0

TABLE XXIX Methods of obtaining employment

\*This total does not include the married women in the series.

# A Comparison of the Type of Work Obtained by Patients Suffering from Cerebral Palsy in Edinburgh, Dundee and Small Towns

Unemployment rates for Dundee were higher than for Edinburgh and most of the small towns (see page 41), but despite this the same proportions of Dundee and Edinburgh patients were in open employment (21 per cent), while 27 per cent of patients in the small towns were in open employment (see Table XVI). The comparisons drawn are not statistically significant owing to the small number of patients in small towns and Dundee compared with Edinburgh.

Most of the males in open employment were in unskilled jobs requiring no training and offering little prospect of advancement. Only one Edinburgh patient had successfully completed his apprenticeship; 3 other patients, 1 in each of the areas surveyed, had started apprenticeships, one as a butcher in Edinburgh, one as a chef in Dundee, and one as a welder in the small towns. All the male patients in Dundee and the small towns worked in industry, but in Edinburgh less than one-third were factory workers and nearly half were office workers.

It seemed that female patients in open employment in Dundee and the small towns were employed in relatively more skilled work than the males; thus in Dundee 1 female was a skilled weaver, 2 were semi-skilled factory workers, and 1 a typistbook-keeper, while in the small towns 1 female was a skilled shorthand-typist and another a wages clerk. Both had been with their employers for some time. All the females in open employment in Edinburgh were employed in offices, 3 as clerks and 1 as an addressograph operator.

Niche employment. There were proportionately more patients in the small towns in niche employment (31 per cent) than in Edinburgh and Dundee, where the proportion was the same (14 per cent). None of the male patients were in jobs requiring any skill or special training. The men employed in industry were all labourers. No patients were in niche employment in the jute industry in Dundee. Three Edinburgh patients were employed as jobbing gardeners but no patients in Dundee or the small towns were employed in this type of work. No male patients were employed in offices in the small towns, probably because the offices were not large enough to be able to employ a disabled worker, and a small staff has to be more versatile. For example, a large architects firm in Edinburgh was able to employ a disabled man full-time as a photostat operator, whereas a smaller office would expect a junior member of staff to do this as part of his work. A large office in Dundee was able to employ one patient as a messenger.

Female patients in niche employment were in jobs requiring no training or skill except for 2 copy-typists, one in Edinburgh and one in the small towns, both of whom were not expected to do as much work as a normal employee. There seemed to be greater opportunities for females to find niche employment in shops than men, as women could be employed on counters in large chain stores where the goods are pre-packed, whereas men are usually employed in departments where the goods are more difficult to handle and usually require two good hands. One man in Dundee was employed in a draper's shop, and 2 girls (one in Edinburgh and one in the small towns) were employed on carefully selected counters of chain stores, while another was employed as an alteration hand and message girl in a draper's in Edinburgh. There seemed also to be more opportunities for disabled women in offices than men, particularly as addressograph operators or receptionists in large offices Four female patients worked in offices in Edinburgh, 2 in the small towns and 1 in Dundee. Females were more difficult to find niche employment for in factories than males, who can be employed as labourers. Only I female in Dundee was employed in a factory and none were employed in this type of work in the small towns. Four females in Edinburgh were employed in factories but none came into contact with machinery; 2 were in cardboard box factories, 1 was a packer in a confectionery factory and the other picked basting threads off garments in a clothing factory. All patients were able to work at their own speeds.

The type of employment available for patients was more varied in Dundee and Edinburgh than in the small towns, but on the other hand employers in small towns were more likely to be interested in the patient, possibly through knowing his parents or relatives. Three of the 5 male patients in niche employment in the small towns obtained work in this way, and it is doubtful whether the apprentice in open employment would have been taken on if his employer had not known his father. It is interesting that the 3 male patients in niche employment in the small towns who obtained their work through the Ministry of Labour lived in a town very near Dundee and worked in Dundee. One of the 3 females in niche employment in the small towns worked in the same office as her father, and another was employed in a large mill, the managing director of which took an interest in employing local disabled people.

In the present Survey 43 per cent of patients in Edinburgh were unemployed, 49 per cent in Dundee and 38 per cent in the small towns. Of this number it has been estimated that about half would benefit from a period of training and assessment. A few of these patients might obtain niche employment if this were carefully selected, but the majority by reason of their multiple handicaps would only be suitable for sheltered work. The remainder of the unemployed patients were too handicapped to be able to work even in sheltered conditions, but 8 Edinburgh patients, 8 in Dundee and 1 in the small towns would benefit from attending an occupation centre. When taking into account the proportion of unemployed patients in small towns it must be remembered that none were employed in sheltered workshops or sheltered training.

# CHAPTER 6

# Difficulties in Finding Work

Many factors combine to determine whether a youth suffering from cerebral palsy finds work and remains employed or not. Clearly his chances are reduced if impairment of motor function is severe or extensive, but they will also be reduced by associated mental impairment, epilepsy, hearing loss, defective eyesight or speech defects, and will be greatly influenced by the patient's previous education and the help he receives from his relatives and friends when he comes to seek work. Probably most important of all is his attitude to himself, his disabilities and his place in society, which, in turn, will have been determined very largely by his home environment and the way he has been handled in early childhood. The complex ways in which personal and environmental factors may combine to increase or reduce a handicapped individual's chances of employment have been well described by Ferguson and Kerr (1960).

The number of our patients is too small and our information is too inadequate to attempt a comprehensive assessment of the relative importance of specific adverse environmental factors. For example, it would have been interesting, had it been possible, to attempt to assess what effect the early prolonged hospitalisation which was endured by some of the patients had on their personality, but such an investigation is necessarily outside the scope of this survey.

#### **Employment by Sex**

It will be seen from Table XXX that a higher proportion of males than females was employed. A total of 39 per cent of females, who had left school in the combined series were in open, niche or sheltered employment, compared with 47 per cent of males. A slightly higher proportion of males were in open employment than in niche employment but rather more females were in niche jobs than in open employment. It is

Employment	Male Number	Approx. Per cent	Female Number	Approx Per cent.
Open	29	28	14	18
Niche	16	15	16	20
Sheltered	4	4	1	1
Sheltered Training	8	8	6	8
Unemployed	47	45	41	53
Total	104	100	78	100

TABLE XXX

Employment of Patients by sex. (Combined Edinburgh, Dundee and Small Towns)

interesting that when each series is considered separately including patients still at school as many as 70 per cent of the females in the small towns were in open or niche employment compared with 40 per cent of the men, whereas in Edinburgh and Dundee 38 per cent of the males were in open or niche employment compared with 31 per cent of females in Edinburgh and 32 per cent in Dundee.

These differences cannot be explained by any important differences between the sexes in severity of physical disabilities or mental impairment. They seem more likely to be the results of differences in the demand for labour and the types of work available for male and female school leavers. That this is the probable explanation is shown by the differences between the proportions of males and females in open and niche employment in Edinburgh, Dundee and the small towns.

#### Employment by Diagnosis and Severity of Physical Handicap

Open or niche employment had been obtained by approximately 48 per cent of patients suffering from hemiplegia, but only by approximately 33 per cent of those suffering from diplegia and 20 per cent of those suffering from dyskinesia. When patients suffering from hemiplegia and those suffering from diplegia are compared by severity of physical handicap, it is found that the proportions of patients in open or niche employment, and the proportions who are unemployed are similar. For example, of mildly affected hemiplegic patients, 61 per cent were in open or niche employment and 34 per cent were unemployed, and of mildly affected diplegic patients, 53 per cent were in open or niche employment and 29 per cent were unemployed. No patients suffering from either hemiplegia or diplegia whose physical handicaps were graded as severe, were in either open or niche employment. The fact that more hemiplegic than diplegic patients are in open or niche employment may be interpreted as being due to the fact that more hemiplegic patients are lightly physically handicapped.

Unfortunately the numbers of patients suffering from dyskinesia is small, and reliable conclusions cannot be drawn from the sample studied. The fact that only 1 of the 6 mildly handicapped patients obtained open or niche employment, however, is in contrast to what happened to lightly handicapped patients suffering from diplegia or hemiplegia, of whom more than half were in open or niche employment. Clinical experience is compatible with this observation, for patients suffering from dyskinesia who have severe speech disorders (which many of them do have) are particularly difficult to place in suitable employment. It is not surprising therefore to find that none of the severely handicapped patients suffering from dyskinesia was in open, niche or sheltered employment, though 25 per cent were in sheltered training.

In Figure 2 is shown the percentage distribution of patients by employment and severity of physical handicap in Edinburgh, Dundee and the small towns combined.

Of the mildly physically handicapped patients, 56 per cent were in open or niche employment, as were 24 per cent of those whose physical handicaps were classified as moderate. None of the patients classified as severely physically handicapped was in open or niche employment. At first sight this might suggest that the all-important factor in determining whether a patient obtains employment is the severity of his physical handicap, but it has to be remembered that mental retarda-

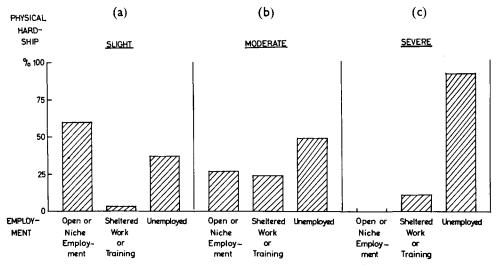


Fig. 2. Percentages of patients employed and unemployed by severity of physical handicap. (a) 100 school leavers with mild physical handicaps. (b) 55 school leavers with moderate physical handicaps. (c) 27 school leavers with severe physical handicaps.

tion, speech defects and abnormalities of hearing and vision tend to be more frequent and severe in those with severe physical handicaps (Hansen 1960, Ingram 1963).

#### **Employment by Intelligence**

32 per cent of patients with slight physical handicaps had intelligence quotients of 90 or above, and 9 per cent had quotients of less than 50. Only 11 per cent of those who were classified as severely physically handicapped had quotients of 90 or above, and 63 per cent had quotients of less than 50. The marked effect of impaired intelligence on the patient's chances of obtaining employment is indicated by the fact that, whereas 30 of the 32 patients who were mildly physically handicapped and had intelligence quotients of above 90 were in employment (approximately 92 per cent), only 12 of the 37 patients (32 per cent) with intelligence quotients of less than 70 in the same category obtained open, niche or sheltered employment (Fig. 3). When impaired intelligence is associated with moderate or severe physical disability the patient's chances of obtaining work are very severely impaired. This is shown by the fact that only 2 out of the 44 youths with moderately severe physical handicaps and intelligence quotients of less than 90 were in open employment, 8 in niche employment and 3 in sheltered employment. 7 were in sheltered training but with little prospect of obtaining work except in sheltered workshops. 24 were unemployed. It is apparent from these findings that the severity of physical handicap and the degree of impairment of intelligence are important factors in determining whether a patient will obtain employment or not. At the same time we were impressed by the way in which some patients with quite significant physical handicaps and mental retardation managed to obtain work and prove satisfactory employees. There were 3 patients, for example, in niche

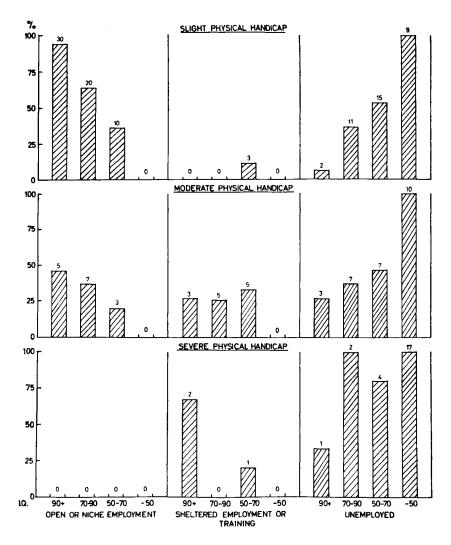


Fig. 3. Percentage of patients employed by severity of physical handicap and intelligence; Edinburgh, Dundee and Small Towns.

employment with intelligence quotients of between 50 and 70 who were moderately severely physically handicapped, and another 5 were in niche employment with quotients between 70 and 90, with moderate physical handicaps. In contrast, 13 of the 63 mildly physically handicapped patients with intelligence quotients of 70 or more were unemployed (approximately 21 per cent).

### Employment and the Presence or Absence of Epilepsy

The differences in the proportions of patients mildly and severely physically handicapped who suffered from epilepsy was not statistically significant. It will be

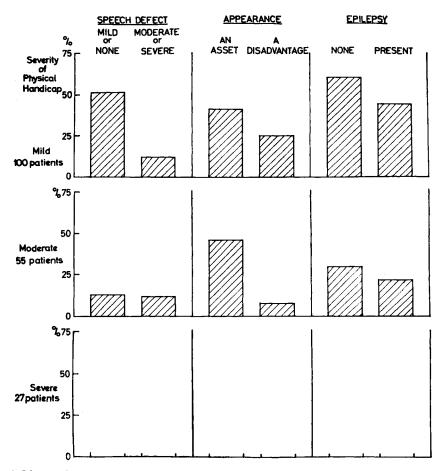


Fig. 4. The employment of patients by the presence or absence of speech disorders, epilepsy and appearance and by severity of physical handicap.

seen from Figure 4, however, that fewer patients with than without epilepsy obtained open or niche employment. Approximately one third of patients with epilepsy were in open or niche employment, whereas almost half of those without epilepsy were in open or niche employment. This difference is hardly surprising when one considers how difficult it may be to find employment for epileptic patients who suffer from no other obvious chronic physical or mental handicap. There is an almost superstitious fear of epileptic attacks amongst many employers and workers which can hardly be explained on a rational basis, though the possibility that epileptic patients will hurt themselves on industrial machinery during an attack may be sometimes a real consideration rather than an excuse for not employing them.

## **Employment and Speech Defects**

As in most recent surveys, speech defects amongst the patients studied were found to be more frequent and severe in those suffering from extensive and severe cerebral palsy than amongst those suffering from mild cerebral palsy. Thus they were more frequent in patients with tetraplegia than in those with paraplegia, in the category of diplegia, and more frequent amongst patients suffering from dyskinesia, which most commonly affects all four limbs, than amongst those suffering from hemiplegia (Table X). It is to be expected that fewer patients suffering from significant speech defects will obtain open or niche employment than those whose speech is normal or only mildly defective. Even when account is taken of the severity of motor handicap, however, it is found that there is significant difference in the proportions of patients with and without speech defects who obtain open or niche employment (Fig. 4).

Speech defects seem to be a particularly important disability amongst intelligent patients suffering from dyskinesia, who were debarred from fine manual work by the presence of their involuntary movements, and who could not take employment which involved talking with members of the public. Thus jobs such as being shop assistants, receptionists and messengers, which would otherwise be within their scope, were rendered impossible for them.

#### The Appearance of Patients and Employment

The appearance of patients severely physically handicapped by cerebral palsy was rarely prepossessing, though we considered that the appearance of 80 per cent of patients with slight physical handicap and 56 per cent of those with moderate physical handicap was an asset or unremarkable rather than a disadvantage. Intelligent patients were often able to improve their appearance considerably by conscious effort. For example, they could diminish the amount of their drooling, modify their posture and conceal deformed upper limbs to a considerable extent, whereas the appearance of unintelligent patients was less often modified by the patients' own efforts. Rather more mildly and moderately physically affected patients with intelligence quotients of above 70, whose appearance was unremarkable or an asset, were employed, than those whose appearance was a disadvantage (Fig. 4).

# **Environmental Factors and Employment**

Clearly the patient's chances of obtaining employment are influenced by more than the severity of his physical and mental handicaps and his associated disabilities. The help he gets from his parents and outside agencies when he seeks work may make all the difference. His educational attainments and the type of school he attended will also be important. It is possible to assess the relative importance of some of these factors, but it is much more difficult to estimate the significance of the child's early experiences in determining his attitude to work, though these are often crucial in determining whether successful employment will be obtained. Clearly patients coming from stable, emotionally well-balanced homes in which the attitude to the child's handicaps has been healthy, are much more likely to overcome the difficulties of obtaining a job and holding it, than is the patient from a very disturbed home background, who may have been over-protected or rejected in early childhood.

The distribution of patients by social class of their fathers and by employment is shown in Figure 5. There appears to be no particular weighting of the severity of physical

handicaps by social class, but there is a tendency for school leavers in social classes IV and V to be less often employed and more often unemployed than those in the higher social classes. Patients in social classes I, II and III tend to stay at school longer than those in the lower social classes, and were more often placed in niche or sheltered working conditions.

Patients in social classes IV and V were at a disadvantage, not only because their parents could not support them financially, but also because often their parents did not know how to obtain the help of statutory and voluntary authorities in seeking work for their children.

In Figure 6 is shown the distribution of patients by the stability of their home backgrounds and employment. Patients' homes were judged to be disturbed if either parent was known to suffer from recurring mental illness or alcoholism, or where the parents periodically separated from one another. The home was judged to be broken if the parents were divorced or separated. Where the patient was illegitimate and the mother had not subsequently married the home was judged to be broken. but where the mother had married and the patient was adopted by her husband the home was considered to be intact. Over 61 per cent of patients who were mildly physically handicapped and came from stable home backgrounds were in open or niche employment, whereas just under 30 per cent from disturbed or broken homes who were similarly physically handicapped were in employment. Frequently the patient coming from a broken home was at a material disadvantage compared with one coming from an intact family. A working mother, separated from her husband and bringing up a large family, frequently had neither the means nor the time to give the patient suffering from cerebral palsy the extra care and attention that he would otherwise have received, but the major disadvantage is probably a psychological one, and this is reflected in the finding that of the 31 patients coming from broken or disturbed homes, 20 had unhealthy attitudes to their disabilities and to problems of finding work and keeping it. (10 of the 31 patients had either not left school or were considered unemployable even in a sheltered workshop.) 8 were thought to be too dependent on their parents and 12 were considered to be unrealistic either about the type of job they could do or the amount and quality of the work which would be expected of them. For example, one severely physically handicapped boy employed in a sheltered workshop thought he could work as a telephonist because he could answer the telephone. He failed to appreciate that he would also be expected to write down messages and look up numbers in the Directory, which he was not capable of doing.

The lack of realism shown by some patients, especially those who had been very overprotected by their parents in early life, was striking and very similar to the findings reported in the patients studied by Crothers and Paine (1959). These authors also commented on the fact that there were 'certain children who, in spite of mediocre intellectual endowment and moderate physical handicaps had obtained fairly satisfactory jobs', whereas others less severely mentally and physically handicapped were unable either to obtain or to hold employment because of emotional difficulties.

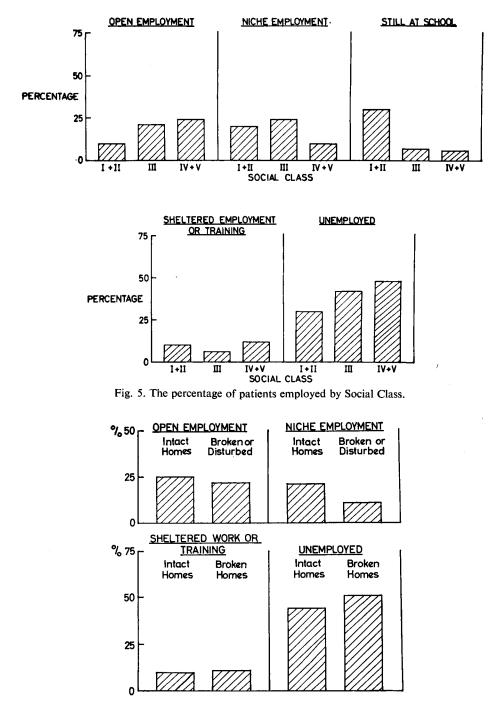


Fig. 6. The employment of patients by stability of home background—127 from intact homes, and 55 from broken homes (31 from disturbed homes, 18 homes with one parent dead, 6 with both parents dead).

Edinkk	Number	Open	Niche	Sheltered	Sheltered Training		Approxi- mate %
Edinburgh		•	0	0	0		
Senior Secondary	2	2	0	0	0	0	2
Junior Secondary	26	14	5	0	0	7	24
Physically handicapped	27	2	7	0	9	9	24 25
Mentally handicapped	28	8	5	3	1	11	25
Junior Occupation							
Centre	4	0	0	0	0	4	4
No education or							
training	8	0	0	0	0	8	7
Institution	16	0	0	1	0	15	15
Total	111	26	17	4	10	54	101
Dundee							
Senior Secondary	1	0	1	0	0	0	2
Junior Secondary	7	6	0	0	0	1	15
Physically handicapped Mentally handicapped	8	1	2	0	1	4	17
Mentally handicapped	19	3	4	1	3	8	43
Junior Occupation						-	
Centre	3	0	0	0	0	3	6
Home tuition	1	0	0	0	Ó	1	2
No education or			÷	•	•	-	-
training	1	0	0	0	0	1	2
Institution	6	õ	ŏ	ŏ	ŏ	Ĝ	13
			· · · · ·				
Total	46	10	7	1	4	24	100
Small Towns							
Senior Secondary	4	2 5	1	0	0	1	17
Junior Secondary	14	5	6	0	0	3	59
Physically handicapped	0	0	0	0	0	0	0
Mentally handicapped	1	0	1	0	0	0	4
Junior Occupation							
Centre	0	0	0	0	0	0	0
No education or							
training	1	0	0	0	0	1	4
Institution	4	0	0	Ō	Ō	4	17
					·		
Total	24	7	8	0	0	9	101

#### Table XXXI

#### Employment of school leavers by residence and last type of school attended

It is difficult retrospectively to gauge the influence of parents' own attitudes in determining how patients approached the problems of finding work, but it is certainly no coincidence that of the patients who were successfully employed in open or niche jobs over 58 per cent had parents whose attitudes were considered healthy, whereas in those who had failed to keep work the attitudes of parents were considered to be unhealthy in just over 70 per cent.

The type of school which the patient attended was determined chiefly by the severity of his mental and physical handicaps and the presence or absence of associated disabilities. In general, patients who were so lightly handicapped that they could attend normal schools were those who obtained open or niche employment, whereas patients who were so severely physically handicapped that education in a special school for children suffering from cerebral palsy was necessary, generally failed

#### TABLE XXXII

Patients who attended Junior Secondary Schools but were unemployed at the time of the survey

Case No.	Age	Sex	Diagnosis	Severity	Home Background	Patients' lives & attitudes
	inburg 18		Diplegia	Mild	Father and mother neuro- tic. Brother in mental	Has an unrealistically high opinion of own
187	16	м.	Right hemi- plegia	Mild	hospital. Oldest of close-knit family of five. Father anxious about his son's lack of progress.	abilities. Very immature. Took a modified course at Junior Secondary School
5	24	F.	Left hemi- plegia	Mild	Disturbed family back- ground. Parents divorced. Mother now dead. Patient keeps house for step-father. Step- mother recently com- mitted suicide	Epileptic. Leads iso- lated, rather lonely life
114	23	F.	Dip- legia	Mod- erate	Illegitimate. Mother now married. Patient left home after quarrel with step-father. Was spoilt by maternal grandparents. Has been living in a suc- cession of sordid furnish- ed rooms	Very insecure. Freg- nant
162	20	F.	Right hemi- plegia	Mild	Mother dead. Patient keeps house for father	Difficult behaviour
195	21	F.	Left hemi- plegia	Mild	Father died recently. Patient keeps house while mother works	Mild epileptic. Not verystrong physique. No psychological problems
176	15	F.	Left hemi- plegia	Mild	Only child. Comfortable home circumstances	Immature. Took a modified course at Junior Secondary School
	ndee ) 17	М.	Dyskin- esia	Mild	Father very neurotic, has been in and out of men- tal hospitals in the past few years and is at present at home, but un- employed. Parents do not get on well. Mother overprotects patient and is over ambitious re job for him	Immature and rather apathetic

to find work. Approximately 77.7 per cent of those who had left Senior and Junior Secondary Schools were in open or niche employment, approximately 32 per cent of those who attended schools for the physically handicapped were in open or niche employment and, rather surprisingly, 43.7 per cent of those who had left schools for the mentally handicapped were in open or niche employment.

When patients who had gone to normal schools failed to obtain or remain in work, it was often because of emotional disturbances. Of the 7 patients who had attended Junior Secondary Schools in Edinburgh and were unemployed at the time of the survey, 5 came from disturbed or broken homes, and all but one had difficult or disturbed behaviour. Only one patient who had been to a Junior Secondary School in Dundee was unemployed; he had done a modified course. Owing to the lack of special schools in small towns, a comparison of the number of unemployed who went to normal school with those in Dundee and Edinburgh was not very useful (Table XXXII).

## CHAPTER 7

# The Habilitation of Patients

The practical difficulties in the habilitation and employment of handicapped young adults described in this chapter were observed over a period of several years at Rhuemore Out-patient Clinic and later in the sheltered workshop—St. Jude's Laundry—run by the Scottish Council for the Care of Spastics in Edinburgh.

Many of these young adults were not included in our survey since some were in an older age group and others did not live in the area. The patients in the various treatment groups described were those who attended at Rhuemore during the same year as that in which the survey was conducted, but some illustrative case reports are taken from previous records.

## Rhuemore Out-patient Clinic of the Scottish Council for the Care of Spastics

Rhuemore contains the Council's Departments of Social Work, Physiotherapy, Speech Therapy and Occupational Therapy, each department being responsible for providing professional services for out-patients of all ages, and for the pupils of Westerlea School for Spastic Children.

A Diagnostic and Assessment Clinic is conducted each week at Rhuemore. Patients, referred through the social workers, are seen at this clinic by a neurologist, psychologist, and an orthopaedic surgeon, and by members of staff from each, therapy department. A meeting is held afterwards to discuss the management of each case, and to arrange for the prescribed treatment to be implemented.

All cases are reviewed at intervals and routinely near school leaving age. At 15 years of age, patients may be registered with the Employment Department. This department is organised by a social worker and occupational therapist in consultation with the medical psychologist, and it is responsible for the Adult Training and Employment Scheme throughout Scotland.

## Referrals to the Employment Department following Clinical Assessment

Patients referred may be placed in one of three main categories:

- (1) Patients who are severely disabled and who can only work at a 'Sheltered Occupation'—using the term in the broadest sense possible.
- (2) School leavers whose parents or teachers wish for advice about the kind of work which they should seek.
- (3) Young adults who have failed to find, or to keep, employment.

The aims of treatment must vary for individual patients referred within these broadly defined categories, and we do not segregate patients into these groups, but some discussion of the groups is offered as being relevant to the individual aims after assessment.



Fig. 1. The laundry at Rhuemore; patients at the reception desk.

#### The Severely Handicapped Group

Out of the total 56 patients who were registered with the Employment Department during one year, 21 were considered to be in this category. Of these, 8 were predominantly mentally handicapped. The group represents an age-range of from 15 to 50 years. Only 2 were 'new' patients and the majority had been having treatment and training for many years. Unless suitable alternative placing is available (3 were placed in work centres near their homes during the year) this group will be the permanent core of the clinic population, as patients are never discharged.

These patients are generally aware that their 'training' has limited aims, and are not usually over-ambitious. Besides their multiple handicaps, inability to travel to work is a very obvious barrier to paid employment. This also precludes acceptance for full-time work in the Ministry of Labour's Approved Sheltered Workshops, but part-time employment is appreciated by the majority, especially if it augments the income received from the National Assistance Board.

Since it is not at present possible to foresee how economic independence could be achieved for these people, the aims of treatment must be carefully and realistically presented, or bitter disillusionment may follow.

#### Example—Patient M.

M. is a severely handicapped 31-year-old man of average intelligence who suffers from dyskinesia. He spent part of his school days at a residential special school, then returned to live with his mother, on whom he is completely dependent.



Fig. 2. The laundry wash-house. Simple Bendix equipment is installed.

M. worked hard at school, and has learned to type with two fingers at a slow painstaking rate. He has been bitterly disappointed that this achievement did not lead to fully paid employment, and for this reason, retired from treatment sessions at Rhuemore in Summer 1960—he had attended for one day a week for over a year. He refused further treatment and did not welcome social visits. After the laundry was established he wrote to ask if he might come and do part time clerical work. He now attends for two sessions each week, and types lists, timetables and short letters for which he receives a gratuity. Allowing for correction and re-typing, his speed is approximately 50 words per hour. He now understands that this will not lead to full-time work, and is very co-operative. He can just walk with support and is now more willing to do so and seems to enjoy his sessions thoroughly.

Patients in the 'severely handicapped group' are by no means 'hopeless'. Personal achievements are very real, even if they cannot always be measured by recognisable standards. Because we are not aiming at the standards which would be demanded from a 'normal' worker, it is in many ways easier to make provision for these people than for the slightly less handicapped patients. There is no urgency for them to make immense effort, because there is no real yardstick by which to measure success. Accommodation for increasing numbers, provision of congenial occupation,



Fig. 3. Rhuemore: patients working on the callendering process, which removes creases from the laundry.

arrangement for transport—these are all problems, but they are more concrete than those arising during training of the next group.

Patients assessed at school leaving age as potentially capable of full-time sheltered, niche or open employment.

Twenty out of the total 56 patients were in this category. Five of these had been in training since leaving school, and at the time of the study were between 18 and 19 years of age. Eight patients who had newly left school had previously received treatment from our clinic. The only 4 patients who were definitely assessed as fit for open employment came from the small group of 7 who had never before been referred to Rhuemore. Evidently they had not required special assistance until the time came to seek work.

All these patients want to work and to earn a living wage and the success of their training can only be measured by the subsequent facts—whether or not they are satisfactorily placed in employment. Training therefore must aim at normal standards, for the existence of any business concern depends upon the reasonable output of its workers. Since 'work' is a daily affair, an effective programme must cover the full day for five days every week. Only in this way can the therapist give adequate assessment and provide treatment in its proper context of working conditions.

Many patients, however, have barely the minimum requirements for employment in mobility, personal independence and physical or mental capacity. Of the group under discussion, only 8 achieved open employment and 1 found a suitable 'niche' job near his home. For the others, 'sheltered' work seems a more realistic



Fig. 4. Rhuemore: folding and packing the laundry.

goal. The Ministry of Labour's Approved Sheltered Workshops must conform to factory regulations, and wages are paid in return for work, but the pace is less demanding. The workshops are planned to accommodate disabled people and a generous training period is allowed. Some new sheltered workshops, including our own laundry, have been opened recently. Until these were established, the treatment and training plan could achieve success only for a very limited number of patients.

## Example—Patient K. (female).

K. suffers from choreo-athetosis with some speech involvement. She attended the training centre for more than three years.

When an Edinburgh restaurant manager, interested in the work of the Scottish Council for the Care of Spastics, suggested that he might employ a handicapped girl as a dishwasher, K. immediately volunteered for the job. She was readily accepted by the staff, and for the first week, which was a slack period, she settled well. When the restaurant became busy, however, she could not cope with the volume of work at the speed required and was dismissed. Disappointed, she returned to Rhuemore.

She is now one of the foremost ironing hands in the laundry and

is at her best on extra busy days when there is increased pressure of work.

Seven patients have been placed or are registered for training in sheltered workshops; 4 remain unplaced and 1 of these has been found to be too mentally retarded and unreliable for any of the work available at present in the laundry. The 3 others could be employed at Rhuemore if a hostel were available nearby.

## The Moderately or Lightly Handicapped Adult Group, 21 years of age and over.

The 15 patients in this category can hardly be described as a group since their needs are so varied.

Some were referred through the Ministry of Labour for advice and training for employment, having already tried the normal channels for work. Others made personal applications to work in the laundry or for help in finding a 'job'; a few required part-time occupation or individual tuition in a skill such as typing. Only 5 are still attending the centre; 2 are working in the laundry and 3 attend for parttime occupation.

Some of the adults who have never been employed are not in fact prepared to face the demands of working life.

#### Example—Patient E. (female).

E. is 28 years old and suffers from choreo-athetosis. She attended Rhuemore for occupational therapy for some years, and then went to a work centre; from there she applied for training in the laundry. E. withdrew her application during preliminary assessment. She found the hours too long and the work too tiring, and missed her friends at the work centre. No doubt, if sheltered work had been available when she was much younger, she could have adjusted to the discipline required.

Three of the most dependable laundry workers are, however, aged between 28 and 38, and none of these had been formerly employed. Several patients could have been capable of sheltered work, but did not live in the vicinity of a suitable workshop; training would therefore have been of very little benefit to them. Two patients had held jobs previously, and after assessment were placed in suitable work.

Probably one of the greatest needs for the older group is hostel accommodation. The existing residential sheltered workshops and other centres prefer to admit residents at a fairly young age. One middle-aged patient is now living in an old people's institution, since he has no home or family. The lack of suitable residential accommodation is worrying for most moderately and severely handicapped patients at present living with their parents.

#### **Need for Training**

Very few patients are assessed as being immediately ready for work without any further pre-training.

The most striking feature, shared to some extent by all those who require prolonged training, is immaturity. This is to be expected, since many of the developmental

milestones have been reached at an age much later than the average. It does seem, however, that these children have been denied experience in many activities, which, given encouragement, they could have enjoyed. Many behave as though they had gone through their childhood on a 'conveyor belt' system which involved no real responsibility or need for awareness of life around them. But the years of carefully organised routine suddenly end at the age of 16. A surprising number of these people are unaware of their limitations, are unduly satisfied with their few hard-won achievements, and do not realise how dependent they are on outside help. Often they are afraid to take an unfamiliar step—their attempts have so often ended in failure that the result is discouragement, then apathy. They want employment but are unaware of the discipline, speed and sustained effort demanded by most jobs.

It would be presumptuous to claim that the lives of patients could have been transformed had they received different treatment in their youth. These are gravely handicapped people, and they cannot achieve complete ability. However, the importance of 'training' by the family at home and from the earliest age onwards cannot be over-stressed. A severely handicapped infant may be unable to move, grasp, play or feed without assistance. Because this child, without making any personal effort, is fed, placed in a chair, a toy put in his hand, he accepts this as the natural means of accomplishment. He is oblivious of the bodily organisation normally required to bring food to his mouth, to get up and on to a chair, to reach for a toy, until he begins to learn to do these things. Later, if he is never taught and asked to perform everyday tasks such as dressing completely, bed-making, housework, he may be only partly aware that those things are in fact being done, and he cannot know how to begin to do them.

The early experience in 'messing around', experimenting, lifting, looking, moving, is a vital part of 'education for life', and the more advanced training in feeding, dressing, washing can only be effective if it is continually encouraged as part of life, rather than as part of an exercise associated only with 'treatment'.

## Example—Patient S. (female).

S. is a teenage girl who was presented for assessment. She appeared grossly handicapped by spastic diplegia and was wheel-chair-bound with some contractures. It seemed unlikely that she could perform many practical tasks.

She proved, however, to be completely independent in self-care at home, able to do her share of housework, washing up, bed-making and manipulating her chair with the greatest of skill.

She is very well occupied and happy and her well-being speaks volumes for her family and her own determined spirit. Sufficient 'training' had always been given at home—she needed no more.

Personal skills which are achieved by the average person without conscious effort may for this group of young people take years of practice, so there is simply not time to gain the wealth of experience enjoyed by most children. We feel that an unhurried period of time in which to mature is most necessary during the adolescent stage, and fairly good results can be seen even where early training seems to have been neglected. At this age patients usually respond well to the opportunity to assert themselves as responsible adults, and can understand the advantages of such achievements as being able to travel alone, to eat in a restaurant, and to go shopping independently.

Independence, however, means more than the physical ability to climb on a bus and to speak intelligibly. One must also know how to obtain information about public service transport; it is necessary to look for landmarks to avoid getting lost and to make use of the freedom of the city; a general knowledge is required of such amenities as the parks, museums, gardens, swimming baths and zoo. Use of leisure time is an important part of life and many patients have few recreations until introduced to the various possibilities; many find they can enjoy activities such as riding, swimming and skating.

Self-confidence, naturally, is frequently lacking. Many patients have attended very good special schools from which they derived much benefit. Unfortunately these are sometimes spoken of as the 'Daft Schools' by local children, and a feeling of inferiority is fostered. In the Rhuemore working group of patients each one is encouraged to accept certain responsibilities, for all patients are 'needed' in the community. Opinions are sought and ideas accepted and tried, initiative encouraged and personalities developed. Good community influence can be very helpful and is a most essential part of this type of training.

The daily work sessions provide a very general training for employment by giving patients a gradual introduction to the importance of time-keeping, the need to maintain standards and the general approach to work. During the sessions, patients are introduced to various types of occupations such as domestic work, including cooking, sewing, cleaning and laundering, gardening, general portering, and bench and office work such as book-keeping, reception and telephone operating. All this is useful work, necessary to the domestic organisation of our clinic.

A small gratuity is paid to each worker, mainly to cover travelling expenses, but also as proof that their work is appreciated.

## Placing in Open or Sheltered Employment

Immaturity and inexperience may to some extent be expected in most adolescents, but the average young person learns by trial and error, and can apply his knowledge usefully.

Some cerebral palsied patients seem to be unable to learn spontaneously from their opportunities and experiences, but require repeated teaching and practice. They cannot adapt learned skills to varying circumstances, and alterations in height or position may present a complete barrier to work. Although their physical handicaps may not be assessed as 'severe' they are simply unable to conceive any alternative approach to their task.

These patients perhaps respond to conditioning rather than training—first to life at home, then at school, then in the training centre, but they seem unable to apply the knowledge learned in one situation to the requirements of another.

These patients are likely to require 'sheltering' always. To be of real value, training

for work must lead directly to a similar type of job. Since our training centre and the laundry are in the same building, the transition from trainee to worker is a very simple one.

## Example—Patient C. (female).

C. is an attractive 18-year-old who suffers from ataxia with tremor and is mentally backward. She attended a Special School (and was ashamed of this) but has several non-handicapped friends and enjoys a fairly full social life. She attends the swimming baths regularly and greatly enjoys this.

C. could not accept the fact that she was handicapped. She wanted 'to work with children', although she showed no aptitude in this direction. One of her main handicaps was lack of initiative; for example, when looking for a plate, if there was none on the shelf in front of her eyes she did not stoop to look on a lower one but simply reported, 'There are no plates'. However, once her tasks were established as a routine, she seemed to be quite happy. 'Sheltered work' was a suitable goal for her and when one of her friends at Rhuemore was enrolled in the laundry, C. agreed to accept the training.

In some cases, lack of experience may be attributed simply to lack of opportunity, as in the case of P.

## Example—Patient P. (female).

P. is a 17-year-old girl who suffers from ataxic diplegia. She has a pleasant appearance and is sociable and lively. Clinical recommendations included further education (since P.'s education had been frequently interrupted) and training for sheltered work. During the practical assessment period it was found that P.'s confident manner was misleading. She was very poor at organising her work and had evidently been allowed to take little part in household responsibilities at home. Her parents kept her well out of harm's way. She never went out by herself, nor had she used an iron, made tea, or worked with a cooking stove. She had no special difficulties in handling, lifting and placing, and with practice her approach to the various tasks rapidly became more competent. She is able to apply these skills and is a most conscientious worker.

'Further education' classes are much enjoyed, but it is too early to say how far she will progress in reading and writing—arithmetic is her best subject. 'Sheltered work' would seem to be an acceptable proposition to P., but this cannot be arranged until her parents' fears for her travelling alone to work can be overcome. At intervals, she presents an eczematous condition involving both hands, which seems to be aggravated by washing powder—though it has appeared at times when this was not a likely cause. It has also been observed that when P. uses some of her newly acquired skills at home, she burns or scalds herself, although this has not happened during training. Meantime, she leads a double life—training, including practice in bus travel, continues at Rhuemore—at home she is given no responsibilities.

Another patient who required sheltered work was G., although she had made good progress in a special class at school. It is possible that she may eventually graduate to 'open' employment.

Example—Patient G. (female).

G. is a 17-year-old girl who suffers from ataxic diplegia. She was referred to us with a school medical report that she appeared minimally handicapped physically, but rather dull mentally.

She was found to be very amiable, eager to work and rather overanxious to please. Her greatest difficulties lie in her inability to place herself conveniently to work and her awkwardness in handling equipment; for example, when loading a washing machine she would put the trolley several feet away from the machine and throw the articles in from that distance. This she found extremely difficult. In baking, she would keep her mixing bowl and tools in whatever position they happened to be, possibly at arm's length. Working a pulley presented a very great problem—how to change grip to let the rope go up in order to bring the pulley down.

G. is now placed in the laundry and is able to work within a reasonable space and to organise her tasks, though she still cannot adjust to any change of routine.

Case B. illustrates the problem of a patient who is barely able to cope with the demands of sheltered work and for whose needs a 'work centre' might have been more suitable.

Example—Patient B. (male).

B. suffers from spastic diplegia and is relatively lightly handicapped physically but very mentally retarded. He came to Rhuemore at 16 years of age, having previously attended an occupation centre. He is well mannered, strong and willing. He improved so greatly in work habits that he was enrolled as a laundry trainee. Although the laundry work is of a fairly simple nature, B.'s frequent lapses of memory and erratic concentration render him an unreliable though enthusiastic worker. We feel that possibly the various tasks impose too great a strain on his mental powers, resulting in periods of depression or excitability. No doubt constant supervision will always be required, but if our workshop expands sufficiently, it may be possible to give B. one constant simple task which could more easily be checked.

In contrast is Q., who is also very backward mentally and markedly physically handicapped. Although slow, he is completely reliable and therefore, in sheltered conditions, a valuable worker.



Fig. 5. Work in the kitchens at Rhuemore.

The effect of disability is not always apparent and some patients who appear reasonably able are genuinely unfit to cope with competitive work. Such a problem is shown by D.

#### Example—Patient D. (female).

D. is 20 years of age and apparently minimally physically handicapped by ataxia but rather backward mentally.

She had been employed in numerous jobs (including laundry work), none of which had lasted for more than a few weeks. She came to Rhuemore at the request of the Ministry of Labour, as a possible candidate for the laundry.

At first she was often late in arriving at work, or stayed away without a reasonable excuse; her performance was very variable from day to day. She had several friends employed in the laundry and was keen to be accepted. After much plain speaking from staff her work habits did improve greatly.

She was accepted for training and has continued to attend regularly, though her work varies from a really high standard when she is alert, to a very poor one when she is apathetic and dreamy. Her efficiency in the laundry is limited by her poor sense of judgement, she seems unable to recognise a properly dried and ironed article from a poorly finished one and when folding sheets and



Fig. 6. A severely handicapped patient helping with kitchen work.

table-cloths in conjunction with another worker, she is unaware of the degree of strength with which she must grip. She frequently drops 'finished' articles while folding or carrying them away for packing.

For the patient who is potentially capable of competitive work, circumstances such as a real need to work and a favourable attitude on the part of the employer form a very potent force. We are often struck by the helpfulness and understanding shown by many employers who must be given credit for their part in 'habilitation'.

Case A. has been fortunate in this respect.

## Example—Patient A. (female).

A. suffers from right spastic hemiplegia and is subject to epileptic fits at irregular intervals. She started training at Rhuemore immediately after leaving her P.H. school at 17 years of age.

Although physically and mentally capable of routine employment, she could not at first face any responsibility and would frequently ask to go home early or to be excused from certain jobs—because 'she was tired', 'her legs were sore' or 'she did not feel up to it'. After several months of training, A.'s father had a serious accident and A. (the only child) suddenly realised that she must be the 'bread winner'. Fortunately a very suitable job was advertised at this time by a most sympathetic employer. At first A. had great difficulty in adjusting to work, even in this exceptionally understanding atmosphere. She deeply resented any teasing from fellow workers and disliked doing the odd jobs which were included in her duties as 'Junior' in the office. 'Fits' occurred at work and she made much of them. She made her usual excuses for getting out of some of her work and every week she would bring tales of woe to her former school-teacher and to the social worker at Rhuemore. She was persuaded to keep on trying and her fellow employees must have given her very real support. The latest report from her employer states that 'A. is pulling her weight and is now regarded as a fully competent worker'.

Some patients seem to have an innate ability to compensate for quite severe handicaps—such a one is R., a dyskinetic youth who works as a packer in a factory. He possesses initiative and drive and has developed into a purposeful employable adult. 'Special' training was not required. Others who have little to offer in skill or aptitude hold down their jobs surprisingly well; their pleasant friendly manner plus an attractive appearance are invaluable assets.

Perhaps the most difficult problem with regard to training is presented by the older patients who have held and lost a succession of jobs. Often they are unaware of their limitations and have never developed good work habits. They are not willing to accept lengthy training—because they have worked and feel that they have nothing to learn. If they are fortunate enough to continue to find work, bitter experience seems to be the only training from which they can benefit.

## Provision of Work for the Disabled

The sheltered workshop at Rhuemore was set up because many of our patients who genuinely wanted to work could not otherwise find employment. In selecting a trade, the main concern was to choose one which would give suitable employment to the greatest number of these people whose abilities we had studied over many years. It was necessary that the business selected should have a reasonable prospect of economic return. Lastly, since this experimental venture was started as an extension to the occupational therapy training programme, it was essential that the selected work should not require special technical knowledge. A "Bendix" Laundry Service was the final choice, as all our candidates could take part in at least one aspect of the work, which includes reception, checking, tending the machines and packing. Very few unforeseen problems arose in training, and the business has grown to match the growing competence shown by our workers.

Fourteen former patients are now employed in the unit which is mechanised to provide a fully-finished laundry service and an experienced laundry supervisor is in charge of the trained workers, in co-operation with the occupational therapy department. Possibilities of further expansion at Rhuemore are very limited, but it is hoped to employ a maximum of 18 full-time workers in the present premises.

Our habilitation programme is an attempt to meet the present needs of our patients, and it must change and expand according to the requirements of the patient group. Our experiences in this field of habilitation are limited to the relatively small number of patients studied at Rhuemore over recent years, but it is felt that some significant facts have emerged which may be fairly generally applicable. The most important one is the necessity for thorough preliminary assessment before starting training for open or sheltered employment. Patients who have completed a course, for example, in commercial subjects, may still be unable to meet the normal demands of a job in this field. Some of these people have been referred to our clinic for advice, having found that their training was not the expected passport to employment.

Since St. Jude's Laundry opened in 1961, only one of the laundry trainees has graduated to other employment—she now works as a lift attendant in a local store; otherwise there has been no turnover of employees. Because all trainees had a thorough preliminary assessment, this situation was anticipated and it must be accepted. Patients such as those employed at Rhuemore are capable of good work only under suitable sheltered conditions and unless these are provided they will not be able to work.

It is also apparent that very prolonged and carefully designed training is required for the majority of our patients, and that the foremost requirement in any scheme of sheltered work must be training staff who appreciate the complexities of patients' difficulties. In the sheltered workshop it is our experience that constant tactful supervision of each process is required.

Choice of work to be undertaken must depend on local conditions, and the interests and abilities of the patients. It is essential that sheltered workshops and work centres should provide a variety of jobs which will give scope for individual talents, but where techniques can be altered to minimise disabilities. Rigid detailed planning on a grand architectural scale does not seem to us desirable. Unless the plans are flexible, readily adaptable and extensible, they are likely to become obsolete before they have begun to fulfil their purpose.

# CHAPTER 8

# Cerebral Palsy as a National Problem

The prevalence of cerebral palsy and the types of cerebral palsy encountered in a given community depend to some extent upon the age distribution and social structure of the population. It was found in Edinburgh, for example, that hemiplegia occurred more commonly amongst children living in wards of the city in which the infant mortality rate was high, than it did amongst children living in wards where the infant mortality rate was lower. The findings in recent regional surveys of large populations have been remarkably similar, however. Apparent differences in the distributions of patients by diagnosis have been due more to different methods of classification than to real differences in the clinical findings. There do not appear to be major differences in the prevalence of cerebral palsy or in the distribution of patients by diagnosis between rural and urban areas, though information on this point is rather scanty (Hansen 1960, Henderson 1961).

In these circumstances it is possible to make tentative estimates of the prevalence of cerebral palsy in Scotland, based on the results of the surveys in Dundee and surrounding areas, 1955, and Edinburgh 1952-53 (Henderson 1961, Ingram 1963).

#### Estimate of the Prevalence of Cerebral Palsy in Scotland

Direct information about the prevalence of cerebral palsy amongst children born since 1955 is lacking. In view of this no estimate of the prevalence in pre-school children is offered. It is unlikely however, that major changes in prevalence occurred between 1955 and 1957. A prevalence of 2.5 patients suffering from cerebral palsy per 1,000 of the population aged between 5 and 15 (*i.e.*, children born between 1938 and 1948 inclusive) is assumed. The estimated number of patients aged between 5 and 15 years in 1962 in the Scottish population is 2,125 (Table XXXIII.)

TABLE XXXIII	
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Approximate estimated figures for surviving patients in Scotland, based on figures for the prevalence of cerebral palsy in Edinburgh (Ingram 1955), and population statistics of the Registrar General, 1961.

	Estimated number Scotland	Estimated number per 100,000 population
Children aged 5-15 years (based on prevalence of 2.5/1,000)	2,125	40
School leavers aged 15-40 years (based on prevalence of 2/1,000)	3,800	75
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In any population of 100,000 people of all ages there are likely to be some 40 children aged between 5 and 15 who suffer from cerebral palsy.

It is difficult to give any reliable estimate of the prevalence of cerebral palsy in people over the age of 25, but the prevalence of the condition amongst people aged between 15 and 25 was found to be more than 2 per 1,000 in both Edinburgh and Dundee in 1962, and is unlikely to be significantly less than this in patients under the age of 40. Assuming a prevalence of 2 per 1,000, there are likely to be about 3,800 cerebral palsied patients aged between 15 and 40 in the Scottish population, or about 750 per 1,000,000 of the general population.

## Expected Distribution of Patients by Diagnosis and Severity of Physical Handicap

In Table XXXIV is shown the expected distribution of patients in Scotland by diagnosis, severity of physical handicap and intelligence. It will be seen that about half of the 1,600 patients are expected to be mildly physically handicapped, and half of these to suffer from hemiplegia, but about 1 in 8 patients is expected to be severely physically handicapped, so on these grounds alone it is very unlikely that useful employment will be possible for them. Rather more than a quarter of the patients are expected to be of average intelligence, but almost a third will have intelligence quotients of less than 70 and must be regarded as significantly mentally handicapped. The majority will certainly require permanent care and many will need nursing.

Diagnosis		Severity			Intelligence quotient				TOTAL
-		Mild	Moderate	Severe	90+	70–90	50-70	-50	
Hemiplegia		469	140	46	198	233	84	140	655
Diplegia		306	210	140	164	152	188	152	656
Dyskinesia		45	83	23	93	23	23	12	151
Other	•••	46	92	0	23	57	46	12	138
то	TAL	866	525	209	478	465	341	316	1600

TABLE XXXIV

The estimated distribution of patients born in Scotland between 1938 and 1948 inclusive by diagnosis, severity of physical handicap and intelligence, based on Edinburgh statistics.

450 patients may be expected to suffer from grand mal epilepsy, and 168 from petit mal. Visual defects may be expected in about 170 patients, and the speech of 784 patients is likely to be defective to the extent that intelligibility is impaired.

#### **Implications for the Community**

Patients suffering from cerebral palsy are an economic burden to the community in which they live and at the same time challenge it to provide adequate medical and social care for them. The extent to which their needs are met varies greatly in different parts of Scotland, depending on the awareness of their problems and the readiness to help shown by statutory and voluntary authorities.

One of the major difficulties faced by those attempting to provide medical and social help for patients who suffer from cerebral palsy is that the prevalence of the condition is relatively low. Only a minority of the population are likely to come into direct contact with cerebral palsy, particularly since so many patients are largely home bound. When they do meet young people suffering from cerebral palsy, it is noticeable that their compassion and desire to help are much more readily stimulated by the appealing child patient than by the adult, who may very often be grotesque in appearance, clumsy in movement and have an uncared-for air.

Another result of the relatively low prevalence of cerebral palsy is that there is rarely a sufficient number of patients in any one administrative area for officials to make special provision for their needs. This is particularly so when a population is as widely scattered as it is in so much of Scotland. It is reasonable to expect that efforts should be made to meet the special needs for medical care and education and employment of patients suffering from cerebral palsy in circumscribed populations of 100,000 people or more, but comparatively few cities in Scotland are of this size. Aberdeen County and City (having a population of 185,000) may be expected to have something over 200 young people who suffer from cerebral palsy, aged between 5 and 40 years; Glasgow County and City will probably have about 1,200 in the same age range, and Greenock, with a population of approximately 75,000, will have about 87 patients. On the other hand the 90 patients in the County of Dumfries (population 87,686 in 1961) and the 85 in the County of Inverness are widely scattered in small centres of population, and to provide for their multiple and diverse needs in any comprehensive way presents major administrative difficulties.

In these more scattered populations the child suffering from cerebral palsy often has to be educated in the local school, either in special classes for children with different handicaps or with younger normal children. It is impractical to organise classes specially for the cerebral palsied. The degrees of enterprise shown by local authorities in organising suitable classes for children suffering from different handicaps vary very greatly.

The problems of the school-leaver suffering from cerebral palsy who is too handicapped to obtain niche or open employment are even more acute if he comes from an area with a widely scattered population. Sheltered training is rarely available locally and there are few sheltered workshops in Scotland, even in the larger towns.

In some areas it should be possible to organise sheltered workshops for school leavers suffering from different types of handicaps which would be suitable for the patients suffering from cerebral palsy who are not too severely disabled. But the peculiar difficulties of young adults suffering from cerebral palsy should not be underestimated (see chapter VII). It is probable that there may be as many as 150 or 200 patients suffering from cerebral palsy aged between 15 and 40 living in Scotland who will obtain work only in specially designed workshops catering specifically for school-leavers with moderately severe or severe cerebral palsy. About 50 of these are likely to live in Glasgow, 25 in Edinburgh, 9 in Aberdeen, 9 in Dundee. Suitable specialised workshops for patients suffering from moderately severe or severe cerebral palsy should be built in these cities, but they should be designed so that they can also accommodate patients from surrounding areas with more scattered populations who are too severely handicapped to hold their own in workshops, together with patients suffering from different handicaps.

There are probably between 60 and 100 such patients in areas of scattered population who require workshop facilities specially designed to cater for those with moderately severe or severe cerebral palsy. The organisation of training, employment and special residential care away from home for this number of patients is a major undertaking. It requires professional planning on a national scale.

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